



# 4<sup>TH</sup> ELPAT CONGRESS

Ethical, Legal and Psychosocial Aspects  
of Transplantation

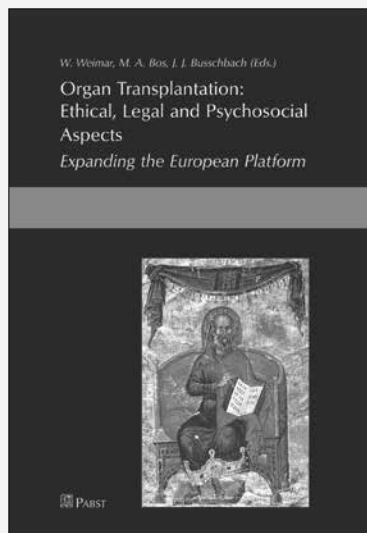
## Global Challenges



### Programme & Abstract Book

22 - 25 April 2016 ANGELICUM Congress Centre, Rome - Italy

[www.esot.org/elpat/home](http://www.esot.org/elpat/home)



W. Weimar, M. A. Bos, J. J. V. Busschbach (Eds.)

## Organ Transplantation: Ethical, Legal and Psychosocial Aspects Expanding the European Platform

This book is based on the International Congress "Organ Transplantation: Ethical, Legal and Psychosocial Aspects. Expanding the European Platform" (Rotterdam, The Netherlands, April 2010).

The contributions are an overview of current issues in the field of transplantation ethics.

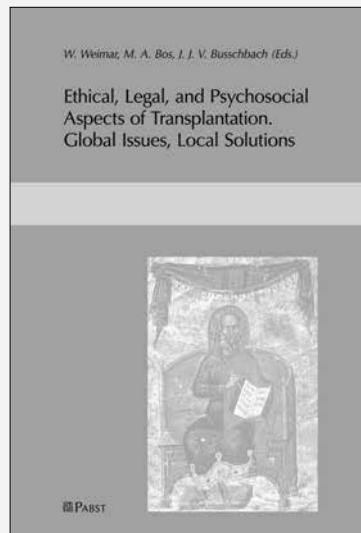
The topics:

- Organ Tourism and Paid Donation;
- Legal and Ethical Boundaries for Organ Transplantation;
- Diverse Populations;
- Deceased Donation;
- Psychological Care for Living Donors and Recipients;
- Samaritan / Unrelated Donation;

are discussed among ethicists, clinicians, psychologists, lawyers and policy makers in the field of organ transplantation.

The ELPAT platform was initiated with the aim to establish continuity in European communication on 'Ethical, Legal and Psychosocial Aspects of Organ Transplantation (ELPAT)', after several ad hoc conferences had been organised in the last two decades. ELPAT aims to facilitate and structure the European research area in this field of science. It is now an official body within the European Society for Organ Transplantation ([www.elpat.org](http://www.elpat.org)).

**2011, 432 pages, ISBN 978-3-89967-639-6, price: 45,- €**  
eBook: price: 36,- € ([www.ciando.com](http://www.ciando.com))



W. Weimar, M. A. Bos, J. J. V. Busschbach (Eds.)

## Ethical, Legal, and Psychosocial Aspects of Transplantation Global Issues, Local Solutions

This book is based on the International Congress 'Ethical, Legal, and Psychosocial Aspects of Transplantation. Global Issues, Local Solutions' (Rotterdam, The Netherlands, April 2013).

The contributions are an overview of current issues in the field of transplantation ethics.

The topics:

- Cultural and Religious Aspects of Living and Deceased Donation;
- Cross-Border Transplants;
- Psychosocial Care;
- Autonomy at the End of Life;
- Public Issues;
- Children as Donors and Recipients;

are discussed among ethicists, clinicians, psychologists, lawyers and policy makers in the field of organ transplantation.

The ELPAT platform was initiated with the aim to establish continuity in European communication on 'Ethical, Legal and Psychosocial Aspects of Organ Transplantation (ELPAT)', after several ad hoc conferences had been organised in the last two decades. ELPAT aims to facilitate and structure the European research area in this field of science. It is now an official section within the European Society for Organ Transplantation ([www.ELPAT.org](http://www.ELPAT.org)).

**2014, 340 pages, ISBN 978-3-89967-931-1, price: 35,- €**  
eBook: price: 25,- € ([www.ciando.com](http://www.ciando.com))



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Guest Editor:  
Prof. Willem Weimar, MD, PhD, Rotterdam



# Welcome!

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Dear Colleague.

On behalf of the organizing committee it is our pleasure to invite you to the 4th ELPAT Congress on Ethical, Legal and Psychosocial Aspects of Organ Transplantation. The congress will take place from 22-25 April 2016 in the Angelicum Congress Centre, Rome, Italy.

This conference is unique. It is different to other medically-oriented transplant conferences in that it addresses all other aspects of transplantation: ethical, legal, and psychosocial. Experts from all over the world will express their views on overcoming global transplant challenges. The conference welcomes professionals including ethicists, philosophers, physicians, lawyers, criminologists, anthropologists, psychologists, coordinators, nurse practitioners and policy-makers involved in the field of organ donation and transplantation.

ELPAT is an interactive platform that supports the exchange of knowledge, ideas, and experiences by encouraging dialogue and facilitating research. ELPAT is an official Committee of the European Society for Organ Transplantation (ESOT) and was founded during the 1st congress in April 2007 in Rotterdam, The

Netherlands. The 2nd congress was held in April 2010 with the aim of expanding the European platform to new EU Member States. The 3rd congress was held in April 2013 with the aim of bridging the divide between international commitments, global outreach and realisation of their potential to improve lives of patients across the world. The 4th congress aims to bring together various disciplines to address global challenges in organ transplantation.

We will achieve these aims through interactive plenary debates, innovative focus sessions, and in-depth workshops on topics that are relevant to transplant professionals worldwide. Submitted abstracts will be clustered according to theme or integrated into the focus sessions and workshops. In addition, there are 2 all-day sessions on hot topics for clinicians. There will of course also be opportunities for networking through social and cultural activities.

We trust that you will enjoy not only our conference, but also the history, culinary delights and ancient architecture of Rome.

We look forward to meeting you in Rome.

Yours sincerely,

**Willem Weimar** (The Netherlands) and  
**Franco Citterio** (Italy),  
Congress Chairs



# Organization

---

## Programme Committee

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## Acknowledgements

### This conference is supported by



Erasmus MC – University  
 Medical Center Rotterdam



The Middle East Society  
 for Organ Transplantation  
 (M.E.S.O.T.)



Italian Transplantation  
 Society (S.I.T.O.)



Turkish World Transplanta-  
 tion Society (TDTD)



European Society for Organ  
 Transplantation (ESOT)



Turkish Transplantation  
 Society (TOND)



The European Liver and  
 Intestine Transplant Association  
 (ELITA)



## Venue

Angelicum Congress Centre  
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The historical site known simply as the Angelicum in Rome is located in the precise geographical centre of the city and dates back to 1569. Along with the annexed Convent and Baroque Church of Saints Dominic and Sixtus, the property is also home to the Pontifical University of St. Thomas Aquinas, one of the Vatican's most important and prestigious places of learning for intellectuals in the Catholic world. The Angelicum Conference Centre, with its two auditoriums and 11 smaller meeting rooms, encapsulates the original cloister, which contains the garden and fountain and forms the heart of the Angelicum site. Richly steeped in history, the Angelicum has received Popes, heads of state and many of the most powerful and important figures of the last 300 years.



ANGELICVM

PONTIFICIA UNIVERSITA' S.TOMMASO D'AQUINO



## Congress Registration

The registration desk is located near the conference rooms.

Opening hours are:

Friday, 22 April	16:00 – 18:30
Saturday, 23 April	08:00 – 18:00
Sunday, 24 April	08:00 – 18:00
Monday, 25 April	08:00 – 13:00

## Accompanying Persons Policy

The fee for accompanying persons is € 50.00.

Registered accompanying persons will be admitted to all social events. The appropriate badge will be essential for admittance.

## Internet

Wifi internet access is available.  
 The code is: ELPAT2016.

## Travel Information

The Angelicum Congress Centre is a 20 minutes walk from Stazione Termini (Rome's main railway station).

**By plane/train/car:**

Please visit our website:

[www.esot.org/events-education/events/3905/info](http://www.esot.org/events-education/events/3905/info)



## Scientific Information

**We are pleased to inform you that  
#ELPAT2016 was granted  
with 17 European CME credits.**

### Abstracts

Abstracts selected for the 4<sup>th</sup> ELPAT Congress will be presented as oral presentations and poster presentations. All presenters (oral and poster) must be registered to the congress.

### Oral presentations

Oral presentations will be held in rooms:

- AULA MINOR
- ROOM 2
- ROOM 3
- ROOM 11

Abstracts selected for an oral presentation will be presented during the parallel sessions on Saturday 23, Sunday 24 April and Monday 25 April.

**Technical and AV assistants will be in attendance to help speakers and presenters.**

### Slide preview centre

Slide preview centre opening hours are:

Friday: 22 April, 15:30 – 17:30  
Saturday: 23 April, 07:30 – 18:30  
Sunday: 24 April, 07:30 – 18:30  
Monday: 25 April, 07:30 – 12:00

All presenters are required to check-in in the slide preview centre to preview and upload their files ***no later than one hour prior to the start of the session*** in which they will speak.

Staff is available to help speakers upload their presentations. When uploading your presentation, please make sure that all fonts appear as expected and all sound/video clips are working.

**Laptop support:** use of personal laptops for presentations is prohibited.

### Security

- Proper identification is required in order to submit a presentation and also to upload, preview and edit files;
- Media storage devices (USB Memory Sticks, external hard disks ...) are returned to the ELPAT Secretariat or destroyed if left behind;
- Use of cameras and video equipment are not permitted.

### Use of ESOT scientific programme content

*Please be aware that the information and materials displayed and/or presented at all sessions of this meeting*

*are the property of the 4<sup>th</sup> ELPAT Congress (and/or the presenter) and cannot be photographed, copied, photocopied, transformed to electronic format, reproduced or distributed without the written permission of ESOT (and/or the presenter). Use of the ELPAT and ESOT name and/or logo in any fashion by any commercial entity for any purpose is expressly prohibited without the express written permission of ESOT.*

### Poster presentations

All posters are located in the Cloister. Poster presentations have been assigned a chronological programme number for reference when locating the abstract in the abstract book. A 'PP##' indicates the poster board number location, that may be different from the publication number. Posters will be displayed throughout the congress.

Presenters are encouraged to be present during the poster viewing times. Please refer to the following schedule in order to identify your poster:

#### Saturday 23 and Sunday 24 April:

Posters 01-04: Cultural, religious and social aspects  
Posters 06-13: Deceased donation  
Posters 15-24: Ethical and philosophical aspects  
Posters 26-28: Legal aspects  
Posters 29-42: Living donation  
Posters 43-46: Organ trade and paid donation  
Posters 47-63: Psychosocial aspects

Posterviewing: 18:30 – 19:30 in the Cloister.

Posters not picked up by the author by the end of the congress will be discarded.

Posters should be put up on  
April 22 from 16:00 – 17:00.  
Posters should be taken down on  
April 24 from 09:00 – 13:00.

### Security and badge policy

Participants are requested to wear their badge at all times. For security reasons admittance is restricted to participants to the meeting. All presenters (oral and poster) must be registered to the congress.

### Follow us on:

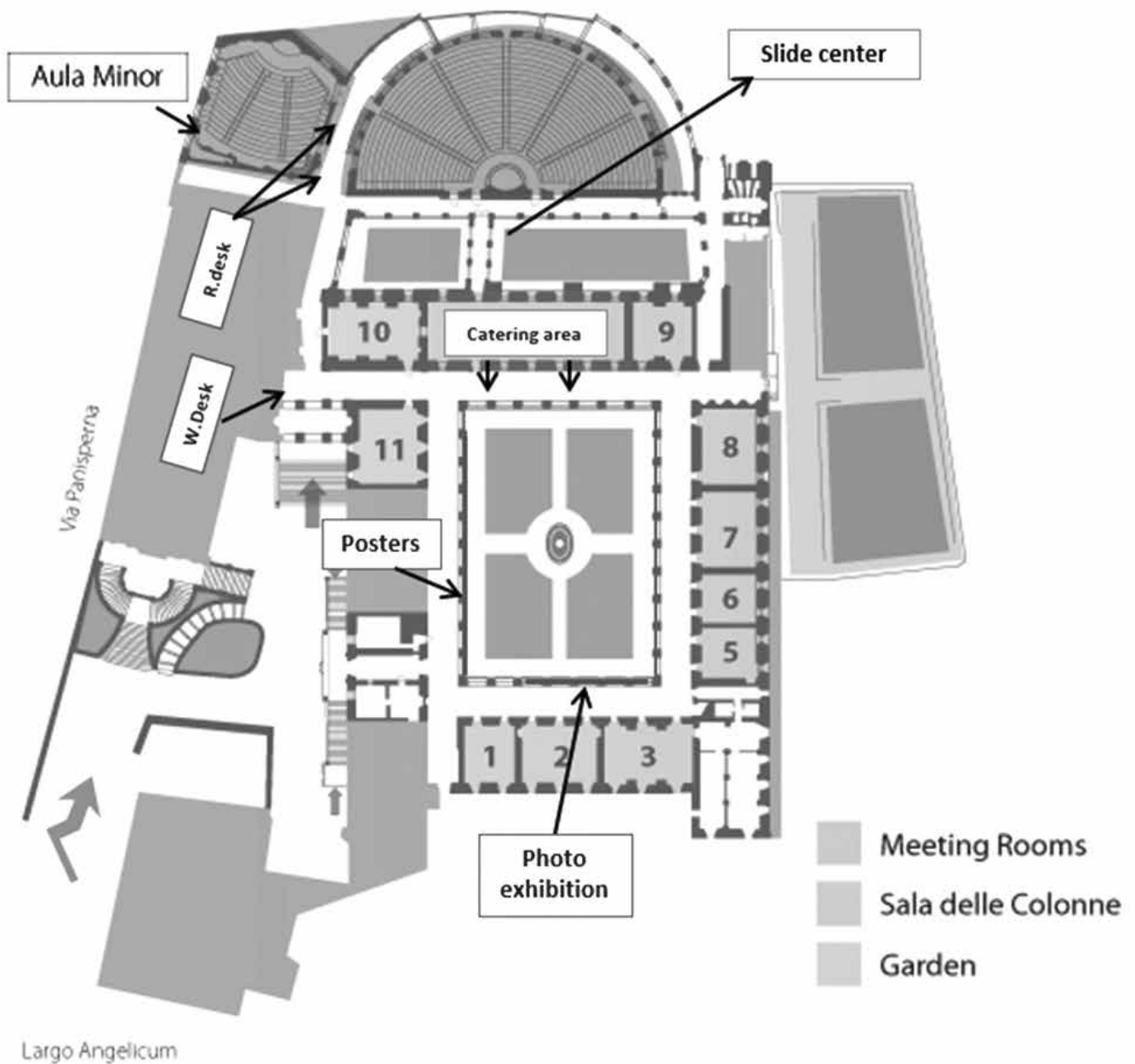


@ESOTtransplant



ESOT-European-Society-for-Organ-Transplantation

## Plan of the Congress Venue



**Plenary meeting room:** Aula Minor

**Meeting rooms:** Room 2, 3 & 11

**Poster area:** Cloister

**Catering area:** Sala delle Colonne

## Social Programme

**Friday, 22 April, 19:30 – 20:30**

### Networking event – Welcome Reception

**Angelicum/Sala delle Colonne**

Welcome drinks will be served after the congress opening session.

**Admittance:** Open to all registered ELPAT congress participants and registered accompanying persons.



**Sunday 23 April, 18:30 – 19:30**



### Book launch 'Ethical issues in paediatric organ transplantation'

*Rebecca Greenberg, Aviva Goldberg, David Rodriguez-Arias (Eds.)*

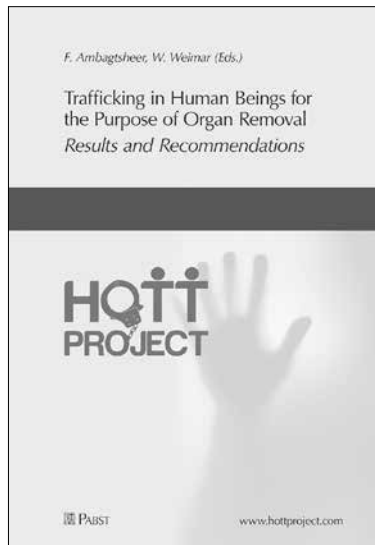
This book offers a theoretical and practical overview of the specific ethical and legal issues in pediatric organ transplantation. Written by a team of leading experts, 'Ethical Issues in Pediatric Organ Transplantation' addresses those difficult ethical questions concerning clinical, organizational, legal and policy issues including donor, recipient and allocation issues. Challenging topics, including children as donors, donation after cardiac death, misattributed paternity, familial conflicts of interest, developmental disability as a listing criteria, small bowel transplant, and considerations in navigating the media are discussed.

*17-5-2016 Published by: Springer International Publishing AG  
ISBN13: 978-3-31929-183-3*

Drinks and snacks will be served in the Sala delle Colonne.

**Admittance:** Open to all registered ELPAT congress participants and registered accompanying persons.

**Monday, 22 April, 18:30 – 19:30**



### **Book launch**

## **'HOTT Project: Trafficking in Human Beings for the Purpose of Organ Removal. Results and Recommendations from the HOTT Project**

*F. Ambagtsheer, W. Weimar (Eds.)*

The book starts with a foreword by Prof. Scheper-Hughes and a literature review (Chapter I). This is followed by an interview study on patients who purchased kidney transplants abroad (Chapter II), an empirical study of prosecuted criminal cases (Chapter III), recommendations to improve non-legislative responses (Chapter IV) and indicators for law enforcement, transplant professionals and victim support workers to identify the crime (Chapter V).

*2016 Published by: Pabst Science Publishers, Lengerich*

*Print ISBN13: 978-3-95853-121-5 · eBook ISBN 978-3-95853-122-2*

This report is published with the financial support of the Prevention of and Fight against Crime Programme European Commission – Directorate General Home Affairs.



Drinks and snacks will be served in the Sala delle Colonne.

**Admittance:** Open to all registered ELPAT congress participants and registered accompanying persons.

# Programme Overview

	Friday 22 April	Saturday 23 April	Sunday 24 April	Monday 25 April
08:00		Registration open	Registration open	Registration open
08:30-09:00		Plenary debate 2	Plenary debate 3	Free communications
09:00-09:30		Social media and transplantation: pushing the envelope?	Heart donation after cardiac death: contradictio in terminis?	7 - 8 - 9 - 10
09:30-10:00		Break	Break	Break
10:00-10:30		Focus sessions 1 - 2 - 3	Focus sessions 4 - 5 - 6	Focus sessions 7 - 8
10:30-11:00		Hot topics for physicians: Living donation	Hot topics for physicians: Deceased donation	Free communications 11 - 12
11:00-11:30		Free communications 1 - 2 - 3	Free communications 4 - 5 - 6	Plenary debate 4
11:30-12:00				Uterus transplantation: necessity or indulgence?
12:00-12:30				Trading gametes in a worldwide market
12:30-13:00				
13:00-13:30		Workshops 1 - 2 - 3	Workshops 4 - 5 - 6	
13:30-15:00		(continued) Living donation	(continued) Deceased donation	
15:00-15:30		Break	Break	
15:30-16:00		(continued) Workshops 1 - 2 - 3	(continued) Workshops 4 - 5 - 6	
16:00-16:30				
16:30-17:00	Registration open			
17:00-17:30				
17:30-18:00	Plenary debate 1			
18:00-18:30	Incentives for living donation: moving beyond the deadlock			
18:30-19:00		Poster viewing & book launch: 'Ethical Issues in Paediatric Organ Transplantation'	Poster viewing & book launch: 'HOTT project: Trafficking in Human Beings for the Purpose of Organ Removal'	
19:00-19:30				
19:30-20:00	Networking event - welcome drinks			
20:00-20:30				

## Scientific Programme

	Friday 22 April
16:30	Registration open
17:30	<b>Plenary Debate 1 - Aula Minor</b> <b>INCENTIVES FOR LIVING DONATION:</b> <b>MOVING BEYOND THE DEADLOCK</b> Sigrid Fry-Revere, Elisa Gordon, Allison Tong
19:30 20:30	Networking event - welcome drinks

17:30-19:30 **Opening/Plenary debate 1** *Aula Minor*  
*Willem Weimar, Rotterdam, The Netherlands & Franco Citterio, Rome, Italy*

### **Incentives for living donation: moving beyond the deadlock**

*Chairs: Benjamin Hippen, Charlotte, United States & Mustafa Al-Mousawi, Kuwait City, Kuwait*

17:45 The kidney sellers; lessons learned in Iran  
*Sigrid Fry-Revere, Lovettsville, United States*

18:00 Ethical and practical considerations in testing financial incentives  
*Elisa Gordon, Chicago, United States*

18:15 Professional and public perspectives  
*Allison Tong, Sydney, Australia*

18:30 Debate

19:30-20:30 **Networking event – welcome drinks**

*Sala delle Colonne*

Saturday 23 April				
08:00	Registration open			
08:30	Plenary Debate 2 - Aula Minor SOCIAL MEDIA AND TRANSPLANTATION: PUSHING THE ENVELOPE? Greg Moorlock, Emma Massey			
10:00	Break			
	Room 2	Room 3	Room 11	Aula Minor
10:30	Focus Session 1 Inequities in transplantation: strategies to improve access	Focus Session 2 Ethical controversies in allocation	Focus Session 3 Improving adherence: from observation to intervention	Hot topics for physicians: Living donation
12:00	Free communications 1 Deceased Donation	Free communications 2 Legal Aspects	Free communications 3 Cultural, religious and social aspects (A)	
13:30				
15:00	Workshop 1 Clinical research in deceased donation: medical, ethical, legal and societal aspects	Workshop 2: Common problems and national approaches to death and deceased donation	Workshop 3 Public issues in organ donation and transplantation	(continued) Living donation
16:30	Break			
17:00	(continued) Workshop 1	(continued) Workshop 2	(continued) Workshop 3	(continued) Living donation
18:30	Poster viewing & book launch:			
19:30	'Ethical Issues in Paediatric Organ Transplantation'			

08:30-10:00 Plenary debate 2

*Aula Minor***Social media and transplantation: pushing the envelope?***Chairs: Katrina Bramstedt, Queensland, Australia & Frank Dor, London, United Kingdom*

08:30 What is wrong with the beauty contest?  
*Greg Moorlock, Birmingham, United Kingdom*

08:45 The donor and patient perspective  
*Emma Massey, Rotterdam, The Netherlands*

09:00 Debate

10:00 **BREAK**

10:30-12:00 Focus session 1

*Room 2***Inequities in transplantation: strategies to improve access***Chairs: Allison Tong, Sydney, Australia & Faissal Shaheen, Jeddah, Saudi Arabia*

10:30 OP01 African Canadian and East Asian Canadian patients are less likely to have potential living donors when first presenting for evaluation  
*Istvan Musci, Toronto, Canada*

10:42 OP02 Psychosocial impact of paediatric living-donor transplantation in donors, recipients and the family: a systematic review  
*Isabelle Aujoulat, Brussels, Belgium*



- 10:54 Increasing access to live donor kidney transplantation: recommendations from a U.S. consensus conference  
*James Rodrigue, Boston, United States*
- 11:09 The socio-economic factors affecting access and results of kidney transplantation  
*Mirjam Laging, Rotterdam, The Netherlands*
- 11:24 Debate

## 10:30-12:00 Focus session 2

Room 3

**Ethical controversies in allocation**

*Chairs: Medard Hilhorst, Rotterdam, The Netherlands & Axel Rahmel, Frankfurt a. M., Germany*

- 10:30 OP05 Young for old – old for young? The moral economy of age and intergenerational relations in organ donation  
*Sabine Woehlke, Göttingen, Germany*
- 10:42 OP06 A public policy based on incentives to address the organ shortage and its consequences: conceptual underpinnings and legal implications  
*Melanie Levy, Tel Aviv, Israel*
- 10:54 Ethical implications of the use of methodologically limited prognosis scores in organ allocation policy  
*Benjamin Hippen, Charlotte, United States*
- 11:09 Old donors, marginal organs, young recipients – can we continue?  
*Undine Samuel, Leiden, The Netherlands*
- 11:24 Debate

## 10:30-12:00 Focus session 3

Room 11

**Improving adherence: from observation to intervention**

*Chairs: Emma Massey, Rotterdam, The Netherlands & Dianne LaPointe Rudow, New York, United States*

- 10:30 Building systems of care that support patient's adherence  
*Sabina de Geest, Basel, Switzerland*
- 10:45 Practical approaches to improving adherence in high risk populations  
*Paul Harden, Oxford, United Kingdom*

- 11:00 OP03 The relationship between health literacy, self-management and complications after kidney transplantation  
*Louise Maasdam, Rotterdam, The Netherlands*
- 11:12 OP04 History of mental health disorders and non-adherence: barriers in access to kidney transplantation  
*Istvan Musci, Toronto, Canada*

11:24 Debate

## 12:00-13:30 Free Communications 1

Room 2

**Deceased donation**

*Chairs: Diethard Monbaliu, Leuven, Belgium & Dale Gardiner, Bristol, United Kingdom*

- 12:00 OP07 Organ donation agency: a discourse analysis of correspondence between donor and organ recipient families  
*Dariusz Galasinski, Wolverhampton, United Kingdom*
- 12:12 OP08 Design and implementation of a publicly responsive deceased donor kidney allocation system  
*Aviva Goldberg, Winnipeg, Canada*
- 12:24 OP09 Advanced nursing practice applied to tissue donation on transplant section of hospital Clínic of Barcelona  
*Marc Bohils, Barcelona, Spain*
- 12:36 OP10 What do we talk about when we talk about increasing donation rates?  
*Sara Bea, Edinburgh, United Kingdom*
- 12:48 OP11 Significantly more consent for organ donation for doctors trained in 'communication about donation'  
*Nichon Jansen, Leiden, The Netherlands*
- 13:00 OP12 Video based E-Learning in 'Communication about Donation' skills for doctors provides a better outcome on consent for tissue donation  
*Edwin Vorstius Kruijff, Breda, The Netherlands*
- 13:12 OP13 No! An anthropological study of Danish families who refused organ donation when asked at the hospital  
*Anja Marie Jensen, Copenhagen, Denmark*

12:00-13:30 Free Communications 2 *Room 3***Legal aspects**

*Chairs: Pablo de Lora, Madrid, Spain & Alexander Capron, Los Angeles, United States*

12:00 OP14 Living tissue and organ donation by minors: the regulatory framework across Europe  
*Kristof van Assche, Ghent, Belgium*

12:12 OP15 Legal considerations on pre-mortem interventions in donation after circulatory death  
*Kourosh Saeb-Parsy, Cambridge, United Kingdom*

12:24 OP16 Family override of consent for deceased donation: the law and policy in Canada, the United Kingdom, and the United States of America  
*Maeghan Toews, Edmonton, Canada*

12:36 OP17 Ethical tensions between end-of-life and organ donation  
*David Rodriguez-Arias, Granada, Spain*

12:48 OP18 The 'DOHA model of organ donation': from an ethical framework to new national transplant legislation  
*Riadh Fadhil, Doha, Qatar*

13:00 OP19 The law and ethics of preliminary medical measures facilitating organ retrieval: an analysis of the new Swiss legal framework  
*Melanie Levy, Tel Aviv, Israel*

13:12 OP20 Healthcare law analyses of the donor registry in the The Netherlands: is registered consent to organ donation legally binding after death  
*Denie Georgieva, Leiden, The Netherlands*

12:00-13:30 Free communications 3 *Room 11***Cultural, religious and social aspects (A)**

*Chairs: Anwar Naqvi, Karachi, Pakistan & Mihaela Frunza, Cluj, Romania*

12:00 OP21 Guardians of "the gift" – emotional challenges of doctors and nurses working with heart and lung transplantation  
*Anja Marie Jensen, Copenhagen, Denmark*

12:12 OP22 Undergraduate nursing and medical students' attitudes and knowledge towards

organ donation: a survey in Modena-Reggio-emilia University  
*Lisa Giovannini, Modena, Italy*

12:24 OP23 Critical care professionals' knowledge and attitudes related to brain death, cadaveric organ donation and transplantation  
*Wei Loon Oo, Serdang Selangor, Malaysia*

12:36 OP24 Overview of family refusals to organ donation in Catalonia  
*Jorge Twose, Barcelona, Spain*

12:48 OP25 Influencers of public trust in the organ donation system in India  
*Nora Pernesch, Chennai, India*

13:00 OP26 Increased organ donation willingness after German transplantation scandals: the influence of public attitudes towards brain-death and body concepts  
*Larissa Pfaller, Erlangen, Germany*

13:12 OP27 The core of social function after solid organ transplantation  
*Anna Forsberg, Gothenburg, Sweden*

**13:30-15:00 BREAK**15:00-18:30 Workshop 1 *Room 2***Clinical research in deceased donation: medical, ethical, legal and societal aspects**

*Chairs: Rutger Ploeg, Oxford, United Kingdom & Bernadette Haase, Leiden, The Netherlands*

15:00 Introduction workshop by the chairs

15:13 OP28 An ethical and legal framework for conducting deceased donor research  
*Alexandra Glazier, Waltham, United States*

15:25 WG1: DCD, in-situ normothermic regional perfusion to increase number and quality of transplantable organs with better utilization compared to conventional preservation  
*Tineke Wind, Maastricht, The Netherlands*

15:30 WG2: DBD, targeted intervention in the donor after diagnosis of brain death during donor management but prior to retrieval, e.g. systemic administration of complement inhibitor  
*Rutger Ploeg, Oxford, United Kingdom*

15:35 WG3: Ex-situ conditioning of 'high risk' donor organs including machine perfusion

and use of pharmacological agents and stem cells

*Diethard Monbaliu, Leuven, Belgium*

15:40 Break-out sessions

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**16:30 BREAK**

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17:00 Plenary session with draft protocol reports and discussion

18:00 Summary and conclusion

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**15:00-18:30 Workshop 2**

*Room 3*

**Common problems and national approaches to death and deceased donation**

*Chairs: Thomas Gutmann, Munster, Germany & Medard Hilhorst, Rotterdam, The Netherlands*

15:00 OP29 Abandoning the dead donor rule: insights from an exploratory survey in Spain  
*Elvira Santiago, Madrid, Spain*

15:12 OP30 The use of the brain death criterion in organ donation after the circulatory determination of death  
*Anne Dalle Ave, Lausanne, Switzerland*

15:24 The Swiss approach  
*Tanja Krones, Zurich, Switzerland*

15:44 The Spanish approach  
*Pablo de Lora, Madrid, Spain*

16:04 Discussion

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**16:30 BREAK**

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17:00 The United Kingdom approach  
*Antonia Cronin, London, United Kingdom*

17:20 The German approach  
*Thomas Gutmann, Münster, Germany*

17:40 The Italian approach  
*Marco Vergano, Torino, Italy*

18:00 Discussion

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**15:00-18:30 Workshop 3**

*Room 11*

**Public issues in organ donation and transplantation**

*Chairs: David Rodriguez Arias, Granada, Spain & Sohal Ismail, Rotterdam, The Netherlands*

15:00 From doubts and fear to public praise: changing perceptions of deceased organ donation in Denmark 1985-2015  
*Klaus Høyer, Copenhagen, Denmark*

15:20 Engaging the public in organ donation  
*Jeantine Reiger, Leiden, The Netherlands*

15:40 Discussion

16:00 OP31 How does public perceive general messages about organ donation – a qualitative research  
*Bernarda Logar Zakrajsek, Ljubljana, Slovenia*

16:10 OP32 Partnerships between media and ethics: students peer-to-peer campaigns for organ donation  
*Mihaela Frunza, Cluj, Romania*

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**16:30 BREAK**

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17:00 Role of transplant coordinators in public engagement  
*Sunil Shroff, Chennai, India*

17:20 The digital donor card – population's adoption & future development  
*Jocelyn Corniche, Lausanne, Switzerland*

17:40 Discussion

18:00 OP34 Organ donation card as an ATM card; a joint initiative  
*Masoud Mazaheri, Tehran, Iran*

18:10 OP35 Depicting moral messages – an analysis of German poster campaigns on organ transplantation  
*Solveig Hansen, Göttingen, Germany*

18:20 OP36 The framing of family veto in organ donation in Canadian media  
*Samantha Anthony, Toronto, Canada*

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## Parallel Sessions

## Aula Minor

**Hot topics for physicians:  
living donation**

10:30-12:00

*Chairs: Annette Lennerling, Gothenburg, Sweden  
& Yaman Tokat, Istanbul, Turkey*

10:30 Justifying nontherapeutic surgery – the ethics of living organ donation  
*Dominique Martin, Victoria, Australia*

11:00 Hippocrates in the 21st century: risks for the kidney donor  
*Frank Dor, London, United Kingdom*

11:30 Living liver donation: risks, selection and informed consent  
*Gabriela Berlakovich, Vienna, Austria*

12:00-13:30

*Chairs: Luigi Biancone, Torino, Italy & Nigel Heaton, London, United Kingdom*

12:00 Strategies to expand the living donor pool  
*James Rodrigue, Boston, United States*

12:30 Encouraging non-directed altruistic living donation  
*Antonia Cronin, London, United Kingdom*

13:00 Psychological donor screening  
*Dianne LaPointe Rudow, New York, United States*

15:00-16:30

*Chairs: Lisa Burnapp, Bristol, United Kingdom & Michael Bos, Groningen, The Netherlands*

15:00 Kidney exchange and paired donation  
*Franco Citterio, Rome, Italy*

15:30 Anonymity forever after unspecified donation?  
*Nizam Mamode, London, United Kingdom*

16:00 Transplant tourism, commercialism and trafficking  
*Frederike Ambagtsheer, Rotterdam, The Netherlands*

17:00-18:30

*Chairs: William Bennet, Gothenburg, Sweden  
& Paolo Muiesan, Birmingham, United Kingdom*

17:00 Living donor liver donation in Europe, data from the European Registry  
*William Bennet, Gothenburg, Sweden*

17:30 Living donor liver transplantation for children: the best you can get  
*Raymond Reding, Bruxelles, Belgium*

18:00 Do we really need living donor liver donation?  
*Yaman Tokat, Istanbul, Turkey & Nigel Heaton, London, United Kingdom*

**18:30-19:30 BOOK LAUNCH Sala delle Colonne  
and POSTERVIEWING**

18:30 Book launch: Ethical issues in paediatric organ donation  
*Rebecca Greenberg, Aviva Goldberg, David Rodriguez-Arias (Eds.)*

For further information see page 10.

**18:30-19:30 Posterviewing****Poster area**

PP 01-04: Cultural, religious and social aspects  
PP 06-13: Deceased donation  
PP 15-24: Ethical and philosophical aspects  
PP 26-28: Legal aspects  
PP 29-42: Living donation  
PP 43-46: Organ trade and paid donation  
PP 47-63: Psychosocial aspects

Sunday 24 April				
08:00	Registration open			
08:30	<b>Plenary Debate 3 - Aula Minor</b> <b>Heart donation after cardiac death: contradictio in terminis?</b> <b>Stephen Large, Michael Nair-Collins</b>			
10:00	Break			
	Room 2	Room 3	Room 11	Aula Minor
10:30	<b>Focus Session 4</b> How informed is the living donor?	<b>Focus Session 5</b> Anonymous living donation & unbalanced kidney exchange	<b>Focus Session 6</b> Rights and duties of health professionals in transplant tourism	Hot topics for physicians: Deceased donation
12:00	<b>Free communications 4</b> Ethical and philosophical aspects (A)	<b>Free communications 5</b> Psychological aspects - Donors (A)	<b>Free communications 6</b> Organ trade and paid donation/incentives	Deceased donation
13:30				
15:00	<b>Workshop 4</b> Pediatric donation and transplantation	<b>Workshop 5:</b> Psychosocial evaluation, support and education of living donor candidates	<b>Workshop 6</b> Understanding the human organ trade	(continued) Deceased donation
16:30	Break			
17:00	(continued) <b>Workshop 4</b>	(continued) <b>Workshop 5</b>	(continued) <b>Workshop 6</b>	(continued) Deceased donation
18:30	Poster viewing & book launch:			
19:30	<b>'HOTT Project: Trafficking in Human Beings for the Purpose of Organ Removal'</b>			

08:30-10:00 Plenary debate 3

Aula Minor

### Heart donation after cardiac death: contradictio in terminis?

*Chairs: Thomas Gutmann, Munster, Germany & Arthur Matas, Minneapolis, United States*

08:30 Can hearts from DCD donors be used for transplantation  
*Stephen Large, Cambridge, United Kingdom*

08:45 An ethical exploration of the determination of death  
*Michael Nair-Collins, Tallahassee, United States*

09:00 Debate

10:00 BREAK

10:30-12:00 Focus session 4

Room 2

### How informed is the living donor?

*Chairs: Frank Dor, London, United Kingdom & Rebecca Hays, Madison, United States*

10:30 OP37 Towards a standardized informed consent procedure for live donor nephrectomy: what do surgeons tell potential donors?  
*Kirsten Kortram, Rotterdam, The Netherlands*



- 10:42 OP38 Discussions with prospective donors: informed consent when knowledge is limited  
*Arthur Matas, Minneapolis, United States*
- 10:54 Informed consent for living donors: ethical dimensions and research opportunities  
*Elisa Gordon, Chicago, United States*
- 11:09 Informing the living donor: Practical approaches to moral dilemmas  
*Lisa Burnapp, Bristol, United Kingdom*
- 11:24 Debate

## 10:30-12:00 Focus session 5

Room 3

**Anonymous living donation & unbalanced kidney exchange**

*Chairs: Nizam Mamode, London, United Kingdom & Linda Wright, Toronto, Canada*

- 10:30 Anonymous living donation programs  
*Willij Zuidema, Rotterdam, The Netherlands*
- 10:45 The participation of compatible pairs in kidney exchange programs  
*Marie-Chantal Fortin, Montreal, Canada*
- 11:00 OP42 Non-directed altruistic, unspecified kidney donation in the United Kingdom – nine year experience  
*Rachel Johnson, London, United Kingdom*
- 11:12 OP43 Anonymity in live kidney donation reconsidered: patients' and donors' experiences, preferences and attitudes towards anonymity  
*Dorthe Slaats, Rotterdam, The Netherlands*
- 11:24 Debate

## 10:30-12:00 Focus session 6

Room 11

**Rights and duties of health professionals in transplant tourism**

*Chairs: John Gill, Vancouver, Canada & Seán Columb, Liverpool, United Kingdom*

- 10:30 OP39 Outcome of transplant tourism: a single center experience  
*Meteb Al Bugami, Dammam, Saudi Arabia*
- 10:40 OP40 Avoiding complicity in foreign transplant abuse  
*David Matas, Winnipeg, Canada*

- 10:50 OP41 Transplant tourism – cases series studies with ethical reflection in Taiwan  
*Alex, Chih-Yu Chen, London, United Kingdom*

- 11:00 Transplant professionals should breach their secrecy oath  
*Frederike Ambagtsheer, Rotterdam, The Netherlands*

- 11:15 Responsibility of professionals in implementing the Council of Europe convention  
*Francis Delmonico, Boston, United States*

- 11:30 Debate

## 12:00-13:30 Free Communications 4

Room 2

**Ethical and philosophical aspects (A)**

*Chairs: Arthur Matas, Minneapolis, United States & Govert den Hartogh, Haarlem, The Netherlands*

- 12:00 OP44 Is it ethical to procure organs after physician-assisted dying or cessation of treatment in a conscious patient?  
*Julie Allard, Montreal, Canada*
- 12:12 OP45 Ethical, legal and psychosocial issues of organ transplantation in the context of euthanasia and physician-assisted suicide: the example of Quebec, Canada  
*Deborah Ummel, Montreal, Canada*
- 12:24 OP46 Organ donation after euthanasia: an ethical controversy  
*Jan Bollen, Maastricht, The Netherlands*
- 12:36 OP47 Psychology, ethics and organ donation following assisted death in Quebec: maximizing patient autonomy and minimizing risks for all  
*Marie Achille, Montreal, Canada*
- 12:48 OP48 Is it ethical to withhold transplants from obese patients unless they show willingness and commitment towards weight loss and healthier lifestyles?  
*Greg Moorlock, Birmingham, United Kingdom*
- 13:00 OP49 Balancing non-maleficence and autonomy: a donor-centered approach to risk assessment  
*Sanjay Kulkarni, New Haven, United States*

- 13:12 OP50 No harm in asking? Social media, living donors and helping ourselves to health-care resources  
*Heather Draper, Birmingham, United Kingdom*

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**12:00–13:30 Free Communications 5 Room 3**

**Psychological aspects – Donors (A)**

*Chairs: Inês Mega, Lisbon, Portugal & Sohal Ismail, Rotterdam, The Netherlands*

- 12:00 OP51 Psychosocial evaluation of living kidney donors: preliminary findings from an international professional survey  
*Riadh Fadhil, Carlton, Australia*
- 12:12 OP52 In their own words: living kidney donors who develop kidney failure  
*Lainie Ross, Chicago, United States*
- 12:24 OP53 ‘Hey sister! Where’s my kidney?’ – managing expectations for donor organs, scarce resources, justice and ethics in South African transplant  
*Harriet Etheredge, Johannesburg, South Africa*
- 12:36 OP54 Psychosocial long-term impact of donation on kidney living donors – a comparative study of two major European transplant centres  
*Entela Kondo, Barcelona, Spain*
- 12:48 OP55 Unspecified kidney donors and their families and friends: a qualitative study exploring psychosocial context of donation  
*Alexis Clarke, Plymouth, United Kingdom*
- 13:00 OP56 Better the donor you know? A qualitative study of renal patient attitudes to ‘altruistic’ live-donor kidney transplantation  
*Phillippa Bailey, Bristol, United Kingdom*

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**12:00–13:30 Free Communications 6 Room 11**

**Organ trade and paid donation/ Incentives**

*Chairs: Hélène Le-Borgne, Brussels, Belgium & Anwar Naqvi, Karachi, Pakistan*

- 12:00 OP57 Deceased organ donation: why the misplaced promotion of altruism could kill the altruism of the dead  
*Leonardo de Castro, Singapore, Singapore*

- 12:12 OP58 Paying families of deceased donors: unwise and unethical  
*Alexander Capron, Los Angeles, United States*

- 12:24 OP59 Efficacy of nine national policies reimbursing and incentivizing live organ donation  
*Sigrid Fry-Revere, Lovettsville, United States*

- 12:36 OP60 The Iran’s commercial renal transplantation program reconsidered  
*Javaad Zargooshi, Kermanshah, Iran*

- 12:48 OP61 A qualitative study into the modus operandi, investigation and prosecution of organ trafficking networks in South Africa and Kosovo  
*Frederike Ambagtsheer, Rotterdam, The Netherlands*

- 13:00 OP62 Interviews with patients who travelled from Macedonia, Kosovo, The Netherlands and Sweden for paid kidney transplantations  
*Frederike Ambagtsheer, Rotterdam, The Netherlands*

- 13:12 OP63 The sad story of kidney buyers on the Balkans  
*Ninoslav Ivanovski, Skopje, F.Y.R Macedonia*

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**13:30–15:00 BREAK**

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**15:00–18:30 Workshop 4 Room 2**

**Pediatric donation and transplantation**

*Chairs: Marion Siebelink, The Netherlands & Karl-Leo Schwering, France*

- 15:00 Paediatric donation: an overview  
*Marion Siebelink, Groningen, The Netherlands*
- 15:15 Care, consent, certainty and conflicts: ethical dilemmas in paediatric DCDD  
*Dominique Martin, Victoria, Australia*
- 15:35 Discussion
- 15:50 OP64 Life lines: a father’s personal account of organ donation  
*Magi Sque, Wolverhampton, United Kingdom*



16:02 OP65 Under what conditions should minors be considered as potential hematopoietic stem cell donors: a systematic review of guidelines and protocols  
*Miha Orazem, Leuven, Belgium*

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**16:30 BREAK**

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17:00 Impact of living transplantation on family dynamics  
*Karl-Leo Schwering, Paris, France*

17:20 Transplantation and social media: ethical considerations in paediatrics  
*Rebecca Greenberg, Toronto, Canada*

17:40 Discussion

17:50 OP67 Where there's smoke... marijuana use in paediatric transplant candidates  
*Aviva Goldberg, Winnipeg, Canada*

18:02 OP68 Ethical management of contraception in adolescent transplant recipients  
*Aviva Goldberg, Winnipeg, Canada*

18:14 OP69 Migration to Germany for renal transplantation of children and adolescents with end stage renal disease  
*Matthias Galiano, Erlangen, Germany*

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**15:00-18:30 Workshop 5**

*Room 3*

**Psychosocial evaluation, support and education of living donor candidates**

*Chairs: Inês Mega, Lisbon, Portugal & Emma Massey, Rotterdam, The Netherlands*

15:00 OP70 An update on the multi-site, prospective kidney donor outcomes cohort, KDOC study in the United States  
*James Rodrigue, Boston, United States*

15:12 OP71 Predictors for longer-term health-related quality of life of living kidney donors: a prospective multicenter study  
*Lieke Wirken, Leiden, The Netherlands*

15:24 How to best evaluate live donor candidates? The Live Donor Assessment Tool, LDAT  
*Dianne LaPointe Rudow, New York, United States*

15:44 An ELPAT psychosocial screening tool for living donor candidates: from idea to prototype  
*Emma Massey, Rotterdam, The Netherlands*

16:04 Discussion

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**16:30 BREAK**

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17:00 OP72 Who should decide?: Potential living kidney donor preferences for making decisions about risk  
*Carrie Thiessen, New Haven, United States*

17:12 OP73 Living kidney donor priorities for outcomes: a nominal group technique study  
*Camilla Hanson, Sydney, Australia*

17:24 OP74 Tailored E-health cognitive behavioral therapy for living kidney donors at risk  
*Lieke Wirken, Leiden, The Netherlands*

17:36 The role of living donor advocates and application to the European setting  
*Rebecca Hays, Madison, United States*

17:56 Discussion

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**15:00-18:30 Workshop 6**

*Room 11*

**Understanding the human organ trade**

*Chairs: Sigrid Fry-Revere, Lovettsville, United States & Michael Bos, Groningen, The Netherlands*

15:00 A critical analysis of the organ trafficking discourse  
*Seán Columb, Liverpool, United Kingdom*

15:15 Prosecuting brokers and doctors in Israel: the latest news on their modus operandi  
*Gilad Erlich, Tel Aviv, Israel*

15:30 Organ trafficking in the context of war and political conflict  
*Nancy Scheper-Hughes, Washington, United States*

15:45 Discussion

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**16:30 BREAK**

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- 17:00 Prevention of transplant tourism  
*John Gill, Vancouver, Canada*
- 17:15 Discussion
- 17:30 OP76 A legal framework to support transnational reporting of transplant-related crimes: the value of extraterritorial jurisdiction  
*Alexander Capron, Los Angeles, United States*
- 17:40 OP77 Protection of human beings trafficked for the purpose of organ removal: recommendations  
*Kristof van Assche, Ghent, Belgium*
- 17:50 OP79 Paying living kidney donors and the problem of exploitation  
*Julian Koplin, Melbourne, Australia*
- 18:00 Discussion

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**Parallel Sessions**
**Aula Minor**
**Hot topics for physicians:  
deceased donation**

- 10:30-12:00  
*Chairs: Adibul Rizvi, Karachi, Pakistan & Rutger Ploeg, Oxford, United Kingdom*
- 10:30 Diagnosing death in the 21<sup>st</sup> Century  
*Dale Gardiner, Bristol, United Kingdom*
- 11:00 Public perception of deceased donation: from fear to praise  
*Klaus Høyer, Copenhagen, Denmark*
- 11:30 Mass media campaigns in organ donation  
*Jeantine Reiger, Leiden, The Netherlands*
- 12:30-13:30  
*Chairs: Bernadette Haase, Leiden, The Netherlands & Franco Citterio, Rome, Italy*
- 12:30 Children as donors  
*Marion Siebelink, Groningen, The Netherlands*
- 13:00 Directed deceased donation  
*Medard Hilhorst, Rotterdam, The Netherlands*

- 15:00-16:30  
*Chairs: Dirk Ysebaert, Antwerp, Belgium & Dale Gardiner, Bristol, United Kingdom*
- 15:00 Donor stewardship and the dual responsibility to donor and recipient  
*Rutger Ploeg, Oxford, United Kingdom*
- 15:30 Dead enough? Models of regulation for donation after circulatory determination of death  
*Thomas Gutmann, Munster, Germany*
- 16:00 Strategies to promote deceased donation in emerging countries  
*Adibul Rizvi, Karachi, Pakistan*
- 17:00-18:30  
*Chairs: Hélène Le-Borgne, Brussels, Belgium & Michael Nair-Collins, Tallahassee, United States*
- 17:00 Organ donation after euthanasia  
*Dirk Ysebaert, Antwerp, Belgium*
- 17:30 Reciprocity as leading principle in allocation: the Israeli solution  
*Jacob Lavee, Ramat Aviv, Israel*
- 18:00 From whom do we need consent for deceased donation?  
*David Shaw, Basel, Switzerland*

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**18:30-19:30 BOOK LAUNCH Sala delle Colonne and POSTERVIEWING**

- 18:30 Book launch: HOTT Project: Trafficking in Human Beings for the Purpose of Organ Removal. Results and Recommendations.  
*F. Ambagtsheer, W. Weimar (Eds.)*

For further information see page 11.

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**18:30-19:30 Posterviewing**
**Poster area**

- PP 01-04: Cultural, religious and social aspects  
PP 06-13: Deceased donation  
PP 15-24: Ethical and philosophical aspects  
PP 26-28: Legal aspects  
PP 29-42: Living donation  
PP 43-46: Organ trade and paid donation  
PP 47-63: Psychosocial aspects

Monday 25 April				
08:00	Registration open			
	<i>Aula Minor</i>	<i>Room 2</i>	<i>Room 3</i>	<i>Room 11</i>
08:30	<b>Free communications 7</b> Cultural, religious and social aspects (B)	<b>Free communications 8</b> Ethical and philosophical aspects (B)	<b>Free communications 9</b> Pediatric donation and transplantation	<b>Free communications 10</b> Living donation (A)
10:00	Break			
	<i>Aula Minor</i>	<i>Room 2</i>	<i>Room 3</i>	<i>Room 11</i>
10:30	<b>Focus Session 7</b> Cultural & religious considerations in living & deceased donation	<b>Focus Session 8</b> Ethical and psychological aspects of face transplant	<b>Free communications 11</b> Psychological aspects - Recipients (B)	<b>Free communications 12</b> Living donation (B)
12:00	<b>Plenary Debate 4 - Aula Minor</b> <b>Uterus transplantation: necessity or indulgence?</b> Niclas kvarnström, Inez de Beaufort <b>Trading gametes in a worldwide market</b> Guido Pennings			

08:30-10:00 Free communications 7

*Aula Minor***Cultural, religious and social aspects (B)***Chairs: Magi Sque, Wolverhampton, United Kingdom & Faissal Shaheen, Jeddah, Saudi Arabia*

- 08:30 OP94 FOEDUS WP 7 – international approach in communication  
*Marie Lingemann, Frankfurt a/M, Germany*
- 08:42 OP95 Renal transplantation in the Middle East: challenges and opportunities  
*Ala Ali, Baghdad, Iraq*
- 08:54 OP96 The outcomes and controversies of transplantation tourism: 11-year lessons from Taiwan  
*Shi-Wei Huang, Taipei, Taiwan*
- 09:06 OP97 Panorama of transplantation in Algeria  
*Khadidja Habchi, Khadidja, Algeria*
- 09:18 OP98 Attitudes about organ donation and transplantation among Montenegrin population  
*Marina Ratkovic, Podgorica, Montenegro*
- 09:30 OP99 Attitude and knowledge about donation and transplantation in a sample of Moldavian population  
*Jorge Twose, Barcelona, Spain*
- 09:42 OP100 Battling transplantation tourism through policy and legal reform in Taiwan  
*Daniel Fu-Chang Tsai, Taipei, Taiwan*

## 08:30-10:00 Free communications 8

Room 2

**Ethical and philosophical aspects (B)**

*Chairs: Greg Moorlock, Birmingham, United Kingdom and Govert den Hartogh, Haarlem, The Netherlands*

08:30 OP101 Head transplantation – a no brainer?  
*Assya Pascalev, Sofia, Bulgaria*

08:42 OP102 The ethical complexity of regenerative medicine: growing and sharing livers  
*Katrina Bramstedt, Queensland, Australia*

08:54 OP103 Acquired familial amyloid polyneuropathy after domino liver transplantation: a new disease, a new challenge  
*Elia Mateus, Lisbon, Portugal*

09:06 OP104 Sweating the small stuff – communication, continuity of care and best interests in organ transplant in Gauteng province, South Africa  
*Harriet Etheredge, Johannesburg, South Africa*

09:18 OP105 The 1966 CIBA conference on transplantation ethics: 50 years later  
*Lainie Ross, Chicago, United States*

09:30 OP106 The evolution of ethics in the history of transplantation  
*Michael Bos, Groningen, The Netherlands*

09:42 OP107 The ethical principle of equipoise applied to uterus transplantation  
*Giuliano Testa, Dallas, United States*

## 08:30-10:00 Free communications 9

Room 3

**Paediatric donation and transplantation**

*Chairs: Karl-Leo Schwering, Paris, France & Marion Siebelink, Groningen, The Netherlands*

08:30 OP87 Does the consent rate to organ donation in paediatric donors vary within different age groups?  
*Jutta Weiss, Erlangen, Germany*

08:42 OP88 Elective ventilation to facilitate organ donation in infants with anencephaly: perinatal professionals' views and an ethical analysis  
*Joe Brierley, London, United Kingdom*

08:54 OP89 Differences in organ donation consent for children following death from non-accidental trauma  
*Laura Miller-Smith, Kansas City, United States*

09:06 OP90 Pre-mortem interventions in dying children to optimize organ donation – ethical & United Kingdom legal analysis  
*Joe Brierley, London, United Kingdom*

09:18 OP91 Favorable outcome of renal transplantation of handicapped and disabled children and adolescents  
*Matthias Galiano, Erlangen, Germany*

09:30 OP92 Researching impact of parental living donation in paediatric liver transplantation: methodological and ethical issues  
*Laure Rougier, Brussels, Belgium*

09:42 OP93 Brain death family denial: US versus United Kingdom  
*Joe Brierley, London, United Kingdom*

## 08:30-10:00 Free communications 10

Room 11

**Living donation (A)**

*Chairs: Paul Harden, Oxford, United Kingdom & Willem Weimar, Rotterdam, The Netherlands*

08:30 OP80 United States KDOC study: direct and indirect costs incurred by living kidney donors  
*James Rodrigue, Boston, United States*

08:42 OP81 The ethics of shifting the U.S. framework of living kidney donation from removing disincentives to adding incentives  
*Giuliano Testa, Dallas, United States*

08:54 OP82 Educating the social network of black patients predicts the likelihood of a living donor evaluation and live donor kidney transplantation  
*James Rodrigue, Boston, United States*

09:06 OP83 Live donor autonomy and professional protectionism. Inconsistency in medical aspects of live donor evaluation. A literature search and discussion  
*Ian Dittmer, Auckland, New Zealand*

09:18 OP84 Transplant professional's views on unspecified kidney donation  
*Alexis Clarke, Plymouth, United Kingdom*

09:30	OP85 0-500: The impact of volunteers on unspecified living kidney donation in the United Kingdom <i>Christopher Burns-Cox, Edge, United Kingdom</i>
09:42	OP86 Shifting paradigms in live kidney donation: attitudes of transplant professionals <i>Jeff Lafranca, Rotterdam, The Netherlands</i>
10:00	<b>BREAK</b>

### 10:30-12:00 Focus session 7 *Aula Minor*

#### **Cultural & religious considerations in living & deceased donation**

*Chairs: Gabriel Danovitch, Los Angeles, United States & Daniel Fu-Chang Tsai, Taipei, Taiwan*

10:30	OP108 Organ donation in multicultural societies – a study in Qatar <i>Dominique Martin, Victoria, Australia</i>
10:42	Low deceased donation rate among Muslims; is it culture or religion? <i>Mustafa Al-Mousawi, Kuwait City, Kuwait</i>
10:57	Cultural reservations & myths about organ donation among South Asian community <i>Sunil Shroff, Chennai, India</i>
11:12	Debate

### 10:30-12:00 Focus session 8 *Room 2*

#### **Ethical and psychological aspects of face transplant**

*Chairs: Dirk Ysebaert, Antwerp, Belgium & James Rodrigue, Boston, United States*

10:30	Moving facial transplant forward <i>Katrina Bramstedt, Queensland, Australia</i>
10:45	The ethics of face transplantation <i>Kathy Coffman, Cleveland, United States</i>
11:00	Debate

### 10:30-12:00 Free communications 11 *Room 3*

#### **Psychosocial aspects – Recipients (B)**

*Chairs: Christina Papachristou, Berlin, Germany & Luigi Biancone, Torino, Italy*

10:30	OP109 Psychological benefits of expanded criteria kidney transplantation versus haemodialysis <i>Hannah Maple, London, United Kingdom</i>
10:42	OP110 Psychological benefits after living donor kidney transplantation <i>Hannah Maple, London, United Kingdom</i>
10:54	OP111 The meaning of uncertainty after heart transplantation – the unraveled source to distress? <i>Matilda Almgren, Lund, Sweden</i>
11:06	OP112 Immunosuppression nonadherence after liver transplantation: should we be concerned? <i>Juri Ducci, Pisa, Italy</i>
11:18	OP113 Hair analysis for ethylglucuronide as an addition to psychosomatic assessment of alcohol abstinence in liver transplant candidates <i>Brigitta Globke, Berlin, Germany</i>
11:30	OP114 Motivations, challenges, and attitudes to self-management in kidney transplant recipients: a systematic review of qualitative studies <i>Camilla Hanson, Sydney, Australia</i>
11:42	OP115 Validation of tool for annual adherence evaluation of kidney transplant recipients in Norway <i>Kjersti Lønning, Oslo, Norway</i>

### 10:30-12:00 Free communications 12 *Room 11*

#### **Living donation (B)**

*Chairs: Lisa Burnapp, Bristol, United Kingdom & Annette Lennerling, Gothenburg, Sweden*

10:30	OP116 Psychosocial profile of potential kidney recipients with living non-related donors <i>Susana Bayardo, Buenos Aires, Argentina</i>
10:42	OP117 Appealing for a kidney donor on social media: an effective way to find a donor? <i>Dorthe Slaats, Rotterdam, The Netherlands</i>

- 10:54 OP118 Public solicitations: beyond the beauty contest  
*Linda Wright, Toronto, Canada*
- 11:06 OP119 Living kidney donor preferences: a novel use of a visual instrument to quantify ESRD risk acceptance  
*Carrie Thiessen, New Haven, United States*
- 11:18 OP120 Donor comprehension of provided information during informed consent process in live donor nephrectomy; does it matter what we tell donors? A pilot study  
*Kirsten Kortram, Rotterdam, The Netherlands*
- 11:30 OP121 Allogeneic haematopoietic stem cell transplantation, HSCT with a sibling as donor – an ethical complex situation  
*Annika Kisch, Lund, Sweden*
- 11:42 OP122 The complexity of live kidney donation: a mixed-methods study  
*Kathe Meyer, Oslo, Norway*
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12:00-13:30 Closing/Plenary debate *Aula Minor*

*Chairs: Linda Wright, Toronto, Canada & Willem Weimar, Rotterdam, The Netherlands*

**Uterus transplantation:  
necessity or indulgence?**

12:00 Prevalence and results  
*Niclas Kvarnström, Gothenburg, Sweden*

12:15 Necessity or indulgence?  
*Inez de Beaufort, Rotterdam, The Netherlands*

12:30 **Trading gametes in a worldwide market**  
*Guido Pennings, Ghent, Belgium*

12:45 Debate

13:30 Closing remarks

# Plenary Sessions

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**17:30 – 19:30 Opening/Plenary debate:**  
**Incentives for living donation: moving beyond the deadlock**

**The kidney sellers; lessons learned in Iran**

*Sigrid Fry-Revere, Lovettsville, United States*

Iran has been experimenting with compensating living organ donors for almost 40 years. In addition to National policies that have changed numerous times over that period, so have provincial policies, some of which remain very different from each other even today. Despite the general legality of paying donors, the legal system in Iran sees “payment” as a “gift” and the contract between donor and recipient as only binding in one direction — more like an adoption under U.S. law, than a commercial transaction for either goods or services. At the provincial level, some areas prohibit all financial transactions between donors and recipients, some encourage heated price negotiations that generally favor recipients, and others have non-profits that treat donors and recipients as equals in need of government services where deals fall through if the needs of both parties can’t be met. There is much to be learned from Iran’s years of experimenting with compensated organ donation, both good and bad. Hopefully with the recent opening of relationships, more studies can be done soon.

**Professional and public perspectives**

*Allison Tong, Sydney, Australia*

The unmet demand for kidney transplantations has sparked intense controversy about introducing incentives for living kidney donors to increase donation rates. There have been calls to pilot regulated schemes for paid living kidney donation. Such debates may provoke a reaction from the general public, and in turn influence their acceptance and support for living kidney donation.

To inform current debates and public policy on incentives for living donation, an understanding of both public and professional perspectives is needed. This presentation will outline and compare empiric evidence on public and professional values and opinions on incentivising living kidney donation, and discuss implications for policy.

**Ethical and practical considerations in testing financial incentives**

*Elisa Gordon, Chicago, United States*

This paper provides an overview of the ethical principles on both sides of the debate of providing financial incentives for living kidney donors. The presentation posits that a pilot study of a government regulated system of financial incentives is a necessary first step to determine whether policy should or should not be further considered. A scientifically and ethically sound pilot study should include as primary outcomes measures that assess key ethical constructs to test assumptions about coercion, exploitation, and commodification made by opponents and proponents of financial incentives. Moreover, the practical and logistic issues with conducting a pilot study will be considered.

08:30 – 10:00 Plenary debate 2:

**Social media and transplantation: pushing the envelope?**

**What is wrong with the beauty contest?**

*Greg Moorlock, Birmingham, United Kingdom*

The use of social media by patients and their families/friends to solicit living organ donations has raised concerns, including the ‘beauty contest’ dynamic it creates. Using social media and dedicated websites, patients can appeal to potential donors, often using distinctly non-medical characteristics to make themselves the most ‘attractive’ recipient for a donor to choose. I will argue that although aspects of competition exist throughout much of transplantation, this is usually passive and can be considered, to some extent, co-operative. In contrast, the more active competition involved with soliciting organs via social media promotes an ‘every man for himself’ ethos amongst potential recipients that may be in tension with the supposedly altruistic nature of organ donation.

Publically solicited donation via social media does, however, have the potential to increase the number of living donors, and I will propose a novel way in which social media could be used to promote directed living donation. The proposed approach will make use of social media’s ability to appeal to, and engage with, potential donors whilst minimising the beauty contest dynamic and related justice issues that arise from the way in which publically solicited donation currently occurs.

**The donor and patient perspective**

*Emma Massey, Rotterdam, The Netherlands*

Using social media to find a living donor is a recent development in living donation which raises ethical, psychological and practical issues. There is to date very little empirical evidence on the experiences of patients who decide to use this strategy to find a donor. What stimulates them to take this step, to what extent do they take ethical and psychological aspects into consideration, what are their expectations, how do they experience the search, reactions from others and contact with potential donors, and what are patients’ needs from professionals in this process? Such research is essential to gain greater insight into the patient perspective and inform his debate rather than make assumptions about how a public search for a donor might be experienced. In this presentation, I will explore these psychosocial and ethical considerations in order to help inform and guide policy.

08:30 – 10:00 Plenary debate 3:

Heart donation after cardiac death: *contradictio in terminis*?

**Can hearts from DCD donors be used for transplantation**

*Stephen Large, Cambridge, United Kingdom*

In this presentation, the UK DCD heart transplant programme will be presented, including the ethical, legal and psychological challenges that arise from this programme. Firstly, I will illustrate the problem of supply of and demand for the donor heart and therefore the reason to explore, propose and create a clinical programme of DCD heart transplantation. The latest data from the programme will be presented. The programme raises a number of ethical concerns which will be discussed and the UK agreement to address these concerns will be presented. The legislation relevant to the programme will be presented. Finally, the psychological challenges highlighted by DCD heart transplantation to the future donor, their family, the recipient and to the surgical team will also be outlined.

**An ethical exploration of the determination of death**

*Michael Nair-Collins, Tallahassee, United States*

Longstanding legal and bioethical criteria for death have held that death is irreversible. In organ donation after circulatory death (DCD), organs are typically removed 2-5 minutes after cessation of circulatory function. At this time, the cessation of circulatory function is often reversible; in successful heart transplantation, that cessation surely is reversible. It follows that the donor is not dead when organs are removed, therefore, vital organ removal causes death. This is inconsistent with the dead donor rule (DDR), which holds that organ removal must not cause death. Proposals to modify death criteria in terms of permanent cessation of circulatory function, for the purpose of engendering nominal consistency with the DDR, renders the rule vacuous and undermines its central motivation as a deontic constraint on practice. The open question is not whether DCD, including heart donation, violates the DDR. The question is: given that it does, what shall we do? The options are: explicitly abandon the DDR, abandon DCD, or continue practice as-is, covertly circumventing legal and ethical prohibitions against homicide using contrived death criteria that provide the appearance, but not the reality, of consistency with the DDR.

12:00 – 13:30 Closing/Plenary debate 4:

- 1) Uterus transplantation: necessity or indulgence?
- 2) Trading gametes in a worldwide market

### Prevalence and results

*Niclas Kvarnström, Gothenburg, Sweden*

The worldwide experience of uterus transplantation is so far 11 published cases (Saudi Arabia (1), Turkey (1), Sweden (9)) and 2 unpublished cases (China (1), US (1)). The results of the Swedish study that is the first case series are promising. Nine women without an uterus (Mayer-Rokitansky-Küster-Hauser syndrome (MRKH) (8) and cervical cancer with previous hysterectomy (1)) were transplanted with uteri from live donors. All donors were related to the recipients. The majority were mothers of the recipients. Two of the transplanted uteri had to be removed within the first 4 months post surgery. The remaining 7 women all went through embryo transfers starting from 12-18 months after the transplantation. Seven pregnancies have so far been achieved (in 6 recipients) with two early miscarriages and 5 live births. The first child was born in September 2014. All children have been delivered with caesarean sections in gestational week 32-36. In 3 cases the caesarean section had to be done earlier than planned due to preeclampsia.

### Necessity or indulgence?

*Inez de Beaufort, Rotterdam, The Netherlands*

I will discuss some ethical issues regarding uterus transplants. These have to do with the possible risks for the receiver and for the donor (e.g. directed living donation, mother to daughter), and for the child; with the question concerning alternatives, e.g. surrogate mothers who carry the child; and the issue of costs: should it be available for everyone and be reimbursed by public health care systems? I will look at these questions against the existential décor of the profound and life altering experience of pregnancy that (many) women cherish and are willing to make significant sacrifices to experience. Finally I will go into some slippery slopes that are associated with the development, such as male pregnancies.

### Trading gametes in a worldwide market

*Guido Pennings, Ghent, Belgium*

Within the field of medically assisted reproduction, much attention goes to cross-border reproductive care. In that case, patients who need gametes move to countries where gametes are available. Much less visible but at least as important is the movement of gametes across borders. Well-known (but poorly documented) is the shipping of sperm from Danish sperm banks to almost all countries where donor insemination is allowed. Although very limited at the moment, it can be predicted that also egg trading will increase in the future. The general legal principles for the trade in gametes will be explained first. Then, four topics will be discussed: how to control donor offspring limits; what should be included in the informed consent of the donors; how to maintain rules about payment and compensation, and, finally, what does transnational shipping mean for donor identifiability.

Commercialization is a major driver of the development of large gamete banks and of the import and export of gametes. National self-sufficiency will not solve all the problems but may prevent much of the most abusive aspects of the trade.



# Focus Sessions

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**10:30 – 12:00 Focus Session 1:  
Inequities in transplantation:  
strategies to improve access**

*Moderators: Allison Tong, Sydney, Australia & Faissal Shaheen, Jeddah, Saudi Arabia*

**OP01 African Canadian and East Asian Canadian patients are less likely to have potential living donors when first presenting for evaluation**

Istvan Musci, Toronto, Canada

**OP02 Psychosocial impact of paediatric living-donor transplantation in donors, recipients and the family: a systematic review**

Isabelle Aujoulat, Brussels, Belgium

**Increasing access to live donor kidney transplantation: recommendations from a U.S. consensus conference**

James Rodrigue, Boston, United States

Despite superior outcomes relative to other ESRD treatment options, historical rates of live donor kidney transplantation (LDKT) are much lower in minorities, older adults, and low income patients in the United States. Also, the notable decline in living kidney donation (LKD) is most prominent black, younger, male, and lower income adults. Improving LDKT access in patients with historically low rates of the most optimal form of treatment is an obligation shared by transplant professionals, community nephrologists, primary care physicians, and patient advocacy organizations. The mechanisms underlying LDKT disparities and LKD differences are unquestionably multifaceted and complex. Also, strategies that may prove efficacious in attenuating disparity in one area may have little effectiveness or, even worse, exacerbate differences in another area. The Live Donor Community of Practice within the American Society of Transplantation, with financial support from ten other organizations, held a Consensus Conference on Best Practices in Live Kidney Donation in June 2014. The purpose of this meeting was to identify LKD best practices and knowledge gaps that might influence LDKT, with a focus on patient and donor education, evaluation efficiencies, disparities, and systemic barriers to LKD. This presentation will highlight trends in LDKT/LKD and emerging novel strategies for attenuating disparities and improving LDKT access, as well as offer specific recommendations for future clinical practice, education, research, and policy from the Consensus Conference workgroup focused on disparities.

**The socio-economic factors affecting access and results of kidney transplantation**

Mirjam Laging, Rotterdam, The Netherlands

**10:30 – 12:00 Focus Session 2:  
Ethical controversies in allocation**

*Moderators: Medard Hilhorst, Rotterdam, The Netherlands & Axel Rahmel, Frankfurt a. M., Germany*

**OP05 Young for old – old for young? the moral economy of age and intergenerational relations in organ donation**

Sabine Woehlke, Göttingen, Germany

**OP06 A public policy based on incentives to address the organ shortage and its consequences: conceptual underpinnings and legal implications**

Melanie Levy, Tel Aviv, Israel

**Ethical implications of the use of methodologically limited prognosis scores in organ allocation policy**

Benjamin Hippen, Charlotte, United States

Organ allocation schemes in many countries make use of prognostic scoring systems. Such systems are typically used to quantify and rank-order consequentialist concerns. Scores such as MELD purports to be able to rank-order liver transplant candidates in terms of mortality risk, whereas the Kidney Donor Profile Index (KDPI) and Estimated Post Transplant Survival (EPTS) score purport to rank order the likely graft outcomes of donor kidneys and survival of kidney transplant candidates respectively. Normative debates concerning how prognostic scores ought to be integrated into a organ allocation system often take for granted both the veracity of the data used to design these prognostic scores as well as the accuracy of the scores themselves. Illustrating the point using several prognostic scoring systems, and using several examples in which the promise of several scoring systems have not lived up to promise, I argue that many such scores suffer from significant, irremediable methodological limitations which lead to these unintentional and undesirable results. Normative debates in which prognostic concerns play a salient role should begin by taking account of core limitations on our ability to reliably and reproducibly prognosticate about donor organ and transplant candidate outcomes.



**Old donors, marginal organs, young recipients – can we continue?**

Undine Samuel, Leiden, The Netherlands

Within Eurotransplant (ET) patients from eight different member states are on the waiting list for an organ. Due to the different organ donation numbers in the member states, the waiting time for these patients differs. Patients are getting older on the waiting list. Donor age is also rising constantly. In 1990 a donor age under 40 was normal, whereas in 2015 the median donor age is about 20 years more. As the donors get older, so do the organs. More organs in the last years are so called “marginal organs” according to their age. These organs are nevertheless transplanted, to recipients of every age. Is it still tolerable, to allocate “old” organs to young recipients? Is there a difference in patient and graft survival, when older or marginal organs were transplanted? Is there a difference concerning which organ has been transplanted? The presentation will take a look at the so called European Senior Program, which focuses on kidneys and recipients over 65 years and has now been evaluated for the first 10 years, but also on all other “old” organs and young recipients.

**10:30 – 12:00 Focus Session 3:  
Improving adherence: from  
observation to intervention**

*Chairs: Emma Massey, Rotterdam, The Netherlands  
& Dianne LaPointe Rudow, New York, United States*

**Building systems of care that support patient’s adherence**

Sabina de Geest, Basel, Switzerland

A major challenge in long term outcomes in transplantation is to improve long term outcomes in solid organ transplant recipients. Implementing models of care that build on the principles of chronic illness management emerges as a relevant strategy in this regard.

The intercontinental BRIGHT study mapped practice patterns in view of chronic illness management in 36 heart transplant centers in 11 countries. A relationship between higher level of chronic illness management and better survival at 1, 3, and 5 years was observed. A limited number of studies focused on the reengineering of transplant program (follow up) care using principles of chronic illness management showing improvement in clinical, patient reported and health utilization parameters.

This evidence urges us to take also a system perspective in development of strategies to improve long term outcomes after solid organ transplantation.

**Practical approaches to improving adherence in high risk populations**

Paul Harden, Oxford, United Kingdom

**OP03 The relationship between health literacy, self-management and complications after kidney transplantation**

Louise Maasdam, Rotterdam,  
The Netherlands

**OP04 History of mental health disorders and non-adherence: barriers in access to kidney transplantation**

Istvan Musci, Toronto, Canada

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**10:30 – 12:00 Focus Session 4:**  
**How informed is the living donor?**

*Chairs: Frank Dor, London, United Kingdom & Rebecca Hays, Madison, United States*

**OP37 Towards a standardized informed consent procedure for live donor nephrectomy: what do surgeons tell potential donors?**

Kirsten Kortram, Rotterdam, The Netherlands

**OP38 Discussions with prospective donors: informed consent when knowledge is limited**

Arthur Matas, Minneapolis, United States

**Informed consent for living donors: ethical dimensions and research opportunities**

Elisa Gordon, Chicago, United States

This paper presents an overview of the ethical issue of informed consent for living donation, highlighting unique considerations of live liver donors and live kidney donors. I will draw upon my empirical research studies conducted with live liver donors and live kidney donors to illuminate concerns regarding the content of information disclosed, comprehension, and voluntariness. A key finding was that many liver donors downplayed the importance of learning about donor risks. I will discuss the ethical implications of this finding for the value of informed consent. I will conclude by discussing practical approaches to improving the content for information disclosure, and new interventions and opportunities for research to optimize the informed consent process.

**Informing the living donor: Practical approaches to moral dilemmas**

Lisa Burnapp, Bristol, United Kingdom

The contribution of living donation to global transplant activity is universally acknowledged and reflected in clinical practice. Evolution has led to revolution; clinical, logistical and moral complexity within living donor transplantation programmes has become the norm. Given the pace of change, how can we be sure that the expectations of donors are met and that they are provided with appropriate and timely information to give valid consent to donate? This presentation will explore some of the key controversies that arise in the informing process, including clinical issues – specific to donor, recipient and organ type, relationship between donor and recipient, confidentiality and sharing of information and the influence of healthcare professionals

on donor decision-making. Rationale for possible approaches will be presented for discussion and debate.

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**10:30 – 12:00 Focus Session 5:**  
**Anonymous living donation  
 & unbalanced kidney exchange**

*Chairs: Nizam Mamode, London, United Kingdom & Linda Wright, Toronto, Canada*

**Anonymous living donation programs**

Willij Zuidema, Rotterdam, The Netherlands

Exchange and unspecified donation programs usually start at an anonymous basis.

However, there is a wide variation in the practice of maintaining anonymity after donation and transplantation.

While there are social, psychological and logistical arguments before and against continuing anonymity, recent studies and experiences suggest that strict anonymity might not be necessary in all circumstances. Advantages and disadvantages of anonymity before and after cross-over and unspecified donations will be discussed.

**The participation of compatible pairs in kidney exchange programs**

Marie-Chantal Fortin, Montreal, Canada

Kidney exchange programs allow incompatible donor/recipient pairs to find a match and get transplanted. The chances of finding a match increase with the number of pairs registered in the program. The participation of compatible pairs in kidney exchange programs increases all recipients' chances of finding a match. However, compatible pairs derive no clear benefits from participating in exchange programs other than knowing they have helped other patients obtain a transplant. In fact, their participation could delay the transplantation process for the recipient.

Offering benefits could encourage more compatible pairs to participate in kidney exchange programs. One proposed benefit is to prioritize compatible-pair recipients for a deceased donor transplant in the event that the first transplant fails. This strategy is called reciprocity for compatible pair participation in kidney exchange programs. It can be seen as a way to thank the compatible pair for participating in the program and allowing more patients to be transplanted. However, could this strategy lead the recipients in compatible pairs to pressure their donor to participate in kidney exchange programs? Should priority points be awarded in cases of graft failure from non-adherence? Should we offer this reciprocity when the graft fails at any time following transplantation, or only when it

fails prior to the expected graft survival period? Since a second transplant is more risky, is giving priority point to recipient would go against medical utility as it would channel organs away from first graft recipients? Would this system be acceptable to the other patients on the waiting list? This presentation explores these ethical issues in detail.

**OP42 Non-directed altruistic, unspecified kidney donation in the United Kingdom – nine year experience**

Rachel Johnson, London,  
United Kingdom

**OP43 Anonymity in live kidney donation reconsidered: patients' and donors' experiences, preferences and attitudes towards anonymity**

Dorthe Slaats, Rotterdam,  
The Netherlands

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**10:30 – 12:00 Focus Session 6:  
Rights and duties of health  
professionals in transplant tourism**

*Chairs: John Gill, Vancouver, Canada & Seán Columb,  
Liverpool, United Kingdom*

**OP39 Outcome of transplant tourism: a single center experience**

Meteb AlBugami, Dammam,  
Saudi Arabia

**OP40 Avoiding complicity in foreign transplant abuse**

David Matas, Winnipeg, Canada

**OP41 Transplant tourism – case series studies with ethical reflection in Taiwan**

Alex, Chih-Yu Chen, London,  
United Kingdom

**Transplant professionals should breach their secrecy oath**

Frederike Ambagtsheer, Rotterdam,  
The Netherlands

Patients travel worldwide to purchase kidneys. Transplant professionals can play a role in identifying kidney purchase. However, due to the tension between their rights and obligations, a lack of understanding and knowledge exists on how to prevent and report purchase. We present the results of a national survey that describes transplant professionals' experiences, attitudes, behaviors, conflicts of duties, legal knowledge

and needs for guidelines toward patients who purchase kidneys abroad. Second, we clarify professionals' rights and obligations regarding organ purchase and propose actions that they can take to report purchase. Of the 100/241 (42%) professionals who treated patients who traveled to a country outside the European Union for a kidney transplant, 31 (31%) were certain that patients purchased kidneys. Sixty-five (65%) had suspicions that patients had bought kidneys. The majority reported a conflict of duties. Eighty percent reported a need for guidelines. Professionals can help prevent organ purchase by disclosing information about organ trafficking networks to law enforcement. Such disclosure can support the investigation and prosecution of networks. We offer key components for guidelines on disclosure of these networks.

**Responsibility of professionals in implementing the Council of Europe convention**

Francis Delmonico, Boston, United States

The Declaration of Istanbul Custodian Group (DICG) Strategic Plan has two major components:

- A Prospective Review Process of proper travel for transplantation when a patient indicates the intent to travel to a foreign destination for organ transplantation.
  - A Retrospective Process to consider when a patient returns to their native country for medical care after he/she received a transplant in a foreign destination.
- DICG will work with ministries of health and professional bodies in each of the WHO regions to implement a goal of combatting organ trafficking. The factors considered in selecting countries for involvement of the DICG are
- (1) an existing program that transplants organs into foreign patients and/or relies on vended organs for foreign or domestic patients,
  - (2) growing need for, and existence of, dialysis based upon increasing rates of end-stage organ failure,
  - (3) an existing relationship between the DICG and one or more transplant programs in the country, and
  - (4) the feasibility of engaging with the country, based upon an identified champion with access to government.

Success will be marked by a legal commitment to adopt and enforce the principles espoused in the Declaration of Istanbul and the WHO Guiding Principles.

**10:30 – 12:00 Focus Session 7:**  
**Cultural & religious considerations**  
**in living & deceased donation**

*Chairs: Gabriel Danovitch, Los Angeles, United States  
 & Daniel Fu-Chang Tsai, Taipei, Taiwan*

**OP108 Organ donation in multicultural**  
**societies – a study in Qatar**  
 Dominique Martin, Victoria, Australia

**Low deceased donation rate among Muslims;**  
**is it culture or religion?**  
 Mustafa Al-Mousawi, Kuwait City, Kuwait

Most Muslim countries either lack a deceased donor program or have low rates of deceased donors. Two major religious issues may act as barriers to donation after death:

1. Respecting the dead  
 Islam respects sanctity of human body, even after death and prohibits its violation. The Prophet considered breaking the bones of the deceased like breaking it alive.
2. Definition of death  
 As brain death is a new concept, and in the absence of a clear religious definition of death, many religious leaders require cessation of all body activities, including heart, to recognize death.

**Islamic ruling on deceased donation**

Islam is a dynamic religion which moves through time with Ijtihad and does not oppose any new developments which benefits humanity. Violation of dead body has been allowed by early Muslims to save an unborn child, or to recover a valuable object from body of deceased.

Many religious leaders believe that when the body is damaged to an extent that it can no longer accommodate the soul, then death occurs. Brain death has been accepted by many religious leaders and organizations. The barriers seems to be more social than religious.

**Cultural reservations & myths about organ**  
**donation among South Asian community**  
 Sunil Shroff, Chennai, India

Organ donation decision is a complex one and generally based on personal beliefs. There are some factors such as cultural beliefs, myths and religious notions that are often cited as reasons for a refusal to donate among the South Asian community and this leads to a lower rate of transplantation. Many of the cultural beliefs and myths originate from a misunderstanding about the religious stance on the subject. Some of the popular cultural beliefs and myths are as follows:

1. My religion does not allow organ donation
2. One should be buried "whole" and it is critical to preserve the integrity of the body
3. Death should not be discussed as it is not auspicious
4. If donation takes place the subject will be born in the next life without the donated organ
5. Doctors will not save life if consent is given for organ donation
6. Anxiety that organs may be used for making profits by the hospital

Constant education of the community about organ and tissue donation can dispel these reservations. Among certain communities the religious leaders have an important role to play by making clear statements about the religious stance on organ donation.

**10:30 – 12:00 Focus Session 8:**  
**Ethical and psychological aspects of**  
**face transplant**

*Chairs: Dirk Ysebaert, Antwerp, Belgium & James  
 Rodrigue, Boston, United States*

**Moving facial transplant forward**  
 Katrina Bramstedt, Queensland, Australia

This session reviews the current worldwide status of facial vascularized composite allotransplantation (VCA) and explores three areas within facial VCA that require continued effort to move facial transplant forward:

- 1) Gender-mismatched VCA;
- 2) Consent for VCA donation; and
- 3) Insurance funding for VCA.

Working through the complexity of these three areas and employing ethical solutions could allow for increased access to facial VCA, as well as shorter waiting times for patients. This session provides guidance and offers solutions, many of which are also applicable to limb transplantation.

**The ethics of face transplantation**

Kathy Coffman, Cleveland, United States

There have been 34 cases of facial transplantation reported, and 4 deaths, 11.7%. Mortality raises the issue of risk versus benefit for face transplantation, a procedure intended to improve quality of life, rather than saving life. One of the most innovative surgical procedures has opened the debate on the ethical, legal and philosophical aspects of face transplantation. Recent findings: Morbidity in face transplant recipients has included: diabetes, infections, impaired renal function, post-transplant lymphoproliferative disorder, (3.45%), lymphoma in an HIV positive recipient, and one suicide. In one case the facial graft was removed in an attempt to save the recipient's life after diagnosis of squamous cell cancer of the tongue. Technical failure, chronic rejection or graft versus host disease have not resulted in graft loss to date. Psychological issues include: chronic pain, mood disorders, pre-existing psychotic disorders, PTSD, social isolation, smoking and substance abuse. Summary: Early publications on ethical aspects of face transplantation focused mainly on informed consent. Many other ethical issues have been identified including lack of coercion, donor family consent and confidentiality, respect for the integrity of the donor's body, and financial promotion of the recipient and transplant team, as well as costs to society for such a highly technical procedure, requiring life-long immunosuppression and possible rescue procedures. The patient's right to autonomy and physician's duty to protect are also involved in decisions regarding candidacy for facial transplantation. The issue of raising false hopes is relevant as many candidates may be screened and few accepted for this procedure.



# Workshops

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**15:00 – 18:30 Workshop 1:**  
**Clinical research in deceased donation: medical, ethical, legal and societal aspects**

*Chairs: Rutger Ploeg, Oxford, United Kingdom  
 & Bernadette Haase, Leiden, The Netherlands*

**Research to improve organ donation and donor organs: yes ..., but how?**

Due to the persistent organ shortage and large number of patients on the waiting list, transplant centres will nowadays accept older and ‘high risk’ organs for transplantation in spite of uncertainty about quality and lower outcomes. With better insight and new technologies we need to increase the number of viable donor organs enhancing utilisation and transplantation.

Our current challenge is to optimise donor management using targeted intervention, improve retrieval and preservation, as well as repair donor organs prior to transplantation. Despite this need, confusion and obstacles persist over ethical, legal and psychosocial aspects how research studies involving donors and organs can be performed. Medical and legal professionals as well as authorities voice many opinions, however, a clear framework, who has to consent, who is when responsible and what kind of regulatory rules for which intervention ought to be in place is lacking.

This ELPAT workshop will discuss three realistic interventions: during donor management, at the start of preservation and ex-vivo after donation but prior to reperfusion, all likely to improve donor organ quality.

Working groups will draft protocols and discuss relevant ethical, legal and regulatory requirements delivering a template how to underpin scientific discovery and facilitate more and better transplants.

**OP28 An ethical and legal framework for conducting deceased donor research**  
 Alexandra Glazier, Waltham, United States

**WG1: DCD, in-situ Normothermic Regional Perfusion to increase number and quality of transplantable organs with better utilization compared to conventional preservation**  
 Tineke Wind, Maastricht, The Netherlands

**WG2: DBD, targeted intervention in the donor after diagnosis of brain death during donor management but prior to retrieval, e.g. systemic administration of complement inhibitor**  
 Rutger Ploeg, Oxford, United Kingdom

**WG3: Ex-situ conditioning of ‘high risk’ donor organs including machine perfusion and use of pharmacological agents and stem cells**  
 Diethard Monbaliu, Leuven, Belgium

*Expert Panel: Alexandra Glazier – legal aspects; David Shaw – ethical aspects; Bernadette Haase – organizational/governance aspects; Dale Gardiner – patient aspects.*

**15:00 – 18:30 Workshop 2:**  
**Common problems and national approaches to death and deceased donation**

*Chairs: Thomas Gutmann, Munster, Germany & Medard Hilhorst, Rotterdam, The Netherlands*

National transplant systems – their legal and organizational frameworks, but also their specific ‘cultures’ – feature different strengths, weaknesses, blind spots and even ‘taboos’. Many of the problems we face at home have found acceptable and even convincing solutions abroad. There are best practices and less convincing ones.

The workshop is one step in a learning process on the European level which ELPAT and ESOT are aiming at: “Why exactly don’t we discuss what others are discussing? Why exactly don’t we learn from the reasonable and successful policies and practices of our neighbours, or: what can they learn from us? What are the main obstacles for an efficient and justifiable deceased donation policy in our countries?”.

Five invited speakers from Switzerland, Spain, United Kingdom, Germany and Italy will present some preliminary results from an ELPAT research project, complemented by two abstract speakers.

Among the topics will be norms and practices in the determination of death, the dead donor rule, legal frameworks for deceased organ donation, organisational models of the organ transplantation system, legal and practical rules concerning the ‘moment of asking’ the relatives, norms and practices concerning ante mortem preparatory measures, and the question how far organ donation is perceived as an integral part of end-of-life-care and of patient autonomy at the end of life.

**OP29 Abandoning the dead donor rule: insights from an exploratory survey in Spain**

Elvira Santiago, Madrid, Spain

**OP30 The use of the brain death criterion in organ donation after the circulatory determination of death**

Anne Dalle Ave, Lausanne, Switzerland

**The Swiss approach**

Tanja Krones, Zurich, Switzerland

**The Spanish approach**

Pablo de Lora, Madrid, Spain

**The United Kingdom approach**

Antonia Cronin, London, United Kingdom

**The German approach**

Thomas Gutmann, Münster, Germany

**The Italian approach**

Marco Vergano, Torino, Italy

**15:00 – 18:30 Workshop 3:**  
**Public issues in organ donation and transplantation**

*Chairs: David Rodriguez Arias, Granada, Spain & Sohal Ismail, Rotterdam, The Netherlands*

As a legal-ethical consensus in most liberal, democratic countries, the idea prevails that individuals should decide on their own whether they want to donate – or not. But if we truly wish individuals to freely donate their organs either while living or after death, then we need to consider how we can create the conditions to ensure the public understand the need for and share the value of organ donation.

This inevitably requires meaningful public engagement which takes concerns, distrust, and ignorance of the public seriously. This Workshop utilizes experiences from around the world that provide learning for policymakers and practitioners seeking to improve public engagement with organ donation.

**From doubts and fear to public praise: changing perceptions of deceased organ donation in Denmark 1985-2015**

Klaus Høyer, Copenhagen, Denmark

In the 1980s, deceased organ donation was surrounded with many public concerns in Denmark. There was no legal support for brain death and surveys indicated a strong opposition in the public towards deceased organ donation. This paper will report on some recent findings indicating a dramatic shift in public opinion during the past 30 years. Based on interviews and a telephone-based survey to the Danish public, we have found a totally transfigured set of public attitudes where deceased organ donation is now associated with great public support and legitimacy. However, this legitimacy seems to rest on donation choices being made voluntarily by individuals – an active and deliberate choice – and this insight should inform future policy considerations. A presumed consent policy, for example, as has been suggested recently, might undermine the current public endorsement. The overall point is that if we wish to ensure long-term social sustainability of the policies enacted to promote organ donation, we need to understand organ donation acquires public legitimacy.

**Engaging the public in organ donation**

Jeantine Reiger, Leiden, The Netherlands

**OP31 How does public perceive general messages about organ donation – a qualitative research**

Bernarda Logar Zakrajsek, Ljubljana, Slovenia

**OP32 Partnerships between media and ethics: students peer-to-peer campaigns for organ donation**

Mihaela Frunza, Cluj, Romania

**Role of transplant coordinators in public engagement**

Sunil Shroff, Chennai, India

Transplant coordinators generally restrict their activities to hospitals for organ donation and transplantation and can either be donor coordinators or recipient coordinators or both. Their knowledge about all aspects of donation and transplantation process is ideally suited for them to conduct public engagement activities to help people understand, accept and commit to organ donation. The purpose of such engagements is to create trust among the public about the programme and in the end to increase the donation rate in the community. This engagement also helps the coordinators to be kept motivated in the programme, helps with their emotional burnout rate and can lead to a lower job attrition rate.

There are no standard templates to measure the impact of such public engagements but one indirect indicator can be the organ donation rate in the region. MOHAN Foundation an NGO from India has over the last six years trained 1030 coordinators and overall the donation rate of the country has gone up three times since the year 2012. In India, the transplant coordinators have played an important role in public engagement by reaching out to 'influencers', especially the youth, police, administrators, corporate workforce and religious leaders and helped the programme move forward.

**The digital donor card – population's adoption & future development**

Jocelyn Corniche, Lausanne, Switzerland

**OP34 Organ donation card as an ATM card; a joint initiative**

Masoud Mazaheri, Tehran, Iran

**OP35 Depicting moral messages – an analysis of German poster campaigns on organ transplantation**

Solveig Hansen, Göttingen, Germany

**OP36 The framing of family veto in organ donation in Canadian Media**

Samantha Anthony, Toronto, Canada

### 15:00 – 18:30 **Workshop 4:** **Pediatric donation and transplantation**

*Chairs: Marion Siebelink, Groningen, The Netherlands  
& Karl-Leo Schwering, Paris, France*

A child is not a small adult. This is even more true in the field of donation and transplantation.

Pediatric donation and transplantation put a great demand on ethical, legal and psychosocial issues and deserve specific attention. Due to the unique character of this topic it is important to share knowledge and experience to develop best practices. This workshop will address these issues.

We will start the workshop with a general introduction on pediatric donation. What are the differences when the donor is a child, and what are the specific challenges? Hereafter we will go into specific ethical issues in pediatric DCD donation followed by a discussion. Oral presentations from specialists in the field will conclude the donation section.

After the break we will extend the focus to pediatric transplantation. This enables completely different questions compared to adult transplantation, starting with the impact of living transplantation on family dynamics. And what about the role of social media in the world of transplanted children? After a discussion we will continue with oral presentations that focus on transplantation.

This workshop is of interest for healthcare professionals as well as for policy makers involved in pediatric donation and transplantation.

#### **Paediatric donation: an overview**

Marion Siebelink, Groningen, The Netherlands

#### **Care, consent, certainty and conflicts: ethical dilemmas in paediatric DCDD**

Dominique Martin, Victoria, Australia

Organ donation after circulatory determination of death (DCDD) remains a field rich in controversy for ethicists and clinicians. Ethical anxieties may be exacerbated in the setting of paediatric DCDD, due to increased uncertainty regarding the prediction of clinical outcomes after withdrawal of life sustaining interventions and to reliance on surrogate decision-makers to authorize donation. In this context, the potential conflicts of interest of parents and health professionals have been linked to concerns that the quality of care provided to potential donors may be compromised if opportunities for DCDD are pursued.

I review here the ethical dilemmas that are commonly reported in the literature about paediatric DCDD and discuss some of the factors that may impede efforts to address such dilemmas, including the rarity of opportunities for paediatric DCDD and ethi-

cal concerns about conducting research with critically ill and dying children. I suggest that ethical anxiety about paediatric DCDD may be disproportionate to the actual risks and potential benefits of donation, and may jeopardize the protection of the best interests of critically ill children and their families. I argue that where opportunities for DCDD exist, they should routinely be considered as part of decision-making about end-of-life care for children.

#### **OP64 Life lines: a father's personal account of organ donation**

Magi Sque, Wolverhampton,  
United Kingdom

#### **OP65 Under what conditions should minors be considered as potential hematopoietic stem cell donors: a systematic review of guidelines and protocols**

Miha Orazem, Leuven, Belgium

#### **Impact of living transplantation on family dynamics**

Karl-Leo Schwering, Paris, France

#### **Transplantation and social media: ethical considerations in paediatrics**

Rebecca Greenberg, Toronto, Canada

#### **OP67 Where there's smoke...marijuana use in paediatric transplant candidates**

Aviva Goldberg, Winnipeg, Canada

#### **OP68 Ethical management of contraception in adolescent transplant recipients**

Aviva Goldberg, Winnipeg, Canada

#### **OP69 Migration to Germany for renal transplantation of children and adolescents with end stage renal disease**

Matthias Galiano, Erlangen, Germany

### 15:00 – 18:30 **Workshop 5:** **Psychosocial evaluation, support and education of living donor candidates**

*Chairs: Inês Mega, Lisbon, Portugal & Emma Massey, Rotterdam, The Netherlands*

This workshop will explore in-depth the issues surround optimal education, psychosocial screening, and support of living donors.

In part 1, prospective cohort studies that can inform the screening tools will be presented and discussed, followed by invited lectures by Dr. Diane LaPointe Rudow and Dr. Emma Massey of two new and innovative psychosocial screening tools.

In part 2, presentations will inform us on donors perceptions regarding risk acceptance, shared decision-making and priorities for pre-donation education.

Subsequently, invited speaker Rebecca Hays will discuss the role and importance of living donors advocates. The discussion will pertain to the challenges and opportunities for optimal psychosocial screening, education and support during the donation process.

**OP70 An update on the multi-site, prospective kidney donor outcomes cohort, KDOC study in the United States**

James Rodrigue, Boston, United States

**OP71 Predictors for longer-term health-related quality of life of living kidney donors: a prospective multicenter study**

Lieke Wirken, Leiden, The Netherlands

**How to best evaluate live donor candidates? The Live Donor Assessment Tool, LDAT**

Dianne LaPointe Rudow, New York, United States

**An ELPAT psychosocial screening tool for living donor candidates: from idea to prototype**

Emma Massey, Rotterdam, The Netherlands

**OP72 Who should decide? Potential living kidney donor preferences for making decisions about risk**

Carrie Thiessen, New Haven, United States

**OP73 Living kidney donor priorities for outcomes: a nominal group technique study**

Camilla Hanson, Sydney, Australia

**OP74 Tailored E-health cognitive behavioral therapy for living kidney donors at risk**

Lieke Wirken, Leiden, The Netherlands

**The role of living donor advocates and application to the European setting**

Rebecca Hays, Madison, United States

**15:00 – 18:30 Workshop 6:  
Understanding the human organ trade**

*Chairs: Sigrid Fry-Revere, Lovettsville, United States & Michael Bos, Groningen, The Netherlands*

This workshop features 4 invited speakers and 4 abstract presentations which present the latest developments of the organ trade.

These include: a critical account of its discourse and definitions, the modus operandi of traffickers and the occurrence of organ trade in the context of international conflict.

These presentations are followed by recommendations for anti-organ trade policy, such as introducing the concept of 'laundering', preventing tourism, protecting victims and critically exploring the concept of 'exploitation'. With more than an hour reserved for discussion, ample opportunity is given to the audience for Q&A sessions with the speakers.

**A critical analysis of the organ trafficking discourse**

Seán Columb, Liverpool, United Kingdom

**Prosecuting brokers and doctors in Israel: the latest news on their modus operandi**

Gilad Erlich, Tel Aviv, Israel

**Organ trafficking in the context of war and political conflict**

Nancy Scheper-Hughes, Washington, United States

**Prevention of transplant tourism**

John Gill, Vancouver, Canada

**OP76 A legal framework to support transnational reporting of transplant-related crimes: the value of extraterritorial jurisdiction**

Alexander Capron, Los Angeles, United States

**OP77 Protection of human beings trafficked for the purpose of organ removal: recommendations**

Kristof van Assche, Ghent, Belgium

**OP79 Paying living kidney donors and the problem of exploitation**

Julian Koplin, Melbourne, Australia

# Oral Presentations

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## Focus session 1:

## Inequities in transplantation: strategies to improve access

## OP01

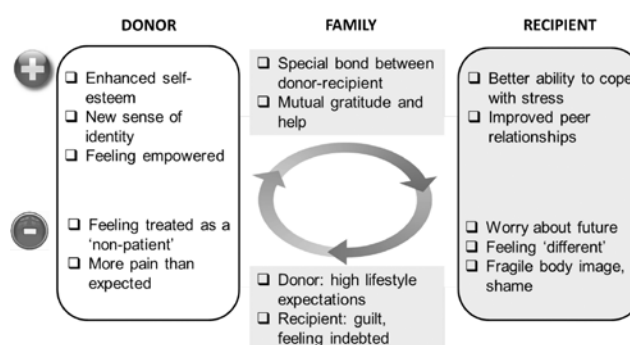
**AFRICAN CANADIAN AND EAST ASIAN CANADIAN PATIENTS ARE LESS LIKELY TO HAVE POTENTIAL LIVING DONORS WHEN FIRST PRESENTING FOR EVALUATION**Istvan Mucsi<sup>1</sup>; Amy Waterman<sup>2</sup>, Famure Olusegun<sup>1</sup>, Yanhong Li<sup>1</sup>, S. Joseph Kim<sup>1</sup><sup>1</sup> University Health Network, Multiorgan Transplant Program, Toronto, Canada<sup>2</sup> David Geffen School of Medicine at the University of California, Division of Nephrology, Los Angeles, United States

Research has shown that Canadian patients who belong to visible minorities may have less access to living donor kidney transplant compared to their Caucasian counterparts but there is a general paucity of data in this area. To better understand these disparities, we examined the association between ethnicity and having a potential living donor identified at the time of first encounter with the transplant center. We conducted a single-centre retrospective cohort study of 1,462 adult patients referred for kidney transplantation between January 1, 2006 and December 31, 2013. Data was extracted from the patients' medical record. Only patients for whom data about ethnicity was available ( $n = 1,462$ ) were included. Univariable and multivariable associations between ethnicity and whether a potential living donor was identified were explored using logistic regression models. The mean ( $\pm$  SD) age was 50 ( $\pm 14$ ) years, 62% were male, and 41% had a history of diabetes. Thirty eight percent of the patients were white, 10% black, 9% East Asian, 7% South Asian and 33% 'other or unknown race'. Fifty-seven percent of patients had at least one potential living donor identified at the time of first encounter with the transplant center. African Canadians were 52% less likely (95% CI 0.32-0.74), while East Asians were 68% less likely (95% CI 0.21-0.49) than whites for having a living donor identified. These associations remained significant even after adjusting for age, gender, comorbidities (diabetes, heart disease and stroke), not being able to communicate in English, marital status and socioeconomic status. Patients with African and East Asian heritage are less likely to have a potential living donor identified at the time of presentation for transplant evaluation in Ontario. They are ultimately also less likely to receive living donor kidney transplants. We need to learn more about specific factors contributing to these disparities in access to kidney transplantation and help patients overcome potentially modifiable barriers to living donor kidney transplant.

## OP02

**PSYCHOSOCIAL IMPACT OF PAEDIATRIC LIVING-DONOR TRANSPLANTATION IN DONORS, RECIPIENTS AND THE FAMILY: A SYSTEMATIC REVIEW**Isabelle Aujoulat<sup>1</sup>; Karl-Leo Schwering<sup>1</sup>, Marion Siebelink<sup>1</sup>, Fabienne Dobbels<sup>1</sup>, Paul Schotsmans<sup>1</sup>, Borry Pascal<sup>1</sup><sup>1</sup> KU Leuven, Department of Public Health and Primary Care, Leuven, Belgium<sup>2</sup> University Medical Center, Groningen, Netherlands

Living-donor kidney and liver transplantation yield superior graft and patient survival in paediatric recipients as compared to deceased-donor transplantation. Nevertheless, their impact on recipients' psychosocial wellbeing and quality of life remains uncertain. This impact can only be adequately understood when investigated in conjunction with the implications for the wellbeing of the donor, as well as for the quality of the relationships within the family unit. Therefore, we systematically reviewed quantitative and qualitative studies addressing the psychosocial impact of paediatric living-donor kidney and liver transplantation in recipients, donors, and the family. In accordance with the PRISMA guidelines, we systematically searched the databases Medline, Web of Knowledge, Cinahl, Embase, ERIC, and Google Scholar. 23 studies met our inclusion criteria, revealing a mixed picture of favourable and unfavourable outcomes. Although many recipients felt more able to cope with situations of emotional and social distress and experienced improved relationships with their peers, others reported symptoms of anxiety or depression, worries about the future and felt ashamed about their body. As for the impact in donors, many experienced a heightened self-esteem, felt more self-confident and appreciated the emotional support that they received from professionals, family and friends, but also complained about post-operative pain and a lack of emotional support. Transplantation often improved family relations, which was characterized by strong feelings of identification, admiration and gratitude between donor and recipient. Nevertheless, feelings of indebtedness or guilt towards the donor sometimes resulted in significant distress for recipients.





As most of the included studies exclusively focused on donor or recipient outcomes, we recommend a more systematic investigation of the long-term gift relationship between paediatric recipient and their donor, by enrolling donors and recipients within the same study.

### Focus session 3:

### Improving adherence: from observation to intervention

#### OP03

#### THE RELATIONSHIP BETWEEN HEALTH LITERACY, SELF-MANAGEMENT AND COMPLICATIONS AFTER KIDNEY TRANSPLANTATION

Louise Maasdam; Marleen van Buren, Mirjam Tielen, Monique Cadogan, Willem Weimar, Emma Massey

*Erasmus Mc, Internal Medicine, Dept. Kidney Transplantation, Rotterdam, Netherlands*

**Introduction:** Health literacy (HL) and self-management (SM) may influence how patients interpret and act on post-transplant self-care, medication and lifestyle recommendations. Among a sample of our patient population 56% were re-hospitalized within one year after kidney transplantation (KT). The aim of this study was to investigate whether HL and SM change over time and influence complications after KT. **Methods:** We performed a prospective cohort study. T0 was at discharge from the hospital after KT, T1 was 6 months later and T2 was 12 months later. We measured SM using an adapted Partners in Health scale (PIH, range 1-8) which has 4 subscales (after-care and knowledge, monitoring physical consequences, emotional and social consequences, healthy lifestyle) and HL using the Dutch Newest Vital Sign (NVSD, range 0-6). Change scores were calculated. Number of re-hospitalizations was summed and complications were categorized as rejection, infections and other. Regression (linear and logistic) analyses were conducted. **Results:** 154 patients participated. At T1 HL scores were significantly higher ( $p = .01$ ) than at T0. HL did not change significantly ( $p = .1$ ) between T1 and T2. After-care and knowledge significantly improved between T0 and T1 ( $p = .00$ ), emotional and social consequences significantly improved between T1 and T2 ( $p = .01$ ), but healthy lifestyle significantly decreased between T0 and T1 ( $p = .00$ ). Higher baseline level of after-care and knowledge and monitor of physical consequences was related to a significantly higher rate of re-hospitalizations at T2 ( $p = .04$ ,  $p = .03$ ). Rejection was related to decreasing scores of emotional and social consequences between T0 and T1 ( $p = .04$ ). Other complications were related to increasing scores of HL between T1 and T2 ( $p = .04$ ). **Conclusion:** Evidence was found for changes in HL and SM over time. HL

and SM were also found to relate to the rate of re-hospitalization, though in the opposite direction than expected. Increasing re-hospitalizations among those who improved in HL and SM skills might be explained by the fact that they respond earlier to symptoms of complications. Also, transplant-specific clinical tests to assess HL and SM are lacking. Future research on the relationship between HL, SM, kidney function and graft survival is needed.

#### OP04

#### HISTORY OF MENTAL HEALTH DISORDERS AND NON-ADHERENCE: BARRIERS IN ACCESS TO KIDNEY TRANSPLANTATION

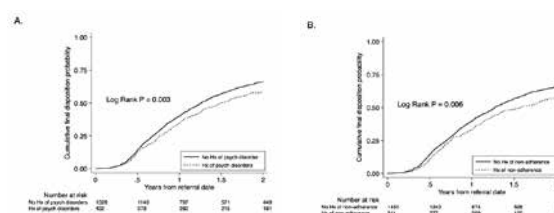
Istvan Mucsi<sup>1,2</sup>; Famure Olusegun<sup>1</sup>, Yanhong Li<sup>1</sup>, Marta Novak<sup>3</sup>, S. Joseph Kim<sup>1</sup>

<sup>1</sup> *University Health Network, Multiorgan Transplant Program, Toronto, Canada*

<sup>2</sup> *Semmelweis University, Department of Behavioral Sciences, Budapest, Hungary*

<sup>3</sup> *University Health Network, Department of Psychiatry, Toronto, Canada*

A history of mental health (MH) disorders or NA (NA) may be barriers to completing the work-up (WU) and/or undergoing kidney transplantation (KT) but this has not been well measured. Patients referred for KT to the Toronto General Hospital from January 1, 2003 to December 31, 2012, and who completed a social work assessment, were included ( $n = 1,769$ ). A history of MH disorders or NA, and the time from referral to WU completion or KT, were examined using Cox proportional hazards models. A history of MH disorders or NA was present in 24% and 17%, respectively. Patients with MH disorders had a 19% lower adjusted hazard of completing the WU within two years of referral (HR 0.81 [95% CI: 0.70, 0.95]). Similarly, patients with a history of NA had a 20% lower hazard of completing the WU (HR 0.80, [95% CI: 0.67 to 0.96]). The adjusted hazard ratio for KT was 0.86 (95% CI: 0.72, 1.02) and 0.80 (95% CI: 0.65, 0.97) for MH disorders and NA, respectively. These findings suggest that a history of MH disorders or NA are potential barriers to KT. Whether targeted psychosocial support can improve access to KT for these patients requires further study.



**Focus session 2:  
Ethical controversies in allocation**

**OP05**

**YOUNG FOR OLD – OLD FOR YOUNG?  
THE MORAL ECONOMY OF AGE AND  
INTERGENERATIONAL RELATIONS IN  
ORGAN DONATION**

Sabine Woehlke; Mark Schweda  
*University Medical Center Göttingen,  
Dept. of Medical Ethics and History of Medicine,  
Göttingen, Germany*

Due to demographic change, questions of age and generational relations begin to receive more attention in public debates on organ donation. The increasing population age leads to a growing demand for transplantable organs, thus intensifying the problem of organ scarcity and fueling concerns about the economic use and just distribution of donor organs. As a consequence, old age is focused as a criterion for resource allocation in postmortal donation, fostering ideas of age rationing for the sake of younger persons. At the same time, old persons are incorporated in new systems of efficient utilization of donor organs (e.g. as a separate subgroup in the ESP ‘old for old’-program or as ‘end-users’ of donor organs with a limited lifetime in so-called domino donations). In living transplantation, too, age and generational relations seem to play a prominent role for moral expectations and decisions regarding organ donation: On the one hand, studies indicate that traditional life plans and family roles make donations from parents to children appear natural and self-evident. On the other, increasing life expectancies and new ideals for the second half of life seem to challenge these underlying norms and promote the popularity of donations from adult children to old parents. In all these contexts, positions and arguments regarding organ donation are interwoven with morally loaded ideas of (old) age, the human life course, and intergenerational relations: images of old age, age norms and rights and responsibilities between generations. At the same time, the moral relevance of these age-related categories is rarely considered and therefore still less than clear in empirical research as well as in ethical theory. Our presentation examines the ways in which age matters in moral debates on organ donation. On the basis of qualitative research on public attitudes toward organ donation (29 focus groups with affected and laypersons in Austria, Germany, the Netherlands, and Sweden [n = 220]), we explore the normative implications of age and generational relations in the context of transplantation medicine. We propose a systematic classification of relevant age-related perspectives and discuss their structure and validity from an ethical point of view.

**OP06**

**A PUBLIC POLICY BASED ON INCENTIVES  
TO ADDRESS THE ORGAN SHORTAGE  
AND ITS CONSEQUENCES: CONCEPTUAL  
UNDERPINNINGS AND LEGAL IMPLICATIONS**

Melanie Levy  
*Edmond J. Safra Center for Ethics, The Buchmann  
Faculty of Law, Tel Aviv, Israel*

Organ transplantation is a very successful medical procedure saving the lives of thousands of patients worldwide every year. However, this ongoing achievement is overshadowed by a major phenomenon: a chronic shortage of transplantable organs. Here we describe the challenging reality that today’s transplantation medicine is facing. Based on an empirical analysis of the organ shortage and its serious consequences on patients and society, we define this phenomenon as a public health problem. This definition opens up the question of the state’s role in transplantation medicine. It leads us to formulate the possibility for the state to promote organ donation through incentives, i.e., regulatory instruments to reward individuals’ willingness to donate, in the context of a public policy. We provide an insight into the conceptual underpinnings and normative justifications of such a public policy, and discuss its potential to increase the number of organs donated. In an original approach, we integrate sociological and anthropological findings as to the nature of the act of donation – the concept of reciprocity most importantly – into considerations on the core attributes of a public policy based on incentives. We argue that incentives do not bring about a systemic change for today’s paradigm of organ donation as an altruistic, solidary and generous act. Addressing regulatory design questions, we present incentives such as priority status on the waiting list for registered donors, tax benefits, discounts on health insurance premiums, and coverage of a donor’s funeral costs. We also examine in more detail a recent non-financial incentive introduced in Israel. Finally, we consider the legal and ethical framework in which state incentives have to operate. Based on an analysis of the legislative history and intent of the prohibition of organ sales, we show that this broadly recognized legal principle does not allow for private commercial transactions involving money between the donor, the recipient and a third party. We conclude that this specific, and other legal and ethical constraints can be addressed by carefully designing the incentives’ modalities.

**Free communications 1:  
Deceased donation**

**OP07**

**ORGAN DONATION AGENCY: A DISCOURSE  
ANALYSIS OF CORRESPONDENCE BETWEEN  
DONOR AND ORGAN RECIPIENT FAMILIES**

Dariusz Galasinski; Magi Sque

*University of Wolverhampton, Faculty of Arts and  
Faculty of Education, Health & Wellbeing,  
Wolverhampton, United Kingdom*

Objective: Studies about the psychosocial issues concerning organ donation and transplantation tend to focus on the experiences of donor or recipient families. Little is therefore known about the part played by correspondence exchanged between these two groups. The aim of this study was to explore correspondence for representations of donation and the reception of organs for transplantation. More specifically, we were interested in how donor and recipient families accounted for the act of organ donation from the deceased. We wished to elicit how the families positioned themselves, the deceased person and their organs with regard to each other and the act of donation. Method: This is the first analysis to address the representation of the act of donation from the viewpoint of both donor and recipient families through interrogation of archived correspondence data, using linguistic techniques. We have found no other study analysing families' written representations of the act of organ donation after death. The data were drawn from an ethically approved archive of letters, from four USA organ procurement organisations, exchanged between donor and transplant recipient families. The letters included 38 from donor families and 40 from recipients and their families. Using both the systemic-linguistic analysis, as well as a hermeneutic-like interpretation of discourses, in terms of the context in which they were submerged, we attempted to reach the ideological underpinnings of the participants' experiences. Results: The agency or responsibility for organ donation from the viewpoint of donor families consistently ascribed causality in donation to the person who died, the donor, however in some instances this act of donation was seen to be facilitated by the surviving family. From the perspective of the recipient families the 'giver' was mainly implied, ambiguous or ascribed to the donor family. Conclusion: This is the first study to provide discourse elaboration of the agency of donation through correspondence between donor and recipient families. Apart from the findings we reviewed above, we have demonstrated the importance of discursive micro-analysis in achieving deeper understanding of the experiences of organ transplantation. Follow-up studies in other cultural and social contexts would offer welcome enrichment of the data and analyses we conducted here. These in turn could underpin better

clinical and social care for those involved in the processes of donation and transplantation.

**OP08**

**DESIGN AND IMPLEMENTATION OF A  
PUBLICLY RESPONSIVE DECEASED DONOR  
KIDNEY ALLOCATION SYSTEM**

Aviva Goldberg<sup>1,3</sup>; Kim Werestiuk<sup>3</sup>,  
Peter Nickerson<sup>2,3</sup>

<sup>1</sup> *University of Manitoba, Pediatrics and Child Health,  
Winnipeg, Canada*

<sup>2</sup> *University of Manitoba, Medicine, Winnipeg, Canada*

<sup>3</sup> *Transplant Manitoba, Winnipeg, Canada*

This presentation will describe the development of the Kidney Transplant Review Committee (KTRC) in response to the ethical challenge of designing a kidney allocation system that maximizes utility and equity, but is also responsive and transparent to patients and the public. The KTRC reports to Transplant Manitoba, the organization in charge of organ allocation in Manitoba, Canada. Focus groups with dialysis patients in Manitoba revealed that there were patients on our kidney transplant wait list who felt that the system was not transparent and were concerned about equity in the organ allocation system (e.g. they felt that kidneys were being allocated based on race or favoritism). In response to these concerns we did two things to increase transparency and trust in the allocation system. First, we published our allocation criteria on our website which clearly explained how the allocation system worked – the first province in Canada to do so. We also developed a Kidney Transplant Review Committee which has representatives from ethics, the transplant medical team and the public (a current or former dialysis patient, a representative from the local Kidney foundation and a patient advocate). The committee meets to review all kidneys allocated through the deceased donation system in the preceding period and determines whether or not the allocation followed the pre-existing allocation rules. In the case of an allocation that has not followed the rules (e.g. an error in waiting time calculation, inability to contact the patient at the 'top of the list', refusal of the transplant offer by the patient or his physician) the committee reviews why they did not proceed according to the rules and discusses ways of improving the system to avoid similar situations in the future. Any changes to the allocation system also need to be vetted through the committee – changes to the points allocated based on waiting time and degree of HLA matching, age matching of donor and recipient and a change to offer blood type compatible organs to pediatric patients first have all been discussed and approved at the committee level. The Kidney Transplant Review Committee has allowed our small program to be open and responsive to the public we serve, analyze ethically charged issues

from both a medical provider and patient perspective, and can serve as a model to other programs seeking to increase transparency and public involvement.

## OP09

### ADVANCED NURSING PRACTICE APPLIED TO TISSUE DONATION ON TRANSPLANT SECTION OF HOSPITAL CLÍNICA OF BARCELONA

Marc Bohils; Francisco Javier Garcia  
*Hospital Clínic, Transplant Section, Barcelona, Spain*

**Background:** Traditionally in Spain, nurse staff participate only part-time in the organ and tissue donation and transplantation process. These include support and assistance during mourning process to donor relatives, facilitate donor maintenance and coordinate organ retrieval and recipient preparation for transplantation and follow-up. Hospital Clínic is a university medical center with a Transplant Coordination Unit (TCU) and a Tissue Bank establishment, authorized for organ and tissue procurement and transplantation. We describe the implementation of in-hospital Advanced Nursing Practice (ANP) applied to tissue donation inside the TCU. **Aims:** Develop an ANP applied to tissue donation inside the TCU with nurse staff full-time dedication to active tissue donor identification, evaluation and retrieval. **Methods and Results:** Describe the ANP tissue donation model implemented since April 2013 based in full-time nursing staff dedicated to tissue donation process with medical transplant coordinator giving permanent support and clinical advice. According to the recruitment model of the hospital, 5 nurse professionals have been integrated in the TCU, for continuous on place 8 hours work covering 24 hours/7 days/365 days a year. **ANP tasks to be performed:** Identify all hospital deaths to perform active detection and careful medical suitability evaluation of previous and present medical line of potential tissue donors, physical exploration, family request and biological risk evaluation, blood sample obtaining, ocular tissue retrieval, multi-tissue extraction team coordination and computer databases and donor files collection. **Conclusions:** Exclusively ANP dedication in tissue donation allows expanding a new role and shaping future workforce. Tissues procurement can be economically self-sufficient when based in a close collaboration with a Tissue Bank allowing the sustainability of the model. This integrated model can be exported to other university hospitals with TCU.

## OP10

### WHAT DO WE TALK ABOUT WHEN WE TALK ABOUT INCREASING DONATION RATES?

Sara Bea  
*University of Edinburgh, Science & Technology Studies, United Kingdom*

The organ shortage crisis is experienced differently across Europe; every country shows particular donation-transplantation rates and some are closer to the so-called self-sufficiency model than others. Thus, the objective of EU donation regulations is to boost donation rates for each and every member-state and to promote a pathway of further standardised donation practices. An example is the 2010 initiative that called for an adaptation of the 'Spanish model' of organ and tissue procurement across states due to its potential to increase donation rates. However, there is a significant knowledge gap on the articulation of such policies in practice and more specifically on the role of Transplant Coordinators (TC); the key health professionals that organise the totality of the donation processes in the hospital. This PhD research project will advance relevant information both about the figure of TCs and the implementation of presumed consent in the practice. The work strives to foster an informed discussion on national donation rates, enablers and barriers. It is based on a study of a TC team in a Catalan hospital with leading donation rates. Ethnographic methodology was used to conduct an in-depth mapping of donation practices; observations were later on paired with interviews with all members of the TC team. Results indicate that any approach to increase donation rates must encompass the totality of the necessary stages that lead to a donation; that is from donor detection, evaluation, and maintenance, to the donation interview and final organ extraction. It is a common trait across existing social science literature on organ donation to focus exclusively on the donation interview as the pivot stage whereby consent to donation is obtained. It will be argued that such a narrow focus neglects the importance of previous stages, namely donor detection and evaluation, that are equally necessary and crucial in any case of donation. I will draw on examples from fieldwork to firstly, elucidate on the proposed framework of embedded donation practices that foreground the role of TCs along with the interdependencies with other HCPs in the hospital. And secondly, to move the debate beyond the classic polarisation of 'informed versus presumed consent'. Instead, I will suggest that the concept of 'distributed consent' can lead to a more comprehensive discussion on increasing donation rates.



## OP11

### **SIGNIFICANTLY MORE CONSENT FOR ORGAN DONATION FOR DOCTORS TRAINED IN 'COMMUNICATION ABOUT DONATION'**

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**Objective:** The training 'Communication about Donation' (CaD), developed by the Dutch Transplant Foundation in 2007, facilitates medical professionals in approaching families of potential organ and tissue donors. According to the Masterplan Organ Donation the CaD training is mandatory for intensivists since 2012, therefore many CaD trainings were organized in the Dutch hospitals. The main part in the practical training includes role-playing with actors. In the period November 2012 – October 2015 family approaches, for only organ donation, are evaluated by a questionnaire. **Methods:** Evaluations took place by 'donation intensivists' in a face to face setting, by telephone or by email. Items about the consent process were evaluated for example; if the doctor was trained in CaD, what was the outcome of consulting the Donor Registry, if donation was requested decoupled from breaking the bad news and, how many family members were present during the request. **Results:** In total 1723 questionnaires were retrieved. The number of doctors trained in CaD was 1094, 531 are not (yet) trained and in 98 cases this information is missing. In 1533 cases the family reached a decision about donation. The consent rate for organ donation in the CaD trained group was significantly higher ( $p < 0.029$ ); 56.3% (579/1028) compared to the non-CaD trained group 50.9% (257/505). After excluding potential donors with 'consent' in the Donor Registry, the family consent rate was 42% for CaD trained doctors and 36.2% for the group not trained in CaD ( $p = 0.069$ ). **Conclusion:** These figures show that it is important that the family of a potential organ donor is approached by a doctor trained in CaD. Although the results are promising the consent rate is still low and we expect that there is room for improvement, compared to other countries. A complete analysis will be shown at the congress.

## OP12

### **VIDEO BASED E-LEARNING IN 'COMMUNICATION ABOUT DONATION' SKILLS FOR DOCTORS PROVIDES A BETTER OUTCOME ON CONSENT FOR TISSUE DONATION**

P. Edwin Vorstius Kruijff<sup>1</sup>; Nichon Jansen<sup>2</sup>, Moniek Huisman- Ebskamp<sup>1</sup>, Maartje De Vos<sup>1</sup>, Rob Slappendel<sup>1</sup>

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**Objective:** In hospitals, physicians are rarely confronted with tissue donation. Besides correctly identifying an eligible tissue donor the physician also has to deal with the bereaved family. When the immediate family members were asked to consent for tissue donation, objection by the next of kin appears to be the main reason for the loss of potential tissue donors, if no registration is found in the Donor Register. Hence, next of kin need a clear understanding of the process and the decision should reflect the wishes of the potential donors' character and known or implied attitude about tissue donation. Therefore physicians guidance of next of kin through the consent process for tissue donation is an essential part of the recruitment process and requires adequate communication about donation skills and techniques. We analysed if physicians educated with a Video based E-learning program on 'communication about donation' skills successfully contribute to a higher consent rate for tissue donation. **Methods:** This retrospective study was conducted in the year 2014, in a Dutch teaching hospital. Two groups of physicians were compared; physicians receiving a lecture on 'tissue donation' and physicians receiving an additional E-learning on 'communication about donation'. The results were analysed on the outcome 'obtained consent' for tissue donation from next of kin. **Results:** Analyses show that physicians receiving a lecture about organ- and tissue donation extended with a video based e-learning on communication about donation obtain a significantly ( $p \leq 0.011$ ) higher consent rate (55.6%) for tissue donation compared to physicians who only receive a lecture (15.5%). Additionally when physicians identify an eligible tissue donor, physicians from the E-learning group consult more conscientiously the Donor Register according to the prevailing protocol for organ and tissue donation. **Discussion:** A mandatory offer for physicians to follow an E-learning on communication about donation must be considered. It could help the availability of tissue donations.

## OP13

**NO! AN ANTHROPOLOGICAL STUDY OF DANISH FAMILIES WHO REFUSED ORGAN DONATION WHEN ASKED AT THE HOSPITAL**

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In Denmark, approximately on third of families refuse donation of their family members' organs when asked at the hospital. Studies have suggested that family refusals are the main reason for the low donation rates in Denmark. Why do families say no, what are their experiences and how can staff provide care and attention for this group? Based on ethnographic interviews with 20 Danish family members who said no to donation in 2013-2014 and 20 Danish doctors and nurses working with family approaches for organ donation, this study explores the family experiences and the motivations for saying no to organ donation. The paper argues that saying no to organ donation is not necessarily a result of negative feelings towards donation. Rather it is based on the unknown wishes of the deceased, the time span of the donation process, the family history and dynamics, and considerations about dying alone and body disfigurement. The paper also shows that declining organ donation is a meaningful decision for the family. They do not regret their decision, and they appreciate the care and attention shown by medical personnel. However family experiences also indicate that there are many improvements to be made in the information levels regarding the expected time span, the communication of anticipated death before brain death is declared and the clarification of what actually takes place during organ procurement and thereafter.

**Free communications 2:****Legal aspects**

## OP14

**LIVING TISSUE AND ORGAN DONATION BY MINORS: THE REGULATORY FRAMEWORK ACROSS EUROPE**

Kristof Van Assche; Sigrid Sterckx

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The use of minors as living donors is a very controversial issue in transplantation. The purpose of this presentation is to examine how living donation by minors is currently regulated across Europe. We first explore the potential clinical need for using minors as living donors and sketch the debate about its ethical acceptability. Subsequently, we assess whether inter-

national legal instruments and guidelines offer any guidance to address these issues. Next, we analyse the legal situation in the United States, where courts have been petitioned to authorise living donation by minors. This is followed by a detailed examination of the legal situation in Europe. This involves an analysis of the supranational regulatory framework established at European level and an investigation of the domestic transplant regulations in the individual EU Member States, Norway and Switzerland. We point out that living tissue donation by minors is allowed in all 30 countries under consideration, with only slight differences in its regulation. By contrast, living organ donation by minors is currently only allowed in six European countries. In these countries, regulations differ widely with regard to the substantive and procedural safeguards that need to be fulfilled. All data have been double-checked by the authors and, where necessary, by medical law experts in the countries concerned. Finally, we briefly compare the legal approach followed in the great majority of European countries with the one preferred in the United States. We conclude by recommending that, in the light of the 'best interests of the child' principle, European transplant regulations may need to be amended so as to exceptionally also allow living organ donation by minors, subject to a range of very stringent safeguards.

## OP15

**LEGAL CONSIDERATIONS ON PRE-MORTEM INTERVENTIONS IN DONATION AFTER CIRCULATORY DEATH**Kourosh Saeb-Parsy<sup>1</sup>; Kathleen Liddell<sup>3</sup>, Christopher Watson<sup>1</sup>, Nicola Padfield<sup>4</sup>, James Neuberger<sup>2</sup>, J. Andrew Bradley<sup>1</sup>, Dyson Matthew<sup>4</sup><sup>1</sup> *University of Cambridge, Department of Surgery, Cambridge, United Kingdom*<sup>2</sup> *NHS Blood and Transplant, United Kingdom*<sup>3</sup> *University of Cambridge, Centre for Law, Medicine and Life Sciences, Cambridge, United Kingdom*<sup>4</sup> *University of Cambridge, Faculty of Law, Cambridge, United Kingdom*

The proportion of organs transplanted following donation after circulatory death (DCD) has steadily increased in the UK and is approaching that from donation after brain death (DBD). Because death must be declared after cessation of circulation following withdrawal of life-supporting treatment, DCD organs are necessarily exposed to a period of warm ischaemia before they can be perfused with cold preservation solution. This has significant deleterious effects on graft and patient outcomes after transplantation. The detrimental impact of warm ischaemia in DCD donors can potentially be ameliorated by pre-mortem treatments of the donor, such as systemic anticoagulation. However, such interventions are currently prohibited

by UK law whereas they are permissible in the US. UK regulations stem from the legal definition of death and prohibition of interventions that are not directly intended to benefit the donor before declaration of death. This paper examines the UK legal framework that would govern potential regulatory changes to enable pre-mortem treatment of DCD donors in order to improve recipient outcomes. It also considers potential legal consequences if circulatory death is deemed to be hastened by an intervention, or if a donor experiences adverse effects without suffering circulatory death after withdrawal of life-supporting treatment.

## OP16

### **FAMILY OVERRIDE OF CONSENT FOR DECEASED DONATION: THE LAW AND POLICY IN CANADA, THE UNITED KINGDOM, AND THE UNITED STATES OF AMERICA**

Maeghan Toews<sup>1,2</sup>; Timothy Caulfield<sup>1,2</sup>, Samantha Anthony<sup>2,3</sup>, Linda Wright<sup>2,3</sup>

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**Objective:** Variations in practice exist among jurisdictions in terms of enforcing an individual's consent for deceased donation in the face of family objection. Practice on this issue may be influenced by the law and how it is interpreted and applied as a matter of policy. This work examines legislation and publicly available policy information from three common law countries to better understand variations in the law and policy governing consent for organ donation. **Methods:** We are conducting a legislative review and analysis, employing common law principles of statutory interpretation to assess the legality of family override in Canada (including 12 common law provinces/territories), the United Kingdom (including Scotland and legislation governing England/Northern Ireland/Wales), and the United States (including the five most populous states: California, Florida, Illinois, New York, and Texas). Additionally, we are conducting a policy analysis examining information available online in each jurisdiction from government bodies, transplant programs, and donation organizations. The results of the legal and policy analyses will be compared to assess the alignment in different jurisdictions of law and policy on the issue of family override. **Results:** Legislation within Canada generally provides that individual consent is binding and sufficient authority for donation to proceed. In contrast, policy information consistently indicates that the wishes of a potential donor's next-of-kin will ultimately be followed. Preliminary results for the other jurisdictions indicate that legislation gov-

erning England/Northern Ireland/Wales and Scotland similarly does not permit families to override an individual's consent or authorisation for donation. Policy information from Scotland indicates strong support for enforcing an individual's authorisation, although there is some acknowledgement elsewhere in the UK that it may be inappropriate in some cases to proceed with donation in the face of family objection. Legislation in the U.S. jurisdictions appears to explicitly prohibit family override, which seems generally consistent with available policy information. **Conclusion:** There is a pronounced disconnect between law and policy in Canada on the issue of family override. In contrast, there appears to be close alignment between policy and legislation in the U.S. jurisdictions and Scotland. In the rest of the UK, although legislation does not permit family override, there seems to be some recognition that it may sometimes be appropriate to respect family wishes.

## OP17

### **ETHICAL TENSIONS BETWEEN END-OF-LIFE AND ORGAN DONATION**

David Rodriguez-Arias

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A tight link exists between end-of-life decision-making and organ donation. The way patients are treated in the last moments of their lives determines how, where and when they die, all of which affects the viability of their organs for a possible transplant. Decisions on the maintenance or withdrawal of life support can be more or less conducive to organ donation. Conversely, the envisioned possibility of a proximate organ donation can interfere with the way patients who are likely to die are handled and taken care of. This is ethically sensitive because the optimal care for patients may not be compatible with the optimal preservation of their organs, and vice versa. When individuals are being simultaneously considered as patients and as a potential source of organs, health professionals dealing with them are faced with delicate conflicts of interest. Such conflicts not only intervene in the way potential donors are treated, but have also an impact on the way important concepts such as futility, irreversibility or death are being defined and used. The purpose of this presentation is to identify and discuss premortem and postmortem practices that have the potential of compromising the interests of potential organ donors. These include, but are not limited to the following: elective ventilation and cranioplasty with bandaging intended to enable brain death in patients with catastrophic brain injury, the use of mechanical chest compression and ventilation in candidates for uncontrolled donation after circulatory determination of death (DCDD), and heparine administration, ECMO and other techniques intended to preserve the organs in both controlled and



uncontrolled DCDD. I'll suggest that, in any of these situations, health professionals are requested to achieve goals that raise the question of whether their priority is to maximize their patients' welfare, or rather the procurement of their organs (the maximization of both often being unachievable). While saving lives or improving the quality of life of patients in waiting lists is a fundamental duty of intensivists, surgeons and emergency doctors and nurses, I'll argue that their primary duty is to foster their patients' welfare (at least, insofar as they have not yet irreversibly lost their vital functions). Donors' informed consent and full disclosure to families on the means and the objectives of their practices are essential ethical requirements for justifying any prioritization of the secondary duty of saving organs at the expense of threatening donors' interests.

## OP18

### THE 'DOHA MODEL OF ORGAN DONATION': FROM AN ETHICAL FRAMEWORK TO NEW NATIONAL TRANSPLANT LEGISLATION

Riadh Fadhil

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Qatar is a multicultural, multinational Gulf country of 2 million people, mostly expatriate workers from South East Asia and the Middle East. Most expatriate workers have poor knowledge of organ donation, and approximately 70% live alone in Doha without their families. There are thus major obstacles for transplantation of expatriates from live related organ donors, and in the approach to families when an expatriate becomes a potential deceased donor. Historically, lack of organ donors in Qatar compelled many wealthy patients, particularly local citizens to seek organs in foreign markets, returning to Qatar with high rates of morbidity and mortality. In response to these challenges, Qatar's major provider of health services, Hamad Medical Corporation, collaborated in 2009 with The Transplantation Society and the Declaration of Istanbul Custodian Group in development of the Doha Donation Accord (DDA). The DDA is an ethical framework that implements the recommendations of the Declaration of Istanbul designed to increase organ donation and prevent transplant commercialism. Implementation of the DDA has increased domestic transplant activity from living related and deceased donors, and reduced travel from Qatar for commercial transplantation. The DDA together with its strategies is now known as the 'Doha Model of Organ Donation'. This paper reports on the translation of the Doha Model's core strategies into the national law. The Organ Transplant Law 21 of 1997 insufficiently addressed the legal and ethical challenges of donation and transplantation. In August 2015, a new national transplant law (No. 15) was introduced. The new complementary

sections of law 15 regulate the full implementation of the DDA e.g., recruitment for the newly created donor registry; defining authority of the ethical committee for psychosocial evaluation of living donation, equitable access to deceased donor organs and transplant services, removal of disincentives to donation; and prevention of commercial transplantation arising from Qatar. In addition to reconfirming sections imported from law 21 that regulate altruistic living donation, deceased donation and combat commercialism. Conclusion: The milestones of law (15)-2015 is exemplary for developing efficient legislation that incorporates tested efficient practices into its core. For transplant laws to be effective in developing organ donation, they should not merely regulate donation procedures and prohibit commercial activities, they should extend further to include regulation of ethical strategies to promote donation

## OP19

### THE LAW AND ETHICS OF PRELIMINARY MEDICAL MEASURES FACILITATING ORGAN RETRIEVAL: AN ANALYSIS OF THE NEW SWISS LEGAL FRAMEWORK

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The Swiss Transplantation Law defines preliminary medical measures as measures intended solely to preserve organs undertaken prior to the death of the donor. These measures play an important role for successful organ transplantation, both in donation after brain death and donation after cardiac death. Since its implementation in 2007, the Swiss Transplantation Law has led to uncertainties in the practice of organ transplantation in Swiss hospitals, most importantly with regard to the two following questions: At what point in time can a request be addressed to the next of kin for the removal of organs from a potential donor? Can the next of kin consent to preliminary medical measures taken prior to the death of the donor, if the latter has not made such a decision during his lifetime? The paper first analyses the delicate legal and ethical questions raised by the issue of consent of the next of kin to preliminary medical measures facilitating organ retrieval. These measures are administered on a patient/potential organ donor, prior to his death and in the interest of a third party, the potential organ recipient, and they can imply certain risks for the patient/potential donor. The paper then focuses on the recent amendment of the Swiss Transplantation Law adopted by the Swiss Parliament in June 2015. This amendment is supposed to address the uncertainties encountered in practice. It specifies under which circumstances preliminary medical measures can be administered, and to what extent the next of kind can consent in case the

potential donor has not done so during his lifetime. The amendment clarifies that the request to the next of kin and consent to organ removal can take place only once it has been decided to discontinue life-sustaining treatment for the patient/potential donor. In case a potential donor has not expressed consent himself, preliminary medical measures can be administered if three conditions are met cumulatively: first, these measures are essential for a successful organ transplantation; second, they impose only minimal risks and burdens on the donor; and third, the next of kin have expressed consent to such measures. If a potential donor has no next of kind or if they cannot be reached, preliminary medical measures may not be administered prior to the donor's death. If a patient has not declared his intention regarding organ donation, such measures may be carried out after his death until the next of kin have reached a decision, within a maximum time frame of 72 hours.

## OP20

### **HEALTHCARE LAW ANALYSES OF THE DONOR REGISTRY IN THE NETHERLANDS: IS REGISTERED CONSENT TO ORGAN DONATION LEGALLY BINDING AFTER DEATH**

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Introduction: According to the EU Directive 2010/45/EU several models of consent to donation can coexist. In order to enable individuals to express their wishes in the different models, some countries developed specific registries where citizens record them. The Netherlands is one of the countries with such a registry. The Organ Donation Act, which is based on an opt-in system, is supported by a national Donor Registry (DR). The legal status of such registry is not described in the EU Directive, thus Member States are free in choosing the status. In The Netherlands the DR is not considered to be a will and therefore not legally binding after death. Question is what the legal purpose is of a registration? A literature review is performed to give an answer to this question. Argumentation: In healthcare law the basic principle is informed consent: a process for getting permission before conducting a healthcare intervention on a person. The EU Directive states that the procurement of organs shall be carried out only after all requirements relating to consent, authorization or absence of any objection have been met. Thus a registered consent in the DR is a legal justification in the form of informed consent for organ procurement. Because in The Netherlands the DR is not the same as a will, a registered consent makes the decision to be an organ/tissue donor not legally binding after the death of the donor. This has several consequences, one of which is the possibility of the donor's family to over-

rule the decision registered in the DR. Conclusion The legal status of a registry within the several models of consent is not regulated by the EU Directive. This is an important issue which has to be taken into consideration by the legislator in the Member State. It does not seem very meaningful to have a registry which is not legally binding after death of the donor, which is the case in The Netherlands. Therefore a discussion on this subject is necessary even if it is just to bring awareness to the people involved in the field of organ donation and transplantation.

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### **Free communications 3: Cultural, religious and social aspects (A)**

## OP21

### **GUARDIANS OF 'THE GIFT' – EMOTIONAL CHALLENGES OF DOCTORS AND NURSES WORKING WITH HEART AND LUNG TRANSPLANTATION**

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With a few exceptions, studies of organ donation and transplantation tend to neglect the professional work challenges and emotional consequences of working in this field. This paper argues it is time to recognize and investigate the efforts of transplant professionals. As guardians of 'the gift', transplant professionals facilitate many aspects of the exchange of organs, maintaining a fine balance between representing the wishes of donors and society, and caring for and supporting transplant recipients. They somehow represent all positions in the organ transfer. Based on anthropological fieldwork at a Danish heart and lung transplant unit and staff interviews, this paper illustrates and discusses how staff handle and cope with the emotional challenges of their working life at the transplant unit, such as organ allocation, post-transplant infections, patient compliance, and recipients deaths. Contrary to dominant public discourse of 'transplant miracles' and 'second chances', the everyday life of transplant professionals is sometimes dominated by sad cases and devastation. However, it is often close patient care and social relations rather than only transplant outcomes that is rewarding for professionals. In conclusion, the paper suggests that paying attention to the experiences of transplant professionals enables new understandings of the wide range of emotional burdens and rewards within transplant medicine.

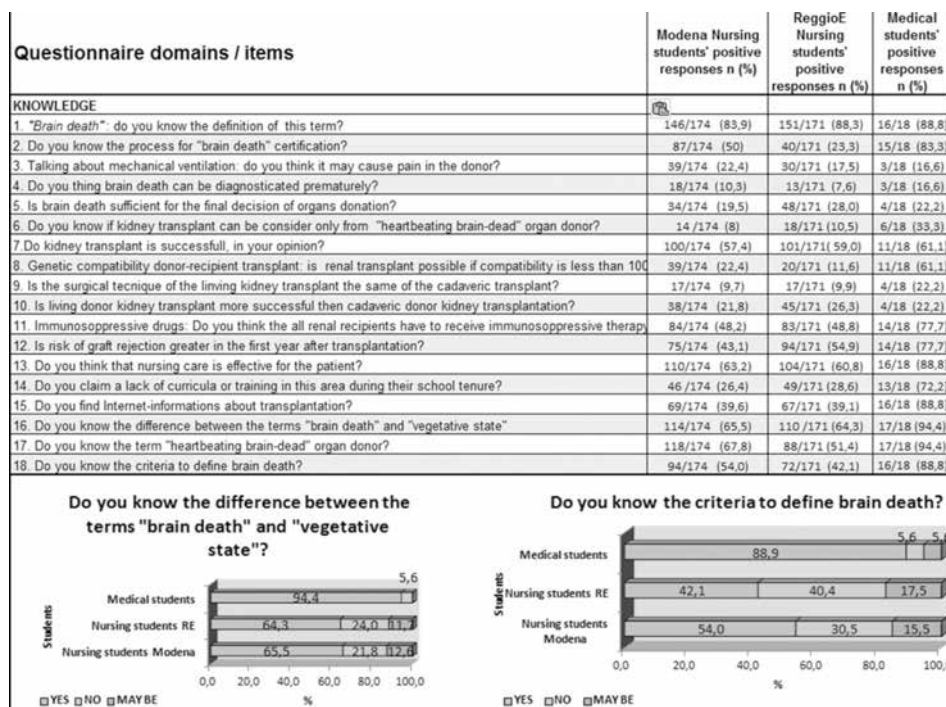
## OP22

# UNDERGRADUATE NURSING AND MEDICAL STUDENTS' ATTITUDES AND KNOWLEDGE TOWARDS ORGAN DONATION: A SURVEY IN MODENA-REGGIO EMILIA UNIVERSITY

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**Introduction:** A recently conducted international study shows a limited knowledge of the problems of organ donation but also the desire of medical students of knowing more about it, and of having this included between the topics of university education. This would permit to the same subjects, after graduation, to raise awareness on citizenship in favor of the activities of organ donation, as well as to facilitate the increase of transplants procedures. **Aims:** The purpose is to show how many students of Medicine and Nursing of Modena and Reggio Emilia have knowledge of procedures and how much availability for the donation of organs and tissues is there. **Methods:** Students completed a self-administered questionnaire with 32 multiple choice questions. The content of the questionnaire has been supported by previous research, through consultation with expert colleagues and by reviewing the literature. The questionnaire includes

demographic data, attitude to organ donation, ethic aspects and transplantation knowledge (Table 1). The questionnaire data were collected, coded and analyzed using GraphPad Prism (Vs 6.01) for Windows. All tests were conducted at a statistical significance level of  $p = 0.05$ . Results: There were 365 students (346 nursing students and 18 medical students). We distributed 365 questionnaires to the students before class lectures and a total of 365 were returned (response rate 100%). The study population was predominantly male (70.5%) and the median age was 23.5. 76% of the students were in favour of organ donation and 71% would be willing to register as a donor on identity card. Only 15% of the students had previously signed a donor card consenting to their own organ donation. At least two third of students among all groups had discussed the issue of donating kidneys with family or friends. Some students did not possess clear knowledge about the concept of brain death (Figure 1), were not able to distinguish it from a persistent vegetative state (Figure 2) and did not know the term 'heartbeating brain-dead' organ donor, especially nursing students. A lot of students (42%, especially medical students 72%) claimed a lack of curricula or training in this area during their education. **Conclusions:** The development of an effective educational directive and in-depth training programme in this area within Italy's nursing-medical schools is required.



## OP23

### CRITICAL CARE PROFESSIONALS' KNOWLEDGE AND ATTITUDES RELATED TO BRAIN DEATH, CADAVERIC ORGAN DONATION AND TRANSPLANTATION.

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Background: Malaysia's organ donation (OD) rates are among the world's lowest. Whether critical care professionals' (CCPs) knowledge and attitudes related to brain death (BD), OD, and organ transplantation (OT) underlie these low rates remains unstudied. Objective: To assess whether tertiary hospital CCPs knowledge and attitudes related to BD, OD and OT influence their willingness to donate organs. Methods: Doctors and nurses in the emergency department, neurology ward and general & neurosurgical ICUs were surveyed using a validated questionnaire in English or Malay containing 25 knowledge and 16 attitude questions. Sociodemographic data were also collected. Data were analysed using Stata 14.1 to assess whether sociodemographic, knowledge and attitude variables were associated with the respondents' willingness to donate organs. Results: Of 565 CCPs invited to participate, 413 (73.1%) responded of whom 163 (39.5%) were doctors and 250 (60.5%) were nurses. Willingness to donate was significantly associated with the BD knowledge score (OR 1.21, 95% CI, 1.11-1.31,  $p < 0.001$ ) and suggestively associated with the OD knowledge score (OR 1.13, 95% CI, 0.99-1.27,  $p = 0.05$ ). Of 358 CCPs convinced of the existence of BD, 72.4% were willing to donate compared with 28.6% of 7 unconvinced counterparts ( $p < 0.001$ ). Of 365 CCPs who believed that BD can be diagnosed reliably, 69.6% were willing to donate compared with 73.3% of 15 unconvinced counterparts ( $p = 0.032$ ). Of 324 (79.2%) respondents who believed that OT is a good form of treatment, 236 (72.8%) were willing to donate compared with 15 (48.4%) who did not believe in OT ( $p < 0.001$ ). 289 (70.5%) of all HCWs would accept an organ themselves of which 225 (77.9%) were willing to donate compared with 48.8% of 43 counterparts who would not accept an organ ( $p < 0.001$ ). CCPs unsure of whether their religion objected to deceased donor organ donation were significantly

less willing to donate (OR = 0.23, 95% CI, 0.12-0.46,  $p < 0.001$ ). Indians (89.8%) had the highest willingness to donate followed by Chinese (86.0%), Malays (60.8%) and other ethnicities (55.6%) ( $p < 0.001$ ). Conclusion: Among tertiary hospital CCPs, both knowledge and attitudes are significantly associated with willingness to donate organs. Efforts to increase knowledge and change attitudes may further improve this willingness.

## OP24

### OVERVIEW OF FAMILY REFUSALS TO ORGAN DONATION IN CATALONIA

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Introduction: The Catalan Transplant Organization (OCATT) is the public organism of the Catalan Government responsible for planning, ordering, coordinating and assessing all the activities related to donation and transplantation of organs, tissues and cells in Catalonia since 1984. The objective of this study was to describe detected cases of possible deceased donors, according to some sociodemographic variables. Methods: The main source of data was the Catalan Registry of Organ Donation and Transplantation. This registry, population based and of mandatory notification, collects, since 2003, all detected cases of brain death (BD) and cardiac death (CD) in the 23 authorized hospitals for organ procurement in Catalonia. We have carried out a descriptive analysis of possible BD or CD donors, categorized as valid donors, medical contraindications, court refusals and family refusals, according to sex, age group (0-60 and > 60 years), cause of death and origin (divided into Spain and seven world areas). Moreover, we have described the percentage of family refusals using these sociodemographic variables and we have also analyzed this data through a multivariate analysis using logistic regression. All the analyses were performed with the statistical program SPSS 18. Results: 61.6% of BD and CD cases finally were valid donors (at least one organ retrieved). Data showed small differences by sex and age group. Regarding cause of death, we observed this percentage was higher in the case of head injuries and cerebrovascular accident in comparison to anoxia or other causes. Greater differences were also observed by the origin of the donor. The percentage of family refusals in general was 19.1%. This percentage was lower in cases where the possible donor was 60 years old or less (18.6%), a male (18.3%), he/she suffered anoxia (15.6%) or head injury (16.1-16.5%) and was Spanish (18.0%) or from North America (16.7%). Finally, the results of the multivariate analysis showed the main variable related to family refusals was origin of donor, due to the fact that people from North Africa and Asia were less ready to donate their organs. Conclusion:



Although in Catalonia the percentage of valid donor is high and the percentage of family refusals seems to be lower than in other countries. Campaigns of donation and transplantation promotion targeted at some specific cultural and religious groups must be carried out in the future, if we are to increase our results even more.

## OP25

### INFLUENCERS OF PUBLIC TRUST IN THE ORGAN DONATION SYSTEM IN INDIA

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Public trust is an essential part of organ donation in order for people to be willing to engage with the system. Especially in many developing countries, where corruption and unequal access to the health system are apparent issues, public trust often is compromised. In India where deceased donation has only come off age within the past 20 years and where organ donation still today by many is perceived to be linked to organ commercialism, understanding how public trust in the system is built and maintained is crucial. Following the question which features of an organ donation system are most important to create and maintain public trust, the main objective of the study is to find out how integrity of the system is perceived by the public and what relevance it has in regards to the functioning and trustworthiness of an organ donation system. The study, which is set in the Indian state of Tamil Nadu, is based on semi-structured expert interviews with doctors, transplant coordinators and people otherwise related to the field as well as structured follow-up interviews with families of deceased organ donors to be conducted in November and December. As the study is still ongoing final results will only be presented at the conference. Preliminary results show that transparency, trustworthiness of people and institutions as well as government support appear to be the most central aspects to perceived integrity and public trust. Experts have furthermore emphasized the importance of the media in shaping public opinion on organ donation. Positive portrayals and success stories seemingly have led to an increase in the willingness to donate organs whereas movies portraying negative myths on organ donation place serious challenges. The largely privatized health system alongside with misconceptions about brain stem death among both the public and health professionals, have been mentioned to fuel myths about organ commercialism and insufficient efforts to save patients lives. Taking into consideration the insecurities and needs of donor families providing some form of incentive or compensation has been mentioned to hold possible yet ethically debatable potential for trust building and increasing donor numbers. As

public perception and opinion shape individual decisions, it is essential to achieve a better understanding about the features of the system that are most crucial for public trust. Only then trust-building measures can target uncertainties and bottlenecks more specifically and sustainably on a societal scale in order to address organ shortage more effectively.

## OP26

### INCREASED ORGAN DONATION WILLINGNESS AFTER GERMAN TRANSPLANTATION SCANDALS: THE INFLUENCE OF PUBLIC ATTITUDES TOWARDS BRAIN-DEATH AND BODY CONCEPTS

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Background: In Germany, two events occurred in 2012 regarding the transplantation system. The media reported about allocation scandals and new regulations concerning regular public information were implemented. Public mistrust as a result of the scandals was repeatedly utilized to explain the current decrease in donation rates. Aim and Method: To test for public attitudes towards organ donation a comprehensive survey was conducted twice (2008/09 and 2014/15). Participants included students of medicine and economics (total n = 1403) attending the university of Göttingen, a hot spot of the scandal. The questionnaire comprised 55 sets of closed questions examining knowledge and attitudes concerning death and bodily identity. Statistical analysis involved a multivariate regression using R 3.2. Results: The survey revealed that donation willingness increased (58% to 75%); in 2014 twice as many held a donor card (52%). Majority agreed that there is a problem of fair allocation (70%). Only < 15% of willing donors and reluctant persons considered transplantation well regulated (less in 2014/15 [p < 0.05 sig.]). Non-acceptance of the brain-death criterion significantly interacts with reluctance. Another factor is sharing a holistic body concept which links the human body to personal identity. Conclusion: Public communication should allow for campaigns to also address these concerns without being reduced to a lack of knowledge.

## OP27

### THE CORE OF SOCIAL FUNCTION AFTER SOLID ORGAN TRANSPLANTATION

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**Background:** In health related quality of life, social function is a crucial aspect. In this study we focused on changes in social function up to a year after solid organ transplantation. **Aim:** To investigate solid organ transplant recipients (SOTR) main concerns related to social function and how these concerns are dealt with one year post operatively. **Method:** Twenty SOTR, 7 women and 13 men with the mean age of 54 years, participated in an in-depth interview study at their 12 month follow-up appointment. The interviews were digitally recorded and transcribed verbatim. The text was analysed with the Grounded Theory (GT) method developed by Charmaz. **Results:** Three main categories describe the respondents' effort in the process to maintain social functioning: 1) deconstruction, 2) restriction and 3) reconstruction. A clear path of transition through adaptation is evident in this process. This starts before transplantation and continues further than the first year post-transplant. **Conclusion:** The social function improves through a process of adaptation. The two most important aspects of social function were working and travelling. The outcome of a successful adaptation was to regain a normal life.

#### Workshop 1:

Clinical research in deceased donation: medical, ethical, legal and societal aspects

## OP28

### AN ETHICAL AND LEGAL FRAMEWORK FOR CONDUCTING DECEASED DONOR RESEARCH

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The need for innovation in the optimization and repair of deceased donor organs prior to transplantation has brought attention to the legal and ethical considerations of conducting research on deceased donors and

donor organs. Confusion over how to apply well understood principles for living human research subjects in the unique context of deceased donation has led to inconsistent practices and has been repeatedly cited as a barrier to conducting clinical research in the field. This has been particularly complicated within the United States given the legal and regulatory landscape. Thus, leaders of the organ donation and transplantation communities within the United States convened a multi-disciplinary task group to identify a path forward. The task group (which the co-authors of this abstract were participants of) identified the need for centralized review and oversight of multi-institutional donor intervention trials given the complexities that come with conducting clinical research in the context of organ allocation. Such a review process would utilize a framework of developed and contextually appropriate ethical concepts in conducting research on deceased donors. These principles include: voluntariness, dignity and maximizing the gift. From these principles a legally and ethically sound approach to authorization to permit the participation of a deceased donor in clinical research can be established. Ambiguity remains about the consequence of the donor research on the transplant recipient as a possible human subject. Further complications as to the impact of research interventions on allocation must also be considered. The successful conduct of clinical research in the field of deceased donation and transplantation requires an understanding of the regulatory and legal nuances as well as identification of a cohesive set of ethical principles in order to preserve the public trust and provide a level of transparency that is fundamental to donation and transplantation. The objective is to increase the availability of deceased donor organs for transplantation; thus, development and application of principles and standards will be needed to gain the professional and public support for innovative deceased donor research.

#### Workshop 2:

Common problems and national approaches to death and deceased donation

## OP29

### ABANDONING THE DEAD DONOR RULE: INSIGHTS FROM AN EXPLORATORY SURVEY IN SPAIN

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A recent survey on public opinion related to the legal and ethical implications of prospected changes in current transplantation protocols (DCD and uDCD) that diverge from the dead donor rule (Nair-Collins et al. 2015) not only seem to suggest that the majority of the surveyed population would welcome a more flexible

regime of transplantation but also that there are some significant religious and cultural factors that explain this positive attitude towards change. Inspired by this study, we have delivered a short exploratory survey to both students and experts in the fields of law, bioethics and philosophy, proceeding from different universities and expert committees in Spain. The survey aimed at retrieving both quantitative and qualitative data about participants' opinion on the acceptability of organ transplantation in four different scenarios, after and before cardio-circulatory death, of which only one respected the dead donor rule. The data, first, confirm that the majority of participants were willing to support transplantation protocols abandoning the dead donor rule (67%). Second, the combination of quantitative and qualitative data confirmed the importance of religious and cultural factors in relation to the acceptance or rejection of new transplantation protocols. Spain is a country that is renowned for its transplantation culture and for the trust that its medical system enjoys among its citizens. As a result, the outcomes of this study also bring to the fore some of the ethical and cultural issues and criteria associated with the protection of the donor, the recipient and their family, and the medical staff, that are likely to be relevant in any prospected debate about the future of organ transplantation and the dead donor rule.

### OP30

#### THE USE OF THE BRAIN DEATH CRITERION IN ORGAN DONATION AFTER THE CIRCULATORY DETERMINATION OF DEATH

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The U.K., France and Switzerland determine death using the unitary criterion of brain death even in organ donation after the circulatory determination of death (DCDD) in which the United States and Canada use the circulatory criterion of death. In our analysis of the scientific validity of the brain death criterion in DCDD, we concluded that, although the brain death criterion in DCDD is attractive in theory because it unifies death into a single phenomenon, its use in practice is invalid. First, the usual pre-conditions (i.e. the absence of reversible causes (such as toxic or metabolic disorders) to determine brain death cannot be met in DCDD. Thus, while the application of brain death tests proves the cessation of tested brain functions, it does not prove that their cessation is irreversible. Second, a stand-off period of 5 to 10 minutes is insufficient to achieve the irreversibility requirement of brain death. The use of brain death in DCDD could be based on permanent cessation of brain functions if: 1) no interventions were performed to restore brain circulation; 2) auto-resuscitation cannot occur; and 3) all brain functions have ceased, including awareness. Because

circulatory cessation irremediably leads to cessation of brain functions, first permanently and then irreversibly, the use of brain death criterion is unnecessary to determine death in DCDD.

### Workshop 3: Public issues in organ donation and transplantation

#### OP31

#### HOW DOES PUBLIC PERCEIVE GENERAL MESSAGES ABOUT ORGAN DONATION – A QUALITATIVE RESEARCH

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**Objective:** The aim of the research was to explore how public perceives and reacts to nine messages, containing general information about organ donation and transplantation (ODT) related to organisational aspects, medical aspects and to cross-border organ exchange. Messages were developed in close cooperation between European transplant professionals and communication experts. **Methods:** A qualitative research using focus group discussions (FGD) was performed in five countries (Croatia, Germany, Greece, Hungary and Slovenia) with three FGD per country. Each FGD consisted of 6-8 participants recruited based on their age, gender, education and attitude towards OD (undecided or positive towards ODT). Evaluation of the messages started with individual assessment of each message, indicating (un)clear/(non)relevant/(un)interesting information. Every message was then discussed in more detail within the group. **Results:** Results of the FGD provided insight in the perception of each message related to its informative (objective) or motivational (emotional) potential. Five messages were perceived as mainly containing factual information, helpful to raise knowledge and to support decision-making process. Three messages were perceived to have a strong emotional impact, addressing motivations towards ODT. Strengths and weaknesses of messages as well as suggestions how to communicate them were proposed. Additionally, FGD revealed major motivators (altruism, reciprocity) and barriers for ODT (lack of knowledge, lack of trust, personal doubts, perceived social obstacles). Differences between the groups of participants were also found. Although decided and undecided participants generated positive and negative responses related to messages, decided participants spontaneously recalled more positive ideas, showed higher knowledge, more proactive stand and reflected



upon death in a more detached manner. Conclusions: When planning communication strategy about ODT it is necessary to pay attention to the messages delivered and to understand their impact on raising knowledge and public awareness. Adequately evaluated messages provide substantial help to meet the goals of such communication activities. This abstract arises from the project FOEDUS (grant agreement n. 20122101) which has received funding by the European Union and was led by CNT-ISS.

## OP32

### PARTNERSHIPS BETWEEN MEDIA AND ETHICS: STUDENTS PEER-TO-PEER CAMPAIGNS FOR ORGAN DONATION

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**Objective:** The study attempts to investigate a recent trend in the campaigns for organ donation: that of peer-to-peer campaigns for organ donation done by students. As underlined by Rice & Atkins (2012) and Feeley et al. (2009), young people attitudes toward organ donation can change when they are approached by messages from their peers. **Methods:** Departing from articles attesting media coverage, we investigated a sample of promotion campaigns for organ donation performed by students, for students. We aimed at studying campaigns from different countries, organized by students in different disciplines. For the subsample of the Romanian campaigns, we contacted the campaign initiators (where possible) and arranged for in-depth interviews (face-to-face and Skype-based). Campaigns efficacy was assessed using the models developed by Figueroa et al. (2002). **Results:** Promotion campaigns designed by students have the potential to positively impact the attitudes of the young public, to a greater extent than general information campaigns. At the same time, there are risks concerning the accuracy of the information provided.

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## OP34

### ORGAN DONATION CARD AS AN ATM CARD; A JOINT INITIATIVE

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Iran is the most leading country in the Middle-East regarding organ donation after brain death (DBD). With more than 650 actual donors in recent years, it could keep its increasing pace since passing the Brain Dead Organ Donation Act in 2000. Iran and other nations in the region have many cultural views in common (due to similar Arabic-Islamic traditions). What gives Iran this distinctive position in terms of DBD, despite that geographical determination, are firstly, the Shiaa dynamism which enables the Shiaa clerics to adopt themselves with newly-developed issues more flexibly than Sunnis (the first decree on organ donation permissibility in the whole Islam world was issued by late Ayatollah Khomeini) and secondly, enormous cultural campaigns made in the last decade. The most successful campaign to promote organ donation in Iran has been the donor card. There is no single national registry in Iran and quite a few centers issue donor cards. Massih Daneshvari Organ Procurement Unit (OPU) registry, however, is the most numerous and prestigious one and it could convince more than 1,300,000 Iranians to register in its website ([www.ehda.ir](http://www.ehda.ir)) as donors since 2005. Comparing the cards issuance rate (the OPU registry) and DBD numbers Per Million Population (PMP in the International Registry in Organ Donation and Transplantation, IRODaT) showed a strong correlation between them. The annual donor cards increased from 15,000 in 2005 to more than 110,000 in 2009 and PMP rose from 1.7 to 4.1. At this period, donor cards were printed manually in the OPU itself. In 2010, the OPU reached an agreement with Bank Melli Iran (BMI, a public Iranian bank): BMI agreed to publish donor cards on ATM cards and mail them to applicants' address. It was a great help and made twice the number of annual issued cards in that year: 203630. Despite primary momentum BMI brought to the card issuance till 2013 (223,948 cards; PMP rose to 8.7), the prolonged process of Identity authentication and practical difficulties in centralized publishing and mailing the cards led to very long delays, considerable delivery failures and decrease in issued cards in 2014 (97,223).

This alarming decrease has led the OPU authorities to this conclusion that the cards must be published and delivered in BMI branches all over the country. Since October 2015, the donor card applicant first registers in the OPU website and then goes to the nearest BMI branch to take the instant ATM-Donor card. It is an effective way to promote the organ donation and make the donor card more available, popular and democratized.

## OP35

### DEPICTING MORAL MESSAGES – AN ANALYSIS OF GERMAN POSTER CAMPAIGNS ON ORGAN TRANSPLANTATION

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**Background:** The German Federal Centre for Health Education initiated the first nationwide campaigns on organ donation after the legislation of the Transplantation Law (TPG) in 1997. Since then, a colorful set of social marketing has covered the public sphere with moral messages, designed by relevant actors in the field. **Aim:** The presentation gives an overview of the key moral messages in campaigns on organ donation that were publicly negotiated in Germany under the last twenty years in order to critically reflect upon their arguments and aims. **Method:** By using established methods of cultural visual analysis, i.e. iconography and social semiotics, we analyze 13 campaigns that were launched for the past twenty years in Germany (85 pictures all included). In order to understand the social values and ethical principles/virtues at stake, we use a multimodal approach to analyze the combination of verbal act and picture. **Results:** We could identify heterogeneity in the moral messages: While the first ones attracted the public through appeals connected to their daily lives, the advertising columns were later covered by campaigns promoting organ transplantation as the 'gift of life'. Moreover, they were accompanied by messages that perform postmortem organ transplantation as a tit-for-tat action or arguing with the suffering of potential recipients. In the context of an amendment of the respective law in 2012, however, the official poster campaigns primarily address the concept of 'the right', i.e. personal and informed decision. Although the official aim of the current campaigns is merely to inform about organ transplantation in order to enable citizens to make their own decision, an in-depth analysis reveals that the campaigns carry contradicting messages and suggest a 'yes vote' more than an skeptical or undecided position. Thus, we state that the argumentative role of the campaign often contradicts its literally

meaning and intention. **Conclusion:** Organ donation campaigns are an influential resource of meaning making. They create a potential for confusing and contradicting public expectations about transplantation and the understanding of organ donation as a supererogatory act.

## OP36

### THE FRAMING OF FAMILY VETO IN ORGAN DONATION IN CANADIAN MEDIA

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**Purpose:** Organ transplantation relies on public support for donation and transplantation, making an analysis of public discourse around organ procurement essential. Given the role of popular culture in reflecting public sentiment and impacting policy development, it is necessary to understand how the media frames organ donation issues. Salience and selection are both critical factors within framing as a theory of media effects. Frames are routinely used in news stories to condense complex issues by emphasizing some aspects while obscuring or omitting others. This study investigates the portrayal of family veto over organ donation in Canadian news media. Family veto occurs when a family overrides the deceased's prior capable, expressed wishes to donate e.g. signed an official organ donor registry. **Methods:** Using the Canadian Newsstand Complete database, we identified articles published in English newspapers addressing family veto between the years 2000-2014. The search yielded 642 articles with the final data set consisting of 123 articles. An initial in-depth analysis to identify coding categories was conducted and all analytic categories were defined in a structured coding framework. Content analysis, using both quantitative and qualitative methods, identified the issues surrounding family veto that featured most prominently in the print media discourse. **Results:** Family veto was predominantly framed as something 'that should not be allowed' in 84 (68%) of the articles, with family veto characterized as 'terribly wrong'. Several articles addressed reasons for family veto, with 'culture' of the hospital as the primary justification. Family veto was represented as a stumbling block in our present system, with the majority of publications calling for change. 82% of the articles offered recom-

mendations to address concerns surrounding family veto, including: proposals for an 'opt-out' system, the need for organ donation awareness campaigns, and legislative change to ensure donor's decisions are respected. Varying interpretations of organ donation legislation occurred in the media discourse, with 77 of the articles (63%) stating or implying that existing legislation permits family veto. Conclusion: Family veto in organ donation was primarily framed in a negative or opposing manner in the Canadian English language popular press. There was a lack of clarity on the legal framework for organ donation within the media. Further research initiatives to explore proposed recommendations and potential changes in practice appear to be warranted.

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#### Focus session 4:

#### How informed is the living donor?

### OP37

#### **TOWARDS A STANDARDIZED INFORMED CONSENT PROCEDURE FOR LIVE DONOR NEPHRECTOMY: WHAT DO SURGEONS TELL POTENTIAL DONORS?**

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Background: A recent systematic review demonstrated that there is no consensus on how the informed consent procedure in live donor nephrectomy should be arranged and practices vary. The aim of this survey study was to evaluate the surgical informed consent procedure for live donor nephrectomy, with special regards to disclosed complications. Methods: A web-based survey was sent to all kidney transplant surgeons in the Netherlands (n = 50). Surgeons were asked how often they mentioned 23 items regarding short- and long-term complications. Results: Response rate was 98% (N = 49), of which 32 were involved in living donor education; transplant (50%), vascular (31%), abdominal surgeons (13%), and urologists (6%) from all eight kidney transplant centers. Informed consent procedures vary between centers, ranging from assumed to signed consent. Some respondents from the same center report different procedures. Bleeding was the only complication every surgeon mentioned. Risk of death was always mentioned by 16 surgeons (50%), sometimes by 12 (37.5%), four surgeons (12.5%) never disclosed this disastrous complication. Reported mortality rates ranged from 0.003% to 0.1%. Mentioning frequencies for all other complications varied per individual surgeon, but also per center. High volume surgeons reported more complications than low volume surgeons. The risk of postoperative pain was more often disclosed by consultant surgeons than fellows, and the risk of death was more often disclosed by surgeons

with a differentiation in transplant surgery. Conclusion: Important complications are not always disclosed during the surgical informed consent process for live donor nephrectomy. Informed consent procedures vary. To ensure donor safety, and to optimally prepare living kidney donors for the procedure, a standardized informed consent procedure for live donor nephrectomy is highly recommended.

### OP38

#### **DISCUSSIONS WITH PROSPECTIVE DONORS: INFORMED CONSENT WHEN KNOWLEDGE IS LIMITED**

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'Informed consent occurs when a competent person makes an autonomous choice about whether or not to access medical treatment, armed with adequate information and understanding regarding the risks, benefits and outcomes' (Beauchamp and Childress). Living donor nephrectomy is an operative procedure that has risks without physical benefits. Because the risks in a highly screened, healthy, living kidney donor are low (e.g., 0.03% mortality), it is difficult to communicate to a prospective donor that they are real. To date, numerous studies have shown that long-term outcomes for living kidney donors are similar to the age, gender, and race/ethnicity-matched general population. New data, comparing kidney donors to a healthy, selected subset of the general population (and donors are a healthy, selected subset) suggests an increased rate of end stage renal disease (ESRD) in the donors (Mjoen et al., *Kid Int*, 2014 [# with ESRD = 8 of 1901 donors]; Muzaale et al., *JAMA*, 2014 [# with ESRD = 99 of 96,217 donors]). However, there are limitations to these studies. First, the statistical analyses and selection of controls have been criticized (Gill and Tonelli, *JAMA*, 2014). Second, and most importantly, the majority of reported ESRD in former kidney donors has occurred in donors who were family members (in 1 study, all 1st degree relatives) of the recipient. It is known that, in the absence of donation, family members of those with ESRD have an increased risk of ESRD (O'Dea et al, *AJKD*, 1998; Skrunes et al *CJASN*, 2014). Finally, although the reported relative risk of ESRD is increased in these studies, the absolute risk remains quite small. Given the uncertainty of the information, and the strong association of ESRD within families, how should a prospective donor be counseled about long-term risk of ESRD that could be attributable to donation? Should unrelated donor candidates be counseled differently than related? Or unrelated donors with ESRD in their families? The challenges of providing information for meaningful informed consent, given these unknowns, will be discussed.

## Focus session 6:

## Rights and duties of health professionals in transplant tourism

## OP39

## OUTCOME OF TRANSPLANT TOURISM: A SINGLE CENTER EXPERIENCE

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Commercial kidney transplantation (CKTx) continues despite objections by the transplant community and efforts to boost altruistic donation. The aim of this study is to review the outcomes of patients undergone CKTx, and then followed in our center. All recipients of CKTx who presented to our center within a year of their transplants, between September 2008 and December 2013, were included. Data were retrospectively collected from patients' hospital charts. Total of 46 recipients, with a mean age of 40 years (range 13-62), and 17 were females. 20% had pre-emptive transplant, and 41% were known, and actually undergoing pre-transplant work up before they travelled for CRTx. The median time between transplantation to presentation was 14 days (range 5-269). 20 presented within 14 days, while 9 were referred by other facilities 6 months after transplantation, and were excluded from further analysis. Only 21 patients had a discharge summary from the transplant facility abroad. At presentation, mean BMI was 29 (range 15-49), and 20% had a BMI > 35, while median serum creatinine was 117  $\mu\text{mol/l}$  (range 41-439). During the first 6 months post transplantation; seven (19%) had perinephric collections requiring percutaneous drainage, five (14%) had wound infections requiring hospitalization including one wound dehiscence, four (11%) had ureteric strictures that needed surgery, two (5%) urinary leaks, and two (5%) mycotic aneurysm of the renal artery. 16 (43%) patients had at least one episode of acute rejection (32% ACR, 11% AMR). Urinary tract infections requiring intravenous antibiotics affected 11 (30%) patients, and other infections included two cases of fungal pneumonia, 1 CMV infection and one BK nephropathy. One patient had major non-compliance issues that threatened his graft. There were three (8%) graft losses, and two (5%) deaths due to sepsis. Patients returning after CRTx suffer a high burden of serious post transplant complications. It is of major concern that a significant number of these patients were known to the transplant service before travelling for their CRTx. A much concerted effort is urgently needed to better inform ESRD patients of the risks and the ethical issues related to CRTx, and to point them towards ethically sound and medically safer alternatives to CRTx.

## OP40

## AVOIDING COMPLICITY IN FOREIGN TRANSPLANT ABUSE

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The presentation would address the question: How do local transplant professionals avoid complicity in foreign transplant abuse? There are a number of techniques which can be used, if the professional knows of the abuse, which the presentation would set out. But how does one know of the abuse? The question of knowledge raises a number of subsidiary questions. One is the standard of proof. Another is onus. Does the local transplant professional have to be satisfied beyond a reasonable doubt that there is no foreign abuse? Or can a local transplant professional cooperate with foreign transplant professionals and facilitate a patient's going abroad for a transplant unless the professional is satisfied on the balance of probabilities that there is abuse abroad? A second subsidiary set of questions is how one determines the facts. Respect for The World Health Organization on Human Cell, Tissue and Organ Transplantation requires transparency, openness to scrutiny and traceability. How does one determine whether these principles are respected? What are the ethical obligations of local transplant professionals in relation to patients going to a country and professionals in a country in which these principles are not respected? A third subsidiary set of questions is, who makes the determinations of transplant abuse abroad? Proposed legislation in some countries requires compulsory reporting by transplant professionals of transplant tourism. Compulsory reporting would either shift investigative responsibility from the profession to the state or lead to joint responsibility. Should the profession endorse compulsory reporting of transplant tourism? China would be used as a case study. The Government of China acknowledges it has been sourcing organs from prisoners for transplants and claims that they are all prisoners sentenced to death. There is compelling evidence that many of these prisoners are prisoners of conscience, primarily practitioners of the spiritually based set of exercises Falun Gong, sentenced to nothing and just arbitrarily detained. The Government of China denies sourcing organs from prisoners of conscience and claims that sourcing of organs from criminal prisoners has ceased. But there is neither transparency, nor openness to scrutiny nor traceability in the Chinese transplant system. What are foreign professionals to do to avoid complicity in organ transplant abuse in this situation? The presentation would attempt to answer all these questions.



**OP41****TRANSPLANT TOURISM – CASES SERIES STUDIES WITH ETHICAL REFLECTION IN TAIWAN**

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**Background and Introduction:** Due to lack of compulsory reported system for overseas transplant, most of the countries did not have correct numbers for transplant tourism cases. Same as Taiwan, there is no sufficient record for patients going overseas for organs. The hospitals and agencies involving in the process are unclear. One preliminary estimation based on the Taiwan National Health Insurance Database has been conducted recently. It is estimated that in the past decade, approximately 4,000 Taiwanese patients went to Mainland China for organ transplants. Most of transplant tourism patients have been charged a huge amount of money. However, the contexts of the transplant tourism remain blurred. **Methods and Case Presentation:** We finished more than one hundred interviews and discovered that the transplant tourism can be either through agency channels or self-arrangement. The transplants arranged by the agencies are mostly for kidney transplants. Among the five hospitals arranged by agencies, some are by military hospitals, and some appear to be public non-military hospitals. However, further investigation discloses that the kidney transplant departments among these hospitals are run by the doctors from the military system. According to the statements from the agencies, in Mainland China only the military hospitals can have the access to the organ supplies but non-military hospitals have difficulty obtaining the organ supplies. After 2007, the situation had some changes but transplant tourism still persisted surreptitiously. In our research, we also demonstrated several real cases in details to draw the whole picture of the transplant tourism business. **Discussion and Conclusion:** Some evidence showed patients still go to China for transplants even after the Istanbul Declaration. Based on what is disclosed by the patients and the agencies, in general, not only Taiwan, there are many agencies in different countries arranging organ tourism. Patients in Middle East, Northeastern Asia and Southeast Asia are the major buyers. After serial policies changes internationally or domestically, the price of renal transplantation has been raised from 28,000 USD before 2007 to 100,000 USD in recent years. Same as the liver transplantation, patients have been charged 250,000 USD that is four times higher than before. After realizing the issue of organ tourism in China, Taiwan government has passed the bill on

promoting organ donation and stopping organ commercialism since 2007. Four typical transplant tourism cases among the investigation will be presented.

**Focus session 5:****Anonymous living donation & unbalanced kidney exchange****OP42****NON-DIRECTED ALTRUISTIC (UNSPECIFIED) KIDNEY DONATION IN THE UK – NINE YEAR EXPERIENCE**

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Non-directed altruistic (unspecified) living kidney donation has been possible in the UK since 2006 following revised legislation (Human Tissue Act 2006). In that first year there were three donors, increasing to 110 in 2014 (1.7 per million population), far exceeding any expectations. This study examines the trends in these donors and their participation in the paired donation programme to create 'altruistic donor chains' (domino paired donation). Unspecified donation began in the UK in 2006. Since January 2012, there has been the option for unspecified kidney donors to donate into the paired donation pool to create (short) altruistic donor chains (ADC) creating two transplants – one for the pool recipient and one for the waiting list patient receiving the pool donor kidney. From April 2015, (long) chains with two pairs from the pool have been possible, creating three transplants in total. National allocation arrangements (through NHS Blood and Transplant [NHSBT]) must be adhered to for all kidneys donated by unspecified donors. There have been 445 unspecified kidney donors in the UK, July 2006 to October 2015. The numbers have increased each year although there may be a fall in 2015 for the first time. 52% of donors were male, with ages between 20 and 85 years. 80% of donors have donated within 3 months of being notified to NHSBT. Between January 2012 and December 2014, 113 (38%) of 301 unspecified donors chose to donate to the pool rather than to the deceased donor waiting list (DDWL). For 15 (13%) a high priority patient on DDWL was identified and took priority. For the 98 remaining, 23 (23%) were not matched in the pool and donated to DDWL. Of the 75 matched, 53 (71%) donated while the match for the remaining 22 fell through, resulting in 17 donations to the DDWL and 5 withdrawals. Thus of the 98 donors entering the pool, only 53 (54%) actually donated to the pool, but those 53 donors created 106 transplants. Since January 2015, a further 8 short ADCs and 6 long ADCs have taken place, generating 34 transplants from 14 donors. The UK programme for unspecified donation has re-

sulted in 445 kidney donors and 513 transplants over nine years and has significantly increased the opportunities for successful transplantation in immunologically complex patients. With ADCs introduced in 2012 and the possibility of identifying long chains in 2015, coupled with an increasing proportion of donors wishing to donate into the pool, unspecified kidney donors make an invaluable contribution to the national living donor kidney transplantation programme.

## OP43

### ANONYMITY IN LIVE KIDNEY DONATION RECONSIDERED: PATIENTS' AND DONORS' EXPERIENCES, PREFERENCES AND ATTITUDES TOWARDS ANONYMITY

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**Background:** In recent years the numbers of unspecified kidney donation and (domino)paired exchange procedures have increased significantly. In the Netherlands and Sweden, anonymity is perpetual in such procedures. Anonymity protects donors and recipients against potential risks. Though, imposed anonymity could be experienced as paternalistic. Little is known about the experiences, preferences and attitudes of donors and recipients towards anonymity. **Method:** Participants who received/donated a kidney anonymously (directly or via (domino)paired kidney exchange) between 2009 and 2014 (NL) and between 2004 and 2014 (SW) were invited for an explorative retrospective survey on experiences, attitudes and preferences regarding anonymity. The survey was completed by 258 donors (D) and 157 recipients (R) (response-rates: D: 72% and R: 48%). Chi-squared and t-tests were conducted to identify differences between D and R. **Results:** Our

results suggest that the majority was satisfied with anonymity before (87%) and after the operation (80%). The desire to meet the other party before (D: 7%, R: 15%) and after the operation was low (D: 22%, R: 31%). Recipients were more open for a meeting than donors,  $p < 0.05$ . If the other party expresses the desire to meet, 58% of the donors and 60% of the recipients would be open for a meeting. Most agreed with maintenance of anonymity before (73%) and after the donation (56%). Donors agreed more with anonymity before and after donation than recipients,  $p < 0.05$ . However, the majority was of the opinion that it should be possible to meet before (61%) or after the operation (73%) if both parties agreed. Swedish participants were more conservative about meetings prior to transplantation compared to Dutch participants. **Conclusion:** Although donors and recipients prefer anonymity, a strict policy on anonymity is viewed as unnecessary if both parties agreed to meet. We might reconsider the anonymity-policy. Revoking anonymity generates practical and ethical challenges. We should carefully consider the pros and cons of the removal of anonymity and experiences of other countries.

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### Free communications 4: Ethical and philosophical aspects (A)

## OP44

### IS IT ETHICAL TO PROCURE ORGANS AFTER PHYSICIAN-ASSISTED DYING OR CESSATION OF TREATMENT IN A CONSCIOUS PATIENT?

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The Supreme Court of Canada recently handed down a decision according to which physician-assisted dying will no longer be illegal in this country as of February 2016. Earlier this year, the province of Quebec passed end-of-life care legislation (Bill 52), making medical aid in dying available as of December 2015. The imminent availability of physician-assisted dying has many implications, including the possibility of combining this practice with organ donation through the controlled donation after cardiac death (cDCD) protocol. cDCD most often occurs in cases where the patient has a severe neurological injury but does not meet all the criteria for neurological death. The donation is subsequent to the decision to withdraw life-sustaining therapy. Cases where patients are conscious prior to the withdrawal of life-sustaining therapy are unusual, and have raised

doubts regarding the acceptability of removing organs from individuals who are not neurologically impaired and who have voluntarily chosen to die. These cases may be compared with likely future scenarios in which patients will request both physician-assisted dying and organ donation. In both instances, patients will be conscious and competent. Organ donation in such contexts raises new ethical issues regarding respect for autonomy, societal pressure, conscientious objection and the dead donor rule. In this presentation, we look at relevant policies in other countries and examine the ethical issues associated with cDCD in conscious patients who choose to die.

## OP45

### ETHICAL, LEGAL AND PSYCHOSOCIAL ISSUES OF ORGAN TRANSPLANTATION IN THE CONTEXT OF EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE: THE EXAMPLE OF QUEBEC, CANADA

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**Background:** Organ transplantation is an innovative 21st century medical therapy that offers the potential to enhance and save life. However, worldwide, there is an organ shortage crisis, as the number of patients on transplant lists far exceeds the number of available organs. In parallel, in the two last decades, euthanasia and/or physician-assisted suicide (PAS) practices have been discussed and legalized in some countries (e.g., Benelux, USA), and since June 2014, Quebec is the first Canadian province to legalize euthanasia in the form of 'Medical Aid in Dying'. **Objective:** Given the recent debates around euthanasia/PAS, organ shortage and organ allocation, there is value in aggregating the results of studies, ethical thoughts and debates published thus far on the links between euthanasia/PAS and organ transplantation. Such an integration may allow to reflect and discuss recommendations towards organ transplantation within the context of euthanasia and/or PAS. **Methods:** After defining our selection criteria (i.e., euthanasia; PAS; organ transplantation), we conducted a literature search covering CINAHL, Medline and PsycINFO. The retrieved articles were synthesized using content analysis. **Results:** Results will be presented in order to highlight the major ethical issues reported in the literature when organ transplantation and euthanasia/PAS are practiced together, especially based on reported cases from Belgium and The Netherlands. These cases will be discussed within the particular framework of the new Quebec law legalizing euthanasia in the form of 'Medical Aid in Dying' starting from December 2015. **Conclusion:** If pal-

liative/end-of-life care and organ transplantation are often considered as two seemingly opposite realities, there is value in combining expertise from both fields as significant ethical, legal and psychosocial challenges arise from these emerging practices.

## OP46

### ORGAN DONATION AFTER EUTHANASIA: AN ETHICAL CONTROVERSY

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Organ donation after euthanasia is medically and legally feasible in Belgium and the Netherlands. Even though this combination of procedures has been performed at least 23 times in Belgium and 14 times in the Netherlands (status in November 2015), this does not imply that the topic is not surrounded by ethical anxiety. Euthanasia is only possible in patients who meet all due diligence criteria: A well informed patient needs to request euthanasia voluntarily and well considered. He or she should be hopelessly and unbearably suffering, and other reasonable solutions should be non-available. In this process, a second independent physician should be consulted. The euthanasia procedure has to be carried out according to the latest standards. Proponents argue that by giving a patient the possibility to donate his or her organs after euthanasia, it is possible to grant his or her last wish. Keeping the procedures of organ donation and euthanasia entirely separated makes it possible to avoid any peer pressure on the patient. Given the speed with which one must proceed, it does not seem possible to keep these procedures apart, nor can one be sure of the fact that the patient is not being persuaded to donate his or her organs. Nevertheless, when a patient would have the incentive to undergo euthanasia because he or she can donate his or her organs, why should this be prohibited? Opponents are of the opinion that the patient should actively request organ donation after euthanasia him- or herself. When being confronted with a patient who meets all due diligence criteria for euthanasia, and does not seem to have any contraindications for organ donation, the physician should not propose nor persuade the patient to donate his or her organs after euthanasia. The impression of a 'hunt' for organs should be avoided at all times. Patients however assume that if there is a possibility to donate organs, their physician will not withhold this kind of information. A physician who does not mention this option could be confronted with angry relatives when they find out afterwards. To be able to donate organs, the euthanasia procedure needs to be carried out at a hospital. This goes against the will of many patients who undergo euthanasia to die at home. Therefore, several patients have requested to be sedated



at home, so they could close their eyes in a familiar environment, avoiding the impersonal nature of a medical setting, and giving their relatives the possibility of saying goodbye in a quiet way. Afterwards, they could be transported to the hospital.

## OP47

### **PSYCHOLOGY, ETHICS AND ORGAN DONATION FOLLOWING ASSISTED DEATH IN QUEBEC: MAXIMIZING PATIENT AUTONOMY AND MINIMIZING RISKS FOR ALL.**

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**Background:** In June 2014, Quebec became the first Canadian province to legalize medical assistance to die (MAtd). With the new law taking effect in December 2015, the Quebec Commission de l'éthique en science et en technologie appointed a committee to reflect upon the moral acceptability of organ donation (OD) in this context and put forward recommendations for a safe and ethically-sound practice. Committee members represented medicine, law, bioethics, nursing, philosophy, sociology and psychology. This presentation describes the point of view of psychology from the perspective of the Canadian code for ethics in psychology (Canadian Psychological Association, CPA, 2000). It also contrasts the aim pursued in Quebec by allowing OD after MAtd compared to the aim pursued in other jurisdictions where assisted death is also legal. **Methods:** Taking into account the strict legal criteria for MAtd in Quebec and using the CPA code as a template for analysis, we identify the individuals and groups affected by donation in this context, and the potential risks and benefits associated with each of the four hierarchical principles of the code (I Respect for the dignity of persons; II Responsible care; III Integrity in relationships; IV Responsibility to society). **Results:** Only rare requests for MAtd are likely to be made by individuals considered suitable donors. While, in considering OD following MAtd, the highest weight should be placed on the dying individual's wishes (Principle I), the impact of donation on the patient, on family/close ones, and on professionals needs to be carefully considered (Principles I and II). The patient's interests should always be placed above our own as professionals and above that of others, including those waiting for transplantation (Principle III). Careful consideration needs to be given to the impact of combining these practices on the public's trust in our health care system and in the donation process (Principle IV). **Conclusion:** The CPA code is helpful in guiding reflection over this delicate question. It has served as a model for the Universal declaration of ethical principles for psychologists (2008) and for ethics code of other allied-health professions. It offers a valuable and complementary perspective to conclude on

the moral acceptability of OD following MAtd. Combining these practices offers several potential benefits and safeguards can be put in place to minimize risks for the patient, for close ones, for professionals and for society.

## OP48

### **IS IT ETHICAL TO WITHHOLD TRANSPLANTS FROM OBESE PATIENTS UNLESS THEY SHOW WILLINGNESS AND COMMITMENT TOWARDS WEIGHT LOSS AND HEALTHIER LIFESTYLES?**

Heather Draper

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This paper will explore whether, and under what circumstances, it is ethically acceptable to withhold transplants from obese patients unless they show willingness and commitment towards combatting their obesity. The ongoing shortage of donated organs means that there are not enough organs for everybody. This makes it particularly important that available organs are used well. The general health risks associated with obesity are well-established, and there is evidence of additional risks associated with transplantation in obese patients. The risks and their extent vary from organ to organ, but include higher rates of delayed graft function, increased rates of complications, and higher rates of post-transplant mortality. This arguably makes obese patients less appealing candidates for transplants, when compared with patients of normal weight. It is considered acceptable within liver transplantation to only consider patients for placement on the transplant waiting list if they commit to abstain from alcohol or drug use. We will explore whether a similar policy could be acceptably applied to obese patients, so that obese patients have to commit to and demonstrate controlling calorie intake and increasing exercise levels in order to be considered for a transplant. Outside of transplantation, similar local policies in the UK – one NHS Trust recommended that obese patients should have to demonstrate a 5% reduction in body weight before being considered for routine surgery – have met with significant opposition. Critics have argued that the causes of obesity are multi-factorial, that weight-loss is extremely difficult and that obese people already face widespread discrimination. We will argue, however, that in some circumstances, such restrictions on access to transplant waiting lists would be ethically acceptable, and could lead to better use being made of available organs.

## OP49

### BALANCING NON-MALEFICENCE AND AUTONOMY: A DONOR-CENTERED APPROACH TO RISK ASSESSMENT

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Despite the increasing emphasis on shared decision-making (SDM) in medicine today, transplant centers in the United States typically make decisions about living kidney donor eligibility without donor input. In this talk, we will argue that centers should engage in SDM with potential donors whose long-term health risks as a result of donation are uncertain. We begin by describing approaches to shared-decision making (SDM) and differentiate SDM from informed consent. Next we describe how the donor selection in the United States falls short of SDM. We outline some reasons for adopting of SDM: 1) increased transparency about medical uncertainty; 2) the potential to increase donor education about risks; 3) increased donor satisfaction; and 4) expansion of the range domains included in the donor risk/benefit ratio. In addition, we identify and address concerns about the adoption of SDM: 1) donor nephrectomy is different from other types of medical and surgical decisions; 2) patients are not able to sufficiently understand the risks of donation; 3) SDM may unfairly disadvantage certain types of potential LKDs; 4) there should be a role for physician conscience; and 5) there is insufficient follow-up data on donor outcomes to help inform SDM decisions. We propose adoption of a constrained SDM process for selected potential LKDs, and describe the implications of this method for consideration of the donor risk/benefit ratio and clinical practice. In these cases, we conclude that SDM has the potential to enhance LKD self-determination and relational autonomy. However, SDM should be implemented cautiously to ensure sensitivity to diverse patient populations, clearly-delineated and justified eligibility criteria, and adequate long-term donor follow-up.

## OP50

### NO HARM IN ASKING? SOCIAL MEDIA, LIVING DONORS AND HELPING OURSELVES TO HEALTHCARE RESOURCES

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This paper will explore whether, and if so under what circumstances, publically funded institutions are obliged to set limits on the extent to which they will cooperate with pro-active potential recipients' efforts to find a living donor using social media. Human charity can be fickle. A welfare system funded by taxation should meet need in a way that is less arbitrary and therefore fairer. Social media campaigns that engage our charitable inclinations can exert unfair demands on the welfare state and disrupt systems that are meant to ensure fairness, as efforts by individuals to attract living donors using social media have demonstrated. Attempting to find the needle in a hay stack may tie up resources that could be targeted towards outcomes whose efficacy is assured with more certainty – such as non-specified living donation. So how can we accommodate individuals' efforts to help themselves, whilst ensuring that public resources are not 'misappropriated' in the process? We will discuss the interplay between several potential solutions including more 'cost-effective' processing of the resulting living donors' offers and encouraging /insisting that those who by-pass the conventional allocation system contribute to the costs of so doing. Measures such as these assume, however, a fundamental difference between living donors with an existing relationship with the potential recipient, and donors found through social media since similar constraints are not currently being placed on e.g. living-related donation. We may therefore be faced with a choice of either abandoning directed living donation completely to avoid the public system being over-whelmed or choosing between the lesser of two types of arbitrary unfairness.

## Free communications 4: Psychological aspects - Donors (A)

### OP51

#### PSYCHOSOCIAL EVALUATION OF LIVING KIDNEY DONORS: PRELIMINARY FINDINGS FROM AN INTERNATIONAL PROFESSIONAL SURVEY

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Psychosocial evaluation (PE) of prospective living kidney donors (LKD) is considered international best practice, consistent with the recommendations of the Amsterdam Forum. The prevalence and nature of screening practices internationally remains largely unknown. We report here preliminary findings from a larger study on PE of all living organ donors, conducted by a working group of the Ethics Committee of the Transplantation Society (TTS). The study aims to assess PE practices internationally; identify key features of PE programs; and evaluate needs for ethical guidance and PE tools. Methods: Professionals working with LKD completed an online questionnaire distributed via email using TTS membership lists, personal contacts, and networks associated with professional societies. Results: There were 393 respondents from 83 countries: 29% from Europe and Central Asia; 25% North America; 14% Latin America and Caribbean; 10% East Asia and Pacific; 8% South Asia; 8% Middle East and North Africa; 6% Sub-Saharan Africa. 82% of respondents reported always performing PE of LKD. Disciplinary expertise of staff reportedly involved in PE varied between geographical regions, however 94% of respondents indicated that a psychiatrist, or mental health or social worker was involved in PE. Information routinely collected during PE varied; of note, only 60% of respondents reported asking questions concerning the LKD's household income and/or financial burdens, whereas 74% of respondents asked the LKD if they had been promised a financial reward. Reported follow up of LKD post nephrectomy also varied: 90% of respondents reported providing follow up of physical health for months or longer, compared with 65% follow up of mental health

and 57% follow up of social wellbeing. Comments by respondents suggested that performance of PE often varies according to perceived risk factors associated with individual LKD that are identified ad hoc, rather than through systematised PE processes or in accordance with guidelines. Conclusion: Despite the high volume of transplants from LKD and recognition of the importance of PE of LKD internationally, PE of LKD may vary significantly across the world. Lack of long term psychosocial follow-up of LKD makes PE pre-donation particularly important. Understanding the factors that underpin differences in practice within and between countries will assist in development of evidence-based international guidelines that may be adapted for use in specific healthcare contexts. This will help to ensure that all prospective LKD receive best practice care.

### OP52

#### IN THEIR OWN WORDS: LIVING KIDNEY DONORS WHO DEVELOP KIDNEY FAILURE

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Background: Psychosocial data about living kidney donation have been collected for almost five decades. The results are almost uniformly positive, even in the early years when graft failure and recipient death were the norm. To date, however, no study has provided psychosocial follow-up of donors who develop a serious health problem like end stage renal disease (ESRD). Objectives: The aims of this study were: 1) to explore the impact of donation and subsequent ESRD on family dynamics; and 2) to explore patients' experience with the healthcare system and finances. Methods: Donors were invited to participate in a qualitative interview if they met one or both of the inclusion criteria: 1) developed ESRD within 10 years of donating and/or 2) lacked health insurance at the time of donation. Parent donors were excluded. Of the 50 who met these criteria, 42 were contacted and 23 participated (55%). Three were subsequently excluded from analysis: two because they donated in the early 1960s when kidney

transplantation was experimental and not covered by insurance and one because he donated non-directedly and all the other participants had donated to first-degree relatives. Results: Twenty qualitative interviews with living donors who have developed ESRD were analyzed. Five findings are described: (1) donors describe the decision-making process as spontaneous and fast, (2) donors describe a lack of appreciation for the need for post-donation self-care; (3) donors do not regret donating despite the adverse outcome; (4) donors would advise future donors to be aware of the need for emotional and physical support post-donation; and (5) donors appreciate the opportunity to tell their life story from living donor to living with ESRD which virtually all perceive as two separate unrelated events. Discussion: Most donors are positive about donation and would do it again, even when they develop end stage renal disease themselves. However, they do propose some important changes to the decision-making process and the informed consent discussions. Although our data are reassuring, we should not be complacent about donors' understanding of the decision-making process or of the risks and consequences of living kidney donation. Improved communication between the living donor and the healthcare community is a first step needed to ensure that living donors understand their long-term risks and receive appropriate life-long follow-up care.

## OP53

### **'HEY SISTER! WHERE'S MY KIDNEY?' – MANAGING EXPECTATIONS FOR DONOR ORGANS, SCARCE RESOURCES, JUSTICE AND ETHICS IN SOUTH AFRICAN TRANSPLANT**

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Introduction: As in the rest of the world, the supply of donor organs in South Africa is far exceeded by the demand for them. Hence, a large number of individuals are listed for transplant in this country, and the wait can be lengthy – ultimately a significant number of listed patients do not receive transplants. Aim and Objectives: The aim of this project was to explore communication, ethics and organ transplant in Gauteng Province, South Africa. The specific objectives were to: 1. Explore communication aspects of organ transplant in Gauteng from a transplant professional and patient/family perspective. 2. Attempt to understand how decisions about organ transplant are made by patients and transplant professionals in the context of personal experiences. Methods: The study was the presenting author's PhD project and took place in the Gauteng province of South Africa across six healthcare

institutions. Altogether, thirty in-depth interviews with transplant professionals, two focus groups with transplant coordinators, two interviews with cadaver donor families, and one focus group with living kidney donors were conducted. Thematic analysis and triangulation of the data utilising qualitative principles was undertaken. Results: The time of waiting for a donor kidney is one of hope, desperation and uncertainty for potential transplant recipients and their families. Transplant professionals, especially coordinators, are charged with managing patient expectations for receiving an organ within this complex matrix. This requires specific, targeted communication. However, such communication often proved challenging, because patients and their families were perceived as making excessive demands of transplant staff, questioning when they would receive a donor organ, and in some cases threatening to report staff to the media or superiors for failing to do their job adequately when a donor organ had not been forthcoming. Given the scarcity of donor organs, and the requirement for fairness when allocating them, communication challenges were further compounded. Conclusion: Communication with potential recipients pre-transplant is challenging, and an understanding of chronic uncertainty could assist transplant professionals in enhancing interactions with patients at this stage, also hopefully mitigating some of the less pleasant elements of these conversations and enhancing ethical practice.

## OP54

### **PSYCHOSOCIAL LONG-TERM IMPACT OF DONATION ON KIDNEY LIVING DONORS – A COMPARATIVE STUDY OF TWO MAJOR EUROPEAN TRANSPLANT CENTRES**

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Introduction: The long-term psychosocial outcome of kidney living donors has still not been studied thoroughly. Thus, important information regarding the decision-making, the preoperative information of the



donors, their selection and their postoperative care is missing. Our study aims to fill in this gap by conducting a detailed follow-up about the psychosocial well-being of donors up to 16 years after donation in two major European transplantation centres, in the Hospital Clinic of Barcelona and the Charité-University Hospital in Berlin. Methods: All kidney living donors who underwent nephrectomy between 1998-2014 were contacted. Data from 706 donors were collected. The donors completed a battery of psychometric questionnaires (HADS, PHQ, SOC, SF-36, ACSA, life events, questions from the ELSA), as well as questions regarding satisfaction, decision to donate and the donor-recipient relationship in a total of 274 questions. This makes our study one of the most thorough long-term psychosocial follow-up studies of kidney living donors. Results: Results regarding the long-term psychosocial wellbeing after kidney donor nephrectomy are presented and compared to the general population of the two countries. The results of the two centers are being contrasted and comparisons for groups regarding age, gender, donor-recipient relationship, personality characteristics and recipient variables are made and risk and protective factors for kidney living donors are presented. Discussion: The results are being critically discussed regarding the donor evaluation practices and their postoperative care, as well as in terms of organisational and cultural differences in the two hospitals. Suggestions for further optimization of the donor selection and care are formulated.

## OP55

### UNSPECIFIED KIDNEY DONORS AND THEIR FAMILIES AND FRIENDS: A QUALITATIVE STUDY EXPLORING PSYCHOSOCIAL CONTEXT OF DONATION

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Research into the experience of UK based Unspecified Kidney Donors (UKDs) has indicated that a number of key stages in the donation process exist that are experienced as difficult and have the potential to cause the donor to reconsider (Clarke, Mitchell & Abraham, 2013). One of the most prolific UKD transplantation centres, Portsmouth Hospital Trust, has reported that approximately 35% of prospective donors who contact the centre withdraw from the process (Kirk et al., 2013). Lack of social support has been identified in around half of those who withdraw (Kirk et al., 2013). There is not, however, a good understanding of the reasons behind

potential donors' decisions to withdraw. There is also a lack of understanding into the role services could have in better informing and supporting potential donors, their families and friends in order to help facilitate donation. This study aims to fill this gap in the literature by exploring UKD using a qualitative approach from a social group perspective. UKDs and self-withdrawing potential UKDs (swUKDs) were invited to interview along with a significant other. Participants were recruited using convenience sampling from three major transplant centres in south west England and nationally via the Give a Kidney One's Enough Charity Website. Interviews are semi-structured focusing on donation experiences, responses from others and experiences with transplant professionals. At time of submission 11 UKDs and 9 significant others have been interviewed, in addition to 5 swUKDs and 3 of their significant others. The interviews to date have been transcribed verbatim and analysed using the framework approach (Richie & Lewis, 2003). This methodology is deemed as particularly useful in generating clinically relevant data that can inform service and policy development (Ritchie & Lewis, 2003). The study is due to close in March 2016. Provisional analysis indicates: a) Tensions in relationships connected to the intention to donate altruistically and continuing fears held by significant others, b) Burden of UKD which was not prepared for fully by all involved, c) Distress expressed by swUKDs post deciding to withdraw from donation, d) Missed opportunities by donation services to provide education to prospective donors and their significant others. Full analysis will be discussed along with recommendations for future research and clinical practice.

## OP56

### BETTER THE DONOR YOU KNOW? A QUALITATIVE STUDY OF RENAL PATIENT ATTITUDES TO 'ALTRUISTIC' LIVE-DONOR KIDNEY TRANSPLANTATION

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In the UK there is a short-fall between individuals requiring a renal transplant and kidneys available for transplantation. Non-directed or unspecified 'altruistic' living kidney donation has emerged as a strategy for bridging this gap between supply and demand, with the number of non-directed living kidney donations increasing each year. This study aimed to explore the attitudes of potential recipients to non-directed

'altruistic' live-donor kidney transplantation. Semi-structured interviews with 32 UK deceased-donor kidney transplant recipients were performed between February 2014 and July 2015. Interviews explored attitudes to directed and non-directed live-donor kidney transplantation. Interviews were recorded, transcribed verbatim and anonymised. Transcripts were analysed using the constant comparison method described in Grounded Theory. Individuals could be categorised into four mutually exclusive groups according to their attitude to receiving a non-directed 'altruistic' live-donor kidney transplant (LDKT): i) those willing to accept a LDKT from any living donor, ii) those willing to accept a specified directed LDKT only, iii) those willing to accept a non-directed 'altruistic' LDKT only, and iv) those not willing to accept an LDKT from any type of live-donor. For those not willing to accept a non-directed 'altruistic' LDKT, the following themes were identified: i) Prioritising other recipients above self; ii) Fear of acquiring an unknown donor's characteristics, and iii) Concern for the donor – unnecessary risk. Gaps in knowledge about non-directed living kidney donation also emerged. For those willing to accept a non-directed 'altruistic' LDKT the following themes were identified: i) Prioritising known above unknown persons, ii) Belief that they are as deserving as other potential recipients, and iii) Advantages of a LDKT. We have identified barriers and facilitators that affect recipients' willingness to accept a non-directed 'altruistic' LDKT. These insights provide the transplant community with targets for intervention, through which the concerns of potential recipients might be addressed.

## Free communications 6: Organ trade and paid donation/ incentives

### OP57

#### DECEASED ORGAN DONATION: WHY THE MISPLACED PROMOTION OF ALTRUISM COULD KILL THE ALTRUISM OF THE DEAD

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This paper makes the point that some financial incentives that could be prohibited on the basis of international guidelines and national regulations are more properly understood as overcoming disincentives – these incentives should be supported rather than prohibited. It proceeds by examining arguments against financial incentives for deceased organ donation and shows how, as illustrated in the Philippine context, some prohibitions against the grant of financial incentives to the bereaved could have the effect of killing otherwise viable opportunities for the recently dead and their relatives to express altruism. A survey of literature in this area provides the background as the paper identifies situations where a prohibition against material assistance serves to perpetrate a disincentive that denies the dead (and the bereaved) a chance to be generous and altruistic. These situations call for material incentives to be provided to the bereaved in order to put them in a situation where they can be enabled to consider activating a decision to make a relative's organ available for transplant. It has been argued that the exploitation of loopholes that allow the use of material incentives for organ donation has 'crowded out' altruistic donation – it is necessary to plug all loopholes in order to promote and enhance the kind of altruistic culture that is very valuable for ethical organ transplantation. This paper agrees that promoting organ donation in the context of an altruistic society is very desirable. The promotion of altruism and generosity strengthens society's moral fiber. However, there are situations when the total prohibition on the use of material incentives could be misplaced and thus have the effect of snuffing out altruism rather than promoting it. The paper discusses how misplaced prohibitions could have a negative impact on altruism by failing to take proper account of important factors such as: who is truly being 'incentivized,' what the incentive is given for, who is providing the incentive, and how the incentive or the giving of it is understood in a particular culture. The significance and impact of these factors could vary widely depending on economic, political and deeply held traditions and cultural institutions. A discussion of the impact of these factors in the context of Philippine society leads to the conclusion that not all material incentives are alike and that this point should



be taken into account in the design of programs meant to promote deceased organ donation.

## OP58

### PAYING FAMILIES OF DECEASED DONORS: UNWISE AND UNETHICAL

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Several countries have established programs to pay next of kin who give permission for the removal of their deceased relative's organs for transplantation. Such payments, which may be given directly to the relatives or pay for funeral expenses or hospital bills unrelated to being a donor, aim to increase the rate of donation. Whether such payments come from private sources or from foundations or government agencies, they constitute transplant commercialism since money is being exchanged for the removal of organs. The Declaration of Istanbul Custodian Group – in alignment with the WHO Guiding Principles and the Council of Europe Convention Against Trafficking in Human Organs – has adopted a new policy statement opposing such practices. Payment programs are unwise because they produce a lower rate of donations than in countries with voluntary programs; associate deceased donation with being poor and marginal in society, as has been seen with paid living donors; undermine public trust in the determination of death; and raise doubts about fair allocation of organs. Most important, allowing families to receive money for donation from a deceased person, who is at no risk of harm, will make it impossible to sustain prohibitions on paying living donors, who are at risk. Payment programs are also unethical. Tying coverage for funeral expenses or healthcare costs to a family allowing organs to be procured is exploitative,

not 'charitable.' Using payment to overcome reluctance to donate based on cultural or religious beliefs especially offends principles of liberty and dignity. Finally, while it is appropriate to make donation 'financially neutral' – by reimbursing the added medical costs of evaluating and maintaining a patient as a potential donor – such reimbursement should never be conditioned on a family agreeing to donate.

## OP59

### EFFICACY OF NINE NATIONAL POLICIES REIMBURSING AND INCENTIVIZING LIVE ORGAN DONATION

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In order to increase the number of living donors, some countries have implemented policies to remove disincentives to donation and to provide incentives to living organ donors. Our goal is to analyze the efficacy of such policies. Nine countries with reimbursement policies were selected for policy analysis, and six of these were selected for statistical analysis. Linear regression was used to predict the number of living organ donors per million of population after policy implementation. Paired t-tests were then used to determine if the change in the number of living organ donors after policy implementation was statistically significant. All nations' policies were found to reimburse living donors for travel costs directly related to the donation. In addition, three nations (Israel, Saudi Arabia, and Iran) provided donors with direct incentives. The policies of Saudi Arabia, the United Kingdom, and Israel significantly increased ( $p < 0.05$ ) the number of living organ donors, while the United States' policy, which was the only one not to reimburse income loss, significantly decreased the number of living organ donors. Singapore and Iran did not experience a significant change in the number of living donors, but the number of donors did increase in both countries after policy implementation. While other factors, such as religion and income, may affect the number of living donors, the data generally suggest that policies that financially assist living donation are effective in increasing the number of living donors in varying degrees, with a rough correlation between how much donors are helped and the degree of increase. The efficacy of these policies suggests that other countries may benefit from considering similar policies for easing their organ shortage problem.

## OP60

### THE IRAN'S COMMERCIAL RENAL TRANSPLANTATION PROGRAM RECONSIDERED

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According to the Health Ministry, currently 10,000 patients are on the waiting list. According to the Health Ministry, while there were 8,000 brain deaths in 2013, only in 665 cases were the organs retrieved for transplantation. According to the Health Ministry, 10 Iranians die each day while on the waiting list. Commercial transplants reached a plateau and were unable to provide enough organs. Of 33,000 recipients of commercial renal transplants, 15,000 died because the responsible authorities didn't address the problems of kidney patients. The program never eliminated the waiting list. Instead, the program eliminated related donation and hindered brain death transplantation. The program deprived patients of already available options like related donation, and created an inefficient black market on which kidneys are unaffordable to the poor. The program went bankrupt. Thus, the current trend is toward brain death and deceased donor transplantation in order to stop and abandon the commercial program completely. Currently, 1,500 (56.1%) of renal transplants are from living 'donors' and 1,171 (43.8%) from deceased organ donors. If there were a grain of truth in the proponents' claims about the commercial program, there would be no reason to abandon their 'model' in favor of deceased donor transplantation. Iran's commercial renal transplantation program was systematically misrepresented and decorated by its 'pioneers' and 'theoreticians' who deliberately misguided the transplantation community by repeating unfounded claims and promulgating disinformation; To conceal the realities of the program, to advertise and 'theorize' unchallenged, and to intimidate critics, a powerful band that are involved in the commercial transplantation program sued the newspapers that reported on the realities of the program. They suppressed the academic freedom of critics, too. Thus, their absolutely unfounded claims about the program's success and 'achievements' acquired a superficial validity by sheer repetition, mostly in non-peer-reviewed journals and at conferences abroad. However, the test of time proved fallacy of the proponents' claims, and fabrications such as 'elimination' of the waiting list didn't provide more kidneys for patients. Considering the high rate of brain death in Iran, presumed consent for brain death and deceased donor organ retrieval can easily eliminate the waiting list in our country.

## OP61

### A QUALITATIVE STUDY INTO THE MODUS OPERANDI, INVESTIGATION AND PROSECUTION OF ORGAN TRAFFICKING NETWORKS IN SOUTH AFRICA AND KOSOVO

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Background: In 2010 a South African hospital plead guilty for allowing its doctors and other employees to conduct over 100 illegal kidney transplants. In 2013 in Kosovo doctors were convicted for participating in 30 illegal transplants. Both cases have a strong connection with Israel. In 2012 and 2013 we travelled to South Africa, Kosovo and Israel to study and compare a) the modus operandi of the criminal networks, and b) the successes and hurdles of authorities in the investigation and prosecution of the networks. This study formed part of the EU-funded HOTT Project on trafficking in human beings for the purpose of organ removal that aims to improve non-legislative responses to the crime. Methods: We conducted fieldwork in each country. We performed 25 interviews with police, prosecutors, legal experts, policy-makers, ministry representatives, health inspectors, patients, nephrologists, transplant surgeons, health insurance company representatives, defense attorneys, representatives of international organizations and national transplant coordinators. Interview transcripts were analyzed qualitatively. In addition, we studied case materials, including charge sheets, witness statements, indictments, closing statements and legislation. Results: Using sophisticated modes of operation, both trafficking networks successfully conducted illegal transplants in an organized manner. Most of the recipients were of Israeli descent and were charged up to US-\$ 120,000 for a transplant. 'Donors' were recruited from Romania, the Russian Federation, Brazil, Israel, Kazakhstan and other Eastern European countries. They were (sometimes falsely) promised amounts between US-\$ 3,000 and US-\$ 26,000. Both networks operated for a long time with relative impunity because of legal loopholes and cor-

ruption, and were discovered and prosecuted very differently. The local disruption of the criminal networks can be defined as the most important success, while the biggest hurdle in both cases comes down to international collaboration. Conclusion: Prosecution of organ trafficking networks is rare. Under the HOTT project, the modus operandi and successes and hurdles in the investigation and prosecution of both cases will be used to develop indicators and recommendations that will benefit countries worldwide in recognizing, investigating and prosecuting organ trafficking.

## OP62

### INTERVIEWS WITH PATIENTS WHO TRAVELLED FROM MACEDONIA, KOSOVO, THE NETHERLANDS AND SWEDEN FOR PAID KIDNEY TRANSPLANTATIONS

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Background: Patients are known to travel worldwide for living kidney transplants. Although travelling abroad does not directly imply an illegal organ purchase, it is commonly seen as an illegal and/or immoral endeavour involving risks. The limited amount of available data about these transplants makes it difficult to draw conclusions about its scale, nature and potential illegality. Objective: We aimed to increase knowledge about transplants abroad (how, where and by whom it was facilitated) as well as to give a description of the motivations, experiences and characteristics of patients travelling abroad. The scope was on kidneys because these are the most frequently bought organs. Methods: Between March and May 2014 half-structured interviews were performed with patients from Sweden, Macedonia and The Netherlands who travelled outside the EU for kidney transplantation. Results: 22 patients (19 men; born between 1949-1985) were interviewed who traveled from Sweden (N = 4), Macedonia (N = 10) and The Netherlands (N = 8). Transplants took place between 2000-2011. The most frequently reported countries were Pakistan (N = 14), India (N = 3) and Iran (N = 2). 7 patients went to their country of origin. For 6 patients a facilitator organized their transplant abroad, the others received help from family while organizing with the transplant center. 17 patients directly paid the doctor, hospital or a broker; some paid

for the transplant service as a whole. 13 patients met the supplier. One supplier received money from a patient. From the others it is unknown. The costs varied from € 280-€ 33,000. Almost all patients mentioned a lack of hygiene and poor hospital conditions. 13 patients received functioning and uninfected kidneys; 9 patients had complications after the transplant (infections, poor kidney function or kidney loss). Patients' motivations to go abroad were the long waiting time for deceased organs, discrimination in the health care system and the impact of dialysis treatment on health. Conclusion: Despite the worldwide prohibition of organ trade, patients still purchase organs. Some purchases take place with the help of brokers. Knowledge about how these transplants are facilitated helps to disrupt and prevent illegal transplant networks. Warning patients against the medical, ethical and legal risks and increasing the supply of organs by encouraging living donation and introducing an opt-out system for donation are strategies to prevent patients from purchasing organs abroad.

## OP63

### THE SAD STORY OF KIDNEY BUYERS ON THE BALKANS

Ninoslav Ivanovski<sup>1</sup>; Galina Severova<sup>1</sup>, Lada Trajceska<sup>1</sup>, Ilina Danilovska<sup>1</sup>, Aleksandar Sikole<sup>1</sup>, Zivko Popov<sup>2</sup>

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The Balkan Region is dramatically changing in the last 25 years. Civil wars, new states, society destructions, introduction of democracy and market economy increased the poverty of the Balkan people, even in the whole South-Eastern Europe. Due to the lack of organized transplant activity, approximately 120 chronic kidney disease patients according to our registry went to the third world countries (India, Pakistan, Nepal, and Egypt) to buy a kidney using mostly illegally the local and international brokers as intermediaries. The usual price for the kidney was between 10,000 to 22,000 Euros, excluding travel costs. Most of the kidney buyers were suffering from many health and social problems during the whole period of follow up in the last 20 years. Thirty six of 120 patients are still alive and mostly irregularly followed at the University Clinic of Nephrology in Skopje. Most of them are from Kosovo (25) and from Macedonia (9). The mean time of follow up is 94 months (range 60-240 months). The actual serum creatinine is 130 micromole/l (range 95-300). All pts are on standard immunosuppression including CNI, MMF and Steroids. Among the kidney buyers are predominantly housewives (16), lower class trader (6), worker and farmers (4), unemployed workers (6), administrative officers (3) and pensioners (1). Bearing in mind that both countries belong to the Balkan region with weak economies, still far from

EU and increased level of poverty, the pts, especially from Kosovo, did not have a regular and qualitative kidney transplant patient's health care. The introduction of not truly verified and cheap generics (CNI and MMF from India, Turkey, Ukraine etc.) by the public health authorities and expensive and not regular lab and outpatient controls in private institutions put the pts in permanent danger for their health and life. In conclusion, we can confirm that the illegal live donor paid transplantation in the third world countries for the Balkan patients is really a life threatening venture.

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#### Workshop 4: Pediatric donation and transplantation

### OP64

#### LIFE LINES: A FATHER'S PERSONAL ACCOUNT OF ORGAN DONATION

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Objectives: 1. To share a father's reflections on his 10-year old son's organ donation. 2. To understand how the donation helped him to manage his bereavement. 3. To demonstrate that young children can have an understanding of organ donation. 4. To show how this understanding can be helpful to parents when making the decision to donate their child's organs for transplant. Method: This 10 minute, British film won the Best Foreign Documentary Film Award at the Action/Cut 2011 Short Film Competition in Los Angeles. The film is narrated by an actor using verbatim transcript from a research interview carried out with the donor father as part of a bereaved donor family study. The study was concerned with surviving relatives' experiences of organ and tissue donation. The study was ethically approved, as was the film. Consent of the involved father was also obtained. Results: The film is a construction of the father's experience of organ donation, told in his own words. It takes the audience from his understanding that his child was critically ill to the moment he believed his child had died. He recounts his experience of brainstem testing and his observations of the intensive care staff when it became clear that the child had died. He reflects on the organ donation discussion and what his child would have wished, as he was aware of the good donation could do. The film finishes with the positive outcome of the donation for the recipients and how this helped the father to find solace in his bereavement. Conclusion: The film has a clear, strong message about organ and tissue donation that fulfils the objectives of the presentation. The film was adopted by NHS Blood and Transplant and dis-

tributed to British National Health Service hospitals to be used for educational purposes.

### OP65

#### UNDER WHAT CONDITIONS SHOULD MINORS BE CONSIDERED AS POTENTIAL HEMATOPOIETIC STEM CELL DONORS: A SYSTEMATIC REVIEW OF GUIDELINES AND PROTOCOLS

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Hematopoietic stem cell transplantation has become a well-established treatment of certain diseases, especially some hematologic malignancies. In order to increase recipients' chance of finding a suitable HLA-matched donor, all Member States of the European Union legally allow minors to donate stem cells to a close relative, usually restricted to life-saving situations in which no suitable competent donor is available. Nevertheless, we are unaware of studies investigating whether this legal practice is supported by ethical guidelines and protocols, and if so, what recommendations are provided with respect to the ethical care for paediatric donors and their families. As these guidance documents have a significant impact on clinical practice, we aim to systematically review guidelines, recommendations and protocols that provide ethical recommendations on stem cell donation by minors. Relevant documents will be identified by searching the websites of national bioethics committees, relevant professional medical organizations, bibliographic databases such as Medline, Web of Science and Embase, as well as databases focused on excellence in healthcare practice such as NICE Evidence Services and Cochrane Central Register of Controlled Trials. We will also contact the paediatric hematology transplant centers in the European Union in order to retrieve their clinical and ethical protocols. Documents will be extracted and screened according to the PRISMA guidelines. Only recommendations, position papers and statements addressing the hematopoietic stem cell donation in minors specifically will be included. We expect to find differences in the approaches to protecting the wellbeing of the minor donor and differences in the extensiveness of family support that should be offered. The results of this study will provide a general overview of ethical recommendations in this field and might also serve as a good starting point for a qualitative interview study of healthcare professionals involved in hematopoietic stem cell transplantation.



**OP67****WHERE THERE'S SMOKE... MARIJUANA USE IN PEDIATRIC TRANSPLANT CANDIDATES**

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Transplant candidacy guidelines suggest rejecting candidates who are dependent on alcohol or other drugs until sobriety or abstinence is demonstrated. This presentation will present the case of a teenager whose kidney transplant assessment was affected by the team's assessment of the teen's marijuana use – while some insisted on a period of abstinence before listing, others felt that such a limitation would unfairly delay the transplant. Marijuana use among adolescents is common, but remains illegal in many jurisdictions (including the one where this transplant assessment occurred). While some users become dependent on the drug, others can use recreationally with little effect on their overall health or wellbeing. There is some evidence that marijuana use can be physically or neurologically damaging, but others conclude it can be neutral, and newer evidence even suggests that THC, the active ingredient in marijuana, may delay organ rejection and therefore be beneficial. This presentation will present the available evidence on marijuana use, the legal status of the drug internationally, and its effect on transplant success. We will then discuss the ethical issues involved in assessing a teenager for transplant candidacy who discloses marijuana use, and offer a framework for clinicians who may be dealing with such disclosures in their practice. Issues explored will be the difference between use and abuse, the importance of trust and disclosure in the medical encounter, the evidence abstinence pre-transplant leading to post-transplant success, the need for transplant professionals to acknowledge the biases that they may bring to an assessment of psychological suitability, justice issues in the allocation of resources and whether there is a place for paternalism in the assessment of transplant candidates.

**OP68****ETHICAL MANAGEMENT OF CONTRACEPTION IN ADOLESCENT TRANSPLANT RECIPIENTS**

Aviva Goldberg

*University of Manitoba, Pediatrics and Child Health, Winnipeg, Canada*

Current consensus guidelines recommend delaying pregnancy until the transplant recipient has stable graft function and is at low risk for opportunistic infection, and many immunosuppressant medications are teratogenic. It is therefore important to counsel female transplant recipients on appropriate contraception prior to

the onset of sexual activity. For teenagers, who may be still be dependent on their parents to help manage their transplant medications and whose capacity regarding medical decisions is in constant evolution, this contraceptive counseling can be fraught with ethical issues. This presentation will outline the ethical issues that can occur when counseling these patients, and offer a framework for clinicians to manage them. We will explore the potentially conflicting responsibilities of the transplant team to respect the recipient's autonomy and confidentiality while simultaneously avoiding harm to the recipient and her potential offspring. We will discuss the issues that arise when a sexually active teen recipient will not agree to appropriate contraception and whether it is appropriate to change to less teratogenic medications in attempt to avoid fetal malformation. While this may benefit the potential fetus, it may harm the teen recipient if the less teratogenic medications are inferior in terms of graft survival, management of hypertension, hyperlipidemia etc. We will explore whether paternalistic decision making is ever warranted in this situation, whether to balance potential benefits to the fetus with potential harms to the recipient, and how to approach these difficult encounters in the clinical setting.

**OP69****MIGRATION TO GERMANY FOR RENAL TRANSPLANTATION OF CHILDREN AND ADOLESCENTS WITH END STAGE RENAL DISEASE**

Mammadova Dilbar; Marek Ines, Galiano Matthias, Krickau Wolfgang, Rascher Wolfgang

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Background: Increased mobility of patients and poor treatment option for children with ESRD caused families from the former Soviet bloc countries to move to Germany for treatment of end stage renal disease, including renal transplantation. Methods: Analysis of structured interviews with 8 patients and their families who came, for the treatment of ESRD, to the University Hospital for Children and Adolescents Erlangen asking for further treatment and finally renal transplantation. Results: In the last 10 years 8 children and adolescents (5 from Armenia, 2 from Azerbaijan and one from Kosovo) came to Erlangen for treatment of renal failure by dialysis or renal transplantation. The age at entry was in the median of 15 years (range 5-17 years). Four out of eight came primarily for renal transplantation. In Germany they quickly got the desired medical assistance through our social system as an asylum seeker. Treatment by dialysis was often complicated by the high burden to adhere with diet, fluid restriction, medication compliance. This was associated with a large proportion of in-patient treatment courses. Presently 4 of 8 children are transplanted with

stable renal function with a good compliance to medical treatment. Quality of life has markedly improved in all patients. Conclusion: Fleeing to a country with a high medical standard is often the only way to survive for a child or an adolescent with terminal renal failure. The consequences of the high mobility of patients and the problems with renal transplantation have to be discussed not only from a medical point of view, but also ethical standards and human rights have to be considered.

## Workshop 5:

### Psychosocial evaluation, support and education of living donor candidates

#### OP70

#### AN UPDATE ON THE MULTI-SITE, PROSPECTIVE KIDNEY DONOR OUTCOMES COHORT (KDOC) STUDY IN THE USA

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The Kidney Donor Outcomes Cohort (KDOC) study, funded by the National Institutes of Health, was established in 2011 to prospectively characterize the short- and long-term surgical, medical, functional, psychological, and financial outcomes of living kidney donation at six transplant centers in the USA. Living kidney donors (n = 194) and their transplant recipients (n = 151) have now completed comprehensive assessments before surgery and at 1, 6, 12, and 24 months after donation time points that correspond to the assessment intervals currently required by the Organ Procurement and Transplantation Network (United Network for Organ Sharing). In addition to medical and surgical outcomes, we are evaluating donor pain and discomfort, quality of life, changes in the donor-

recipient relationship, health behaviors, psychological benefits, body image, fatigue, life satisfaction, and decision stability. In this presentation, we summarize the KDOC design, cohort characteristics, data collection processes, barriers encountered in implementing the study, and preliminary longitudinal data on the psychosocial outcomes. Information disseminated will provide some novel insights into the unique challenges associated with prospective data collection in a large cohort of living donors and their recipients as well as preliminary psychosocial findings focused on outcomes that are important to donors.

#### OP71

#### PREDICTORS FOR LONGER-TERM HEALTH-RELATED QUALITY OF LIFE OF LIVING KIDNEY DONORS: A PROSPECTIVE MULTICENTER STUDY

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Background: Longer-term post-donation health-related quality of life (HRQoL; i.e., physical, psychological, and social-relational functioning) is comparable to that before donation and to that of the general population for the majority of living kidney donors. However, a small subgroup of donors experiences worse longer-term functioning after donation, for example showing symptoms of depression, anxiety, or persistent fatigue. Current guidelines for psychosocial screening procedures are often not evidence-based, resulting from a scarcity of research identifying possible predictors for worse longer-term functioning after donation. The



current study examined an encompassing account of predictors for longer-term HRQoL of living kidney donors, including the expert opinion of transplant professionals within the screening process. Methods: HRQoL of living kidney donors was assessed before, and six and twelve months after donation in 230 donors from seven Dutch transplantation centers. Potential socio-demographic, psychological, social, and physical predictors were assessed before donation. Also, risk estimation questionnaires were filled out by transplant professionals (nephrologists, coordinating nurses, social workers, and psychologists) after the first consultation with the donors. Results: Being single, worse pre-donation physical and psychological functioning and specifically higher levels of fatigue, were related to worse longer-term physical functioning after donation. The donor-recipient relationship, worse pre-donation physical and psychological functioning, and lower levels of social support were related to worse psychological functioning after donation. Also, higher risk estimations of transplant professionals were related to worse longer-term post-donation functioning. Conclusion: The risk factors for worse longer-term HRQoL identified in the current study could be used to optimize screening procedures for living kidney donors. Furthermore, interventions for donors at risk could focus on these risk factors to prevent worse longer-term outcomes in donors with a high risk profile.

## OP72

### WHO SHOULD DECIDE?: POTENTIAL LIVING KIDNEY DONOR PREFERENCES FOR MAKING DECISIONS ABOUT RISK

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Background: Transplant centers debate how to manage risks to potential living kidney donors (LKDs) when there is insufficient evidence about their long-term post-donation outcomes. We sought to determine how LKDs believe such disagreements should be resolved. Methods: We conducted semi-structured interviews with adult potential LKDs at three major centers in the US. Interviews were completed before LKD candidates were notified if they were eligible to donate. The interview stated that LKDs are sometimes willing to accept greater risks than transplant centers are comfortable with. Participants were asked who they thought should decide what level of risk donors should be allowed to take in such situations. Interview transcripts were cod-

ed using a standard inductive major and minor coding method in NVivo 11. Results: Our sample included 97 potential donors (138 were invited to participate; 19% declined, another 11% did not complete their interview before told their donor eligibility status). Our sample comprised 39% men and 87% Caucasians; the mean age was 46 years and 70% had completed college or beyond. In cases of disagreement about acceptable levels of donor risk, many respondents provided reasons both for and against donor involvement in the decision. Ultimately, 39% believed the center should decide, 20% sought shared-decision making (SDM), 5% wanted the center to advise and leave it up to the donor, 14% stated the donor should decide only up to a certain threshold of risk, and 21% thought it should be up to the donors. Prior LKD evaluation did not affect preference for SDM. Reasons for a center-based decision included: professional expertise, emotional impartiality, responsibility for donor safety, need to ensure that recipients receive high-quality organs, liability, center reputation, and physician conscience. Reasons for donor-based decisions included donor autonomy, closeness of the donor-recipient relationship, risk comprehension, donor risk-taking in other areas of everyday life, donor assumption of liability, and that sense that centers are not adequately aware of the donors' values or recipients' needs. Discussion: Potential LKDs have nuanced attitudes toward risk acceptance and decision making. They endorsed SDM less frequently than patients faced with other types of surgical decisions. Participants raised many of the reasons for and against SDM that have been raised by ethicists and policy makers. LKD preferences and suggestions for managing disagreements about risk should help inform center policy and decision-making processes.

## OP73

**LIVING KIDNEY DONOR PRIORITIES FOR OUTCOMES: A NOMINAL GROUP TECHNIQUE STUDY**

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**Background:** Living kidney donors must accept risks associated with nephrectomy. While this is ethically justified with informed consent, screening and access to follow up, the outcomes that are most important to donors are yet to be established. We aimed to identify living kidney donor's priorities for outcomes and describe the reasons for their choices. **Methods:** Living kidney donors were purposively sampled from two Australian transplant centres. Participants identified important outcomes of kidney donation, ranked the importance of the outcomes, and discussed reasons for their priorities. For each outcome, we calculated a mean rank score from zero (least important) to 10 (most important) and analysed the transcripts thematically. **Results:** Across eight nominal groups, 67 participants aged 27-78 years identified 32 outcomes. The highest ranked outcomes were: time to recovery (mean rank score 5.39, SD = 3.77), family life (5.24, SD = 4.02), donor-recipient relationship (4.25, SD = 4.07), diet and lifestyle restrictions (3.90, SD = 3.55), and kidney function (3.76, SD = 3.50). Kidney failure and mortality ranked 10th and 13th respectively. Women ranked the donor-recipient relationship, life satisfaction, and family life higher than men; whilst men ranked kidney failure, physical function (fitness), mortality and kidney function higher. The themes underpinning participants' priorities included: overriding concern for recipient wellbeing, undeterred by low risks, heightened susceptibility and unfulfilled expectations. **Conclusions:** Living kidney donors prioritised outcomes that could potentially disrupt their lifestyle

and relationships, were unexpected, or caused fear and anxiety about their health. Donor assessment and follow up should address expectations regarding recovery time, relationship challenges and possible constraints on vocational and recreational activities; and donors may be more empowered with advice about diet, exercise and other healthy lifestyle practices to prevent long-term health problems. This may increase donor satisfaction and improve outcomes that matter to donors.

## OP74

**TAILORED E-HEALTH COGNITIVE BEHAVIORAL THERAPY FOR LIVING KIDNEY DONORS AT RISK**

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**Background:** Previous research indicates that small subgroups of living kidney donors experience problems in physical or psychosocial functioning after donation, such as depressed mood, fatigue, or pain. Currently, evidence-based psychosocial interventions for living kidney donors at risk are scarce. E-health cognitive-behavioral interventions have been found to be effective for a broad range of adjustment problems, including dealing with pain or fatigue, negative mood, and social relationships. **Methods:** Based on focus group interviews with donors and transplant professionals, literature study, and evidence-based interventions for patients with chronic somatic conditions, an E-health intervention for (potential) donors with a high risk profile was developed. Tailored therapist-guided E-health cognitive behavioral therapy was offered, in which donors worked on specific treatment goals determined together with an e-Coach, who provided online weekly support in working through one or more treatment modules related to, for instance, dealing with fatigue, social-relational problems, and negative mood. In the current study, the feasibility of and satisfaction with this newly developed E-health intervention was evaluated in a small group of (potential) living kidney donors who reported some adjustment problems on a screening questionnaire. **Results:** Treatment duration varied from 6 to 16 weeks. Donors were satisfied with the content and information provided by the E-health intervention (mean evaluation: 8.0 ± 0.0 on a 10-point scale) and would recommend it to others. Therapist contact was evaluated as stimulating and useful, and the intervention led to improvement on

treatment goals. Conclusion: The feasibility and satisfaction with the intervention was evaluated positively. These promising results warrant future research on the effectiveness of the intervention in a randomized controlled trial.

## OP76

### A LEGAL FRAMEWORK TO SUPPORT TRANSNATIONAL REPORTING OF TRANSPLANT-RELATED CRIMES: THE VALUE OF EXTRATERRITORIAL JURISDICTION

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In this paper we present the key findings of a working group convened by the Declaration of Istanbul Custodian Group to explore the potential value of extraterritorial jurisdiction (EJ) in combatting organ trafficking and transplant tourism. We argue that the application of EJ to domestic laws governing trafficking in human organs and human trafficking for organ removal ('transplant-related crimes') is ethically justified as it supports the values embedded in such laws in countries affected by these crimes. EJ provides a legal basis that would support reporting and investigation

of transplant-related crimes where these extend across national jurisdictional borders. Enhancing reporting activities and prosecution of crimes would assist in deterring and preventing trafficking and transplant tourism. Briefly, we outline a possible transnational reporting system that could be used to increase the efficacy of EJ, and discuss the potential ethical dilemmas that might arise for health professionals involved in reporting. In conclusion, we suggest that EJ would strengthen existing laws prohibiting organ trafficking and, when combined with an effective reporting system, would increase the efficacy of current international efforts to combat organ trafficking and transplant tourism.

## OP77

### PROTECTION OF HUMAN BEINGS TRAFFICKED FOR THE PURPOSE OF ORGAN REMOVAL: RECOMMENDATIONS

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This report presents a comprehensive set of recommendations for protection of human beings who are trafficked for the purpose of organ removal or are targeted for such trafficking. Developed by an interdisciplinary group of international experts under the auspices of the HOTT project, these recommendations are grounded in the view that an individual who parts with an organ for money within an illegal scheme is ipso facto a victim and that the crime of trafficking in human beings for the purpose of organ removal (THBOR) intersects with the crime of trafficking in organs. Consequently, the protection of victims should be a priority for all actors involved in anti-trafficking activities: those combating organ-related crimes, i.e., health organizations and survivor support services, and those combating trafficking in human beings, i.e., the criminal justice sectors. Taking into account the special characteristics of THBOR, the authors identify the key stakeholders in the protection of human beings trafficked for organ removal or targeted for such trafficking: states, law enforcement agencies and judiciary, non-governmental organizations working in the areas of human rights and anti-trafficking, transplant centers and health professionals involved in transplant

medicine, and oversight bodies. For each stakeholder, the authors identify key areas of concern and concrete measures to identify and protect the victims of THBOR. The aim of the recommendations is to contribute to the development of a non-legislative response to THBOR, to promote the exchange of knowledge and best practices in the area of victim protection and to facilitate the development of a policy-driven action plan for the protection of THBOR victims in the EU and worldwide.

## OP79

### PAYING LIVING KIDNEY DONORS AND THE PROBLEM OF EXPLOITATION

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One common argument against paying living kidney donors is that doing so would exploit the poor. However, exactly what is meant by this claim is often left unclear. In this paper, I discuss three ways that the charge of exploitation can be understood: 1. 'Fair benefits' accounts of exploitation assess whether A grants B a fair distribution of the gains of social cooperation 2. 'Fair process' accounts of exploitation focus on whether A seeks to take advantage of B under circumstances where it is inappropriate to do so. 3. Complicity in injustice, a related form of wrongdoing, occurs when A takes advantage of the fact that B is a victim of structural injustice and, in doing so, reinforces these unjust background conditions. I argue that each raises distinct moral concerns, and each can contribute important ethical insights to the organ market debate. However, only 'fair benefits' accounts of exploitation have received serious attention in the philosophical literature on kidney sales to date. According to the standard analysis of 'fair benefits' exploitation, exploitation can be avoided by ensuring vendors receive a generous price for their organs. I argue that this analysis is incomplete in important aspects. While price controls may be able to address fair benefits exploitation, 'fair process' exploitation and complicity in injustice are not amenable to the same regulatory solutions. In certain contexts, these latter forms of wrongdoing are likely to occur regardless of how much kidney vendors are paid.

## Free communications 10: Living donation (A)

### OP80

#### USA KDOC STUDY: DIRECT AND INDIRECT COSTS INCURRED BY LIVING KIDNEY DONORS

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Direct and indirect costs associated with living kidney donation have not been well characterized in the USA. We collected cost data in the 12 months following donation from 182 LKDs participating in the multi-center, prospective Kidney Donor Outcomes Cohort (KDOC) Study. We prospectively collected pre- and post-donation cost data from a large cohort of living donors (N = 194) participating in the multi-center prospective Kidney Donor Outcomes Cohort (KDOC) study. Pre-donation, 96% of donors reported one or more direct costs, including ground transportation (80%), healthcare (24%), lodging (17%), and air transportation (14%), totaling \$ 101,484 (USD; mean = \$ 523 ± 942). Excluding paid vacation or sick leave, donor and companion lost wages totaled \$35,918 (mean = \$ 187 ± 556) and \$14,378 (mean = \$ 76 ± 311), respectively. One-third of LKDs used paid vacation or sick leave to avoid incurring lost wages. Post-donation, 92% had one or more direct costs following donation, including ground transportation (86%), healthcare (41%), meals (53%), medications (36%), lodging (23%), and air transportation (12%). Donors missed 33,072 total work hours, 40% of which were unpaid and led to \$ 302,175 in lost wages (mean = \$1,660). Caregivers lost \$ 68,655 in wages (mean = \$ 377). Although some donors received financial assistance, 89% had a net financial loss in the 12 months, with one-third (33%) reporting a loss exceeding \$ 2,500. Moderate direct and indirect costs both before and after donation are common and potential donors should be advised of these possible costs. Also, financial neutrality for donors should be an immediate priority for the transplant community in the USA, following the lead of several other countries that have implemented cost reimbursement programs for donors.



## OP81

# THE ETHICS OF SHIFTING THE U.S. FRAMEWORK OF LIVING KIDNEY DONATION FROM REMOVING DISINCENTIVES TO ADDING INCENTIVES

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There is a persistent shortage of organs for kidney transplantation, with more than 80,000 patients on the wait list, 30,000 new patients added annually, and a median wait time of 3-4 years. Living donor (LD) transplant is the only alternative to deceased donor transplantation (DD), with known mortality risk and no significant increased risk of donor ESRD when compared to the general population. LD transplantation has seen a 15% decline in the past 10 years. Removing disincentives or adding incentives to donation is seen as strategy to reverse the downward trend. We argue that in the absence of a longer donor follow-up (DFU) any strategy to nudge people into organ donation should be carefully scrutinized and may violate the principle of autonomy. Per the Organ Procurement and Transplantation Network post donation FU is required only for two years, and clinical and laboratory data are not required for 100% of the donors. There are no incentives for the donor to comply with DFU. Retrospectively-collected data show that ESRD develops in 70/10,000 donors longer than two years post donation when U.S. mandatory DFU is exhausted. Longer DFU will allow preventive measures to avoid ESRD. Lack of comprehensive, prospectively-collected DFU data makes the present donor informed consent sub-optimal since the donor misses essential information to make an autonomous decision. The inability to provide comprehensive informed consent threatens the principle of autonomy, violating the ethical foundations of donation. Great attention has been given to the issue of immediate postoperative donor safety while consistent DFU is lacking. Before addressing the strategies that may increase living donation like removal of disincentives or addition of incentives, the issue of donor long-term medical FU should be tackled. DFU should apply for life to 100% of the donors, and methods should be implemented to assure compliance and proper data collection. The new data, obtained from all donors in a prospective fashion, will be available to potential future donors who will be empowered to give a proper informed consent with full respect of their autonomy. Only then the discussion regarding removing disincentives or adding incentives to living donation may be initiated.

## OP82

# EDUCATING THE SOCIAL NETWORK OF BLACK PATIENTS PREDICTS THE LIKELIHOOD OF A LIVING DONOR EVALUATION AND LIVE DONOR KIDNEY TRANSPLANTATION

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We developed a House Calls intervention, in which trained health educators deliver a live donor kidney transplant (LDKT) and living donor educational program in the patient's home and with invited guests (e.g., family members, friends, co-workers). In two separate randomized controlled trials, House Calls has proven effective at increasing the likelihood of patients having a living donor evaluated and receiving a LDKT. However, it is presently unknown whether specific patient and contextual characteristics predict favorable versus unfavorable outcomes. Therefore, in the context of a randomized controlled trial with 152 black patients on the waiting list for kidney transplantation, we examined the relationship of two study outcomes (occurrence of living donor evaluation and live donor kidney transplantation [LDKT]) with demographic (age, sex, education, marital status, occupational status), clinical (dialysis status, transplant waiting time, prior kidney transplant, and physical quality of life), psychosocial (LDKT knowledge, concerns, and willingness at six week assessment), and socio-contextual (social network included in education, number of support network members educated, educational venue, presence of other patients, education time, and number of donor inquiries) variables. Pre-dialysis initiation (odds ratio [OR] = 4.64, 95% confidence interval [CI] = 1.05, 20.41), the number of social network members receiving LDKT and donation education (OR = 1.40, CI = 1.22, 1.61), and the number of living donor inquiries (OR = 4.91, CI = 2.58, 9.33) were significant predictors of the occurrence of a living donor evaluated. Pre-dialysis initiation (OR = 7.44, CI = 1.26, 43.92), more LDKT knowledge (OR = 2.30, CI = 1.20, 4.44), higher willingness to talk to others about donation (OR = 3.10, CI = 1.16, 8.29), the number of social network members participating in LDKT and donation education (OR = 1.13, CI = 1.03, 1.24), and the number of living donor inquiries (OR = 1.94, CI = 1.22, 3.08) were significant predictors of LDKT. Findings offer preliminary evidence regarding the importance of providing direct LDKT and living donation education to social network members to optimize the likelihood of

living donor evaluations and eventual LDKT for black patients. More research is needed to examine the degree to which such strategies lead to actual attenuation of racial disparities in LDKT rates.

## OP83

### **LIVE DONOR AUTONOMY AND PROFESSIONAL PROTECTIONISM. INCONSISTENCY IN MEDICAL ASPECTS OF LIVE DONOR EVALUATION. A LITERATURE SEARCH AND DISCUSSION**

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The literature addressing the medical aspects of fitness to be a live organ donor, donor autonomy and professional protectionism was reviewed. Guidelines have been constructed aimed at ensuring the safety of live organ donors from the point of view of peri-operative risk and, in the case of kidney donation, the avoidance of long term morbidities such as renal failure. Part of this discussion has revolved around the concept of *primum non nocere*, a long held medical professional belief that we should not do harm to patients. It has been questioned; – Whether this can address issues such as self-determination adequately – Why we should hold this particular tradition so highly, and pointed out that we do perform treatments that result in harm. Transplant centres make judgement as to what the acceptable risk is that they will allow potential donors to undergo and reserve the ‘right’ to refuse to proceed with the donor operation. There is considerable variation in the risk that transplant centres will accept, possibly because of the lack of evidence based data to support many of the conclusions made about risk. The published experiences of Dr Hoyer, a German transplant surgeon, who donated a kidney but was turned down (temporarily) for hyperlipidaemia highlight these issues. There is little or, no evidence, that transplant centres include the potential harm of declining a donor in coming to their decisions as to whether to allow the donation to occur. Standard practice in most areas of medicine has evolved to include effort to ensure that patients have autonomy in their treatment decisions after receiving appropriate information regarding the risks and benefits of that treatment. Beauchamp and Childress recognise the difficulty in balancing moral issues, particularly where it may be necessary to infringe one moral norm to adhere to another and describe the conditions that must be met for this to occur. It is timely to rethink where the balance should be when disparate views are held by the potential live organ donor and the transplant team in the area of medical risk assessment and suitability to donate.

## OP84

### **TRANSPLANT PROFESSIONAL'S VIEWS ON UNSPECIFIED KIDNEY DONATION**

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Unspecified Kidney donation (UKD) was introduced in the UK in 2006. In 2012 unspecified kidney donors (UKDs) accounted for 1 in 20 of all live kidney donors. The number of UKDs donating across the UK however varies widely between centre locations, with three centres accounting for 45% of all donations. The reasons for this are unclear. We are conducting a five year National Institute for Health Research funded project, Barriers and Outcomes of Unspecified Kidney Donation (BoUND), which began in July 2015, in order to understand UKD in the UK more fully. The full project aims are to 1) determine whether variation in practice across the UK is preventing some unspecified donations 2) determine whether psychosocial and physical outcomes after unspecified donation are equal to those in specified donors (donation to a known individual) and 3) determine the economic benefit of unspecified donation. This presentation reports on our preliminary findings regarding staff perspectives on UKD. Previous research has found staff attitudes and practices to have an impact on donation trends. To explore this further within UKD, four focus groups were held at 4 transplant centres across the UK. Professionals were asked about their experience of working with UKDs in their teams and about any challenges or ethical issues they faced. 35 transplant professionals participated. These included living donor nurses, nephrologists, surgeons, renal care nurses, a clinical psychologist, independent assessors, and laboratory technicians. The interviews to date have been transcribed verbatim and will be analysed using the framework approach (Richie and Lewis, 2003). This methodology is deemed particularly useful for generating clinically relevant data that can inform service and policy development (Ritchie and Lewis, 2003). Preliminary analysis at time of submission revealed • Conflicting views about the motivations of UKDs • Challenges in the



acceptability of medical risks for UKDs vs practices in directed kidney donation • Ethical issues to be a regular feature • Calls for more explicit guidelines to reduce practice variability. The full analysis will be presented along with discussion regarding how these early findings will inform the ongoing BoUND research.

## OP85

### THE IMPACT OF VOLUNTEERS ON UNSPECIFIED LIVING KIDNEY DONATION IN THE UK

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**Introduction:** Before 2006, living donation in the UK could only happen between genetically related and close social contacts. The Human Tissue Act 2004 and the establishment of Human Tissue Authority (HTA) in 2006 legalised unspecified (non-directed altruistic) living kidney donation. Method Clinical standards were developed, including medical and psychological tests to standardise donor work-up. In 2007 the UK's first unspecified donation took place. The volunteer donor-driven process challenged many beliefs held by both the medical professionals and the British public as a whole. As numbers continued to grow each year, in 2011, an altruistic donor charity (Give a Kidney – one's enough) was launched by donors, healthcare professionals and supporters with the mission 'No waiting for a transplant for want of a kidney'. Quantitative research was performed by the charity in 2011 and 2014 to assess public awareness of and attitudes towards altruistic donation across the UK as well as the influence of the charity. The charity has partnered NHSBT in media campaigns, providing stories both locally and nationally. Results: Public awareness has grown and international links have been formed with similar groups in New Zealand, The Netherlands and USA. Professionals use the charities website as a national resource. The charity is regularly invited to help develop national policy and media strategies. The UK is now approaching 500 unspecified donations and these donors are essential to the National Living Kidney Donor Sharing Schemes, triggering long and short chains to maximise the number of transplants from each donation. Summary: Unspecified donation in the UK is a success. 441 non-directed donors have donated, resulting in 509 transplants. After the first year, when costs are equivalent, this has saved the UK health economy approximately £ 25,000 per year with a transplant over dialysis expenditure. While this impact is already substantial, the demonstration that there is significant untapped donor willingness raises the exciting possibility that it could be expanded further and achieve the charity's ambition of 'no waiting for a transplant

for want of a kidney'. We would commend this to all national transplant programmes. Presenting author Christopher Burns-Cox, Emeritus Consultant Physician, UK (Authors) Paul Gibbs, Consultant Transplant Surgeon, Queen Alexandra Hospital, Portsmouth, UK Paul van den Bosch, General Medical Practitioner, UK Jan Shorrock, PR Officer, Give a Kidney, UK.

## OP86

### SHIFTING PARADIGMS IN LIVE KIDNEY DONATION: ATTITUDES OF TRANSPLANT PROFESSIONALS

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**Background:** The transplant community increasingly accepts extended criteria (EC) live kidney donors, because of organ shortage, although long-term follow-up data of these donors and their respective recipients is still lacking. Great differences are present in acceptance of these donors, and guidelines do not offer clarity. The aim of this survey was to reveal these differences and to get an insight in both center policies as well as personal beliefs of transplant professionals. Methods: An online survey was sent to 1,128 ESOT members. The questionnaire consisted of an objective part asking for center policies regarding acceptance of EC live kidney donors, and a subjective part for transplant surgeons, regarding their personal beliefs in this matter. Questions about several EC, pre-operative imaging, multidisciplinary team discussions and operative techniques were included. Comparisons were made between transplant centers of three regions in Europe (Northwest, Mediterranean and East) and between other countries worldwide. Results: 331 questionnaires were completed by professionals from 55 countries (30 in Europe). 55% were transplant surgeons, 35.3% were nephrologists. Significant differences exist between regions in acceptance of donors with EC. Median refusal rate for potential live donors is approximately 15%. Furthermore, differences are seen regarding pre-operative work-up, specialists who perform screening and preoperative imaging. Almost a quarter of transplant professionals sometimes deviate from their center policy, resulting in more or less comparable personal beliefs regarding EC. Discussion By performing this survey amongst a large group of transplant professionals, we gained insight in both center policies as well as personal opinions of acceptance of EC donors. Variety is seen, proving the need for a standardized approach in selection. Although short-term outcome of these donors seems to be good, long-term follow-up is warranted to ensure donor safety.

**Free communications 9:  
Pediatric donation and transplantation**

**OP87**

**DOES THE CONSENT RATE TO ORGAN DONATION IN PEDIATRIC DONORS VARY WITHIN DIFFERENT AGE GROUPS?**

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**Background:** In Germany organs of a deceased person may only be retrieved if the person itself or an authorized person gave permission (opt-in). Especially in children < 16 yrs parents are usually asked for consent unless children ≥ 14 yrs declared refusal to organ donation during lifetime. We analyzed whether there are differences in consent rates between different donor age groups. **Methods:** All potential organ donors (i.e.: no medical contraindication to donation plus verified brain death) aged 18 yrs or younger reported to the DSO (Deutsche Stiftung Organtransplantation = German organ procurement organization) from 1/2006 to 11/2015 registered in our database were included in this study. Different age groups were formed: group 1: 1 yrs (n = 69); group 2: 1-5 yrs (n = 172); group 3: 6-15 yrs (n = 298); group 4: 16-18 yrs (n = 254). **Results:** 793 potential donors ≤ 18 yrs (group 1-4) could be analyzed. In 522 cases (65,8%) consent to organ donation was given, in 258 cases (32,5%) donation was refused, and in 13 cases (1,6%) due to medical reasons the process was stopped before family approach. The overall consent rate in pediatric donors is comparable to the consent rate in adult donors in Germany (65%; 2014). The consent rate for the pediatric donors varied between the different age groups, being the lowest in donors aged 1-5 yrs: 63,8% (group 1, n = 44), 56,4% (group 2, n = 97), 69,1% (group 3, n = 206) and 68,9% (group 4, n = 175). **Discussion:** In our experience the decision of the parents for or against organ donation especially in the age group 2 to 4 are based at least partially on the fact that they realize their children's social interaction with the environment. Older children (group 3-4) often show the ability to express empathy with ill and weak human beings which is taken into account by the parents' decision. This might explain the higher consent rate in these two groups. In contrast, children aged 1-5 are mainly self-referred. Parents of infants (group 1) decide mainly based on their own moral concepts as these children are at the lowest level of social interaction compared to the other age groups. We know from several conversations with these parents that their main motivation is to give sense to the senseless death.

Further studies are necessary to confirm these explanations.

**OP88**

**ELECTIVE VENTILATION TO FACILITATE ORGAN DONATION IN INFANTS WITH ANENCEPHALY: PERINATAL PROFESSIONALS' VIEWS AND AN ETHICAL ANALYSIS**

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**Aims:** Organ donation by infants with anencephaly ceased worldwide following ethical concerns about death-verification using neurological criteria. However, donation after circulatory definition of death offers an opportunity to reconsider this and indeed such donation had been reported in the UK. Following the elective ventilation and referral for organ donation of an infant with anencephaly and donation in another child we sought local perinatal professionals' views of this practice as little is known about professional attitudes about this issue. **Methods:** Anonymous online survey: demographics, ethical viewpoints and potential public/maternal perceptions (standard 5-part Likert scale and free text) of all level 3 NICU/fetal medicine units in London. **Results:** Demographics: 49 replies (38 female): 4 obstetricians, 14 neonatologists, 6 fetal clinicians, 23 nurses, 1 anaesthetist, 1 reproductive specialist. Experience: 0.5 – 33-years (average 12). 21 had experience of anencephalic delivery, 10 reported pregnancy continued for religious reasons. **Ethics:** (i) 73% thought anencephalic donation acceptable; of which 64% supported elective ventilation, 20% neutral and 16% disagreed. (ii) Provision of treatments not in infant's strict best interest to facilitate donation: 22% strongly agreed, 36% agreed, 33% neutral, 9% disagreed. (iii) Accept ventilation to permit donation if societal benefit: 53% agreed, 33% neutral, 13% disagreed. (iv) Public opinion: 59% disagreed anencephalic donation would harm public opinion about donation, 19% agreed. **Ethical analysis of standard DCD concerns adapted to infant with anencephaly:** Theoretic risk of conversion to PVS – non existent; prolongation of dying – can be mitigated by analgesic and sedation as in other situations – e.g. deferral of ICU withdrawal until relatives arrive from overseas. Kantian concern babies used only as a means – clearly wrong as expressed in recent media coverage of UK infant with anencephaly case – best interest expressed in family loving environment. Resource use – balanced by decreased cost of recipients to healthcare services. Given informed consent this is OK. **Conclusions:** We found a supportive local environment for donation in the setting of anencephaly,

including support for elective ventilation, though some clinicians expressed concern about public acceptability of elective ventilation. Given this, and our ethical analysis, we recommend provision of organ donation information as part of palliative care counselling for women carrying a foetus with a condition likely to be fatal in infancy.

## OP89

### DIFFERENCES IN ORGAN DONATION CONSENT FOR CHILDREN FOLLOWING DEATH FROM NON-ACCIDENTAL TRAUMA

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**Background:** Solid organ transplantation has the potential of saving pediatric lives, with over 2100 children in 2015 listed for potential transplant in the United States alone. Approximately 32% of wait listed pediatric patients will die prior to transplant. The major limiting step for transplantation is organ availability and missed opportunities may contribute to waiting list deaths. Pediatric recipients are dependent on pediatric donors due to size limitations. Children who progress to death following non-accidental trauma (NAT) are frequently good donation candidates, due to less involvement of transplantable organs. However, the social and emotional issues surrounding these cases may result in differences in obtaining parental consent. **Data shows** that following an effective request policy (ERP) increases the likelihood of consent. At our institution, this policy includes ensuring close communication with our organ procurement organization (OPO) to create a plan of approach prior to first mention, and to ensure the mention occurs after declaration of brain death or the families' decision to withdraw life-sustaining support. **Objective:** To determine if there is a difference in consent rate among families of patients who die following NAT, and if there are discrepancies in application of an ERP compared with all comers. **Methods:** We reviewed data on patients referred for consideration of organ donation between 2011 and 2014. We included all patients, aged 0-18 years, who were approached for consent for organ donation. We compared the consent rate between patients who died from non-accidental trauma as compared with all other diagnoses, and if the ERP was followed. **Results:** Between 2011 and 2014, 85 patients were approached by our OPO. Fourteen (16%) died from NAT. Among all patients, 53 families (62%) consented for donation. Among patients dying from NAT, 6 families (43%) consented for donation. In non-NAT cases, the ERP was followed 73% of the time. In NAT cases, the ERP was used 50% of the time and 88% declined when we

failed to follow the ERP. **Conclusions:** Patients who die from non-accidental trauma frequently make clinically suitable organ donors. Our data shows this patient population may be less likely to consent to organ donation. One explanation may be the difficulty in following an effective request process, with communication more likely to be unplanned and poorly timed. To optimize the opportunity for donation, this patient population warrants special attention to the manner and timing of our approach for consent.

## OP90

### PRE-MORTEM INTERVENTIONS IN DYING CHILDREN TO OPTIMIZE ORGAN DONATION – ETHICAL & UK LEGAL ANALYSIS

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A range of interventions in dying patients can improve the possibility of successful organ donation and likely long-term success of transplantation. Ethical and legal analysis of these pre-mortem interventions has almost entirely focused on adults, leaving the differences involved in children's end-of-life care not specifically addressed. Differences include the ethical backdrop to caring for dying children and, of particular relevance, the legal framework for decision-making in children's medicine. Recent controversy about donation after circulatory determination of death and whether associated pre-mortem interventions not in a dying individual's specific medical best interests ought to be undertaken led in 2009 to UK Department of Health legal guidance: 'Legal issues relevant to non-heart beating organ donation.' We argue the restrictive approach to pre-mortem interventions in the UK guidance may be incorrect for adults in light of recent Mental Capacity Act [2005] Supreme Court judgements – but is certainly so for children under 16-years of age as the relevant legislation is the Children Act [1989], leading to a harm/benefit welfare checklist approach to assess a child's best interest. Risk of harm can be balanced against benefit to the child being the best donor possible, the wishes of the family and the clear social good in donation. A positive assessment on such a welfare checklist coupled with parental consent would render pre-mortem interventions rational and lawful. Interventions include: (i) Change in location of dying – transfer before death to a location at which organs can be optimally retrieved (ii) Change in time of dying and medical interventions to delay death (iii) Interventions to improve the quality/quantity of donated organs. In a situation in which parents consent to donation and explicitly to pre-mortem interventions and healthcare professionals consider this in the child's extended best

interest, then proceeding seems justified and lawful. This seems appropriate given the frequency with which invasive measures outside the domain of donation – deferring withdrawal of life-sustaining therapy – are routine in paediatric end-of-life care. Pre-mortem interventions can often be ethically justified and seem not to be forbidden by current legislation if the potential harms can be balanced by extended welfare considerations. This means they ought to be considered to optimise organ donation in childhood.

## OP91

### FAVORABLE OUTCOME OF RENAL TRANSPLANTATION OF HANDICAPPED AND DISABLED CHILDREN AND ADOLESCENTS

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*M. Galiano and K. Sauerstein contributed equally.*

Background: Organ transplantation as a treatment option is often critically discussed in children and adolescents with developmental delay, mental retardation, intellectual disabilities or psychiatric disorders. From an ethical and legal point of view access to this life-saving procedure has to be provided in these vulnerable patients, since discrimination is prohibited. Methods: The course of renal transplantation in eight children and adolescents with major disabilities has been analyzed retrospectively by chart reviews of children treated with ESRD at the University Hospital for Children and Adolescents Erlangen. Results: Of 8 children and adolescents analyzed (actual median age: 12.5 years, range: 9-17 years) one patient received a second transplant 5 years after primary transplantation. Graft failure after 5 years was due to an unknown diabetic nephropathy of the donor (data excluded for this study). Major non-renal diagnoses: Translocation (T22/T21), mental retardation, postpartal hypoxia, autism, Joubert syndrome, Senior-Loken syndrome. Median time living with a functional transplant was 4.9 years (range: 1.3-10.2 years). Median serum creatinine at the time of analysis was 0.91 mg/dl (range: 0.71-1.35), indicating favorable renal outcome 5 years after transplantation. Quality of life improved definitely in all patients. Conclusion: Renal transplantation of disabled children is associated with favorable outcome, possibly due to the high adherence of patients and parents to comply with medical treatment and care. With the support of EFI project the FAU Erlangen-Nuremberg.

## OP92

### RESEARCHING IMPACT OF PARENTAL LIVING DONATION IN PEDIATRIC LIVER TRANSPLANTATION: METHODOLOGICAL AND ETHICAL ISSUES

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Background: Nearly one thousand pediatric liver transplantations (PLTs) have been performed since 1984 in our centre. Liver transplantations with parental living donors were initiated in 1993, and account today for the majority of the PLTs done in our hospital. Based on our extensive clinical experience, as well as previous results from our research on psychosocial issues, we would like to raise the question of the long-term psychosocial impact of parental living donation, on the recipient, the donor and family dynamics. However, in order to implement clinically relevant and scientifically sound research on such complex issues, important methodological and ethical questions need to be addressed. Methods: We searched the literature, sought several experts' opinions (including child psychiatrists from our hospital), and received input from discussions with colleagues from the multi-disciplinary health care team of the pediatric liver transplantation program. Results and discussion: To explore the psychosocial impact of a PLT with a parental living donor leads us to consider the whole family context, which is a dynamic and changing system with unique features. Therefore, a qualitative exploratory approach, based on observations as well as individual, dyadic and/or family interviews should be preferred over a quantitative confirmatory one. Moreover, such research need to be imbedded within the clinical practice. Therefore, the clinical psychologist of the team would conduct the research. This involves ethical precautions, among which, an association with an external researcher. Thus, if clinical questions emerge during the research process, the psychologist may consider as a priority the clinical aspect, leaving the research to the external researcher. What about using the donors' psychological evaluations before transplantation? This is potentially a valuable research material to be used in a prospective or retrospective study. However, is it ethically correct to use it? How and when should we seek consent from the donor (and/or both parents)? How may the research findings be used to inform practice? Being aware that the living donation, in rare cases, is still kept a secret within the family, sometimes years after transplantation, how do we approach the families that we wish



to include? ... These are some among the many issues that we have tried to address in our research protocol. Conclusion: A number of ethical and methodological issues have been partly identified and discussed, but still deserve further attention.

## OP93

### BRAIN DEATH FAMILY DENIAL: US VERSUS UK

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As the UK has no legal definition of death Common Law acceptance of death verification by practitioners using accepted guidance (AOMRC Code of Practice) gives the legal and medical standard. Death is most frequently confirmed using circulatory determination, but in those ventilated with catastrophic brain injury neurological determination (NDD) can be used. Whilst theoretical differences exist there is little practical difference in international NDD. Given recent controversy regarding NDD in a US child, a UK case is worthy of comment. Re: A (A Child) [2015] EWHC 443 (Fam) involved a 19-month-old boy who choked on fruit leading to cardiac arrest, catastrophic brain damage and NDD. The child's Muslim family could not accept this and agreement about stopping ICU support could not be reached. As death had occurred, the body fell under jurisdiction of the coroner who recommended removal of ventilation and transfer to the mortuary. The team approached the court. In the US case the family of Jahi McMath, a 13-year-old girl with catastrophic brain injury following post tonsillar haemorrhage, similarly refused to accept NDD and filed a lawsuit to continue 'life-support.' Despite ruling McMath dead based on hospital physicians and independent evidence the Judge ordered ventilation continue until appeal. At this, the family argued US Uniform Determination of Death Act application had violated constitutional religious and privacy rights; because Jahi's heart was beating to them she remained alive. McMath, or her body depending on NDD acceptance was moved to another US state in which religious views must be considered in death determination. Religious objection to NDD, permitted in several US States & Israel, ranges from undefined accommodation by professionals of religious views in New York to full legal veto in Israel and New Jersey if personal religious beliefs would be violated. The UK Judge clarified three points of law: (i) Shared jurisdiction exists over a body attached to mechanical ventilation: Coroner jurisdiction to determine who, where and how someone died; Court jurisdiction under both 'the parens patriae' and inherent jurisdiction. (ii) Given an unresolvable difference between clinicians and family where ventilation is

continuing, the High Court not coroner should resolve it.' (iii) Ruling A died when brainstem tests were satisfied and ordering ventilation removed to allow 'dignity in death,' the judge confirmed acceptance of NDD equating to the death of the person. The UK does not provide for religious control over how one's death is verified.

## Free Communications 7:

### Cultural, religious and social aspects (B)

## OP94

### FOEDUS WP 7 – INTERNATIONAL APPROACH IN COMMUNICATION

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Objective: Aim of a European project on 'communication and public awareness' was to develop a communication approach in the field of organ donation and transplantation (ODT). The approach had to be comprehensive and integrated, serving as a good starting point for all national competent authorities regardless of their levels of expertise in communication. Work package 7 (WP7) was part of a joint action called FOEDUS (Facilitating Exchange of Organs Donated in EU member States, grant agreement n. 20122101, project coordinator: CNT ISS). Method: The project was administered in several steps, stretching from theoretical foundations to practical applications. Main steps were: • an analysis of studies on the theoretical state of the art of conducting and evaluating communication measures • a survey among communication partners regarding their perceptions and needs • the development of a multi-stage process to generate communication messages • a description on how public perceived a set of developed messages and reacted to them in terms of cognitive and emotional response. Results: Results accomplished within FOEDUS WP7 add together to an integrated approach in communication. To this time, WP7 is the first attempt for a European-wide collaboration focusing on communication in the field of ODT. Outlook: All results will be included in a final manual on 'Communication in the field of organ donation and transplantation. The structure and main contents of the project can be presented at ELPAT congress. (Thomas Breidenbach, Marie Lingemann, Bernarda Logar Zakrajšek and Danica Avsec on behalf of FOEDUS WP7 members.)

## OP95

**RENAL TRANSPLANTATION IN THE MIDDLE EAST: CHALLENGES AND OPPORTUNITIES**

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Renal Transplantation is the best option for treating patients with end stage renal disease. Transplantation in the Middle East is shaped by the prevailing religious socioeconomic and health indicators in the different countries. Living organ donation is the most widely practiced type of donation in the Middle East. However some countries like Saudi Arabia, Iran, Egypt, and Kuwait have functioning deceased donation programs. Here we present analysis of the strengths, weaknesses, opportunities and threats of renal transplantation in the Middle East. Data from different countries will be presented in the view of this analysis. The main strength is the intention to have a better future. The established transplantation programs and the possible positive impact of the Middle East Society for Organ Transplantation [MESOT] to gather all individual programs in to a functioning network is vital. Low health spending, poorly developed infrastructures, inadequate dialysis programs, organ shortage are the main weaknesses. Commercial transplantation is a great ethical concern. The opportunity lies in investing the existing models of organ donation. To overcome legal challenges, incorporation of Islamic fatwa and governmental legislations are mandatory. Media and technology should have a positive impact to increase awareness at large toward transplantation. Deceased donation has the potential to widen donor's pool but it needs acceptance, and regulation. The threat is the recently changing geopolitics and shifted economy with its negative impact by increasing organs black market. Middle East is endemic in certain transplantation related infections like viral hepatitis and TB which detrimentally affect patient and graft survival. Kidney donation in the Middle East imposed by social and tribal challenges with risk of exploitation of poor by rich or even gender inequalities of using female donors. As in most of other countries in the region, specific donor data and follow up is not available. In conclusion; renal transplantation in this area is hampered with obstacles in Middle East countries. Local experiences can be implemented into governmentally and society funded new, improved models that can help overcome current obstacles. The Achill's tendon is the awareness of the public, the medical community, and the governments about the importance of organ donation and transplantation are indispensable to overcome the current threats.

## OP96

**THE OUTCOMES AND CONTROVERSIES OF TRANSPLANTATION TOURISM: 11-YEAR LESSONS FROM TAIWAN**

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Importance: Transplant tourism has increased rapidly in the past two decades, accounting for about 10% of world organ transplants. However it is ethically controversial and discouraged by professional guidelines. Objective: To investigate outcomes and trend of overseas transplantation in Taiwan to provide an evidence basis for ethical reflection. Design, Setting, and Participants: The National Health Insurance (NHI) Research Database was used to identify 2,381 domestic and 2,518 overseas kidney transplantation (KT) recipients from 1998 to 2009. For liver transplantation (LT), 1,658 domestic and 540 overseas recipients were identified from 1999 to 2009. Domestic recipient was defined as having the KT or LT procedure in the NHI records and overseas recipients were those who were prescribed immunosuppressive medication for KT or LT but without a KT or LT operation. Main outcomes and Measures: Patient survival, graft survival and cause of death in KT and LT recipients. Results: The numbers of overseas transplantation increased after 2000, reached a peak in 2005 and decreased after 2007. Compared to their domestic counterparts, the overseas KT recipients were older, male predominant, with shorter pre-op hemodialysis period and more comorbidities. Similarly, the overseas LT recipients were older, male predominant and had more hepatoma cases. The 1-, 5-, and 10-year patient survival rates were 96.9%, 91.7% and 83.0% respectively for domestic KT and 95.8%, 82.2% and 73.1% for overseas KT ( $p < 0.001$ ). The 1-, 5-, and 10-year patient survival rates were 89.2%, 79.5%, 75.2% for domestic LT and 79.8%, 54.7%, 49.9% for overseas LT ( $p < 0.001$ ). Conclusions and Relevance: The better outcomes of domestic transplantation were probably due to superior patient characteristics. Some LT cases might not be medically indicated and some KT cases were clinically suboptimal for transplantation in the overseas group. After domestic policy reform and international ethical challenges, the numbers of overseas transplantations decreased but the practice still persists surreptitiously. Compulsory registration policies for overseas transplantation with international conventions to sanction organ trafficking and transplant tourism should be established to stop these controversial practices.



## OP97

PANORAMA OF TRANSPLANTATION  
IN ALGERIA

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Algeria is the biggest African country and counts more than 38 million inhabitants with 20,000 patients on hemodialysis. The health care system is composed of two sectors: the public one which is totally free and the private one. Though, the medical care is ensured by the policy for the patient on hemodialysis and for those transplanted. The activity of transplantation can be done exclusively in public centers; currently 13 are authorized to do it (11 civilians, 2 militaries, 12 of them are localized in the north!) So, in 1986, the first renal transplantation performed started with living kidney related donor, followed by some other performances with cadaveric donors in the east of the country. Then, it's only in 2006 that the activity has been developed following a political decision. In term of legislation: the law N85-05 defines the rules for living kidney donor and the donor in a state of brain death. The law 'N90-7' of creation of the National Council of Ethic amends and supplements the law N85-05. Our society is still traditional; families are large and family links are strong, so we can have many donors volunteer for donating to a same receiver. Paradoxically, as we have no access to the genetic study, the high rate of inbreeding in our country and the risk of disease recurrence on the graft pose an ethical problem relating to transplantation from a living donor. Actually, the majority of grafts come from living related donors. It is only in 2012 that the donation between spouses was authorized further to shortage of grafts (immunized patients and ABO incompatibility). Concerning the brain dead donor, only two cases had been reported since 2010 in BLIDA (located in 80 km from Algiers). It will be tempted to release a partial list of obstacles to the development of the program of transplantation: Transplantation in our country suffers because of inter alia the lack of development of the other medical specialties like the anatomic pathology: for exemple, grafts biopsies are interpreted in only one reference's center, with delayed results and concerning immunology, the detection and monitoring of DSA are currently available in a unique laboratory in Algiers and it is irregularly done. Data analysis of our transplant unit (2007-2014) will be detailed. The mean age calculated was 43.28 years. Conclusion: In 2012 there were 145 Tx, in 2014 only 166; but in 2015, 'the year of transplantation', as named by the authorities, big efforts are being made to revitalize the transplantation. The training of transplant teams, development of the genetic and the improvement of quality care are essential for better results

## OP98

ATTITUDES ABOUT ORGAN DONATION AND  
TRANSPLANTATION AMONG MONTENEGRIN  
POPULATION

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Introduction: In Montenegro there was no transplantation program until 2012. The transplantations were performed abroad; 15% in areas of black organ markets. The first kidney transplantation from living donors were performed in September 2012. Until now 25 kidney transplantations from living related donor were performed. Legislation was finalized in 2012. Montenegro is a young country with many traditional attitudes. Death is followed by numerous customs and represents one of the greatest sociological phenomena in our society. Until now, only one deceased donor has been realized. The attempt to legally provide presumed consent was not adopted by the Parliament in 2014. Less than 300 citizens took donor cards. Methods: We organized a public survey about the attitudes of population on organ donation. It was conducted by a team of physicians, renal nurses and medical students. It was anonymous and conducted in public places and in different institutions like university, medical institutions and other organizations. This was the biggest survey in this topic ever done in Montenegro. Results: The survey covered 6,000 respondents, 48% male, 52% female, with the highest number in the age group between 30 and 50 years. The largest number of respondents was with higher education (58%), 36% with secondary and

6% with elementary education. The highest proportion of respondents belongs to the Orthodox religion, 63%, 20% belong to the Islamic, 10% to Catholic, and 2% were atheists and others. 45% of respondents said they would like to be deceased donors, but 52% had negative attitude. Among respondents with positive attitude, 80% would donate any organ, and 20% answered that they would donate only few organs. 70% of respondents were only partially informed about the legal regulations. Only 20% of respondents had some experience in this area. 96% of respondents said that there is not enough information about organ donation in public media. In the last question, respondents wrote the main problems they recognized: lack of information, lack of interest, religious dogma, fear and distrust. We made a stratification of respondents by age, gender, religious affiliation and level of education, but we found no statistically significant differences in answers in any group. Conclusion: Despite great effort of activities, discrepancies still exist counted prejudices and open issues that need to be systematically considered in order to raise the number of deceased donors and deceased transplantation rate.

## OP99

### ATTITUDE AND KNOWLEDGE ABOUT DONATION AND TRANSPLANTATION IN A SAMPLE OF MOLDAVIAN POPULATION

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**Introduction:** In 2010, the Republic of Moldova started activities related to organ donation and transplantation by establishing the Transplant Agency (TA). In 2014, TA obtained the first brain-dead donor. In the same year, the TA started a strategy to improve donation through different activities and, one of these, was to carry out a survey for studying the perceptions and opinions of the Moldavian population. The aim of this study was to assess the attitudes and knowledge regarding donation and transplantation in a sample of the Moldavian population. **Methods:** The self-administered questionnaire was voluntary and comprised 12 questions related to donation and transplantations and also 5 sociodemographic variables: age, sex, residence, educational level and occupation. Data collection was in November of 2014. We obtained 1144 questionnaires. A descriptive analysis of the survey questions was carried out as well as a multivariate analysis using logistic regression to find the social determinants of supporting donation and information available to them. **Results:** 65% of people interviewed were in fa-

vour of donation, but 21% were against. People with higher level of studies seem to be more in favour. Over 65% have good or very good feelings in relation to donation. 38% of people believed it necessary to always obtain relatives' permission before organ retrieval or 20% only if the deceased's opinion was unknown. Regarding information, 25% feel they had sufficient information. Moldavian transplantation law or existence of TA was known by 28% and 40% of people respectively. 87% of respondents wished to receive more information about donation and transplantation, without differences by groups. **Conclusion:** The survey shows a favourable attitude of the population towards donation and transplantation, with 65% in favour, and emphasizes a high level of interest in increasing their information in this field (87%). It seems a clear opportunity to develop promotion campaigns with the aim of increasing donation and transplantation knowledge in the Moldavian population.

## OP100

### BATTLING TRANSPLANTATION TOURISM THROUGH POLICY AND LEGAL REFORM IN TAIWAN

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Transplant tourism has been an international and domestic bioethical and human right concern in the past two decades. Although the 'Declaration of Istanbul' and the 'WHO guiding principles on human cell, tissue and organ transplantation' both prohibit the commercial traffic for human organs, transplantation tourism still continued to happen in certain countries. In this presentation, the author will analyze the progress of organ tourism between Taiwan and China based on the 11 years National Health Insurance Database, explore the national and international trend and regulations on organ tourism, and refer to the relevant regulations in Spain and Israel. The policy and legal reforms to battle against transplant tourism will then be introduced, which include: the government announced a guideline on prohibiting doctors' participation in any form of organ brokering in 2006, requested physician's voluntary reporting of overseas transplant patient information to Taiwan Organ Registry and Sharing Center (TORSC) in 2007. And in June 2015, Taiwan passed the amendments to the Human Organ Transplantation Act which made patients receiving illegal organ transplants overseas facing a maximum of five years in prison and a up to USD 50,000 fine. Compulsory registration for overseas transplantation and prohibiting using executed prisoners as organ donors were also included in the amended law.

## Free communications 8: Ethical and philosophical aspects (B)

### OP101

#### HEAD TRANSPLANTATION – A NO BRAINER?

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Recent reports that Italian surgeon Sergio Canavero would be able to perform a human head transplant by year 2017 and that the first volunteer for the procedure, Valery Spiridonov, has already stepped forward are posing a number of neurobiological, philosophical and neuroethical questions and unprecedented challenges concerning the nature of such a transplant and the personal identity of the resultant individual, her metaphysical and social status: Who is the donor and who is the recipient in a head-to-full body transplantation? Who will the resulting person be and how should that 'new' person be treated – morally, legally and socially – given that she incorporates characteristics of two distinct, previously unrelated individuals, contains genes from each and possess both old and new physical, psychological, and social experiences that would not have been available without the transplant? Head transplantation challenges linguistic conventions and conceptual 'part-whole' binaries, and calls into question the extant philosophical views on personal identity. The presentation examines critically the major philosophical and ethical challenges of head transplantation and identifies key social, policy and legal issues which need to be addressed in the debate on the medical, legal and moral permissibility of this revolutionary procedure.

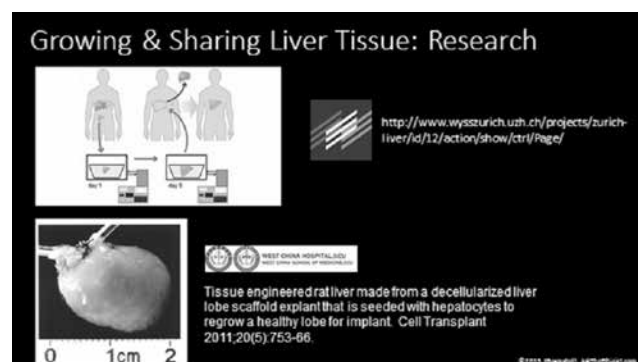
### OP102

#### THE ETHICAL COMPLEXITY OF REGENERATIVE MEDICINE: GROWING AND SHARING LIVERS

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This session explores technology under development which would allow patients with liver disease to be their own living donors by way of ex-vivo liver regeneration. This same technology would also potentially maximize the deceased donor liver pool by allowing such organs to be split into three segments and regenerated into three, unique whole organs for transplant via ex-vivo regeneration. In both settings, liver regeneration presents numerous ethical challenges including patient selection (e.g., tissue age, percent steatosis, MELD score), informed consent, resection volume,



and rescue procedures. This presentation provides ethical guidance for translational research.

### OP103

#### ACQUIRED FAMILIAL AMYLOID POLYNEUROPATHY AFTER DOMINO LIVER TRANSPLANTATION: A NEW DISEASE, A NEW CHALLENGE

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Domino liver transplantation (DLT) started in 1995, using a donor liver with familial amyloid polyneuropathy (FAP), then increasing the pool of donors. Our Center started DLT in 2001, however cases of acquired amyloid neuropathy are increasingly being recognized following this procedure. Also our center experience showed that the onset of FAP symptoms occurs earlier than expected. Many years later, these patients are alive, but have a new disease that was not expected and which is difficult to deal with; they have a worse quality of life and are older: might they be given a new opportunity to be retransplanted? Who is more urgent to transplant, these patients or the ones already on the waiting list? From 2001 to 2011 we have done 1,078 liver transplants; we carried out 262 domino transplantations. The symptomatic group started with sensory complaints involving their feet 4 to 10 years after DLT; three of these patients have been retransplanted to halt FAP progression, and their clinical and para-clinical improvement is described. Five other patients are on the waiting list for retransplant. Patients with FAP acquired by transplantation are candidates for liver retransplantation to minimize the progression of symptoms. Liver retransplantation is considered to be a high-risk procedure, but so far the results have been favorable. With this actual shortage of liver donors, should we continue with the Domino Liver Transplantation or should we stop?

## OP104

### **SWEATING THE SMALL STUFF – COMMUNICATION, CONTINUITY OF CARE AND BEST INTERESTS IN ORGAN TRANSPLANT IN GAUTENG PROVINCE, SOUTH AFRICA**

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**Introduction:** Cadaveric organ transplantation is unique in that, for a transplant to take place, a large amount of multi-disciplinary communication is required within a limited time frame – depending on the ischemic time of donor organs. The consequences of a break-down in this communication can be very serious. Given time limitations, effective interprofessional communication facilitates ethical transplant practice, by avoiding delays which potentially compromise patient outcomes and are in neither the best interests of the donor family nor the potential recipient. The aim of the current study was to explore aspects of transplant communication in Gauteng Province, South Africa. **Methods:** The study was the presenting author's PhD project and took place across six healthcare institutions utilising qualitative methods. Altogether, thirty in-depth interviews with transplant professionals, two focus groups with transplant coordinators, two interviews with cadaver donor families, and one focus group with living kidney donors were conducted. Thematic analysis and triangulation of the data was undertaken. **Results:** Participants felt strongly that, under significant time pressure, it was still vitally important to communicate detail, as this served to avoid misunderstandings amongst the team and disappointment amongst potential recipients. Lack of detail hindered the process of decision-making regarding the transplant, and resulted in confusion which in some cases directly affected recipient outcomes. Donor teams found this situation particularly complex, as much of their transplant activity took place in unfamiliar hospitals, where staff were sometimes unwilling to perform transplant-related duties and unwilling to provide detailed and useful reports of their clinical findings. **Conclusion and recommendations:** Interprofessional communication between multidisciplinary transplant teams in Gauteng Province is fractured and characterised by a number of gaps which affect continuity of care and ethical practice. This in turn highlights challenges for patient best interests. It is recommended that multi-disciplinary transplant teams evaluate the detail in their communications, and consider making use of a communication algorithm to augment this process, hence facilitating more effective interprofessional communication, in the best interests of recipient and donor family.

## OP105

### **THE 1966 CIBA CONFERENCE ON TRANSPLANTATION ETHICS: 50 YEARS LATER**

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In March 1966, the Ciba Foundation sponsored the first international, interdisciplinary conference focused on ethical and legal issues in transplantation. The attendees included not only physicians and surgeons but also judges and legal scholars, a minister and a science journalist. In this presentation, we will consider some of the topics in deceased donor and living donor transplantation that were discussed by the attendees, what we have learned in the intervening half-century, and the relevance of their discussions today. Specifically we examine the definition of death, whether it is ethical and legal to 'maim' a living individual for the benefit of another, how to ensure that the consent of the living donor is voluntary and informed, the case of identical twins, the question of whether minors can serve as living donors, the health risks of living donation, the ethics and legality of an organ market, and the economic barriers to living donation. We show that many of the concerns discussed at the Ciba symposium remain highly relevant and their discussions have helped to shape the ethical boundaries of organ transplantation today.

## OP106

### **THE EVOLUTION OF ETHICS IN THE HISTORY OF TRANSPLANTATION**

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The development of clinical transplantation in the late 19th and early 20th century is associated with several paradigm shifts related to the aims pursued in transplantation. Until around 1850 the cause of disease was still seen as misbalance in the body and its essential fluids; treatment focused on restoring this balance by purging and bloodletting. But also some experiments were conducted in bone and skin grafting to restore function. The rise of modern surgery (Billroth in Vienna) shifted attention to internal organs and their function. A number of students of Billroth began experimenting with human and animal organs (Kocher, von Eiselsberg); however the aim was not primarily to replace disfunctioning organs but to achieve rejuvenation of the body (especially elderly men) by administration of 'fresh' animal or human cells/tissues (pancreas, ovarium, testicles, adrenal glands). From



1900 onwards several doctors/students of Billroth (Ullmann, Unger) also started to transplant whole organs, in particular kidneys, in xenotransplant models. Experimental transplants in dogs were directly followed by transplants of animal organs in men (mostly young women). Although all transplants failed and recipients died, the ethics of these experiments were not questioned. In 1905, Eduard Zirm performs the 1st successful corneal transplant, using the cornea of a living 11 yr. old boy as donor. Again, using a living donor did not raise any objection. Successful vascular anastomosis around 1910 (Jaboulay, Carrel) became the overture to modern transplantation. In 1933, Russian surgeon Yurii Voronoy performed the 1st (reasonably) successful kidney transplant by attaching the kidney of a deceased person to the thigh of a patient. However, this transplant model also leads to some weird science (Guthrie/Demichov: two-headed dogs, Voronoff: monkey glands against senility), aiming to promote rejuvenation. Even some of the giants of early transplantation, Carrel and Lindbergh, get carried away by the ideal of immortality through the culture of organs, while Carrel becomes an advocate of eugenics to create a superior race. From all these examples, it becomes clear that transplant ethics (relating to animal use, donors and recipients) has for a long time lagged behind the drive for medical success and breakthrough. A consistent view on transplant ethics does not go back much further than the first kidney transplants in the 1950s.

## OP107

### THE ETHICAL PRINCIPLE OF EQUIPOISE APPLIED TO UTERUS TRANSPLANTATION

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Uterus Transplantation (UTX) is a new and so far the only 'treatment' for Absolute Uterine Infertility (AUI). The ethical foundations of this novel 'treatment' are still in development. The ethical principles of Equipoise and Double Equipoise assume interesting connotations in UTX since it can be performed with both deceased (DD) and living donors (LD). Equipoise dictates that for any new therapy to be ethically acceptable, the outcome must be similar or better than any already existing therapy. Double Equipoise adds living donor safety to the equation. AUI 'treatments' besides UTX are adoption or surrogate motherhood. The outcome of these alternatives is not reestablishing health in a patient but to obtain the birth of a healthy child. When UTX is performed with a DD the principle of Equipoise is not yet fulfilled since to date there is no report of a live birth from a recipient of DD UTX.

When UTX is performed with a LD, preliminary outcome demonstrates (four living births to date) that LD UTX is as good as surrogate motherhood or adoption in giving a child to a woman affected by AUI. It is important to note that there is clear data from solid organ transplantation that the immunosuppressive therapy is not harmful to the fetus. The Double Equipoise would be also fulfilled if the Living Donor is not harmed in the process of donation. The total hysterectomy needed to provide the uterus is a well-known surgical procedure that has been performed countless times and for which risks and complications are well documented. In the spirit of donor autonomy and full informed consent it appears that also the Double Equipoise is fulfilled when a LD UTX is performed. When compared to surrogate motherhood, LD UTX is possibly more acceptable from an ethical point of view since the risks of in vitro fertilization, pregnancy, and delivery are all carried by the mother and not by the surrogate. In conclusion, UTX provides many women affected by AUI with the possibility of carrying their own pregnancy and having healthy children. UTX fulfills the basic ethical principles of organ transplantation when performed with a living donor and may do the same when it will be successfully performed with a deceased donor.

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## Focus session 7: Deceased donation

## OP108

### ORGAN DONATION IN MULTICULTURAL SOCIETIES – A STUDY IN QATAR

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We present here selected results from a qualitative study undertaken in the Gulf state of Qatar where the resident population comprises > 80% non-citizen migrants, mostly temporary workers from South Asian countries. The study aimed to evaluate the potential influence of experiences of migrant life, especially perceptions of social inclusion, on knowledge of and attitudes towards organ donation and transplantation (ODT). Although there are significant socioeconomic inequalities within Qatar's resident population, and temporary migrants lack many privileges associated with citizenship, all residents are legally entitled to healthcare services, including ODT. Qatar's donation and transplant system explicitly seeks to promote equity and to engage all cultural and ethnic groups regardless of citizenship, race, religion or economic status. Minority groups in multicultural societies often



have lower rates of consent for deceased donation, despite higher rates of demand for transplantation within some groups. To successfully engage these groups in donation opportunities, we must understand how migration may influence attitudes and intentions towards donation. This is particularly important in the context of increasing migration in many regions and of dynamic transnational labour markets. Methods: Participants were recruited at malls, and data were collected in semi-structured interviews conducted in Doha in May 2015 with members of five non-citizen resident populations: Indian (5 m), Filipino (5 m, 7 f), Sri Lankan (5 m, 4 f), Nepalese (11 m, 3 f), Bangladeshi (4 m). Results: Participants across all groups evaluated and made sense of their experiences of life in Qatar through the lens of their home country. The influence of home was also observed in their knowledge, understanding and attitudes towards ODT. Experience of inequities in access to transplantation and familiarity with organ trafficking in their home countries strongly influenced their understanding of living organ donation in particular. Although most had little knowledge of deceased donation, their attitudes towards this were predominantly positive. Four participants who were registered donors identified reciprocity in the Qatari system as a factor motivating willingness to donate. Conclusion: Promotion of donation within migrant communities should be sensitive to experiences of ODT in their countries of origin. Further, equitable inclusion of migrant communities in ODT programs may encourage donation even where social segregation persists.

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**Free communications 11:**  
**Psychosocial aspects – Recipients (B)**

**OP109**

**PSYCHOLOGICAL BENEFITS OF EXPANDED CRITERIA KIDNEY TRANSPLANTATION VERSUS HAEMODIALYSIS**

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**Introduction:** Over recent years there has been an increasing reliance on expanded criteria kidneys for transplantation, yet their use remains controversial. The aim of this study was to determine whether there were psychological and health related quality of life advantages for patients receiving expanded criteria kidneys, when compared to on haemodialysis and those receiving standard criteria kidneys. Methods: Haemodialysis patients (HDx) and Recipients (Rx)

from our 2014 cohort were asked to complete a questionnaire within 12 m of their transplant. Transplant patients were subdivided into standard (STx) and expanded criteria (ETx) according to internationally agreed definitions. The questionnaire included validated measures of life satisfaction, mood, distress and health-related quality of life (HRQoL). Results: 222 questionnaires were completed (98 HDx vs. 124 Rx). There was a significant difference in age between HDx and Rx groups (58.4 vs. 53.7 yrs;  $p = 0.03$ ) and between the STx and ETx groups (48.6 vs. 59.0 yrs;  $p < 0.001$ ). Life-satisfaction and mood were significantly lower in HDx patients when compared to Rx patients (15.0 vs. 23.0;  $p < 0.001$ ; 2.0 vs. 0.0;  $p < 0.001$  respectively). There was no significant difference between STx and ETx groups (24.0 vs. 21.0;  $p = 0.050$  and 0.0 vs. 0.0;  $p = 0.405$  respectively). Distress was significantly higher in HDx patients when compared to Rx patients (14.0 vs. 12.0;  $p = 0.005$ ). HRQoL was significantly lower in HDx patients (33.0 vs. 39.0;  $p < 0.001$ ). There was no difference in distress or HRQoL between the STx and ETx groups (12.0 vs. 12.0; 39.9 vs. 38.1;  $p = 0.356$  respectively). Discussion: This study has demonstrated that transplantation conveys a psychological and health-related quality of life advantage over remaining on dialysis, regardless of whether the transplant is from a standard or expanded criteria donor. Given the favourable graft and patient survival outcome after expanded criteria transplantation, this study further endorses the use of these kidneys.

**OP110**

**PSYCHOLOGICAL BENEFITS AFTER LIVING DONOR KIDNEY TRANSPLANTATION**

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**Introduction:** Living donor kidney transplantation remains the gold standard treatment for end-stage renal failure. There is an assumption amongst the transplant community that the physical benefits are met with a corresponding psychological benefit, however there is very little within the recent literature that has focussed specifically on quantifying this. The aim of this study was to measure how recipients of living donor kidney transplants benefit psychosocially from transplantation. Methods: A sample of living kidney donor recipients were asked to complete a questionnaire at 3 different time points: pre-operatively and 3 and 12 months after transplantation. The questionnaire contained validated measures of wellbeing, distress, mood, stress, health-related quality of life (HRQoL), life sat-

isfaction, self-esteem and anxiety. Results: 51 recipients participated in the study (mean age: 42.9 yrs, SD 14.7). Wellbeing, distress and HRQoL scores all improved significantly over the first year after transplantation ( $p < 0.001$ ,  $p < 0.001$  and  $p = 0.001$ , respectively). For each measure the significant difference occurred between pre-operative and 3 month scores. Very little change was demonstrated between 3 and 12 months ( $p > 0.05$  for all measures). Mood scores steadily improved over the 3 time points (2.0 vs. 1.0 vs. 0.0;  $p = 0.037$ ). Stress, anxiety, life-satisfaction and self-esteem scores did not improve significantly over the first year after transplantation ( $p = 0.368$ ;  $p = 0.096$ ;  $p = 0.105$ ;  $p = 0.396$ , respectively). There was no difference in outcomes between those who were on dialysis prior to transplantation and those who were transplanted pre-emptively. Discussion: This study has demonstrated that benefit following kidney transplantation is quantifiable by improvements in wellbeing, distress, HRQoL and mood. Stress, anxiety, life-satisfaction and self-esteem scores do not improve. This may reflect the ongoing burden of chronic illness, such as multiple hospital visits, reliance on medications and the threat of complications and transplant failure.

## OP111

### THE MEANING OF UNCERTAINTY AFTER HEART TRANSPLANTATION – THE UNRAVELED SOURCE TO DISTRESS?

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**Aim:** The focus in this study was to explore the patients lived experience and to understand what it means to the patient to be heart transplanted. **Background:** It is well known that distress and psychological problems are common after heart transplantation (HTX), it's shown to be from 32% to 88%. This distress seems to last over time. However, little is known about what is causing this distress and how it affects the heart transplant recipients (HTRs) and their daily life. **Method:** The study was conducted with an inductive phenomenological-hermeneutic approach based on Ricoeur's philosophy. The inclusion criteria were heart transplant recipients who were due to their 12 months follow-up. Four women and ten men ( $n = 14$ ) were interviewed.

The participants were consecutively included from the two centers in Sweden performing HTX. Results: The thematic structural analysis showed that the HTRs had strong feelings of uncertainty about survival, recovery, close relationships, and their ability to live a normal life in the future. Being in uncertainty means losing the sense of coherence, which demolish the HTRs view of life. They were striving for normality and to regain a sense of coherence, but this was no longer achievable. Being in uncertainty must be seen as a natural state after HTX. For the HTR this becomes the basis for reorganising oneself and creating a new view of life. It may be a condition where the person can make a transition from one perspective in life towards a new more complex orientation. The health care professionals strive for normality, certainty and predictability. The HTRs natural process of uncertainty in creating a new meaning and view of life is blocked, which causes great distress.

## OP112

### IMMUNOSUPPRESSION NONADHERENCE AFTER LIVER TRANSPLANTATION: SHOULD WE BE CONCERNED?

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**Background:** Compared to other transplant populations, the long-term impact of immunosuppression nonadherence (ISNA) in adult liver transplantation (LT) is largely unknown. **Materials and methods:** We carried out a systematic literature review until September 30, 2015 to retrieve evidence on long-term clinical impact of ISNA in adult LT recipients. Papers were retrieved and evaluated by two independent investigators. A third investigator eventually resolved conflicts. Literature reviews and duplicates were excluded. **Results:** A total of 18 studies were included. Incidence of ISNA varies from 10% to 62% and increases with time after LT. The majority of studies ( $= 11$ ) focused on clinical and psychosocial correlates of ISNA by means of cross-sectional surveys ( $= 9$ ) or retrospective designs ( $= 2$ ). Six studies are prospective, but observation periods mostly limited to 1 year ( $= 5$ ), while only one prospective cohort study has reported longitudinal assessments of ISNA up to 3 years after transplantation. One retrospective cohort study explored the association of self-reported ISNA with intraindividual immunosuppressant blood level variability, showing that ISNA portends a higher risk for early graft failure in the early post-transplant period. No study has so far been based on a theoretical background. **Conclusions:** ISNA after adult LT is alarmingly high, but evidence

of a link between ISNA and a poorer immune event-free graft survival is still scarce. Reasons include the immunological privilege of liver grafts, the reduced impact of acute cellular rejection on graft survival, as well as type and design of reported studies. A theoretical background including modifiable and nonmodifiable risk factors of ISNA, intraindividual drug level variability, and the occurrence of time-dependent liver graft tolerance is presented to guide future research in the area.

## OP113

### HAIR ANALYSIS FOR ETHYLGLUCURONIDE AS AN ADDITION TO PSYCHOSOMATIC ASSESSMENT OF ALCOHOL ABSTINENCE IN LIVER TRANSPLANT CANDIDATES

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Background: Listing for liver transplantation (LTX) is possible for patients with alcoholic liver disease (ALD) on condition that an abstinence period of at least six months is proven. The assessment of alcohol abstinence constitutes a complex issue. As the gold standard the history of alcohol consumption is taken and the patient is referred to the department of psychosomatic medicine. Only during the last years alcohol biomarkers started to be put to use in the setting of transplantation. Ethylglucuronide (EtG) is a direct alcohol metabolite, deposited in human hair, with a high sensitivity and specificity for detection of alcohol consumption for a period of three months. Materials and Methods: EtG hair (hEtG) analysis was performed in patients, who were deemed candidates for LTX, referred to our hospital with alcoholic-, cryptogenic- or suspected mixed type cirrhosis between 2012 and 2015. We analysed samples from 221 patients (m : f 149 : 72). 182 of these patients were also presented to the department of psychosomatic medicine for evaluation. Results: Upon retrieval of the hair sample 90% of patients claimed abstinence during the last three months, whereas only 76% had negative test results. The median self-reported duration of abstinence was 11 months; the median duration of alcohol consumption was 20 years. In a multivariate analysis we identified 'favourable psychosomatic assessment,' a 'long duration of abstinence' and 'male gender' as predictors for negative hEtG results. In 147 cases, the EtG test results confirmed

the psychosomatic assessment, whereas in 35 cases we received equivocal results. Those cases were reviewed and reassessed individually. Conclusion: Hair analysis for EtG cannot and should not replace psychosomatic assessment. Still, in our collective it proved to be a valuable addition in the process of evaluating alcohol abstinence. We gain a tool to overlook a timespan of three months as well as the possibility to confront and reassess patients with equivocal results. Therefore it enables us to offer further support to patients who still need to overcome alcoholism and at the same time prevent patients, who do not meet the required criteria from entering the Eurotransplant waiting list. Patients with cryptogenic liver disease are often confronted with allegations of alcohol abuse. Combining psychosomatic evaluation and hEtG analysis, as an objective test, might enable these patients to fend off such accusations. This can also contribute to formation of a solid doctor-patient relationship.

## OP114

### MOTIVATIONS, CHALLENGES, AND ATTITUDES TO SELF-MANAGEMENT IN KIDNEY TRANSPLANT RECIPIENTS: A SYSTEMATIC REVIEW OF QUALITATIVE STUDIES

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Background: Kidney transplantation offers superior life expectancy and quality of life outcomes compared to other modalities for renal replacement therapy. However, the complex and ongoing medication and self-management regimens impose a treatment burden on patients, and non-adherence remains a leading cause of graft loss. We aimed to describe motivations, challenges and barriers to self-management in kidney transplant recipients. Methods: MEDLINE, Embase, PsycINFO, and CINAHL were searched from database inception to October 2014. We used thematic synthesis to analyse the findings. Results: Fifty studies involving 1,238 participants aged from 18 to 82 years across 19 countries were included. We identified five themes: empowerment through autonomy (achieving mastery,

tracking against tangible targets, developing bodily intuition, routinizing and problem-solving, adaptive coping), prevailing fear of consequences (inescapable rejection anxiety, aversion to dialysis, minimizing future morbidity, trivialization and denial, defining acceptable risks), burdensome treatment and responsibilities (frustrating ambiguities, inadvertent forgetfulness, intrusive side-effects, reversing ingrained behaviours, financial hardship), over-medicalizing life (dominating focus, evading patienthood, succumbing to burnout), and social accountability and motivation (demonstrating gratitude towards medical team, indebtedness to donor, peer learning, adaptive coping). Conclusions: Self-efficacy and relational responsibility encourage self-management, however, these tasks can be mentally and physically taxing. Transplant recipients trade off their treatment burden against the risks of side-effects and complications. Multi-component interventions including education, psychosocial support, decision aids and self-monitoring tools may foster self-management capacity and improve transplant outcomes.

## OP115

### VALIDATION OF TOOL FOR ANNUAL ADHERENCE EVALUATION OF KIDNEY TRANSPLANT RECIPIENTS IN NORWAY

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Adherence to immunosuppressive therapy is paramount for long-term kidney graft function. For capture of adherence data it is recommended to use a combination of several subjective and objective tools. We aimed to validate the Basal Assessment of Adherence to Immunosuppressive Medication Scale (BAASIS®) in kidney transplant recipients (KTx). Comparative validation tools were clinician's collateral reports scoring recipients as poor/suboptimal/excellent, pill count in a two weeks period, variation in concentration of immunosuppressive drugs (tacrolimus; Tac) and clinical outcome at one year. The primary objective of this ongoing study is to validate a tool for annual capture of adherence data in KTx recipients. KTx recipients using Tac as part of their immunosuppressive therapy were includable in a single center open randomized prospective trial. Persons with language difficulties were excluded. A total of 300 KTx were to be included (start Sept 2014). The majority of the recipients were included

between one and four weeks after transplantation and followed for one year. They completed the BAASIS at inclusion and an additional eight times. The recipients were grouped into adherent (Ad-group)/non-adherent (non-Ad group) according to the BAASIS answers. Results from the two groups were then compared to the response from treating physicians, pill count, and variation in Tac concentrations measured from 1 to 12 months post transplant. Standard deviation (SD) and percent coefficient of variation (CV%) of Tac were calculated. Tac CV% has previously been shown to be a useful marker of non-adherence. As of November 1st, 2015 we have included 230 patients and evaluated 104 patients at 1 year. Preliminary results tend to show an increasing number of non-adherent recipients as time goes by. The results also indicate that grouping of the patients according to the BAASIS questionnaire did not seem to coincide with the other adherence measurement tools. Data set including analysis will be shown at the congress.

## Free Communications 12: Living donation (B)

## OP116

### PSYCHOSOCIAL PROFILE OF POTENTIAL KIDNEY RECIPIENTS WITH LIVING NON-RELATED DONORS

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Introduction: Kidney transplantation is the best option for patients with stage V chronic renal disease. Best results are obtained with living donor transplants. In Argentina, living non-related organ transplantation is possible through judicial authorization. Objective: To know the psychosocial profile of potential kidney recipients with living non-related donors. Material and Method: Revision of psychological interviews of 15 potential kidney recipients with living non-related donors performed at Hospital Italiano de Buenos Aires, Argentina, between 1997 and 2015. Quantitative and qualitative analysis. Results: n = 15. Male 60%, average age: 48 years, range: 19-70 years, married 67%, college/university education 60%, currently working 66%. Complies with health care: 93%. Reports family support: 93%. No addictions reported. Psychological/psychiatric treatment: 60%, receives anxiolytic medication 47%, with adjustment/mood disorders 80%. With prior transplant 26.6%, on dialysis 93%. Relationship with donors: long-term friendship 75%; indirect family 25%. Motivation reported by donors: offers volun-



tary 100%, the recipient not having other direct donors or/and these direct donors had already donated or were considered not suitable; donors also reported the deterioration of recipient's health, affected quality of life, affection due to relationship, empathy/identification, desire to help. Prior to accepting donation, 30% of the recipients had an initial reaction to decline the offer, since they considered it an excessive gesture and they did not know if they would do the same thing, concern about the donor. Discussion and Conclusions: This is a sample with a small number of patients. However, it should be borne in mind that cases needing judicial authorization are not common. Recipients are mostly adults, married, educated and currently working and have a long-term affection bond with the donors. At first, some recipients doubted whether to accept the offer. Donors volunteered out of affection, because of the recipient's health condition and quality of life and because there were no suitable living related donors.

## OP117

### APPEALING FOR A KIDNEY DONOR ON SOCIAL MEDIA: AN EFFECTIVE WAY TO FIND A DONOR?

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Background: Despite a high living donor kidney transplantation rate in the Netherlands, there is still a shortage of kidneys for transplantation. Not all patients are able to find a living kidney donor. Social media might open doors for patients to discuss their situation with their social network, to raise awareness for their need in a broader public and to find a potential living donor. But are their appeals for a kidney effective? Method: We collected data on all donors who reacted to the public appeals of our patients and who approached our transplant center from January 2013 until July 2015. Appeal effectiveness was measured in four ways: the number of potential donors who (1) approached us, (2) entered the screening, (3) were scheduled for donor-nephrectomy and (4) donated a kidney. Results: In 2.5 years, 30 potential donors contacted us in reaction to public appeal from four highly sensitized recipients and one blood type O recipient. After receiving verbal and written donation education, nine persons withdrew of which one for medical reasons. Two persons are still considering donation and 19 entered the screening. Of these 19, six could not donate to their intended recipient for immunological reasons, only one of them agreed to donate anonymously to another recipient and is still in screening. Four donors withdrew from the procedure

and three were rejected for medical reasons. Three are still in screening for donation to their intended recipient, one is scheduled for donor-nephrectomy, we referred one to another center and one donor has donated to the intended recipient. Conclusion: Kidney patients do find willing kidney donors by appealing for a kidney on social media, but finding a suitable donor is difficult. Preliminary results suggest that most of these potential donors were unwilling to donate anonymously to another kidney patient. In conclusion, social media can be used effectively to find potential donors, but finding a compatible donor remains a challenge for the highly sensitized patient population.

## OP118

### PUBLIC SOLICITATIONS: BEYOND THE BEAUTY CONTEST

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Public solicitations (PS) for organs is an increasingly popular way to access transplantation. The controversy about PS has focused on issues of inequitable access to organs, questions of informed consent of the living donor (LD), possible exploitation and organ sales, and the utility of increasing organ donation by this practice. A successful PS can produce many volunteers offering to donate to the solicitor by contacting the local transplant program. However, many of these volunteers have limited knowledge of what living donation involves. Some, but not all, of them will offer to donate to other listed patients if they are unmatched to the intended recipient or if another donor is found for the recipient, providing welcome opportunities for a life-saving therapy. Whilst more potential LDs offer welcome opportunities for transplant, this scenario raises two important ethical issues. First, a sudden windfall of potential LDs produces a surge of demand for valuable transplant programme resources of personnel and time to manage information to volunteers. The second is the prioritization and possible evaluations of the donor volunteers. The hospital may wish to respond positively to multiple offers of organs, but these demands impact on the rights of their other potential donors and recipients for the same resources. Hospitals are often publically funded institutions with societal obligations for responsible stewardship and just distribution of human and financial resources. This presentation will outline and analyze the organizational ethical issues that arise from PS, including discussion of the transplant centre's duties and obligations to all its patients. We will propose ways of addressing these challenges that enhance equity among patients, stewardship of resources, and overall utility in the use of transplantable organs.



## OP119

# LIVING KIDNEY DONOR PREFERENCES: A NOVEL USE OF A VISUAL INSTRUMENT TO QUANTIFY ESRD RISK ACCEPTANCE

Carrie Thiessen<sup>1</sup>; Jacqueline Gannon<sup>1</sup>, Kristie Kennedy<sup>2</sup>, Danielle Dobosz<sup>1</sup>, Sienna Li<sup>1</sup>, Adam Mussell<sup>3</sup>, Laura Skrip<sup>1</sup>, Peter Reese<sup>3</sup>, Elisa Gordon<sup>2</sup>, Sanjay Kulkarni<sup>1</sup>

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**Background:** Studies report that potential living kidney donors (LKD) are willing to accept high rates of post-nephrectomy end-stage renal disease (ESRD). However, recent research increased the estimated lifetime risk of ESRD among LKDs. Given this new data, we sought to elicit potential LKDs' willingness to accept the risk of ESRD. **Methods:** We conducted a multicenter prospective study of adults being evaluated to become directed LKDs. We created a 10,000 dot diagram representing a 0-100% chance of ESRD to help LKDs visualize absolute and relative risks of ESRD at baseline and post-nephrectomy. LKDs selected the maximum chance of post-donation ESRD that they were willing to accept. LKDs completed surveys about risk-taking propensity, emotional closeness to their intended recipient, health, and demographics. Due to a non-normal distribution, willingness to accept ESRD was broken into quintiles. Univariate and multivariate ordinal logistic regression assessed factors associated with willingness to accept ESRD. **Results:** Our sample comprised 103 LKDs (87% response rate) from 3 centers. Most were white (85%), female (61%), completed post-secondary education (67%), and had a household income > \$ 65,000 (56%). Participants intended to donate to their friend (22%), sibling (19%), other relative (18%), spouse (17%), parent (15%), child (9%), and other (2%). On average, participants were willing

to accept a 21% chance of developing post-donation ESRD (range 0.01-100%, Figure). Unadjusted analysis showed donation to a parent (OR 3.5,  $p = 0.04$ ) or child (OR 5.2,  $p = 0.02$ ) and closer relationship (OR 1.4,  $p < 0.001$ ) were associated with increased willingness to accept post-donation ESRD; LKDs who were older (OR 0.97,  $p = 0.047$ ) and had better mental health (OR 0.93,  $p = 0.03$ ) were less willing to accept this risk. Controlling for other factors, LKDs who were college educated (OR 2.5,  $p = 0.05$ ) or reported a closer relationship with their intended recipient (OR 1.49,  $p = 0.01$ ) had higher levels of risk acceptance. Hispanic (OR 0.14,  $p = 0.02$ ) and older (OR 0.96,  $p = 0.03$ ) LKDs had a lower willingness to accept the risk of ESRD. **Conclusion:** 93% of potential LKDs are willing to accept more than the newly reported rate of 0.9% post-donation ESRD. LKDs were willing to accept greater risks if they had a closer relationship with their intended recipients. Future work should examine why Hispanic and older LKDs are more risk averse. Our findings suggest that visual aids can clarify LKD risk attitudes, which may be used in the risk/benefit calculation to determine donor candidacy.

## OP120

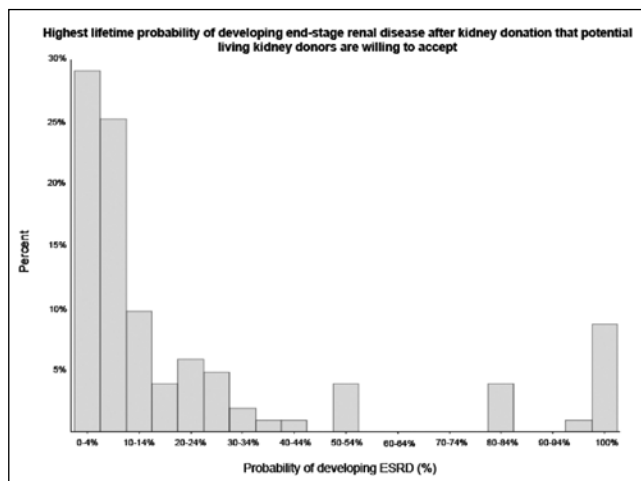
# DONOR COMPREHENSION OF PROVIDED INFORMATION DURING INFORMED CONSENT PROCESS IN LIVE DONOR NEPHRECTOMY; DOES IT MATTER WHAT WE TELL DONORS? A PILOT STUDY.

Kirsten Kortram<sup>1</sup>; Emerentia Spoon<sup>1</sup>, Caspar Looman<sup>2</sup>, Hendricus Kimenai<sup>1</sup>, Jan IJzermans<sup>1</sup>, Frank Dor<sup>1</sup>

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**Background:** Living kidney donors are a unique group of 'patients', undergoing surgery for the benefit of others. Safety and informed consent are even more important than in other surgical procedures. Current literature demonstrates great variations in informed consent practices. Donors report varying degrees of satisfaction with the information and preparation for live donor nephrectomy. But whether this stems from a lack of education or comprehension remains unclear. It has been suggested that donors do not actually hear everything we tell them, but that they only use the information to confirm their decision, instead of weighing risks and benefits. But it is still vital that these donors receive all necessary details. **Aim:** To assess the informed consent procedure in live donor nephrectomy, test donors on their comprehension of the provided information, and assess donor satisfaction with the informed consent procedure. **Methods:** The preoperative surgical outpatient clinic visits of 46 potential living kidney donors were observed. Provided information was scored using standardized checklists, team mem-



bers (N = 9) received an 'informer score' for each consultation by the observer, one point was awarded for each mentioned item. Immediately after giving consent for donor nephrectomy, and again on the day of admission for donation, donors received a questionnaire testing their knowledge of the upcoming operation. Informers as well as donors could score a maximum of 20 points. Scores were compared between donors and informers. Outpatient scores were also compared with admission scores. Demographic data and baseline donor characteristics were documented for correlation purposes. Results: Median informer score was 12 out of 20 points (range 2-20). Median donor score was 6 out of 20 (range 2-11). Donors scored best on duration of admission and convalescence, and worst on long-term complications. Risk of mortality was disclosed by 91% of informers, but only reproduced by 22% of donors at the outpatient clinic and 14% on admission. Donors living with children under 18, a higher educational level and registered (post-mortem) donors scored significantly better. Median donor satisfaction was 9 out of 10 (range 4-10). Conclusion: There were marked variations between the information provided by different informers, important complications were not always disclosed. Overall donor scores were low, although satisfaction was high. Whether donors are actually well enough informed at the time of giving consent remains debatable.

## OP121

### ALLOGENEIC HAEMATOPOIETIC STEM CELL TRANSPLANTATION (HSCT) WITH A SIBLING AS DONOR – AN ETHICAL COMPLEX SITUATION

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Donating haematopoietic stem cells to a sibling and receiving stem cells from a sibling can be a complex issue. There is on one hand a person with a serious illness in need of a donor and on the other a person who happens to be the suitable and chosen sibling donor for his/her seriously ill sibling. At least three challenging ethical situations may arise, connected with the two persons involved being siblings. 1) The sibling donor undergoes a procedure that includes risks without deriving any medical benefit to himself/herself, and with no guarantee about the outcome of the transplantation for the sick sibling. 2) A sibling donor has not volunteered to be a donor, in contrast to an unrelated donor who has actively volunteered to a donor registry in order to help somebody. 3) The eligibility criteria for related donors usually differ from those for unrelated donors. The reason for this is primarily that reduced intensity conditioning has made HSCT possible for older people, and thus the siblings are also older. There are siblings

who would usually not be eligible as voluntary, unrelated donors, but are acceptable as related donors. To investigate experiences of patients undergoing HSCT and of sibling stem cell donors, two interview studies were performed: with ten patients and their sibling stem cell donors prior to transplantation/donation. Qualitative content analysis was used. The results reveal the donors going through a complex process they have accidentally got into. The main theme Being a cog in a big wheel supported by four subthemes: Being available, Being anxious, Being responsible and Being obliged, illustrate the experienced key role of the donor. The main theme Being in no man's land, supported by three subthemes: Trust in the sibling donor, Concern about others and Loss of control illustrate the complex situation of the patient. Both donors and patients deal with a mixture of emotions and thoughts. The quality of their relationship has an impact on their experiences and neither the donors nor the patients disclose their thoughts and emotions about being a sibling donor or having a sibling as donor, to anybody. From these interview studies we learn that it is a challenge to take care of seriously ill patients and their sibling donors. We need to assure the confidentiality of potential sibling donors and their sense of security. Each donor's personal situation and the relationship with the sibling recipient should be taken into consideration in the care, as well as patients' and donors' individual needs of support and follow-up.

## OP122

### THE COMPLEXITY OF LIVE KIDNEY DONATION: A MIXED-METHODS STUDY

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Background: Live kidney donation is mostly described as a positive experience, however, previous research has demonstrated various motivations to donate, and suggests that the donation or the recipient outcome may influence the donors' lives. As there is a lack of research on long-term experiences post-donation, we performed a mixed-methods study to obtain insight into long-term consequences from the donors' own perspectives. Methods: The study had a mixed-methods design using a cross-sectional survey on quality of life (QoL) and fatigue followed by in-depth interviews. We included 217 Norwegian donors who donated a kidney

at Oslo University Hospital between 2001 and 2004. The quantitative data were analyzed using descriptive analysis and generalized linear regression. Candidates for in-depth interviews were selected by outcomes in QoL and fatigue, age, gender, and relationship to the recipient ( $n = 16$ ). The interviews were analyzed using an interpretative approach. Results: Donors scored generally high on QoL and low on fatigue, and described delight and pride in being able to help. The recipients' improved health and positive impact on recipients' family was an important aspect. Negative experiences were changed relations within families or losing touch with the recipient. Siblings depicted their obligation to donate while parents worried about their recipient. Regretting donors scored higher than average on all domains of fatigue. Recipient health, worries about own health and worsened relationship with the recipient influenced willingness to donate in retrospect. Conclusions: Our results illustrate the complexity of live kidney donation. The positive experience seems to be a mix between privilege and pride. The positive impact on others' lives justified donation despite complicated family dynamics. Identifying and following donors who are at risk for regretting donation is important.

# Poster Presentations

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## Cultural, religious and social aspects

### PP01

#### WHAT SHOULD BE PRIORITIZED IN CANADIAN TRANSPLANTATION RESEARCH? RESULTS: OF A NATIONAL SURVEY

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Background: Involving patients in setting research priorities has been acknowledged as a way to enhance the quality, relevance and transparency of medical research. The aim of this study was to gather the views of Canadian researchers, healthcare professionals (HCPs), patients and caregivers on research priorities within the Canadian National Transplant Research Program (CNTRP). Methods: Transplant patients, candidates, caregivers and researchers were invited to attend a pilot workshop focused on key areas of uncertainty in the field of organ donation and transplantation. Following this workshop, a national web-based survey was developed to elicit the viewpoints of the wider Canadian transplant community. The survey, which included closed- and open-ended questions, was administered from April to July 2015. Descriptive statistical analyses were performed, and a qualitative content and thematic analysis was used for the open-ended questions. Results: A total of 505 people completed the survey: 40.4% patients, 24.9% caregivers and 34.7% researchers and HCPs. The following five research topics were identified as the most important: (i) how to manage psychological complications such as depression or anxiety (72.9%); (ii) the impact of presumed consent on organ donation (63%); (iii) how to increase the number of organs available for transplantation (62.6%); (iv) how to manage long-term medical complications of transplantation (58.6%); and

(v) how to develop tolerance in organ transplantation (57.2%). Conclusion: This is the first survey to explore research priorities in organ transplantation in Canada. The Results: will inform the discussion at a national workshop on patient engagement within the CNTRP, thus enabling the development of a Canadian patient-oriented research strategy in organ transplantation and donation.

### PP02

#### WHY BADLY TREAT WHAT YOU CAN WELL PREVENT?

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Transplantation is one of the medical activities with more expectation of success. For patients with end stage renal disease, kidney transplantation provides a better quality of life compared with those on dialysis, even for those with advanced age or co-morbidities. Greater access to food since the Second World War, high exposure to chemical and toxic, associated with changes in lifestyles, increased diabetes, hypertension, obesity, cardiovascular disease, chronic renal failure and transplantation demands. The dream of replacing damaged parts in the human body materialized with the transplants, but the hope in transplantation reached much higher levels than the actual results deserve. The transplant was used as flags of technical and scientific differentiation and success. Nonetheless transplantation was faced with shortage of organs and increased demand. The claim to the right to treatment quickly was confused and understood as the right to transplantation. This distortion of values and rights created pressures on the medical profession and at the political level. The notion of time on list awaiting transplantation gained weight over the biological and medical criteria. The emergence of potent immunosuppressive agents and the increasing use of plasmapheresis has allowed allocations of kidneys less HLA compatible, with short-term satisfactory effects, although more costly to healthcare systems. Overall evaluation of indirect costs of these increasingly expensive medications and their effects on long-term (new diseases and apparently unrelated deaths with a functioning kidney) are still missing. Campaigns for living donors still not have the necessary impact. Organ commerce and trafficking have proliferated with bad results both to donors and recipients. So, for the best use of a scarce public good, we should: 1. Change allocation rules in



order to achieve more efficiency in transplantation, increased patient and organ survival, fewer side/secondary effects and lower costs. 2. Study better causes that lead to chronic diseases and transplantation, as well as the pharmacogenetic profile of patients. 3. Create prevention and education measures for the health of the population, including control of hypertension, obesity and diabetes and personalize medication by pharmacogenetic profile. 4. Create a European program of vigilance of those diseases and promote new lifestyles to prevent illness and promote health reducing the need for transplantation. The claim to the right to transplantation must be replaced by the claim to the right to health.

### PP03

#### KNOWLEDGE AND ATTITUDE OF JUNIOR INTENSIVISTS TOWARD ORGAN DONATION AND ORGAN DONOR MANAGEMENT – SURVEY OF A SINGLE INSTITUTION

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**Introduction:** Solid organ transplantation is one of the best, if not the only, life-saving treatment for patients with organ failure. In Singapore, the waitlists of solid organ patients, except for the kidney, have increased gradually over the last decade. This happened despite the introduction of the presumed consent system governed by the Human Organ Transplant Act (HOTA) in 1987 and the Medical (Therapy, Research and Education) Act in 1972. However, a fast aging population and low donation rates continue to worsen the situation. In 2013, the deceased donor rate was at 5 per million population (pmp). This rate is sadly lower than that of European countries of similar population sizes like Denmark (10.4 pmp) or Finland (17.8 pmp) in 2013. One proposed solution to this problem is to garner support from healthcare professionals, particularly intensivists who play a key role in the donation process. In this study, we investigated the knowledge and attitude of junior intensivists toward organ donation and organ donor management in a major public hospital providing the most comprehensive healthcare services in Singapore. **Method:** The study was based on a voluntary survey in Singapore's largest tertiary hospital, Singapore General Hospital. Participants approached comprised of mostly medical officers/residents from anaesthesiology, internal medicine, cardiothoracic surgery, general surgery and neurosurgery. Most would have worked in one of the Hospital's intensive care units (ICU) before (Surgical ICU, Medical ICU, Cardiothoracic ICU and Neuro ICU.) The questionnaire comprised of five sections, asking for participants' de-

mographic information, knowledge of organ donation legislation, personal attitude toward legislation and donation, knowledge about donor management and personal preference of donor management. Descriptive tests were used to analyse the answers of the questionnaire. Results: Please refer to the table. Conclusions: Despite the personal beliefs of many junior intensivists to donate their organs, the majority was not familiar with local organ donation laws. This may indirectly hamper their clinical practice when talking to relatives of patients regarding organ donation. To increase buying in from the intensivists, we need various supports from hospital management such as an institution approved protocol for donor management and training opportunities to increase the knowledge and confidence of junior doctors in communicating to potential donors' next-of-kin about brain death diagnosis and obligatory organ donation.

### PP04

#### REJECTING ORGAN DONATION – A TYPOLOGY OF RELUCTANCE

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**Background:** In Germany, a significant discrepancy between expressed positive attitudes towards organ donation and active willingness to donate one's organs after death is constantly stated. Current legal changes as well as media campaigns are based on this assumption and thus aim to increase the willingness to donate by targeting potential donors and appeal them to 'save lives' through their donations. **Aim:** Our presentation focuses on a better understanding and differentiated characterization of those who are uncertain or skeptical about organ donation. We assume that reluctance to donate organs is based on different reasons of 'saying no' to organ donation and discuss them as forms of reluctance. **Method:** Based on qualitative social research, we explore if and how skepticism about organ donation can be expressed and enacted against the background of moral imperatives pro donation. So far we conducted nine focus groups and ten interviews (different socio-economic background/54 participants all included) with those who are skeptic or reluctant regarding organ donation. **Results:** Four types of reluctance to organ donation can be identified: (a) The no-killing-position indicates that the brain-death is not the definite death of human beings and thus the current practice of organ donation is comparable to homicide. (b) The information-deficit-position refuses to take decisions under uncertainty and claims that true decisions can only be made if all consequences can be foreseen. (c) The mistrust-position rejects organ do-

nation in the light of a suspected corrupt and devious medical system. (d) The (bodily) integrity-position puts reluctance to organ donation on a level with protecting one's own bodily and personal integrity. Unlike the other positions, it does not refer to the current practice of organ donation. The positions express irreducible and generalizable values of justice and human dignity and thus reveal important influence on the willingness to donate one's organs. Conclusion: Even though some types of reluctance can't be easily articulated in terms of an argument in everyday life, underlying values that generate uncertain or reluctant attitudes can be reconstructed as morally justified and consistent positions and thus have to be considered and addressed in ethical discourses and political debates in a sensitive way.

## Deceased donation

### PP06

#### DOES THE PERSONAL ATTITUDE TOWARDS THE CONCEPT OF BRAIN DEATH INFLUENCE THE WILLINGNESS OF MEDICAL PROFESSIONALS IN GERMANY EITHER TO DONATE OR TO RECEIVE ORGANS?

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Background: In Germany organs can only be donated in cases of brain death. Opinion-formers such as the media discuss brain death frequently and often contentiously. It is known that a minority of people, including medical staff, do not accept the concept of brain death (cbd). This study examines the correlation between the acceptance of the cbd by professionals involved in

organ donation with their own willingness to either donate organs or to accept a transplant in case of organ failure. Methods: About 10,000 questionnaires were distributed anonymously among medical staff involved in organ donation, in 50 Bavarian hospitals of different treatment levels. Results: Altogether, 2,983 questionnaires were filled out. The majority of all respondents had a positive attitude towards organ donation (n = 2,325, 81%); in total 71% (n = 2,066) were willing to donate their organs after brain death (bd) and 57% (n = 1,580) were willing to accept a transplant in the case of organ failure. The majority (n = 2,367, 82%) of all respondents (physicians [90%, n = 736], nurses [79%, n = 1,603]) accepted the cbd. In this group, 11% (n = 269) would not donate their organs in the case of bd. This contrasts with the 6% (n = 167) who disagree with the cbd, of whom 68% (n = 114) would not donate their organs. Of those accepting the cbd, 62% (n = 1470) would accept an organ in the case of organ failure, whereas 29% (n = 681) are uncertain and 9% (n = 208) would refuse. Among those who do not accept the cbd, 14% (n = 23) would accept an organ if needed, 55% (n = 92) would refuse. Conclusion: Transplantation medicine is widely accepted in society. Nevertheless, a significant number of those who disagree with the cbd refuse transplantation as well as donation. Although this group is relatively small, it is an important group, as medical staff involved in the donation process often have a considerable influence over the formation of opinion. Therefore, it is essential that this group gets a particularly intensive training including principals of the cbd.

### PP07

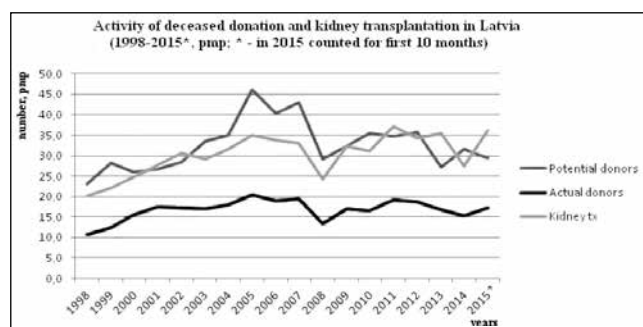
#### INFLUENCE OF ANNUAL EDUCATIONAL MEETINGS WITH ICU SPECIALISTS ON RATES OF DECEASED DONATION

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The rate of donations from deceased donors is closely connected with the activity of ICU in reporting TPM teams about potential donors. One of the possible ways to increase this activity is to organize good contact with ICUs in all hospitals where potential deceased organ donors may appear. For this reason we have organized special conferences and seminars for ICU professionals on the results of organ donation and transplantation in previous years, problems associated with donor examination and reasons for refusals from donation, effective organ donation as well as "feed-back" for ICU personnel by presenting some interesting clinical cases and patient demonstrations. These meetings were started in 2002 and initially such conferences were performed annually. Regular meeting resulted in increase in the number of information about potential donors (+ 45%)

and actual donations (+ 17%) and transplantations (+ 17%) during the following years. Economical crisis and following decrease in the number of population (since 2008) was followed by decrease in the number of donations and transplantations. Expanding of the donation criteria and associated growing volume of information to be present to ICU professionals working with potential donors resulted in the necessity to divide these conferences into two meetings during the last two years, that again gave some increase in the number of information on potential donors and actual donations in 2015. To conclude our experience shows that the possibility to maintain close contact with ICU personnel and provide them with up-to-date information on donation is a very important issue. Organization of educational programs and annual meetings can be an effective way to ensure higher donation rates in small countries.



## PP08

### 'A LITTLE DOLLOP OF GOOD IN A VERY DARK TIME': WHAT ORGAN DONATION MEANT TO DONOR FAMILIES

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**Objectives:** 1. To understand what organ donation meant to surviving relatives. 2. To elicit the tributes bereaved families' paid to their donors. **Method:** This presentation is drawn from a qualitative interview study carried out with donating families to elicit their experiences of organ and tissue donation and the perceived influences on their decision making. Participants were recruited from targeted regions which included representation from 10 participating NHS Trusts. The study sample comprised 43 participants from 31 families. All participants were White British. Unusually for bereavement research, there was an equal number of men ( $n = 21$ ) and women ( $n = 22$ ). Participants were representative of a variety of family relationships. Participants were bereaved a mean of seven months at the time of recruitment to the study. Twelve families agreed to DBD and 18 families agreed

to DCD. There were four cases of non-proceeding DCD and four DCD tissue donations only. The study was ethically approved. **Results:** Through donation, participants felt that their relative's death had not been in vain and that their life had not been wasted. Non-proceeding DCD was described as a disappointment by some participants and pragmatically accepted by others. Motivations behind the decision to donate were reflected in statements such as making a difference in terms of improving someone's quality of life and life expectancy, enriching or extending the lives of others, creating, saving or giving life to someone else and relieving the suffering of other families. There was also evidence of reciprocity behind the decision to donate. Some participants described how receiving letters about the outcome of their relative's donation impacted their grief and bereavement. They felt sad and upset, yet pleased and happy. Their pleasure came from content in the letter that acknowledged the difference their relative had made to the lives of people. There was some evidence to suggest that families remained positive about the donation despite notification that the recipient had subsequently died. Participants paid tribute to their donors in recognition of their contribution to others. **Conclusion:** No participant regretted the donation decision they made at the time of their relative's death. There was acceptance of the decision when carrying out their relatives' wishes. Participants described contrasting emotions when reading about the outcomes of donation and in particular, information about the transplant recipients. Some participants said they would agree to donation again.

## PP09

### ORGAN DONATION AFTER EUTHANASIA IN THE NETHERLANDS

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In 2014, there was still a shortage of available organs for transplantation, 1,044 patients were waiting for an organ in the Netherlands [1]. Maximizing the pool of organ donors is part of the solution. In 2001, the Dutch Termination of Life on Request and Assisted Suicide Act was adopted, legalizing euthanasia under strict conditions. In 2010, 3,136 reports were made of euthanasia and assisted suicide; in 2014, 5,306 reports were made [2]. Among them were patients with a desire to donate their organs after their deaths. Although a potential source of post mortal donor organs, only a few cases of organ donation after active euthanasia have been described. The combination of euthanasia and donation is medically ethical yet also politically a

sensitive issue [3]. Since 2012, 16 combinations of these procedures have been performed in the Netherlands [4]. Literature mentions 16 Belgian cases between 2005 and 2013 [5, 6]. This limited number can be the result of lack of knowledge about this subject among health-care professionals or because of practical, ethical and/or legal considerations. Performing this combination has possible advantages, both in number as well as in transplant outcomes. By describing a recent case in our centre, we will try to outline the state of the art in the Netherlands and disseminate knowledge about the possibilities and limitations of organ donation after active euthanasia.

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## PP10

### SEEKING TRANSPARENCY ON ALLOCATION OF KIDNEYS FROM DECEASED DONORS

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Kidney transplantation is the preferred treatment for many end stage renal disease patients; however, the small number of organs for transplantation does not allow all patients to have access to this scarce resource. An allocation system for deceased donor kidneys should be anchored to transparent policies and rules. It should take into account the relationship between supply and demand, hence seeking a balance between the higher net benefit of survival that can be provided by a particular organ and the transplant candidates' waiting time (as well as the probability of being transplanted). Nowadays, many deceased donor distribution protocols are based on candidates' waiting time (or time on dialysis) not taking into account graft and patient post-transplant survival. The Portuguese deceased donor kidney allocation scheme is based on a system of points assigned to each possible receptor given a specific potential donor, similarly to other systems implemented in the US or the UK. However, the key factor in organ allocation is time on dialysis (first

come, first served basis). The point system from the Portuguese rules for the selection of donor-recipient pair in transplantation with cadaveric donors is opaque and tends to over select patients with longer time on dialysis. These rules have also been associated with an augmentation in the number of acute rejections. As an alternative to the existing allocation system, we propose a colour system classification (Table 1) that will allow clinicians to know the position of a particular patient in the access to kidney transplantation at all times. Within each colour group, the candidates order will be determined taking into account the number of HLA compatibilities with the donor and, if a tie still persists, the decision is made by the time on dialysis. By setting only four colour groups on the basis of justice (time on dialysis and probability of transplantation) and, within each of these groups, candidates are ordered based by efficiency (HLA compatibilities); the proposed criteria meant to be balanced. This proposed new allocation system for kidney transplantation has the advantage of being more transparent than the current Portuguese rules; with it, clinicians can explain to the patient in a more intuitive manner how far they are from being transplanted. Also, the realization that patients classified as green will likely wait too long for an organ, can easily sway them toward the solution of transplantation with a living donor.

Table 1. Kidney allocation colour system

Not ECD		ECD	
Recipients ≤ 65 years old	Clinically Urgent	RED	Clinically Urgent
	cPRA ≥ 85% or ToD ≥ 3 <sup>rd</sup> Quartile <sup>1</sup>	ORANGE	cPRA ≥ 85% or ToD ≥ 3 <sup>rd</sup> Quartile <sup>1</sup>
	cPRA ≥ 50% or ToD ≥ Median <sup>1</sup>	YELLOW	cPRA ≥ 50% or ToD ≥ Median <sup>1</sup>
	cPRA < 50% and ToD < Median <sup>1</sup>	GREEN	cPRA < 50% and ToD < Median <sup>1</sup>
Recipients > 65 years old			

ECD – Extended Criteria Donor; cPRA – calculated PRA; ToD – Time on dialysis  
<sup>1</sup> – wait listed patients' time from first dialysis to transplantation

## PP11

### COMMON MISCONCEPTIONS ABOUT THE ROLE OF NURSES IN DECEASED ORGAN DONOR REFERRAL IN JOHANNESBURG, SOUTH AFRICA

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Introduction: In South Africa (SA) death rates in hospitals are attributed to many causes, including hypertensive head bleeds and traumatic injuries. Yet, the referral of potential deceased heart-beating organ donors is



alarmingly low. This is evidenced by the national current donor rate of 1.2 donors pmp – far below international averages. This research was conducted amongst nurses in Johannesburg, SA in order to explore the role of nurses' personal attitudes towards organ donation and how they affect referral. Methods: The study was approved by Wits University Human Research Ethics Committee (IRB) (Medical). It is currently being conducted across 10 hospitals. Data are being collected using a self-administered questionnaire to all nurses. Data are being analysed by means of descriptive analysis in SAS (2014) at the significance level of 5% Results: Results are preliminary, from the first 103 questionnaires. Of all the respondents: 56% would consider being deceased donors and 66% living donors; 91% felt that the decision to be an organ donor should be made by an individual during their life and 75% understood organs to be allocated at a national (not regional) level. Regarding the role of the transplant coordinator, 76% felt the coordinator should visit the unit at least weekly; 61% felt the main role of the coordinator was to teach the community about organ donation with less emphasis on the currently accepted roles of hospital-based procurement and teaching. In terms of the cadaveric donor referral process 87% felt it should be doctor driven and only 29% felt it was the responsibility of the nurse. However, 82% felt that if there was a nationally endorsed SA Department of Health protocol for referral they would follow it. Conclusion: From the results it appears that a system of mandatory referral outlined in a national policy or protocol may assist in increasing referral rates, because data suggests that nurses in the study setting are unfamiliar with the overall principles of organ donation. This is evidenced especially by the misconceptions that: • doctors should refer organ donors (actually, in SA, any health professional can refer a donor), • organs are allocated nationally (in SA allocation is actually regional) • the main role of the transplant coordinator is to educate the general public (actually, the role of the coordinator is to manage and consent referred organ donors). Given the low donor rate and the large number of individuals waiting for an organ, an action plan for SA is urgently needed.

## PP13

### RECOGNISING THE GIFT OF ORGAN AND TISSUE DONATION: AN EVIDENCE-BASED APPROACH

Wendy Walker<sup>1</sup>; Magi Sque<sup>1</sup>, Benedict Carpenter<sup>2</sup>, Suzanne Roberts<sup>3</sup>

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Objectives: 1. To describe the meaning of recognition for donor families. 2. To illustrate the creation of a public memorial, from conception to design. Method: This presentation draws on the findings of a qualitative study, designed to elicit donor families' views and preferences on appropriate ways of personally and publicly recognising the gift of organ and tissue donation. To our knowledge, this was one of the first studies to examine this important issue in detail. Our study sample comprised bereaved, adult family members, who gave consent to organ and/or tissue donation from a deceased relative at an Acute NHS Trust in the Midlands, UK. Three participants from two donor families participated in a face-to-face interview. Two donor families provided a written response to pre-determined interview questions. Data were subjected to conventional content analysis. This involved a systematic process of applying codes to the text and grouping the data into categories and themes. The study received ethical approval. Results: The findings of our exploratory investigation established the meaning of recognition for participant donor families and identified ways in which recognition may be realised. Donor families indicated unanimous support for organ and tissue donation to be formally recognised by the hospital where their relative died. An interesting observation was the extent to which families represented their experience of donation when deciding on the physical, emotional and relational qualities of a memorial design. For example, an association with nature seemed contiguous with the symbolism of life, and several of the participants were of the opinion that the memorial should transmit a sense of joy and pride. Participants identified three functions of a public memorial; recognition, remembrance and raising public awareness about organ and tissue donation. Facilitators of the donation process were identified as also worthy of recognition. Conclusion: The concept of recognition has an important functional meaning in the context of deceased donation. Involving donor families in the design of a public memorial provides a means of expressing recognition and ensures a fitting tribute. Further research is recommended to test the efficacy of the different forms of recognition in the public domain.



## Ethical and philosophical aspects

## PP15

# PATIENT AUTONOMY IN THE PROCESS OF ORGAN DONATION AFTER MEDICALLY ASSISTED DEATH

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In June 2014, Criminal Code by incorporated medically assisted death into provincial health care legislation. The new law is expected to come into force by the end of 2015 and allows people with a terminal illness that is causing unbearable suffering to ask a physician to administer a lethal dose of medication. Opinions about this new law vary widely. A number of Canadian physicians said they are not comfortable offering assisted death. But more than three quarters of Canadians support doctor-assisted suicide. Association of medically assisted death and organ donation rapidly engaged transplantation health care providers, jurists and ethicists. They were particularly divided about implication of the patient's family in this process and the solicitation for organ donation in this particular process. Quebec's new law does not obligate the dying patient to inform his family about his wish. Most participants thought organ retrieval immediately after death could impose a terrible shock to uninformed families. They would learn at the same time the death of their loved one and the fact that his/her organs were retrieved rapidly after death for transplantation. This perspective could be difficult to deal with for the family would not have any say in both these processes beforehand. This could also be detrimental to organ donation in general. The public could blend the process of medically assisted death for the purpose of organ retrieval. On the other hand, some, particularly jurists argue that refusing the possibility of organ donation to the patient would conflict with his autonomy. Patient's autonomy is a strong determinant of today's health care decision. But it could be argued that a person's autonomy is imbricated in a family networks and links. To ignore family interests in favor of the much simpler ethic of unquestioned fidelity to the sole patient desire would escape the complexity and rather emotional and long lasting importance of these procedures. Another question raised by this new medical process : is it morally acceptable or is it mandatory to ask the person looking for medically assisted death about his/her willingness to donate his/her organ? Opinion and arguments were divided. Calling on autonomy, one will argue that a patient must know about all of his/her choices in order to make a fully informed decision. And some claim that offering this choice should become a standard of care at the end of life. But this demand could border on direct solicitation.

## PP16

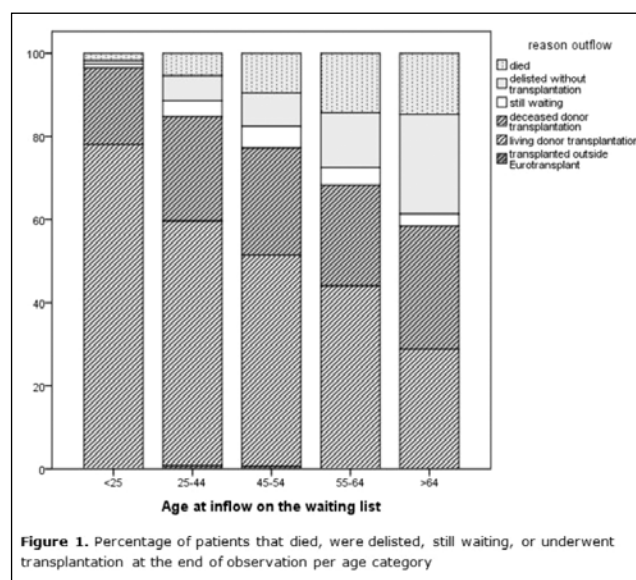
# WHAT HAPPENS TO ELDERLY PATIENTS ON THE WAITING LIST FOR A KIDNEY TRANSPLANTATION?

Mirjam Laging<sup>1</sup>; Judith Kal-van Gestel<sup>1</sup>, Cynthia Konijn<sup>2</sup>, Michiel Betjes<sup>1</sup>, Willem Weimar<sup>1</sup>, Joke Roodnat<sup>1</sup>

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Background: Elderly end stage renal disease patients are increasingly referred for transplantation. How are their chances on the waiting list for a kidney transplant? Methods: Between January 2000 and July 2011 2,022 patients had been placed on the regional waiting list for kidney transplantation. Patients were categorized according to age at inflow on the waiting list: < 25, 25-44, 45-54, 55-64, and > 64 years. Reasons of outflow per age category were analyzed. Results: In February 2015 1,499 (74%) patients were transplanted, 234 (12%) patients were delisted without a kidney transplantation, 210 (10%) died while on the waiting list, and 79 (4%) were still waiting. In the youngest age group 96% were transplanted. The majority received a living donor kidney transplant (Figure 1). In the other age groups 85%, 77%, 68%, and 58% respectively, were transplanted. In the oldest age group only half the transplantations were performed with a living donor kidney. The percentage of delisted patients in the five age groups was 1%, 6%, 8%, 13%, and 24% respectively. The percentage of patients that died was 2%, 5%, 10%, 14%, and 15%. Finally, 1%, 4%, 5%, 4%, and 3% of patients were still waiting. Conclusion: In the highest age categories 28% and 39% of patients on the waiting list were not transplanted because they did not survive or because their condition worsened. In this population, living donor kidney transplanta-



tion lags behind. They usually cannot afford waiting for a deceased donor kidney. In order to improve their survival living donor kidney transplantation should be promoted in elderly patients.

## PP17

### **ANONIMITY IN DECEASED ORGAN DONATION AND TRANSPLANTATION: THE IMPORTANCE OF CONSISTENCY**

Eline Schiks; N. E. Jansen, B. Schaefer,  
B. J. J. M. Haase-Kromwijk

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Organ donation and transplantation is an anonymous process. Yet, this does not withhold donors, donor families and recipients to use the internet and social media to search for each other. This led to a discussion on the desirability of anonymity. Although this discussion is mainly focussed on living donation, it gives rise to questions on the ethical desirability of anonymity in deceased organ donation and transplantation. This abstract focusses on the relation between the interests of the donor and his family. It is shown that this relation should be consistent with other discussions on organ donation and transplantation. It has taken practice as starting point, but this does not imply that this is the most ethically justified way. It is used to show that the discussions for which the relation between the donor and his family is relevant – the discussion on anonymity and the discussion on consent – should be connected. When a potential donor is dying, the family will be asked whether they give their consent to let him become a donor. Even when a donor has a ‘yes’ registration, the family is, in practice, able to overrule. The main reason for this is to protect the well-being of the donor family. This means that the family’s well-being is considered to be of more importance than the autonomy of the donor or the ability to save multiple lives. It would be inconsistent to consider the deceased donor as most relevant in the discussion on anonymity. The autonomy of the donor would be valued higher, while the autonomy of the deceased donor is less relevant in the discussion on anonymity. Revealing the identity will not impact his live, but that of the donor family. Not taking the donor family into account would mean that the donor family is able to prevent that their loved-one saves a live (or multiple) in order to protect their own well-being, but that they do have no voice in the decision on whether the identity of their loved-one will be revealed to the recipient, while this is also related to their well-being. It is therefore advised to combine the discussions on consent and on anonymity, in order to hold a consistent view on the desirable status of the donor and the donor family in the debate on organ donation and transplantation. By discussing consent, one has to be aware of the impact on the discussion on anonymity and the other way around.

## PP18

### **A PART OF ME? POST-TRANSPLANT EXPERIENCES AND REFLECTIONS AMONG DANISH HEART AND LUNG RECIPIENTS**

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This paper deals with the post-transplant experiences of Danish heart and lung recipients. Based on anthropological fieldwork at a transplant unit and interviews with 15 organ recipients in the weeks, months and years after the transplant, this study investigates how Danish organ recipients embody their new body parts while struggling for medical and existential survival. It also discusses how recipients articulate their gratitude towards, donors, families and hospital staffs. The paper argues that receiving an organ necessitates carefully articulated stories in order to either ignore or embrace the sometimes threatening otherness of the organ. The paper demonstrates that the biography of the donor, rather than the part of the donor may constitute existential challenges for Danish organ recipients. Finally the study also investigates how the otherness of body parts is articulated and “mentally embraced” in recipient dreams and stories as an attempt to cope with the challenges of having the organ of another person in your body. Overall, the paper suggests that the key to understanding complex recipient experience is paying attention to the various ways recipients strategically articulate and perform the wondrous connections between their new body parts and themselves.

## PP19

### **PREGNANCY AFTER KIDNEY TRANSPLANTATION: DO THE MOTHERS SEE THEIR CHILDREN GROW UP?**

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Introduction: Subfertility is common among young women suffering from end-stage renal disease, however kidney transplantation offers these women an increased chance to become pregnant. The available data shows that successful pregnancy after kidney transplantation is possible, but often complicated by hypertension, proteinuria and deterioration of graft function. In this study we focused on the long-term outcomes after pregnancy in renal transplant recipients. Methods: We performed a single centre retrospective study of renal transplant recipients between 1971 and 2013. Medical records of all women transplanted in our centre from

the age of 45 or younger were assessed. Pregnancies with a gestational age longer than 6 months were included. Patient and graft survival as well as pregnancy outcomes were recorded. Results: Between 1971 and 2013, 479 female patients aged 45 years or younger received a kidney transplant. Only 9% (42/479) gave birth to one or more children (range 1-4) after kidney transplantation. These 42 women gave birth to 60 children (2 twins); one pregnancy ended in intrauterine death. In 45% of pregnancies a caesarean section was performed. The women had a median age of 30 years at delivery (range 19-40). Median MDRD-GFR after delivery was worse compared to pre-conception; 59 (range 25-117) vs 48 (range 4-96) ml/min/1,73 m<sup>2</sup> ( $p = 0,001$ ). The median transplant-to-delivery interval was 7,5 (range 1- 27) years. One third (18/58) of these pregnancies were complicated by preeclampsia and two developed HELLP syndrome. During follow-up 15 mothers lost their graft after pregnancy, after median 5 years (range 0-22). Two of them lost their graft within one year after delivery. Five mothers (12%) died during our follow-up. One mother died within a year after delivery (with a functioning graft), the others died 3, 5, 17 and 18 years after delivery. In the general Dutch population 1,1% of children loses one of their parents before they reach adulthood. Discussion: Although pregnancy is possible after transplantation, it carries a high risk of complications. Furthermore there is a substantial group of women that lose their graft in a short term after delivery and one out of eight mothers die before their children reach adulthood. Female kidney transplant recipients with a desire to have children should be informed that they might have to raise their children under difficult circumstances and have an increased morbidity and mortality after delivery.

## PP20

### TESTING THE DEAD DONOR RULE

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The so-called “dead donor rule” (hereafter DDR) is a landmark principle of organ transplantation that instructs physicians not to kill patients in order to harvest their organs (Robertson, 1999). Likewise, the DDR operates as a condition of possibility for a fundamental distinction that also governs transplantation surgery: that of cadaveric organ donation versus living donation. Critics of both neurological and circulatory determinations of death have insisted for years that, if we espouse a biological conception of human death, our current protocols of organ transplantation are in violation of the DDR. Such violation might be ethically justified, but the public should be, at least, fully aware about the clinical and physiological facts (Truog & Miller, 2012). A team of Spanish researchers from

different areas (Sociology, Medicine, Bioethics and Legal Philosophy) sponsored by the Spanish Ministry of Science and Innovation is conducting a survey on the public views about the DDR. In order to do so we have designed a clinical vignette that resembles the controversial transplantation case reported by Escudero and colleagues (2013). We have distributed it among different populations (undergraduate students from diverse regions in Spain, as well as clinicians and Law Professors) with an accompanying attitudinal questionnaire that replicates a previous study conducted in the USA by Michael Nair-Collins et al. (2013). Our preliminary findings show that respondents at large readily justify the harvesting of organs from patients who, although biologically alive, may be considered “as good as dead” for the purpose of organ transplantation (Truog & Miller, 2012).

References: Robertson, J. (1999): “The Dead Donor Rule”, *The Hastings Center Report*, 29, 6, November-December. Truog, Robert & F. G. Miller (2012): *Death, Dying and Organ Transplantation*, Oxford University Press. Escudero, D. et. al. (2013): “Craneoplastia con vendaje. Nuevas formas de limitación del tratamiento de soporte vital y donación de órganos”, *Medicina Intensiva*, 37 (3): 180-184. Nair-Collins, M., S. R. Green, A. R. Sutin (2014): “Abandoning the dead donor rule? A national survey of public views on death and organ donation”, *Journal of Medical Ethics*, published online first September 26, 2014 (doi:10.1136/medethics-2014-102229).

## PP21

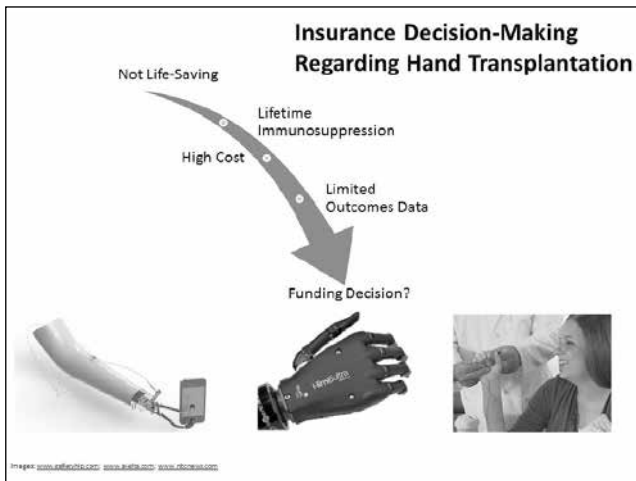
### AN ETHICAL ANALYSIS OF THE JOURNEY TOWARD INSURANCE FUNDED VCA

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The technologies amid VCA (vascularized composite allografting) range from experimental interventions such as penile and uterus transplants to crossover therapy of hand transplantation. All VCA technologies have four things in common which collide to cast them in a negative light with insurance funders: 1) the view that VCA is not life-saving; 2) lifetime use of immunosuppression; 3) high cost of VCA; 4) limited outcomes data set. This presentation provides an ethical analysis of these four issues in the context of justifying insurance funded hand transplantation, including a critical analysis of the third-party payor approach to funding decisions. Overall, to optimize patient access, VCA Teams must take an active approach to paving funding paths for these technologies.



## PP23

### FAST FACTS ON ORGAN AND TISSUE DONATION AND TRANSPLANTATION: A CANADIAN RESEARCH INITIATIVE

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The Canadian National Transplant Research Program (CNTRP) is a national coalition of over three hundred researchers, trainees, patient partners and clinicians in adult and pediatric organ, tissue and hematopoietic stem cell (HSC) transplantation, from 29 Canadian healthcare centres and universities. Members represent biomedical science, clinical medicine, health services and policy and population research. The primary goals of the CNTRP are to increase organ and HSC donation and transplantation in Canada and enhance the survival and quality of life of transplant recipients. Ethical, legal and economic factors touch many aspects of the CNTRP's research studies. To provide accessible information on important topics in organ and tissue donation and transplantation, the Ethics, Economics and Legal section of the CNTRP developed a series of Fast Facts (FFs) for dissemination on their website ([www.cntrp.ca/fastfacts](http://www.cntrp.ca/fastfacts)). Writers and reviewers of FFs include clinicians, legal scholars, practicing bioethicists and healthcare providers, enabling collaboration between disciplines nationally in establishing current, relevant facts on controversial and contentious issues. The target audience includes healthcare practitioners, government officials, policy makers, researchers, learners, patients and the general public. The FFs represent a knowledge transfer initiative by the CNTRP. The FFs are concise, easy to read and available in English and French. Rather than opinion pieces, they outline facts and issues on aspects of donation and transplantation that can inform policy. To date we have FFs on Consent, Incentives for Organ and Tissue Donation, Ethical Issues in Organ and HSC Donation and Transplantation, Living Donation, Death Determination

and Deceased Organ Donation, Human Bodies and Biological Materials, and Public Solicitations for Organs and HSC. More FFs are planned on topics including pediatric transplant, economics and psychosocial issues. This presentation will outline each FF, their development, the value of such communications and how they are used.

## PP24

### TO TEST OR NOT TO TEST: AN ETHICAL CONUNDRUM

Prakash Rao; Donna King, Ijeoma Okere, Julien Napoleon, Misty Marchioni, Dayanand Deo, Maria Aguilucho, Sogra Jafri, Shivani Patel  
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In today's changing healthcare environment, transplant programs are financially struggling to stay afloat; cutting back wherever feasible. One area of cost conservation is limiting patient testing to the acceptable minimum. During the process of testing patient samples, labs may conclude that additional testing will significantly benefit the patient's care; however, labs are prohibited from testing in the absence of a requisition from the transplant program clinicians. This creates an ethical dilemma for the lab, where inadvertently the lab may be forced into a not so appropriate decision for the transplant recipient, as illustrated in the vignette below. Over a 2-year period, samples from a 65 y/o patient were sent for crossmatching with several kidney donors. Crossmatches were performed using both flow cytometry and complement-dependent cytotoxicity (CDC) testing. The flow cytometry testing resulted in the T Cell crossmatch being consistently positive while the B Cell crossmatch was consistently negative. The CDC testing contradicted the flow cytometry results and showed consistent negative Results: for T Cell and B Cell. The patient had no Class I antibody specificities. Based on the positive flow cytometry crossmatch results, the patient was repeatedly passed over for donors. The discrepant positive crossmatch results suggested the presence of auto antibodies which would have predicted a safe transplant. An auto flow crossmatch was repeatedly suggested without success. Finally, the transplant lab director adamantly conveyed to the transplant program that the auto crossmatch, in the absence of donor specific antibodies, would validate the results of the negative donor specific crossmatch and, more than likely, result in a safe transplant. The auto crossmatch was carried-out, and as expected, the presence of auto antibodies was confirmed and the transplant was carried out safely. At last report, the kidney is functioning and the recipient is doing well. Our lab has since instituted a new policy whereby all unexplained crossmatches are investigated and flagged in the patient's electronic record. Ethical conundrums



such as the above are not unique to our institution. It highlights the ongoing challenges of a changing healthcare environment and reinforces the importance of continuous dialogue between the transplant lab and the clinical programs.

## Legal aspects

### PP26

#### LEGAL REGULATION OF TRANSPLANTING SUBOPTIMAL ORGANS

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A shortage of suitable organs and the growing number of patients dying on transplant waiting lists have necessitated increasing use of less-than-ideal organs from deceased donors. This includes organs from older donors or those with co-morbidities, infections, current or previous cancers or history of high risk behaviour such as smoking, excessive alcohol and illicit drug use. The outcomes from transplantation of such 'suboptimal' organs are generally acceptable for the patient population compared to the even greater risk of death while waiting for an organ. However, compared to optimal organs, transplantation of sub-optimal organs exposes individual patients to greater risk of transmission of disease and major morbidity, graft loss or death. This necessitates the development of effective approaches that address not only the medical issues, but also the fundamental legal and ethical issues in the use of suboptimal organs. This paper focuses on two potentially relevant actions in tort law: negligence and product liability. It examines whether the definition of 'product' in product liability extends to transplanted organs and the implications of this issue. It further examines the impact of a patient's awareness of the risks associated with suboptimal organs, and his or her informed consent to those risks, for liability in both areas of tort law.

### PP27

#### AUTOLOGOUS CORD BLOOD BANKS: HOW TO ANSWER FAMILY REQUESTS WHILE ALSO GUARANTEEING QUALITY AND LEGAL REQUIREMENTS

Ruth Barrio<sup>1</sup>, Jaume Tort<sup>1</sup>, HSCT Advisory Commission<sup>1</sup>, Pilar Godina<sup>2</sup>, Josep Davins<sup>2</sup>, Roser Vallès<sup>2</sup>

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**Introduction:** The autologous cord blood bank is a health unit that carries out the activity of processing, preservation and storage of cord blood for families who want to keep the cord blood of their children, in case they develop a haematological disease that might be treated with a cord blood transplant. Several scientific associations, bioethical committees and working groups have published reports advising against the authorization of autologous cord blood banks, citing a lack of scientific rigour in preserving the cord blood for one's own use. The current indications for this type of transplant are high risk solid tumours, some non-Hodgkin lymphomas and acquired aplastic anemia. There are few publications in this field, but the number of cases published compared to the allogenic (donated cord blood) is 1 autologous per 3,330 allogenic cord blood transplants (approx). Furthermore, when European Directive 2004/23/CE of 31st March was introduced in Spain through Royal Decree 1301/2006, 10th November, and later Royal Decree Law 9/2014, of 4th July, autologous cord blood banks were permitted. However this was under the condition that if units were stored in Spain, they should be available for any one that might need them. **Methods and results:** In Catalonia in order to respond to many families and some professionals that requested the preservation of cord blood for an autologous use, and so as to fulfil the law, cord blood banks began to be authorized. However, they had to meet several requirements in order to guarantee the correct information given to families, as well as the quality and safety of the cord blood. Therefore, specific informed consent was approved including current information regarding scientific evidence of autologous cord blood transplant. Banks should also have a cord blood bank quality certification; those accepted were the American Association of Blood Banks (AABB) and the FACT-NETCORD. Other aspects such as custody of the kit before and after collection, the revision and authorization of the contract signed with families ... were established as mandatory. **Conclusions:** By overseeing the information and establishing as mandatory a quality certification for cord blood banks, we shall ensure that the collected and processed cord blood meets quality requirements, and also that families have the right information before making their decision.



## PP28

# OPT OUT LAW FOR ORGAN DONORS AFTER BRAIN DEATH TRIGGERED CROATIAN TRANSPLANTATION MIRACLE

Lada Zibar<sup>1,2</sup>; Ozana Katarina Tot<sup>1,2</sup>, Tomislav Nedić<sup>1,3</sup>

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Croatia is small mideuropean country with 4.5 million inhabitants. It is a postsocialist country, still transitional, combating not only with current economic crisis but also with postwar socioeconomic legacy. However, despite the obstacles, it succeeded in keeping in step with the most developed countries in terms of routine organ transplantation (TX). Thus, the first routine kidney TX started as long time ago as in the late sixties. By the beginning of the 21st century we faced a serious organ shortage and since that time we undertook several measures that led to a marvelous success – to the top of the world in organ donation and TX. The first measure was the law. The presumed consent or the opt out law was implemented in 1988. It considers each citizen a donor after brain death if he/she did not declare against the donation in the written, by the law prescribed, form during the life. The following measures included appointing hospital coordinators for donation at the beginning of the century and finally entering Eurotransplant (ET) in 2007. It was in 2011 when Croatia climbed to the first place in the number of organ donors – with 33.6 used organ donors per million people. That it was not anecdotal speaks the fact that it has still been on the throne, since that time. Still, there have been refusals for donation from the family part. And it has still been common to inform the family and to ask for permission. But the law has been cited within that sad conversation and it strongly facilitates not only for the family to make up the decision but also the doctor's position, in terms of his/her comfort by asking. And while the needs for organs within Croatia have been almost fulfilled, the phenomenon of the high number of donors overcame the national benefit, and became transnational, within the ET. Whether the law has been the best concerning the one's liberty as a philosophical issue will always be controversial, especially if taking into account the questionable health literacy. That means that there is a presumption of the will of which most people are not aware at all, for a medical situation (TX) often completely unfamiliar to the potential donor. Is the principle ignorantia iuris nocet applicable to the situation? We wouldn't know. In the meantime, our patients and the rest of the ET patients enjoy the consequences of our legislation.

## Living donation

## PP29

# CONCERN FOR LOST INCOME FOLLOWING DONATION DETERS SOME PATIENTS FROM TALKING TO POTENTIAL LIVING DONORS

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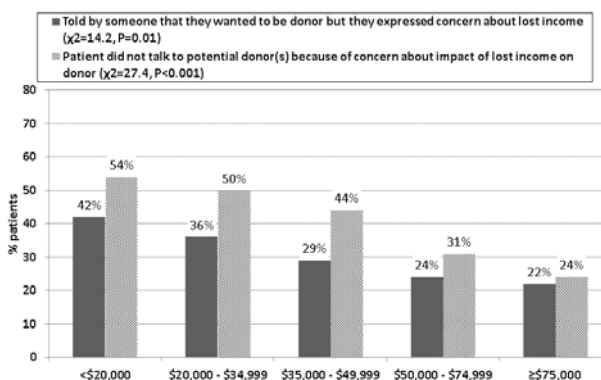
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Some living kidney donors report lost income during recovery from surgery. Little is known about whether concern for living donor lost income affects the decision to undergo donation evaluation and the willingness of transplant candidates to discuss LKD with others. We examined whether transplant patients were told by potential donors about lost income concerns and whether patients chose not to discuss LKD with others due to lost income concerns. Kidney transplant patients (185 wait-listed candidates, 171 deceased donor recipients, and 100 live donor recipients) at two USA centers completed a questionnaire to assess whether concern about donor lost income was a consideration in discussions about living kidney donation with others. One-third (32%) were told by a family member/friend that they were willing to donate but were concerned about potential lost income. The majority of those who expressed financial concern (64%) did not initiate donation evaluation. Many patients (42%) chose not to discuss living donation with a family member/friend due to concern about the impact of lost income

Relationship between annual household income of transplant patient and concern for lost income after living kidney donation (N=456)



on the donor. In the multivariable model, lower annual household income was the only statistically significant predictor of both having a potential donor express lost income concern and choosing not to talk to someone because of lost income concern. Findings from the current study underscore how concern about income loss for living donors may affect decision making by both transplant candidates and potential donors.

### PP30

#### CLINICAL OUTCOMES AND EVALUATION OF DONORS' QUALITY OF LIFE AFTER LIVING DONORS LIVER TRANSPLANTATION

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**Background & Aims:** There are few studies of the health-related quality of life (HRQOL) in living liver donors. We evaluated the potential morbidities and identified the predictive factors regarding the HRQOL of living donors after Living donors liver transplantation (LDLT). **Methods:** This cross-sectional study was a single-center analysis of 120 donors for LDLT. Between 2011 and 2013, HRQOL was assessed at evaluation, at 3 months, and yearly post-donation in prevalent liver donors using the short-form survey (SF-36). The severity of morbidities was assessed with the Clavien classification. **Results:** A total of 12 (10%) of the donors developed postoperative complications of Clavien grades I (3%), II (4%), and IIIA (3%). There was no grade IV morbidity or mortality. Most post-operative complications were treated without surgical procedures. The analysis of the questionnaires revealed that the donors had difficulty in the decision-making process, and suggested that it may be necessary to administer multistep informed consent and more time for donors to think of making a decision. Compared with published Asia norms in SF-36, our donors scored similar with the general population. All donors returned to normalcy. **Conclusions:** In summary, most living donors maintain above average HRQOL, supporting the notion that living donation does not negatively affect HRQOL. These results suggested that the donors' HRQOL was guaranteed in terms of the SF-36 investigation regardless of the donation period in our series. Targeted support for donors at risk for poor HRQOL may improve overall HRQOL outcomes for living liver donors.

### PP31

#### LET'S TALK ABOUT IT. EARLY GROUP-EDUCATION OF FAMILY AND FRIENDS A WAY TO LIVING KIDNEY DONATION?

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**Introduction:** Renal transplantation and especially pre-emptive renal transplantation offers the best treatment for patients with end stadium renal disease. The waiting list in the Netherlands for a post mortal kidney donation is long. Many patients start with dialysis. The Nephrologists advice patients to talk to family about their situation. They find it difficult to talk with relatives and friends about their illness and treatment options, especially to ask for a kidney donation. We hypothesized that timely education of family and friends of patients improves understanding, prevent misconceptions about future health status and stimulates discussion about living kidney donation. **Methods:** The nephrologist informs all involved healthcare professionals about a new patient with CKD. Within a week the social worker contacts the patient and makes an appointment for a home visit. At this visit the social worker makes an assessment about social and living conditions and gives general information about renal replacement therapy, renal transplantation and living kidney donation. At the same time the patient is informed about the option of a timely education of family and friends. When the patient agrees they organize a meeting of family and friends at the patients home. The informative meeting involves an intimate discussion about current and future health status of the patient and treatment modalities. Data of patient survival on dialysis, after living kidney donation and deceased donor transplantation are given. Benefits and risks of living kidney donation for recipient and donor are presented. **Results:** Patients, families and friends welcomed the family counselling. They all felt improved mutual understanding and bonding with the patient. The patients were relieved after the social worker initiated discussion about living kidney donation. Until August 2015, group education was given to 76 families of CKD patients. Potential kidney donors showed up in 60 cases. **Conclusion:** The early group-education of families and friends of patients with CKD leads to a better informed and understanding family and social network. It makes it possible to talk about the patients situation. Relatives consider living kidney donation and make pre-emptive kidney transplantation possible. We recommend this education to all patients with CKD stage 3-4. Nierkompas study February 2011-February

2013 E. Massey et al. confirm our experiences with this form of family education.

### PP33

#### ADDING ANOTHER VOICE TO THE LIVING DONOR KIDNEY TRANSPLANT DISCUSSIONS AT THE CIBA SYMPOSIUM OF 1966

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Fifty years ago, in 1966, the Ciba Foundation sponsored a seminal international conference on the ethics of transplantation (Wolstenholme & O'Connor, eds. *Ethics in Medical Progress: With Special Reference to Transplantation*. Boston, MA: Little, Brown and Co.; 1966). Attendees included surgeons, physicians from many medical disciplines, legal professionals, a minister, and a science reporter. The living donor's voice was missing. In this presentation we give voice to the living donor through two qualitative interviews with men who donated in the United States in the early 1960s and subsequently developed end-stage renal disease (ESRD). We elected to separate these interviews from a larger qualitative study examining insurance issues in living kidney donation because both interviewees described their donations as experimental and therefore outside the realm of insurance coverage, making their own lack of insurance irrelevant. Initial and follow-up interviews took place by phone in July 2014 and May 2015. The donors' narratives provide insight into five topics discussed at the Ciba meeting: 1) pressure to donate; 2) special donor categories; 3) socioeconomic consequences of donation; 4) donor health; and 5) lack of regret. These donors would have enriched the conversation with the following contributions: 1) Both donors deny feeling pressured to donate but do describe being chosen (one by his family because he was without family obligations; one by the transplant team because he was an identical twin). 2) The identical twin was also a minor, making the permissibility of his donation controversial. 3) Both talk about the out-of-pocket costs, a concern for some Ciba attendees who thought reimbursement was owed. 4) Although healthy at the time of the Ciba meeting, both would develop ESRD decades later, attesting to the need to treat living donors as lifelong patients. 5) Despite this adverse turn of events, both express no regret, although there may be some ambivalence as neither asked family members to serve as their living donor. Evaluating their narratives in the context of the Ciba symposium, one appreciates the relevance of their contributions. We owe it to liv-

ing donors, past and present, to include their voices in future discussions.

### PP34

#### BILIARY COMPLICATIONS AFTER LIVING DONOR LIVER TRANSPLANTATION: INCIDENCE AND RISK FACTORS

Szu-Han Wang

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Background and aims: Biliary complications (BCs) are a common source of morbidity after liver transplantation, leading to long-term and repeated therapies. Biliary strictures and leaks are the most common complications after living donor liver transplantation (LDLT). The aim of this study was to determine factors for biliary complications after LDLT: Incidence and Risk Factors. Methods: A total of 144 patients who underwent LDLT with right lobe graft during the period January 2007 to May 2013 at a single medical center with a least two years of follow up. Patients were divided into two sub-groups; BC and non BC group. Potential risk factors for BCs after LDLT included pre-operative recipient-related factors, donor-related factors, operative time, and postoperative factors. Results: 50 (34.7%) patients developed BCs after LDLT. Biliary leaks occurred in 15 patients (10.4%), and strictures occurred in 35 patients (23.1%). 104 patients biliary reconstruction without receiving a t-tube, of them, 24 (23.1%) patients developed BCs and 40 patients receive a t-tube, of them, 26 (65.0%) patients developed BCs. Most biliary strictures were treated first with endoscopic retrograde cholangiography (65%). Risk factors associated with BCs included the T-tube insertion [odds ratio (OR) = 10.1, 95% confidence interval (CI): 2.1–12.1]. There was no association between biliary strictures and the number of ducts (hazard ratio [HR] 1.71 [0.35–2.25],  $P = 0.84$ ). Long-term graft survival did not differ between those who had or did not have biliary complications. Conclusion: Biliary strictures are common after LDLT. With careful follow-up, they can be successfully treated, with excellent long-term graft survival rates.

## PP36

# WHAT DO WE KNOW SO FAR? A SCOPING REVIEW OF THE LITERATURE ON PUBLIC SOLICITATIONS FOR LIVING ORGAN AND HEMATOPOIETIC STEM CELL DONATIONS

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Background: Asymmetry between demand and supply has led desperate patients to seek organ and hematopoietic stem cell donations (HSC) through alternative methods. The widening of the living donor pool and use of social media in recent years have increased public appeals for directed living organ and HSC donations from altruistic strangers. Controversial media appeals and interest stories have contributed to fervent public debates through conventional news outlets. With the advent of the Internet and social networking websites, public solicitations (PS) have gained more visibility, and transplant programmes face a myriad of ethical dilemmas surrounding PS. We surmised that mapping the academic perspectives on PS would provide more clarity of the facts, concerns and ethical arguments. Such an exercise has not been conducted previously on PS, and the lack thereof is reflected in the varying interpretations of the topic. Methods: A scoping review methodology was designed to 1) explore the academic literature on this topic, and 2) summarize and disseminate key research findings. An established methodological framework for conducting and reporting scoping reviews, to review the prominent ethical arguments, counter-arguments and policy implications put forth in the literature was adhered to. Results: From an initial 4616 articles identified from four databases MedLine, EMBASE, PsycInfo and CINAHL, we screened titles and/abstracts in an iterative manner to assess eligibility for full-text review. Of these, we retrieved full-texts for 280, and extracted, coded and analysed 41 papers. While we searched articles on both solid organ and HSC, only three articles addressed PS of HSC donation. We mapped several themes under three major headings, (1) interpretations and modes of PS, (2) ethical arguments for and against PS, and (3) policy implications to address PS. Conclusions: Within the academic literature, PS for directed living donations that operate in parallel to a public and equitable deceased donor organ allocation system generated divisive perspectives. Clarity from reviewing the literature can help justify ethically defensible responses, while fostering increases in living organ and HSC donations to relieve patients from long wait-

lists. Recommendations to aid transplant programmes in responding to patients and solicited donors will be outlined.

## PP37

# OPTING OUT: A PILOT STUDY ASSESSING THE REASONS FOR AND THE PSYCHOSOCIAL IMPACT OF WITHDRAWING FROM LIVING KIDNEY DONOR EVALUATION

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Introduction: There is scant information about the experiences of individuals who begin donor evaluation but decide not to donate for non-medical reasons. Methods: We conducted a retrospective qualitative study of adults who opted out of living kidney donation between 2012-2014 at Yale-New Haven Hospital Transplant Center. Transcripts were coded using an inductive major and minor coding method. We employed standard descriptive statistics to assess participants' demographic characteristics. Results: Seven individuals who opted out of living kidney donation participated in our study (response rate 64%). The sample had a mean age of 42 years, with 3 women; the majority considered direct donation (n = 5) to relatives (n = 4). Most individuals decided to opt out of donation for a combination of reasons (Table 1). While many participants mentioned the health risks of surgery (n = 6), these were raised while evaluating the relevance and strength of other concerns. Financial worries related to a potential post-operative complication were the most common (n = 3) primary reason for opting out. Three participants reported a profound sense of loneliness when making their decision to opt out; although all felt supported by the center, none contacted the center at that time. Six participants told their intended recipient that they had decided not to donate and their reasons

Table 1: Reasons for opting out

Reason	Participant						
	1	2	3	4	5	6	7
Peri-operative health risks	X	X	X	X	X		
Potential impact on child-bearing						X	
Financial issues			X	X	X		
Other caretaking responsibilities				X			
Anticipated lack of social support post-donation				X			
Family opposed	X						
Kidney not good enough					X		
Recipient non-compliance		X				X	
Recipient not sick enough						X	
Relationship with recipient complicated						X	
Relationship with recipient became worse during evaluation							X
Not emotionally involved enough	X						X
Save kidney for family							X
Concerns about the exchange program	X		X				

X = reason mentioned

□ = reason most important for the participant



for opting out, without a negative impact on the donor-recipient relationship. All participants believed the centers should offer alibis, statements of unsuitability for donation, to potential donors who opted out. Discussion: This study demonstrates that well-designed and carefully implemented research can be effectively and ethically conducted with individuals who opt out of donation. Our results underscore the significance of financial concerns as a barrier to living kidney donation in the US. Participants' comments also indicate areas where the independent living donor advocate's role may merit further expansion: renewal of offers of support to potential donors who have not re-contacted the center to continue their evaluation after a designated period of time, follow-up with and debriefing of individuals who have opted out, and reiterations of alibi offers at the time a potential donor opts out. Further research on those who opt out will improve our ability to protect the autonomy and ensure the welfare of all potential living donors.

## PP38

### LOSS OF FOLLOW-UP ANALYSIS IN CATALAN LIVING KIDNEY DONOR REGISTRY

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Introduction: Many studies on the evolution of living kidney donors have a proportion of loss to follow-up of 20% to 50%, which might carry a selection bias and potentially compromising their conclusions. This study aims to detect factors leading to the loss of follow-up. Methods: Data from the living kidney donor registry of Catalonia has been used. 573 cases who became living kidney donors between 2000 and 2011 were available. Donors without any follow-up, with a total follow-up time below one year or after two years since the last follow-up visit, were considered lost to follow-up. We also considered the situation of the recipient by merging the data with the Catalan renal registry. To know whether all donors are currently active, dead or moved from Catalonia, the data was merged with the Health Card Registry. Results: We observed 112 (19.6%) lost to follow-up. At one, five and ten years from the donation 90.6%, 81.2% and 69.6% of donors remained on follow-up. Donors > 34 years presented 18.6% of lost to follow-up, and 70.5% remained on follow-up at 10 years. In donors ≤ 34 years loss of follow-ups over time was 31.1% ( $p = 0.042$ ) and 58.7% ( $p = 0.034$ ) remained on follow-up at 10 years. Donors of a kidney still functioning at time of analysis had 16.7% loss of follow-up and 74.5% remained on follow-up at 10 years. In comparison, donors of a kidney that eventually failed, or when the recipient had

died, showed 26.7% and 46.2% ( $p < 0.001$ ) of loss of follow-up and 65.6% and 44.9% ( $p = 0.001$ ) remained on follow-up at 10 years respectively. Using Cox analysis, the risk of follow-up loss was 1.80-fold (IC 95% 1.02-3.20) for donors ≤ 34 years. Donors of a kidney that eventually failed, or when the recipient had died, presented a 1.63-fold (IC 95% 0.87-3.06) and 2.71-fold (IC 95% 1.59-4.64) risk of follow-up loss versus the donors of a kidney still functioning. The follow-up centres presented values from 2.36 to 3.43-fold risk, compared with the centre with the lowest number of follow-up loss. For the donors with follow-up, one (0.2%) died and seven (1.5%) moved from Catalonia. For the 112 loss of follow-up donors, the figures were 2 (1.8%) and 20 (17.9%) respectively. Conclusions: A high percentage of loss of follow-up in the Catalan living kidney donor registry was observed. Follow-up centres should be aware of younger donors and donors whose recipient has died to prevent loss of follow-up. Further merges with other health registries are necessary to obtain information, that otherwise cannot be obtained, regarding the health status of kidney living donors lost of follow-up.

## PP39

### ATTITUDES AND PRACTICES OF NEPHROLOGISTS IN GERMANY REGARDING LIVING KIDNEY DONATION – A NATIONAL ONLINE SURVEY

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Nephrologists and other medical specialists are key stakeholders in the advancement of kidney living donation and the selection of living donors. At the same time they are affected by the developments in this field and are asked to take their own ethical position towards them. The consideration of their standpoint, actions and experience are of outmost importance regarding both policy development and medical practice. We performed an online survey with all registered nephrologists in Germany on the issue of living kidney donation. The participants were either affiliated to a transplantation center or working in a private practice or at a dialysis centre. They were asked to answer anonymously questions regarding their experiences, attitudes and practices related to living kidney donation. We are presenting results about a) practices of nephrologists in Germany regarding the decisions making and selection of living donors, as well as patterns and difficulties in this procedure; b) the attitudes of the survey participants towards altruistic donation, paired-exchanged donation and financial incentives in



living kidney donation. The results will be discussed within the current legal regulatory context in Germany and the growing tendencies within the field of living donation globally. The influence of health care organisational and structural characteristics, as well as cultural influences on practices and attitudes towards living kidney donation will be examined.

## PP40

### FOUR WAYS TO ETHICALLY TRANSPLANT TWO KIDNEYS FROM A LIVING DONOR

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A living donor (D) may face a dilemma when he wants to give a second kidney. This happens in two situations: D has already given a kidney and wants to give a second one (sequential donation), D wants to satisfy two recipients (R) at the same time (simultaneous donation). In a different situation, when the withdrawal of life support (WLS) or euthanasia has been decided, the patient/family could be asked to give one or two kidneys before the WLS or after the cardiac death (DCD). 1) In a sequential donation, D wants to provide quickly a better kidney than a cadaveric kidney, thinking, in the case of a parent to child donation, that the latter could be sufficient for himself. If D is compatible with R, in order to avoid a period of dialysis, I suggest that D should be awarded on the cadaveric waiting list (CWL) by the priority related to the age of his younger R. The double transplantation (Tx) can be done as soon as a cadaveric kidney is available for D. 2). Another option would be to participate in a "circular" Kidney Paired Donation (KPD). The pair is included in a chain and D receives the kidney from the last donor of the chain. This is the only option if D and R are incompatible. It allows to increase the number of Tx due to the chain, the CWL is shortened in proportion to the length of the chain, D receives simultaneously a living kidney, there is no waiting time for a cadaver kidney. 3) In a simultaneous donation, the situation is paradoxically more favorable. The KPD program should be used even if D is compatible with one or two of the Rs. In this case, one R is inserted in the chain with D, and the second R receives the kidney from the last donor of the chain. Even if D has two Rs, he gives only one kidney, he does not have the burden to choose one of the two Rs, none of the Rs receives a kidney from D, they are grafted at the same time. It allows to increase the number of Tx due to the chain, the CWL is shortened in proportion to the length of the chain. 4) Kidney donation before or after WLS should be offered to the potential DCDs as part of the end of life care. The advantages and disadvantages of the "before WLS" option are known and will be discussed. What is totally omitted by the literature is that those kidneys

should be considered as kidneys from Non Directed Altruist Donors (NDAD), which could fuel the KPD programs. The total volume of all kidney Tx would increase by over 50%, and the new marginal donors would be the brain dead donors and DCDs. Conclusion: It is possible to obtain two kidneys from one living D without doing harm. The "before WLS" option and KPD will sharply increase the number and quality of Tx.

## PP41

### PRE TRANSPLANTATION PSYCHOSOCIAL ASSESSMENT OF DONORS IN A LIVING DONOR KIDNEY TRANSPLANTATION PROGRAM

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Background: Psychosocial assessment of donors has been an important issue in Living Donors Kidney Transplantation Programs. This remains a main object of clinical investigation. Since 2003, psychological and psychiatric assessment are regularly performed in candidates for kidney donation, at our hospital. Aims: To describe results from pre transplantation psychosocial assessment of 80 kidney living donors: demographic characteristics, relationship with recipients, motivations to donate, quality of life (QoL) and psychosocial issues; to compare these results between groups and explore possible correlations. Methods: 80 living donor transplantations were performed and all donors completed a psychosocial evaluation protocol: sociodemographic questionnaire, semi structured interview, Hospital Anxiety and Depression Scale (HADS), Living Donation Expectancies Questionnaire (LDEQ), SF-36. Results: Most donors were women (69%), mainly in thirties and fifties; 79% were married, 63% were related, 21% were mothers and 9%, fathers. Considering unrelated donation, wives (n = 14) and husbands (n = 12) were predominant (31,3%). Most of subjects worked (71%); 18% were unemployed. More than 95% considered that pre evaluation had no negative impact on work, social and familial life. 99% referred the desire of improving recipient's QoL, and save their lives, as the main motivations to donate. 60% of subjects had no fear of medical implications of donation and the others expressed worries about their future. Above 85% referred closely emotional relation with recipient. 60% considered they need not time to think and 88% had a spontaneous decision. 92% considered to have enough information about procedures and risks. 98% didn't

feel any pressure for donation. From HADS: 15% had light or moderate anxiety; 98% had normal values for depression. About 15 donors had psychiatric/psychological history and actual psychological symptoms, depressive being the most important (14%); only three subjects had actual psychiatric diagnosis. 7.5% had psychological/psychiatric intervention with follow-up consultations, in 5 because of decision making difficulties. Conclusions: Unrelated donors are more than 1/3 and represent special needs for psychosocial evaluation respecting whether psychological or motivational/ethical issues. A few donors were accepted having some minor psychological issues and they needed follow up. Donors were strong-minded to donate and 60% had no fear of medical implications.

## PP42

### ARE VOLUNTEER BONE MARROW DONORS A SUITABLE SOURCE FOR RECRUITING 'GOOD SAMARITAN' DONORS?

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Renal transplantation is the most effective medical treatment for most patients with renal insufficiency. The limited number of organs available from deceased donors emphasizes the increasing importance of living kidney donors for the growing demand of renal transplants in patients with end stage renal failure. Live donor renal transplantation represents the most promising solution for decreasing the gap between organ supply and demand. Living kidney direct donation (related donors) is a common practice in almost all countries with kidney transplant programs. In the past, only donors genetically related (parents, offspring, siblings, ...) were considered, however, with time, also emotionally related donors such as spouses and friends are used for kidney transplants with similar good outcomes. Living unrelated donors (nondirected donors or "good Samaritans") are exceptions to almost all those countries. Samaritan donors are people who are willing to donate to patients they do not know, but these possible donors were always looked at with reluctance. The main reasons for this reluctance are: the possibility that these donors may not be mentally stable; the difficulty of assuring the principle of beneficence to the donor; and the possibility of exchange, or even commercialization of the organs. The Bone Marrow Donors Worldwide nowadays collects data from more than 25 million volunteer bone marrow donors of more than 50 countries. Volunteer bone marrow donors are very well accepted worldwide and do not have the moral and ethical reluctance of good Samaritans because bone marrow donation is a procedure less invasive and doesn't have the risks and irreversibility of the surgical practice of a living donor nephrectomy. Could be the pool of volunteer bone marrow donors

a good source for recruitment of nondirected organ donors? Volunteer bone marrow donors are already predisposed for donation to unknown patients and we accept that they have a real altruistic motivation in this act. Obviously, screening, evaluation and acceptance of good Samaritan donors must be much more demanding than the screening of volunteer bone marrow donors, although being a bone marrow donor can be a first step to be evaluated for a good Samaritan. If a volunteer bone marrow donor generously and freely expresses his/her will to become a good Samaritan donor should this intention be denied with no more questions? Is the self-satisfaction of helping a patient giving him a kidney, enough compensation for the damage of a nephrectomy?

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## Organ trade and paid donation

## PP43

### COMPLICATIONS OF THE KIDNEY TRANSPLANTATION IN COUNTRIES WITH BLACK ORGAN MARKETS

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Introduction: Until September 2012, many CKD patients went to third-world countries for living unrelated (paid) kidney transplantation, because of the lack of the transplantation program. These patients were deciding on the illegal purchase of the necessary transplantation in black market of organs such as India, Pakistan, or cadaveric transplantation in Russia. Complications these patients came back with were the best indicator how they were dangerous and risky. Methods: Data refer to patients from Montenegro who developed complications after living unrelated and paid cadaveric kidney transplantation abroad, in the period of last twelve years. Results: Among 12 patients who underwent living unrelated kidney transplantation in Pakistan, different complications were observed and treated upon arrival. There were two cases of severe bilateral pneumonia caused by *Pneumocystis carinii*, with a pleural rupture and respiratory insufficiency. One of these patients had tertian malaria, one acute Varicella Zoster infection, one pneumonia caused AH1N1 Influenza. One patient had acute rejection and ileus at the same time; one with suprapubic cystostomy due to unresolved urethral stenosis before transplantation. One male patient developed spon-

taneous rupture of bladder and one rupture of both Achilles tendon. One patient developed acute adrenal insufficiency. Among two patients who underwent living unrelated kidney transplantation in India, one got severe polyoma BK infection and developed rapid loss of graft function. There have been 21 paid kidney transplantations from cadaveric donors performed in Moscow. Hyperacute rejection was noticed in two patients. Both of them underwent a re-transplantation one month after hyperacute rejection. One of them got thrombosis and arterial embolization of the graft. One developed an acute rejection three months after with unresolved urinary obstruction. In one patient abdominal aortic aneurysms was not resolved prior to transplantation, and the rupture occurred afterwards. One patient died after kidney transplantation in coma caused by Creutzfeldt-Jakob disease. Conclusion: Our data show that over 50% of patients in group of living unrelated transplantation have returned with complications, as well as over 50% in the group of patients with deceased donor transplantation. A possible cause of high incidence of complications was the inadequate preoperative evaluation. Many of the patients were sent without treatment of post-operative complications. This gave us motivation to work on the establishment of the transplant system.

#### PP44

##### CURRENT STATUS OF ORGAN PROCUREMENT FROM PRISONERS IN CHINA

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China is the only country in the world systematically using organs from prisoners for transplantation. For four decades, China's transplant medicine relied on organ procurement from executed prisoners. On December 3, 2014, the director of the China Organ Donation and Transplantation Committee and former vice-minister of health, Jiefu Huang, announced that China would completely cease the use of prisoner organs for transplantation after January 1, 2015. However, the announcement of December 2014 is neither a law nor a governmental regulation and has itself no force of law. Nor is it followed by any changes to China's organ donation laws/regulations. Chinese transplant officials have repeatedly, also after January 2015, stated that death-row prisoners have the same right as regular citizens for organ donation; they are allowed, or even encouraged to donate organs voluntarily. These prisoner organs are now simply classified as "voluntary donations from citizens". By re-defining prisoners as regular citizens for "voluntary" organ donation, China's national organ donation system whitewashes the use of organs from both death-row prisoners and prisoners of conscience. Since 2006, mounting evi-

dence suggests that prisoners of conscience are killed for their organs in China with the brutally persecuted Buddhist practice, Falun Gong, among others, being the primary target (see European Parliament resolution of December 12, 2013). To end the abuse, the use of organs from any kind of prisoners in China must be prohibited by law. China must make its organ donation system transparent and verifiable to independent professional organizations and open to international inspections to gain credibility.

#### PP45

##### TISSUE AND CELL'S TRAFFICKING: A BYPRODUCT OF TRANSPLANT ACTIVITY'S TRASH. THE FUTURE IS NOW. A PUBLIC HEALTH PROBLEM

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Transplantation is one of the most beautiful achievements for humanity in the last century and became the last hope to many patients. As other beautiful achievements, it has been used by criminals. The future of transplantation will be focused on tissue and cells transplantation. Trafficking of human beings to organ removal and trafficking of human organs are an early stage of trafficking on tissues and cells comparable with slaves trafficking in the 17th and 18th century. As 400 years ago, the motive for the crime is development, economy and profit. Transplant surgery is the modern "cotton gin" to this new commerce. Poverty exploitation, unprotected people, are always the victims. Even so, there are some differences since then. The paying buyers are the patients themselves and the "cotton" transplanted is not so harmless. Unsafe tissues and cells inappropriately collected and allocated can be so dangerous to the recipient and his family, that the dreamed transplant/implant becomes a nightmare. Beyond the trafficking crime, there is a most dangerous associated crime that is the crime of spreading dangerous infectious diseases. The infectious diseases transmitted by human body parts, if not correctly screened by medical history and screening tests, are a public health hazard because the live vehicles have free pass inside their communities. So, this crime is committed against a potentially countless people, being very difficult to track the spreading of virus as HIV, HCV and

HBV. This crime is not fiction. AIDS and Hepatitis were spread by this way by companies selling human parts (skin, bones, vessels, cornea, tympanic membrane, etc.) collected in morgues and sold as medical or dental products implanted in small clinics, offices dentists, otolaryngologists, ophthalmologists, etc. It has been spread HIV, HCV and HBV infection by this kind of trafficking and are not yet visible control measures to this reality. Polices around the world also seem not yet enough worried about this. The value of shares on the stock exchange of the companies working with regenerative medicine and stem cell treatments is one of the largest in recent years and so the crime in these areas is potentially more attractive, being public banks a preferential target of attack by these criminals. Universities and patient associations, as well as research international consortia can be searched as a cover for international networks that organize this type of trade. The collaboration between public health authorities and international police is urgent.

#### PP46

##### ILLEGAL TRANSPLANT AND MEDICAL RESPONSIBILITY UNDER THE LIGHT OF LAW AND ETHICS

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Human organ trade is based on one fact: Desperation. Both donor and recipient are desperate. The first for money, the second for health, yet both are desperate for survival. Black market «balances», with the right 'price', this desperation as well as the disproportion between high organ demand and poor supply. In that way, the patient avoids long transplant waiting lists and the donor directly receives money for his organ. Illegal transplants exist when the organ to be transplanted is illegally purchased and they are a worldwide phenomenon. Tracing the organ back to the donor is extremely difficult while there are surgeons that perform those transplants knowing that their colleagues won't report them. Donors will not talk, in fear of prosecution and in some cases the hospital staff itself knowingly becomes involved. All that in contradiction to the Oath of Hippocrates, dating back to 5th century BC and stating that the physician should always behave in an altruistic manner towards the patient. Medical responsibility, especially in cases of illegal transplants, is set under the European and international legislation as well as the rules of medical ethics and moral conduct. Its importance becomes even more crucial due to the rapid developments in the field of biomedicine and the continuous increase in global demand for human organs, cells and tissues, creating difficult moral dilemmas for health professionals that need to be addressed.

#### Psychosocial aspects

#### PP47

##### EVALUATION OF THE MEDICAL AND PSYCHOSOCIAL OUTCOMES OF A YOUNG ADULT CLINIC FOR KIDNEY TRANSPLANT RECIPIENTS: RESULTS FROM INTERVIEWS WITH YOUNG PATIENTS

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Transition from pediatric to adult care can be a challenging process. For many, it is associated with lowered adherence to medical regimen, episodes of rejection, graft failure or loss, and sometimes mortality. Self-Determination Theory (SDT) states that patients who perceive their healthcare environment as autonomy supportive will feel motivated and competent in managing their condition and show increased adherence. Guided by SDT, which has found empirical support in other clinical populations, our objective is to conduct an evaluation of the medical and psychosocial outcomes of the Young Adult Clinic (YAC) set up at Centre Hospitalier de l'Université de Montréal (CHUM) in 2008 in an effort to create a more patient-centered environment for young kidney recipients. A mixed method design, combining quantitative data obtained by means of self-reported, empirically validated questionnaires and review of medical records for all patients (N = 50-55) and qualitative interviews with a subset of them (N = 10-12, or until saturation) will be employed. Qualitative data presented here was analyzed using Interpretative Phenomenological Analysis. Quantitative data will be subjected to statistical analyses to test the explanatory value of SDT. Qualitative results thus far suggest that key factors have had a positive impact on patients experience: the smooth transition, the degree to which they feel supported in developing autonomy, the presence of pediatric nephrologists to help bridge transition, being with patients of the same age, the informal and personalized approach and the health care providers' flexibility & availability. To our knowledge, the CHUM's YAC is a unique example of a clinic tailored specifically to the needs of young renal transplant recipients and transfers. Our data will provide new knowledge and a point of reference that may help guide future efforts by other centers to develop comparable services.



## PP48

**HEALTH TRANSITION AFTER LUNG TRANSPLANTATION**

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**Aim:** This study aimed to explore lung transplant recipients (LTRs) process of transition, from prior to the transplantation until one year after. The LTRs main concerns and how they dealt with these concerns were also studied. **Background:** Lung transplantation (LUTX) is an established treatment for patients with end-stage pulmonary disease. Lung transplantation requires some kind of transition for the LTR. However, this has to our knowledge not previously been studied. **Methods:** An inductive approach with Grounded Theory (Charmaz, 2010) was utilized. The inclusion criteria were adult LTRs who were due to their 12 months follow-up after transplantation. The participants were consecutively included from the two centers in Sweden performing LUTX. In total, ten males and five females (n = 15) were interviewed with open-ended questions. **Results:** The generated grounded theory consisted of the core category Reconstructing daily occupations and four main categories: Restricting, Regaining, Reorganizing and Enriching daily occupation. The common denominator for the informants was their active efforts to regain and reorganize, i.e. reconstruct their daily occupations and thereby experience good health. A key approach through the process of change was the LTRs adjustment to various physical demands, complications and changes in everyday life. A trajectory of health-transition was identified which started before the transplantation with the lung disease and severe illness, and lasted up to one year after the transplantation and most probably beyond this. **Conclusions:** The result demonstrates a strong relationship between reconstructing daily occupations and experiencing good health. This result makes it possible for health care professionals to promote health by supporting the LTRs in their striving for reconstruction of their daily occupation. We suggest that the existing multidisciplinary transplant teams also include an occupational therapist which enables guidance and support to the LTRs.

## PP49

**"IF YOU LOSE IT, IT'S GONE. THIS IS YOUR ONLY CHANCE." PERSPECTIVES OF ELDERLY KIDNEY TRANSPLANT RECIPIENTS ON KIDNEY TRANSPLANTATION: AN INTERVIEW STUDY**

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**Background:** Elderly recipients are susceptible to cognitive impairment, frailty, comorbidities, immunosuppressive complications, and chronic graft failure, which pose specific challenges in post-transplant care and self-management. We aimed to describe the attitudes and experiences of elderly kidney transplant recipients to inform strategies that address their needs. **Methods:** Face-to-face semi-structured interviews were conducted with 30 kidney transplant recipients aged 65 years and over, purposively sampled from 5 renal units in Australia. Transcripts were analyzed thematically. **Results:** Six themes were identified: restoring vitality of youth (revived mindset, embracing enjoyment of life, drive for self-actualization); persisting through prolonged recovery (yielding to ageing, accepting functional limitations, pushing the limit, enduring treatment responsibilities); imposing sicknesses (combatting devastating comorbidities, painful restrictions, emerging disillusionment, anxieties about accumulating side-effects, consuming treatment burden); prioritizing graft survival (privileged with a miracle, enacting a moral duty, preserving the last opportunity, negotiating risks for longevity); confronting health deterioration (fear of dependence, vulnerability and helplessness, narrowing focus on immediate concerns, relying on support, uncertainty of survival); and value of existence (refusing the burden of dialysis, alive at all cost, contemplating life's trajectory, trusting physicians). **Conclusions:** Kidney transplantation restored vigor and vitality in elderly kidney transplant recipients. However, the slow convalescence, and burden of managing comorbidities and complications were sometimes unexpected and overwhelming. Preparing elderly recipients for self-management responsibilities, clarifying their expectations of post-transplant outcomes, and providing support through prolonged recovery, may improve satisfaction and empower elderly



recipients to preserve what they perceive as their last transplant opportunity.

## PP50

### ATTITUDE PROFILES TO IDENTIFY PATIENT PERSPECTIVES ON THEIR OWN MEDICATION ADHERENCE

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**Background:** Nonadherence after kidney transplantation can lead to poorer clinical outcomes and is common among young adult kidney recipients. In a previous study by Tielen et al., four attitude profiles towards medication nonadherence were found. In this study we investigated whether attitude was related to actual adherence behaviour. **Methods:** A cross-sectional study was conducted among renal transplant patients aged 20 to 30 years. In addition to sociodemographic and medical characteristics we performed the BAASIS-interview (Basel Assessment of Adherence to Immunosuppressive Medication Scale). The first four questions produce a categorization of adherence vs nonadherence in the last four weeks (BAASIS). Additionally patients rated their overall medication adherence on a visual analogue scale whereby 0-95% was classified as non-adherent and 95-100% adherent (VAS). Participants were also asked to rate the extent to which they identified themselves with the following attitude profiles: (a) concerned and controlled, (b) appearance orientated, (c) opinionated and independent, and (d) easy going and pliable. **Results:** Sixty-two patients participated (66% men; mean age 26 yrs). Sixty-five percent were classified as nonadherent in the past month (BAASIS). There was no difference in adherence using the BAASIS between the profiles. According to the VAS scale, patients in profile A rate themselves as adherent while patients in profile D rated themselves nonadherent. Notably all five patients in profile D were men. In profile C every young adult works while in profile A most were unemployed. **Conclusion:** The nonadherence rate was high among these young adults. Attitude profiles were related to patient's subjective rating of their adherence using the VAS. The added value of attitude profiles is that they give more information about patients' preferences. Asking which attitude profile young patients identify themselves with in the clinic could be a useful tool to assess risk of nonadherence.

## PP51

### SOCIOECONOMIC DEPRIVATION AND BARRIERS TO LIVE-DONOR KIDNEY TRANSPLANTATION: A QUALITATIVE STUDY OF DECEASED-DONOR KIDNEY TRANSPLANT RECIPIENTS

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Socioeconomically deprived individuals with renal disease are less likely to receive a live-donor kidney transplant than less deprived individuals. This qualitative study aimed to identify themes that might explain the observed socioeconomic disparity in live-donor kidney transplantation. Semi-structured interviews with 32 UK deceased-donor renal transplant recipients were performed and analysed using the constant comparison method described in Grounded Theory. Deceased-donor renal transplant recipients were selected with the aim of identifying barriers to those eligible for transplantation, but specific to live-donor transplantation. Purposive sampling selected interviewees from areas of high SED, followed by a comparison group of individuals from areas of low SED, aiming for maximum diversity in terms of age, gender, ethnicity, primary renal disease and previous renal replacement therapy. Themes common and distinct to each group emerged. Six themes appeared to differentiate between individuals from areas of high and low SED. Four themes emerged almost exclusively from interviews with participants from areas of high SED: i) Passivity in clinical encounters, ii) Disempowerment in clinical encounters, iii) Lack of social support from potential donors, and iv) Short-term health focus. Two themes emerged almost exclusively from interviews with the low SED group: i) Financial concerns for donors, and ii) Location of donor. Several of the emerging themes from interviews with high SED individuals related to low levels of patient activation, defined as an individual's knowledge, skill, and confidence for managing their health and health care, suggesting socioeconomic deprivation describes more than merely low income. In keeping with this, financial concerns did not emerge as a barrier from interviews with the high deprivation group. Interventions aiming to redress the observed socioeconomic inequity should therefore be targeted at both patients and clinical teams to increase empowerment, and to ensure shared decision-making.

## PP52

# PATIENTS' PERSPECTIVES ON CARDIO-VASCULAR RISK FACTORS AFTER KIDNEY TRANSPLANTATION

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Background: Cardiovascular (CV) disease is a major cause of mortality in kidney transplant recipients (KTRs). These patients have a high prevalence of risk factors such as hypertension, diabetes and dyslipidemia. Despite their regular medical care, few of these patients reach the recommended therapeutic targets. One hypothesis to explain this phenomenon is that the prevention of CV disease is not a priority for patients, leading to poor adherence to treatment plan. In a patient-centered approach, knowing the preferences and priorities of KTRs could improve the management of CV disease in KTRs and potentially reduce the mortality. Methods: 20 adult KTRs participated in a semi-structured interview about their personal experience, and perspective on CV risk factors post-transplant. The interview was digitally recorded and transcripts were analyzed using thematic and content methodology. Results: CV risk factors seem underestimated and few see the relationship with kidney transplantation and post-transplant care. Patients were concerned about getting better knowledge and education on CV risk factors post-transplant. Success was defined in terms of graft function and survival whereas failure was defined as graft rejection and going back to dialysis. Transplant survival was considered the main priority post-transplant accepting other consequences and risks as part of the price. Other post-transplant priorities are related to the short-term adaptation to daily life (e.g. transportation to the clinic, mental health, employment, etc.). Conclusions: KTRs' first priority post-transplant is the transplant survival disregarding other potential risks like the CV risk factors. These results will help to better understand the priorities of patients in their post-transplant care and their perspectives on CV risk factors and their management. This knowledge will help develop an individualized and patient-centered approach on these kidney-transplant recipients.

## PP53

# THE DEVELOPMENT OF A NURSE-LED SELF-MANAGEMENT INTERVENTION FOR KIDNEY TRANSPLANT RECIPIENTS USING INTERVENTION MAPPING: THE ZENN-STUDY

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Background: Improving self-management is a potential way to optimize post-transplant outcomes. However, proven effective interventions aimed at promoting self-management after kidney transplantation are limited. The objective of this study was to describe the systematic development of a nurse-led self-management intervention for kidney transplant recipients. Methods: The Intervention Mapping approach was used in order to develop a pilot intervention which incorporates patients' needs, theories and evidence based methods. The needs of kidney transplant recipients were assessed by reviewing the literature, conducting focus groups and a Q-methodological study (step 1). Based on the needs assessment change objectives were formulated (step 2). Evidence-based methods to achieve these objectives were selected and subsequently translated into practical implementation strategies (step 3). The intervention protocol was developed accordingly (step 4). Implementation is scheduled for November 2015 to June 2016 (step 5), and feasibility will be evaluated using a pre-post questionnaire and interviews with patients and medical staff (step 6). A patient advisory committee as well as an expert steering group advised on the development throughout the process. Results: The intervention is designed to improve self-management utilizing evidence-based methods derived from health behavior change theories, principles of solution focused brief therapy and motivational interviewing. Four sessions, each of them takes 15 minutes, are added to the standard medical care provided by the nurse practitioners in the outpatient clinic. In this series of sessions, patients will be encouraged to develop goal setting, action planning and pursuit skills and apply these to self-management issues they currently face. Conclusions: The intervention mapping approach provided a useful framework for integrating patients' needs, evidence and theories in intervention development.

## PP54

### THE MESI: A NEW QUESTIONNAIRE FOR ADHERENCE EVALUATION IN FRENCH TRANSPLANT PATIENTS

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**Background:** Therapeutic adhesion is a critical determinant of transplantation outcome, with an increased risk of late rejection, chronic allograft dysfunction and graft loss in low-adherent patients. However, both the prevalence and the impact of poor adherence are underestimated. Numerous questionnaires dedicated to adherence and compliance evaluation are available, but most of them have been developed and validated in other therapeutic fields, such as arterial hypertension. In transplantation, about 20 questionnaires have been developed, but none of them has been validated in the French language. The aim of this study was to translate in French and validate the MESI (Medikamenten-Erfahrungs-Skala für Immunsuppressiva), a questionnaire developed in Germany evaluating patients' adherence to immunosuppressants in transplantation. **Methods:** The MESI was transculturally adapted using the international guidelines (the Guillemin protocol) and its psychometric properties were assessed: reliability (intra-observer reproducibility, Kappa coefficient, and the Cronbach's alpha) and validity (content, criterion, and construct validity evaluated by exploratory factorial analysis). A cross-sectional study was conducted in 160 kidney, liver, lung and heart transplant recipients). The MESI and Morisky 8-items (MMAS-8) were applied at the same time. Patients' adherence was considered limited for MESI > 15. **Results:** The pre-test conducted on the final version of the transculturally adapted MESI showed no difficulties in understanding its content. The French MESI displayed characteristics comparable to those of the German version, with good accuracy, preciseness and reliability: intra-observer reproducibility variance = 0.126, Cronbach's alpha = 0.78 [0.70-0.83], weighted Kappa coefficient = 0.70. Exploratory factorial analysis demonstrated unidimensionality of the first three questions ( $r > 0.85$ ). There was no correlation between the adapted MESI and MMAS-8 ( $\rho = -0.19$ ,  $p = 0.5$ ). **Conclusions:** The MESI is the first validated questionnaire dedicated to

the evaluation of adherence in French-speaking transplant patients. Its adequate psychometric properties allow the assessment of patients' experiences and attitudes towards their immunosuppressive treatment, early after transplantation and thereafter. The low correlation between the MESI and the MMAS-8 may be explained by the fact that these two instruments do not exactly measure the same outcomes, the MESI being an adherence questionnaire while the MMAS-8 is rather a compliance questionnaire.

## PP55

### ANALYSIS OF STUDIES ON COMMUNICATION IN ORGAN DONATION AND TRANSPLANTATION

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**Objective:** Planning and implementing communication measures in the field of organ donation and transplantation (ODT) requires broad expertise. To obtain a general overview on how the topic is presented in literature, an analysis of studies was conducted. **Aim** was to investigate the state-of-the-art in developing and evaluating communication measures – especially campaigns – and to derive some recommendations on how to effectively communicate about ODT. The present analysis was part of a joint action called FOEDUS (grant agreement n. 20122101), funded by the EU and led by ISS-CNT. **Method:** The task was completed in different sections. Within a literature search, a review of important publications was conducted on the basis of the search terms “organ donation”, “transplantation”, “communication”, “campaign”, “media” and “evaluation”. Findings were analysed regarding their focus and conclusions. Where possible, recommendations were extracted. **Results:** The analysis of studies provided important insights into the state-of-the-art of campaigning in ODT. Despite a limited number of findings, helpful information was obtained and numerous strategic and operational recommendations extracted. **Conclusions:** An analysis of state-of-the-art publications is pivotal when developing a communication strategy or single communication measures as one can benefit from gained experiences and good practices. The approach and specific results of the analysis of studies can be presented at the ELPAT congress. (Marie Lingemann, Danica Avsec, Bernarda Logar Zakrajšek and Thomas Breidenbach on behalf of FOEDUS WP7 members.)

## PP56

### FACTORS AFFECTING MEDICATION ADHERENCE AMONG KIDNEY TRANSPLANT RECIPIENTS

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**Introduction:** Adherence to therapeutic recommendations, related to drug administration, diet and healthy lifestyle, is necessary to obtain optimal medical treatment effects. Medication adherence is crucial for graft preservation and survival among renal transplant recipients. Medication non-adherence can be considered as a phenomenon that emerges from the interaction of socioeconomic, psychological and health-care system related factors. Previous evidence in other medical conditions has shown that personal factors such as social support are strongly associated with adherence to therapy. **Aim:** The aim of the study were to assess the level of medication adherence among our kidney transplant recipients, to identify potentially modifiable risk factors and their associations with medication non-adherence. **Materials and Method:** This cross-sectional study was performed on 50 kidney recipients who were at least 6 months post-transplant. Participation in the study was voluntary and anonymous, in order to obtain reliable answers. Medication adherence was assessed by using the 8-item self-reported Morisky Medication Adherence Scale (MMAS-8). Also, all study participants were evaluated with the 12-item Multidimensional Scale of Perceived Social Support (MSPSS) and Beck Depression Inventory (BDI). Data on patients' demographic, socioeconomic and living status, information about recipient's lifestyle and habits were collected using a non-standardized questionnaire. **Results:** The mean age of the study participants was  $39 \pm 8$  years and 21% were active smokers. The majority or 71% reported high medication adherence, while 23% medium level. The remaining 6% scored between 3 and 8 on the 8-point MMAS were patients with low medication adherence. Among demographic factors, we found the lower socioeconomic level ( $p = 0.019$ ) and lower educational level ( $p = 0.02$ ) to have a significant diminishing effect on the medication adherence. Non-adherence was associated with increased depression ( $p = 0.01$ ) and active smoking ( $p = 0.003$ ). We found a significant correlation between medication non-adherence and lower social support ( $p = 0.0001$ ). Our results suggested that the main sources of social support in our participants, were family members and significant others. **Conclusion:** Our results suggest possible targets for future intervention intended to increase medication adherence among kidney transplant recipients.

## PP58

### PSYCHOSOCIAL EFFECTS OF TRANSPLANTATION IN GROUP OF PATIENTS RECEIVING KIDNEY FROM LIVING DONORS AND GROUP OF PATIENTS RECEIVING KIDNEY FROM DECEASED DONORS

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**Introduction:** There are numerous and widely known reports regarding health benefits for recipients getting organs from living donors. But evaluation of life quality in this group of kidney recipients in comparison to the group of those who received a kidney from deceased donors, is a question of no less importance. **Material and Methods:** 89 patients with transplanted kidney took part in the research. 48 received an organ from living donors (LD) and 41 from deceased donors (DD). The researchers gathered data through interviews (regarding patients state of being) and parameters evaluating directly state of transplant and patients health. All participants filled in standardized questionnaires – life quality tool (WHOQOL-BREF) and an authorial form prepared especially for kidney transplant patients (KBpP). **Results:** Health state of recipients have been evaluated through indirect (information from interviews) and direct methods (laboratory tests results). The effects were similar in both recipients groups. However, the differences have been observed in psychosocial factors: higher level of gladfulness ( $p < 0,01$ ) and feeling of self-efficiency ( $p = 0,07$ ) in the LD kidney recipients group. Those patients were also more active in social life ( $p < 0,02$ ) and more satisfied with social relations ( $p = 0,07$ ). The LD group life quality was also higher in terms of psychological functioning ( $p < 0,01$ ) and contentment with their life environment. **Conclusions:** The results indicate that patients receiving a kidney from living donors can benefit more in terms of psychosocial profits. Results of the research show as well, what type of support would be suitable for transplant patients to achieve high quality of life after the transplantation. The most important is a combination of medical care, aware support of patients' close ones, and emotional-cognitive help in adapting to a new life situation.



## PP59

### THE AFFECTIVE TONE OF NARRATION AND POSTTRAUMATIC GROWTH IN ORGAN TRANSPLANT RECIPIENTS

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The aim of the study was to verify the hypothesis that positive affective tone of narratives is connected to the experience of posttraumatic growth among transplant patients. Kidney transplant patients (N = 51) and liver transplant patients (N = 48) participated in the study. In the first stage, about 10 weeks after transplant, the participants told two stories about important, freely chosen events from their lives. During the second meeting 10-12 months later, we measured posttraumatic growth. Results indicated that the affective tone of narratives about past events was associated with the level of post-traumatic growth measured 10-12 months later. This proves that the affective tone of narratives about life, understood as a relatively constant individual characteristic, promotes posttraumatic growth.

## PP60

### ASSESSMENT OF MOTIVATION IN LIVING ORGAN DONORS. A LITERATURE SEARCH AND DISCUSSION

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The literature addressing the assessment of motivation of live organ donors was reviewed. Transplant professionals have felt that an essential part of the process of the work-up of a potential live organ donor is an assessment of the donor's motivation, which includes; – Is there financial inducement – Are there social pressures on the donor – Is there some form of coercion – What is the donor's relationship to the recipient – What is the donor's expectation of the recipient outcome – Can the donor express a valid reason for donating? However, there is no consistent position as to what the answers to the questions should be, and as to what influence these might have on the outcomes to the live donor. Moreover in the last 50 years the perception as to what the acceptable answers are to these questions has changed, leading to inconsistency between transplant centres approaches. Shaw has recently commented that donors can find the gathering of information to assess motivation as anxiety provoking and stressful. Crammond et al in the 1960's noted that they thought it very important for the transplant team to avoid a "Jehovah complex". Many authors have noted that potential live

donors make their decision to donate (or not) at an early stage of the process and then use the information they receive from professionals to justify this decision. This includes their reasoning behind the decision to donate which is widely varied and includes; moral obligation, religious conviction, parental or familial responsibility, and societal ethic or imperative. There is substantial variation between cultures as to what the pressures are that might be placed on a donor and many donors see these as being acceptable and part of the "real" situation that they find themselves in; conversely transplant professionals often feel that they need to guard against these pressures. It is timely to re-think what the purpose of our "motivation assessment" is and what role the assessment should have, with respect to the decision by the transplant team as to whether the prospective donor should be "allowed" to proceed to donation or not.

## PP61

### ALCOHOLIC LIVER DISEASE: PSYCHOSOCIAL ASPECTS AND CONTROVERSIES IN LIVER TRANSPLANT CANDIDATES

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In Europe, 30% to 50% of liver transplants are currently due to alcoholic liver disease. Post-transplant survival and other predictors of clinical course do not differ significantly from those in other types of transplanted patients (as long as there is no relapse of drinking). A significant percentage of these patients lapse or relapse to heavy drinking post-operatively which has been associated with an increased risk of liver damage and mortality. It is therefore crucial to design specific selection and follow-up strategies aimed at this particular type of patient. In this presentation we discuss several good and poor prognosis factors as well as others more controversial. We also intend to review several definitions of post-transplant relapse, its monitoring and the psychopharmacological and psychotherapeutic treatment.



**PP63****BEYOND THE BODY: DIFFICULT PATIENTS IN LIVER TRANSPLANTATION**

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The constant scientific evolution that has occurred in the field of liver transplantation, with the decrease of mortality and morbidity, and the consequent increase of life expectancy, has permitted a bigger understanding about the transplant process, where the psychosocial variables involved mark their influence. Each patient has an unique subjective position – an unique way of being – that follows a particular psychological structure through which he or she deals with and manages “the process of becoming ill”, the perspective of an imminent major surgery and the experience of “the other in him or herself” – the symbolic representation of an organ transplantation. That said, we understand the transplant process as a singular and remarkable life event with different levels of elaboration and anguish, that are heavily influenced by the individual’s history. It is known that the effectiveness of a liver transplant largely depends on the active role of the patient in what concerns the adherence to immunosuppressive medication, the presence to doctor’s appointments, a lifestyle changes in general, because non-adherence is one of the leading causes of organ failure and a possible death. Building upon the well known human difficulty with the acceptance and the sustainability of change, particularly in such a complex situation as a liver transplant is, the role of the transplant team involved may have a preponderant impact in the increase of adherence probabilities. Given the fact that numerous human, psychological and ethical variables, both from the patients and health care professionals, affect the liver transplantation process, we can now rethink the importance of the doctor-patient relationship, leading us to a question: are there “difficult” patients or relationships difficulties?

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We welcome all contributions that enhance or illuminate relevant practice and science.

All material is assumed to be submitted exclusively to ELPAT: via e-mail. The Editor expects adherence to the principles outlined by the committee on Publication Ethics ([www.publicationethics.org.uk](http://www.publicationethics.org.uk)).

The manuscripts are written in clear, grammatical English.

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*Full-length reports of completed research* should not exceed 3,000 words of text, with an abstract of not more than 200 words, no more than 50 references and a combined total of no more than 10 tables or figures.

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*Full-length reports of completed research* must conform to the following format:

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*Page 3: Abbreviations.* This page should list abbreviations not likely to be familiar to the reader. They should be listed alphabetically with their meanings. Please do not abbreviate terms unless they are used frequently.

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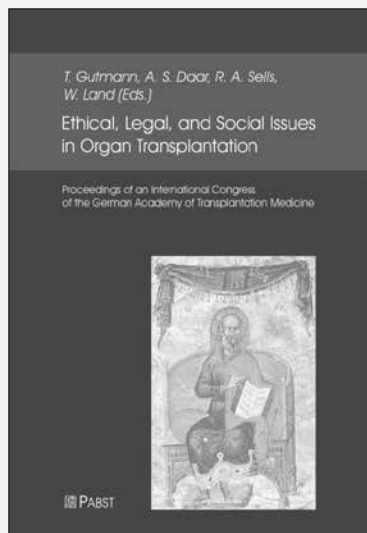
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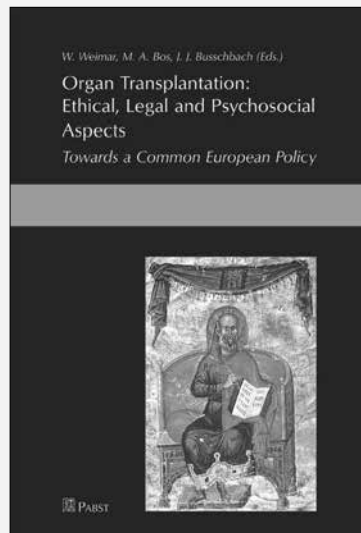
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- Commercialization and trafficking;
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The ELPAT platform is initiated with the aim to establish continuity in European communication on 'Ethical, Legal and Psychosocial Aspects of Organ Transplantation (ELPAT)', after several ad hoc conferences had been organised in the last two decades. ELPAT is thus an attempt to facilitate and structure the European research area in this field of science. It is now an official body within the European Society for Organ Transplantation.

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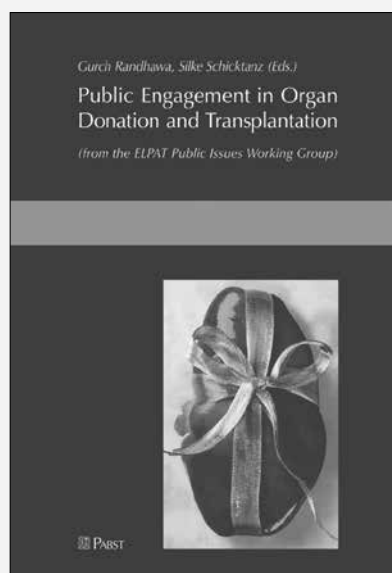


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## Public Engagement in Organ Donation and Transplantation

(from the ELPAT Public  
Issues Working Group)



2013, 176 pages,  
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Public campaigns in different European countries highlight an increasing awareness that public acceptance of organ donation is a crucial factor for the medical field of organ transplantation. However, addressing this complex matter requires a fresh perspective as to how governments truly engage with their public on issues which touch upon health care, morbidity, and mortality.

In this volume, eighteen contributions provide a timely review of how, in different countries and contexts, engagement and understanding of the public regarding organ donation can and should be investigated. The book provides detailed recent analysis of cultural impacts and religious attitudes of communities, patients, and even professionals. Furthermore, various forms of public engagement, including dialogues, campaigns, and media are discussed from methodological as well as theoretical perspectives. This volume offers new insights in how we gain a better understanding of public hopes and fears, interests and concerns about particular developments within organ donation and transplantation.

All contributors are members of the European Platform ELPAT (Ethical, Legal and Psychosocial Aspects of organ Transplantation).

Gurch Randhawa is Professor of Diversity in Public Health at the University of Bedfordshire, United Kingdom.

Silke Schicktanz is Professor of Cultural and Ethical Studies of Biomedicine at the University Medical Center Göttingen, Germany.

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