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European Society
for Organ Transplantation

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3rd ELPAT CONGRESS

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

20-23 APRIL 2013

**World Trade Center
Rotterdam
The Netherlands**

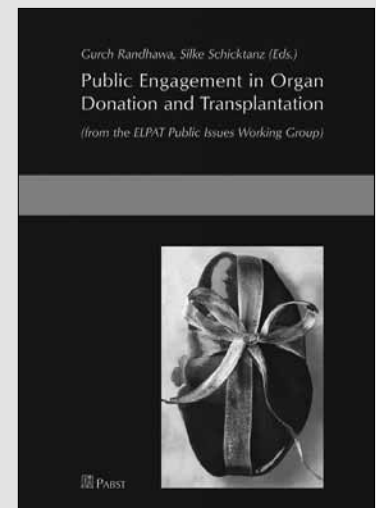
*The 3rd ELPAT congress has received
funding from the European Union in the
framework of the Health Programme*



G. Randhawa, S. Schicktanz (Eds.)

Public Engagement in Organ Donation and Transplantation

(from the ELPAT Public Issues Working Group)



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.

176 pages · ISBN 978-3-89967-821-5 · Price: 20.– Euro



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

Painting on the cover by Gerrit Huisman

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).

432 pages, ISBN 978-3-89967-639-6, Price: 45,- Euro



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Welcome!

It is with pleasure that I welcome you on behalf of the organizing committee to the 3rd ELPAT conference in Rotterdam on Ethical, Legal, and Psychosocial Aspects of Organ Transplantation. After two successful conferences in Rotterdam, ELPAT has become a permanent platform for the exchange of information, ideas and expertise in these fields. ELPAT is an official section of the European Society for Organ Transplantation (ESOT).

We are honoured to announce our congress as a joint event between ELPAT, ESOT and the International Transplantation Society (TTS). With 'Global Issues, Local Solutions' as our main theme, the focus is on bridging the divide between international commitments, global outreach and the realization of their potential to improve the lives of patients across the world.

The 3rd ELPAT conference is receiving funding from the European Commission. It addresses the following themes: Cultural and Religious Aspects of Living and Deceased Donation, Cross-Border Transplants, Psychosocial Care, Autonomy at the End of Life, Public Issues and Children as Donors and Recipients.

There will be invited lectures, workshops, and 'focus sessions' covering the various ethical, legal, and psychological aspects of organ transplantation. These topics will also be discussed in free communication sessions. I'd like to invite you to actively take part in these discussions.

Wishing you a fruitful conference,
on behalf of the organizing committee,



Willem Weimar,
Chair



Organization

Organizing Committee

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Mike Bos
Jan van Busschbach
Frank Dor
Gert van Dijk
Bernadette Haase-Kromwijk
Emma Massey
Axel Rahmel
Willem Weimar (Chair)
Jan IJzermans
Willij Zuidema

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General Information

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Venue

Beurs-World Trade Center
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 Beursplein 37
 3011 AA Rotterdam
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Phone: +31 10 405 44 44
 Fax: +31 10 405 50 16
 E-mail: info@wtcro.nl
 Internet:
 www.wtcrotterdam.nl



The Beurs-WTC is located in the city centre. The building is highly distinctive, thanks to its elliptical 90 meter tower with green glass facades.

Congress Registration

The registration desk is located in the Shipping Hall (ground floor).

Opening hours are:

Saturday, 20 April	13:00 – 19:00
Sunday, 21 April	08:00 – 18:00
Monday, 22 April	08:00 – 18:00
Tuesday, 23 April	08:00 – 14:00

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.

This conference is supported by



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 supported by



'The 3rd ELPAT congress has received funding from the European Union in the framework of the Health Programme'

Media

Contact

In case of queries please contact the press officer of the conference:

Frans Meulenberg
E-mail: f.meulenberg@erasmusmc.nl
Phone: +31 (0) 6 51841074

Internet

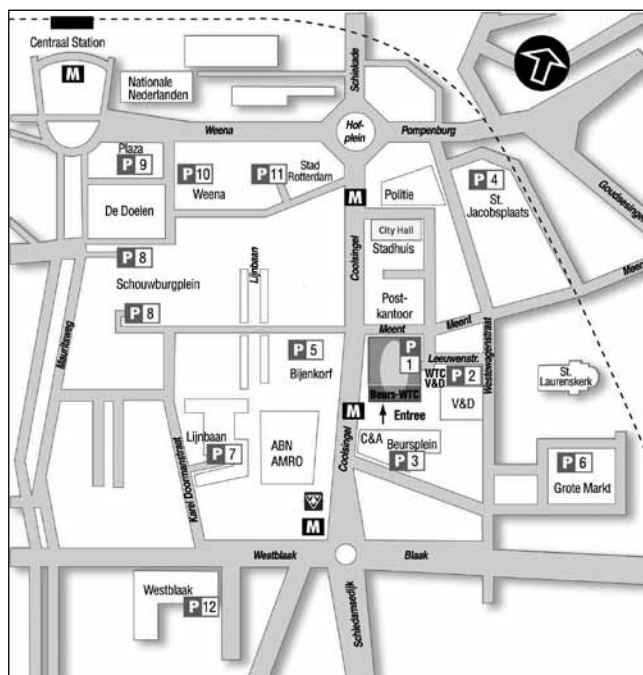
Wifi internet access is available.

Sign in with:

Username: ELPAT

Password: ELPAT

Map of city centre



Travel Information

Schiphol Airport (main airport) in Amsterdam has a direct train connection with Rotterdam Central Railway Station. Trains run just under one hour or under 30 minutes by the Fyra high-speed train for a small surplus.

See: <http://www.ns.nl/en/travellers/home>
or <http://www.nshispeed.nl/en> for the timetable and prices.

From **Rotterdam Airport** you can reach the city centre of Rotterdam by car in 15 minutes and by bus (no. 33) within half an hour.

Local Transportation

Walking:

You can walk in approximately 10 minutes to Beurs-WTC. Follow the signs 'Stadhuis' or 'Beurs'.

Public transport from Rotterdam Central Railway Station:

Beurs-WTC is easily to reach both by car and by public transport. In front of the building you can find subway and tram station 'Beurs'.

Metro: Take the subway and get off at station 'Beurs' (second station), exit 'Beursplein'.

Tram: Take tramline 8, 21, 23 or 25. Get off at the Coolingsingel in front of the ABN-AMRO Bank.

For tram and metro an OV-chipcard is needed.

RET OV-chipcards

(http://www.ret.nl/service-en-verkoop.aspx?sc_lang=en)

Additional information about public and local transport:

train: <http://www.ns.nl/cs/Satellite/travellers>

bus, metro, tram: http://www.ret.nl/service-en-verkoop.aspx?sc_lang=en

all public transport: www.9292ov.nl

By car:

Beurs-WTC has her own car park and the possibility to make use of the adjacent WTC-V&D car park. For more information visit www.wtcrotterdam.com.

Visitor centres



City promotion centre ROTTERDAM.INFO

Coolingsingel 195-197 (entrance Binnenwegplein)

3012 AG Rotterdam

Phone: +31 10 7900185

E-mail: info@rotterdam.info

Internet: <http://en.rotterdam.info/visitors/>

Opening hours: Mon – Sun 9:30 – 18:00

VVV Rotterdam Info Café

Stationsplein 45 (entrance Weena)

3013 AK Rotterdam

Opening hours: Mon – Sat 9:00 – 17:30

Sun 10:00 – 18:00

ROTTERDAM APP

The Rotterdam App is a free mobile application that highlights the very best that Rotterdam has to offer. To download the Rotterdam App, go to m.rotterdam.info/download on your mobile phone or download it via the App Store or Google Play.

Scientific Information

Abstracts

Abstracts selected for the 3rd ELPAT Congress will be presented as oral presentations and poster presentations.

Oral presentations

Abstracts selected for an oral presentation will be presented during the parallel sessions on Sunday 21, Monday 22 April and Tuesday 23 April.

Plenary Room Setup – Rotterdam Hall

The plenary room is equipped with:

- a remote control, a laser pointer and a LCD monitor at the lectern

Meeting Room Setup – Penn, Leewen and Goudriaan Room

Each meeting room is equipped with:

- a primary computer with monitor at the lectern (laptop)
- a wireless mouse and a laser pointer

Audiovisual (AV) technicians are present who can assist presenters with their presentations. Before the session starts, the AV technician in the **Veder Room** will verify whether all presentations are uploaded and accounted for. If the technician notices a missing presentation, he/she will contact the organization for verification and notify the moderator if necessary.

Once the presentation is launched, the presenter can control the program from the podium using a computer mouse and/or keyboard (which can also be used instead of a laser pointer).

Speaker room/preview room

The speaker room is located in the **Veder Room**. The opening hours are:

Saturday: 20 April, 11:30 – 17:00
 Sunday: 21 April, 07:30 – 17:00
 Monday: 22 April, 07:30 – 17:00
 Tuesday: 23 April, 07:30 – 11:00

All presenters are required to check-in in the **Veder Room** to preview and upload their files no later than one hour prior to the start of the session in which they will speak. Even if a presenter is unavoidably delayed, he/she is still required to go directly to the **Veder Room**.

DO NOT GO STRAIGHT TO THE SESSION WITHOUT FIRST UPLOADING YOUR PRESENTATION IN THE VEDER ROOM!

Use of ESOT scientific programme content

Please be aware that information and materials displayed and/or presented at all sessions of this meeting are the property of the 3rd ELPAT Congress (and/or the presenter) and cannot be photographed, copied, photocopied, transformed to electronic format, reproduced or distributed without the written permission of ELPAT (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 prohibited without the expressed written permission of ESOT.

Poster presentations

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

There will be no organized or moderated discussions over posters. Authors are expected to offer an explanation during the Official Poster Viewing: welcome reception and lunch breaks on Sunday and Monday. Please refer to the following schedule in order to identify your poster:

Sunday 21st and Monday 22nd April:

Posters 01 – 06: Cultural and Religious Aspects of Living and Deceased Donation
 Posters 07 – 09: Cross-Border Transplants
 Posters 10 – 29: Psychosocial Care
 Posters 30 – 34: Autonomy at the End of Life
 Posters 35 – 37: Public Issues
 Posters 38 – 40: Children as Donors and Recipients

Posterviewing: 13:30 – 14:30 in the **Rotterdam Hall**

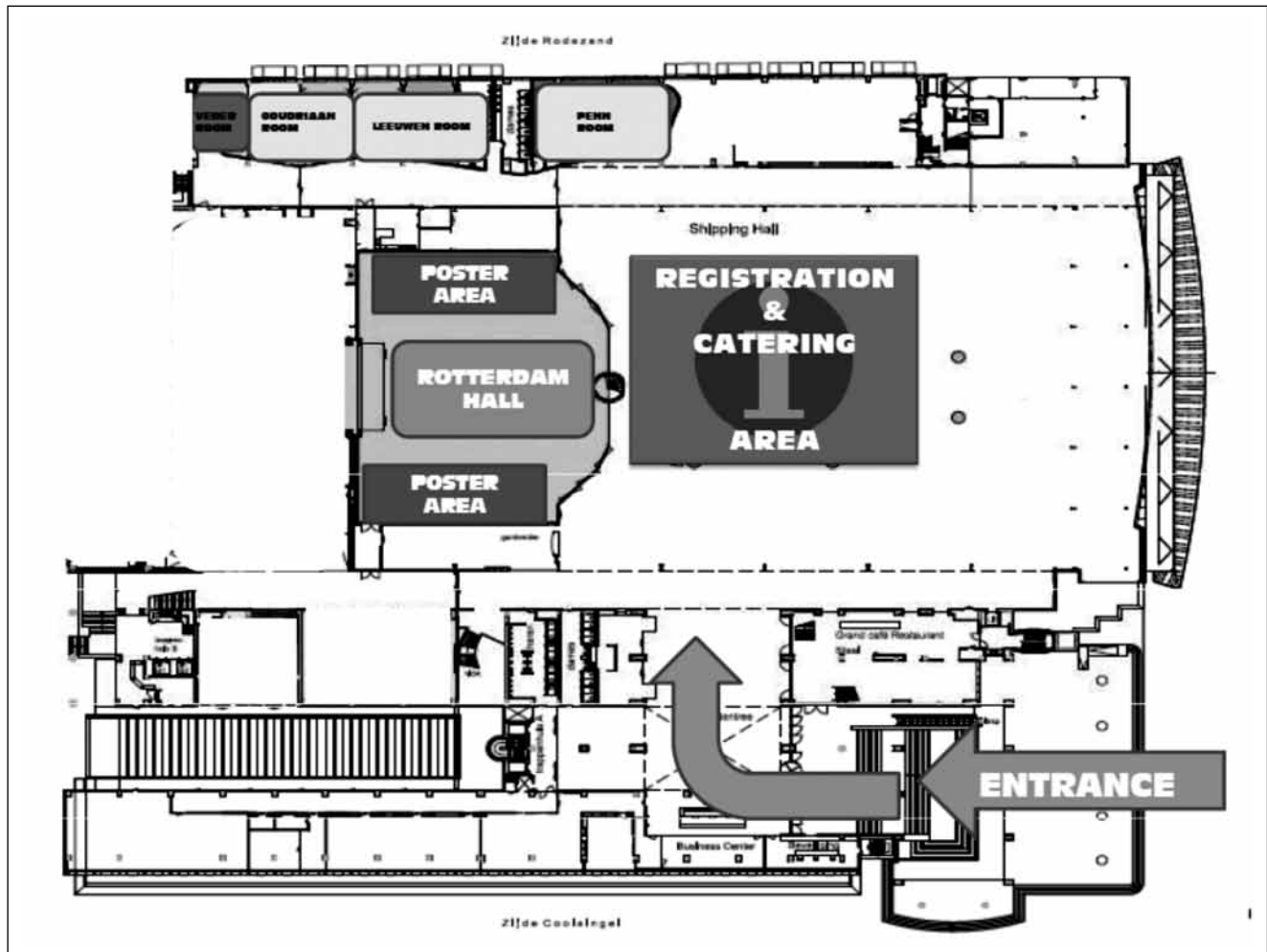
Posters not picked up by the author by the end of the congress will be discarded.

The mounting day is on April 20th from 13:00–15:00. The dismounting day is on April 23rd from 09:00–14:00.

Security and badge policy

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

Plan of the Congress venue



Plenary Meeting room: Rotterdam Hall

Meeting Rooms: Penn Room
Leeuwen Room
Goudriaan Room

Preview Room: Veder Room

Social programme

Saturday, April 20th, 18:00 – 19:00

Welcome Reception & Posterviewing

Beurs-World Trade Center Rotterdam –
Rotterdam Hall

Welcome drinks will be served after the congress opening session in the Rotterdam Hall, where it will also be possible to view the posters.

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



Sunday, April 21st, 19:00 – 22:30

Visit and Dinner

Wereldmuseum

19:00 – 19:45 hrs Welcome reception

19:45 – 20:30 hrs Visit Samurai exhibition

20:30 – 22:30 hrs Walking dinner

You are welcome to join us at the Wereldmuseum, located in one of Rotterdam's most authentic historic buildings, with a fantastic view on the river 'Maas'. Here you will enjoy a wonderful dinner in the 'ballroom' of Prins Hendrik's former Yacht Club, which has been restored to its former glory.



In addition, you will be given the opportunity to visit the theme exhibition 'Samurai'.

The **Samurai** exhibition transports the visitor to feudal Japan where warlords, the *Daimyō*, fought each

other by employing the services of fearsome samurai warriors.

Impressive armour, spectacular helmets and swords that were deemed to be the 'soul of the samurai' illustrate the highly developed warrior culture. War banners, *nobori*, of the Kitamura collection which are painted with family coats of arms and protective mythological figures, identified the samurai on the battlefield.

The code of ethics, *Bushidō*, imposed a lifestyle of honour, loyalty and respect within the warrior class. The samurai elite devoted themselves with equal dedication to various arts: calligraphy and the tea ceremony and they wore delicately crafted *netsuke* and *Inrō* lacquerwork. The mystical *Nō* theatre, the official form of theatre among the samurai, uses animated masks to depict legendary warriors who came back from the dead to the battlefield. A



surprising element is the Dutch influence on the samurai warrior equipment, caused by the special bond between the two countries.

This theme exhibition is open to registrants from 19:45 to 20:30 hrs.

Admittance: Open to all registered ELPAT congress participants and registered accompanying persons. Your badge is your entrance ticket.

How to get there: Visiting address Wereldmuseum Rotterdam, Willemskade 25, 3016 DM Rotterdam. The Wereldmuseum is easy to reach by public transport or by car.

Phone: 0031 10 2707172

E-mail: info@wereldmuseum.nl

Internet: www.wereldmuseum.nl

Monday, April 22nd, 18:00 – 19:30

ELPAT Congress Reception – City Hall

The city of Rotterdam is organizing a special welcome reception for all participants and we hope you will join us at the Rotterdam City Hall. Here you will enjoy delightful drinks in the company of your colleagues and friends and meet new people.

Admittance:

Open to all registered ELPAT congress participants and registered accompanying persons.

The City Hall is within walking distance of the World Trade Center at the Coolingsingel 40 (two blocks, approx. 5 min). Your badge is your entrance ticket.



Programme Overview

	Saturday April 20th	Sunday April 21st	Monday April 22nd	Tuesday April 23rd
08:00	Registration open (13:00 - 19:00 hrs)	Registration open (08:00 - 18:00 hrs)	Registration open (08:00 - 18:00 hrs)	Registration open (08:00 - 14:00 hrs)
08:30		Plenary Session 1	Plenary Session 2	Focus Sessions 7 - 8 - 9
9:00		Break	Break	Free Communications 13
09:30				Break
10:00		Focus Sessions 1 - 2 - 3	Focus Sessions 4 - 5 - 6	Focus Sessions 7 - 8
10:30		Free Communications 1	Free Communications 7	Free Communications 14 - 15
11:00		Free Communications 1 - 2 - 3 - 4	Free Communications 7 - 8 - 9 - 10	Closing Ceremony GLOBAL OUTREACH
11:30		Postviewing	Postviewing	Light Lunch
12:00		Lunch	Lunch	
12:30		Workshops 1 - 2 - 3	Workshops 4 - 5 - 6	
13:00		Free Communications 5	Free Communications 11	
13:30	Opening Ceremony GLOBAL ISSUES, LOCAL SOLUTIONS	Break	Break	
14:00		Continuing Workshops 1 - 2 - 3	Continuing Workshops 4 - 5 - 6	
14:30		Free Communications 6	Free Communications 12	
15:00				
15:30	Welcome Reception and Postviewing		Congress Reception at the City Hall	
16:00				
16:30		Reception, Exhibition visit and Dinner at the Wereldmuseum		
17:00				
17:30				
18:00				
18:30				
19:00				
19:30				
20:00				
20:30				
21:00				
21:30				
22:00				
22:30				

Scientific Programme

Saturday April 20 th	
13:00	Registration open (13:00 - 19:00 hrs)
16:00	<p>Opening Ceremony</p> <p>GLOBAL ISSUES, LOCAL SOLUTIONS</p>
18:00 19:00	Welcome Reception and Posterviewing

16:00 – 18:00 Opening Ceremony: ‘Global Issues, Local Solutions’

Rotterdam Hall

*Chairs: Michael Bos, The Hague, The Netherlands;
Willem Weimar, Rotterdam, The Netherlands*

16:00 Welcome and opening
Pim van Gool, President of the Dutch Health Council, The Hague, The Netherlands

16:10 Overview ELPAT
Willem Weimar, Chair

16:30 Ethics and the acquisition of organs
Martin Wilkinson, Auckland, New Zealand

17:00 Ethics and the allocation of organs
Linda Wright, Toronto, Canada

17:30 Organ donation and transplantation in emerging economies
Anwar Naqvi, Karachi, Pakistan

18:00 – 19:00 Welcome Reception & Posterviewing

Rotterdam Hall

Sunday April 21 st				
08:00	Registration open (08:00 - 18:00 hrs)			
08:30	Rotterdam Hall Plenary Session 1			
10:00	Break			
10:30	Goudriaan Room Focus Session 1 Living Liver Donation	Leeuwen Room Focus Session 2 Ethics and DCD	Penn Room Focus Session 3 Home Based Education	Rotterdam Hall Free Communications 1
11:30	Free Communications 2 Cultural and Religious Aspects of Living and Deceased Donation (1)	Free Communications 3 Cross-Border Transplants	Free Communications 4 Psychosocial Care - Donors (1)	Public Issues (1)
13:00	Lunch (Shipping Hall)			
13:30				Posterviewing
14:30	Workshop 1 Cultural and Religious Aspects of Living and Deceased Donation	Workshop 2: Cross-Border Transplants	Workshop 3 Psychosocial Care	Free Communications 5 Autonomy at the End of Life
16:00	Break			
16:30	Continuing Workshop 1	Continuing Workshop 2:	Continuing Workshop 3	Free Communications 6 Donation after Cardiac Death (DCD)
18:00				
19:00	Reception, Exhibition visit and Dinner at the Wereldmuseum			
22:30				

08:30 – 10:00 Plenary Session 1

Rotterdam Hall

Chairs: Benjamin Hippen, Charlotte, United States;
 Jan van Busschbach, Rotterdam, The Netherlands

08:30 The place of the living versus the dead body in Turkish transplant practices
 Aslihan Sanal, Hamburg, Germany

09:00 Emerging international transplant medicine: what ethical conclusions may be drawn?
 Jacqueline Chin, Singapore, Singapore

09:30 Promoting living donation and home-based education
 James Rodrigue, Boston, United State

10:00 BREAK

Goudriaan Room**10:30 – 11:30 Focus Session 1:
Living Liver Donation**

*Chairs: Nigel Heaton, London, United Kingdom;
Frank Dor, Rotterdam, The Netherlands*

10:30 **Living Liver Donation**
Nigel Heaton, London, United Kingdom

11:00 **Living donor liver transplantation: ethical considerations**
Charles Miller, Cleveland, United States

Leeuwen Room**10:30 – 11:30 Focus Session 2:
Ethics and Donation after Cardiac
Death (DCD)**

*Chairs: Chris Rudge, Kent, United Kingdom;
Bernadette Haase-Kromwijk, Leiden,
The Netherlands*

10:30 **The establishment of a national donation ethics committee and the UK ethical guidance on DCD donation**
Sir Peter Simpson, Bristol, United Kingdom

11:00 **Ethical and legal aspects of DCD in an European perspective**
Michael Bos, The Hague, The Netherlands

Penn Room**10:30 – 11:30 Focus Session 3:
Home Based Education**

*Chairs: James Rodrigue, Boston, United States;
Jan van Busschbach, Rotterdam,
The Netherlands*

10:30 **Family interventions to improve consideration for live kidney transplantation**
Ebony Boulware, Baltimore, United States

11:00 **#132 First results of a randomized controlled trial on a home-based educational intervention**
Sohal Ismail, Rotterdam, The Netherlands

11:15 **#125 Toward a learner-centered model for patient education**
Owen Surman, Long Beach, United States

Rotterdam Hall**10:30 – 13:00 Free Communications 1:
Public Issues (1)**

*Chairs: Silke Schicktanz, Göttingen, Germany;
Gurch Randhawa, Luton, United Kingdom*

10:30 **#10 'Reel' transplants**
Linda Wright, Toronto, Canada

10:45 **#110 A regulated system of incentives for living donation: a challenge to define and understand the objections**
Arthur Matas, Minneapolis, United States

11:00 **#135 Knowledge as a predictor for having a living kidney donor?**
*Annemarie Luchtenburg, Rotterdam,
The Netherlands*

11:15 **#26 Good intentions: Good intentions: moral reasoning on organ procurement among health professionals and members of the public in Denmark**
Klaus Hoeyer, Copenhagen, Denmark

11:30 **#139 Contact between living anonymous donors and recipients: ethical issues**
Linda Wright, Toronto, Canada

11:45 **#152 Public attitudes and associated factors of organ donation in Taiwan**
Daniel Fu-Chang Tsai, Taipei, Taiwan

12:00 **#177 Training 'communication about donation' takes a prominent role in Dutch hospitals**
Nichon Jansen, Leiden, The Netherlands

12:15 **#184 Regulation, regulation, regulation: its function and threat to vital transplant research**
Antonia Cronin, London, United Kingdom

12:30 **#78 20 Double portraits living kidney donation**
*Janneke Vervelde, Amsterdam,
The Netherlands*

12:45 **#141 Improving cooperation between forensic pathologists and transplant teams in Belarus: a strategy for increasing transplant organs supply**
Andrei Famenka, Minsk, Belarus

Goudriaan Room**11:30 – 13:00 Free Communications 2:
Cultural and Religious Aspects
of Living and Deceased Donation (1)**

*Chairs: Mihaela Frunza, Cluj, Romania;
Anantharaman Vathsala, Singapore, Singapore*

11:30 #94 Organ donation and cultural issues in Cape Town, South Africa
Fiona McCurdie, Cape Town, South Africa

11:45 #101 Unspecified and specified living kidney donation to unrelated recipients: the Rotterdam experience
Willij Zuidema, Rotterdam, The Netherlands

12:00 #99 Seriously ill patients as unspecified living kidney donors
Willij Zuidema, Rotterdam, The Netherlands

12:15 #124 Right liver lobe and kidney 'double' donation by good Samaritan living donors: single center experience
Amit Sharma, Richmond, United States

12:30 #107 Religious aspects on organ donation
Dorothee Grammenos, Erlangen, Germany

12:45 #83 Personal attitudes and beliefs regarding organ and tissue donation: a cross-sectional survey of Australian emergency department clinicians
Claudia Marck, Fitzroy, Australia

Leeuwen Room**11:30 – 13:00 Free Communications 3:
Cross-Border Transplants**

*Chairs: Jacqueline Chin, Singapore, Singapore;
Igor Codreanu, Chisinau, Moldova*

11:30 #116 A policy for transparency
Alexandra Glazier, Waltham, United States

11:45 #57 Should we perform organ transplants on asylum seekers and refugees in Canada?
Marie-Chantal Fortin, Montreal, Canada

12:00 #14 The rise and decline of a state-sponsored crime: the case of organ trafficking in Israel
Asif Efrat, Herzliya, Israel

12:15 #32 Combating the kidney commerce: efforts against the organ trade in Pakistan
Asif Efrat, Herzliya, Israel

12:30 #87 Organ trafficking – mechanism and main characteristics
Natalia Codreanu, Chisinau, Moldova

12:45 #33 The regulatory challenges of international transplant medicine: developments in Singapore
Tracey Chan, Singapore, Singapore

Penn Room**11:30 – 13:00 Free Communications 4:
Psychosocial Care and
Donation (1)**

*Chairs: Ebony Boulware, Baltimore, United States;
Annette Lennerling, Gothenburg, Sweden*

11:30 #160 Psychological functioning of unspecified anonymous living kidney donors before and after donation
Lotte Timmerman, Rotterdam, The Netherlands

11:45 #63 Impact of death mode and the willingness to donate organs on the separation process of bereaved parents from their deceased children
Tamar Ashkenazi, Tel Aviv, Israel

12:00 #100 NiCe: patient-centered care for live kidney donors
Ellen Bossenbroek, Rotterdam, The Netherlands

12:15 #161 Psychosocial risk and protective factors for living donation – results from a European multicentre prospective study (ELIPSY)
Ana Teresa Menjivar, Barcelona, Spain

12:30 #106 Quality of life, psychosocial wellbeing and satisfaction of living donors – results from a European multicentre retrospective study (ELIPSY)
Christina Papachristou, Berlin, Germany

12:45 #167 Critical care staff and the donation request: a focus group study
Jack de Groot, Nijmegen, The Netherlands

13:00 – 14:30 LUNCH and POSTERVIEWING

Rotterdam Hall

13:30 – 14:30 Posterviewing

Posters 01 – 06: Cultural and Religious Aspects of Living and Deceased Donation
 Posters 07 – 09: Cross-Border Transplants
 Posters 10 – 29: Psychosocial Care
 Posters 30 – 34: Autonomy at the End of Life
 Posters 35 – 37: Public Issues
 Posters 38 – 40: Children as Donors and Recipients

*Goudriaan Room*14:30 – 18:00 Workshop 1:
Cultural and Religious Aspects of Living and Deceased Donation

*Chairs: Farhat Moazam, Karachi, Pakistan;
 Gurch Randhawa, Luton, United Kingdom*

14:30 **Kidneys from deceased donors: Public's views from Pakistan**
Farhat Moazam, Karachi, Pakistan

15:00 **Access to donation and transplantation**
Gurch Randhawa, Luton, United Kingdom

15:30 **#11 Altruism vs. reciprocity – a Polish migrant perspective: an 'altruistic gift'**
Chloe Sharp, Luton, United Kingdom

16:00 BREAK

16:30 **#60 The impact of religion on deceased organ donation in Lebanon**
Antoine Stephan, Hazmieh, Lebanon

16:45 **#84 New independent Ethics Committee meeting unrelated donors in Kuwait succeeds in reducing commercial transplantation**
Mustafa Al-Mousawi, Kuwait City, Kuwait

17:00 **#117 Orchestrating an exceptional death – donor family experiences and organ donation in Denmark**
Anja Borneo Jensen, Copenhagen, Denmark

17:15 **#153 A national survey of public's attitude toward individual autonomy or family decision in organ donation in Taiwan**
Daniel Fu-Chang Tsai, Taipei, Taiwan

17:30 **#155 Cultural and religious factors in discussing stem cell transplantation in Romania: analysis of blogs**
Sandu Frunza, Cluj, Romania

*Leeuwen Room*14:30 – 18:00 Workshop 2:
Cross-Border Transplants – Transplant Tourism

*Chairs: Susanne Lundin, Lund, Sweden;
 Frederike Ambagtsheer, Rotterdam, The Netherlands*

14:30 **Transplant tourism: the ethics and regulation of international markets for organs**
Glenn Cohen, Cambridge, United States

14:55 **How health-care providers can identify and prevent transplant tourism**
John Gill, Vancouver, Canada

15:20 **#38 Nothing but a word? The ethical meanings of the term transplant tourism**
Merle Annika Michaelsen, Göttingen, Germany

15:35 Panel discussion: Transplant Tourism

16:00 BREAK

**Workshop 2 continuing:
 Cross-Border Transplants – Transplant Tourism**

16:30 **Report: trafficking in human beings for the purpose of the removal of organs**
Maarten Abelman, The Hague, The Netherlands

16:55 **International norms, local worlds: an ethnographic perspective on organ trafficking in the Israeli context**
Zvika Orr, Jerusalem, Israel

17:20 Panel discussion: Organ Trafficking

*Penn Room*14:30 – 18:00 Workshop 3:
Psychosocial Care

*Chairs: Fabienne Dobbels, Leuven, Belgium;
 Yesim Erim, Essen, Germany*

14:30 **Which knowledge and skills do (transplant) professionals need to support their patients' self-management?**
Ad Kaptein, Leiden, The Netherlands

15:00 **Patients as partners: the road to success**
Per Åke Zillén, Saltsjö-Boo, Sweden

15:30 **Self-management support in patients with alcoholic liver cirrhosis**
Yesim Erim, Essen, Germany

16:00 BREAK

16:30 **#162/#163 Psychological factors associated with medication adherence among young adult kidney transplant recipients**
Karlijn Meys, Rotterdam, The Netherlands

16:45 **#9 Telemedicine as an innovative project-study for psychosocial screening of living recipients at the transplantation-center Freiburg**
Silvia Hils, Freiburg, Germany

17:00 **#157 Health literacy and self management among kidney transplant patients**
Louise Maasdam, Rotterdam, The Netherlands

17:15 **Panel discussion: From bench to bedside: how can you make a difference in delivering self-management support?**

Rotterdam Hall

14:30 – 16:00 **Free Communications 5: Autonomy at the End of Life**

Chairs: Thomas Gutmann, Münster, Germany; Gert van Dijk, Rotterdam, The Netherlands

14:30 **#104 When is the best time to ask relatives for consent to organ donation?**
Dorothee Grammenos, Erlangen, Germany

14:45 **#114 Factors influencing bereaved families' decisions about organ donation: an integrative review of the literature**
Wendy Walker, Wolverhampton, United Kingdom

15:00 **#76 Current issues in European uncontrolled donation after cardiac death protocols**
Ivan Ortega-Deballon, Torrejon del Rey, Spain

15:15 **#24 Developing end of life care giving bereaved families the option of corneal donation**
Heather Savage, Belfast, United Kingdom

15:30 **#146 Death criteria and donation after circulatory death: should we reconsider the dead donor rule?**
David Rodriguez-Arias, Madrid, Spain

15:45 **#19 Exploring organ donation with bereaved relatives: healthcare professionals experience in 3 European countries**
Barbara Neades, Edinburgh, United Kingdom

16:00 BREAK

Rotterdam Hall

16:30 – 17:45 **Free Communications 6: Donation after Cardiac Death (DCD)**

Chairs: Dirk Ysebaert, Antwerp, Belgium; Michael Bos, The Hague, The Netherlands

16:30 **#122 Kidney transplantation from donors after circulatory death: an initial report of 71 cases from China**
Dicken Ko, Boston, United States

16:45 **#12 Donation after cardiac death: are Australian emergency clinicians supportive?**
Claudia Marck, Fitzroy, Australia

17:00 **#165 The ethics of artificial circulatory support in organ donors**
Jeffrey Punch, Ann Arbor, United States

17:15 **#111 DCDD: what are we waiting for?**
Pablo De Lora, Madrid, Spain

17:30 **#18 Donation after cardiac death – systematic review of attitudes of medical personnel and the general public**
Sohaila Bastami, Zürich, Switzerland

19:00 – 19:45 **Reception**
19:45 – 20:30 **Exhibition visit**
20:30 – 22:30 **Dinner**

Wereldmuseum
Willemskade 22
Rotterdam

Monday April 22nd				
08:00	Registration open (08:00 - 18:00 hrs)			
08:30	Rotterdam Hall Plenary Session 2			
10:00	Break			
10:30	Goudriaan Room Focus Session 4 Donor Recruitment, Altruism and Compensation	Leeuwen Room Focus Session 5 Principles of Allocation	Penn Room Focus Session 6 Anonymity	Rotterdam Hall Free Communications 7 Psychosocial Care for Living Donors (2)
11:30	Free Communications 8 Autonomy at the End of Life	Free Communications 9 Public Issues (2)	Free Communications 10 Children as Donors and Recipients	
13:00	Lunch (Shipping Hall)			
13:30				Posterviewing
14:30	EDTCO Workshop 4 Autonomy at the End of Life	Workshop 5 Public Issues	Workshop 6 Children as Donors and Recipients	Free Communications 11 Cultural and Religious Aspects of Living and Deceased Donation (2)
16:00	Break			
16:30	Continuing Workshop 4	Continuing Workshop 5	Continuing Workshop 6	Free Communications 12 Psychosocial Care for Recipients (1)
18:00	Congress Reception at the City Hall			
19:30				

08:30 – 10:00 Plenary Session 2

Rotterdam Hall

*Chairs: Alexander Capron, Los Angeles, United States;
Rutger Ploeg, Oxford, United Kingdom*

08:30 **The unnoticed problem of the duality between neurological and circulatory death**
David Rodríguez-Arias, Madrid, Spain

09:00 **Why considering the ‘public’ in organ transplantation issues? Chances and risks of public opinion research**
Silke Schicktanz, Göttingen, Germany

09:30 **Organ transplantation and children with neurocognitive disability**
Robert Truog, Boston, United States

10:00 BREAK

Goudriaan Room**10:30 – 11:30 Focus Session 4:
Donor Recruitment, Altruism and
Compensation***Chairs: Arthur Matas, Minneapolis, United States;
Stellan Welin, Linköping, Sweden***10:30 Purely altruistic organ procurement
models are inadequate in meeting today's
transplantation needs!**
*Faisal Omar, Linköping, Sweden***10:45 Organ donation and charity**
*Govert den Hartogh, Haarlem,
The Netherlands***11:00 Discussion**Leeuwen Room**10:30 – 11:30 Focus Session 5:
Principles of Allocation***Chairs: Janet Radcliffe Richards, Oxford, United
Kingdom;
Axel Rahmel, Leiden, The Netherlands***10:30 Organ allocation: principles, pragmatism
and practice**
*Antonia Cronin, London, United Kingdom***11:00 #59 Directed donation of deceased donor
organs – a donor intent driven policy**
*Aviva Goldberg, Winnipeg, Canada***11:15 #129 The pediatric priority in organ
allocation is not necessary and is
counterproductive – proposal for an
alternative ethical model**
*Jean-Luc Wolff, Sherbrooke, Canada*Penn Room**10:30 – 11:30 Focus Session 6: Anonymity***Chairs: Nizam Mamode, London, United Kingdom;
Willij Zuidema, Rotterdam, The Netherlands***10:30 Anonymity in living donation: when, how
and why?**
*Nizam Mamode, London, United Kingdom***10:50 Ethics and the requirement of anonymity in
organ donation**
*Medard Hilhorst, Rotterdam,
The Netherlands***11:10 Experiences with anonymity**
*Lisa Burnapp, London, United Kingdom*Rotterdam Hall**10:30 – 12:45 Free Communications 7:
Psychosocial Care for Living
Donors (2)***Chairs: Christina Papachristou, Berlin, Germany;
Jan van Busschbach, Rotterdam,
The Netherlands***10:30 #69 Identifying predictors of psychosocial
outcomes after living kidney donation**
*Najma Hannah Maple, London, United
Kingdom***10:45 #67 Anonymity in UK unspecified kidney
donors: a nationwide survey**
*Najma Hannah Maple, London, United
Kingdom***11:00 #158 Psychosocial screening of the
unspecified living kidney donors in
The Netherlands**
*Marry de Klerk, Rotterdam, The Netherlands***11:15 #134 Modifiable factors in access to living
donor kidney transplantation among
diverse populations**
*Sohal Ismail, Rotterdam, The Netherlands***11:30 #70 Perioperative psychosocial factors and
wound healing in living kidney donors**
*Shanique Simmonds, London, United
Kingdom***11:45 #102 Knowledge about dialysis,
transplantation and living donation among
prospective living kidney donors and
recipients**
*Lotte Timmerman, Rotterdam,
The Netherlands***12:00 #61 Requesting family consent: a stressful
situation for the coordinator**
*Boutros Ghamen, Hazmieh, Lebanon***12:15 #178 Predictive characteristics of negative
psychosocial outcomes in living liver- &
kidney donors: a final update on the
systematic literature review**
*Johan van Gogh, Rotterdam,
The Netherlands*

Goudriaan Room**11:30 – 12:45 Free Communications 8:
Autonomy at the End of Life**

*Chairs: Maqi Sque, Wolverhampton, United Kingdom;
Michiel Betjes, Rotterdam, The Netherlands*

11:30 #75 Carrying out research into the effects of organ-preservation methods
Andrea Sautter, Mannheim, Germany

11:45 #183 Non-standard kidneys for transplants: clinical margins, medical morality and the law
Antonia Cronin, London, United Kingdom

12:00 #105 'Keeping her whole': bereaved families' accounts of declining a request for organ donation
Maqi Sque, Wolverhampton, United Kingdom

12:15 #97 Attitudes towards organ donor advocacy, an impact on organ donation
Anne Flodén, Gothenburg, Sweden

12:30 #103 Donor relatives as advocates for organ donation
Dorothee Grammenos, Erlangen, Germany

Leeuwen Room**11:30 – 13:00 Free Communications 9:
Public Issues (2)**

*Chairs: Judit Sándor, Budapest, Hungary;
Linda Wright, Toronto, Canada*

11:30 #130 Transplant candidate education: what the patient heard
Owen Surman, Boston, United States

11:45 #112 The regulation of living organ donation in the UK; progress since 2006 and meeting the challenge of social media
Alan Clamp, London, United Kingdom

12:00 #53 Transplant professionals' views on the ethical challenges associated with altruistic unbalanced paired kidney exchange
Marie-Chantal Fortin, Montreal, Canada

12:15 #156 Consensus – a threat to active engagement
Anne Hambro Alnaes, Oslo, Norway

12:30 #98 Nudges for organ donation. How do they work?
Ana Manzano-Santaella, Leeds, United Kingdom

12:45 #22 A regulated market for organs from living donors – efficient and equitable? Lessons learned from Iran
Christina Papachristou, Berlin, Germany

Penn Room**11:30 – 13:00 Free Communications 10:
Children as Donors and Recipients**

*Chairs: Assya Pascalev, Sofia, Bulgaria;
Marion Siebelink, Groningen, The Netherlands*

11:30 #89 Organ and tissue donation by minors: widely diverging regulations in Europe
Kristof van Assche, Brussels, Belgium

11:45 #95 Living kidney donation by minors: an ethical analysis based on a systematic review
Kristof Thys, Leuven, Belgium

12:00 #27 Children and transplantation: ethical issues in paediatric transplantation and family centred care
Rebecca Bruni, Toronto, Canada

12:15 #36 Organ donation – an issue in neonatology as well? Data and facts from Germany
Jutta Weiss, Erlangen, Germany

12:30 #29 Ethical reappraisal of shifting therapeutic goals in paediatric renal transplantation
Marie José Clermont, Montreal, Canada

12:45 #68 Paediatric live solid organ donors: a no or a yes?
Najma Hannah Maple, London, United Kingdom

13:00 – 14:30 LUNCH and POSTERVIEWING

Rotterdam Hall**13:30 – 14:30 Posterviewing**

Posters 01 – 06: Cultural and Religious Aspects of Living and Deceased Donation

Posters 07 – 09: Cross-Border Transplants

Posters 10 – 29: Psychosocial Care

Posters 30 – 34: Autonomy at the End of Life

Posters 35 – 37: Public Issues

Posters 38 – 40: Children as Donors and Recipients

Goudriaan Room**4:30 – 18:00 EDTCO Workshop 4:
Autonomy at the End of Life**

*Chairs: Beatrice Dominguez-Gil, Madrid, Spain;
Gert van Dijk, Rotterdam, The Netherlands*

14:30 **Ethical and legal aspects of ante-mortem interventions**
Alexander Manara, Bristol, United Kingdom

15:00 **The moment of seeking consent for organ donation from bereaved relatives**
Nichon Jansen, Leiden, The Netherlands

15:30 **Acceptability of the dead donor rule**
Thomas Gutmann, Münster, Germany

16:00 BREAK

16:30 **Euthanasia and organ donation**
Dirk Ysebaert, Antwerp, Belgium

17:00 **#30 Organ donation after active euthanasia: morally acceptable?**
Gert van Dijk, Rotterdam, The Netherlands

17:15 **#140 Rethinking the role of consent in relation to post mortem use of the body for organ transplantation**
Austen Garwood-Gowers, Nottingham, United Kingdom

17:30 **#46 A practice-based approach to unravelling the content of the donation interview: an ethnographic study of a transplant coordination team's procurement practices in a Catalan hospital**
Sara Bea, Edinburgh, United Kingdom

Leeuwen Room**14:30 – 18:00 Workshop 5:
Public Issues**

*Chairs: Silke Schicktanz, Göttingen, Germany;
Katrina Bramstedt, Gold Coast, Australia*

14:30 **The silence of Good Samaritan kidney donation in Australia: a survey of hospital websites**
Katrina Bramstedt, Gold Coast, Australia

15:00 **Organ donation and the art of making decisions**
Ralph Hertwig, Berlin, Germany

15:30 **#115 Public solicitation of organs from living donors – an ELPAT view**
Mihaela Frunza, Cluj, Romania

15:45 **#81 When prisoner organ donation becomes ethically justified**
Andrew Millis, Atlanta, United States

16:00 BREAK

16:30 **#47 Improving communication and consent for organ donation: the development & evaluation of a hospital based intervention**
Myfanwy Morgan, London, United Kingdom

16:45 **#149 A regulated website for patient stories and altruistic donors: an ethical way to accept living donors who have been solicited through media?**
Jean-Luc Wolff, Sherbrooke, Canada

17:00 **#25 Organ donation as a civic privilege – defining the extent of society's education obligations**
Dominique Martin, Carlton, Australia

17:15 **#41 From organ donation to tissue procurement: public perceptions of the introduction of whole cadaver donation in Denmark**
Maria Olejaz, Copenhagen, Denmark

17:30 **#90 The effect of the implementation of directive 2010/53/EU on the regulation of living donation in EU member states**
Kristof van Assche, Brussels, Belgium

Penn Room**14:30 – 18:00 Workshop 6:
Children as Donors and Recipients**

*Chairs: Paul Schotsmans, Leuven, Belgium;
Robert Truog, Boston, United States*

14:30 **The child as a donor: a multi-disciplinary approach**
Marion Siebelink, Groningen, The Netherlands

15:00 **Gift dynamics and identity construction within the family**
Karl-Leo Schwering, Paris, France

15:30 **Living kidney donation by minors: ethical aspects**
Sigrid Sterckx, Ghent, Belgium

16:00 BREAK

16:30 #142 Long-term outcomes of living kidney donors < 18: a matched cohort analysis
Arthur Matas, Minneapolis, United States

16:45 #64 Should minors be considered as potential living liver donors?
Laura Capitaine, Ghent, Belgium

17:00 #58 Who shall live – should children with developmental disabilities be organ transplant candidates?
Aviva Goldberg, Winnipeg, Canada

17:15 #51 Do bereaved parents of organ donors want to know about or meet with the recipients? The relationship between parents' willingness and 'meaning of life' measures
Tamar Ashkenazi, Tel Aviv, Israel

Rotterdam Hall

14:30 – 16:00 Free Communications 11:
Cultural and Religious Aspects
of Living and Deceased Donation (2)

*Chairs: Faisal Omar, Linköping, Sweden;
Anantharaman Vathsala, Singapore,
Singapore*

14:30 #126 Maximizing 'o'pportunities for living kidney donation
Linda Wright, Toronto, Canada

14:45 #108 The influence of ethnicity, socioeconomic factors and donor type on the outcome of kidney transplantation
Mirjam Laging, Rotterdam, The Netherlands

15:00 #21 The perception of organ donation by physicians
Bassit Nour El Houda, Marrakech, Morocco

15:15 #121 Cultural and religious aspects of living and deceased donation in the opinion of the various religious, churches and sects members – current clinical problems and positive changes
Maciej Nowacki, Warsaw, Poland

15:30 #154 Attitudes towards living organ donation in two Romanian universities
Harald Jung, Tirgu Mures, Romania

15:45 #2 Analysis of kidney donation potency in the pilote communities in Hochiminh city
Thuy Diem, Ho Chi Minh, Vietnam

16:00 BREAK

Rotterdam Hall

16:30 – 18:00 Free Communications 12:
Psychosocial Care for Recipients (1)

*Chairs: Fabienne Dobbels, Leuven, Belgium;
James Rodrigue, Boston, United States*

16:30 #16 Psychosocial needs assessment post-kidney transplant: feasibility of a post-transplant specific support group
Olusegun Famure, Toronto, Canada

16:45 #119 Post-transplantation lives: an ethnographic account
Katrin Amelang, Göttingen, Germany

17:00 #86 Pancreatic transplantation in patients with T1DM: a source of traumatic stress?
Sue Jackson, Bristol, United Kingdom

17:15 #34 Compliance to treatment and family support in kidney-pancreas transplantation recipients
Susana Bayardo, Buenos Aires, Argentina

17:30 #72 The perceived threat of the risk of graft rejection
Madeleine Nilsson, Gothenburg, Sweden

17:45 #74 Predicting barriers to adherence to therapy after heart transplantation – preliminary results of a prospective longitudinal study
Frank Vitinius, Cologne, Germany

18:00 – 19:30 Reception at the City Hall
Coolsingel 40, Rotterdam

Tuesday April 23 rd				
08:00	Registration open (08:00 - 14:00 hrs)			
08:30	Goudriaan Room Focus Session 7 Living Organ Donation: Results of the EULOD Project	Rotterdam Hall Focus Session 8 ELPAT Issues in starting a Deceased Donor Programme	Penn Room Focus Session 9 Ethics, Immuno- suppressants and Big Pharma	Leeuwen Room Free Communications 13 Psychosocial Care for Recipients (2)
10:00	Break			
10:30	Continuing Focus Session 7	Continuing Focus Session 8	Free Communications 14 Hot Topics in Allocation	Free Communications 15 Psychosocial Care - Donor Screening
11:30	Rotterdam Hall Closing Ceremony Global Outreach			
13:00	Light Lunch			
14:00				

Goudriaan Room

08:30 – 11:30	Focus Session 7: Living Organ Donation: Results of the EULOD Project
<i>Chairs: Bijan Fateh-Moghadam, Münster, Germany; Jan IJzermans, Rotterdam, The Netherlands</i>	
08:30	Living donation clinical practices in Europe <i>Annette Lennerling, Gothenburg, Sweden</i>
08:50	Attitudes, barriers and opportunities: results from focus groups conducted in four European countries <i>Assya Pascalev, Sofia, Bulgaria</i>
09:10	Legal issues of living organ donation in the member states of the EU <i>Leonie Lopp, Münster, Germany</i>
10:00	BREAK
10:30	Ethical analysis of the arguments for and against living organ donation <i>Mihaela Frunza, Cluj, Romania</i>
10:50	Recommendations on identification and assistance of victims and potential victims of organ trafficking <i>Natalia Codreanu, Chisinau, Moldova</i>

Rotterdam Hall

08:30 – 11:30	TTS/ELPAT Session 8: Starting a Deceased Donor Programme
<i>Chairs: Paul Harden, Oxford, United Kingdom; John Forsythe, Edinburgh, United Kingdom</i>	
08:30	Deceased organ donation program in Croatia <i>Mirela Busic, Zagreb, Croatia</i>
09:00	Success factors and hurdles in upgrading deceased and living organ donation in Israel <i>Jacob Lavee, Ramat Gan, Israel</i>
09:30	Success factors to decrease foreign transplants in Colombia <i>Nestor Pedraza, Bogotá, Colombia</i>
10:00	BREAK
10:30	Success factors and hurdles in developing donation from deceased donors in Thailand <i>Vasant Sumethkul, Bangkok, Thailand</i>
11:00	Challenges in implementing the deceased donor programme in India <i>Sunil Shroff, Chennai, India</i>

Penn Room**08:30 – 10:00 Focus Session 9:
Ethics, Immunosuppressants
and Big Pharma***Chairs: Simon Rowe, Reading, United Kingdom;
Teun van Gelder, Rotterdam,
The Netherlands***08:30 My liver, my drugs, my transplant, my life**
*Liz Schick, Anzère, Switzerland***08:45 Generics are not the same – in the patient
perspective**
*Per Åke Zillen, Satsjö-Boo, Sweden***09:00 Substitution of brand name drugs for cheaper
generics: an ethical dilemma?**
*Teun van Gelder, Rotterdam,
The Netherlands***09:30 The Big Pharma perspective – is it so
different from clinical practice?**
*Simon Rowe, Reading, United Kingdom****Leeuwen Room*****08:30 – 10:00 Free Communications 13:
Psychosocial Care for Recipients (2)***Chairs: Sigrid Sterckx, Ghent, Belgium;
Medard Hilhorst, Rotterdam,
The Netherlands***08:30 #147 The relationships among medical
data, psychological factors and socio-
demographical variables in kidney
transplant recipients**
*Zsofia Luca Hajdu, Debrecen, Hungary***08:45 #1 Psychosocial evaluation of candidates
for liver transplantation predicts post
transplantation outcome**
*Mina Rowe, Jerusalem, Israel***09:00 #15 Coping in relation to perceived
threat of the risk for graft rejection and
health related quality of life among organ
transplant recipients**
*Anna Forsberg, Lund, Sweden***09:15 #175 A Q-methodological study to explore
attitudes towards medication adherence in
recently transplanted kidney recipients**
*Mirjam Tielen, Rotterdam, The Netherlands***09:30 #151 Whose problem is it? Improving
adherence in young adults**
*Anna Hames, London, United Kingdom***09:45 #31 Psychosocial benefits of upper-limb
transplantation**
*Adam Chelmonski, Oborniki Slaski, Poland****Penn Room*****10:30 – 11:30 Free Communications 14:
Hot Topics in Allocation***Chairs: Rutger Ploeg, Oxford, United Kingdom;
Ninoslav Ivanovski, Skopje, Macedonia***10:30 #170 The ex vivo lung perfusion
system: ethical issues in allocation and
reimbursement**
*Linda Wright, Toronto, Canada***10:45 #52 Early liver transplantation for severe
alcoholic hepatitis**
*Abbas Dakhil, Al-Diwanyiah, Iraq***11:00 #20 Is it possible to transplant restored
kidneys?**
*Miyako Takagi, Tokyo, Japan***11:15 #7 Comparing outcomes from intensive
hemodialysis and high risk transplantation**
*Benjamin Hippen, Charlotte, United States****Leeuwen Room*****10:30 – 11:30 Free Communications 15:
Psychosocial Care – Donor Screening***Chairs: Nizam Mamode, London, United Kingdom;
Nichon Jansen, Leiden, The Netherlands***10:30 #55 Living liver donation: how can a
metasummary of their experiences
inform the psychosocial screening?**
*Deborah Ummel, Montreal, Canada***10:45 #166 Living donor psychosocial assessment/
follow-up practices in the partners'
countries of the ELIPSY project**
*Xavier Torres, Barcelona, Spain***11:00 #138 Who has high expectations of
donation? Exploring the psychological
profile of living kidney donors**
*Lotte Timmerman, Rotterdam,
The Netherlands***11:15 #137 Disclosure of recipient-specific risk
factors may improve the living donor (LD)
informed consent process**
Rebecca Hays, Madison, United States

11:30 – 13:00 Closing Ceremony: ‘Global Outreach’

Rotterdam Hall

*Chairs: Francis Delmonico, Boston, United States;
Carla Baan, Rotterdam, The Netherlands*

11:30 **The Declaration of Istanbul: the first five years, the next five years**
Gabriel Danovitch, Los Angeles, United States

12:00 **Global outreach: how to set up a transplant programme**
Paul Harden, Oxford, United Kingdom

12:30 **Global issues, local solutions. How can the European Commission contribute?**
Marcus Klamert, Brussels, Belgium

13:00 – 14:00 LIGHT LUNCH

Plenary Sessions

16:00 – 18:00 Opening Ceremony: ‘GLOBAL ISSUES, LOCAL SOLUTIONS’

Ethics and the acquisition of organs*Martin Wilkinson, Auckland, New Zealand*

Transplantation is unusual in health care: it is short of its raw material – organs – rather than money. That is its public policy problem. And its raw material comes from people's bodies. That is its ethical problem.

This talk describes the approach to transplantation ethics in my book *‘Ethics and the Acquisition of Organs’*.

I claim that 1) People have rights over their bodies, a subset of which I call personal sovereignty rights' and 2) Thinking about what these rights are, how important they are, and when they apply (in particular, whether they apply past death) allows us to reach reasoned conclusions about such problems as the role of the family, opt in versus opt out, organ conscription, live donation, directed donation, and organ sales.

As an example, I will consider organ conscription from the dead, which probably few of you agree with but which is hard to argue against without something like the personal sovereignty approach.

Ethics and the allocation of organs*Linda Wright, Toronto, Canada*

Allocation of an absolutely scarce life-saving resource i.e. transplantable organs, poses difficult ethical questions. Within the context of a significant shortfall to satisfy demand, allocation policies strive to reflect society's values in respecting autonomy and fidelity whilst balancing issues of fairness and utility in the distribution of organs. Transparency of organ allocation is essential in maintaining public trust in the transplant system.

Transplantation has supported two very different allocation systems for deceased and living donor organs, one partial, directed and private; the other impartial, largely non-directed and public. Established algorithms have been challenged as we expand possibilities for transplantation such as kidney paired exchange programmes and the use of anonymous living donors. The demand for organs has pushed us to question some long held assumptions, such as non-direction of deceased donor organs, leading some countries to inaugurate changes to policy.

Going forward, we need to examine policies from consequentialist and deontological viewpoints, the rights of the collective versus the individual, donor interests versus those of recipients, differing concepts of equity and justice as well as the importance accorded to variables including age, locality and predicted outcomes. This presentation will give an overview of the major issues in organ allocation today.

Organ donation and transplantation in emerging economies*Anwar Naqvi, Karachi, Pakistan*

The developing world is faced with several major challenges and hence transplantation becomes a low priority in most countries. As a result the transplantation rate is very low in most developing countries. The commonest transplantation is that of kidneys and due to lack of dialysis facilities the awareness about transplantation is generally very poor. Living donors are the commonest source of kidneys but in some countries use of unrelated donors has resulted in selling of kidneys to the rich in their own country or for recipients coming from richer neighbours.

The strategy of increasing organ donation and transplantation would begin with prioritizing the end stage organ failure in their respective healthcare system. The transplant centres should preferably be established in public sector hospitals so that the profit motive currently seen in private sectors is not operative. Comprehensive legislation for transplantation of living and deceased donors should also be considered a priority as the framework will be very useful in preventing unethical transplantation.

Major renal and liver centres in the country in the public sector could be strengthened to become the flagships in promoting the clean image of transplantation (e.g. SIUT) which the people can see as examples of transparency being fair and equitable for all stakeholders.

Since the donor and recipient are both members of the society, the transplant based on beneficence and altruism is appreciated and therefore sale or commerce in transplantation is looked down upon.

The ethical principles in transplantation are universal and poor resources should not be any excuse for promoting transplantation for only those who could pay.

08:30 – 10:00 Plenary Session 1

The place of the living versus the dead body in Turkish transplant practices*Aslihan Sanal, Hamburg, Germany*

In Turkey, transplants have been a challenging practice from early on. Launched in the 1970s as a small practice at Hacettepe Medical School in Ankara, it would have to wait until the end of the Cold War and the dawn of neoliberal economic policies to spread out to several regions of the country, and even then, with very fragmented biopolitical agendas. Lack of infrastructure, lack of organ donations, and physicians anxieties towards diagnosing brain death, institutional fights and many other issues would effect transplants' political economy. For one thing, Turkey was in a socioeconomic transition, and transplantation as a medical practice had proven how science and technology could mold the social body for progress. Physicians were proud of it. However, along with the expansion of transplants, organ trafficking had emerged as a side economy partly due to social inequalities and poverty. Yet physicians seemed to agree that transplant's central problem was the lack of 'cadaveric donations' for organ transplants due to cultural taboos surrounding the dead body. Today, I will talk about the place of the dead and the living body in transplant medicine from a cultural anthropological point of view as I will try to address some of the central debates emerging from this tension.

Emerging international transplant medicine: what ethical conclusions may be drawn?*Jacqueline Chin, Singapore, Singapore*

In a personal viewpoint published by the American Journal of Transplantation in April, 2012, Alastair Campbell and I presented a case study describing Singapore's interest in (a) strengthening its organ transplant capacity by sustaining an adequate patient load for developing a high level of medical skill, and (b) harnessing the economic potential of participation in international medical care, set off against (c) the threat to professional ethics and social solidarity that international transplant medicine can create. The paper also described current efforts in Singapore to mitigate risks to professional and ethical integrity within the system, and the risks that remain.

In discussing ethical conclusions to be drawn, I propose to consider the following questions: (i) How might the identified risks be mitigated and, if this does not succeed, what are some further risks for a national and international practice of transplant medicine? (ii) What other strategies for addressing organ transplantation needs are available, and which is the most promising approach?

Promoting living donation and home-based education*James Rodrigue, Boston, United States*

Live donor kidney transplantation (LDKT) is the optimal intervention for most patients with kidney failure who are transplant candidates. However, there are many barriers to LDKT, especially for minorities and socioeconomically disadvantaged patients and potential donors. Dr. Rodrigue will discuss the rationale, theoretical underpinnings, and development of the House Calls intervention, which includes the social system of the patient to increase knowledge and awareness of LDKT and living donation. Findings from two randomized House Calls trials completed in the United States will be reviewed, and its evaluation in three other ongoing studies will be discussed. New developments to further enhance the House Calls intervention will be described. Dr. Rodrigue will conclude with a discussion of some key clinical, pragmatic, and ethical issues that should be considered prior to implementation of the House Calls intervention.

08:30 – 10:00 Plenary Session 2

The unnoticed problem of the duality between neurological and circulatory death*David Rodríguez-Arias, Madrid, Spain*

International laws accept a ‘bifurcated criterion’ for declaring death: Irreversible loss of circulatory function and irreversible loss of brain function are considered sufficient in that there is no legal requirement for both criteria to be simultaneously fulfilled. It is frequently assumed that irreversible loss of brain function is the ‘gold standard’ for the determination of death. Many authors accept donation after circulatory death (DCD) because they believe that loss of circulatory function is an adequate surrogate marker for total brain failure. In DCD, organ donors are considered dead while there is no direct evidence that they have a total and irreversible brain failure. The objective of this presentation is to discuss whether or not this is problematic in general, and for health professionals in particular.

Why considering the ‘public’ in organ transplantation issues? Chances and risks of public opinion research*Silke Schicktanz, Göttingen, Germany*

Low organ donation rates have stimulated interest in the use of socio-empirical studies to explore public (or sometimes sub-publics) attitudes towards donation and transplantation.

In my presentation, I will elicit three major ethical and methodological issues in the field of public opinions and public policies: First, I want to discuss the ethics behind the idea of ‘public debates’, public deliberation, and public engagement. Second, I will present different concepts of public engagement and discuss the underlying paradigms and their ethical rational of information, propaganda, advertisement, and deliberation. Thirdly, I will discuss the chances and risks of different forms of engagement. Moreover, I will consider some major methodological and practical issues for measuring attitude or engaging with the public.

Finally, I want to present briefly – as case study – how public opinions studies on financial incentives for organ donation might be helpful to improve professional as well as policy discussions.

Organ transplantation and children with neurocognitive disability*Robert Truog, Boston, United States*

Recent news reports describe several children who were denied organ transplants because of their neurocognitive disability. Surveys of transplant centers confirm that many programs consider neurocognitive disability a relative or absolute contraindication to transplant.

Transplant programs routinely consider medical outcomes in allocating organs for transplant, giving higher priority to patients expected to have better outcomes. Programs may defend their consideration of neurocognitive disability on grounds that these conditions often may negatively impact outcomes, because of co-morbidities or decreased life expectancy associated with the cause of the disability, or reduced adherence to medications and follow-up care. Little data are available, however, to support these assertions, and in some cases disability may improve outcomes, as in the case of disabled children with attentive parents who may be more adherent to their medications than otherwise healthy teenagers.

The question is whether consideration of neurocognitive disability in transplant decisions is ethically justified. In this session, I will review arguments for and against such consideration, and suggest strategies and safeguards for assuring that children with neurocognitive disability are not unfairly denied transplants, while at the same time assuring that these scarce resources are used wisely and efficiently.

11:30 – 13:00 Closing Ceremony: ‘GLOBAL OUTREACH’

The Declaration of Istanbul: the first five years, the next five years

Gabriel Danovitch, Los Angeles, United States

Ethical and legal issues attaching to the pre-mortem care of potential organ donors continue to raise controversy and uncertainty in many European jurisdictions, often acting as a constraint on higher numbers of deceased organ donors. In the United Kingdom, this issue was flagged up by the Organ Donation Taskforce in its first 2008 Report *Organs for Transplants* as a matter requiring ‘urgent attention’ in order to provide a clear unambiguous framework of good practice for clinicians in this field. Whilst this issue has primarily arisen in the context of non-heart-beating donation and the provision of care, it also has relevance in respect of prospective heart-beating donation following a determination of brain death. It is suggested that much typically turns on what is regarded as being in the best interests of the patient and that his/her wishes relating to organ donation are a proper factor to be taken into consideration in deciding on end-of-life care. This in turn then raises questions relating to the time when one elicits donor consent or solicits consent from relatives, and the ‘moment of asking’. Moreover, it mandates the need for sensitivity and care in relation to actual or perceived conflicts of interest. Within the constraints of individual legal jurisdictions this paper attempts to identify appropriate ethical and legal practices and policies relating to the end-of-life decision-making and care of potential organ donors.

Global outreach: how to set up a transplant programme

Paul Harden, Oxford, United Kingdom

There are many countries in the developing world that have limited or no transplant services. In many developing countries transplantation with generic immunosuppression is a much more cost-effective way of treating end-stage kidney failure, and may be the only affordable option. Clinical partnerships between transplant centres in the developed world and new or embryonic transplant programmes in the developing world, can lead to tremendous joint success in helping to develop transplantation services and establishing a regional training centre. To ensure sustainability it is important to secure local government support, and key committed individuals are required in both centres to make the partnership function well. The International Society of Nephrology and Transplantation Society have recently launched a new initiative to create Sister Transplant Centers with limited funding, but a substantial package of support including short fellowships, mentor visits, facilitation of training courses and multidisciplinary training.

It is extremely rewarding to see practical dissemination of transplantation experience and protocols and their beneficial impact on upgrading existing clinical services and establishing new ones in developing centres. This session will demonstrate how practical global outreach can lead to the provision of transplantation as a life saving treatment in developing countries.

Global issues, local solutions. How can the European Commission contribute?

Marcus Klamert, Brussels, Belgium

The presentation will start by giving an overview of figures on living and deceased organ donors and transplants in the EU. This will be followed by a description of the legal mandate of the European Commission under the EU Treaty and the legal instruments adopted thereunder. The recently adopted Commission Implementing Directive laying down information procedures for the exchange, between Member States, of human organs intended for transplantation will be presented. This will be followed by a short introduction to decision-making in the EU in the area of public health, explaining the institutional set-up within the EU to ensure that the supranational mandate of the EU can be realised. The diverse responsibilities that are divided between procurement and transplant centres, national competent authorities and the Commission under this EU regime will be laid out. Legal measures and non-legal activities within the EU framework will be discussed. This will cover projects co-funded by the European Commission under the Action Plan, such as ACCORD and ELIPSY, and initiatives to ensure quality and safety by training professionals involved in organ donation will be presented. The presentation shall show the potential as well as the limits of the European Commission’s mandate within the European Union.

10:30 – 11:30 Focus Session 1: Living Liver Donation

*Chairs: Nigel Heaton, London, United Kingdom;
Frank Dor, Rotterdam, The Netherlands*

In the Western World, the majority of solid-organ transplants comes from deceased donors. In the last decade, deceased donation rates have flattened out, while the number of patients with end-stage organ failure has steadily increased, resulting in a large discrepancy between organ supply and demand. Living donor transplantation is one way to decrease this discrepancy. Living donor kidney transplant programs are increasingly successful in shortening wait lists, and, in some countries, living donor kidney transplants outnumber the deceased donor kidney transplants, and demonstrate many benefits over their deceased counterparts. For living donor liver transplants, the situation is rather different, as it is not universally accepted. For instance, living liver donation rates vary geographically (eg, living donation is more accepted in Asia than in the Western world). In this session, two experts in the field of liver transplantation will discuss ethical considerations on the future of living liver donation. There will be plenty of room for discussion on donor safety, anticipated recipient outcome, and need from different ethical, legal, and psychosocial points of view.

Living Liver Donation

Nigel Heaton, London, United Kingdom

Living donor liver transplantation: ethical considerations

Charles Miller, Cleveland, United States

10:30 – 11:30 Focus Session 2: Ethics and Donation after Cardiac Death (DCD)

*Chairs: Chris Rudge, Kent, United Kingdom;
Bernadette Haase-Kromwijk, Leiden,
The Netherlands*

This session will focus on the way in which ethical and legal guidance concerning Donation after Circulatory Death has been provided in the UK, including a description of the establishment and actions of the independent UK Donation Ethics Committee and a report from the ESOT DCD meeting held in Paris in February 2013.

DCD donation raises many concerns in terms of the withdrawal or limitation of life sustaining treatment, actions that may be taken before death, the certification of death, consent for organ donation and actions that may be taken after death to optimise the potential for successful organ donation and transplantation. Cli-

nicians involved in the care of possible DCD donors need reassurance and guidance that all the steps necessary for successful donation are both legally and ethically appropriate. The UK has developed such guidance in recent years, and these themes were a major part of the recent ESOT meeting on DCD donation. A summary of the relevant discussions will be presented by two very eminent leaders in this field.

The establishment of a national donation ethics committee and the UK ethical guidance on DCD donation

Sir Peter Simpson, Bristol, United Kingdom

The UK Donation Ethics Committee was formed three years ago, in response to a recommendation from the UK's Organ Donation Task Force. Our role is not to promote organ donation, but rather to remove the obstacles, both real and perceived, to successful organ donation and transplantation. We consider ethics in its broader context, to include moral, ethical, legal and faith based issues and our Committee, though not representational of any particular organisation, includes ethicists, philosophers, lawyers, intensivists, transplant physicians and surgeons, specialist nurses, transplant coordinators and managers, many of whom have more than one area of expertise and provide links to the Departments of Health and faith based organisations.

Divided into two parts, our publication 'An Ethical Framework for Controlled Donation after Circulatory Death' sets out guidance and recommendations for current practice and further work. Part 1, the ethical framework, considers issues surrounding the definition, diagnosis and confirmation of death and conflicts of interest both real and perceived. We also discuss ways of exploring a competent individual's views about organ donation, of deciding that continuation of life-sustaining treatment is no longer of overall benefit and determining whether organ donation is of overall benefit to an incompetent patient.

Part 2 is structured around the potential donor pathway. Guidance considers a number of key issues such as deciding that further treatment is no longer in a patient's best interests, seeking consent for organ donation, management before withdrawal of life sustaining treatment, the process itself of withdrawal of life-sustaining treatment and managing death and subsequent interventions.

This guidance is certainly not intended to be read in isolation, but rather in relation to existing documents concerned with the diagnosis and confirmation of death and clinical aspects of donation after cardiovascular death. It provides healthcare professionals with a framework on which to base many of the difficult, ethically related decisions which confront them, in organ donation and transplantation.

Ethical and legal aspects of DCD in a European perspective

Michael Bos, The Hague, The Netherlands

This presentation will give a summary of the 6th International Conference on Organ Donation after Circulatory Death that took place in Paris from 7-9 February, 2013. This conference aimed to achieve European best practice guidelines and recommendations.

10:30 – 11:30 Focus Session 3: Home Based Education

*Chairs: James Rodrigue, Boston, United States;
Jan van Busschbach, Rotterdam, The Netherlands*

Research has shown that patients find it difficult to discuss living donation with their loved ones. Both the patient and those in their social network are often reluctant to broach the subject which can lead to a passive deadlock on this issue. This session will focus on barriers to engagement and innovative efforts to improve education on living donation aimed at supporting education and communication between the patient and their social network. Specific attention will be given to patients from ethnic minority backgrounds. Firstly, the keynote speaker, Dr. Ebony Boulware, will provide an overview of barriers to family communication on living donation and new efforts to address these barriers in educational programmes. Secondly, the first findings from a randomised control trial testing a home-based educational programme in the European setting will be presented. Finally, factors that influence adult learning and how this can be optimized by adapting communication strategies to the specific patient-learner will be explored.

Family interventions to improve consideration for live kidney transplantation

Ebony Boulware, Baltimore, United States

Live kidney transplantation represents an optimal therapy for patients with end stage kidney disease, but it is often underutilized. United States ethnic/racial minorities are less likely to utilize live kidney transplantation than non-minorities, contributing substantially to overall low rates of utilization. Reasons for underutilization are multifactorial, but they include patients' reluctance to engage family members as potential donors. Recent studies have shed new insight into barriers to family engagement in live kidney transplantation. In this presentation, recent evidence on the need for interventions to improve patients' consideration of live kidney transplantation will be reviewed and recent studies describing family-centered interventions to improve live kidney transplantation will be discussed.

#132 First results of a randomized controlled trial on a home-based educational intervention

Sohal Ismail, Rotterdam, The Netherlands

#125 Toward a learner-centered model for patient education

Owen Surman, Long Beach, United States

10:30 – 11:30 Focus Session 4: Donor Recruitment, Altruism and Compensation

*Chairs: Arthur Matas, Minneapolis, United States;
Stellan Welin, Linköping, Sweden*

Organ transplantation is a lifesaving procedure. However, there is a shortage of both living and cadaveric donor organs to transplant. There are many ethical issues involved in the donation process. One aspect for cadaveric donations is how, when, and from whom consent should be obtained. Different countries have adopted different policies for cadaveric donation – some have an opt in policy (no donation without active consent); others have an opt out policy (donation unless a no). There are also variations in the role of relatives. At the same time, there also differences between countries in living donation policies.

One important idea both for living donation and cadaveric donation is that consent to donation should be based on informed consent and given voluntarily and without duress. But what is allowed, and what is ruled out by this? Are incentives consistent with non-coercion and voluntariness? If so, is there a limit on how much? Could we advertise for donors? Could we give donors or donor relatives financial rewards for donations? Can such procedures be defended by the lifesaving character of donations? Or is any such incentive inherently wrong?

Purely altruistic organ procurement models are insufficient in meeting today's needs in transplantation!!!

Faisal Omar, Linköping, Sweden

In almost all fields of medicine, transplantation particularly, there is a gap between available resources and health care needs, bringing into question matters of fair distribution amongst those with competing legitimate claims on the limited resource. As a result of this, we find organ transplant programs are continuously pushing the technical envelope to mitigate the chronic shortage in organs; programs innovate and integrate new methods, some more successful than others: Domino Transplants, Extended Criteria Donor Transplants, Blood type Incompatible Transplants. In addition, within certain international transplant net-

works and programs organ allocation processes have become very complicated, backlogged, and expensive to manage, where numerous criteria: age, weight, cardiovascular health, waiting time, psychosocial considerations...etc. are continuously traded off in computer based algorithm in the pursuit for fairness; on the other hand some transplant programs continue lacking clearly defined uniform allocation guidelines and procedures. Neither scenario is ideal for efficient or fair resource distribution. Evaluating these programs and allocation procedures using ethical tools is helpful to identify potential sources of unfair access. While this is important it is critical to stay focused on the root problem, which is the chronic mismatch between the number of organs available vs. competing claims for them i.e. patients who stand to benefit from a transplant but will not have access in time. In this talk I will be arguing that reliance on Altruism as the sole instrument for organ procurement has proven unsustainable, and that a rethink is desperately needed. Bridging together evidence from Behavioral agency theory a strong case is made for incentivizing (using clearly defined, and ethically defensible incentives) organ donation as a positive pro-social behavior; a realistic, affordable, and ethical way to make organ transplantation more widely and fairly available.

Organ donation and charity

Govert den Hartogh, Haarlem, The Netherlands

Organ donation should be an act of charity. This is probably the most widely shared view about the morality of donation. In countries with an opt-in system it is often used as an argument against changing the system. Such arguments rest on several assumptions:

- that government policy should not only be interested in actions, but also in the motives for these actions;
- that charity cannot be the norm, something to be expected from people, let alone a duty.

In my presentation I will question these assumptions.

10:30 – 11:30 Focus Session 5: Principles of Allocation

Chairs: Janet Radcliffe Richards, Oxford, United Kingdom;

Axel Rahmel, Leiden, The Netherlands

Organ allocation: principles, pragmatism and practice

Antonia Cronin, London, United Kingdom

Identifying which patients should be listed for transplantation and defining how to allocate organs to them at a time when organ shortage has prompted an ever-increasing use of non-standard donor organs

once thought unsuitable for transplantation, has created new challenges. Some organs are better than others and this affects transplant outcome. So, should a predictive index measure of transplant outcome guide allocation? How would such a scheme affect existing models which prioritise urgent medical cases? Would this achieve equitable access to organs?

Using a series of short presentations on patient selection and prioritization for transplantation, donor organ quality and transplant outcome, this focus session will address the implications of these and other challenges for the principles of equity and justice, which underpin deceased donor organ allocation.

Possible solutions and ways forward for those charged with operational oversight of deceased donor organ allocation will be considered.

#59 Directed donation of deceased donor organs – a donor intent driven policy

Aviva Goldberg, Winnipeg, Canada

#129 The pediatric priority in organ allocation is not necessary and is counterproductive – proposal for an alternative ethical model

Jean-Luc Wolf, Sherbrooke, Canada

10:30 – 11:30 Focus Session 6: Anonymity

*Chairs: Nizam Mamode, London, United Kingdom;
Willij Zuidema, Rotterdam, The Netherlands*

This session will consider the role of anonymity, for both donors and recipients, in living donor programmes. This includes unspecified (altruistic) donation and any variety of paired or pooled (i.e indirect) donation. The ethical arguments for and against anonymity will be described, and a review of different scenarios, with possible harms and benefits will be presented. Examples where loss of anonymity has proved beneficial or harmful will be given, and comparisons of existing approaches across Europe will be made.

The aim of the session is to stimulate lively debate on a controversial topic, in the hope of providing a rational grounding in the arguments for those who need to consider the approach to anonymity at a local or national level.

Anonymity in living donation: when, how and why?

Nizam Mamode, London, United Kingdom

Anonymity of donors or recipients in living donor transplantation is a complex issue. Across Europe there is a wide variation in practice, although in some countries there are practical difficulties in maintaining

anonymity. The consequences of losing anonymity can be very significant; thus there are compelling arguments for maintaining anonymity of both parties prior to unspecified donor transplantation, and specified indirect transplantation. After transplantation, there are still good reasons to avoid disclosure of identities. Although anonymity could be lifted if both parties explicitly request it, there are significant, potentially negative consequences of such an approach. Both donor and recipient should be counselled regarding these, and transplant teams should consider the considerable financial and psychosocial costs if problems are encountered as a result of contact.

Ethics and the requirement of anonymity in organ donation

Medard Hilhorst, Rotterdam, The Netherlands

Although it has been common practice in organ donation to require anonymity (where feasible), these two are not necessarily or intrinsically linked. If we take reciprocity as the most fundamental, underlying ethical principle in public affairs, non-anonymity should at least be considered as an option. Should we then leave it to the parties involved, according to their tastes and views? But this opens up a further debate: what central values do we (want to) facilitate, uphold, make known, in transplantation? What can be required and what duties flow from it?

Experiences with anonymity

Lisa Burnapp, London, United Kingdom

Is principle realistic in practice? Using case studies drawn from direct clinical practice, this interactive part of the session explores the practicalities and implications of maintaining anonymity between donors and recipients in living donor transplantation. The audience will be encouraged to consider if the benefits of anonymity outweigh the risks of disclosure in the context of real cases and to contribute their own views and experience to the debate. Emphasis will be placed upon identifying practical solutions to the daily dilemma of translating theory into practice.

08:30 – 11:30 Focus Session 7: Living Organ Donation: Results of the EULOD Project

*Chairs: Bijan Fateh-Moghadam, Münster, Germany;
Jan IJzermans, Rotterdam, The Netherlands*

The project on 'Living Organ Donation in Europe' (the EULOD project) ran from 2010 until 2012 and was a coordination action, funded by the European Commission. This project aimed to 1) establish an

inventory of living donation practices in Europe, 2) explore and promote living donation as a way to increase organ availability and 3) develop tools that improve the quality and safety of living organ donations in Europe. This session presents the results and recommendations that the project generated.

Living donation clinical practices in Europe

Annette Lennerling, Gothenburg, Sweden

Introduction: In Europe living donation is increasingly accepted as a possible solution to reduce the organ shortage. In 2011, 20 % of all kidney transplantations and 3.5 % of all liver transplantations performed in Europe were with a live donor organ. Large differences across Europe can be observed in numbers, practices and the type of relationship between donor and recipient that are accepted. In response to this the project 'Living Organ Donation in Europe' (EULOD) a Coordination Action, funded by the Seventh Framework Programme of the European Commission was initiated.

Methods: Transplant professionals from 331 European kidney- (KTC) and liver transplant centres (LTC) were invited to complete an online survey.

Results: Responses were received from 113 KTC (40 countries) and 39 LTC (24 countries). Medical donor screening was similar, but criterion for acceptance differed. The majority of the KTC (60%) performed less than 25 living kidney transplantations a year. Two thirds of the liver units performed less than six living liver transplantations a year. The reimbursement policy differed and a majority of the donors did not get reimbursed for income loss.

Conclusion: As a result suggestions are made to improve the quality and safety of living organ donation in Europe.

Attitudes, barriers and opportunities: results from focus groups conducted in four European countries

Assya Pascalev, Sofia, Bulgaria

Background: Living organ donation (LOD) is an important source of transplantable organs and a means of alleviating the organ shortage. Many countries have implemented LOD as a medically, legally and morally justified approach to treating end-stage diseases. Yet, despite demonstrated advantages, relative safety and legal acceptance, the rates of LOD in the European Union (EU) remain low.

Methods: Focus groups were conducted in four EU countries, Belgium, Bulgaria, Estonia and Romania, to explore attitudes and perceptions of transplant professionals and other stakeholders to LOD and to identify ethical, legal, financial and other barriers.

Results: Participants attributed the low rates of LOD to demographic, financial or medical factors.

No religious or legal barriers were reported. Harm and risks to live donors were major ethical concerns. LOD to anonymous recipients was viewed negatively because of its potential for commercialization. Lack of resources and lack of public awareness were cited as barriers in the new EU member states. Independent Ethics Committees were seen as important for donor protection.

Conclusions: The results offer valuable information about the attitudes of transplant professionals and other stakeholders to LOD, identify major barriers and suggest steps for improving LOD rates. Raising public awareness, government support and investment in LOD are needed to improve LOD.

Legal issues of living organ donation in the member states of the EU

Leonie Lopp, Münster, Germany

Almost every Member State of the EU has a specific law for organ donation and those also include specific regulations for living organ donation (LOD). While the legal issues of LOD in need of regulation are similar in all the countries, the provisions differ at least partly. All countries, for example, require the donor's consent for the particular LOD. In contrast, the countries' regulations with respect to the required donor-recipient-relationship differ significantly. Some countries do not require a specific relationship between donor and recipient, making unspecified LOD possible. Others, however, limit a donation to certain relationships between donor and recipient, while even other countries request a certain relationship, but contain an 'open clause' in addition, making LOD's outside of the enumerated relationships legally possible under specific circumstances.

After comparing the different regulations to establish a best practice proposal for LOD and questioning whether LOD should be restricted by law, most restrictions seem unjustifiable. This is especially the case when considering the problem of organ shortage.

Lost in Translation?

Organ Donation, Organ Sale and Trafficking: International Legal Aspects

Judit Sándor, Budapest, Hungary

The Protocol to Prevent, Suppress and Punish Trafficking in Persons, especially Women and Children (the Palermo Protocol) declares in its Preamble that '...effective action to prevent and combat trafficking in persons, especially women and children, requires a comprehensive international approach in the countries of origin, transit and destination that includes measures to prevent such trafficking, to punish the traffickers, and to protect the victims of such trafficking, including by protecting their internationally recognized human rights.' But what follows from

these broadly stated international duties? What are the obligations of the States, the researchers and the law enforcement authorities in order to comply with the international legal frameworks in this field? Furthermore, what are the conceptual obstacles that prevent stakeholders from recognizing the vulnerability of the poor (in other countries) and from realizing the need to develop special, transnational guarantees in this particular field? What is the role of the often stated economic solutions, such as partial commodification of organs and what are the possible alternative policies? The presentation will analyze the transnational aspects of organ sale and trafficking, based on the theories of international justice.

Ethical analysis of the arguments for and against living organ donation

Presenter: Mihaela Frunza, Cluj, Romania

Authors: Assya Pascalev, Yordanka Krastev, Adelina Ilieva, Bulgarian Center for Bioethics

The ethics of living organ donation (LOD) has generated heated debates ever since the practice became a reality in 1954. Despite its success and relative safety, LOD remains morally controversial and legally restricted leading to missed opportunities to help patients and alleviate the organ shortages. These consequences raise the question whether the reservations are ethically justified.

Our study offers a critical analysis of the major ethical arguments for and against LOD in order to assess its moral permissibility and implications for medical ethics, the physician-patient relationship, laws, policies and the ethos of transplant professionals.

We argue that LOD is morally justified on the basis of donor autonomy and, to some degree, on grounds of beneficence and justice. Consequently, the moral permissibility of LOD is limited to autonomous donors and cannot be extended to minors and other incompetent persons who lack autonomy. The principle of justice requires that LOD involve some benefit to the donor to offset the burdens (risks, harms, pain and discomfort). Insofar as LOD is a burden to the donor, it should be subsidiary to other therapies whenever a comparable alternative is available. LOD requires strict safeguards to establish valid consent, benefit to the donor and conflict-free assessment by a fiduciary-physician. Developing LOD should go hand-in-hand with exploration of new technologies to allow transplantation to progress with fewer moral challenges.

Recommendations on identification and assistance of victims and potential victims of organ trafficking

Natalia Codreanu, Chisinau, Moldova

Identification of victims of organ trafficking (VOT) is a relatively new issue in the global context of trafficking.

Most of the analysed data showed that the number of identified VOT represents a small part of the number of actual victims, while even a lower number of victims receives appropriate assistance. Earlier identification of VOT is crucial to ensure the protection of rights of victims and to prevent the trafficking in the case of potential victims. It is also very important in ensuring a successful prosecution of the traffickers. Within the EULOD project a number of recommendations have been developed in order to increase the earlier identification of VOT and to improve the assistance measures devoted to the victim's needs. The recommendations are designed for the National Authorities and the NGO-s involved in identification and assistance of VOT and are focused on implementation of the pro-active approach of identification process. The key points of the recommendations are: • The range of actors participating in the identification process should be expanded by involving the medical staff involved in organ donation process; • Specific trainings and guidelines dedicated to identification methodology should be elaborated and incorporated into existing training modules. Early identification requires training on a regular basis of all actors likely to come into contact with (potential) trafficked persons; • Hotlines dedicated to organ donation and transplantation and regular national info campaigns on organ trafficking should be implemented; • Assistance of victims and potential VOT should include accommodation, counselling and information, legal assistance, health care, psychological services, vocational training, employment opportunities, and protective measures; • Long term medical follow-up should be ensured to VOT in order to identify, to report and manage any negative consequences that may result from the illegal organ donation.

**08:30 – 11:30 TTS/ELPAT Session 8:
Starting a Deceased Donor
Programme**

Chair: Paul Harden, Oxford, United Kingdom

Deceased organ donation program in Croatia
Mirela Busic, Zagreb, Croatia

As generally agreed, the organ shortage in all health care systems is primary caused by failure to identify and or convert potential donors into real actual donors. Deceased donation practice yet largely varies among the countries worldwide since the brain death concept and clinical practice in determination of brain death is not yet globally harmonized. In many countries different initiatives have been implemented to increase donor rate. However, in the recent few years only few European countries, like Portugal and Croatia succeeded to ensure sustained and tremendous increase in deceased organ donation. In 2011 Croatia recorded a phenom-

enal boom in the transplantation program and ranked as a world leader in regards the utilized donor rate (33.5 donors pmp) and kidney and liver transplants. There are number of key factors that have greatly influenced development of deceased donor program. However, results achieved in 2011 are the crown efforts of many years of enthusiasm of health workers, sustained organizational efforts, and systematic investing in deceased donation programmes, founded on a unique commitment to the discipline and health administration and political support for the transplantation program to be a national public health interest.

**Success factors and hurdles in upgrading
deceased and living organ donation in Israel**

Jacob Lavee, Ramat Gan, Israel

Background: Israel's organ donation rate has been traditionally among the lowest in Western countries. A unique new Organ Transplantation Law has made a marked impact on the national organ donation.

Methods: In 2008 Israel's Parliament passed into legislation the Organ Transplantation Law which (1) bans reimbursing transplants performed abroad under the definitions of organ trade; (2) grants prioritization in organ allocation to candidates who are registered donors for at least 3 years prior of being listed; (3) removes disincentives for living donation by providing modest insurance reimbursement and social supportive services. The initial impact of the implementation of this law has finally been witnessed in 2011.

Results: The number of deceased organ donors significantly increased from 60 in 2010 to 89 in 2011 ($p = 0.01$). There has been a significant increase in organ donation rate (from 7.8 donors per million population in 2010 to 11.4 in 2011, $p = 0.01$), an increase in kidney transplantations from living donors, and a marked decline in the number of patients who underwent kidney transplantation abroad (from 155 in 2006 to 35 in 2011, $p = 0.005$).

Conclusions: The implementation of the new law has resulted in a significant increase in organ transplantations both from deceased and living donors.

**Success factors to decrease foreign transplants
in Colombia**

Nestor Pedraza, Bogotá, Colombia

In 2005 Colombia made 16.5 % of its organ transplants in foreign patients. The total Organs Transplanted were 756, 124 in foreign, of which kidneys were (598 citizen/95 foreign), Livers (115/22), and Hearts (37/3) and Lungs (6/4). Colombia changed their policies and created the Transplant Network Organization, a subdivision of the National Health Institute (INS). According to the new legal framework, each program should ask the INS for a written permission to transplant a foreign patient, and the INS should demonstrate that there is

not a suitable Colombian recipient for that specific organ.

Otherwise the health system increased the waiting list for each organ and set the network to share organs for one region to another. Several laws, executive orders and a declaration of the Council of State were made in these years to translate the law into clinical practice.

Each year the number of foreign patients transplanted in Colombia decreased and by 2012 it represents less than 0.7% of the total of organs transplanted. This number can be favorable compared with some percentages for other countries.

Success factors and hurdles in developing donation from deceased donors in Thailand

Vasant Sumethkul, Bangkok, Thailand

Universal Health Coverage scheme started in Thailand since 2002. This offered comprehensive health care including outpatient and inpatient services, surgery and critical care. Initially, renal replacement therapy (RRT) was not covered due to budget constraints. However, from 2008 RRT was accepted in the UHC. CAPD first policy and hemodialysis support has increased the cumulative prevalence of dialysis patients from 30 per million populations in 1997 to 630 pmp in 2010. The cost of providing dialysis increased more than 20 fold.

Thai Transplantation Society realized a need to make organ transplant expansion. This can reduce the number of dialysis patients and provide patients' longevity. Developing donation from deceased donor is a vital step. We decide to plan for intensive collaboration among medical professions first. Key doctors from Transplantation Society, National Health Security Office, Ministry of Public Health, Red Cross Organ Donation Centre, College of Neurosurgeons, Critical Care Society and General Medical Council have regular meetings. Potential barriers to organ donation are identified. National forum for the diagnosis of brain death was discussed among the medical communities and lawyers. The revised version was endorsed. Interactions between transplant coordinators, donor hospitals, health policy makers, organ donation center and Thai Transplantation Society are regularly organized. The model of 'Excellence Donation and Transplantation Hospitals' is set up.

All of the above led to a preliminary success. The number of total kidney transplantation increased from 173 transplantations in 2005 to 402 in 2011 and 453 in 2012. Deceased donation rate increased by 66 %. The model of collaboration between national health policy makers and medical professions proved to be effective in the expansion of deceased organ donation.

Challenges in implementing the deceased donor programme in India

Sunil Shroff, Chennai, India

The Deceased Donor Programme (DDP) in India has been possible since 1995 due to central legislation recognizing brain death (BD). Organizing a DDP is a logistics as well as a medical challenge due to lack of awareness of BD among medical professionals and their failure in identification, certification and maintenance of BD. The programme has been more successful in South India due to the efforts of the government, hospitals and NGOs. The state of Tamil Nadu runs the most successful programme with an organ donation rate of 12 per million population (national rate 0.1 per million population) in Chennai city. Here the government provides the organ sharing and allocation framework, MOHAN Foundation (an NGO) creates public awareness, trains and places transplant coordinators in both public and private hospitals and runs the online-waiting list registry for the state. As health is a state subject in India, individual states need to be more proactive in promoting the programme and providing adequate infrastructure in public hospitals. Also, hospital ICUs need to have a better understanding of the deceased donation process so as to integrate BD management into their routine care. This can be the key to success of DDP in India.

08:30 – 10:00 Focus Session 9: Ethics, Immunosuppressants and Big Pharma

*Chairs: Simon Rowe, Reading, United Kingdom;
Teun van Gelder, Rotterdam, The Netherlands*

Generic products are available once the patent protection afforded to the original developer has expired. Generic manufacturers do not have to prove the safety and efficacy of the drugs through clinical trials, since these trials have already been conducted by the brand name company. For registration of the generic formulation demonstration of bio-equivalence with the original brand name product is sufficient. There is a strong pressure on prescribers to substitute brand name drugs for the cheaper generics.

My liver, my drugs, my transplant, my life

Liz Schick, Anzère, Switzerland

Anyone can potentially find themselves in need of a transplant. This presentation shows how transplantation is the beginning of a whole new journey, where the patient must also take a responsible role in their transplant management. Transplant recipients can achieve all sorts of goals; some of those goals will be shared in the opening part of this session.

Liz Schick also shares her views on the importance of her transplantation, the effect her transplant had on her life and her attitude towards her drugs and how important they are. In addition, Liz presents her perceptions of the whole transplant experience; illness, the diagnosis, the waiting list, surgery and life post-transplant.

**Generics are not the same –
in the patient perspective**

Per Åke Zillén, Saltsjö-Boo, Sweden

**Substitution of brand name drugs for cheaper
generics: an ethical dilemma?**

Teun van Gelder, Rotterdam, The Netherlands

Within the field of solid organ transplantation the patents for a number of immunosuppressive drugs have expired in the last few years. Tacrolimus, cyclosporine and mycophenolate mofetil are now available as generic drugs. In some countries the market penetration of these generic formulations is as high as 70%, whereas in some other countries this figure is below 10%. Several professional societies have published position papers on the risks and benefits of generic substitution of immunosuppressive drugs, and it is a heavily debated topic at national and international transplant meetings. There are published studies that report more rejections following generic substitution.

Patients often suspect that the cost-driven substitutions may compromise their quality of care. They have been treated with the originator drug for a considerable time, with good experience, and they feel uncertain to switch to another formulation, even with their doctor's consent. When patients are not allowed to choose freely this may affect their adherence to medication, potentially influencing clinical outcome. Forcing generic substitution upon patients seems incompatible with patient-centered medicine.

Workshops

**14:30 – 18:00 Workshop 1:
Cultural and Religious Aspects
of Living and Deceased
Donation**

*Chairs: Farhat Moazam, Karachi, Pakistan;
Gurch Randhawa, Luton, United Kingdom*

**Kidneys from deceased donors: Public's views
from Pakistan**

Farhat Moazam, Karachi, Pakistan

Organ transplantation is only possible through the generosity of others outside a patient-physician dyad, and remains the most sociologically complex medical specialty. Yet our comprehension of the diverse ways through which humans make sense of the body/self and its relationship with others, factors that profoundly influence donor decisions, has not kept pace with rapid scientific advances in this field. Meanwhile by default, in international (English) academic discourse on deceased donation, 'altruism,' conceived narrowly as a rational, non-contextual, secular decision taken by an autonomous agent, has assumed center stage as the ethically acceptable motive for deceased organ donations.

Little empirical data exists about how, and if, this assumption resonates with the public in societies where 'the general order of existence' (Clifford Geertz) is shaped by shared traditions that center on family and religious values. As Pakistan, a Muslim majority country, is planning to initiate deceased donor programs, we undertook in-depth interviews with 105 members of lay public to explore this issue. The aim was to gauge public knowledge about stance of Muslim ulema about deceased donation, and to understand attitudes and motives towards such donations. Our findings reveal a local moral world which is different in significant ways from the more familiar paradigm of altruistic deceased donation.

Access to donation and transplantation

Gurch Randhawa, Luton, United Kingdom

Research has revealed that there is an urgent need to increase the number of organ donors from minority ethnic groups in countries such as the UK, US, Canada, and the Netherlands, where there is a strong tradition of immigration, in order to tackle inequalities in access and waiting times.

Minority Ethnic groups are disproportionately affected by kidney problems for a number of reasons, including higher levels of Type 2 diabetes and high blood pressure which are major causes of end-stage kidney disease.

Despite this higher than average demand for transplants, 70% of Minority Ethnic families in the UK refuse consent to organ donation, twice as many as the 35% of white families. This underlines the need

for greater engagement with BME communities to increase awareness and donations and prevent the conditions that lead to organ failure.

This paper highlights learning from 3 recent studies in the UK focussing on Kenyans, Polish and South Asian communities to provide a deeper understanding of the importance of social networks within these communities in developing greater understanding and debate about organ donation.

**#11 Altruism vs. reciprocity – a Polish migrant
perspective: an 'altruistic gift'**

Chloe Sharp, Luton, United Kingdom

**#60 The impact of religion on deceased organ
donation in Lebanon**

Antoine Stephan, Hazmieh, Lebanon

**#84 New independent Ethics Committee
meeting unrelated donors in Kuwait
succeeds in reducing commercial
transplantation**

Mustafa Al-Mousawi, Kuwait City, Kuwait

**#117 Orchestrating an exceptional death –
donor family experiences and organ
donation in Denmark**

Anja Bornoe Jensen, Copenhagen, Denmark

**#153 A national survey of public's attitude
toward individual autonomy or family
decision in organ donation in Taiwan**

Daniel Fu-Chang Tsai, Taipei

**#155 Cultural and religious factors in discuss-
ing stem cell transplantation in Romania:
analysis of blogs**

Sandu Frunza, Cluj, Romania

**14:30 – 18:00 Workshop 2:
Cross-Border Transplants**

*Chairs: Susanne Lundin, Lund, Sweden;
Frederike Ambagtsheer, Rotterdam,
The Netherlands*

Organ donation and transplantation increasingly occur in a global context. This workshop addresses illegal forms of cross-border transplants: transplant tourism, organ trafficking and human trafficking for the purpose of organ removal. The workshop consists of two parts. In the first part, the term 'transplant tourism' will be addressed, as well as the different meanings assigned to it and its implications. The presentations will be followed by a panel discussion. The second half of the workshop focuses on trafficking. What is human trafficking for the purpose of organ removal and

how does it differ from organ trafficking? Finally, the socio-cultural factors shaping the moral perceptions, discourses, practices and public policies regarding cross-border organ trafficking will be addressed, and followed by a discussion.

Transplant Tourism

Transplant tourism: the ethics and regulation of international markets for organs

Glenn Cohen, Cambridge, United States

Medical Tourism' is the travel of residents of one country to another country for treatment. In this talk I focus on travel abroad to purchase organs for transplant, what I will call 'Transplant Tourism.' With the exception of Iran, organ sale is illegal across the globe, but many destination countries have thriving black markets, either due to their willful failure to police the practice or more good faith lack of resources to detect it. I focus on the sale of kidneys, the most common subject of transplant tourism, though much of what I say could be applied to other organs as well. Part I of the talk briefly reviews some data on sellers, recipients and brokers. Part II discusses the bioethical issues posed by the trade, and Part III focuses on potential regulations to deal with these issues.

How health-care providers can identify and prevent transplant tourism

John Gill, Vancouver, Canada

Patients at risk for transplant tourism may be readily identified. Health care providers are often aware of patients who are at risk for transplant tourism but may be reluctant to intervene.

In the case of transplant tourists, the health care provider's duties to their patient may conflict with their moral beliefs or ethical obligations to society.

The presentation will discuss the health care provider's role in preventing transplant tourism, including identification of patients at risk, differentiating transplant tourists from those who travel for the purposes of transplantation, preventing transplant tourism, and reporting transplant tourists.

The challenge of distinguishing transplant tourism from travel for transplantation and organ trafficking in clinical practice will be discussed using an actual clinical case.

#38 Nothing but a word?

The ethical meanings of the term transplant tourism

Merle Annika Michaelsen, Göttingen, Germany

Panel discussion: Transplant Tourism

Organ Trafficking

Report: trafficking in human beings for the purpose of the removal of organs

Maarten Abelman, The Hague, The Netherlands

The Dutch National Rapporteur on Trafficking in Human Beings focuses on current developments in the field of organ donation and the forced removal of organs. It builds on two previous reports and describes recent developments in the Netherlands and in international legislation on these types of human trafficking. The report moreover discusses the recent debate on the commercialisation of the market for human organs. There are no indications of a high incidence of trafficking in human beings for the removal of organs (sometimes referred to as 'organ harvesting') within the Netherlands. Neither do Dutch citizens appear to be involved in this crime abroad often. Nevertheless, the Rapporteur calls for watchfulness. The Netherlands are experiencing a shortage of organ donors. Live organ donations are rare, and must be voluntary and non-commercial. Because of the severe shortage of organs, patients seem to be willing to pay for them. There have been various calls for financial incentives for organ donation. A number of points need to be considered in this context. While financial incentives could alleviate the shortage of organs, they could also make organ donation a commercial activity. Creating a commercial market for organs brings about a risk of human trafficking. That risk could be avoided by offering donors an exemption from health insurance premiums rather than a direct monetary reward. Trafficking in organs and human trafficking for the purpose of the removal of organs are not constrained by national borders. It is important for states to try to reach new joint solutions and, where possible, coordinate policies and strategies with respect to organ donation.

International norms, local worlds: an ethnographic perspective on organ trafficking in the Israeli context

Zvika Orr, Jerusalem, Israel

International norms have denounced and banned the trafficking of human organs for transplant. However, these unequivocal norms have not always been accepted and implemented in local settings. Based on multi-sited ethnography that includes participant observations, in-depth interviews and content analysis of documents, this paper aims to address this gap. Focusing on the Israeli context, this paper examines the particular socio-cultural factors shaping the moral perceptions, discourses, practices and public policies regarding cross-border organ trafficking. These factors include: fundamental moral attitudes, particularly deontological versus utilitarian approaches; the human rights discourse in its transnational as well as vernacularized versions; deeply-rooted religious views on

ethics, social relations and the body; dominant socio-economic conceptions, particularly the neoliberal paradigm; and bodily perceptions, including the perceived connection between the body and the self. This paper explores how in the Israeli case, the complex interactions between these factors have produced a relatively tolerant attitude toward the buying and selling of organs amongst different stakeholders. By analyzing the construction of the 'local moral worlds' and the experiences of diverse actors, this study sheds light on the tensions and relations between international norms on the one hand, and the practices and discourses in Israel concerning organ trafficking on the other.

Panel discussion: Organ Trafficking

14:30 – 18:00 Workshop 3: Psychosocial Care

*Chairs: Fabienne Dobbels, Leuven, Belgium;
Yesim Erim, Essen, Germany*

Transplantation is life-saving, but the post-transplant follow-up is complex: patients are asked to manage their medical regimen, including life-long medication intake to prevent rejection and treat co-morbidities, monitoring of symptoms and signs of rejection, and executing health behaviors, such as smoking cessation, no or limited alcohol use, regular exercise, and healthy diet. Moreover, patients need to manage emotions and changes in roles. Given that clinical outcomes largely depend on the patient's ability to manage their illness in daily life, self-management support deserves special attention both in research and the clinic.

This session starts with an overview of knowledge and skills transplant professionals need to support their patients' self-management, followed by insights from a patient as expert in managing his illness in daily life independently. Specific attention is also given to self-management issues in challenging populations, including patients with substance abuse, low health literacy and young adults. Finally, the increasing use of health technology as an innovative tool to monitor and support self-management is also addressed, using pre-transplant screening applications as an example. The interactive panel discussion at the end of the session will provide some key insights on how evidence can best be translated from research into clinical practice.

Which knowledge and skills do (transplant) professionals need to support their patients' self-management?

Ad Kaptein, Leiden, The Netherlands

Self-management is a crucial component of biopsychosocial care in patients with kidney transplants. There-

fore, incorporating self-management into medical care for these patients is a *conditio sine qua non* in modern health care. Patients are not passive receivers of high tech biomedical care. They are active participants in the medical care in which they are involved.

Various models can be applied in the study of greater patient involvement in their health care. In the Common Sense Model (Leventhal et al.), illness perceptions and treatment beliefs are helpful concepts in stimulating self-management. Recent research examples will be discussed. On an organizational level, the Chronic Care Model (Fisher et al.), provides conditions that help empower patients, which translates into a better outcome of health care and a higher quality of life. Examples from this model will be discussed as well.

Increasing health literacy, engaging patients in decision-making, and strengthening patients' capacity to undertake effective self-management are instrumental in quality medical care for people with kidney transplants. Transplant professionals must be encouraged and stimulated to incorporate these skills into their care for patients with kidney transplants. Empirical illustrations from the nephrology field but also from other chronic illnesses categories will be presented and reviewed.

Patients as partners: the road to success

Per Åke Zillén, Saltsjö-Boo, Sweden

A prerequisite for treatment success is high quality professional care in combination with high quality self-care by the patient. One cannot do without the other. Therefore, in relation to chronically ill patients, the treatment plan is or should be divided into two parts: One for the professionals (what professionals only can deliver) and one for the patient (what only the patient can carry out). Thus, the professionals and the patient are working together towards a common goal with the patient as the key member of the health care team. The patient is also the key member of his/her own supportive 'home team'.

Necessary attitude adjustments (on both sides) and educational concepts to achieve an empowered and responsible self-care will be discussed. Everything patients can do themselves in relation to preparations for and maintenance of a kidney transplant will be used as a practical example of a working partnership.

Self-management support in patients with alcoholic liver cirrhosis

Yesim Erim, Essen, Germany

End stage alcoholic liver disease (ALD) has long been considered a controversial indication for liver transplantation but is today an accepted treatment option. About 25-35 % of all liver transplantations are presently conducted because of ALD; with clinical outcomes comparable favorably to those documented for

other liver diseases. Besides an increased risk for return to heavy drinking after transplantation, ALD patients should refrain from alcohol before transplantation to improve their health. Abstinence can reduce severe complications of the liver disease, sometimes even to the extent where transplantation can be delayed or is no longer required.

Pilot studies attempting to prophylactically modify drinking behavior after transplantation found that waiting until after transplantation has no success whereas treatment before transplantation may be efficacious. Consequently in our transplantation center in the University Hospital of Essen, the objective is to ameliorate the risk of post-transplantation drinking by initiating alcoholism therapy before transplantation. In this presentation we report on the evaluation of the ALD patients, the regularly established addiction therapy and on its impact on alcohol consumption and physical improvement.

#162/#163 Psychological factors associated with medication adherence among young adult kidney transplant recipients

Karlijn Meys, Rotterdam, The Netherlands

#9 Telemedicine as an innovative project-study for psychosocial screening of living recipients at the transplantation-center Freiburg

Silvia Hils, Freiburg, Germany

#157 Health literacy and self management among kidney transplant patients

Louise Maasdam, Rotterdam, The Netherlands

Panel discussion:

From bench to bedside: how can you make a difference in delivering self-management support?

**14:30 – 18:00 EDTCO Workshop 4:
Autonomy at the End of Life**

*Chairs: Beatrice Dominguez-Gil, Madrid, Spain;
Gert van Dijk, Rotterdam, The Netherlands*

The workshop ‘Autonomy at the end of life’ will focus on the possible tension between medical aspects (the number and the quality of the donated organs), the wishes of the dying patient and the interests of the potential organ recipients.

More and more, organ donation is seen as an integral part of end-of-life-care. Required measures to improve or stabilize the viability of the organs may however come into conflict with the autonomy of the dying patient. What medical therapies, for instance, can be implemented before circulatory or brain death has been formally established, if there is no express consent from the dying patient or the relatives? Is consent always needed for preparatory measures that no longer benefit the patient? Lack of consent from relatives is one of the most important obstacles precluding the conversion of potential into actual organ donors. Debate has mainly focused on the importance of consent policy – opting in versus opting out. Now there is a growing consensus that the legal framework is not the most important determinant of the difference in consent rates. The way relatives are approached and care is carried out in the daily practice is seen as a crucial variable these days. An important modifiable factor is the moment to approach the family with regards to the determination of death and the request for organ donation.

Determination of death is on its own a recurrent matter of scientific and ethical deliberation particularly when preceding deceased donation, since it is followed by the recovery of organs. A parallel debate surrounds the respect for the dead donor rule to be preserved by those who deem artificial current standards on this issue. Finally, active euthanasia is legally possible in some European countries, such as Belgium and the Netherlands. In these countries, patients sometimes approach their physicians with a request of organ donation after active euthanasia. This controversial combination of procedures raises important ethical questions, for instance as to the voluntariness of the request.

Ethical and legal aspects of ante-mortem interventions

Alexander Manara, Bristol, United Kingdom

Ethical and legal aspects of ante-mortem interventions are particularly relevant to the practice of Maastricht Type 3 DCD, since changes in the routine end of life care are essential for this type of donation to be possible. In particular the timing of the withdrawal of treatment has to be delayed to allow all the necessary preparations to be made for organ retrieval. The continuation of current interventions and the introduction of new

ones are also required to reduce the warm ischaemic injury to organs. Since these potential donors usually lack capacity at the time of their final illness ICU clinicians have an overarching legal and ethical obligation to limit treatments to those which offer some overall benefit to their patients. The interventions that facilitate Type 3 DCD are not primarily in the best medical interests of the dying patient leading many clinicians to question the lawfulness of controlled DCD particularly the absence of primary legislation.

An important contemporary theme is that patients' best interests extend beyond simply their medical best interest and should respect other emotional, social, spiritual and religious wishes and aspirations of a patient whenever possible. If a patient has expressed a wish to donate their organs after death and their death is imminent and inevitable then it is reasonable to expect that they would have wanted harmless measures taken to ensure that the organs are transplanted in the best possible condition. In the UK this broader interpretation of best interests has been supported by the court and is enshrined in the UK Mental Capacity Act. Once it is established that an individual wished to be an organ donor, then certain interventions can be considered to be in their best interests if they facilitate donation and do not cause the person or their relatives distress or harm.

This is the basic principle underpinning the ethical and legal justification for many of the ante-mortem interventions necessary to facilitate DCD. The main debate then becomes which interventions can be considered not to cause harm or distress and can therefore be considered ethical and legal. Using this approach most would consider obtaining blood samples, maintaining life-sustaining treatment, and altering the time and place of treatment withdrawal to be in a patient's best interests if they wished to be an organ donor since they represent no harm. Others may consider that some other interventions such as systemic heparinisation, or femoral cannulation might cause harm, pain or distress to a dying patient or their close family and therefore not in the patient's best interests, legal or ethical.

Until specific legislation is created, individual jurisdictions and ICUs will need to define which interventions they consider have the potential for causing harm or distress to patients or their families. In the meantime professional organisations have an important role in providing authoritative guidance.

The moment of seeking consent for organ donation from bereaved relatives

Nichon Jansen, Leiden, The Netherlands

In the Netherlands, the moment of approaching relatives for consent to organ donation is formally allowed after the diagnosis of death of the potential donor. However, in the case of potential donors donating after circulatory death (DCD Category 3), families would be approached after an 'infaust' prognosis rendering

treatment 'futile', but before death has occurred. In recent years, the practice of making this request to relatives prior to the death of the patient has become increasingly common in the Netherlands and appears to have seeped into DBD practice as well. This is in cases when brain death is expected but not yet fully diagnosed. The question is if 'early requesting' is only effected in the Netherlands, where it has been controversial, or also in other European member states. Members of the European Platform ELPAT (Ethical, Legal and Psychosocial Aspects of Organ Transplantation), Deceased Donation Working Group, decided to explore some of the ways in which this practice may vary in three European countries; United Kingdom, Spain and Sweden. The results were different than expected in advance.

Acceptability of the dead donor rule

Thomas Gutmann, Münster, Germany

The debates about the whole-brain criterion of death, and especially the practice of organ donation after circulatory death (DCD) have led to a discussion about the meaning and plausibility of the dead donor rule. In the USA and the UK, e.g., relating to a normative concept of irreversibility, there is broad consensus to declare possible organ donors dead after 2 (or even less) to 5 minutes of cessation of cardiac and circulatory functions, although these persons are not yet dead following the whole-brain criterion of death. (This is why there will be no DCD in Germany for legal reasons). In this situation we have to deal with the critique that such a definition of death is but a 'moral fiction' in order to symbolically maintain the dead donor rule while current practices of vital organ donation, as a matter of fact, violate it. This critique has a point: The normative foundation of organ donation is not death, but donors' autonomy. Being an organ donor should be understood as an end-of-life-decision as well as a decision about what may be done with the body post mortem.

Euthanasia and organ donation

Dirk Ysebaert, Antwerp, Belgium

In the euthanasia laws of the Netherlands (2001) and Belgium (2002), euthanasia is defined as the intentional termination of a patient's life by a physician, at the explicit request of a legally competent adult. This request must be made voluntary, well-considered, repeated and in a state of consciousness. The patient must be in a condition of constant and unbearable physical and/or mental suffering that cannot be medically alleviated, that results from a serious and incurable disorder and leaves the patient in a medically futile (but not necessarily terminal) situation.

In Belgium, by the end of 2012, organ donation was realized in eleven patients with debilitating neuromuscular or neuropsychiatric disease who spontaneously requested the donation of their organs after their re-

quest for euthanasia was granted. The actual donation procedure followed the method of DCD, resulting in procurement and transplantation of excellent viable kidneys, livers, lungs and even pancreatic islets. The crucial element in this procedure is the clear separation between the request for euthanasia, the euthanasia procedure, and the organ recovery procedure itself, respecting patient's autonomy in each step. Improved self-image of these patients can be witnessed when this possibility of organ donation is granted, adding a last positive experience to the unfortunate decision to euthanasia.

#30 Organ donation after active euthanasia: morally acceptable?

Gert van Dijk, Rotterdam, The Netherlands

#140 Rethinking the role of consent in relation to post mortem use of the body for organ transplantation

Austen Garwood-Gowers, Nottingham, United Kingdom

#46 A practice-based approach to unravelling the content of the donation interview: an ethnographic study of a transplant coordination team's procurement practices in a Catalan hospital

Sara Bea, Edinburgh, United Kingdom

**14:30 – 18:00 Workshop 5:
Public Issues**

*Chairs: Silke Schicktanz, Göttingen, Germany;
Katrina Bramstedt, Gold Coast, Australia*

The silence of Good Samaritan kidney donation in Australia: a survey of hospital websites

Katrina Bramstedt, Gold Coast, Australia

The websites of transplant hospitals can be a vital source of information for pre- and post-transplant patients, as well as those contemplating living donation. In the USA there are about 116 Good Samaritan donations each year (living donations to strangers), while Australia averages about 3 such donations per year. An issue that limits the number of Good Samaritan donations in USA is the fact that a significant percentage of presenting individuals lack health insurance and thus are automatically disqualified to donate, or they chose not to risk an uncompensated health consequence. But what might be limiting these donations in Australia where all residents are insured? Less than 7% of Australian kidney transplant hospital websites mention their Good Samaritan program. We pose that in Australia (where over 1100 patients are awaiting kidney

transplant) the lack of hospital website content about Good Samaritan donation makes the concept virtually silent in the community. Breaking the silence by hospitals openly disclosing program information on their websites could increase community awareness, potentially paving the way for more donations. Further, using a hospital website to educate the public about a clinical service should not be viewed as ethically problematic (solicitation), but rather an ethical essential.

Organ donation and the art of making decisions

Ralph Hertwig, Berlin, Germany

The domain of organ transplantation requires decisions of citizens, patients, relatives, doctors and policy makers alike. Policy makers must consider how to choose legal defaults. Citizens weigh the costs and benefits of becoming a registered organ donor. Relatives may be asked to infer the presumed will of a braindead patient. Doctors must consider, for instance, how to transparently communicate the implications of living or postmortem donations. In this talk, I will offer a wide-ranging view on how people make decisions in general and specifically about organ donation on the basis of boundedly rational simple heuristics and social norms and what we know about the efficient communication of complex and emotional issues including health risks.

#115 Public solicitation of organs from living donors – an ELPAT view

Mihaela Frunza, Cluj, Romania

#81 When prisoner organ donation becomes ethically justified

Andrew Millis, Atlanta, United States

#47 Improving communication and consent for organ donation: the development & evaluation of a hospital based intervention

Myfanwy Morgan, London, United Kingdom

#149 A regulated website for patient stories and altruistic donors: an ethical way to accept living donors who have been solicited through media?

Jean-Luc Wolff, Sherbrooke, Canada

#25 Organ donation as a civic privilege – defining the extent of society's education obligations

Dominique Martin, Carlton, Australia

#41 From organ donation to tissue procurement: public perceptions of the introduction of whole cadaver donation in Denmark

Maria Olejaz, Copenhagen, Denmark

#90 The effect of the implementation of directive 2010/53/EU on the regulation of living donation in EU member states

Kristof van Assche, Brussels, Belgium

**14:30 – 18:00 Workshop 6:
Children as Donors and Recipients**

*Chairs: Paul Schotsmans, Leuven, Belgium;
Robert Truog, Boston, United States*

This workshop will examine ethical issues in pediatric organ donation from a variety of perspectives. The session will begin with a discussion of the many facets of pediatric organ donation, including being sure that all potential donors are identified, developing strategies for assuring that the autonomous choices of parents are respected, facilitating communication with parents that is compassionate and informative, and educating the public, including children, about the value of organ donation. We will then turn to a discussion about living kidney donation in children. The psychological implications of having a child give the 'gift' of an organ to a family member are complex, and may emerge years after the transplantation itself. In addition, we cannot simply assume that parents have the right to make this decision for their child. In some cases, however, we may conclude that donation is in a child's best interest if the child can experience significant psychological benefit from donation. The workshop will conclude with presentation of four abstracts that continue discussion of the above topics and explore new areas, such as the role of disability in selecting transplant recipients and whether it is wise to have bereaved parents meet transplant recipients.

**The child as a donor;
a multi-disciplinary approach**

Marion Siebelink, Groningen, The Netherlands

Donation concerns also children. When parents are asked to decide about donation, after having just been informed about the (unanticipated) death of their child, it probably is one of the most grave and difficult moments in life. On the other hand, there is a growing shortage of size matched organs for transplantation. Children still die on the waiting lists. It is therefore important to get insight in and improve factors influencing pediatric donation. These factors can be divided into four domains. Some questions are:

The medical organizational domain; did the medical professional identify all the potential donors?

The legal/ethical domain; what is the family's autonomy and what is the child's autonomy regarding donation decisions?

The communicative domain; how was the option for donation presented to the parents?

The public domain; is the child able to think and talk about this topic? Did parents discuss this with their children? What is the opinion of primary schools about a lesson on organ donation and how should this be done?

By answering these questions there is more understanding about the key factors which leads to a proper decision-making by all who are concerned.

Gift dynamics and identity construction within the family

Karl-Leo Schwering, Paris, France

Little attention has so far been given to gift dynamics within the family in living-related organ donation, especially in the case of young children. It is therefore necessary to analyze the gift relationship between the donor and the recipient in the family. Reference will be made to Marcel Mauss' gift exchange theory, which enables a better understanding of the psychosocial impact of living related donation.

We believe the younger the child, the less it will be aware of the gift exchange implications for the donor and for himself. As a consequence, parents and members of the medical staff tend to think that there is no need to worry about possible adverse psychological consequences related to the gifted organ.

Instead, we assume that some major challenges of the gift dynamic, i.e. feelings of indebtedness and guilt, will be faced with a significant delay by the child recipient. These issues are likely to emerge years after the transplantation process as such, and eventually during adolescence. A case study will enable us to highlight this hypothesis, and to raise some questions about autonomy and identity construction.

**Living kidney donation by minors:
ethical aspects**

Sigrid Sterckx, Ghent, Belgium

The breach of physical integrity of a living donor may be warranted if the person decides that the benefits outweigh the risks. However, in principle, the decision to donate should be an autonomous one, which presupposes competence. Competence requires the capacity to comprehend and judge the information provided, to intend a certain outcome, and to communicate freely one's wishes. Competence thus not only depends on cognitive maturity but also on psychosocial maturity. We will discuss how this applies to living kidney donation by minors, and conclude that there are convinc-

ing reasons to consider minors not to be competent to consent.

This need not rule out the use of minors as living kidney donors, if donation is in their best interests. Parents are generally granted the right to make health care decisions for their minor children. However, it is far from clear whether this should extend to interventions for the benefit of a third party. We will discuss potential grounds to allow parents (or, considering the partiality of parents, other surrogate decision makers such as an ethics committee or a judge) to give proxy consent, on the basis of best interests. We argue that living kidney donation can only be in a minor's best interests if the minor can experience significant psychological benefits as a result of the donation.

We conclude that, if a number of strict criteria are met, living kidney donation by minors may be ethically permissible.

#142 Long-term outcomes of living kidney donors < 18: a matched cohort analysis
Arthur Matas, Minneapolis, United States

#64 Should minors be considered as potential living liver donors?
Laura Capitaine, Ghent, Belgium

#58 Who shall live – should children with developmental disabilities be organ transplant candidates?
Aviva Goldberg, Winnipeg, Canada

#51 Do bereaved parents of organ donors want to know about or meet with the recipients? The relationship between parents willingness and 'meaning of life' measures
Tamar Ashkenazi, Tel Aviv, Israel

Abstracts

Focus Session 3: Home based education

#132

FIRST RESULTS OF A RANDOMIZED CONTROLLED TRIAL ON A HOME-BASED EDUCATIONAL INTERVENTION

Sohal Ismail Msc, Annemarie Luchtenburg Ms, Willij Zuidema Ms, Willem Weimar MD, PhD, Prof., Jan Busschbach PhD, Prof., Emma Massey PhD; Erasmus University Medical Center, Rotterdam, Zuid-Holland, The Netherlands

Objective: Living donor kidney transplantation (LDKT) is the most successful form of renal replacement therapy (RRT). We observed a significant inequality between Western and non-Western patients in the access to LDKT. In a randomized controlled trial we investigated the effectiveness and efficacy of a home-based educational intervention to reduce this inequality. **Methods:** In this trial 160 patients who were on the wait list for a deceased donor kidney transplantation were randomized over two conditions. The control group received standard care: hospital education (informational video and handbook) (n = 80). The experimental group received standard care plus an educational intervention in their homes using multisystemic therapy (n = 80). The intervention was a European translation of the programme developed by Rodrigue in the USA. A questionnaire was administered to patients and invitees to measure a change in the following factors: knowledge, risk perception, subjective norm, self-efficacy, and communication. **Results:** The ratio of Western and non-Western patients in the control group was (40/40) and in the experimental group (22/43) (p = 0.074). Compared to the control group, patients who received the home-based education showed significant improvements in their overall knowledge on kidney disease and RRT's (p < 0.001) and communicated more with their loved ones about RRT (p = 0.048). On average patients invited 5 invitees for the educational session. These invitees showed improvements in their overall knowledge (p < 0.001) and their self-efficacy regarding discussing RRT's with the patient (p = 0.032). In addition the invitees showed a decrease in their risk perception towards LDKT (p < 0.001) and they were more willing to donate a kidney (p = 0.016) after the educational intervention. **Conclusions:** We argue that these improvements in knowledge, communication, risk perception and willingness to donate support well-informed decision making regarding patient's optimal treatment option.

#125

TOWARD A LEARNER-CENTERED MODEL FOR PATIENT EDUCATION

Terre Allen PhD;

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Objective: Explain the learning paradigm as it relates to patient education, policy, and professional exchange in transplantation related teaching and learning. Barr and Tagg (1995) advocated for a paradigm shift in education research away from a focus on what is taught to a focus on what is learned. Bransford, Brown, & Cocking (2000) advanced a foundation approach to the learner-centeredness. They suggested that the learning occurs in a community context (i.e., learning is a social activity not merely an information acquisition activity). Importantly, the learning paradigm emphasizes that adult learners' acquisition processes vary greatly, and involve a wide array of pre-learning aptitudes, attitudes, behaviors, and cultural capital/bias. As such, what is learned (the learning outcome) is a complex interplay of learner-specific attributes in combination with the "what and how" of the teaching context. Working backward from "what is learned" results in a more comprehensive discovery of learning and learning improvement. The responses to learning questions, then, aid in the development of instructional communication strategies that yield the best results for a specific patient-learner. As such, the learning paradigm is potentially transformative for transplant patient education research. What transplant patients learn/don't learn, how they learn, and what cultural capital/bias they bring to their learning experiences should be of keen interest to medical professionals involved in transplantation policy, education, and professional exchange. This presentation will outline what it means to have a "learner-centered model for patient education."

Free Communications 1: Public issues (1)

#10

"REEL" TRANSPLANTS

Brigitte Talevski MSW, RSW;

University Health Network, Toronto, Ontario, Canada

The media are the first line of influence regarding society's conceptions about the ways in which we function. Beliefs about organ transplantation are no exception. Magazine articles, television programs and films all contribute to the dissemination of information about this highly specialized area of medicine. When the information is accurate, it is very helpful and can positively affect individuals to consider donation, whether through a deceased or living donor program. However, when "Hollywood goes haywire" and imaginative

writers pen stories geared for entertainment rather than education, the general public may absorb myths and misinformation about the very delicate and personal decision to endorse or pursue organ donation or transplantation. This presentation will highlight clips from film and television over the years that have either positively or negatively influenced beliefs about organ donation. The presentation will explore the impact on individuals undergoing psychosocial assessment for consideration of organ donation or transplantation. Clinicians need to be aware of such possible misconceptions that should be explored with patients and their families.

#110

A REGULATED SYSTEM OF INCENTIVES FOR LIVING DONATION: A CHALLENGE TO DEFINE AND UNDERSTAND THE OBJECTIONS

Arthur Matas MD;

University of Minnesota, Minneapolis, MN, United States

A major crisis in kidney transplantation today is the organ shortage. Even with expansion of deceased (e.g., ECDs) and living (e.g., nondirected, exchanges) donation, transplant rates in most countries are static. Increasing transplant rates benefits individual recipients and society: a) a transplant provides longer survival and better quality of life than dialysis; b) more transplant recipients (than dialysis patients) return to school or the work force; and c) the annual cost of maintaining a transplant is a fraction of that of dialysis. A regulated system of incentives has the potential to increase transplant rates, save lives, increase the number of productive citizens, shorten waiting time for those on dialysis, and reduce health care costs. Key elements of an acceptable system – donor and recipient protection, regulation, transparency, and oversight – have been proposed (AJT, 12: 306, 2012). Public surveys have constantly shown that the public supports incentives and that incentives would increase likelihood of donation. In spite of the potential societal good, many health care providers oppose a trial of incentives. It is unclear what (if any) objections balance the potential good. If screening and acceptance criteria are the same as for currently accepted donors, donor risk would be the same. Concern about candidates misrepresenting their health status can be minimized by thorough (perhaps > 1 time) evaluation. A trial (which could have a built-in moratorium for evaluation) would determine whether or not total donation rates increased. Regulated systems of incentives (or actual sale) for other body parts (or surrogate motherhood) have not undermined morality or altruism, nor led to evidence of exploitation. Yes – unregulated systems have failed. But it is important to understand and discuss objections to a regulated system that meets the standards of today's conventional transplants.

#135

KNOWLEDGE AS A PREDICTOR FOR HAVING A LIVING KIDNEY DONOR?

Annemarie Luchtenburg Ms, Sohal Ismail Msc, Willij Zuidema Ms, Willem Weimar MD, PhD, Prof, Emma Massey Phd, Jan Busschbach Phd, Prof; Erasmus MC, Rotterdam, The Netherlands

Introduction: Living donor kidney transplantation (LDKT) is regarded as the optimal treatment option for patients with end-stage renal disease. The aim of this study was to investigate if knowledge about dialysis, transplantation and living donation differentiates between patients with and without a living donor at their first visit to the outpatient pre-transplantation clinic. Methods: We measured the knowledge regarding kidney diseases and renal replacement therapies of 78 kidney patients who were newly referred to the outpatient pre-transplantation clinic. All were asked to fill in the validated Rotterdam Renal Replacement Knowledge-Test (RRK-T) which is available in 9 languages. The R3K-T contains two subscales: 'Dialysis and Transplantation' (10 items) and 'Living Donation' (11 items). After the first visit all patients were provided with several educational materials: hospital education. The patients without a living donor were also asked to complete the questionnaire again during a later visit to the outpatient clinic. Results: At the first visit 49/78 patients had a living donor. This group scored significantly higher on the total scale of the R3K-T ($p = 0.002$) and on the two subscales ($p = 0.012$ and $p = 0.005$) compared to the group of patients without a living donor. When the R3K-T was administered again to patients without a living donor after the hospital education, they had the same score on overall knowledge ($p = 0.104$) and the same scores on both subscales ($p = 0.134$ and $p = 0.190$) as on the first examination. Discussion: Greater knowledge of dialysis and renal replacement therapies appears to differentiate between patients with and without a living donor during their first visit to the outpatient pre-transplantation clinic. Moreover, those without a living donor do not appear to benefit in terms of knowledge from the standard educational efforts. Patients without a living donor may benefit from a more interactive and tailored educational programme in addition to the current education.

#26

GOOD INTENTIONS: MORAL REASONING ON ORGAN PROCUREMENT AMONG HEALTH PROFESSIONALS AND MEMBERS OF THE PUBLIC IN DENMARK

Klaus Hoeyer PhD;

University of Copenhagen, Copenhagen, Denmark

Objective: Prevailing practices in organ procurement are consistently revised to procure more organs. In Denmark it is currently considered to treat cardiac arrest in brain-dead donors. We know that the uptake

and implications of new procedures will depend on their legitimacy among the affected health professionals and donating families; and yet we know very little about what health professionals and the potentially donating public think about the prospect of new methods. The purpose of this study was to understand the moral reasoning among the people supposed to accept a new practice in organ procurement. Methods: We interviewed 59 health professionals working with organ procurement in Denmark, and 16 members of the general public. The health professionals were interviewed individually to acquire in-depth understanding of their moral reasoning and values; and in groups to allow observation of their reasoning in mutual responses. Members of the general public were interviewed individually and selected to represent different age groups, gender, ethnic background, and registration status in relation to organ donation. Results: Health professionals were mostly morally opposed to resuscitation of brain-dead donors and felt that it would disturb the preferred peace supposed to surround cases of brain death. Nevertheless they felt inclined to transgress their own moral boundaries and requested clear policies making it into general demand rather than a personal choice. Members of the public rarely saw a conflict between dignified dying and resuscitation. Neither wanted to know about organ use, and saw allocation issues as morally disturbing and better left to others. Conclusion: To legitimate more aggressive modes of organ procurement, transplantation had to remain an abstract good for the involved actors.

#139

CONTACT BETWEEN LIVING ANONYMOUS DONORS AND RECIPIENTS: ETHICAL ISSUES

Michael Campbell MHSc^{1,2}, Linda Wright MHSc, MSW, RSW^{1,2};

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Transplant Recipients sometimes wish to express gratitude to their Living Anonymous Organ Donors (LADs). Transplant programmes may be uncertain about what kind(s) of contact they should enable between willing LADs and Recipients. Recipients of DD organs are encouraged to write anonymous letters of thanks to the DD's family. In traditional living donation (e.g. donation from a family member or friend) Recipients can thank their Donors in person, and Donors benefit from seeing the Recipient's health improve post-transplant. Should transplant programmes extend this benefit to LADs by facilitating meetings between LADs and Recipients? LADs agree to donate anonymously, but they may not be committed to this condition after donating, resulting in requests to meet Recipients. However, meetings may result in disappointment, unrequited wishes for continued contact, or problematic behaviours. Transplant programmes are

limited in their ability to protect LADs and Recipients from one another after they have met. This presentation will explore the potential benefits and risks of: (1) permanent anonymity, (2) facilitating meetings before surgery, and (3) facilitating meetings after surgery. It will review relevant literature and summarize the practices and experiences of centres in North America and Europe. We conclude that, in some cases, it is ethically acceptable to facilitate meetings between LADs and Recipients post-transplantation where legal. Programmes that facilitate meetings between LADs and recipients should develop policies and standard operating procedures to ensure consistent practice and clarify responsibilities of involved parties. We propose ways to: inform LADs and Recipients about the option to meet, enable them to express their desire to meet, and determine the appropriate time to meet. We will suggest staff roles in: (1) determining parties' readiness to meet, (2) preparing parties to meet, (3) facilitating meetings, and (4) post-meeting debriefings.

#152

PUBLIC ATTITUDES AND ASSOCIATED FACTORS OF ORGAN DONATION IN TAIWAN

Daniel Fu-Chang Tsai MD, PhD;

National Taiwan University College of Medicine, Taipei City, Taiwan

Objective: Organ donation rates in most Asian countries are generally lower than many European and North American countries. However, the prevalence and incidence of chronic kidney disease and people who are on dialysis remained very high in certain Asian countries such as Taiwan, which made the organ shortage a pressing and serious medical-social problem. This study aimed to investigate the public awareness and factors related to organ donation in Taiwan with the hope for developing more effective programs and policies in promoting organ donation in the future. Methods: Questionnaire survey was conducted through anonymous telephone interview. All Taiwanese aged 20 years old and above were eligible participants for the survey. Among 3,699 telephone calls we dialed, 1,117 participants responded to our telephone interview and completed the questionnaire. The response rate was 30.20%. After excluding incomplete data, 948 eligible subjects were included in final analysis. Based on the level of willingness to donate organs, participants were classified as "strong group", "middle group" and "low group". Then logistic regression was further applied for determining the associations between participants' willingness to donate organs and their individual characteristics. Results: After adjusted for potential confounders, males showed significantly higher willingness to donate organs than females. Younger people (aged 20-39, OR = 1.57, 95% CI = 1.01-2.45; 40-59, OR = 2.10, 95% CI = 1.29-3.42) showed significantly higher willingness to donate organs than older people (60 and above). In

addition, Catholics/Christians are more willing to donate organs than people with religion of Buddhism and Taoist. Also, people with higher family income showed more willingness toward organ donation than people with lower family income. Conclusion: We found that the willingness toward organ donation was associated with gender, age, religions, and family income. These findings might have important implication for policy concerning promoting organ donation.

#177

TRAINING 'COMMUNICATION ABOUT DONATION' TAKES A PROMINENT ROLE IN DUTCH HOSPITALS

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Background: The training 'Communication about Donation' (CaD), developed by the Dutch Transplant Foundation in 2007, facilitates professionals to discuss donation with bereaved families and guide them in the donation decision-making process. Requesting for donation is difficult and complex and frequently results in a family objection. The training started in a few hospitals in 2008 and is now embedded in a large number of hospitals in the Netherlands. Methods: The training was first implemented in a pilot setting in 5 hospitals and afterwards psychologists were trained, according to a Train the Trainer module, to become a trainer in their local hospital. For measuring the effect of the training a questionnaire was completed by medical professionals after each training. Results: From 2008 to 2012 in total 115 psychologists from 53 hospitals participated the Train the Trainer module to become a qualified CaD trainer. In the meanwhile over 2500 medical professionals are trained in approximately 263 CaD trainings. The questionnaires, completed by each medical professional, showed that the training is very helpful in providing communication techniques and skills and in how to inform a grieving family about donation. The life-like situations as practiced with an actor are highly valuable (score 4.6 on a scale from 1 to 5). Insight into their own attitude towards donation contributed to a better understanding of the impact on the donation conversation (score 4.1). The exercise 'loss of a loved one' had impact on the emotions of the medical professionals, but attributed to understanding the different emotional reactions bereaved families can display (score 3.9). Conclusion: What started as a small initiative to facilitate professionals in discussing donation with relatives, the CaD training now plays a prominent role in more than half of the Dutch hospitals.

#184

REGULATION, REGULATION, REGULATION: ITS FUNCTION AND THREAT TO VITAL TRANSPLANT RESEARCH

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Transplant research is under threat from excessive Regulation. In the UK the Human Tissue Act 2004 introduced a system of licensing for transplantation research that, by separating it from the transplantation process (then exempt from licensing), has damaged this vital activity by a combination of inflexible interpretation of the Act and fear of criminal liability on the part of researchers. Similar difficulties have been encountered across Europe. Now, following the EU Directive (2010) on standards of quality and safety of human organs intended for transplantation, new UK Regulations to implement it have been published. Initial draft Regulations imposed on the whole transplantation process a licensing system similar to that for research, with criminal sanctions for breaches. This went beyond what is required by the Directive and was considered likely to have an inhibitory effect similar to that already seen in research. Following public consultation, and as a result of the overwhelming view of stakeholders that the proposed licensing system was unnecessary, the Department of Health (DH) decriminalised all sanctions under the final Regulations, with the sole exception of operating without a licence. While this does not eliminate the negative effect of licensing, it does suggest an awareness by the DH that excessive Regulation unnecessarily harms the transplantation process. This paper examines the function of Regulation in this domain, and highlights an opportunity for the Human Tissue Authority (the UK Regulatory body for both the new licences and research licences under the Act of 2004) to end the current illogical and harmful separation of transplantation and transplantation research by ensuring that all centres licensed for organ donation, retrieval, and transplantation are also fully licensed for related research. A successful British approach may provide a useful precedent for other European jurisdictions.

#78

20 DOUBLE PORTRAITS LIVING KIDNEY DONATION

Janneke Vervelde, Jacintha Jenniskens;

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Twenty double portraits living kidney donation is a book initiated by Jacintha Jenniskens, social worker at the AMC. She provided text and organization of interviews, Diederik Schiebergen (Publ.) design and photography and Nico de Bruijn (IDP2) editing and

production. The book has been produced in collaboration with the Academic Medical Center and thanks to the financial support of the Kidney Foundation. Exclusive to the Dutch Kidney Foundation two editions appear. A large format will be sold to the general public and small books are freely available as educational information to potential donors and recipients. Purpose of the book: The purpose of this book is to raise awareness of the various possibilities of living kidney donation and to the current practice of kidney donation. Target audiences are both prospective kidney donors and recipients. In addition the book will be distributed to institutions that professionally can be confronted with renal transplantation. Description of content: The book focuses on relationships between donor and recipient, their motivation and their feelings before and after the transplant. The book is educative due to the broad variability in somatic, psychological and socio-economic aspects. By this approach some common misconceptions may be cleared to the reader. Media attention: Attention has been given to the book in the TV program "Surgery Live". The program reported a living kidney donation live on TV. Nearly 1,000,000 viewers watched the program. Response: Individual donors and recipients responded that the stories in the book gave a true reflection of reality and they recognized their personal situation. The stories matches with the needs of potential living kidney donors and acceptors. It helps them to make their own decision and also to explain their own feelings to other people by showing them the content of the book.

#141

IMPROVING COOPERATION BETWEEN FORENSIC PATHOLOGISTS AND TRANSPLANT TEAMS IN BELARUS: A STRATEGY FOR INCREASING TRANSPLANT ORGANS SUPPLY

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Aim: The objective of the study is to provide arguments supporting the position that organ procurement for transplantation from the deceased donors can occur without compromising the forensic pathologists' medico-legal responsibilities. **Methods:** Legal and regulatory framework, as well as peculiarities of practice related to the role of forensic pathologists in the procurement of transplant organs from the deceased donors in Belarus, are analyzed by reviewing of relevant legal acts, regulations, and guidelines. **Concerns** which often are raised with regard to the process of authorization or denial of the procurement of organs from the deceased donors are then analyzed in terms of their objectivity and reasonableness. **Results:** In Belarus, current legal and regulatory framework governing the forensic pathologists' specific medico-legal responsibilities does not specify the criteria of the decision-making process with regard to authorization or denial of the procurement of organs from the

deceased donors. Under these circumstances, forensic pathologists quite often deny organ procurement for transplantation from the deceased donors on the basis of the belief that their ability to carry out their medico-legal responsibilities can be compromised. However, most arguments for such a denial have no reliable evidence to support them, and apparently stem from lack of cooperation between forensic pathologists and transplant teams. **Conclusion:** The results of the study suggest that in most cases, organ procurement for transplantation from the deceased donors does not interfere with fulfilling the statutory mandate of forensic pathologists to decide on cause and manner of death, and provide a solid factual foundation for expert opinions. Suggestions are made for encouraging cooperation between forensic pathologists and transplant teams in Belarus, to maximize the potential for forensic pathologists' approval of the procurement of organs from the deceased donors.

Free Communications 2: Cultural and religious aspects of living and deceased donation (1)

#94

ORGAN DONATION AND CULTURAL ISSUES IN CAPE TOWN, SOUTH AFRICA

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Objective: To review the impact religion and culture have on consent for deceased donor organ donation. **Background:** South Africa has a history of unequal access to health care, education and opportunities. The racial groups which make up the population embrace many cultures and religions which has resulted in different attitudes towards organ donation. The health care system is divided into private and public sectors – the public sector serves 84% of the population. **Method:** A review of families approached for consent for deceased donation from 2004 to 2008 in a public and a private sector hospital was carried out. **Results:** The racial distribution of the families approached for organ donation varied – on average, in the private hospital 70% were white; mixed race 24% and black 6% and in the state hospital 7% were white, mixed race 40% and black 53%. In the private hospital in 2004 and 2008, consent for organ donation in white families was high – 85% and 100% respectively and was low for black families, 10% in both years. In the state hospital, consent from mixed race families remained fairly constant in the 2 years (2004 and 2008), 50% and 55% respectively, while there was an improvement from 20% to 30% in black families. Reasons given for refusal of consent included that the culture or religion did not allow organ donation (Moslem and Black families) or

that the elders of the family or the ancestors did not approve of organ donation (Black families). Conclusion: Organ donation remains a problem in South Africa's multicultural society with many factors playing a part although, with increased access to information and better public education, there appears to be some improvement.

#101

UNSPECIFIED AND SPECIFIED LIVING KIDNEY DONATION TO UNRELATED RECIPIENTS: THE ROTTERDAM EXPERIENCE

Willij Zuidema S.W., Ruud Erdman PhD, Jacqueline Wetering van de MD, PhD, Frank Dor MD, PhD, Joke Roodnat MD, PhD, Emma Massey PhD, Lotte Timmerman MSc, Jan IJzermans MD, PhD, Willem Weimar MD, PhD; Erasmus MC, Rotterdam, The Netherlands

Background: In unspecified living kidney donation, formerly known as Good Samaritan, altruistic or anonymous donation to a stranger, the recipient is not specified by the donor. There is no relationship between them and there is no material benefit for the donor. While most specified donors have a relation with their intended recipient, a number of them do not. Methods: Between May 2000 and November 2012 we, Erasmus MC, Rotterdam have been approached by 213 individuals with the intention to donate a kidney to an emotionally and genetically unrelated patient. Results: After the screening process 92/103 (89%) have donated a kidney. A minority of them 13/92 (14%) specified their recipient, while the vast majority 79/92 (86%) were unspecified living kidney donors. Overall these 92 donors realized 157 kidney transplants, to 89 wait-list patients and 68 recipients of incompatible couples. The willing donors of these couples participated in 54 unspecified donor-triggered domino-paired procedures including 44 doublets, 7 triplets and 3 quartets. Conclusion: We conclude that waiting list patients as well as recipients of incompatible couples profit from unspecified living kidney donation. This successful outcome warrants further extension of this program.

#99

SERIOUSLY ILL PATIENTS AS UNSPECIFIED LIVING KIDNEY DONORS

Willij Zuidema S.W., Hendrik Kimenai MD, Ruud Erdman PhD, Emma Massey PhD, Lotte Timmerman MSc, Frank Dor MD, PhD, Jan IJzermans MD, PhD, Willem Weimar MD, PhD; Erasmus MC, Rotterdam, The Netherlands;

In recent years we have been approached by 195 individuals for information about unspecified kidney donation. 122 of them were enrolled in the screening. Until now 79 donated directly to the waitlist or in domino-paired procedures, which resulted in 145

kidney transplants. 12/79 donors were patients themselves. 7/12 patients had a medical indication for nephrectomy: 5 because of therapy resistant loin pain, 1 with renal artery aneurysm, 1 who refused urostomy after iatrogenic ureter injury during a leiomyosarcoma resection. 5/12 had life-threatening diseases: Two with M. Huntington, 1 with ependymoma, 1 with oligodendroglioma, and 1 patient with progressive COPD. Methods: All these donors underwent the standard medical and psychosocial screening. In addition, unspecified donors undergo an interview with a clinical psychologist and complete the Symptom Checklist (SCL-90). Follow-up was median of 30.5 (range 6-96 months). Results: Seven donors donated to the wait-list and five in domino-paired procedures. In total, these 12 donors enabled 17 kidney transplants. The psychological screening revealed genuine motivation, adequate risk perception, normal sense of reality. The median SCL-90 score was 119, which is average for the Dutch general population. Median hospital stay was 4.5 days. Within 3 weeks all had completely recovered from their nephrectomy. Those with loin pain became free of complaints. All donors were satisfied with the procedure and had no regrets. One donor died, as result of his ependymoma, 29 months after donation. Conclusion: Patients with kidney complaints or life-threatening illness may have a genuine motivation to become an unspecified kidney donor. In the absence of medical and psychological contra-indications we feel it ethically justified to accept their offer in view of their self-reported satisfaction with the donation. Raising awareness on this subject could further increase the living donor pool.

#124

RIGHT LIVER LOBE AND KIDNEY 'DOUBLE' DONATION BY GOOD SAMARITAN LIVING DONORS: SINGLE CENTER EXPERIENCE

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Background: Donation of a right lobe liver lobe and a kidney by an altruistic living donor is rare. We report a series of such 'double' organ Good Samaritan donors from our institute. Methods: All potential living liver donors evaluated at our center from 1998 to 2010 were studied. Results: We evaluated 345 potential living liver donors. There were 27 potential Good Samaritan donors and 12/27 donated successfully. There were 5 donors (4/5 Good Samaritans) who donated a liver lobe either before or after donating a kidney. All donors were Caucasians (ages 30-52 years, 60% females). All donors had donated their left kidneys and right liver lobes. The time interval between the two donations ranged from 5 months to 4 years. All donors were successfully employed after the kidney donation and at

the time of donating the liver lobe. There was no significant medical, surgical or psychiatric history prior to donation. The mean hospital stay after donation was 5 days and all donors returned to their prior occupations. Only one donor had a cut-surface bile leak that required closed percutaneous drainage. While 50% (2/4) of the Good Samaritans initiated contact with the recipients, all five donors felt satisfied after donating their right liver lobes. The serum creatinine and liver function tests (before and after kidney and right liver lobe donation respectively) were within normal limits. Conclusions: All our Good Samaritan living liver-kidney donors were well-educated, successfully employed Caucasians with previous charitable acts of donation. All had excellent surgical and psychological outcomes after donation with return to previous occupations. 'Double' donation of liver-kidney by Good Samaritans, after thorough medical and psychological evaluation, is ethical and facilitated by the extremely motivated donors themselves.

#107

RELIGIOUS ASPECTS ON ORGAN DONATION

Dorothee Grammenos MD¹, Carl-Ludwig Fischer-Fröhlich MD², Franz Schaub MD³, Günter Kirste MD³, Thomas Breidenbach MD, PhD¹;

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Introduction: In Germany there are approximately 20% people with migration and/or different religious backgrounds. The question of organ donation is often a special task in approaching these families. Therefore high refusal rates due to lacking experience with foreign culture and religion are often a problem. In addition to our data we know from personal experience and discussion with hospital staff that there are obstacles and uncertainty by dealing with foreign families. **Methods:** We analyzed 6,616 documented donation requests within the database of the German Organ Procurement Organization (DSO) from 2009-2011. 54 variables were analyzed on their influence on consent rate. In this survey we focused on religious reasons for refusing an organ donation. **Results:** The refusal rate within our analyzed data was 38.1% (2,519). In 131 cases (5.2%) the refusal was due to religious reasons. 50.4% of these were combined with other reasons mainly desintegration of body integrity (19%) and acceptance of death (13%). In cases of refusal associated to religious beliefs more often (13%) communicational barriers caused by migration background were reported (17/131) as compared to refusals not associated to religious beliefs with 0.6% (16/2,519). Interestingly the refusal rates due to religious reasons are higher in the two southern regions of Germany (38.9%) than in the Middle and the North. There is no difference regard-

ing age and family relationship of the approached persons. **Conclusions:** People with migration or religious backgrounds are a significant part of our society. The refusal rates due to lack of knowledge and uncertainty are relevant. In order to improve conversation with these target groups we have to sensitize and educate DSO coordinators and ICU staff. It would be to contact religious opinion leaders as well.

#83

PERSONAL ATTITUDES AND BELIEFS REGARDING ORGAN AND TISSUE DONATION: A CROSS-SECTIONAL SURVEY OF AUSTRALIAN EMERGENCY DEPARTMENT CLINICIANS

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Organ donor rates in Australia are lower compared to other developed countries, despite recent attempts to address this. Healthcare professionals' personal attitudes and beliefs regarding organ and tissue donation (OTD) are known to influence professional attitudes and practice. The aim of this study, which was part of a larger cross-sectional online survey, was to assess emergency department (ED) clinicians' general beliefs and personal attitudes towards OTD. The survey was based on available literature and the Hospital Attitude Survey (DonorAction®). Data were collected from 811 clinicians, invited through the Colleges for Emergency Medicine and Nursing. Most ED clinicians were very supportive of OTD (96.2%), believed that OTD can save lives (98.5%), and that organs and tissues will be allocated fairly (82.6%), however 30.1% didn't agree that OTD can help the next of kin cope with grief. Holding positive general beliefs increased positive personal attitudes towards OTD ($p < 0.01$). Most reported willingness to donate their own organs and tissues after death (90%), and give family-consent for their children (79.6%) or adult family (86.6%) to donate. Most (86%) had discussed their wishes with next of kin but only 50.7% had registered on the Australian Organ Donor Register. Males, older participants, Buddhists, Hindus, participants with an Asian or Mediterranean background, and especially Muslims indicated significantly less often that they were willing to donate their own or family members' organs and tissues, and communicate and register their wishes. Although Australian ED clinicians were generally very positive towards OTD, targeted education may assist in reassuring ED clinicians and modifying professional behaviour. As positive personal attitudes to OTD correlate strongly with optimal donation rates, such education may assist in improving rates of OTD from EDs in Australia.

Free Communications 3: Cross-border transplants

#116

A POLICY FOR TRANSPARENCY

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The United Network for Organ Sharing (UNOS) recently adopted a new policy designed to provide public transparency regarding deceased donor organ transplantation for waitlisted candidates who are neither citizens nor residents of the United States. The enacted policy does not prohibit transplantation in non-residents or alter organ allocation. The policy does however replace the previous "5% rule" or quota of transplants for non-residents with a mandate to the UNOS International Committee to review data and prepare an annual public report of listings and transplants by citizenship and residency categories. To support this mandate, in March 2012 UNOS began collecting data on all new deceased donor candidate listings and transplants utilizing revised data categories that include residency status as well as whether candidates travelled to the U.S. for purposes of transplantation. The first 6 months of collected data reveal that 241 (0.9%) newly listed candidates for deceased organ transplants are categorized as non-citizen/non-residents of the U.S. Of that group, 83 are identified as travelling to the U.S. for transplant. The vast majority of these patients were listed as liver or kidney transplant candidates. During the same period approximately 0.3% of deceased donor transplants were performed on patients identified as non-citizens/non-residents (recognizing that this number will increase as the new data categories were not in effect for most patients now receiving transplants). Non-residents/non-citizens comprised 0.4% of deceased donors providing organs for transplant. Data will continue to be assembled for the ultimate annual report. In the interval, the International Committee will assess listings and transplants of non-citizen/non-resident patients by organ type and center. The adoption of this new UNOS policy and subsequent reporting of the citizen and residency data fulfills a WHO guideline to prove transparency regarding transplant tourism as a necessary component to the maintenance of public trust.

#57

SHOULD WE PERFORM ORGAN TRANSPLANTS ON ASYLUM SEEKERS AND REFUGEES IN CANADA?

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In Canada, there are no guidelines at either the federal or provincial level regarding the provision of organ transplantation services to non-residents. At our transplant centre, we have, in the past, agreed to put asylum seekers and refugees on our renal transplant wait list, in part because they had health insurance through the Interim Federal Health Program to cover the costs of medication and hospital care. Severe cuts were recently made to this program by the federal government. At the time, our centre had just transplanted a refugee claimant whose claim was still pending. The loss of this insurance jeopardized the outcome of the renal transplantation, since the patient did not have the financial resources to pay for his healthcare services and the necessary immunosuppressive drugs. This situation led us to question whether we should continue to transplant refugee claimants and asylum seekers, because of both financial and ethical considerations. Should we treat Canadian citizens first, given the organ shortage? Are transplant physicians obliged to treat non-resident and resident patients without distinction? How should we manage the risk of refugee claimants being returned to their country of origin where immunosuppressive drugs or post-transplant care may not be available? Finally, how are physicians to carry out their professional duty to work in the best interests of their patients in a political context where the financial support for some patients (i.e., refugee claimants and asylum seekers) is no longer available? This presentation will explore these challenging ethical issues in detail.

#14

THE RISE AND DECLINE OF A STATE-SPONSORED CRIME: THE CASE OF ORGAN TRAFFICKING IN ISRAEL

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Why would a country choose to actively participate in the illicit organ trade? Why would it later reverse course and cease that participation? The paper answers these questions with respect to Israel, where patients in need of transplantation received public funds to allow them to purchase organs abroad, thereby making the country one of the major participants in the global organ trade. I argue that the Israeli policy of financing transplant tourism resulted from a desire to help

desperate patients overcome the local organ shortage, mixed with considerations of economic efficiency. Yet pressures from the Israeli and international medical community, together with media reports, led to the enactment of a transplantation law that prohibits the trade in organs – a prohibition that has sharply reduced the outflow of patients. The article highlights the main influences and political considerations that motivated Israel's policy change, including concerns for the country's international reputation, and offers lessons for other countries where organ trafficking flourishes. Methodologically, this study is based on the author's interviews with all relevant actors: physicians, the Ministry of Health's bureaucracy, politicians, medical insurers, and patients. The analysis also draws on records of the legislative debate over the transplantation law, as well as relevant court cases.

#32

COMBATING THE KIDNEY COMMERCE: EFFORTS AGAINST THE ORGAN TRADE IN PAKISTAN

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Israel*

Beginning in the mid-1990s, Pakistan became one of the world's primary destinations of transplant tourism. This practice was facilitated by the Pakistani government's indifference and a legislative vacuum. Yet, in 2007 the government took measures to fill that vacuum and eliminate transplant tourism by issuing the Transplantation of Human Organs and Tissues Ordinance, which prohibited commercial dealings in organs. The paper examines the political dynamic that generated this dramatic change of policy, as well as the limitations of that change. At the center of the analysis is a campaign against the organ trade, led by the Sindh Institute of Urology and Transplantation (SIUT). I examine how SIUT physicians assembled a coalition of prominent civil society actors and pressed their demand for transplant legislation, with support from the media and the Supreme Court. I also examine how this coalition managed to overcome the opposition of the organ-trade lobby, that is, the physicians and hospital owners involved in the trade. The lobby sought to amend or revoke the transplant ordinance, including through a petition to the Federal Shariat Court, but was ultimately defeated. Yet the lobby did manage, through its ties to government authorities, to undermine the enforcement of the law, despite demands for strong enforcement that came from Parliament, the judiciary, the media, and the SIUT-led activists. Overall, the Pakistani case offers several important lessons for the efforts to eliminate the organ trade. In particular, this case suggests the importance of establishing a broad societal coalition against the trade, the key role of the media in raising awareness of the trade, and the

necessity of persistent pressure to make sure that the authorities not only pass a law, but enforce it.

#87

ORGAN TRAFFICKING – MECHANISM AND MAIN CHARACTERISTICS

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Today the organ trafficking (OT) remains an illegal transnational activity that affects dramatically the health and safety of thousands of organ donors and recipients worldwide, despite the efforts of national and international authorities. During our study we aimed to analyse the mechanism of OT in Moldova in terms of its main indicators: actors, actions and means. The methodology included: interviews with victims of OT and analysis of the trial cases, cases reported by NGO's and media. Results: During our study we collected data on 40 cases of OT. The majority of victims (90.5%) were men, between 20-32 years at the time of trafficking. 95% of them were from rural area. In the majority of cases the victims have been recruited in their communities, usually by someone known. Often, accomplices or recruiters were getting people in the past have been trafficked for organ removal. In 90% of cases, the country of destination was Turkey. There is only one case when a part of liver was removed from a living donor. All other cases are related to kidney retrieval. In most recent cases, the traffickers avoid using violence to constrain the victim to sell an organ, appealing to "gentle" methods. Besides the abuse of position of vulnerability and victim's indebtedness, our study shows that traffickers often use the deceit and the fraud as means to convince the potential victim. Conclusions: The detailed analyses of the data indicates some common features and patterns for the OT in Moldova, especially regarding the specific elements of the crime and victims profile. "Cooperation" of the victims during the recruitment complicates the identification of cases and collection of evidences regarding the criminal offence. Given the dynamic and complex nature of OT it becomes imperative to encourage the research in this area.

#33

THE REGULATORY CHALLENGES OF INTERNATIONAL TRANSPLANT MEDICINE: DEVELOPMENTS IN SINGAPORE

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Transplant tourism is spurred by the global shortage of organs and the potential for regulatory arbitrage in purchasing an organ in jurisdictions that do not prohibit sale or lack effective regulatory mechanisms to enforce prohibition. Various nations once identified as

transplant tourism hotspots have since enacted legislation prohibiting organ sales and emplaced regulatory oversight. However, concerns persist that the legitimisation of altruistic unrelated living donor transplants conceals underlying commercialism and unethical practices. These concerns are heightened when transplant candidates travel across borders in search of international transplant medicine. This article examines the regulatory challenges associated with differentiating international transplant medicine from transplant tourism, and various regulatory mechanisms that have been developed to address them from the domestic perspective – in particular those recently implemented in the Singapore. It seeks to identify the strengths and weaknesses of the Singapore system, and what lessons this has for international standards and practices.

Free Communications 4: Psychosocial Care and Donation (1)

#160

PSYCHOLOGICAL FUNCTIONING OF UNSPECIFIED ANONYMOUS LIVING KIDNEY DONORS BEFORE AND AFTER DONATION

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Objective: There has been debate on the psychological functioning of living donors who donate their kidney to an unrelated and unknown patient (“unspecified living donors”). This is the first prospective study to investigate group and individual-level changes in psychological functioning among a large group of unspecified donors. **Methods:** The Symptom Checklist (SCL-90) was completed by 49 unspecified living kidney donors before (median 9 months) and after donation (median 19 months). We obtained sociodemographic characteristics, procedural characteristics, and self-reported experiences of donation from medical records. **Results:** Group level analysis showed that overall psychological symptoms increased after donation ($p = 0.007$); the means remained within the average range of the normal population. Individual level analysis showed that 33 donors showed no statistically significant change, 3 donors a statistically significant decrease, and 13 donors a statistically significant increase in psychological symptoms. Two donors showed a clinically significant increase. Only time since donation was correlated with a larger increase in psychological symptoms. **Conclusions:** We found more increases in psychological symptoms than decreases, particularly if the follow-up time was longer. For almost all donors these increases were not clinically significant and the clinically significant

changes found are comparable to natural fluctuations in psychological symptoms in the general population. Due to the low reported symptoms predonation, regression to the mean could be the case. In addition, there is a possibility that potential donors under-report their psychological symptoms prior to donation in order to pass the screening. Although we found that changes were not associated with donation-related factors, it is possible that other donation-related factors or other life events not measured have an influence on psychological functioning. In conclusion, it remains unclear whether the fluctuations are attributable to the donation process and therefore further research is needed.

#63

IMPACT OF DEATH MODE AND THE WILLINGNESS TO DONATE ORGANS ON THE SEPARATION PROCESS OF BEREAVED PARENTS FROM THEIR DECEASED CHILDREN

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Background: The separation process of bereaved parents from their deceased children has an impact on their mourning process and their subsequent willingness to donate the organs of their beloved ones. **Objective:** To examine the impact of death mode (brain or cardiac) and willingness for organ donation on bereaved parents’ attitude towards the separation process from their deceased children. **Methods:** Oral interviews were conducted with 216 bereaved parents, 1 to 27 years following the death of their children, who were divided into four groups: Organ donors (100) and non-donors (37) after brain death and tissue donors (46) and non-donors (33) after cardiac death. **Findings:** Overall 55.3% of the parents felt that the separation process from their child was satisfaction, 16.1% reported it was “somewhat” satisfaction and 24.1% felt the separation was not satisfaction ($c2 [3] = 16.59 p < .001$). A significantly higher incidence of satisfaction of the separation process was noted among parents who donated the organs of their children ($M = 3.88$, $SD = 1.44$) compared to parents who declined tissue donation (tissue donors: $M = 2.67$, $SD = 1.71$, non-tissue donors: $M = 3.07$, $SD = 1.72$). Brain death was found to be more associated with satisfaction of the separation process compared to cardiac death. **Conclusions:** Brain death of children provides bereaved parents longer time than cardiac death for the separation process and subsequently facilitates their satisfaction. Parents of children who have died of cardiac causes should also be provided time for the separation process in order to enhance their satisfaction and ease their mourning process.

#100

NiCe: PATIENT-CENTERED CARE FOR LIVE KIDNEY DONORS

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Introduction: In our experience, live kidney donors and their care providers often indicate that cure and care were not in line with the donors' biomedical and contextual factors. "Kidney donor-centered care" (NiCe) is an intervention to align this care. NiCe defines how nurse practitioners (NPs) provide patient-centered care to kidney donors and therefore substitute the care given by the surgical residents. **Purpose:** Aim of this study was to determine whether the implementation of NiCe, which connects the care and support with the biomedical and contextual factors for live kidney donors at the Erasmus MC, would result in an increased patient satisfaction. **Methods:** The NiCe study was a quantitative study, with a qualitative component. The control group (N = 27) consisted of donors admitted between October 16th 2011 and February 12th 2012 and the intervention group (N = 26) of donors between February 13th 2012 and April 30th 2012. Three different methods of data collection were used. A validated four-point Likert scale questionnaire of Consumer Quality Index was used to measure patient satisfaction. Donors' medical files were screened for complications and mortality. The qualitative part consisted of a log book in which professionals could report their experiences, to evaluate the process. **Results:** The care by the surgical team was significantly better appreciated in the intervention group versus the control group (2.87 vs 3.3, $p < 0.05$). Also the care was more aligned after the implementation of NiCe ($p < 0.05$). There were no significant differences regarding complications, readmissions, communication and care by NPs and nurses. According to the care providers involved in this study, there were no difficulties in the process of NiCe implementation. **Conclusion:** A greater patient satisfaction was reached in the intervention group. Therefore the most important recommendation for the future is to continue NiCe for live kidney donors.

#161

PSYCHOSOCIAL RISK AND PROTECTIVE FACTORS FOR LIVING DONATION – RESULTS FROM A EUROPEAN MULTICENTRE PROSPECTIVE STUDY (ELIPSY)

Christina Papachristou PhD¹, Xavier Torres MA², Ana Menjivar MD², J Peri PhD², Levent Yucetin MD³, Leonidio Dias MD⁴, Ines Carvalho MA⁴, Niklas Kvarnström MD⁵, Ingela Fehrman-Ekholm MD⁵, Christian Hiesse MD⁶, Chloe Balleste MD², David Paredes MD², Ignacio Revuelta MD², Fritz Diekmann MD², C Fondevilla MD², A Rimola MD², C Legendre MD², Fabian Halleck MD¹, Nina Babel MD¹, Marti Manyalich MD²;

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Introduction: European Living Donor Psychosocial Follow-Up (ELIPSY) is a European multicenter study, co-funded by EAHC and conducted in 6 different countries (Germany, Spain, France, Portugal, Sweden, Turkey) examining the psychosocial outcome and the impact of donation on living donors. ELIPSY aims to assess in a prospective study the psychosocial profile of living donors prior to donation among the participant countries and their respective psychosocial outcome one year after donation in order to identify risk and protective factors for the living donors. **Methods:** More than 80 living kidney donors from 6 different transplant centres were assessed before and one year after donation. The donors completed a series of psychometric questionnaires measuring psychosocial wellbeing, quality-of-life, psychopathology and personality (HADS, PHQ, SOC, SF-36, ACSA, EPQR-A, life events, questions from the ELSA), as well as aspects regarding satisfaction, decision to donate and the donor-recipient relationship, making ELIPSY one of the most thorough studies of living donors up-to-date. **Results:** The post donation mental health and the psychosocial wellbeing of living kidney donors and their satisfaction one year after donation are linked to their psychosocial profile before donation. Comparisons for groups regarding age, gender, the donor-recipient relationship etc. are made. Psychosocial risk and protective factors for living donors are identified. **Conclusions:** The results are discussed critically regarding the evaluation practices of donors before donation. Suggestions regarding the optimization of the preoperative assessment and the post-operative care of donors are formulated.

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QUALITY OF LIFE, PSYCHOSOCIAL WELLBEING AND SATISFACTION OF LIVING DONORS – RESULTS FROM A EUROPEAN MULTICENTRE RETROSPECTIVE STUDY (ELIPSY)

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Introduction: European Living Donor Psychosocial Follow-Up (ELIPSY) is a European multicenter study, co-funded by EAHC and conducted in 6 different countries (Germany, Spain, France, Portugal, Sweden, Turkey) examining the psychosocial outcome and the impact of donation on living kidney and liver donors. The ELIPSY project aims to assess thoroughly in a retrospective study the psychosocial outcome of living donors among several European countries by using a variety of psychometric questionnaires and donation-related questions. Methods: 250 kidney and 30 liver living donors from 6 different transplant centres up to 5 years after donation were examined. The donors completed a series 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. Results: The post donation mental health and psychosocial wellbeing of living donors and their satisfaction up to 5 years after donation is presented. Links between the psychosocial donor outcome and the recipient outcome controlled for age, sex and the donor-recipient relationship are examined. Similarities and differences in the outcome among the countries over time are described. Conclusions: The results are discussed in terms of differences in the donor evaluation practices and the legitimacy for living donation. The detailed information derived directly from the donors gives an insight about the practice of living donation and leads to suggestions for optimization of donor evaluation and donor care.

#167

CRITICAL CARE STAFF AND THE DONATION REQUEST: A FOCUS GROUP STUDY

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Introduction: The results of the donation request are mostly measured by the consent rates and less by the satisfaction of the relatives about their decision-making, especially (dis)satisfaction about refusal. Our goal is to elicit Dutch critical care staffs' views and experiences with the donation request and to collect advice that may give relatives' satisfaction with their decision. Methods: Five focus groups with a total of 32 participants (IC-physicians, IC-nurses and transplant coordinators) of 5 university hospitals. Qualitative analysis following grounded theory approach was used. Results: Four themes (organ donation in society; donation request seen by critical care staff; donation request seen by relatives; aftercare) divided in 13 categories were identified. Donation request by IC-physicians is influenced by the way organ donation is regulated in society (law, donor register, education, media) as well by their personal ideas about organ donation. Personal ideas of IC-nurses can be changed by watching the donation procedure. Critical care staff feels not always comfortable with the request, which is done in cooperation between different disciplines in the delicate context of brain death. Sometimes the interests of patient, relatives and those on the waiting list are irreconcilable. Relatives mentioned their own values more frequently than values of the potential donor to come to a decision. Critical care staff see this imbalance, but react emphatically to the relatives' initial point of view. Reconsideration of refusal is scarcely discussed, though refusal yet seems less seriously considered by relatives. Critical care staff is mostly not aware of (dis)satisfaction about relatives' decision. Aftercare is more done in case of consent. Conclusion: We hypothesize that more attention for relatives who are inclined to refuse donation may contribute to reconsideration of their decision and possibly better results in organ procurement.

Workshop 1: Cultural and religious aspects of living and deceased donation

#11

ALTRUISM VS. RECIPROCITY – A POLISH MIGRANT PERSPECTIVE: AN 'ALTRUISTIC GIFT'

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The overall study examined the relationships between deceased organ donation, altruism, social capital, gift exchange theory and religion from a Polish perspective. The study took a grounded theory approach and thirty one participants were interviewed in total through one-to-one interviews or small focus groups. One aspect of the study was to investigate the relationship between deceased organ donation, altruism and gift exchange theory; altruism is where the individual in need is the focus of organ donation and gift exchange theory suggests that the donor family or donor expects a return for donating. Within this line of enquiry, many of the participants viewed donating organs as a 'gift' where nearly all of the participants did not expect a return for becoming a donor as donation is about helping others. Some participants compared living to deceased organ donation believing that living donation was more of a 'gift' as the individual was taking a risk and was making more of a 'sacrifice'. Donating organs was argued to be in line with Polish Catholic teachings where individuals were helping humanity. Paradoxically, many of the participants were uncomfortable donating their organs for money as it would lose its value as a 'gift' but many supported the concept of receiving a reward for donating such as funeral costs from the government. The argument as to whether donation is a form of altruism or a reciprocated act is complex. The rhetoric surrounding donation advocates helping others with a 'gift', expecting no return however, having a return in the form of help for the family was seen to be acceptable. Receiving help in exchange for helping others was viewed to be a way of engaging individuals in organ donation without the organ losing its 'gift' status.

#60

THE IMPACT OF RELIGION ON DECEASED ORGAN DONATION IN LEBANON

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Introduction: Statistics on the general population in Lebanon show that 22% of interviewed individuals refused organ donation after death based on religious misconceptions [lower than reported rates from Tehran-Iran (25.9%) and KSA (27.5%)] Objective: The aim of this study is to show that the religious misconceptions of health professionals are similar to those of the

general population and that they have a negative impact on the national deceased donation rate. Methods: In-hospital awareness courses for health professionals were conducted in 19 hospitals across the country. Questionnaires were distributed to 13 physicians, 164 nurses at the beginning and were collected at the end of each session. Out of 312 questionnaires distributed, 177 were completed. Questions included: 1) what is the attitude of the major monotheists' faiths regarding organ donation? 2) Do all monotheist religions agree that brain death is the death of the person? 3) In case of conflict do you have to consult religious leaders? 4) Would you donate your organs, your relatives' organs, your children's organs after death? Why? Results: Preliminary results show that health professionals have the same rate of religious misconceptions as the general population in that 24% of them refuse and do not encourage donation for religious reasons. These results were not affected by the religious affiliation of the concerned hospitals (Muslim vs. Christian regions) distributed all over Lebanon. Conclusion: The results of this study highlight the need for an increased awareness about the position of various religions towards deceased organ donation at the level of health professionals as well as the general public. This will help decision makers in planning future policies and targeted interventions.

#84

NEW INDEPENDENT ETHICS COMMITTEE MEETING UNRELATED DONORS IN KUWAIT SUCCEEDS IN REDUCING COMMERCIAL TRANSPLANTATION

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Kuwait transplant law of 1987 prohibits organ sale but allows altruistic donation from unrelated donors. In the past the committee interviewing unrelated (LUR) donors, to ensure conformity with law, consisted of transplant physicians and surgeons, psychiatrist, social worker and a representative from the legal department in the Ministry of Health. Between 1999 and 2008 the committee met 802 prospective LUR donors and rejected 220 (27.5%). Study of a random group of recipients of LUR donor kidneys revealed that the vast majority (96%) of them did in fact pay the donors. As a result of this study the Ministry of Health accepted a recommendation to form a new ethics committee to meet LUR donors. In the new committee transplant specialists were replaced with independent physicians and an ethicist. The new committee held its meetings outside the transplant center. Between June 2011 and June 2012 it met 61 prospective LUR donors and rejected 34 (55.7%). As the word spread about the low acceptance rate the number of applicants also dropped. As a result of high rejection rate of LUR donors the number of LUR donor kidney transplantation in Kuwait has been the lowest in 10 years in 2012; but unfortunately

this has not resulted in an increase in living related donor transplants as most patients find alternative ways to receive an unrelated donor kidney abroad.

#117

ORCHESTRATING AN EXCEPTIONAL DEATH – DONOR FAMILY EXPERIENCES AND ORGAN DONATION IN DENMARK

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Objectives: Denmark has one of the lowest donation rates in Europe. We discuss public attitudes, changing legislation to presumed consent and the organ shortage. However we know very little about the families of organ donors. What do they go through, how do they decide about organ donation and what are the emotional and social implications of saying yes to donation? This PhD study therefore explored the family experiences of donating organs. **Methods:** This study is based on anthropological fieldwork. I performed participant observation in four Danish Neuro-intensive Care Units observing the daily medical practices as well as the specialized medical management of organ donors. I observed 60 family conversations of 25 organ donation cases, I performed 52 interviews with 80 family members of 50 organ donors, I interviewed 67 members of hospital staff and participated in conferences, seminars and EDHEP training sessions. **Results:** For Danish families, donation is more than a yes or a no. Organ donation and brain death challenges familiar boundaries between life and death and common practices surrounding dead human bodies. Simultaneously, organ donation enables some families to make sense of a sudden tragic death, often by finding comfort in the usability of the dead body. Family experiences and attitudes towards donation depend on the interaction with hospital staff. By applying the concept of ‘orchestration’, this study leads us to focus on how families and hospital staff mutually attempt to make organ donation culturally acceptable by ritualizing death in certain ways, handling the dead body in respectful manners and telling certain stories about donation. **Conclusion:** The complex social interplay between donor families and hospital staff is crucial for understanding how Danish families perceive and make decisions about organ donation.

#153

A NATIONAL SURVEY OF PUBLIC’S ATTITUDE TOWARD INDIVIDUAL AUTONOMY OR FAMILY DECISION IN ORGAN DONATION IN TAIWAN

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Whether the decision for organ donation is based on “individual autonomy” or “family decision” has been

an important ethical-legal question in transplantation. This study aimed for evaluating public attitude toward individual autonomy or family decision in organ donation in Taiwan. **Methods:** National questionnaire survey was conducted through anonymous telephone interview. Among 3699 telephone calls we dialed, 1,117 participants responded to our telephone interview and completed the questionnaire. Six questions were asked to determine participants’ attitude toward individual autonomy or family decision in organ donation. After excluding incomplete data, 812 eligible subjects were included in the final analysis. **Results:** For those deceased who had expressed wishes and signed for organ donation, 54% of respondents thought that medical staffs do not need to have family’s consent before retrieving organs, but 42% of respondents thought they should have family’s consent first. If the families refuse the patient’s wishes for donation, 55% of respondents thought they should respect patient’s wishes, but 36% thought the family should decide. For those deceased who had refused to donate organs, 67% of respondents thought the patient’s wishes should be respected, but 31% thought that families should decide. 71% of respondents thought the organ donation consent form should include an option of allowing the family to decide. For those deceased who had not expressed their wishes for organ donation, 79% of respondents thought that the families had the right to decide. 86% of respondents thought that families can decide to terminate life supporting system for terminally ill unconscious patients. Besides, we found that respondents who are female, with higher education, and without religions (compared to Buddhism/Taoist) had higher respect for individual autonomy.

#155

CULTURAL AND RELIGIOUS FACTORS IN DISCUSSING STEM CELL TRANSPLANTATION IN ROMANIA: ANALYSIS OF BLOGS

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Introduction: Stem cell transplantation represents a developing medical field, especially due to its promises to cure previously fatal diseases. However, from a Christian religious perspective, stem cell research is considered with caution, depending on the religious view on the source of stem cells. In Romania, major opinion polls regularly depict religious institutions as being highly trusted for population and influential even in daily life. Apart from the traditional communication channels, religious persons incrementally use blogs to disseminate their ways of thinking. **Materials & methods:** We analyzed articles from five popular religious blogs that discuss the pro and con arguments on stem cell transplantation. In our analysis we have used qualitative and quantitative methods of discourse

analysis (counting frequencies, identifying discursive patterns and topics, ranking arguments). Discussion: Most articles published on religious blogs base themselves on foreign (usually US) websites, taking their (pseudo) scientific information and arguments from the main pro-vita discourse. Most of the time, articles are against stem cell research, accusing scientists of destroying human embryos for harvesting the cells or of using problematic means to derive them from adult cells. At the same time, paradoxically, humanitarian articles attempting to raise funds for patients who are looking for stem cell transplantation are also published and promoted. Conclusion: Attitudes of Romanian Christian bloggers concerning stem cell transplantation are ambivalent: on the one hand, they would like the procedure to be banned due to its religious implications, on the other hand, they are ready to support the desperate pleas for such procedures when they come from religious patients.

Workshop 2: Cross-border transplants

#38

NOTHING BUT A WORD? THE ETHICAL MEANINGS OF THE TERM TRANSPLANT TOURISM

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More and more people travel around the world for health care. So-called 'medical tourism' has become a global phenomenon. The 'tourism' metaphor is applied in various medical contexts, resulting in different terms like transplant tourism, reproductive tourism or stem-cell tourism. Yet, 'tourism' is a metaphor highlighting certain aspects of the phenomenon and obscuring others. In consequence, the ethical connotations of this term are as various as its definitions. To explore the ethical meanings of the tourism metaphor, we conducted a quantitative and qualitative analysis of the academic bioethical discourse on medical tourism, based on 45 articles from 2008-2009. Articles were systematically retrieved via PubMed and BELIT and analysed with the software ATLAS.ti. The analysis revealed different meanings of the metaphor depending on the context and the intentions of the authors: Whereas by using a term like transplant tourism some authors implicitly criticize market structures in the field of transplantation, others employ the metaphor to legitimize free market structures in global health care. Thus, by referring to the semantics of tourism as an economic sector, authors may stress opposite moral positions. Moreover, other important aspects of global health care, like suffering as a motive for cross-border care, are not reflected by the term. Thus, a popular term like transplant tourism is in danger of obscuring

rather than highlighting relevant ethical aspects. The tourism metaphor can illustrate some of the relevant aspects of cross-border health care. Yet, implicit criticism or hidden approval hinder open debate. A thorough discussion of the pros and cons of cross-border transplantation should openly consider all relevant ethical aspects. The aim of our paper is to reflect the term critically and to develop alternatives that carry less normative connotations.

Workshop 3: Psychosocial care

#162

PSYCHOLOGICAL FACTORS ASSOCIATED WITH MEDICATION ADHERENCE AMONG YOUNG ADULT KIDNEY TRANSPLANT RECIPIENTS

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Background: There is much evidence for elevated levels of medication non-adherence among patients transplanted at a young age. The aim of this study was to investigate how coping and satisfaction of psychological needs (autonomy, competence and relatedness) are related to medication adherence among young transplant recipients. Method: We conducted a cross-sectional, face-to-face interview study among kidney transplant recipients aged 21-30 years currently enrolled at our out-patient clinic. Adherence was measured using the Basel Assessment of Adherence to Immunosuppressive Medication Scale (BAASIS®). Independent variables were: age at transplantation (Group 1 < 18; Group 2 > 18); socio-demographic characteristics, psychological needs (Basic Psychological Needs Scale); coping strategies [COPE-easy]; and mood (Positive And Negative Affect Schedule). Results: Of the 93 invited, 66 (71%) patients participated (67% male; median age 25; 47% in Group 1 and 53% in Group 2). Sixty-four percent of patients were classified non-adherent in the past 4 weeks. Twenty participants (30%) reported non-adherence on the Taking dimension (missing a dose at least once) while 34 (51.5%) reported non-adherence on the Timing dimension (doses taken > 2 hrs before or after prescribed time). Age at first transplantation, socio-demographic characteristics, satisfaction of psychological needs and coping were not significantly related to adherence classification. However, greater satisfaction of autonomy and relatedness needs was related to higher self-rated overall adherence. Non-adherent recipients scored significantly lower on negative affect. Conclusion: A high level of non-adherence was found among young transplant recipients. Promoting

autonomy and relatedness may offer a way of increasing medication adherence in young patients. Contrary to the literature, adherent patients were found to have higher negative affect. The strict medication regime may be experienced as limiting and thus influence mood. Fear of rejection may also generate negative mood but promote adherence.

#163

PSYCHOLOGICAL PROCESSES THAT CONTRIBUTE TO PSYCHOLOGICAL WELL-BEING AND SOCIAL PARTICIPATION AMONG YOUNG ADULT KIDNEY TRANSPLANT RECIPIENTS

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Background: Kidney disease and transplantation can have a significant impact on the development and well-being of young individuals. The aim of this study was to investigate how coping and satisfaction of psychological needs (autonomy, competence and relatedness) are related to the outcomes of psychological well-being and social participation. **Method:** We conducted a cross-sectional, face-to-face interview study among kidney transplant recipients aged 21-30 currently enrolled at our out-patient clinic. Exclusion criteria included having undergone a transplant in the past year, not speaking sufficient Dutch and cognitive limitations. The main outcomes were measured using the Positive And Negative Affect Schedule (PANAS), the Satisfaction With Life Scale (SWLS) and the Course of Life Questionnaire (CLQ). Independent variables were: age at transplantation (Group 1 < 18 years; Group 2 > 18 years); psychological needs [Basic Psychological Needs Scale (BPNS)]; and coping strategies [COPE-easy]. **Results:** Of the 93 invited, 66 (71%) patients participated (67% male, median age 25, 47% were in Group 1 and 53% in Group 2). Group 1 reported significantly lower achievement of autonomy development milestones than Group 2 but no other differences in other outcomes. Satisfaction of all psychological needs, lower avoidance, greater active coping and lower substance use as a coping strategy were significantly related to higher psychological well-being. Satisfaction of autonomy and relatedness needs was related to greater achievement of social development milestones. **Conclusion:** Greater satisfaction of psychological needs, in particular autonomy and relatedness, was related to greater psychological well-being and social participation. These modifiable factors may be amenable to intervention for those who report re-

duced well-being or social participation, particularly those transplanted in childhood.

#09

TELEMEDICINE AS AN INNOVATIVE PROJECT-STUDY FOR PSYCHOSOCIAL SCREENING OF LIVING RECIPIENTS AT THE TRANSPLANTATION-CENTER FREIBURG

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Introduction: Living kidney-transplantation is a main focus at the Transplantation-Center Freiburg. In the last 30 years more than 3,000 living kidney transplantations were performed. The successful operation is a key factor, but also to take care of the post-operative treatment for the possibly longest patient and graft survival. Therefore in Freiburg a prospective, controlled, randomized and open project-study was started to screen the medical and psychosocial factors of living recipients. **Method:** A group of 25 patients enter their data daily at home into an interactive web-based telemonitor. The entered data are checked daily by medical staff of the Transplantation Center. Additionally the patients are monitored by an Interview and Questionnaires. The BAASIS-Interview, including the analog scale VAS, is to gather the adherence concerning immunosuppression intake. The ESRD-SCL TM to measure the quality of life and the BSI-18-Instrument to cover the psychological liability for kidney recipients. As a control group 25 living kidney recipients without a telemonitor are matched. The data evaluation is reviewed with inductive and descriptive statistics. The project started in July 2010 and will end in December 2012. **Results:** Medical observation in patient's environment, less activities in health facilities and encouragement of patient's independence and self-responsibility are expected as result of the project analysis; also early diagnosis of rejections and infections. All those points result in an early rejection therapy, increasing patient's safety and quality of life and positive psychosocial aspects. Current observations confirm this thesis. **Conclusion:** The project should confirm evidence that a telemedicine supported post-operative treatment increases the recipient's medical and social benefit. The daily communication between patients and the Transplantation Center induces a high degree of trust and less activities in health facilities and reduced hospital-readmissions will give the recipients more safety and life quality.

#157

HEALTH LITERACY AND SELF MANAGEMENT AMONG KIDNEY TRANSPLANT PATIENTS

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Introduction: Previous research showed that almost 60% of the patients are re-hospitalized within the first year after kidney transplantation. The extent to which patients understand health advice and can identify symptoms and act accordingly, are factors that may contribute to complications after transplantation. The aim of this study was to investigate the relationships between health literacy (HL), self-management (SM), patient characteristics and socio-economic characteristics among a cohort of kidney transplant patients. **Methods:** From May 2012 to November 2012, we invited patients who were recently transplanted to participate. Inclusion criteria were reading and understanding the Dutch language and age > 18. We measured SM using an adapted version of the Partners in health scale (PIH, 24 items) and HL using the Dutch Newest vital sign (NVSD, 6 items). Other data (socioeconomic status, work, donor type, medical data, and ethnicity) were collected from the medical status. **Results:** Of the 99 potential participants, 80 (80%) were included. Socio demographic data: 65% male, mean age 55, 74% living donor recipients, and 24% of Non-European descent. Patients who scored statistically significantly lower on HL were of Non-European descent, were not transplanted pre-emptively, and were retired. Also, a significant negative correlation was found between HL and age. No statistically significant associations were found between SM and socio-demographic and patient characteristics. There was a significant positive correlation between HL and 3 subscales of SM: emotional social aspects, knowledge and aftercare, and physical care. **Conclusions:** We identified a number of subgroups among kidney transplant patients who appear to have a lower HL: older patients, retired patients and Non-European patients. In turn, lower HL was related to poorer coping with emotional and social consequences, poorer monitoring of physical care and lower perceived knowledge and aftercare after kidney transplantation.

**Free Communications 5:
Autonomy at the end of life**

#104

WHEN IS THE BEST TIME TO ASK RELATIVES FOR CONSENT TO ORGAN DONATION?

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Introduction: Due to the German law (informed consent) the patient himself/herself or in case of no will is documented (approx. 70%) the relatives have to decide if an organ donation can be realized. The German Organ Procurement Organization offers special education for the ICU staff to sensitize them for the right setting and especially the right timing for family approach. **Methods:** 139 donor family members answered our standardized questionnaire. In this article we focused on their experiences from being approached for consent to organ donation. **Results:** 29.5% (n = 33) of our respondents were confronted with the possibility of an organ donation within their first contact with the ICU staff. In 43.7% (n = 49) the patients' relatives were asked for their consent of organ donation when brain death was suspected but not completely confirmed. Only 16% (n = 18) were asked after confirmation of brain death. 10.7% (n = 12) initiated the question themselves. 34% of the donor relatives, who were asked for their consent for organ donation within the first contact with the ICU staff, experienced this moment as too early and 18% of these as shocking. Only 4% sensed the moment as too early being asked when brain death was suspected; 43% found the timing suitable. Among the donor relatives who were approached after confirmation of brain death no one experienced the question as too early or shocking. **Conclusions:** The right timing of family approach has a strong impact on the donor relatives' perception. This perception influences the confidence building and willingness to donate relative's organs as well as the confidence in their decision. According to our findings it is important to educate the ICU staff and to further develop our family care program.

#114

FACTORS INFLUENCING BEREAVED FAMILIES' DECISIONS ABOUT ORGAN DONATION: AN INTEGRATIVE REVIEW OF THE LITERATURE

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Over the past decade, researchers have used both quantitative and qualitative research methods to iden-

tify barriers and motivators to organ donation. Family members play a prominent role in donation decision-making and their ultimate choice is known to significantly affect the number of organs available for transplantation. This presentation reports on the process and outcomes of an integrative literature review, designed to provide insight into bereaved families' experiences of approach for organ donation and the factors that influenced their decision to agree or decline consent to donation. A comprehensive search was undertaken using three search strategies, pre-defined search terms and precise inclusion and exclusion criteria. The final sample comprised 20 primary research studies originating from eight Western countries. Reports were published between 2001 and 2011. The research available for review was limited to family decision-making in the context of donation following brain death. The quality of each primary report was evaluated using criteria applicable to quantitative and qualitative research. Study findings were extracted and synthesized using a tool for deriving and depicting themes from textual data. The analytic process culminated in the development of three global themes (past, present and future) that focused on the temporal dimensions of bereaved families' perceptions of the factors influencing their decisions about organ donation. The review findings provide valuable insight into ways of increasing the rate of consent to organ donation through the development family-centred care interventions that reflect the needs of the bereaved. Further research to explore bereaved families' experiences of approach for organ donation after circulatory death and observation of real-time decision-making with bereaved families who decline organ donation is essential to providing a more complete understanding of the factors affecting donation decisions.

#76

CURRENT ISSUES IN EUROPEAN UNCONTROLLED DONATION AFTER CARDIAC DEATH PROTOCOLS

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Spain and France has respectively 15 and 8 years of experience in uDCD. Recent technical breakthroughs achieved in resuscitation for victims of out-of-hospital cardiac arrest (OHCA) have an impact in uDCD protocols. Whilst some authors perceive these technical developments as a threat to uDCD protocols, others think that both management paths are compatible and should coexist. Objective: To assess current uDCD programs in light of updated evidence on OHCA resuscitation procedures. To address these questions: What is the current gold standard of care indicated for victims of OHCA? How does that standard impact on uDCD protocols? Material and methods: Review of the scientific/ethical literature related to both uDCD programs/innovative resuscitation procedures. Re-

sults: Some cases have been reported of uDCD donors who recovered pulse upon arrival to the hospital, of which some were discharged from the hospital with good neurological recovery. Recently recommended procedures/management for selected OHCA patients improve their outcomes/survival. There is need to elucidate whether or not some current uDCD donors are considered patients and the following interventions are performed while ongoing CPR, they could survive: a) induced hypothermia from the prehospital setting to the ICU; b) thrombolysis treatment; c) direct access to a Cath Lab-H24 or/and to extracorporeal life support (ECLS). Emergency medical services in Spain and France need scientific/technical/ethical criteria to discriminate patients from potential donors among the victims of OHCA. Conclusions: Operational criteria for high-quality CPR should seek a balance between the technical imperative (doing all what is possible), considerations about outcomes with quality-of-life, and distributive justice (costs/benefits). Uncontrolled DCD protocols can be performed in a way that does not hamper the legitimate interests of patients, potential organ donors, their families, the organ recipients, and the health professionals involved in these processes.

#24

DEVELOPING END OF LIFE CARE GIVING BEREAVED FAMILIES THE OPTION OF CORNEAL DONATION

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Background: The Critical Care unit at The Ulster Hospital historically has a very high referral rate for Donation following Brain Stem Death but no tissue only referrals. Across the region 5 corneal only donations occurred in the year 09/10. It was widely felt within the unit families would not consider corneal only donation due to our culture of open coffins and the wake. The document 'Organs for Transplant A report of the Organ Donation Taskforce 2008' reviewed the process of organ donation and transplantation within the UK and made 14 recommendations one of which is to make organ and tissue donation a usual, not unusual event in end-of-life care in all hospitals. The introduction of a Specialist nurse in organ donation into the Intensive Care unit followed the recommendations in February 2010. Aim of the service: To ensure all families are given the opportunity to donate corneas if that is their or the wishes of the deceased. Whilst it is recognised only a small percentage of the population can donate solid organs there are few contraindications to corneal donation. Process: An education framework was developed and implemented to give the nursing staff the skills and knowledge to approach families of all patients who died in ICU to consider Corneal donation. In addition corneal donation leaflets and posters were placed in relative areas with positive feed-back

from both families and nurses. Result: Nursing staff have taken responsibility for the approach to families and feel Corneal donation is a positive outcome within their unit. 2010/2011 family approach rate has increased from 16 % to 69% overall with some months the approach rate being 100%. Family consent rate currently overall 33%.

#146

DEATH CRITERIA AND DONATION AFTER CIRCULATORY DEATH: SHOULD WE RECONSIDER THE DEAD DONOR RULE?

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Objective: Despite continuing scientific controversy on whether brain death (BD) should be equated to death, organ procurement from brain dead patients is widespread and is for the most part a fairly uncontroversial practice, certainly due to the fact that neurological death remains a reliable criterion for establishing a prognosis of irreversibility. Where controversy is now focused is in cases of donation after circulatory death (DCD). DCD protocols reactivate a debate which used to be only associated to BD: the debate over the Dead Donor Rule (DDR), which establishes that organ retrieval must not cause the death of the donor. The objective of this paper is to discuss the role the DDR may play in preserving DCD donors' interests and societal trust in organ transplantation. Method: Critical review of the clinical and bioethical literature on DCD and the DDR. Results: Similarly to what occurs with BD protocols, there are reasonable scientific doubts about whether DCD donors are dead. These doubts have to do with the potential reversibility of circulatory arrest and with the possibility that all brain functions may not be irreversibly destroyed at the time of organ procurement. These doubts may create discomfort and discontent among health care professionals involved in DCD. They also constitute a potential factor of societal distrust with respect to the transplantation system. Conclusion: If DCD protocols are to achieve their full potential for facing organ scarcity, the sources of health professionals' discomfort and discontent must be identified and addressed. One valid option to limit the risk of a loss of social trust in organ donation is to promote a public and transparent debate on the unsettled moral aspects relative to organ procurement.

#19

EXPLORING ORGAN DONATION WITH BEREAVED RELATIVES: HEALTHCARE PROFESSIONALS EXPERIENCE IN 3 EUROPEAN COUNTRIES

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Bereaved families are the crucial link in obtaining organs for donation and are involved in the organ donation decision making process. The challenges of requesting organ donation from relatives have been widely documented often resulting in organs for donation being lost (Scottish Transplant Group, 2002; Sque et al., 2008). Despite this, a study of the Healthcare Professionals (HCP's) experiences with relatives in the decision to donate organs in 3 European countries (n = 42) using a phenomenological methodology (Heidegger 1962 ; Gadamer 1989), demonstrated that the family involvement in the organ donation decision making process was vital, even in countries where legislation allowed the removal of organs for transplant if no objection had been recorded by the deceased (Neades, 2008). Analysis of this data demonstrated not only were there different levels of education for the HCP's requesting donation and different protocols of practice in use for the approach to relatives at this difficult time, but in addition, the HCP's discussed their own views on the benefits and challenges of involving relatives in the decision to proceed to organ donation. The HCP reflections on their experiences in exploring organ donation with relatives not only described the reaction of relatives to the news of the impending death of their family member but in addition provided insights into the beliefs, attitudes and values of the HCP in relation to requesting organ donation. This paper summarises the experiences of these 3 groups of HCP's in their efforts to balance the need to respect the wishes of the dead in relation to donating their organ with their professional responsibilities to support the bereaved relatives and the factors which would influence their decision to proceed or decline to proceed to organ donation.

Free Communications 6: Donation after cardiac death (DCD)

#122

KIDNEY TRANSPLANTATION FROM DONORS AFTER CIRCULATORY DEATH: AN INITIAL REPORT OF 71 CASES FROM CHINA

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In 2007, a landmark decision that is supported by the international transplant community, the Chinese national government has established regulations to gradually abolish the use of organs from executed prisoners and created a legal and sustainable voluntary organ donation system. Currently in China, even the potential donors who met the criteria of brain death still have to wait for cardiac arrest before organ donation. With the collaborations of the Chinese central government, the Red Cross Society and Chinese Transplantation Society, the number of donation after circulatory death (DCD) donors has increased rapidly in recent years. We report 71 DCD kidney transplants performed in our hospital at Sun Yat-sen University between February, 2007 and June, 2012 with aims to demonstrate the results of DCD kidney transplantation and risk factors associated with kidney allograft outcome. The primary non-function rate was 2.8%, and delayed graft function rate was 28.2%. The 1-year and 3-year graft survival was 95.7% and 92.4%. Donor age, serum creatinine level before recovery, and hypertension history were negatively correlated with 1-year eGFR after transplant. Donor age > 40 years, hypertension, cold ischemia time > 24 h, and serum creatinine before recovery of > 115 µmol/L were risk factors for delayed graft function after DCD kidney transplantation. The discarded kidneys and DGF grafts had lower flow rates and higher resistant indices. In conclusion, graft survival of DCD kidney transplantation is excellent despite of higher rates of primary non-function and delayed graft function after transplantation. Donor age, pre-recovery donor serum creatinine, hypertension history, cold ischemia time, resistant index and flow rate are useful factors to predict graft outcomes after DCD kidney transplantation. This report illustrates the initial success in creating a legal and sustainable voluntary organ donation system in China.

#12

DONATION AFTER CARDIAC DEATH: ARE AUSTRALIAN EMERGENCY CLINICIANS SUPPORTIVE?

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To improve organ donation processes and outcomes many Australian hospitals have introduced formal Donation after Cardiac Death (DCD) pathways following the 2010 publication of the National Protocol for DCD. The protocol highlights that DCD is often logistically complex and can present ethical issues. While DCD only occurs in Australia in the controlled situation of death following withdrawal of cardio-respiratory support in Intensive Care Units, many end of life decisions regularly occur in emergency departments (EDs). As emergency clinicians play a significant role in identifying potential DCD donors, it is critical to assess their support and knowledge. A cross-sectional online survey was conducted of 648 Australian emergency clinicians, including 487 doctors and 161 nurses (16.2% response rate). Knowledge and attitudes regarding DCD were assessed by rating agreement with statements and free text comments. Quantitative data were analyzed using Pearson's Chi Square test or Fisher's exact tests in Predictive Analytic Software and thematic analysis was used for qualitative data. Results showed that although 71% of emergency clinicians supported DCD, 32% were familiar with the processes involved in DCD, and 23% were familiar with the national protocol. Those who had received specific education regarding organ donation and had experience with this showed a higher rate of support for the process of DCD. Free text comments revealed that some held ethical or logistical concerns, or did not have enough knowledge regarding DCD. The majority of ED clinicians (61%) desired additional education on the topic of DCD. For those involved in OTD education and processes, it is critical to engage with emergency clinicians to increase acceptance and understanding of DCD, so that patients in EDs who may be potential DCD donors are identified and their families provided with the opportunity to consider DCD.

#165

THE ETHICS OF ARTIFICIAL CIRCULATORY SUPPORT IN ORGAN DONORS

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Extra-Corporeal Support (ECS) and external cardiac massage + ventilation (ECMV) are both techniques that allow oxygenated blood to be circulated to tissues in the absence of native cardio-respiratory function. ECS and ECMV have both been used in several organ donation settings including Type II (uncontrolled) donors after circulatory death (DCD), Type III (controlled) DCD, and Type IV DCD (circulatory collapse after brain death). Objective: to review the ethical basis for using ECS and ECMV in deceased organ donation and to define the circumstances when it is acceptable. The dead donor rule is the single most inviolable rule in organ donation. Western definitions of death invoke the permanent cessation of circulatory blood flow to the brain. Given that utilization of ECS and ECMV have the potential to restore circulation to the brain, they both have the potential to violate the dead donor rule if organs are recovered while ECS or ECMV perfusion of the donor's brain is occurring. However, if ECS is established retrograde through the femoral vessels in the abdominal great vessels, and aortic flow is interrupted above the diaphragm by aortic occlusion there is no flow to the brain. ECS is therefore ethically permissible in this setting since the dead donor rule is not violated. ECMV is not ethically permissible unless the individual is not declared dead until after it has been terminated. Both ECS and ECMV are permissible in the setting of brain death because the physiology of intracranial hypertension prevents the restoration of blood flow to the brain. Conclusion: protocols that rely on ECMV support of non-brain dead organs donors should be reevaluated, while protocols that utilize ECS should require aortic occlusion.

#111

DCDD: WHAT ARE WE WAITING FOR?

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Objective: Our aim in this paper is to defend that once we have accepted the rationale for the cardio-circulatory criterion of death, namely that the life-sustaining measures are no longer beneficial, and the family or representatives of the patient have accepted withdrawal and the subsequent removal of organs for transplantation, there is no justification for the prevalent "waiting periods" for cardiac arrest and eventual auto-resuscitation. Method: Ours is a normative enterprise so we will survey the relevant literature on the ethics of donation after cardio-circulatory death (DCDD) and the definition and criteria of death. We will limit

our search to articles written in English or Spanish after 1966. We will also survey the current protocols of DCDD in those countries in which it is practiced. Results: Because the evidence on the phenomenon of auto-resuscitation is scant (De Vita), every country has adopted a "consensual", and somewhat arbitrary decision as to the period of time in which the surgical team should wait before death is declared. Conclusions: The observation period seems to have two aims: (1) avoiding a rule that instructs physicians "not to kill" and (2) eliminating the occurrence of auto-resuscitation. As to the first goal, we will contend that in this context the distinction between actions and omissions has no real moral force. As to the second, we will argue that if the clinical trajectory of the patient is certainly leading to an imminent death, and the withdrawing of life support follows the consent of the family or relatives, the expectation for auto-resuscitation is disingenuous and causes significant harms: to those who are expecting a life-saving organ but also to the family who is expecting that the death of the loved one has the positive consequence of aiding someone in need.

#18

DONATION AFTER CARDIAC DEATH – SYSTEMATIC REVIEW OF ATTITUDES OF MEDICAL PERSONNEL AND THE GENERAL PUBLIC

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Objective: Organ donation after cardiac death (DCD) may be a viable path to combat the organ shortage, but the concomitant ethical issues may differ from those raised in donation after brain death (DBD). Furthermore, medical personnel and the public may perceive DCD differently than DBD. This article systematically reviews empirical studies on attitudes of medical personnel and the public towards DCD and discusses the findings from an ethical perspective. Methods: A 7-step approach for systematic reviews of empirical studies in bioethics was used. After defining the research goal, the databases PUBMED, CINAHL, EMBASE, PSYINDEX, and PSYCINFO were selected due to their coverage of biomedical, psychological, sociological and ethical topics. Search algorithms were devised using controlled vocabulary of the respective databases (where applicable) and criteria for the relevance assessment of the articles determined. The Critical Appraisal Skills Programme tool was used to assess article quality. An integrative approach to the data was taken by combining it for further analysis. The authors used thematic analysis to synthesize the qualitative data and identify relevant themes. Quantitative data

corresponding with the identified themes was extracted and data on common subjects was juxtaposed and presented later. Results: The authors identified the following themes: Levels of support for DBD vs. DCD, attitudes towards post-mortem measures without previous consent, lack of knowledge about DCD, concerns about the dead donor rule, the potential for conflict of interest, making donation happen, and the call for standardized DCD protocols. Conclusions: All of these topics are ethically relevant and worthy of further discussion. The authors conclude that deeply embedded concerns about DCD exist among the general public and health care providers. These must be taken seriously in order to foster trust in the transplantation system.

Focus Session 5: Principles of allocation

#59

DIRECTED DONATION OF DECEASED DONOR ORGANS – A DONOR INTENT DRIVEN POLICY

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There is currently no international consensus regarding requests by families of deceased donors to direct organs to recipients outside of the normal allocation system. While rare, transplant centres have occasionally been asked to direct an organ to a specific individual (usually a relative or loved one of the deceased) or to a specific class of recipient (e.g. a “good Christian”) In the absence of direction from the government, OPOs or transplant societies, individual centres or health professionals are left to deal with cases as they arise, often with little time to make a considered decision. This paper aims to give some background on this issue, and discuss the concerns that may arise, and suggest a public policy approach that could be ethically acceptable, improve transparency in the system and reduce pressure on transplant professionals charged with time-sensitive organ allocation decisions. The US law, which allows directed donation to any named individual, is contrasted with the previous policy and current policies in the UK. The more recent UK policy of directed donation in some circumstances is also discussed. The paper offers an alternate approach that can temper the desire to keep the vast majority of deceased donor organs allocated in a non-directed manner with the recognition that compassion requires occasional exceptions to this rule. This donor-intent driven policy charges the surrogate decision maker with representing the donor’s wishes, and allows direction when the donor, when alive, would have wanted his or her organs directed in this manner. The policy allows the donor (through the surrogate) to decide which rela-

tionships were important to him or her. Public solicitation is avoided in most cases, and the transplant centre does not need to decide which relationships are “close” enough to warrant directed donation.

#129

THE PEDIATRIC PRIORITY IN ORGAN ALLOCATION IS NOT NECESSARY AND IS COUNTERPRODUCTIVE – PROPOSAL FOR AN ALTERNATIVE ETHICAL MODEL

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In the US, a pediatric deceased kidney allocation priority could be a disincentive for living donation. There is a so-called improvement in overall access to transplantation for children based on a shorter waiting time. However, this apparent advantage is lost abruptly. In Quebec, our previous allocation rules were essentially based on HLA matching. Since the middle of 2004, we simply give priority for only one kidney from each donor between 5 and 45 y for a recipient under 18 y. We wanted to see if the phenomenon observed in the US occurred in Quebec, we have examined the ethical problems posed by such a policy and we propose an alternative, integrated and progressive model, eventually applicable to other organs than the kidney. Methods: We compared the living and cadaveric pediatric transplantation activity before and after the implementation of the priority. Access was measured by multiple parameters. Results: Table1 (abbreviated data) Total living Cad WTCad days (mo.) MMDr 2000 7 0 7 428 (14) 0.5 2001 6 2 4 718 (24) 0.75 2002 13 7 6 428 (14) 0.4 2003 22 10 12 700 (23) 0.9 2004 16 3+2 1 +10 471 (16) 1.3 2005 21 3 18 253 (8) 1.2 2006 8 0 8 63 (2) 1 2007 13 1 12 95 (3) 1.2 2008 13 5 8 191 (6) 1.3 The waiting time was unnecessary shortened to 3-4 months, the living donation decreased, the DR mismatching increased. Ethical problems: This priority could be considered discriminatory (ageism) against the whole adult list, the brutal transition at 18y is unfair. Alternative proposal: equity requires that we target organs for the younger persons who are so poorly off that they will not make it to old age without being given priority: applying a factor Q/age to the whole list would produce an entitlement that is inversely proportional to age without any brutal transition. A safety net (age/10) would secure the system.

Free Communications 7: Psychosocial Care and Donation (2)

#69

IDENTIFYING PREDICTORS OF PSYCHOSOCIAL OUTCOMES AFTER LIVING KIDNEY DONATION

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Background: Living kidney donation is the treatment of choice for patients with end stage renal failure. Living kidney donors undergo major surgery for the benefit of their recipient with justification coming from the expectation that the psychosocial gain outweighs the risks of physical harm. Aims: To identify factors of importance to living donors that may impact psychosocial outcomes after donation. Method: A cross-sectional qualitative study was performed at Guy's Hospital, London. A topic guide was devised following scoping interviews and discussions with members of the living donor team and a selection of previous kidney donors. A purposive sample was designed and agreed. Twenty-three in-depth interviews were conducted on a sample of pre- and post-operative donors. Each interview was recorded and transcribed verbatim. Transcripts were indexed, sorted by theme and summarised before being placed into frameworks for analysis. Results: Several themes were identified from the study relating to decision making, familial concern, parental responsibility and the role of the donor as the recipient's carer. Being asked to donate and having no alternative donors available was associated with feelings of entrapment and increased stress and anxiety. Those donors with recipients on long-term dialysis or who were prime carers of their recipient sought to gain most from donation as they experienced similar physical constraints and an identical psychosocial impact on their own lives. Conclusions: This qualitative study has identified a number of themes important to living donors that may impact positively or negatively on their post-operative recovery and long-term psychosocial outcome. Factors such as the circumstances and feelings towards the donation, feelings of entrapment and the role of primary carer should be identified within donor-recipient pairs to ensure that donors are selected appropriately and adequately supported pre- and post-operatively.

#67

ANONYMITY IN UK UNSPECIFIED KIDNEY DONORS: A NATIONWIDE SURVEY

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Background: Unspecified living kidney donation in the UK is becoming increasingly popular. Anonymity is an on-going issue which has been discussed at length nationally and internationally. Aims: To ascertain UK unspecified donors' experiences and attitudes towards anonymity. Methods: All 117 UK unspecified donors donating since the scheme began in 2007 and July 2012 were sent a questionnaire in September 2012. Participants were asked about recipient contact and regret on finding out the outcome of their donation. Results: 85 responses were received (73% response rate). 46 (54.1%) received a letter/card from their recipient following donation; 32 < 3 months (69.6%), 13 (28.3%) 3-6 months and 1 (2.2%) 6-12 months. 38 donors did not receive a letter/card; 34 (89.7%) of whom either wanted or "maybe" wanted to receive one. 55 (64.7%) knew the outcome of their donation with 2 (3.6%) regretting finding out. 13 had further contact with their recipient, initiated on 9 occasions by the recipient (69.2%) and 4 occasions by the donor (30.8%). All initial contact was written and on 3 occasions led to telephone calls and/or meeting in person. Those who had met their recipient did not regret doing so. In 52 cases (72.2%) neither party had initiated contact. 3 (4.2%) had a request to meet their recipient declined. 10 (13.8%) wished to meet their recipient but had not yet made contact. 1 of 6 donors unable to yet make contact intended to do so. Conclusions: Contact between unspecified donors and recipients is common, occurs early and is preferred by the majority of donors. A break in anonymity is infrequent with few meeting face-to-face. Some donors and recipients decline contact and in a third of cases contact is initiated by the donor. Break in anonymity has negative consequences for some.

#158

PSYCHOSOCIAL SCREENING OF THE UNSPECIFIED LIVING KIDNEY DONORS IN THE NETHERLANDS

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Background: The first unspecified donation (formerly known as anonymous or altruistic donation) was performed in 2000 in Rotterdam. Since 2007 unspecified living kidney donors have been accepted in all 8 university centers in The Netherlands. However, little is known about the psychosocial screening of these donors. In this study we describe the psychosocial screening of unspecified living kidney donors in the 8 kidney transplant centers in The Netherlands. **Methods:** We collected data about which professionals conduct the screening, which validated instruments are used, and what the psychosocial contraindications are. From each center the living donor coordinator responded to this questionnaire. **Results:** In all centers a multidisciplinary team is involved in the screening of unspecified living kidney donors. Most donors are screened by a nephrologist, social worker and a nurse practitioner/living donor coordinator. A consultation is also included with a psychologist or psychiatrist. One center added an independent physician for the unspecified donor screening. Four centers use the SCL-90 (a clinical diagnostic self-report scale for psychological complaints). One center uses a NEO-Five Factor Inventory (NEO-FFI) assessment (a personality test). Three centers do not use validated questionnaires. In all centers the psychologist used the same topics during the interview: motivation for donation, reality awareness, realistic expectations of donation, and psychiatric illness in the past. Contraindications include active psychosis or addiction, personality disorder and psychosocial instability. In one center age is a contraindication, unspecified donors must be older than 25 years. **Conclusion:** All centers screened the unspecified living kidney donors with a psychologist/psychiatrist using an in-depth clinical interview. Sixty-three percent of the team used additional validated questionnaires. Psychosocial screening of unspecified living kidney donors is based on the National and International guidelines, but there are variations in the contraindications used.

#134

MODIFIABLE FACTORS IN ACCESS TO LIVING DONOR KIDNEY TRANSPLANTATION AMONG DIVERSE POPULATIONS

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Objective: Despite living donor kidney transplantation (LDKT) being the optimal treatment option for patients with end-stage renal disease, we observed a significant inequality in the number of LDKT performed between patients of non-Western European and Western European origin. The aim of this study was to explore modifiable hurdles to LDKT that may help explain this inequality. **Methods:** A questionnaire on knowledge, risk perception, communication, subjective norm, and willingness towards LDKT was completed by 160 end-stage renal patients who were referred to the pre-transplantation outpatient clinic (participation rate 92%) prior to their consultation with the nephrologist. The questionnaire was available in 9 languages. Multivariate analyses of variance and binary regression analyses were conducted to explore and explain differences between patients with and without a living donor controlling for socio-demographic factors. **Results:** There were significantly fewer patients of non-Western descent (11/82) that brought a living donor to the outpatient clinic than patients of Western descent (38/78). Patients without a living donor were less likely to be employed than patients with a living donor ($p < 0.001$). Furthermore, patients without a living donor were undergoing haemodialysis more often ($p = 0.003$) and spent on average 15 to 23 months longer on dialysis ($p = 0.002$) compared to those with a living donor. Non-Western descent, long duration of dialysis, low knowledge, little communication on kidney disease and low willingness to communicate with individuals from the social network were significantly related to the absence of a living donor. **Conclusions:** After correcting for non-modifiable socio-demographic factors, knowledge, willingness to communicate and actual communication were identified as modifiable factors that are related to the likelihood that a patient brings a potential living donor to the first visit at the pre-transplantation clinic. This observation makes knowledge and communication strong candidates to address in interventions aiming to reduce the inequality in LDKT among potential transplant candidates.

#102

KNOWLEDGE ABOUT DIALYSIS, TRANSPLANTATION AND LIVING DONATION AMONG PROSPECTIVE LIVING KIDNEY DONORS AND RECIPIENTS

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Objective: In order to give informed consent, living kidney donors and recipients must have a good understanding of renal replacement therapies (RRT) options and risks. The purpose of this study was to explore the knowledge level about dialysis, transplantation and living donation among donors and recipients. **Method:** Eighty-five living kidney donors and 82 living donor kidney recipients completed the self-report Rotterdam Renal Replacement Knowledge-Test (R3K-T) in their native language (available in 9 languages) one day before surgery. This questionnaire consists of 10 items about Dialysis & Transplantation (DT, score: 0-10) and 11 items about Living Donation (LD, score: 0-11). **Results:** Recipients scored significantly higher on the DT-subscale ($M = 8.40$, $SD = 2.53$) than donors ($M = 6.36$, $SD = 2.87$). Donors scored significantly higher on the LD-subscale ($M = 8.36$, $SD = 1.43$) than recipients ($M = 6.93$, $SD = 2.44$). Using multiple linear regression analyses we found that recipients knew less about DT if their native language was not Dutch and if they were undergoing pre-emptive transplantation. Recipients knew less about LD if they were female, if their native language was not Dutch and if they had a religious affiliation. Donors knew less about LD if their native language was not Dutch. **Conclusion:** It appears that recipients and donors retain different information even when informed together. The finding that donors did not answer all questions about LD correctly is in line with conclusions of earlier studies that some living kidney donors do not make the decision to donate based on consideration of risks and benefits. Despite patient education and the questionnaire being offered in various languages, non-Dutch speaking donors and recipients scored lower on RRT knowledge. Therefore, extra efforts should be made to ensure that these donors and recipients understand the information given.

#61

REQUESTING FAMILY CONSENT: A STRESSFUL SITUATION FOR THE COORDINATOR

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Introduction: This task is often daunting. Its outcome is closely linked to the psychological attitude of the coordinator, who has to manage his anxiety towards death. This anxiety might lead him to adopt deleterious attitudes including excessive rationalization, lying, escape, avoidance... **Method:** To help the coordinator overcome his anxiety and learn how to establish a good rapport with families of potential donors, a series of teaching seminars were conducted in participating hospitals. An important part of each seminar was devoted to simulation exercises on family approach. Following each seminar health professionals that attended, were asked to evaluate the impact of the teaching sessions by answering the following Questions: 1) Do you agree with our strategy of the family approach? 2) Did the training and the simulation help you to explain the brain death concept to the donor's family? 3) Did the simulation reduce your stress when asking a family for organ donation? 4) Did this training teach you how to support the family in their decision? **Results:** One hundred and sixty four (164) nurses and 13 physicians in 19 participating hospitals took part in the seminars. The majority of the participants (73%) were female. Preliminary results suggest that the health professionals who attended the session found them beneficial in terms of explanation of brain death (79%), reduction of stress and offering support to the donor's family (80%). Seventy-seven percent (77%) agreed with the strategy of the family approach. **In conclusion:** Through simulation, anxiety and associated behaviors were adapted and converted into efforts to create new solutions and prepare coordinators to anticipate and confront real problems that might arise in the future.

#70

PERIOPERATIVE PSYCHOSOCIAL FACTORS AND WOUND HEALING IN LIVING KIDNEY DONORS

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Background: Living kidney donors have little or no major physical or psychosocial co-morbidity. Research investigating factors which influence wound healing

and recovery have identified a role for psychological stress and patient affect; however these findings have been demonstrated using wounds specifically created for study or involved patients with a known pathology. Aims: To investigate the extent to which preoperative stress, anxiety and depression: 1) impact upon surgical wound healing in healthy living kidney donors and 2) impact on indices of recovery (pain, affect, fatigue and physical functioning). Method: Preoperative stress was assessed using the PSS, and mood was measured both pre- and postoperatively using the HADS and STAI. Postoperative measurements of pain, fatigue and physical functioning were assessed by the NRS-101, ICSF and SF-36, respectively. The quality of wound healing was assessed by the WAI. Results: Fifteen donors were included in this study. Analysis revealed that preoperative stress was positively associated with postoperative anxiety ($r = 0.72$, $p < 0.05$) and impaired physical functioning ($r = 0.73$, $p < 0.05$). Preoperative anxiety was positively associated with postoperative anxiety ($r = 0.70$, $p < 0.05$), fatigue ($r = 0.61$, $p < 0.05$) and impaired physical functioning ($r = 0.61$, $p < 0.05$). Neither preoperative stress nor patient affect exhibited a significant effect on wound healing and no significant associations were found between indices of recovery and wound healing. Conclusions: This is the first study assessing the effect of psychological factors on wound healing and recovery in living kidney donors. Despite the small sample size preoperative stress and anxiety were found to be significantly associated with postoperative anxiety, fatigue and physical functioning. Limitations of this study included the study size and how wound healing was measured. A larger study using more objective measures of wound healing is necessary to further investigate the link between psychological factors and wound healing.

#178

PREDICTIVE CHARACTERISTICS OF NEGATIVE PSYCHOSOCIAL OUTCOMES IN LIVING LIVER & KIDNEY DONORS: A FINAL UPDATE ON THE SYSTEMATIC LITERATURE REVIEW

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It has been demonstrated that psychosocial outcome following living donation is predominantly favorable. However, little is known about which factors predict poor mental health in a subpopulation of living liver and kidney donors after donation. A systematic literature review was initiated by the ELPAT Psychological Care Working Group to identify the available empirical research on these psychosocial vulnerability markers in potential living donors. Included studies describe assessment of mental illness parameters both, pre- and post- donation and Quality of Life as out-

come measure, in a population of living liver or kidney donors. No restrictions were maintained regarding geographical origin and date of publication. Scientific reports were searched for through PubMed, PsycInfo, and Embase. A grand total of $N = 638$ papers was retrieved and reviewed, based on title and abstract. $N = 105$ articles were reviewed based on their full text. The definitive number of articles included describing predictive characteristics has not yet been determined at the time of abstract submission. The retrieved literature suggests that there are a small number of possibly predictive characteristics of negative outcome. However, a lack of prospective studies on psychosocial health in living donors exists. Low sample sizes might have influenced the low incidence of psychosocial problems found, and their subsequent lack of predictive capacity.

Free Communications 8: Autonomy at the end of life

#75

CARRYING OUT RESEARCH INTO THE EFFECTS OF ORGAN-PRESERVATION METHODS

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A standard medical treatment always needs to be improved by constant research; this also applies to organ transplantation. However, medical research on the donor with regard to organ donation at a later point is problematic. When the donor is unconscious, consent can only be presumed. The view that methods which are not harmful to the donor are justifiable remains questionable. It is crucial to determine the point in time at which a patient should take part in a study which aims at improving the process of organ donation. The justifiability of research after donor was pronounced dead can be based on an informed consent on the part of the donor or his relatives, a presumed consent or prevailing interests of the community. In the majority of cases, however, an informed consent of the donor does not exist. In most cases, promotion campaigns concentrate on the positive effects for the recipient, instead of emphasizing the positive aspects for the donor, such as making autonomous decisions with regard to one own body and the relief for the relatives that arises from a decision made by the potential donor himself. In the process of obtaining the family's consent for organ donation, the question if necessary medical research may be performed may provoke a refusal regarding both the research and the donation itself. Therefore, in most cases the researcher has to rely on a justification by presumed consent. Consent relating to the donation can include research methods, on the condition that there are no contradictory interests of the donor. Such contradictory interests will be

assumed if harmful methods are used. Methods which require a prolonged support of the donor's cardiovascular system or which lead to a further defacement of his body can be considered harmful.

#183

NON-STANDARD KIDNEYS FOR TRANSPLANTS: CLINICAL MARGINS, MEDICAL MORALITY AND THE LAW

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Advances in kidney transplantation have been impressive, but have not eliminated significant variability of outcome, related to donor organ quality. Organ shortage means that in addition to 'standard' deceased donor kidneys (SD), 'non-standard donor' (NSD), 'expanded criteria donor' (ECD), or 'marginal' kidneys, which fail to meet standard criteria and are often associated with less good outcomes, are now being transplanted. This paper outlines the clinical rationale and ethical argument underpinning the use of such donor kidneys and examines their legal status in the UK, which we claim remains largely undefined and untested. While it is probable that the general principles governing medico-legal consent and liability also apply to organ donation, the special circumstances of donation, notably the inadequate supply of donors, make it difficult to know how far existing medico-legal precedents can or should apply. The non-standard status of deceased donor organs creates potential problems for the validity of 'appropriate consent' to donation required by statute. It may also be relevant to the use of interventions intended to optimise donor organ quality. Further, the SD/NSD distinction in clinical practice may produce unexpected legal effects. For example, the recent UK Regulations, which bring into force the EU Directive on standards of quality and safety of human organs intended for transplantation, could produce a negative legal restraint on the use of NSD kidneys. There is an urgent need for clarification of the effect of using NSDs in general criminal and civil law liability.

#105

'KEEPING HER WHOLE': BEREAVED FAMILIES' ACCOUNTS OF DECLINING A REQUEST FOR ORGAN DONATION

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This study explored accounts of negative organ donation decisions. We were interested in how family members accounted for their refusal. In particular, how they discursively located themselves, their deceased relative and the body of the deceased in the decision-making

process. Secondary analysis was used to examine a primary dataset of transcripts of qualitative interviews that explored the end of life decision-making and hospital experiences of a sample of 25 bereaved family members who declined organ and tissue donation from 22 deceased relatives. One of the most striking characteristics of our corpus was that the main reason given by participants for declining the donation request was the wish to keep the deceased person 'whole', not to cut up their body. In other words, there was a very clear 'personal' perspective in the accounts of the decisions given by the participants. Participants constructed their accounts not so much as ones in which the body would be cut up, but, rather, as one in which they 'fear', 'can't imagine' or 'can't bear' that the body would be cut up. Linguistically, the refusals were constructed as focusing upon those who actually made the decisions. Requesters of organ donation should therefore pay attention to the decision-maker in terms of their own attitudes, as well as their imagery of what actually happens. It is this image, we think, that prevented the bereaved family members from agreeing to the donation request. In other words, what staff approaching families deal with, in fact, is a combination of fact and stereotype, rather than a factual image of what happens to the body. It would appear therefore, that it was this 'narrative' of organ donation that needed to be changed to achieve positive decisions.

#97

ATTITUDES TOWARDS ORGAN DONOR ADVOCACY, AN IMPACT ON ORGAN DONATION

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End-of-Life Care in the intensive care unit (ICU) involves caring for brain dead (BD) persons who by their death become potential organ donors (POD). In this situation, the concept of organ donor advocacy is critical. Objective: To investigate attitudes and actions of ICU nurses in the context of organ donation (OD) based on their experiences. Methods: Four studies were performed consisting of Swedish ICU nurses. Study I: n = 9; II: n = 702; III: n = 15; IV: n = 502. The interviews (I, III) were analyzed by Phenomenography. The questionnaires (II, IV) were analyzed by Principal component analysis, Multi-trait analysis, Cronbach's Alpha and Descriptive statistics. The instrument Attitudes towards organ donor advocacy scale (ATODAS) was developed for study IV. Results: Less than half of the ICU nurses (48%) trusted clinical neurological examination to establish BD without a confirmatory cerebral angiography. The participants perceived BD and the diagnostics of BD in four qualitatively different ways. The participants said that the nurses' perceptions could affect the family's attitude to OD. In total, 39% had ex-

perienced that the question about OD was never raised with the relatives, 25% indicated that mechanical ventilation was withdrawn in order to reduce suffering for a presumably dead person. Almost half considered that caring for a mechanically ventilated POD was a great burden involving emotional strain. There was an overall perception of a lack of organization regarding OD in the ICU and that identification of PODs did not take place due to the lack of structure and guidelines. Conclusions: The lack of organization, ambiguity and various perceptions of the BD diagnosis seem to be a crucial aspect when caring for a POD. These aspects are essential for the ICU nurse's possibility to fulfill their professional responsibility towards the deceased, next of kin, colleagues and organ recipients.

#103

DONOR RELATIVES AS ADVOCATES FOR ORGAN DONATION

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Introduction: At present nearly 70% of the Bavarian relatives of potential donors have to decide if an organ donation takes place in the acute bedside bereavement situation since the will of the deceased one has not been documented. The refusal rate is approximately 50%; main reasons are desintegration of the body or problems with the acceptance of brain death. Since 2005 in Bavaria we try to give special support to donor families since 2005. Part of this special support is our family care program from whom we gain the most trustable advocates for organ donation. Methods: 139 donor family members participated in our survey. We asked for their experiences in the acute situation and their appraisal of our supporting offers. Results: 62% of the donor relatives had the chance to talk directly to a co-ordinator of the German Organ Procurement Organization in the acute bedside bereavement situation. 92% of these experienced this support as helpful or very helpful. The majority (82%) would give their consent for organ donation again. 36% could even gain consolation from the given consent. By participating in our special daily event for donor relatives 93,9% experienced the event as optimal and 84,8% declared that their participation helps by dealing with their grief. Furthermore from these meetings we are able to identify potential advocates, who are willing to support organ donation in public. Conclusion: The strongest advocates in favour of organ donation are relatives of a deceased donor because they have no personal profit from their given consent and trust that the right decision was made. In order to gain such families empathic and honest care for donor relatives in the acute situation and afterwards is an important premise.

Free Communications 9: Public issues (2)

#130

TRANSPLANT CANDIDATE EDUCATION: WHAT THE PATIENT HEARD

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Introduction: Transplant candidate education requires detailed informed consent. Patient centered teaching promotes active self-care (medical adherence), and preparation for long-term medical challenges. Sensitivity to psychosocial challenges, and use of "talk-back" techniques are aids to learning, as are awareness of individual health care literacy and acquired bias. Author OSS, a transplant psychiatrist of close to four decades, reports on recent clinical observation of transplant candidate comprehension. Method: Referral bias related to medical stress, HCV infection, mood disorder, and psychosocial issues. Evaluations were semi-structured: up to 90 minutes. Greater than 50% of time focused on defining patient skills, knowledge of illness, understanding of kidney/liver function, awareness of risk/benefit of transplantation, and retention of pre-transplant teaching. Intervention focused on psychotherapy and counseling, and contextual medical teaching based on patient learning styles and gaps in transplantation literacy. Results: Independent of mood, cognition, education level, cultural origin and psychosocial issues liver transplant candidates understood the organ to be a filter. Renal failure patients could not explain lethality of hyperkalemia. Few could name more than one or two side effects of immune suppression. Asked about post-transplant medication patients cited "protection" of liver/kidney prevention of rejection; or rarely, "prevention of rejection and infection". Understanding of immunologic function was vague. Teaching included contextual historical reference (e.g. recognition of allograft rejection in Sir Peter Medawar's WWII study of burn treatment; transplantation and decades required for current levels of surgical success). Effective immune suppression equals importance of operative organ placement. Liver function was explained in context with MELD score components. Kidney function was discussed in the context of medical compliance requirements. Patients reacted very favorably. Conclusions: Comprehension improved with familiar narration.

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#112

THE REGULATION OF LIVING ORGAN DONATION IN THE UK; PROGRESS SINCE 2006 AND MEETING THE CHALLENGE OF SOCIAL MEDIA*Allan Marriott-Smith BSc, PGDip, MBA, Alan Clamp PhD, MBA, Victoria Marshment BA; Human Tissue Authority, London, United Kingdom*

Aims: To establish the impact the implementation of the Human Tissue Act 2004 had on living organ donation rates in the UK. To establish how provisions on non-directed altruistic and paired and pooled donation supported the introduction of sharing programmes. A discussion of the recent review of the regulatory framework to facilitate living donations between people with no pre-existing relationship, who have been brought together by a third party (e.g. a website which offers to match donors and recipients). **Methods:** A mixed methodology: review of data, a survey of living donor coordinators and clinicians, review of media coverage of social media sites which match donors and recipients. Consideration of the original framework for assessing living organ donations, which consisted of a cohort of Independent Assessors, based in each transplant unit in the UK, who voluntarily carried out interviews with donors and recipients on behalf of the HTA. Consideration of the new framework for assessing living organ donations (launched September 2012), which includes "enhanced" Independent Assessors who are specially trained to deal with complex cases and the introduction of a signed declaration on reward. **Results:** Under the original framework the number of living donation cases assessed by the HTA rose from 997 in 2007/8 to 1217 in 2011/12. The increase in non-directed altruistic cases was 9 to 39. Under the new framework the numbers of cases assessed by the HTA has broadly remained static, and the first cases of directed altruistic donation have been assessed. **Conclusions:** Increase in living organ donation since 2007. Largely sceptical response to social media becoming a tool to match donors and recipients, but with elements of support. How the experience in the UK can inform other countries.

#53

TRANSPLANT PROFESSIONALS' VIEWS ON THE ETHICAL CHALLENGES ASSOCIATED WITH ALTRUISTIC UNBALANCED PAIRED KIDNEY EXCHANGE*Céline Durand MA¹, Marie-Chantal Fortin MD, PhD^{1,2};**¹ Centre de recherches du CHUM, Montréal, Canada; ² Hôpital Notre-Dame, Montréal, Canada*

Background: Kidney transplant recipients (R) in the 0 blood group are at a disadvantage when it comes to kidney exchange programs (KEPs), because they can only receive organs from 0 donors (D) whereas 0 D are universal. A way to remedy this situation is

through altruistic unbalanced paired kidney exchange (AUPKE), in which a compatible pair consisting of an 0 blood group D and a non-0 R is invited to participate in a KEP. The aim of this study was to gather empirical data about transplant professionals' views on the ethical challenges associated with AUPKE. **Methods:** 19 transplant professionals working in 4 Canadian transplant programs took part in semi-structured interviews between 11/2011 and 05/2012. The content of these interviews was analyzed using the qualitative data analysis method described by Miles and Huberman. **Results:** An important ethical issue raised by transplant professionals concerned the providing of information on AUPKE. Some professionals felt the transplant team has a moral duty and responsibility to inform all compatible pairs about the possibility of participating in a KEP. However, they also mentioned the risk of influencing pairs in their decision and of causing those unwilling to participate to feel guilty. Another issue raised was the fact that the participation of compatible pairs is more beneficial to society and the KEP than it is to the pairs themselves. **Discussion:** Transplant professionals were concerned about informing compatible pairs about AUPKE. However, further studies are needed to determine who should provide what type of information. The respondents were also concerned about the lack of benefits for compatible pairs who participate in KEPs, given their show of altruism. This raises the question of how society and KEPs should recognize this generous act.

#156

CONSENSUS – A THREAT TO ACTIVE ENGAGEMENT*Anne Hambro Alnaes MD;**Institute of Community Medicine, Faculty of Medicine, Oslo University, Oslo, Norway*

In December 2011 a governmentally appointed commission drafted a new transplantation law intended to replace Norway's 1973-legislation. The following case study consists of coverage in mass media (2010-2012) supplemented by an analysis of comments in the Ministerial Hearing, together evidencing the degree of public engagement on organ donation in Norway. Deceased donations increased from 14 (2002) to 26 per million population (2012) although, for unknown reasons, the proportion of living kidney donation decreased noticeably. The law proposal intends to strengthen the presumed consent principle written into the 1973 Act. Justifying the reinforcement of this policy, recent years' figures show that over 80% consented to donate on behalf of their deceased – the routine doctors use at the requesting-meeting. In the new law, it will not be possible for families to revoke a deceased's wish to donate. When the deceased' opinion is un-documented and no family can be traced, the opting out principle is the default arrangement, a point causing dissent in the commission. Of the 121

organizations and institutions invited to evaluate the law proposal, 38 of 55 responses included comments. Little controversy ensued. Consensus on organ donation is, however, less convincing when we consider the non-responses from institutions representing the growing number of non-Western migrant minorities, exemplified by the silence from the Norwegian Islamic Council. Unofficial information from hospital doctors indicate that organ donation from members belonging to these migrant minorities is infrequent. The number of non-Western migrants is expected to increase three-fold by 2050 and thus constitutes an expanding proportion of Norway's hitherto homogenous population (5 million). The expected demographic change entails that the apparent present consensus about organ donation needs to be interpreted and that efforts to engage in dialogue with minority groups' religious leaders may usefully be increased.

#98

NUDGES FOR ORGAN DONATION. HOW DO THEY WORK?

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Objective: The current UK government favours 'nudge interventions' to prompt behavioural change in public health matters. Nudges are non-regulatory interventions designed to influence behaviour by modifying the context in which people make choices (Thaler and Sunstein 2008). Recently, in the UK a new Driving Licence scheme came into force based on 'nudge theory', making it compulsory to answer a question about organ donation when completing an online application. This paper aims to explore how nudges for organ donation work and whether they can increase organ donation rates. Methods: The literature was reviewed to explore in what basis nudges are contested in public policy both on theoretical and on their empirical basis. Those critical assessments were contrasted with the complexities of deceased organ donation for transplantation in the UK context. Of the critiques of nudges, three key concerns were interrogated: complexity, simplicity of human behaviour and the absence of inequality and welfare considerations. Result: Policy makers are seduced by nudges logic because they appear simple and effective ways to shape individual behaviour. Also they appear cheap because they do not require legislation. Nudge interventions do not approach the complexity of causality attributions in health and social systems. The role of emotions and affective attitudes attached to organ donation are not approached by them. When governments nudge individuals, they are implying that the responsibility for decisions and the consequences of those decisions lie with the individuals and not healthcare organisations. Conclusion: Nudging is directly addressed at the individual and therefore, it implicitly overlooks structural macro-structures that

embed health systems. This is also the case for organ donation. Emphasis on individual behaviour may detract from other concerns within the procurement process which are not dependent on individual altruism.

#22

A REGULATED MARKET FOR ORGANS FROM LIVING DONORS – EFFICIENT AND EQUITABLE? LESSONS LEARNED FROM IRAN

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Introduction: Deceased donation and living related and unrelated donation are the main legal sources of organ procurement, next to the global black organ market. There have been many proponents of a regulated compensated organ market from living unrelated donors to combat organ shortage and increasing mortality on the waiting list. Iran has been the first country to introduce such a program in 1988. Methodology: The paper aims to answer whether the Iranian model is successful in terms of efficiency and equity, at what social cost and whether it can/should be adopted by others. The study is based on existing literature regarding the Iranian program of paid donation. Results: The Iranian model achieved its target to eliminate the patient waiting list giving a fair chance to terminally ill recipients. The model is recipient-centered and displays major inefficiencies attracting mainly donors with a low socioeconomic status. It appears to have negative emotional, physical and economic consequences for the donors due to inefficiencies in selection, postoperative attendance and poor regulation regarding the amount and payment of the reward. Loopholes in regulation allow gaming of the system by Iranian and global citizens, and the model crowds-out altruism. The real social cost and trade-off in physical health and socioeconomic wellbeing between recipients' and donors' remains unclear. Conclusion: Though the model has been an attempt to protect recipients and donors from the negative consequences of a black organ market and maintain an altruistic character, it resembles the unregulated black market with some advantages compared to it. Proponents of a regulated organ market for living donors should consider the above aspects before introducing it. The transfer/adaptation of the model in other contexts and its role in a global environment are discussed.

Free Communications (10): Children as donors and recipients

#89

ORGAN AND TISSUE DONATION BY MINORS: WIDELY DIVERGING REGULATIONS IN EUROPE

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This presentation will examine the regulatory framework that governs the use of minors as living organ and tissue donors in Europe. I will first analyse the international legal instruments that specifically address organ and tissue procurement from minors. The primary focus will be on the Council of Europe's Convention on Human Rights and Biomedicine and its Additional Protocol on Transplantation of Organs and Tissues of Human Origin. In this respect, it is interesting to note that Article 14 of the Additional Protocol has recently been re-examined. In addition, the implementation of Directive 2004/23/EC and Directive 2010/53/EU (formerly 2010/45/EU) has prompted some EU Member States to revise their policy on living organ and tissue donation by minors. Subsequently, I will provide a survey of national regulations in the 27 EU Member States, complemented with Norway, Russia and Switzerland. This survey will reveal widely diverging viewpoints. Many of the countries under consideration have opted for an absolute prohibition of the procurement of regenerative and non-regenerative organs and regenerative tissue. A lot of other countries only allow removal of regenerative tissue under strict conditions. Finally, a few countries also allow procurement of regenerative and non-regenerative organs if, inter alia, an independent body is of the opinion that this would clearly be in the minor donor's overall best interests. Interestingly, in one country, procurement of regenerative organs is even allowed without such authorisation. The analysis of national regulations in 30 European countries will also reveal divergences with regard to the possible age limit imposed in countries that allow procurement from minors and with regard to the role the minors themselves have been attributed in the decision-making procedure.

#95

LIVING KIDNEY DONATION BY MINORS: AN ETHICAL ANALYSIS BASED ON A SYSTEMATIC REVIEW

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Background: Kidney transplantation is the optimal treatment option for many children suffering from end-stage kidney disease. Living kidney donation is an increasingly common strategy to prevent long-term pre-transplant dialysis, which is associated with an increased risk for severe comorbidity and an inferior quality of life. Although a donor age less than 18 years is generally considered as an absolute contra-indication to living kidney donation, the desirability of an absolute prohibition of living kidney donation by minors is subject to considerable scholarly debate. The aim of this research is to describe and evaluate the recommendations of guidelines, position papers and reports on living kidney donation by minors. Methods: We systematically searched the databases Medline, Embase, ISI Web of Knowledge, Google Scholar as well as the websites of various bioethics committees, transplant organizations and societies for guidelines that contained recommendations for or against living kidney donation by minors. We included 39 documents in the study. Results: Most guidelines endorse an absolute prohibition of living kidney donation by minors because of concerns on the decision-making capacity of minors, the impartiality of parental authorization, the best interests of the minor and the necessity of the donation. Some guidelines, however, would exceptionally allow living kidney donation by minors, provided that adequate safeguards are put in place, including an assessment of the minor's autonomy and maturity, authorization by an independent body, assuring that the anticipated psychosocial benefits outweigh the medical and psychosocial risks for the donor and the restriction to situations of last resort. Conclusions: The lack of consensus on the ability of competent minors to consent to living kidney donation indicates that more research on mature minors' decision-making capacity and autonomy in the context of living kidney donation may be desirable.

#27

CHILDREN AND TRANSPLANTATION: ETHICAL ISSUES IN PAEDIATRIC TRANSPLANTATION AND FAMILY CENTRED CARE

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Background: Two concepts are currently fundamental to paediatric bioethics (1) the framework of family-centred care and (2) the patient centred commitment to the best interests and rights of children. While these two concepts often work synergistically, family and patient interests sometimes differ, challenging health-care professionals with ethical tensions. Adding to this tension is the fact that health care consent laws are highly patient-centred. The conflict between family and patient-centred models is often present in clinical ethics consultation. This presentation will critically examine these ethical issues in the domain of paediatric organ transplantation. Objectives: 1) To explore the ethical issues in patient and family-centred care and the compatibility and sustainability of these models in paediatric organ transplantation. 2) To examine ethical issues in paediatric transplantation including: informed consent and the impact of family dynamics in the context of living organ donation, parents as living donors, and conflict in determining best interests of the child generally. We will also explore the conflict of interest that parent-donors face when giving consent on behalf of a child-recipient and have parental obligations to other dependent children. Conclusion: We will identify the ethical issues inherent in the tensions and synergies in patient and family-centred care in paediatric transplantation. We will provide a systematic analysis and framework for decision making of these ethical issues and propose good practices for clinical care.

#36

ORGAN DONATION – AN ISSUE IN NEONATOLOGY AS WELL? DATA AND FACTS FROM GERMANY

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Introduction: Organ transplantation often offers children with organ failure the only opportunity to survive. Although the number of pediatric recipients younger than 12 months of age on the waiting list is small, children within this age-group often die before an organ becomes available due to the limitation of size-matched organs. Neonatologists are often reluctant to ask parents about organ-donation, although it means consolation for parents. To estimate the potential of donors and the need of organs from that group we investigated the situation in Germany. Methods: We reviewed the DSO-data base for donors realized and recipients transplanted under 12 months in Germany from 2007 until 2011. We analyzed the number of donors, the causes of brain death and the number of organs transplanted. Results: We identified about 5 realized organ donors annually aged younger than 12 months. In total the 22 donors provided 62 grafts, mostly livers (23) and hearts (22) and kidneys (19). During that period one small intestine was procured, no lungs or pancreata. In the same period, 137 organs were transplanted into recipients under 12 months in Germany. Liver transplants dominated (105), followed by heart transplants (27) and kidney-transplants (5). According to the official death-statistic in Germany about 12-15 children under 1 year died with the diagnosis coded "brain edema" (2008-2010). Conclusion: Brain death on a neonatological ICU is a rare but realistic event. When focusing on the organs donated mostly to be sized-matched more organs were transplanted than donated in Germany (despite liver-splitting). Demand for such organs exceeds the supply provided within the country. Consequently organ donation on neonatological ICUs is a very important issue. In spite of the difficult setting there should be a clear commitment of the whole staff towards organ donation.

#29

ETHICAL REAPPRAISAL OF SHIFTING THERAPEUTIC GOALS IN PAEDIATRIC RENAL TRANSPLANTATION

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Since the beginnings, renal transplantation has been the best treatment for children and teenagers with renal failure. Dialytic therapy was viewed as a temporary bridge therapy. The therapeutic goals of transplantation were improvement of quality of life, optimization of growth, neurocognitive development and schooling, with ultimate objectives being normal vocational rehabilitation and social functioning. Organs were chosen to last as long as possible. Younger donors, mostly male with traumatic injury were preferred. In many jurisdictions younger donors are preferably allocated to younger patients (e.g. SHARE-35 policy of UNOS). Renal transplantation is not a small undertaking and has always been thought to be worthwhile mostly in children without major comorbidities except cognitive delay. For a few years now, paediatric patients with additional comorbidities are considered for renal transplantation. In our unit this number has risen from 5% to 20%. They are either cancer survivors, or they suffer from other diseases with significant and burdensome therapies, and their life expectancy is unknown. Transplant either from living or cadaveric donor is demanded by the parents and/or offered by medical teams (not always by the nephrology team). Transplantation is complicated by a larger number of impediments, increased hospitalisation time and follow-up visits, increasingly burdensome medical regimen, without real benefit of quality of life or lifespan. In these circumstances, is it right to ask for a living donor or to restrict the transplantation to organ from living donor? Or to ask transplant communities for the best organs available if the goal is more limited and the follow-up more uncertain than previously. This paradigmatic shift in the goal of therapy in pediatric renal transplantation has to be discussed as the number of children and teenagers with comorbidities and offered transplantation is rising.

#68

PAEDIATRIC LIVE SOLID ORGAN DONORS: A NO OR A YES?

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Introduction: Solid organ transplantation is the treatment of choice for a variety of diseases in children and adults. It is an enterprise based on the generosity

of the donor and relies upon trust that the system is fair, just and ethical. The availability of suitable organs from suitable donors remains the major limitation in transplantation. The potential role of children as living organ donors adds to the already complex ethical issues, making it highly controversial and thus repeatedly challenged. Aims: To address the key ethical, legal and practical issues relating to paediatric solid organ donation. Conclusions: The merits of paediatric donation are predominantly considered within the context of sibling donation where the tissue type match is of significant benefit to the recipient. In circumstances where the recipient is of a rare blood group or sensitised, and therefore less likely to receive a deceased donor kidney, paediatric living donation from a sibling is a potential option. This is even more so where there are no other living donors and where likely deterioration and/or death of the recipient would result in a significant detrimental effect on the child. In such cases the "best interests" argument is commonly referred to and has been used to set legal precedents. In spite of the potential benefits of paediatric living donation, minors who are being considered as such are extremely vulnerable and consequently the risk of harm is extremely high. Cases are likely to be psychosocially complex with complicated family dynamics and significant consequences in the event of making an erroneous decision. Paediatric live donation in general should not be a supported programme. As previous experience and available data is so limited, an international consensus is essential to assist in the management of such cases.

**EDTCO Workshop 4:
Autonomy at the end of life**

#30

ORGAN DONATION AFTER ACTIVE EUTHANASIA: MORALLY ACCEPTABLE?

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Since 2001, the Netherlands has been one of the few countries in the world where active euthanasia is not punishable under law, provided the physician meets several due care criteria. Approximately 3500 cases of euthanasia are reported each year, which is about 3% of all deaths. Lately, several patients have made requests to hospitals to donate their organs after euthanasia has been performed on them. They feel their organs should not be wasted and organ donation can give meaning to death. Some of these patients are unspecified living kidney donors. Most patients with a request for euthanasia suffer from malignancies that make organ donation medically impossible. However, medically good results of organ donation after euthanasia have

been shown in Belgian patients who suffered from MS or cerebrovascular accident. Although Dutch law allows for organ donation after euthanasia, no cases have yet been reported in the Netherlands. Only in Belgium is this combination of procedures incidentally done. Definition of problem: Organ donation after euthanasia raises several important ethical and practical questions. Is it morally acceptable to grant a patient's request for organ donation after euthanasia? Should the organ donation after euthanasia be a DCD or a DBD? Is the patient free to refuse euthanasia when they realize preparations for organ donation are going on? Should the possible recipients of the organs be notified before the euthanasia is performed? Can the organs be used in the center where the euthanasia is performed? Can the organs be allocated to people in countries where euthanasia is not allowed? Will the trust of people in physicians decline when this possibility is opened to people? Main conclusion will be that this combination of procedures is morally acceptable, provided several criteria are met. A proposal for these criteria is made.

#140

RETHINKING THE ROLE OF CONSENT IN RELATION TO POST MORTEM USE OF THE BODY FOR ORGAN TRANSPLANTATION

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The role of consent in relation to extraction of organs for transplant is much disputed. This is partly because the ends that consent is seen as serving are themselves disputed. A utilitarian, for example, will treat consent as a functional tool, to be protected to the extent that protecting it serves the common good. By contrast, a libertarian or dignitarian will treat it as one of the means of supporting respect for the individual. The latter vision is more consonant with European ideals of democracy and human rights and with the rhetoric of donation – a term which implies a real choice to give something up. However, whilst transplant law tends to refer both to donation and to consent one cannot escape the impression that it is prepared to sacrifice robust respect for these to the end of attempting to maximise use. No system within Europe precludes the use of a person's body for organ transplantation after death where they have not chosen this in life. In addition, the only systems interested in keeping records of 'objecters' are those who use the fact of a person not having a recorded objection as a basis for treating it as acceptable to use their organs. These problems are compounded by the fact that limited interest is shown in facilitating the living having a proper understanding of the implications of agreeing to donate – which extend in most jurisdictions to the possibility that one might be subject to organ preservation and/or other transplant facilitative interventions prior to and/or after death.

This paper will critically explore these problems and suggest an alternative approach more consonant with respect for the individual.

#46

A PRACTICE-BASED APPROACH TO UNRAVELLING THE CONTENT OF THE DONATION INTERVIEW: AN ETHNOGRAPHIC STUDY OF A TRANSPLANT COORDINATION TEAM'S PROCUREMENT PRACTICES IN A CATALAN HOSPITAL

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The European Union passed new regulation in 2010 in order to alleviate the organ shortage crisis. It was proposed that all member states should implement the 'Spanish model' of organ and tissue procurement due to its potential to increase donation and transplantation rates. There is a significant lack of literature on the articulation of such policies in practice, as well as on the key medical professional figure that oversees the totality of the donation process in the hospital: the transplant coordinator. This research aims to bridge this knowledge gap by presenting results from a current research project carried out with a team of transplant coordinators from a Catalan hospital. Ethnographic methodology was deployed to conduct a sociological analysis of the medical practices of organ and tissue procurement. In order to study the perspective of the transplant coordinators from within, observations of the practitioners' daily activities were paired with in-depth interviews with all the members of the team. Work in progress indicates that every donation interview is adapted to every particular case rather than being the application of a given protocol. However, there are a set of shared assumptions that underlie the transplant coordinators' discursive strategies during the moment of asking. Donation is offered as an end-of-life option to the potential donors' relatives; organs and tissue are considered as that which has become useless for someone and can be used to help someone else; both donation and transplantation are seen as a collective endeavour since anyone can become a donor or a recipient. Thus donation is presented as an act of common sense, a mutual responsibility to make possible the continuation of the practice of transplants.

Workshop 5: Public issues

#115

PUBLIC SOLICITATION OF ORGANS FROM LIVING DONORS – AN ELPAT VIEW

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The issue of public solicitation is amongst the most controversial in living organ donation. The objective of our paper is to critically assess the arguments concerning public solicitation and to offer recommendations. While the legal framework is not that different between the EU and US (both condemn financially-driven solicitation), the practices of both transplant centers and of individuals needing a transplant vary. The main difference can be observed between certain liberal practices in the US (where one can find commercially operated websites soliciting organs altruistically donated from living donors), and more conservative practices in the EU (where such websites are absent). This is an attempt to clarify the terminology concerning public solicitation, the different levels of public solicitation, and the motivations of recipients and donors. Firstly we elaborate an operational definition for public solicitation that is consistent with the ELPAT classification of living donors (Dor et al, Transplantation 2011). Secondly we evaluate the various arguments from the literature, both in favor of public solicitation and against it. Although they look contradictory, in most cases the same arguments are used both to defend the legitimacy of public solicitation and to condemn it. The arguments are classified according to the manner in which they ground the actions of recipients and/or donors, and regarding the influence on the donation/transplantation process at individual and societal level. Finally, we offer a set of recommendations. While we do not recommend it as a general practice, in our opinion, the acceptability of public solicitation by the patient or medical team could be explored for special cases that have been endorsed by national transplant organizations (e.g. highly sensitized individuals or other patients with little chance of receiving a transplant otherwise).

#81

WHEN PRISONER ORGAN DONATION BECOMES ETHICALLY JUSTIFIED

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Prisoners have generally been excluded from organ donation because of bioethical and infectious disease concerns. While these concerns hold true for developing transplantation systems, the ethical safeguards and knowledge that have come to exemplify modern transplant systems mitigate the validity of these arguments and suggest that ethically justified prisoner donation can occur. First, we deconstruct the topics of informed consent, coercion, and disease from which prisoner donation opponents argue. Next, we juxtapose developing versus mature transplant systems in order to elucidate the important differences between the two. Given these differences, we suggest modern transplantation can permit bioethical prisoner donation and we present a plan that appropriately considers the prisoner's circumstance. Lastly, we consider ethical paradigms beyond bioethics, which has come to dominate discussion on transplantation issues. Drawing from the human rights and public health ethics paradigms, we further the case for prisoner donation in mature transplant systems. Conclusion: The bioethical concerns inherent of prisoner organ donation are of paramount concern. However, discussion of prisoner organ donation has ignored the context in which donation takes place. Future policymaking should not only consider the ethical concerns of prisoner donation, but also the systems in which prisoners might become donors. Modern transplant systems allow for ethical prisoner organ donation. Furthermore, the failure of modern systems to pursue this venue not only results in the failure to secure prisoner rights, as suggested by human rights doctrine, but also the rights of the population as a whole.

#47

IMPROVING COMMUNICATION AND CONSENT FOR ORGAN DONATION: THE DEVELOPMENT & EVALUATION OF A HOSPITAL BASED INTERVENTION

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The quality of communication by hospital staff is known to have a major influence on bereaved families' satisfaction with end of life care and their consent to organ donation. It is hypothesised that the relatively low rates of consent among minority ethnic families in the UK (50% lower than for the general population) partly reflects both a lack of staff awareness about the diversity of end of life practices and expectations associated with an increasingly multi-cultural society in the

UK, and the lack of specific communication strategies to address these topics. This deficit of understanding and communication strategies may constrain interactions with minority ethnic families. We developed an intervention comprising a DVD and an accompanying training programme informed by a large programme of community and hospital based research (DonaTE Programme). The video is structured around five key dimensions: Emotional expression, Faith and cultural beliefs, Extended family, Language and communication & Anxieties about organ donation. Each dimension emphasises the fluidity of identities, particularly related to ethnicity and the heterogeneity of families, and is supported through 'talking heads' that include ICU doctors, nurses, hospital chaplains and patients reflecting on their experiences and offering strategies to best support families, specifically those from minority ethnic groups. We first describe the structure and content of the DVD and additional family drama as a case study illustrated with short video excerpts, and the intervention materials. We then consider the evaluation underway at 6 hospital sites: (a) before-and-after study using questionnaires based on the Theory of Planned Behaviour to assess outcomes for individual staff; and b) data identifying relative changes in consent/conversion rates for ethnic minority families at study hospitals compared with non-study hospitals. Issues of national dissemination are also discussed.

#149

A REGULATED WEBSITE FOR PATIENT STORIES AND ALTRUISTIC DONORS: AN ETHICAL WAY TO ACCEPT LIVING DONORS WHO HAVE BEEN SOLICITED THROUGH MEDIA ?

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The transplant community is united in its goal of increasing organ donation. Modern media (television, newspapers, Internet) allow information to be transmitted to massive audiences instantly, and many people use online sources as their primary mode of information gathering. Use of electronic media, including both dedicated and social media websites (e.g. Facebook or Twitter), is perceived by some as increasing recipients' chances of finding suitable living donors. Organ solicitation on websites has created moral and ethical discomfort among transplant professionals. Some have decried these websites as inherently unfair, the equivalent of a beauty contest, or worry that it opens the door to financial or emotional exploitation of desperate recipient candidates. Canada has no guidelines for transplant centers on how to deal with donor-recipient pairs who meet after public solicitation. We explore the ethical issues in public solicitations for organs and offer a proposal to address the problem. While these arguments are difficult to reconcile, we propose a way to accept a solicited organ donation between strangers.

We suggest that transplant societies promote an official, non-profit, multilingual website where patients listed for transplant could publish their need for an organ, free of charge. This website would enable oversight by a professional body to establish accurate information, specific domains of individual profiles and represent a platform where recipients and donors could publish their need and obtain information, without meeting. While donors and recipients could post to the website, any donors recruited would be asked to donate to the next eligible individual, according to existing official allocation rules (i.e. not necessarily those on the website). Patients coming from other websites should be refused by the transplant centers. This presentation will explore this suggestion and its challenges.

#25

ORGAN DONATION AS A CIVIC PRIVILEGE – DEFINING THE EXTENT OF SOCIETY'S EDUCATION OBLIGATIONS

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In many countries, young people are entitled to join the organ donor register on attaining their legal majority at the age of 18, just as they become eligible to vote. Choosing whether to become a (potential) organ donor is akin to exercising the right to vote in two important respects: (i) both activities confer substantial benefits to society and may benefit individuals personally; (ii) both respect and express the value of individual autonomy while recognizing the necessary role of individuals in sustaining vital public goods such as healthcare resources and democratic governance. To ensure that citizens are politically enfranchised, education about the political system and voting is a core element of many secondary school education programs. However, education about deceased donation is considerably less prevalent. In this paper, I argue that societies have a moral obligation to provide young people with sufficient education that they may make an informed decision whether to join the organ donor register when eligible to do so. I review some possible objections to this claim, such as the difficulty inherent in distinguishing between education and promotion of donation. I also discuss the potential implications for Australia, where mandatory voting might be taken to imply that mandated choice about donor registration would be ethically justifiable.

#41

FROM ORGAN DONATION TO TISSUE PROCUREMENT: PUBLIC PERCEPTIONS OF THE INTRODUCTION OF WHOLE CADAVER DONATION IN DENMARK

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Objective: Denmark is currently introducing whole cadaver donation so that additional procurement teams will harvest tissue following the removal of organs. The new system is introduced within the remits of the existing organ registry, but no existing studies have explored how the Danish public perceives of the difference between organ and tissue removal and very limited international evidence exists to guide policymakers on how to communicate the planned changes to donor families and/or the wider public. This study was conducted to investigate what members of the Danish public thought about the planned shift. Methods: We interviewed 23 members of the general public. They were selected to represent different ages, gender, ethnic groups, religious orientation, and status in relation to the registry. Participants were interviewed individually to acquire in-depth understanding of their moral reasoning and values. Results: A central value for the donation of cadaveric material is that it may be used to save lives, and the uses of tissue were generally rated as less important than organs because they were seen as less likely to save lives. On the other hand, most respondents thought that if more material, which would be of use for others, could be procured then not taking it was similar to wasting it. Waste was seen as morally problematic. Only in few instances would use value of bodily material be seen as degrading the moral status of the donor. It was central for respondents, however, that planned uses of procured material were aimed at medical interventions and not influenced by monetary incentives. Conclusion: Central elements of the moral reasoning in the public have been indentified and can now be investigated further with quantitative methods.

#90

THE EFFECT OF THE IMPLEMENTATION OF DIRECTIVE 2010/53/EU ON THE REGULATION OF LIVING DONATION IN EU MEMBER STATES

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In 2010, the European Commission adopted Directive 2010/53/EU (formerly 2010/45/EU) on standards of quality and safety of human organs intended for transplantation. The Directive aims at increasing organ availability, enhancing the efficiency of transplantation systems and improving the quality and safety of organs. The Directive has specific relevance for living donation, since one of its aims is to promote living donation in a manner that guarantees the highest possible protection of living donors and does not jeopardise the public's trust in the healthcare community. This presentation will first give an overview of the provisions of the Directive that bear directly on living donation, including requirements concerning consent, voluntary and unpaid donation, confidentiality of data, anonymity, compensation for expenses and loss of income, training of healthcare professionals, reporting of serious adverse reactions, and registration and follow-up of living donors. In addition, this presentation will discuss the different ways this Directive has been implemented in the 27 EU member states. Interestingly, the obligation to transpose the Directive has urged two countries to adopt, for the first time, specific legislation on living donation. Most other countries have chosen to amend their existing legislation by introducing the general requirements prescribed by the Directive, without making changes to their core provisions on living donation. By contrast, some other countries have taken the opportunity to also modify some of their core provisions, including those relating to the modalities of consent, the information to be given to potential donors and the categories of acceptable donors and recipients. This presentation will conclude by highlighting the most striking of these changes and by indicating the reasons why they have been implemented in the light of the transposition of the EU Directive.

Workshop 6: Children as donors and recipients

#142

LONG-TERM OUTCOMES OF LIVING KIDNEY DONORS <18: A MATCHED COHORT ANALYSIS

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Living donor (LD) kidney transplants are rarely performed using donors < 18 years of age, and there is no data on how such donors fare relative to older LDs. Methods: Between 1963-2008, 3698 LD transplants were done at our institution. LDs were asked to provide updates on health status, urinalysis, and serum creatinine testing. 39 LDs, donating between 1967-1996, were < 18 (mean, 17.1 ± 0.7 yrs; range, 15.5-17.9 yrs) (all related to recipients – 12 children, 25 siblings, 2 identical twins, 1 cousin); 60% were male. Donors < 18 were matched 1:2 with older donors based on year of donation, gender, relation to donor, BMI at transplant and eGFR at donation. One donor was matched 1:1 and two could not be matched due to missing weight. For controls, mean age at donation was 30.8 ± 9.6 yrs. Results: For donors < 18, mean f/u was 31.6 ± 8.2 yrs; age at last f/u was 48.7 ± 8.2 yrs. At last f/u, 95% were still alive, 37.5% were hypertensive, and 5% diabetic. Reassuringly, at last f/u, no donor < 18 had eGFR < 45 ml/min/1.73m², and 27.5% had eGFR < 60 ml/min/1.73m²; vs. 11.3% and 48.1% in matched controls. Donors < 18 were not more likely to develop hypertension or diabetes. Odds ratio (95% CI), for < 18 vs. controls was: for survival at f/u, 4.28 (0.90, 20.30) ($p = 0.067$); for current MDRD < 60 ml/min/1.73m², 0.36 (0.14, 0.93) ($p = 0.035$); for being hypertensive at f/u, 0.42 (0.17, 1.05) ($p = 0.064$); for being diabetic at f/u, 0.34 (0.07, 1.59) ($p = 0.171$). Conclusions: To date, donors < 18 (vs. matched older donors) have had no increased risk of becoming hypertensive or diabetic later in life; there has also been a significantly lower risk of developing an estimated GFR < 60 ml/min/1.73m².

#64

SHOULD MINORS BE CONSIDERED AS POTENTIAL LIVING LIVER DONORS?

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For many patients, living donor liver transplantation represents their only hope of receiving a life-saving graft. In certain (albeit rare) cases, a minor will be the only suitable donor. Living liver donation by minors has been reported in several countries. In the available

academic literature and professional guidelines, little attention is paid to the development of an ethical framework for this practice. The focus is frequently limited to donation of regenerative tissues and kidneys. However, liver donation differs in important respects due to the increased medical risks and the lack of substitute therapies. Therefore, in this paper, we assess whether living liver donation by minors is ethically appropriate and, if so, what constitutes the boundary of legitimate practice. A clear distinction should be made between competent and incompetent minors. We argue that the use of incompetent minors as living liver donors ought to be uniformly rejected given the high level of medical risk which cannot possibly be outbalanced by any psychological benefits. In order for a minor to be able to make the challenging decision of living liver donation, the acquisition of higher-order cognitive capacities is needed. Since these have traditionally been associated with adolescence, we propose a blanket prohibition on living liver donation for minors who have not reached the age of 15. For 15-18-year-olds, an independent body should assess whether the adolescent is indeed mature enough and, if so, also sufficiently unconstrained to come to a well-considered decision.

#58

WHO SHALL LIVE – SHOULD CHILDREN WITH DEVELOPMENTAL DISABILITIES BE ORGAN TRANSPLANT CANDIDATES?

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Children with end stage organ failure must undergo a complicated evaluation process in order to be considered organ transplant “candidates”. Contraindications to transplant include conditions which would make transplantation technically unfeasible (i.e. Small patient size) or those which would be worsened by the medications required post-transplant (eg. Untreated tuberculosis). Psychosocial factors are also considered, including the ability of the child and family to cope with the rigors of post-transplant care and to adhere to the medical plan. This presentation will deal with whether developmental delay should be included in this list of absolute and relative contraindications to transplantation. Since transplants are a scarce resource, some have argued that there are allocation concerns that must be addressed. They argue that developmental delay should be a listing criteria, since these patients may receive transplants that could otherwise go to individuals with a greater potential to benefit from the transplant and to contribute to society. Others take the opposite view, stating that any consideration of the patient’s developmental status is illegal and immoral, even in cases of extreme disability. We will argue that allocation of scarce resources should generally avoid social worth criteria, but that completely ignoring the patient’s neurologic status is likewise inappropriate.

We will advocate a shared decision making model that focuses on the benefits and burdens of transplantation for any particular child, recognizing that both benefits and burdens can be affected by a child's neurological process. I will use medical literature (including empiric evidence on outcomes in these children) statements from professional societies and philosophical arguments on morally relevant allocation criteria to bolster this argument.

#51

DO BEREAVED PARENTS OF ORGAN DONORS WANT TO KNOW ABOUT OR MEET WITH THE RECIPIENTS? THE RELATIONSHIP BETWEEN PARENTS' WILLINGNESS AND "MEANING OF LIFE" MEASURES

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Background: Meetings between families of organ donors and recipients are possible in Israel depending on the wishes of both parties. The connection is made by approaching either the local transplant coordinator or Israeli National Transplant. Objective: To examine the desire of parents who have lost their children and who have donated either organs or tissues to meet the recipients. In addition we examined the correlation between the degree of willingness to meet the recipients and the degree of meaning of life after the loss amongst bereaved parents. Methods: We interviewed 146 bereaved parents who had given consent for donation of organs or tissues from their deceased children. We used 3 tools which were constructed especially for this research: extended demographics, the meaning of life after loss and the meaning of organ donation. Findings: The age of the participants ranged from 31 to 83 years. The period after the loss ranged from 1 to 27 years. Nearly two-thirds of the parents were interested in meeting with the recipients: 35% had already done so, 23.9% were interested in meeting them but had not yet done so, 23.9% requested only to know the outcome of the transplant, 12.3% were not at all interested in meeting with the recipients and 4.4% did not answer. The correlation between these findings and the significance of the organ donation and the meaning of life after the loss, as well as the time which passed after the loss will be presented at the congress. Conclusions: Medical teams should be ready to enable donor families to meet the recipients if this is requested, even months and years after the loss.

Free Communications (11): Cultural and religious aspects of living and deceased donation (2)

#126

MAXIMIZING "O"PPORTUNITIES FOR LIVING KIDNEY DONATION

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Transplant programs have duties to ensure responsible stewardship of organs and to maximize patient benefits. Compatible, non-identical blood group living donor pairs with group O donors can increase kidney transplantation for O recipients by participating in Altruistic Unbalanced Paired Kidney Exchange (AUPKE). AUPKE matches recipients of incompatible donor-recipient pairs (e.g. group B donors with O recipients) with donors of compatible, non-identical pairs (e.g. group O donors with B recipients), enabling additional ABO compatible transplants. While most living donors give directly to their intended recipients, some compatible pairs may wish to participate in AUPKE to help others. However, many programmes do not routinely discuss AUPKE in the informed consent process, resulting in missed opportunities to increase the number of kidney transplants. This presentation will evaluate ethical arguments for and against routinely informing compatible donor-recipient pairs about AUPKE. Proponents claim that AUPKE: (1) promotes equity by creating transplant opportunities for disadvantaged recipients, (2) may result in compatible pair recipients receiving higher quality grafts or grafts that are more closely age matched, (3) may elicit positive emotions in donors from the knowledge that they have improved the lives of additional recipients, and (4) shortens the kidney transplant waiting list. Critics oppose AUPKE on several grounds: (1) compatible pair recipients may receive grafts of poorer quality than those from their intended donors, (2) AUPKE devalues the emotional bond between donors and intended recipients, and (3) compatible pairs could be coerced to participate. We conclude that the objections to AUPKE are surmountable. AUPKE coheres with accepted ethical principles including beneficence, respect for autonomy, justice, non-maleficence and fidelity. The duty to maximize transplantation within ethical and legal boundaries supports offering AUPKE to compatible pairs, providing that participation is voluntary and patient care is not compromised by non-participation.

#108

THE INFLUENCE OF ETHNICITY, SOCIOECONOMIC FACTORS AND DONOR TYPE ON THE OUTCOME OF KIDNEY TRANSPLANTATION

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Background: In our previous study we showed that an accumulation of unfavourable clinical and socioeconomic factors reduces the access to living donor kidney transplantation. In the present study we analyzed the influence of these factors on long term graft survival after kidney transplantation. **Methods:** This retrospective study included all 1,338 patients who received a kidney transplant between 2000 and 2011 in our center. Both clinical and socioeconomic variables were studied. Clinical variables were: recipient age, gender, and ethnicity, original disease, maximum and current PRA, ABO blood type, previous transplants, pre-treatment, time on dialysis, comorbidity, transplant year, HLA mismatches, donor age and gender, delayed graft function, six variables representing immunosuppressive therapy, and donor type (living or deceased). Each recipient's postal code was linked to a postal code area information database, to extract socioeconomic information on: housing value, income, percentage non-Europeans in the area, and urbanization level. Chi square, ANOVA and univariate and multivariate Cox Proportional Hazards analyses were performed. **Results:** Recipients of deceased and living donor kidney transplants differed from each other with respect to most variables studied. In multivariate analysis graft survival censored for death was significantly influenced by recipient age, current PRA, time on dialysis, donor age, delayed graft function, CNI treatment, and donor type. Socioeconomic factors and ethnicity did not have a significant influence on survival. **Conclusion:** Though the access to living donor kidney transplantation is influenced by ethnicity and socioeconomic factors, these factors do not influence the prognosis once transplantation has been performed. Nevertheless, since deceased donor type is an important negative factor for graft survival, patients with unfavorable socioeconomic characteristics are disadvantaged.

#21

THE PERCEPTION OF ORGAN DONATION BY PHYSICIANS

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Organ and human tissue donation in Morocco falls short of needs. This is due in part to the refusal of families but also to a lack of awareness. We conducted

a survey of a representative sample of medical interns and residents to assess their knowledge and attitudes to organ donation and their training needs. This is a cross-sectional study of medical interns and residents, an anonymous questionnaire containing questions assessing the knowledge, opinions, attitudes and needs organ donation was given to doctors. Among 130 distributed questionnaires we collected 115 completely answered surveys. Gender distribution was 70 females/45 males, 87 residents and 28 interns, 80% were aged 25 to 34 years, 60% practice their profession of 1 to 5 years, 28% don't know that the organ removal of dead is made in Morocco. 74% know the structures authorized to organ removal. Only 6% are aware of the organs and tissues that can be taken. 76% know the definition of brain death. 88% were in favour of the removal of organs and tissue of deceased persons. 35% don't believe that brain death is the death of the individual. 10% don't know that Islam allows organ donation from a living and a cadaveric donor. 98% believe that organ donation saves lives, 62% will give their organs and tissues after death. 25% refuse organ donation of a parent and 30% refuse it of their children after death. 40% think that the hospital coordinating must act after the expression by the family of the deceased's wishes. 91% would receive training in this area. Our findings show that there is a discordance between knowledge and attitudes of doctors towards organ donation. A medical, psychological and sociological study is needed to better understand the obstacles to organ donation and to target the necessary training.

#121

CULTURAL AND RELIGIOUS ASPECTS OF LIVING AND DECEASED DONATION IN THE OPINION OF THE VARIOUS RELIGIOUS, CHURCHES AND SECTS MEMBERS – CURRENT CLINICAL PROBLEMS AND POSITIVE CHANGES

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Introduction: Religion, subjective morality and the social community membership are the common factors in many cases straightly determining the final decision concerning to the acceptance or non-acceptance of living or deceased organ donation. Nowadays there are still many clinical problems arising from specific, closely-established and respected opinions and beliefs of some religious, cultural and ethnic groups. In recent years in some communities it has been also observed quite a big change in the perception of modern transplantation and organ donation. **Aim:** The aim of

our work was to present current clinical problems and positive changes in the opinion of the various religious, churches and sects members according to the cultural and religious aspects of living and deceased donation. Material and Methods: In the study, we have selectively analyzed a group of scientific publications selected from international medical and the religious literature published after 1980. As search tools, we have used popular scientific bibliographic database, such as Medline, EBSCO, Springer, Ovid, google scholar and main web-sites and journals of selected various religions, churches and sects. Results and Conclusion: In recent years it has been noted in a few cases a soft mitigation of views regarding the perception of modern transplantation and living or deceased donation, but still many of these changes are ambiguous and vague. There are still many religious and specific communities (included some sects members) that totally reject the possibility of different types of organs, tissues and cells donations in purpose of transplantation.

#154

ATTITUDES TOWARDS LIVING ORGAN DONATION IN TWO ROMANIAN UNIVERSITIES

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••• of organs for transplantation was living organ donation (LOD). There is still a cautious approach concerning the acceptance of a living donor, in order to avoid organ trafficking and manipulation of vulnerable population. Aim of our study was to investigate ethical questions related to LOD as viewed by socio-humanistic and medical students in universities from Cluj-Napoca and Tirgu Mures. Material and method: we interviewed a number of 292 students by asking them to complete a 19-items multiple choice questionnaire. Statistical evaluation of the results included descriptive parameters, single variable frequency and multivariate frequency distribution analysis with the significance level of Chi-square test of 0.05. Results: from the total of 292 students, 135 attended medical while 157 socio-humanistic specializations, with M:F rate 3:1 and mean age 21 years. While over 90% of the respondents agreed to donate an organ to an emotionally related person, only 25% potentially accepted unspecified donation, with significantly higher proportion in medical students ($p < 0.05$). Socio-humanistic students considered organ solicitation via internet and advertisement ethically and morally acceptable in a smaller proportion than medical students (23% vs. 36%) but they did not encourage penal prosecution for organ trafficking as much as their medical colleagues (34% vs. 44%). Almost 50% of both groups would accept the Iranian model of compensations. Conclusions: the ethical and moral views of the young students concerning LOD are important in developing adequate educational strategies on a highly emotional and con-

troversial ethical theme. Medical, moral and communication elements must be combined in order to improve students' knowledge. Acknowledgement: Harald Jung acknowledges financing by the SOP HRD from European Social Fund and Romanian Government under contract POSDRU 60782.

#02

ANALYSIS OF KIDNEY DONATION POTENCY IN THE PILOTE COMMUNITIES IN HOCHIMINH CITY

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Objectives: to explore the knowledge, attitude, and behavior about kidney donation after death and the factors associated with the decision to donate among the selective populations in HoChiMinh city. Subjects and method: interviewing of 1,068 people from 18 years old by questionnaire, the interviewees filled in themselves. Main results: 77% and 63.8% agreed to donate their own kidney and the kidney of their relatives respectively after death. 5-36% had incorrect knowledge. 21% had negative attitude towards donation. The factors associated with donation comprised of profession, economic status, good knowledge about organ shortage and brain death, positive attitude especially the conversation within the family. The main reason of refusal was the family constraint. The main requirement when a person donates was the equality of organ using. Conclusion: Most people agreed with donation at HCM city. We need education campaigns to ameliorate the public point of view. The education must be the background for the development of transplantation in our country.

Free Communications 12: Psychosocial care for recipients (1)

#16

PSYCHOSOCIAL NEEDS ASSESSMENT POST-KIDNEY TRANSPLANT: FEASIBILITY OF A POST-TRANSPLANT SPECIFIC SUPPORT GROUP

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Lifestyle changes accompanied with transplantation may have implications for medication adherence over time. The use of social support groups has correlated with increased medical adherence in patients with chronic conditions. The objective of this study was to conduct a psychosocial needs assessment of post-

transplant patients, to determine the utility of a support group, and identify barriers to attending one in an urban hospital centre. A Likert scale was used to assess the degree of patients' concern about specific psychosocial needs. Questions were grouped into "domains of transplantation" which addressed: medical complications of transplantation, return to normalcy, financial costs of transplant and social support post-transplant among others. Patient information regarding time since transplantation was used to stratify the results. Patients who were > 2 years post-transplant were significantly more concerned about medical complications than patients in the other time groups (χ^2 [4, n = 42] = 22.05, $p < .001$), returning to normalcy (χ^2 [4, n = 28] = 10.21, $p < .04$) and had a greater desire to talk with other transplant patients (χ^2 [4, n = 28] = 12.08, $p < .02$). Patients who were 3-6 months post-transplant were significantly less concerned about complications following transplant (χ^2 [4, n = 42] = 22.04, $p < .001$). Patients indicated their unwillingness to attend a social support group due to transportation barriers. The main area of concern for patients was the medical complications of transplant, particularly for patients who had their graft for greater than two years. Stemming from the results observed regarding the patients' unwillingness to attend a support group on site on a regular basis, alternative support methods were discussed.

#119

POST-TRANSPLANTATION LIVES: AN ETHNOGRAPHIC ACCOUNT

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According to public images and media stories, organ transplantation allows persons with serious, often life-threatening illness not only to live on but to live 'normal again'. Yet, organ transplantation does not cure. What it offers is a particular version of health: a health, which is based on a life-long dependence on medicaments and medicine. How is normality after organ transplantation produced and maintained then in everyday life? My doctoral thesis takes transplantation medicine's promise of a 'return to normality' as a starting point: Taking liver transplantation as an example, the production and specific conditions of post-transplantation life are scrutinized. The ethnographic study is based on participant observations in one of the bigger German liver transplant centers, in a rehabilitation clinic and in the homes of liver-transplanted persons during 2007 and 2010. In addition, qualitative interviews have been conducted. The proposed paper will present some of the central findings of the study. Special attention will be given to the entanglements of recipients' everyday lives with the clinic: Their return to individual and societal normality is not without difficulty but the result of manifold efforts – by medical staff, organ recipients and their families. In terms of

health and social roles transplanted persons remain on the margins of the medically and socially defined 'normal'. The study shows how this situation or rather the everyday prominence of clinic and therapy regimen is nevertheless made into a life characterized through 'normality'.

#86

PANCREATIC TRANSPLANTATION IN PATIENTS WITH T1DM: A SOURCE OF TRAUMATIC STRESS?

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Introduction: Prior to 2004, very few pancreas transplants were performed in the UK, with only University of Minnesota performing significant numbers worldwide. Psychological research suggests that a considerable number of patients require psychosocial support. However, the specific issues faced by patients requiring psychological intervention remain unclear. This study was undertaken to try to better optimize psychological support for patients post pancreatic transplantation. Methods: 20 individuals with T1DM were interviewed (10 male; 5 pre-transplant, 15 post-transplant). Semi-structured interviews were digitally recorded, transcribed verbatim and analysed independently by 2 researchers using inductive thematic analysis. Results: A variety of themes were identified some of which were related to the experience of traumatic stress. Transformation was a major theme associated with many subthemes, for example, new beginning described how the transplant enabled a fresh start; while different persons described how the transformation following transplantation was comprehensive. This latter theme included references to disturbing changes in personality and emotional sensitivity as well as significant periods of insomnia and changes in energy levels. The major theme of Adjustment described the complexity of life post-transplant. Powerful memories, one of the many subthemes of adjustment, included participants incredibly detailed memories of the morphine dreams and hallucinations they experienced in hospital as well as the strong feelings associated with their memories of uncontrolled, unpredictable hypos prior to transplantation. Conclusions: The change following transplant is instant and dramatic for most patients, but it does involve negotiating complex changes in identity as well as adjustment in every aspect of life. Emotional sensitivity, problems sleeping, hyperarousal and flashbacks are symptoms associated with traumatic stress. These data suggest that this patient group may require psychological support to assess and address potential traumatic stress associated with T1DM and transplantation.

#34

COMPLIANCE TO TREATMENT AND FAMILY SUPPORT IN KIDNEY-PANCREAS TRANSPLANTATION RECIPIENTS

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Introduction: A history of inadequate compliance to treatment is observed during evaluation prior to kidney-pancreas transplantation. Compliance after transplantation is of the utmost importance. Family support usually plays a beneficial role. **Objectives:** To investigate compliance to treatment prior to transplantation, on the waiting list and following transplantation, as well as differences with blind patients, care providers' commitment and quality of care provided. **Patients and Methods:** 107 recipients (54 M/53F); mean age: 34 years; 23 blind recipients) were transplanted between 1995 and 2011. Data were obtained from psychological interviews, medical histories and follow-up records. Compliance and quality of care were classified as bad (B), fair (F), good (G) and very good (VG). **Results:** By 2012, 91 patients (86%) were alive (patient, pancreas and kidney survival rates at one year were 91%, 85% and 88%, respectively; and 87%, 76% and 79% at 5 years, respectively); mean follow-up was 63.2 months and mean dialysis time before transplantation was 46 months. 64% patients were single, 57% had secondary education, 62% of them were unemployed/retired. Compliance was as follows: before transplantation: B: 31%, F: 21%, G: 38% and VG: 10%; on the waiting list: F: 21%, G: 27%, and VG: 52%; after transplantation: B: 1%, F: 7%, G: 17% and VG: 75%. Among blind people: before transplantation: B: 22%, F: 35% and G: 43%, on the waiting list: F: 5%, G: 30%, and VG: 65%; after transplantation: G: 13% and VG: 87%. Before transplantation, 78% of patients were self-reliant. Following transplantation, the care providers were as follows: mother: 51% (G/VG quality: 79%, B/F: 21%) and other relatives: 49% (G/VG quality: 55%; B/F: 45%). Thirteen patients (12%) required family care both before and after transplantation (mother: 77%, spouse: 23%; VG quality: 100%). **Conclusions:** Compliance to treatment, even when it ranges from bad to fair in candidates for kidney-pancreas transplantation, improves while on the waiting list and increases following transplantation, both in blind and non-blind patients. When family care is required, the mother is considered to provide it with more quality and frequency.

#72

THE PERCEIVED THREAT OF THE RISK OF GRAFT REJECTION

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Background: When Organ Transplant Recipients (OTRs) are asked about what they fear the most, the most common answer is graft rejection. Graft rejection is a real threat against an OTR since it is the body's natural way, through its immunological defence, to protect itself against foreign bodies or unknown substances. **Aim:** To investigate perceptions of graft rejection and to develop and test a valid and reliable instrument that measures the perceived threat of the risk of graft rejection. **Methods:** Data collection included interviews and questionnaires. In the interview study sixteen patients, kidney-, liver-, heart-, or lung transplanted, six males and ten females, aged between 21-63 years, with a follow-up time of between three months and ten years, participated. The questionnaire study included 185 OTRs between the age 19-65 years, transplanted with a kidney, a liver or a heart and/or a lung and follow-up time of one year \pm three months and three years \pm three months. The instruments used were SF-36 and the Perceived Threat of Graft Rejection (PTGR) which was developed for the purpose. Data analysis was performed by the use of phenomenography and by descriptive and parametric statistical methods. **Results:** OTRs perceived graft rejection in various ways involving five domains; abstract threat to life, concrete threat to health, trust in the body, striving to control the threat and one's identity. It was possible to develop an instrument for measuring the perceived threat of the risk of graft rejection by three homogeneous and psychometrically sound factors. These were labeled intrusive anxiety, graft related threat and lack of control. Perceptions seem to be independent of demographic and clinical variables such as type of organ transplanted, time since transplantation and experiences of graft rejection, age and sex.

#74

PREDICTING BARRIERS TO ADHERENCE TO THERAPY AFTER HEART TRANSPLANTATION – PRELIMINARY RESULTS OF A PROSPECTIVE LONGITUDINAL STUDY

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Objective: Only few studies have focused on the interaction between psychological variables and lack of adherence in patients after heart transplantation

(HTx). Aim of the current study was to identify possible psychological predictors of post HTx barriers to adherence at a pre-transplant stage. Methods: Patients listed for HTx were evaluated before HTx (= pre HTx) every three months (t0a, t0b and so on), immediately after HTx (t1) and six months thereafter (t2). Adherence pre HTx was measured by the Transplant Evaluation Rating Scale (TERS) and a structured interview. Depression, anxiety, and QoL in patients were assessed by the PHQ-D, HADS-D and SF-36. Adherence post HTx was assessed using the Medication Experience Scale for Immunosuppressants (MESI). Results: N = 33 patients have been evaluated regarding t0a, ten patients have been transplanted. One patient died after transplantation, another patient was lost to follow-up. There is a high correlation between TERS (t0a) and depression (.64), and TERS (t0a) and MESI ($r = 0,876$, $p = 0,004$). Conclusion: These results indicate that TERS pre HTx is a powerful predictor of post HTx adherence measured by the MESI. There is need for further longitudinal data which will allow to identify additional predictive variables for non-adherence post HTx and to determine adequate screening-instruments to identify risk patients. Furthermore, this will allow to design tailored early-stage perioperative psychosomatic interventions for patients. Keywords: adherence, TERS, MESI, HTx, heart transplantation

Free Communications 13: Psychosocial care for recipients

#147

THE RELATIONSHIPS AMONG MEDICAL DATA, PSYCHOLOGICAL FACTORS AND SOCIO-DEMOGRAPHICAL VARIABLES IN KIDNEY TRANSPLANT RECIPIENTS

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Background: Health is defined by the WHO as the complete feeling of well-being, thus improving quality of life is a desired outcome of medical service provision and a concern when considering holistic health for people with kidney diseases. Objectives: To prove the importance of holistic health in kidney transplant recipients; they are also considered bio-psycho-social subjects and therefore we examined the connection between clinical parameters, psychological factors and some selected socio-demographic data. Methods: Data was collected from 234 KT patients (61% male, mean age 48.8 years, 39% female, m.a. 51.9 years) at the University of Debrecen Transplant Center using the following instruments: 1. Medical data: renal function as urea, creatinine, GFR, hemoglobin, hypertension, and serum protein levels. 2. The Hungarian version of the KDQOL-SF, Social Support Survey, IPQ-R, GHQ-

12, BDI, CES-D-10, IIRS. 3. Demographic variables (e.g. age, gender, income, education, other chronic illnesses). Results: We found that GFR has the strongest connection with psychological factors ($p < 0.01$) but creatinine levels and urea levels also significantly correlated with patients' rating of subjective well-being, illness intrusiveness, depression, social support as well as cognitive and emotional representations of illness. We cannot confirm the previous finding that female patients are reporting worse QoL than male patients, even though females reported fewer physical symptoms connected with their kidney disease. However, we did find support for the previous conclusion that reported QoL increases with higher education and club membership. Conclusions: The results of this study provide useful information about the psychological background of kidney transplant patients which has so far received relatively little attention but can help clinicians provide more appropriate interventions that may impact self-care. It can also give important clues for further research on clinical health psychology in supporting the healing process.

#01

PSYCHOSOCIAL EVALUATION OF CANDIDATES FOR LIVER TRANSPLANTATION PREDICTS POST TRANSPLANTATION OUTCOME

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PhD, Keren Balut PhD, Hadar Merhav MD, Rifaat

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Background & Objective: Psychological and social support is a major component in the recovery process following liver transplantation (LT). The pre-transplant psychosocial evaluation may serve as a tool for predicting the patient's prognosis. The aim of the present study was to determine the correlation between the pre-LT psychosocial evaluation and post-transplant outcome; morbidity and mortality. Methods: In this retrospective study, 93/100 patients (93%) underwent LT at Hadassah Hebrew University Medical Center between 2000-2012 and pre-LT psychosocial evaluation. Insight, support system and compliance were evaluated by professional psychologists and social workers. Each parameter was scored on a 1 (optimal), 2 (sub-optimal) and 3 (non-optimal) scale. Total score for each patient was the sum of the three parameters. Patients were analyzed according to optimal (total score of 3, 80% of cases) and non-optimal (total score > 3) study groups. Post-transplant outcome was compared between groups, focusing on survival, biopsy proven rejection episodes and complications. Results: Post-transplant follow-up period was (5 ± 3.3 vs. 4.3 ± 2.9 years, $p = 0.179$) Survival rate was significantly higher ($p = 0.001$) in the optimal group; 85.3% vs. 56%. Incidence of infection episodes (35.3% vs. 52%, $p = 0.07$) and renal complications (19.1% vs. 40%, $p = 0.02$) were lower in the optimal group, while occurrence of

other complications (rejection episodes, biliary complications, hyperkalemia, diabetes and reoccurrence of underlying disease) were similar. There was no significant difference in the following parameters: mean age (50.3 ± 14.4 vs. 51.5 ± 10.1), gender (Males 67.7 vs. 56%), MELD (21.9 ± 4.9 vs. 21.4 ± 6.6), Prograf based regimen (41.2 vs. 44%) and etiologic distribution, between groups. Conclusions: Our experience while following the patients, indicates that optimal pre-LT psychosocial assessment predicts better long term outcome regarding survival, renal complications and infection episodes.

#15

COPING IN RELATION TO PERCEIVED THREAT OF THE RISK FOR GRAFT REJECTION AND HEALTH RELATED QUALITY OF LIFE AMONG ORGAN TRANSPLANT RECIPIENTS

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Background: Organ transplant recipients (OTRs) perceive graft rejection as a stress factor and a threat. Objective: The primary aim of the present study was to examine types of coping used to handle the threat of the risk for graft rejection among OTRs, and to investigate relations between coping and perceived threat as well as Health Related Quality of Life (HRQoL). A second aim was to test the General Coping Questionnaire (GCQ) for reliability in relation to the threat of the risk for graft rejection. Methods: Three different questionnaires, the Perceived Threat of the Risk of Graft Rejection (PTGR), GCQ and the SF-36 were mailed to 229 OTRs between 19-65 years old. Patients were transplanted with a kidney, a liver or a heart and/or a lung. All patients with follow-up time of one year \pm three months and three years \pm three months were included. With an 81% response rate the study comprised of 185 OTRs. Results: The differences between the transplanted organ groups in their use of coping were small. Likewise coping related weakly with sex, age, time since transplantation and whether they had experienced graft rejections or not. The respondents tended in general to use more of the 'positive' coping (strategies related to positive well-being). Conclusion: The measured coping in relation to the perceived threat of the risk for graft rejection seems to be relatively stable over time and quite independent of demographic and clinical variables. However, when the threat of graft rejection is always on the patients mind nothing can distract him or her from worrying. This implies the need for person-centered care and an individual approach towards OTRs facing the risk of graft rejection.

#175

A Q-METHODOLOGICAL STUDY TO EXPLORE ATTITUDES TOWARDS MEDICATION ADHERENCE IN RECENTLY TRANSPLANTED KIDNEY RECIPIENTS

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Background: Nonadherence to medication is a common problem, especially with increasing time since kidney transplantation, with clinical consequences such as graft loss and patient mortality. The aim of the present study was to explore attitudes towards medication and to study the incidence of nonadherence in the very early postoperative period just after discharge from hospital. Methods: Kidney recipients were invited to participate in this study in which Q-methodology was used 6 weeks after transplantation. Respondents also completed the Basel Assessment of Adherence to Immunosuppressive Medications Scale (BAASIS® interview) and we calculated the intra-patient variability in the pharmacokinetics of tacrolimus. Results: 113 renal transplant recipients (19-75 years) participated in the study. Results revealed three attitude profiles: (1) Confident & Accurate (2) Concerned & Reliable (3) Appearance oriented & Assertive. In the BAASIS® interview 19 of 113 (17%) patients reported being non-adherent. None of the attitude profiles were related to self-reported non-adherence. In the profile 'Concerned & Reliable' there were significantly more patients with high intra-patient variability of tacrolimus trough levels. Conclusions: Even 6 weeks after kidney transplantation patients reported a high incidence of non-adherence to medication which is cause for clinical concern. Patients with a more anxious attitude as found in the 'Concerned & Reliable' profile showed a higher variability in tacrolimus trough levels suggesting a higher degree of non-adherence.

#151

WHOSE PROBLEM IS IT? IMPROVING ADHERENCE IN YOUNG ADULTS

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Aims: Non-adherence is highly prevalent in the young adult transplant population, adolescents having the lowest rates of patient and graft survival. Patient characteristics associated with non-adherence have been described, but the complexity of psychosocial factors involved and ways of ameliorating these are rarely detailed. The presenters (a clinical psychologist and specialist social worker) are part of the multidisciplinary transition team in the liver disease and transplant

service at King's College Hospital, who assess and manage non-adherence in young adults as they move into the adult service. This presentation highlights the psychosocial factors associated with non-adherence and describes an effective multidisciplinary model of management. Method: The literature relevant to working with non-adherence in young adults will be critically reviewed. Data will be presented from a case-note review of all patients presenting to the transition psychosocial team with non-adherence over a twelve-month period. The complexities of working with non-adherence will be illustrated through three case studies in which there were different psychosocial contributing factors. The multidisciplinary interventions as part of the wider transition service will be outlined. Results: A large number of young adults were seen over 12-months, both pre- and post-transplant. The most prevalent psychosocial stressors contributing to non-adherence included mood difficulties, adjustment to illness/transplant, developmental factors, family difficulties, safeguarding issues and other social concerns. Three case studies illustrate the multidisciplinary model for managing non-adherence in this population. Following intervention, adherence rates, psychosocial wellbeing and effective medical follow-up were significantly improved. Conclusions: Managing non-adherence in young adults who are at risk of transplant and post-transplant is a pertinent area for transplant professionals. The maintaining factors of non-adherence are varied and complex. When non-adherence is appropriately identified and maintaining factors are understood, individualized management plans can contribute to better clinical and psychosocial outcomes.

#31 PSYCHOSOCIAL BENEFITS OF UPPER – LIMB TRANSPLANTATION

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Aim of study: The Polish program of upper limb transplantation started on April 2nd, 2006. Up to date there have been 5 recipients, including one bilateral transplantation. Given their experimental and breaking-through character, each of these procedures has provoked the patients as well as the healthcare professionals to pose several questions. Besides the obvious ones regarding the function of the transplanted limbs, the psychosocial benefits to the patients were also discussed. Inasmuch as the first subject could be clarified by the healthcare professionals only, the second issue called for an interdisciplinary research team comprising of both medical and humanist scholars. The aim of the study was to gain the notion of the psychosocial function of the hand transplant recipients. Methods: The empirical material was obtained with individual in-depth interviews with the hand transplant recipi-

ents (N = 5). The scope of the study included: 1. the perceived experience of the reconstructed body; 2. presence of the reconstructed body in the actions undertaken by the recipients; 3. their social disposition. Results: Regaining a complete body was considered as the most important benefit from the upper-limb transplantation, with the function of the graft being of minor importance. The interviewed recipients are well aware of the fact that they seem able-bodied despite not quite being so. Thanks to the reconstructive transplant procedure the shape and look of their bodies became socially accepted and made the recipients: 1. regain their identity as members of the society; 2. consider themselves higher in the social hierarchy; 3. regain the value of their bodies; 4. have higher self-esteem; 5. be more self-confident; 6. feel safer; 7. feel more able; 8. be happy of having a body.

Free Communications 14: Hot topics in allocation

#170

THE EX VIVO LUNG PERFUSION SYSTEM: ETHICAL ISSUES IN ALLOCATION AND REIMBURSEMENT

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Lung transplantation is a life-saving treatment, but only 15-20% of donor lungs are transplantable. Many discarded lungs may become transplantable through the Ex Vivo Lung Perfusion system (EVLP) which uses novel technologies to maintain lungs outside the body for assessment, treatment and repair. Research indicates the EVLP system can salvage many lungs that would be rejected otherwise, significantly increasing the number of transplantable lungs and improving outcomes for recipients. Transplant programs could conceivably send lungs across borders for EVLP repair. In the research context, lungs sent from other centres will be implanted in recipients listed at EVLP repair centres (EVLP RCs). In treatment, it will be possible for EVLP RCs to return treated lungs to the sending hospital for transplantation. Alternatively, there may be opportunities to transplant the lungs in a recipient at the EVLP RC. These possibilities were unforeseen when laws and regulations regarding dispositional authority were developed. This presentation will address the authority of EVLP RCs to distribute lungs from other Organ Procurement Organizations. We will determine whether EVLP RCs should implant repaired lungs locally, or whether they should be allocated to other programmes in neighbouring jurisdictions. The high cost of funding for this new treatment strategy

needs to be addressed. Whilst paying for organs is illegal in Canada and the USA, the reimbursement of transportation, testing and repair costs is not. EVLP may involve the exchange of human organs and money across provincial and national borders, requiring an ethically sound economic model to ensure accountability of involved parties. After reviewing applicable laws, regulations and ethical guidelines related to these issues, we will seek the input of conference participants to elicit recommendations for policy and practice that will inform our research.

#52

EARLY LIVER TRANSPLANTATION FOR SEVERE ALCOHOLIC HEPATITIS

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A 6-month abstinence from alcohol is usually required before patients with severe alcoholic hepatitis are considered for liver transplantation. Patients whose hepatitis is not responding to medical therapy have a 6-month survival rate of approximately 30%. We selected patients from seven centers for early liver transplantation. The patients had no prior episodes of alcoholic hepatitis and had scores of 0.45 or higher according to the Lille model (which calculates scores ranging from 0 to 1, with a score ≥ 0.45 indicating nonresponse to medical therapy and an increased risk of death in the absence of transplantation) or rapid worsening of liver function despite medical therapy. In all, 26 patients with severe alcoholic hepatitis at high risk of death (median Lille score, 0.88) were selected and placed on the list for a liver transplant within a median of 13 days after nonresponse to medical therapy. Fewer than 2% of patients admitted for an episode of severe alcoholic hepatitis were selected. The centers used 2.9% of available grafts for this indication. The cumulative 6-month survival rate (\pm SE) was higher among patients who received early transplantation than among those who did not ($77 \pm 8\%$ vs. $23 \pm 8\%$, $P < 0.001$). This benefit of early transplantation was maintained through 2 years of follow-up (hazard ratio, 6.08; $P = 0.004$). Three patients resumed drinking alcohol: one at 720 days, one at 740 days, and one at 1,140 days after transplantation. Early liver transplantation can improve survival in patients with a first episode of severe alcoholic hepatitis not responding to medical therapy.

#20

IS IT POSSIBLE TO TRANSPLANT RESTORED KIDNEYS?

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In Japan the average waiting time to receive a kidney from brain-dead patients or those in cardiac arrest is

about 14 years. Therefore patients receive a kidney from a living family member, or undergo dialysis. Approximately 30,000 new patients are introduced into dialysis and about 20,000 of them die every year. At present, about 300,000 patients are on dialysis. In a comparison of dialysis and transplant, patient survival rate is much better in transplant than dialysis (10 years patient survival rate: dialysis 40%, transplant 80%). The continuing organ shortage requires evaluation of all potential donors, including those with malignant disease. It means that cancerous kidneys are removed from patients, then after having the diseased part removed, restored kidneys are transplanted to recipients. In Japan, total nephrectomy is often performed as a treatment for small renal tumors (≤ 4 cm), leaving a considerable number of potentially transplantable kidney to be discarded every year. In January 2010, Tokushukai Medical Group (TMG) has started Clinical Trial in the restored kidney transplantation to evaluate the curative efficacy (renal function, QOL) and safety. Estimated 5-year recurrence rate of cancer after restored kidney transplantation would be less than 6%. As a field work, we asked the living donors whether you wanted it to be used instead of your kidney when restored kidney transplantation was possible in those days. There is an increasing need to balance the risk of using organs from donors where there may be a low risk of disease transmission, against the likelihood of death on the transplant waiting list. This would be breakthrough for the shortage of donors, and as a new supplier, we consider restored kidney humanely and ethically. Given the severe shortage of organs for transplantation, a very cautious approach may no longer be appropriate.

#07

COMPARING OUTCOMES FROM INTENSIVE HEMODIALYSIS AND HIGH RISK TRANSPLANTATION

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Introduction: The superiority of renal transplantation over dialysis for most patients is often taken as a given among transplant professionals, based on outcomes after transplantation and after thrice-weekly dialysis or peritoneal dialysis. However, this comparison ignores the salutary outcomes reported for patients undergoing short daily hemodialysis or nocturnal hemodialysis, a decline in organs from standard criteria donors, the growth of procurement from expanded criteria donors, the aging of the waiting list, and an increased prevalence of transplantation in the setting of high-immunologic risk. Methods: A broad literature search is undertaken of national databases and of studies published within the last 10 years on > 4 year survival outcomes for patients with ESRD receiving either daily short he-

modialysis or frequent nocturnal hemodialysis. These outcomes are compared to recently reported outcomes in North America and Europe for recipients of kidney transplants from standard criteria deceased donors, expanded criteria donors, and positive cross-match transplantation. Due note is made of the methodological problems with comparing different study groups. Results: ECD transplantation confers poor outcomes across multiple age groups, but confers especially low patient and graft survival for recipients ≥ 60 years old. Studies of intensive hemodialysis typically include a younger cohort. Age matching between transplant recipients and patients on intensive dialysis suggests electing for additional risk in younger, sensitized recipients may not outweigh the observed survival benefits of more intensive dialysis. Conclusions: There is circumstantial evidence that in the setting of higher medical and immunologic risk, intensive hemodialysis may be superior to renal transplantation. While such a generalization must be validated by well-designed studies, this finding has important implications for debates over resource allocation, organ allocation, and how to counsel individual patients considering their options for renal replacement therapy.

Free Communications 15: Psychosocial care – donor screening

#55

LIVING LIVER DONATION: HOW CAN A META-SUMMARY OF THEIR EXPERIENCES INFORM THE PSYCHOSOCIAL SCREENING?

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Background: Living donor liver transplantation (LDLT) is a viable option for end-stage liver patients who face a shortage of available livers from deceased persons. However, this process is more complex surgically and psychologically for donors than the more common living kidney donation, and could generate multifaceted psychosocial problems for both recipients and donors. Unlike patients awaiting a kidney transplant, end-stage liver patients have no alternative form of treatment (e.g. dialysis) and face a high mortality rate while on the waiting list. For donors, the surgery is much more invasive as there is no equivalent to laparoscopic nephrectomy. Objective: Given the recent developments in LDLT in several western countries, there is value in aggregating the results of empirical studies published thus far to examine what has been documented regarding the particular experience of LDLT donors and recipients. Methods: After defining our selection criteria (i.e., empirical studies; published in English, French and German), we conducted a literature search covering CINAHL, Medline and Psy-

INFO. The retrieved articles were meta-summarized following the method described by Sandelowski and Barroso (2003), including the calculation of frequency and intensity effect size. Results: Results will be presented in order to highlight the major episodes and important moments associated with LDLT for donors and recipients. Those include the will to become a donor in order to maintain an emotionally close recipient alive, the potential influence of donation on the donor-recipient relationship, and gratitude post-transplantation. The results also suggest specific needs that should be addressed during the psychosocial screening process. Conclusion: Psychosocial interviews and screening procedures involving intended donors and recipients of living liver donation would benefit from being revised to take into account what has been learned from research in the area thus far.

#166

LIVING DONOR PSYCHOSOCIAL ASSESSMENT/FOLLOW-UP PRACTICES IN THE PARTNERS' COUNTRIES OF THE ELIPSY PROJECT

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Living donor (LD) transplantation has increased recently, but psychosocial aspects of living donation have not been well characterized, as risk factors for the donors. European Living Donor Psychosocial Follow-Up (ELIPSY) is a project confounded by EAHC, seeking to develop a common methodology for all EU countries for LD assessment/follow-up in the psychosocial sphere. Objective: To evaluate current psychosocial LD assessment/follow-up practices among European centers for key aspects and differences between kidney and liver programs. Methods: Within a timeline of 30 months, this phase of the project sought to identify current LD psychosocial assessment/follow-up practices. The final version of the survey contained three parts. Two of them each included seven questions focused on kidney or on liver programs. Meanwhile, the third part was an open question. The survey was completed in 10 European countries with 65 participating centers running LD programs. Among them 58 belong to ELIPSY partner countries – Spain, Turkey, Portugal, Cyprus, France, Germany, and Sweden; seven were from countries participating in the European

Living Donation and Public Health (EUCLID) project – United Kingdom, Poland, and Romania. The results were analyzed separately for each program seeking to compare and define differences among them. Results: Positive answers regarding psychosocial assessment/follow-up practices were obtained for 26 (42%) kidney and nine (38%) liver centers. Some centers perform several psychosocial follow-ups but did not explain their tools, whereas the centers that did explain the tools used the same ones for both programs. Conclusions: The survey results showed wide heterogeneity among centers. There was no consensus concerning methodology, professionals, psychosocial assessment/follow-up tools, and appropriate time to perform it. This heterogeneity highlights the importance of the next stages of ELIPSY project, to provide a methodology for LD, promoting harmonization of practices among EU countries.

#138

WHO HAS HIGH EXPECTATIONS OF DONATION? EXPLORING THE PSYCHOLOGICAL PROFILE OF LIVING KIDNEY DONORS

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Objective: High expectations regarding personal consequences of donation (e.g. personal growth) are suggested to be an important component in the psychosocial screening of potential living kidney donors. However, little is known about who has high expectations and what the potential consequences may be. In this study, we explored the relationship between the psychological profile of living kidney donors and their expectations before donation. Methods: A cohort of potential living kidney donors (N = 137) completed the following questionnaires before donation: Living Donation Expectancies Questionnaire, Brief Symptom Inventory, Positive And Negative Affect Schedule, Satisfaction With Life Scale, Mental Health Continuum-Short Form, Stress-subscale of Depression Anxiety Stress Scale, Brief COPE, Social Support List Interactions, and the Social Support List Discrepancies. We obtained sociodemographic characteristics from medical records. Results: Using multiple linear regression analyses we found that higher expectations regarding Interpersonal Benefit were related to higher depression, higher negative affect, lower phobic anxiety, and higher experienced social support. Higher expectations regarding Personal Growth were related to higher negative affect and a lower level of education. Expectations regarding Spiritual Benefit were higher if the donor had a religious affiliation and among those with a lower education. Higher expectations regarding negative Health Consequences were related to older

age, higher negative affect, less use of an active coping style, and a lower level of education. Conclusions: Donors with higher negative affect and lower education had higher positive and negative expectations regarding the donation process. What is not yet clear from these data is the direction of causality between these factors. An important question is the extent to which high expectations of donation relate to subsequent mental health after donation. We are currently investigating this in a prospective cohort study among all our living donors.

#137

DISCLOSURE OF RECIPIENT-SPECIFIC RISK FACTORS MAY IMPROVE THE LIVING DONOR (LD) INFORMED CONSENT PROCESS

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LD transplants require recipient and donor agreement to a shared transaction, in which each patient's experience affects the other's outcome. Although informed consent for LD has long included general understanding of ESRD treatment options and outcomes, there is little policy guidance about subgroup-specific outcome disclosure. This is increasingly important as recipient candidacy criteria have expanded (e.g., older, > 2nd tx, obese, sensitized, HIV +), with corresponding increased outcomes range. Disclosure of recipient health factors may/may not change LD decisions, but will improve donor preparedness. LDs generally decide to donate using moral reasoning, not rational process (Valapour et al, 2011). LDs also have higher tolerance for risk than recipients do for them, or than controls (Young et al. 2008; Boulware et al. 2005). That said, recipients and LDs both identify recipient risk factors as important for LDs to know, (Rodrigue et al. 2011). Given that data suggests donor regret is linked to poor recipient outcome, and unexpected recipient outcome is a risk factor for LD depression, it is critical to be able to provide more specific information about an intended recipient's potential outcome rather than general information about LD transplant results. True informed consent demands that the LD candidate understand potential outcomes of deciding to donate – or not. Process and policy guidelines are needed to balance recipient privacy needs with the LD candidate's right to adequate information. When recipient risk factors significantly impact expected outcome, (3rd/4th transplant? History of poor self-management?) omitting this from LD informed consent is hard to defend. Donor might be advised solely that recipient meets 'high risk' criteria, particularly for NDD or paired kidney exchange; in cases when LD and recipient share relationship, shared discussion of outcome expectations may be warranted.

#96

NEW ORGANS WITHIN US*Aslihan Sanal PhD;**European Molecular Biology Laboratories,
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In this conference, I will talk about kidney-transplant patients and transplant practices in Turkey. My examples will be from *New Organs Within Us*, an ethnography which begins with the life histories of patients and follows their psychological dramas to the dramas of everyday life in hospitals, to physicians' qualms about declaring brain death, to the emergence of organ trafficking in the Middle East and in Europe, and to media scandals linking economic processes to patients' subjectivities. In Turkey organ donations from cadaveric donors have been very low. This, physicians believed was rooted in cultural and religious taboos surrounding the dead body. Consequently, as transplants became a routine practice by the mid-1990s and poverty was widespread living-related transplants became the core donor pool for transplant practices. Organ trafficking became a natural extension of this. In time, a kidney was donated in exchange for a dowry, for an apartment, for covering debts or less. Also for this reason, patients learned to live with the kidney of another person while confronting issues related with kinship, inequalities, taboos, and poverty most of the time. With the transplant, they had to internalize worlds they had learned to keep at a distance all their lives. Their boundaries were destabilized metaphorically and literally. In the light of this ethnography, I will try to illustrate how the taboos surrounding death and the dead body shape the biopolitics of transplant practices and consequently form patients' subjectivities through a moral experience tainted by social inequalities and poverty.

to discuss whether or not this is problematic in general, and for health professionals in particular. Method: Exploratory-descriptive study with a survey design to gather information from 587 health professionals (in France, the US and Spain) involved in the clinical care of potential organ donors and/or in the determination of death process. Results: Health professionals believe that brain death is a more reliable standard for determining death than circulatory death. While the vast majority of HPs consider it morally acceptable to retrieve organs from brain-dead donors, retrieving organs from DCD patients is much more controversial. For significant minorities of professionals (about 1/3 or them), cardiac measures by themselves do not accurately measure the death of the brain in DCD protocols, and the death of the brain is – according to them – necessary for an individual to be declared dead. Conclusion: DCD brings into question the notion that death is a unified concept. This contradicts the assumption, made by defenders of the bifurcated standard, that both cardiopulmonary and neurological criteria represent a unified notion of death so that one does not have to choose between them.

#145

THE UNADVERTED PROBLEM OF THE DUALITY BETWEEN NEUROLOGIC AND CIRCULATORY DEATH*David Rodríguez-Arias PhD;**Spanish National Research Council Madrid,
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Objective: International laws accept a “bifurcated standard” for declaring death: Irreversible loss of circulatory function and irreversible loss of brain function. Legally, there is no need for both criteria to be simultaneously fulfilled. It is frequently assumed that irreversible loss of brain function is the ‘gold standard’ for the determination of death. Many authors accept donation after circulatory death (DCD) because they believe that loss of circulatory function is an adequate surrogate marker for total brain failure. However, in DCD, organ donors are considered dead while there is actually no direct evidence that they have a total and irreversible brain failure. The objective of this paper is

CULTURAL AND RELIGIOUS ASPECTS OF LIVING AND DECEASED DONATION

1

(#40) THE ROLE OF ETHICS COMMITTEES IN LIVING ORGAN DONATIONS' DECISION MAKING PROCESS IN CENTRAL AND EASTERN EUROPE

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There has been an increasing role of bioethics in legislation regulating organ transplantation in Eastern Europe. New legislative measures in public health law have stipulated the presence of ethicist(s) in the committees supervising the living organ donation process. One of their roles is to wither suspicions surrounding paid organ exchanges between donors and recipients. The relevance of their activity is enhanced in countries permitting unrelated living donations where there is a legacy of corruption being present in the domestic medical system leading to a heightened potential for abuse. The decision-making practice of such committees is far from being unitary in translating the law into practice through purely objective criteria. Accordingly, there is an inherent risk of the process becoming formal instead of following its initial task of evaluating exhaustively each case. Comparatively, certain transplantation units give the green light to such life-saving procedures at a higher percentage rate than in others even within the same country. Consequently, in light of the suspected subjectivity of decision-making in such committees, it is interesting to evaluate the decision-making process from certain contextual variables. In this study, we hypothesise that such indicators are related to the legal, institutional and cultural environment under which the committees operate, the heterogeneous professional background of the committee members, and the longitudinal experience of committee members in evaluating such practices. The question arising out of this analysis occurring in Romania, Hungary, and Lithuania, is whether best practices of such ethics committees can be translated from one cultural and legislative context to another on the same efficiency level and if yes, which would be those aspects of the decision making process where the professional guidelines could be of real help.

2

(#43) INTERINSTITUTIONAL COLLABORATION (LOCAL HEALTH AUTHORITY, FONDAZIONE IRCCS POLICLINICO SAN MATTEO, NON-PROFIT ASSOCIATIONS AND GENERAL PRACTITIONERS) IN THE PROVINCE OF PAVIA IN ORDER TO REDUCE THE RATE OF OPPOSITION TO THE ORGAN DONATION IN THE POPULATION

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The opposition rate (O.R.) of the population is one of the crucial factors in determining the number of organ transplants. The Italian law on transplantation is based on a "soft opt-in" expression of willingness. In 2011 in Italy the O.R. was 28.3% while in the province of Pavia where the Local Health Authority (L. H.A.) and the Transplant Coordination Unit work the average of the O.R. was 18,9 %. The aim of this project is to promote a further awareness of the citizens. This activity will be performed by General Practitioners (GP), in the same time they will collect the expression of the willingness of the citizens about organ donation. The OR will measure our progress. In 2011 we organized educative courses on transplant for GPs and for front office staff of the L.H.A. These courses have introduced a more articulated action plan that will begin in 2013. This new project is based on three levels: 1. formation of GPs in small groups, 2. circulation, by GPs, of an informative brochure for citizens, 3. consultation with single patient and his relatives in order to collect their willingness about organ donation and registration of their responses on medical record. This initiative will be performed by Pavia L.H.A., Fondazione IRCCS Policlinico San Matteo, and the non profit association "Trapiantami un sorriso, Pavia per i trapianti". This association collaborates with hospitals, L.H.A, and other voluntary non-profit associations. At the end of 2013 it will be possible to measure the progress of this five years plan.

3

(#62) INCREASE KIDNEY TRANSPLANTATION – THE ERA OF MANDATORY CONSENT CHOICES FOR IRISH ORGAN DONORS

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Kidney donation is one of the most altruistic acts that can be carried out by a human being to help another. When human kidneys fail, it leads to the inevitable death of the person days or weeks after the diagnosis of End Stage Kidney Failure (ESKF) is given. Kidney transplant from a live donor or a deceased donor would be the best treatment available for the patient to survive without life long renal replacement therapy, with further superior outcome and quality of life. The ultimate goal for a physician looking after chronic di-

alysis patients is to get them through a successful kidney transplant, where a human donor kidney will be surgically transplanted into their body. Therefore, the needed number of donated kidneys should be available. Countries worldwide are trying to implement some guidelines, programmes, and legislation to help to augment this process. I looked at some of the models with special consideration to the presumed consent of deceased donors, rather than, the current practice of pre-emptive informed consent from the deceased or that of the family of the deceased in the absence of the latter, with more inclination of going with the families' wishes! Presumed consent law is clearly increasing the rate of transplant in some countries like Spain, but has the opposite effect in others, like France. The Spanish altruistic model has been far superior to the Iranian incentive model in nearly abolishing transplant waiting list. This diversity made me look even closer at what might be the contributing factors to this and stipulate building on the positive outcome from the Spanish experience, a draft proposal suitable for modern Ireland with a potential of being applied worldwide. This model takes pride in humane choice right.

4

(#143) USE OF EXPANDED CRITERIA LIVING DONORS: THE POSSIBLE SOLUTION OF SEVERE ORGAN SHORTAGE IN THE BALKANS

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Background: The Balkan region has dramatically changed over the past 20 years. Despite the efforts for renal transplants, dialysis remains the usual way for treatment of ESRD. Due to the lack of deceased organ donation, the living renal transplantation is a predominant transplant activity. Trying to solve the problem, we started accepting so called expanded criteria living donors (ECLD) Methods: Two hundred and twenty living renal transplants are performed in our Kidney Transplant Centre in the last 20 years. As ECLD were accepted 88 donors older than 65 years, 4 ABO incompatible, 21 unrelated (predominantly spousal), 10 with mild arterial hypertension, 4 with large simple cyst, 2 with multiple renal arteries and one with double ureter (ECLD Group). The quadruple sequential immunosuppressive protocol was used in all cases including induction with ATG or IL-2R antagonists, Cyclosporine, MMF/AZA and Steroids. The Kaplan-Meier one, three and five years graft survival rate, rejections, DGF and renal function were analysed. The results were compared with the group of 90 recipients with standard criteria living donors (SCLD) performed in the same time. Results: One, three and five years Kaplan-Meier graft survival rate for ECLD group was 94%, 83%, 74%, respectively, compared with 95%, 87%,

78% in the SCLD group (n.s.). The percentage of DGF was 14% in ECLD group compared with 6% in SCLD group ($p < 0.05$). The rejection episodes rate was 18% (ECLD) compared with 16% (SCLD). The actual serum creatinine 5 years after the surgery was 170 and 154 micromole/lit in ECLD and SCLD, respectively ($p < 0.05$). Conclusion: Our study justifies the use of ECLD especially in the regions where the living renal transplantation is predominant. It may ameliorate the actual organ shortage in the Balkans.

5

(#148) REFLECTIONS ON THE ISRAELI LAW OF TRANSPLANTATION

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The Anatomy and Pathology Law, 1952 allowed removal of organs from cadavers for transplantation simply by a medical decision prescribed by law. The law was amended in 1980 granting special standing to the deceased's wishes. When no written document was left by the deceased, the law granted some considerations to the deceased's family, unless the cadaver is needed for "saving life" as defined in the law. However, instructions issued by the Health Ministry granted the deceased's family a right to override the deceased's written consent and to refuse removal of organs causing a shortage in obtaining organs. Abstention to remove organs for transplantation in "saving life" cases when permitted by law may create a breach of duty to save life and professional negligence. When considering live donor transplantation courts ruled out the possibility of minors and vulnerable adults to serve as live donors, even with parental consent. The legality of organ removal from competent donors was questionable until 1994 when the Penal Law was amended to legalise removal of organs for transplant. However, the Supreme Court ruled, that organ donation should be based on altruism with no financial benefit. In 2008 the Organ Transplant Law was passed regarding live donors, and stated that although persons may not give or receive financial rewards for living organ donations, a donor may receive compensation for financial losses accrued directly from his donation. This law has been criticised for not increasing the number of organs for transplants, because it doesn't allow significant compensation for donors. However, despite the legal prohibition, once money is involved there is a danger of financial transactions related to organs for transplant. This may lead also to commodification of human organs, including claims regarding of unsuitability which may affect the amount of compensation.

6

(#179) THE IMPLICATIONS OF UK ORGAN DONATION RECOMMENDATIONS AND POLICY CHANGES FOR HEALTH CARE PROFESSIONALS

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The recommendations published by the UK Organ Donation Taskforce and the planned introduction of an 'opt-out' organ donation policy in Wales raise many new and challenging issues within organ donation practice. Though these proposals are expected to help improve the number of transplantations which take place and improve organ donation practices in UK, there are several key practical and ethical problems to be addressed. Abiding by these recommendations will mean increased pressures and responsibilities for health care professionals as they will be expected to advocate organ donation, undergo training and achieve set standards. Medical staff now face a vast array of complex ethical decisions and must attempt to balance the needs of the many patients on the organ donor waiting lists whilst respecting the rights of the potential donors and being sensitive to the needs of donors' next of kin. This 12 month project explores the proposed changes in transplantation practices in the UK and how these will affect the medical staff involved in organ donation procedures. Approximately 30 semi-structured, in depth, qualitative interviews will be carried out between November and January with medical staff employed in three key departments involved in the care of potential organ donors; accident and emergency, intensive care and operating theatres. The interviews will investigate what the medical staff hold as the main issues in their medical practice and explore how they go about tackling these. Fieldwork notes will also be made from attending organ retrievals at local hospitals, regional organ donation committee meetings and shadowing specialist organ donation nurses. Emerging findings from a thematic analysis of the data will be presented at the conference.

CROSS-BORDER TRANSPLANTS

7

(#23) PENAL LEGISLATION IN ORGAN TRAFFICKING. A STUDY OF COMPARATIVE CRIMINAL LAW

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Organ transplant is one of the foremost therapeutic advances on the 20th century. Nonetheless, the successful results of these interventions have also brought a remarkable disproportion between the supply and the increasing demand of organs. And this obstacle, among other reasons, has caused a new form of criminality, human organ trafficking, undermining the mentioned scientific achievement. In this context, Resolution 1782 (2011) of the Council of Europe Parliamentary Assembly concludes that: "considering that human organ trafficking is nowadays a serious international problem and that it infringes the basic standards of Human Rights, it is necessary to design a legal international instrument in order to define trafficking in organs, tissues and cells, to stipulate actions to warn and to protect the victims and, at the same time, to take legal action to sanction those who perpetrate it". As a result, the states and the most important international organizations have gathered efforts to penalize those practices. The poster as proposed for the 3rd ELPAT Congress aims to contribute to the understanding of this new type of crime, analysing, on the one hand, the relevant criminal law provisions in some European countries. Specifically, the objective would be to compare the penal legislation in Spain, France, Italy, Germany, Portugal, the Netherlands and England and, on the other hand, the most recent resolutions in the Council of Europe and in the United Nations.

8

(#56) TRANSPLANT ABUSE IN CHINA: LOCAL SOLUTIONS TO A GLOBAL PROBLEM

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The overwhelming proportion of organs for transplants in China comes from prisoners. The Government of China acknowledges that this is so and accepts that sourcing of organs for transplants from prisoners is wrong. The Government in March 2012 committed to ending the reliance on prisoners for organs in five years. The position of the Government of China is that the prisoners who are the sources of organs are sentenced to death. Research in reports published in June 2006, January 2007, and in the book *Bloody Harvest*, November 2009 all of which I co-authored with David Kilgour and in the book *State Organs* August 2012 I co-edited with Torsten Trey concluded that the bulk

of prisoners who are sources of organs are prisoners of conscience, mostly practitioners of the spiritually based set of exercises Falun Gong, sentenced to nothing. Ethan Gutmann presents research, published in *State Organs*, about other transplant abuse victim prisoners of conscience – Uighurs, Tibetans and Eastern Lightning House Christians. Chinese transplant abuse is a global problem because of transplant tourism, because of the relations between the Chinese and global transplant profession, because of clinical trials in China of anti-rejection drugs by multi-national pharmaceutical companies, and because killing people for their organs is a crime against humanity which concerns all humanity. Local solutions exist. Some solutions are legal – using existing laws or enacting new laws. Some are professional, using peer pressure in the medical profession generally and the transplant profession specifically. Some are policy based, including health policy. The presentation will explore these locally based solutions, set out what has been done, and make suggestions for what viably could be done to combat this global ethical transplantation problem.

9

(#181) ROLE OF PSYCHOLOGIST IN TRANSPLANT COORDINATION INTERDISCIPLINARY TEAM. AN EXPERIENCE IN DONOR INSTITUTIONS (2008-2012)

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The psychologist's work in an interdisciplinary coordinated transplant team in donor institutions, is very important for the interaction with families with severe state of mourning. The family group's physical urgency forms part of the subjective suffering notion; something irrupts and has to be framed in some way. Manifestations as: guilt, negation, frustration, helplessness, mistrust, ambiguity, aggression, fears are a field of urgent psychological intervention, providing a tridimensional strategy composed by: a clinical vision, a social vision and an institutional vision. For this study we have analyzed donation interviews performed in public and private institutions from the city of San Miguel de Tucumán, Tucumán, Argentina, during a four-year period (February 2008-February 2012). Interviews from this period (126) were analyzed. From the total ones 57 were positive to donation (45.2%). From the positives interviews, the psychologists took part in 45 (80%) facilitating the enforcement and adherence of the family in this subject. The incorporation of a psychologist to a multidisciplinary team highlights the importance of the comprehensive treatment of the donor's family as an ethical position of the task. It allows the development of strategies to address each family in its particularity, prompting a donation interview situation in a spirit of contention. Organ donation, beyond the scope

of the medical discipline for their psychological and social character and the incorporation of a psychologist in the coordination team, opens a way of sharing between involved health professionals and the family. Motivated and emotionally related donors should be allowed to donate one of their kidneys provided that they are carefully selected and thoroughly informed.

PSYCHOSOCIAL CARE

10

(#03) COPING STRATEGIES AND SELF EFFICACY AS A MEDIATOR OF QUALITY OF LIFE IN RENAL TRANSPLANT PATIENTS

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Renal transplantation is the surgical placement and vascular integration of a human kidney from a living or cadaveric donor into a patient who has end stage renal disease (ESRD). Although renal transplant brings many benefits to patients, it is potentially associated with a number of drawbacks. These drawbacks are also stressors for patients (Fallon, 1997). Thus renal transplant patients experience stress which influences their health-related quality of life (HRQOL). Coping, defined as cognitive and behavioral efforts to manage stressors (Lazarus and Folkman, 1984), consider it an important predictor of HRQOL of renal transplant patients. According to their (1984) model of stress and coping, appraisal is a cognitive mediator affecting coping. It is necessary for the health care providers to understand the coping strategies patients use and factors influencing coping, then develop interventions to help patients use effective coping strategies to reduce stress related to renal transplant. Purpose: The purpose of this study is to investigate the effect of related self-efficacy, social support, coping, and HRQOL in renal transplant patients in Middle East. Research on coping in renal transplant is in its initial stage in Middle East, although HRQOL of renal transplant has been maturing in our population. No researchers assessed appraisals of renal transplant. Personal and situational factors that influence the appraisal processes were not addressed. Methodology: A descriptive, correlational, cross-sectional design with a sample that includes patients at two distinct periods post-transplant early less than 1 year and later 1 to 3 years will be used. In this study, cognitive appraisal of health, self-efficacy, social support, coping strategies, and HRQOL will be measured using self-report instruments. This study will be conducted at transplant center East eastern Province Saudi Arabia. Sample: Adult renal transplant recipients who meet inclusion criteria. Sample Size: 70 participants will be recruited from our outpatient transplant clinic (N = 30 < 1 yr post transplant; N = 40 1-3 yrs post-transplant). Standardized instruments will be

used. Statistical Analyses: Data will be analyzed using SPSS software. Statistical significance will be at ($P < 0.05$).

11

(#06) IMPACT OF CLINICAL FACTORS ON PSYCHOLOGICAL WELL-BEING AND QOL IN RENAL TRANSPLANT RECIPIENTS

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Renal transplantation is considered the only treatment that restores reasonably normal kidney function and health. Although renal transplant brings many benefits to patients, it is potentially associated with a number of drawbacks. Thus, renal transplant patients experience stress and uncertainty, which influence their health-related quality of life. The purpose of study is to investigate the effects of clinical factors: 1. duration of dialysis before transplant and time post-transplant, 2. side effects of immunosuppressives, 3. transplant-related hospitalizations, and 4. donor type on cognitive appraisal of health, perceived self-efficacy, coping and health quality of life after renal transplantation using a theoretically derived mode in Middle East population. A descriptive, cross-sectional design with a convenience sample will be used in this study to examine effects of clinical factors on the psychosocial outcome in renal transplant patients. In this study, Cognitive appraisal of health, Perceived self-efficacy, Coping strategies, and HRQOL will be measured using standardized instruments. This study will be conducted at our transplant center located at the Eastern Province in Saudi Arabia. The population of this study will be adult renal transplant recipients. The population will be renal transplant recipients who are managed at our center. Inclusion criteria, 18 years of age, received a renal transplant on only one occasion. With a functioning kidney graft at the time of enrollment: less than 1 year post-transplant, and 1 to 3 years post-transplant, able to understand Arabic. Exclusion criteria: if they had received more than one renal transplant; if they had received another organ transplant. Using a descriptive cross-sectional design, a sample of 100 participants following renal transplant will be recruited from our outpatient clinic after 1 year post transplant and will be repeated 3 years later. The following instruments will be used to measure the key constructs: The Cognitive Appraisal of Health Scale Perceived Health Competence Scale, The Brief (COPE) Quality of Life Index Transplant Version, Brief Symptom Inventory (BSI). The collected data will be analyzed using SPSS. Analysis of variance and correlation/regression. Statistical significance will be considered at $P < 0.05$.

12

(#35) RECIPIENTS' SELF-PERCEIVED QUALITY OF LIFE FOLLOWING LUNG TRANSPLANTATION: A TWENTY-YEAR EXPERIENCE

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Lung Transplantation (LT) is a therapeutic option for certain patients. Although morbidity and mortality rates are not to be disregarded, increase in life expectancy and improvement in quality of life (QL) are considered of paramount importance. The relationship between spirometric values and QL is currently being discussed. Objectives: a) To evaluate recipients' QL perception after LT and changes experienced in different areas, b) To determine the relationship between QL perception and spirometric value FEV1, c) To evaluate satisfaction with: decision to undergo LT, information available, previous expectations, d) To determine difficulties reported with treatment after LT and smoking relapse occurrence. Material and Methods: A total of 20 patients underwent LT at Hospital Italiano Buenos Aires between 1992 and 2011. X 44,2 m, (r: 3m - 13y). AT LT, X 47 years (F:44, M:51). Application WHQOL SF 26 and survey designed with closed options (Much, Fairly Much, Little, Nothing). Review of the FEV1 measures. Results: n = 20 (12: F, 8: M). At survey X age: 49.1 years (F: 47.3) (M: 52.5). Etiology: 12 COPD, 6 fibrosis, 2 other. 60% were married, 45% elementary education, 70% unemployed. WHOQL: Average QL: 80% , Low QL: 20%. Average QL: FEV 1: between 24.8% and 84.1, Low QL: between 29% and 77%. QL areas changes: Physical: 85%, Psychological: 80%, Family: 65%, Work-related: 40%. Survey: "Very satisfied with transplantation": 90%, "Many changes in QL": 85%; "Very satisfied with previous expectations": 60%, "Very/Fairly informed": 75%, "Did not need more information": 80%, "No difficulty attending medical appointments": 95%, "No difficulty with medication": 60%. Smoking relapse: 10%. Conclusions: Patients report an average QL perception, with changes in the physical, psychological, family areas and minor changes in the work-related one, high satisfaction with transplantation, achievement of expectations and information availability. Few difficulties with the treatment were reported. No relationship between FEV1 and QL was found. Two cases of smoking relapse were reported.

13

(#54) HOW CAN THE PAST EXPERIENCE OF DONORS AND RECIPIENTS INFORM THE PSYCHOSOCIAL SCREENING OF CANDIDATES TO LIVING KIDNEY TRANSPLANTATION?

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Background: Given the shortage of organs from deceased persons, living kidney donation (LKD) is currently being promoted and increasingly practiced in all western countries. While the experience of giving or receiving a kidney from LKD is recognized as complex and multifaceted, little research has examined systematically the experience of donor-recipient dyads. **Objective:** Guided by our analysis of five donor-recipient dyads and informed by our previously published meta-summary, this presentation examines how the past experiences of donors and recipients can inform the psychosocial screening of future candidates. **Methods:** Five donor-recipient dyads were recruited and each member of the dyad was interviewed individually. Participants included were diversified in terms of type of donor-recipient relationship and time elapsed since donation. Data was analysed following the principles of Interpretative Phenomenological Analysis. **Results:** Results obtained give insight into both the positive and negative aspects of the screening process. Several donors reported anxiety about their own health and concerns over discovering a health issue that could prevent them from donating a kidney. Most recipients found the donor's screening period stressful and tainted by the fear that the donation process could stop any time. **Conclusion:** Results highlight points of clinical interest and are discussed in the context of how the psychosocial screening process could be adapted in order to remain closer to donors' and recipients' reported needs, namely the need for additional support for both members of the dyad, and how important themes could be discussed in psychosocial interviews with intended donors and recipients prior to donation to help them prepare for the multiple steps involved in the process, such as the surgery but also, how life is with one single kidney and how to give back post-donation.

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(#66) DOES STRESS IMPAIR WOUND HEALING MEASURED BY HIGH-RESOLUTION ULTRASOUND IN LIVING KIDNEY DONORS? A PILOT STUDY

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Background: Stress has been demonstrated as an influential factor in the rate of wound healing. Living donors provide an ideal group on which to assess the impact of stress on surgical wounds as they have little or no major physical or psychosocial co-morbidities. **Aims:** To ascertain whether pre-operative stress led to inferior wound healing in living kidney donors, using high-resolution ultrasound. **Methods:** 14 living kidney donors undergoing hand-assisted laparoscopic donor nephrectomy were included. Stress was assessed using the Perceived Stress Scale (PSS) and was measured 10-14 days pre-operatively. Two wounds and an area of normal skin were scanned using the Episcan® High-Resolution Ultrasound machine on days 1-3 and 2-3 weeks post-operatively. Image analysis included change in wound size and median colour intensity; a value calculated by the ultrasound machine reflecting residual tissue oedema. **Results:** Median PSS score was 4.5 (Range 0-8, SD 2.75). Increased stress was strongly correlated with poorer wound healing as demonstrated by lower median intensity scores (indicating increased tissue oedema) at follow up across two separate wounds (Hand port: $r = 0.788$, $p = 0.001$; Lap port: $r = 0.660$, $p = 0.014$). Stress was poorly correlated with reduction in wound size (Hand port: $r = 0.64$, $p = 0.836$; Lap port: $r = 0.42$, $p = 0.175$) and rate of wound size reduction (Hand port: $r = 0.258$, $p = 0.395$; Lap port: $r = 0.503$, $p = 0.096$). Stress was not associated with age ($r = 0.101$, $p = 0.731$), gender ($r = 0.366$, $p = 0.198$) or length of stay ($r = 0.392$, $p = 0.165$). **Conclusions:** The results of this pilot study show that pre-operative stress is strongly correlated with poor wound healing at 2-3 weeks after surgery. High-resolution ultrasound is beneficial for the detection of microscopic tissue changes invisible to the naked eye. A larger longitudinal study is necessary to assess the impact of ultrasound changes on immediate and long-term clinical outcomes.

15

(#71) EDUCATION AS A TOOL FOR IMPROVEMENT OF WILLINGNESS FOR TRANSPLANTATION IN DIALYSIS PATIENTS

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Background: Structured transplant education could help kidney patients to better understand their options, the risks and benefits involved in transplantation process. It might correct knowledge deficits, concerns, unfavorable beliefs and increase patients' willingness to consider transplantation. Previous study performed at our Institution, suggested that our existing system of providing patient information needs significant improvement. Objective: This study aimed to assess the impact of an educational program on patients' willingness for transplantation. Materials and methods: Fifty-eight transplant-eligible haemodialysis patients were included in this interventional study. Data on patients' demographics and likelihood of referral for transplant evaluation were collected via semi structured interviews. We used Rapid Estimate of Adult Literacy in Medicine-Transplantation test (REALM-T) and non-standardized transplant-related knowledge questionnaire. Structured educational intervention included printed educational materials, followed by discussions with transplant professionals. Questionnaires were completed before and 1 week after intervention. Results: 67% of participants were willing for pretransplant evaluation. There was a statistically significant difference between willing and unwilling patients related to knowledge and health literacy, suggesting that willing ones had statistically higher health literacy ($p = 0.0023$) and transplant related knowledge ($p = 0.005$). Study patients demonstrated significant improvement in their level of knowledge ($p = 0.000$) and health literacy ($p = 0.000$) after intervention. The odds of negative change of transplantation willingness after the intervention were significantly lower, when tested with Mantel-Haendzel test (OR 0.03, CI: [0.04-0.196], $p = 0.001$). For 90% of participants, the language, style and understandability of the handbook made it easy to follow. Comments that have been received included "very interesting and very useful". 66% made suggestions. Conclusion: We concluded that patient's knowledge, health literacy, and willingness for transplantation, could be improved by a structured educational program.

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(#77) INTERVENTION STUDIES IN TRANSPLANTATION MEDICINE: RESULTS FROM AN UPDATE OF GERMAN CONSULTATION-LIAISON GUIDELINES

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Objective: Six German scientific federations are currently working to update the S3 guideline on Psychiatric and Psychosomatic Consultation-Liaison (CL) Services. The council's working group on transplantation (tx) medicine has aimed to update the state of empirical research concerning the effectiveness of CL-interventions in the field of tx-medicine. Methods: A systematic literature search was performed using PubMed, Medline, PsycInfo, Psynindex, Current Contents, Cochrane Database and Evimed. In addition, experts in the field of tx-medicine were consulted. This search identified nearly two hundred relevant studies. Only randomized controlled trials (RCTs) related to CL services were included in this review. The quality of the investigations was assessed by two independent groups with regard to e.g. blinding, loss to follow up, allocation concealment. Results: We identified only seven RCTs dealing with CL-interventions with patients awaiting transplantation or with post-transplantation patients. The CL-interventions were carried out by a variety of health care professionals: physicians, psychologists, social workers, and nurses in the field of end-stage pulmonary disease, renal disease, and hemato-oncological disease. The interventions included telephone-based interventions, psychotherapeutic interventions (individual or group sessions) and electronic monitoring of medication intake. The trials showed that CL-interventions improved depression, health-related quality of life, and adherence to treatment. Conclusions: The generalization of the results is limited by the low number of studies and the heterogeneity of study populations and interventions. We have not identified studies on CL-interventions with heart-transplanted patients. Key words: transplantation, consultation-liaison services, psychiatric, psychosomatic

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(#85) LIVER TRANSPLANT AS A TRIGGER FOR GROWTH

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Purpose: The aim was to verify the presence and the nature of growth in a group of liver transplant patients, as a growing literature documents that positive life changes may also accompany this experience (Park, Lechner, Antoni, & Stanton, 2010) and defines post-traumatic growth (PTG) (Tedeschi & Calhoun, 2004). Further, coherently with the recent literature on social identification and health, the relationship between the PTG scores and the social identification with liver transplant people has been tested. **Methods:** 224 liver transplant patients (85% male) completed a questionnaire composed by the Post-traumatic Growth Inventory (Tedeschi, Calhoun, 2004), the In-group identification scale (Doosje, Ellemers, and Spears, 1995), the Brief-COPE scale (Carver, 1997). **Results:** Results show that the 35% of patients grew highly, the 35% grew moderately and that the 30% didn't grow or grew slightly. Coherently with the PTG model, these positive psychological changes included an increased appreciation for life in general, more meaningful interpersonal relationships, an increased sense of personal strength, changed priorities, and a richer existential and spiritual life. Further, correlation analysis showed that higher levels of PTG were related to higher level of social identification with liver transplant people ($r = .30-.39$) and to higher level of active coping ($r = .28-.39$). **Conclusion:** Results highlight the existence of positive psychological changes in liver transplant patients that occurs as a result of the struggle with the challenging transplant experience. Further, the posttraumatic growth seems to be related with positive resilience resources (i.e. active coping and social identification). All in all, posttraumatic growth seems to be an interesting and effective construct to a deeper understanding of transplant experience.

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(#113) HEART TRANSPLANTED PATIENTS AND THE SOCIAL INTEGRATION AFTER THE TRANSPLANTATION

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Background: Heart transplantation is the first option for treatment of heart failure that causes increased

survival. The quality of life among the transplanted patients is in discussion. However, this surgery intervention causes many psychological and social problems such as depression and anxiety among the psychological ones and loss of work and problems in their family. It is important to consider the individual recourses used to achieve the healthy adjustments to social life. **Purpose:** The aim of this study was to estimate the situation of heart transplantation patients' life, verifying how were these patients before, during and after the transplantation, and how their return to society were done. **Procedure:** Interviews with women and men, after their heart transplantation, were done in Brazil and in Spain. The research is qualitative, and the patients informed about the process of the transplantation. We also use the Method of "Speech of a Collective Subject" (in Portuguese this method is named "Discurso do Sujeito Coletivo", Lefevre & Lefevre, 2005). The theoretic fundaments are the concept of "habitus" by Pierre Bourdieu, and we discuss the notion of "expertise" and "specialized competence" in our societal milieu, developed by Anthony Giddens. **Results:** In this research we analysed the effects of "habitus" by the return of heart transplanted patients to society and we found that "habitus" did not change significantly their lives. Differences between women and men were explored, in a gender analysis.

19

(#120) A SYSTEMATIC REVIEW IDENTIFYING PSYCHOSOCIAL RISK FACTORS FOR LIVING KIDNEY DONORS

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Living kidney donation is the preferred treatment for patients with end-stage renal disease, because of better long-term recipient and graft survival, shorter waiting list times, and better quality of life for the recipient than after postmortal donation. Although most donors recover well after surgery, about 10-25% of donors experience emotional or physical problems on the longer term. The current review provides an overview of psychosocial risk factors identified in the literature for longer term physical and emotional problems in living kidney donors. **Methods:** A literature search was conducted using PubMed, Embase, Web of Science and Psych INFO. Due to the limited number of pre-post donation prospective studies, cross-sectional and prospective quantitative studies were included. **Findings:** Psychosocial factors including psychological distress and unrealistic expectations before the donation, as well as fatigue and perceived negative donor-recipient relationship changes after the donation have been reported as predictors for longer term physical and emotional problems in living kidney donors. **Discussion:**

The limited number of studies on this topic provides a preliminary indication of specific psychosocial risk factors for developing longer term emotional and physical problems in living kidney donors. More prospective research is needed to get insight in pre-donation predictors of these problems, in order to enable better screening of potential donors and to focus pre- or post-donation interventions.

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(#131) DO KIDNEY TRANSPLANT RECIPIENTS HAVE A RIGHT TO KNOW ABOUT INCREASED LIVING DONOR RISK?

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Pre-transplant, LD health information is disclosed to the recipient only when it may affect recipient outcome, (eg risk factors for ID transmission, organ size, matching). Otherwise, LD risk profile is kept confidential, to promote LD autonomy and right to withdraw. Evolving practice warrants exploration of boundaries in this shared transaction, given that poor outcome on either side is known to affect the other patient's experience and satisfaction. LD acceptance criteria have expanded in the last decade, in response to organ shortages and reassuring LD outcomes data. In the US, more LDs are hypertensive, obese, or older. Each carries increased surgical and long-term risk in the general population; long-term LD data is lacking for these subgroups. These unknowns are shared with LDs during evaluation. Recipient reluctance to 'endanger' loved ones is a reported barrier to LDT (Waterman et al). In efforts to increase LDT, various methods have been employed to educate and reassure recipients, including home-based intervention (Rodrigue et al; Garonzik-Wang et al). Given tremendous recipient benefits of LDT, providers have inherent conflict in practice. When should a (perhaps reluctant) recipient be reassured, and when should the recipient be advised a LD candidate's status is outside known risk profiles? Risks of disclosure include higher rate of recipient LD refusal, and LD discomfort. Benefits include reduced recipient regret/guilt, and better informed consent. In non-directed donation or paired exchange, benefits are reduced, given the limited exchange of post-surgical outcomes. Even a narrow process of disclosure shifts provision of care. LDs should be advised of process, and consent to it. Disclosure of LD risks to the recipient should be considered after LD has met acceptance criteria, and wishes to proceed. Policy recommendations are warranted.

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(#150) COOPERATION WITH PATIENT/REQUEST FOR TRANSPLANTATION

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Cooperation is common affair, based on division of mastery and authority. Cooperation is not hierarchic. It's mastery is based on knowledge and experience, which is opposite to mastery based on role or position. In Poland, there is no obligation of having family's agreement for taking organs from dead relatives, because there is obligation of alleged agreement. In practice we are striving to get this agreement. If a family is against transplantation we dissent from taking organs. Positive attitude to medical care results in potential agreement for taking organs from dead relative. The point is to answer the questions: 1. Do the way of caring about a still living patient and the relation between doctor and patient's family have an influence on family's agreement for taking organs after death? 2. Does the way of caring about respondents have an influence on their agreement for taking organs? Research methods: 1. Questionnaire made of 18 questions. 2. A total of 173 people have participated in this research. Summary: Thirty-two percent of people are satisfied with the level of medical care. The majority of them are of the opinion that doctors are treating them without expected carefulness. Thirty-eight percent believe that doctors are capable to stop the therapy to get organs for transplantation. Conclusions: There is a necessity to recognize the correlation between correct doctor-patient relationship, trust gain and reliability of doctor's opinions. Patients' conviction that they are well treated may lead to regaining believe in straightforwardness of doctors' opinions, less dissatisfaction and criticism for medical care.

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(#159) UNSPECIFIED LIVING KIDNEY DONORS IN THE NETHERLANDS: AN OVERVIEW

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Background: The first unspecified donation was performed in 2000 in Rotterdam. After the 'Big Donor Show' in 2007, these unspecified living kidney donors are a rapidly growing source of living donors. Here we describe the unspecified donors who have been reported from 2000 until now in all transplant centers in The Netherlands. Methods: We asked the centers about the registered unspecified donors, the number of donors with a contraindication and their reasons and the number of unspecified donors who actually donated. Results: From January 2000 to January 2013, 284

unspecified donors started with the screening evaluation in all 8 centers. The median numbers of registered donors per center was 24 (range 7-121). After the screening process 106 donors have a contraindication to become a living donor. The reasons for refusal were 35 on their own initiative, 42 for medical reasons, 24 for psychological, and 5 for social-economic reasons. 142 donors have already donated their kidney, 10 donors are still waiting for an operation and 26 donors are in screening at the out-patient clinic. The blood type of these 142 donors was 75 times O (53%), 52 times A (37%), 8 times B (5%) and 7 times AB (5%). 50% of the donors were female. 56 donors donated directly to a recipient on the wait list and 86 in a domino-paired procedure: 68 made 2 transplants possible, 13 donors donated in a triplet construction and 5 donors in a quartet procedure. So these 86 unspecified donors were enrolled in chain constructions which resulted in 195 kidney transplants. Conclusion: In total 142 unspecified donors made 251 kidney transplants possible. With 86 chain constructions we have increased the number of kidney transplants by 127% from 86 to 195. All unspecified donors should be enrolled in chain constructions.

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(#168) METHODOLOGY OF RECIPIENT FOLLOW-UP STRATEGY

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Introduction: European Living Donor Psychosocial Follow-Up (ELIPSY) is a project co-funding by EAHC with the aim to develop a common methodology for all EU countries to assess/follow-up the psychosocial sphere of the Living donor (LD). Such follow-up methodology will be used as well to correlate the impact of the recipient's outcome. Objective: To design a recipient follow-up methodology using the best indicators with the purpose to link recipient's outcome to the living donor's follow-up. To find the variables tools that will be used in order to implement this methodology. Methodology: The recipient evaluation will be applied in two studies; a prospective study when the evaluation of the recipient will be assessed one year after the donation process and for the retrospective study when the recipient evaluation will be done in the same moment of donor assessment. To follow the recipient outcome an easy but rigorous questionnaire will be used which contains 16 questions. Two final versions of the questionnaire were created, respectively one for the evaluation of kidney recipients and the other one

for the evaluation of liver recipients. The questionnaire has to be filled in by the health professional responsible for the recipient. Results: The centers have adapted the application of the questionnaire to their characteristics and resources. The methodology was successfully applied in all the centers for the recipient of the donors included in the ELIPSY project, respectively 60 for the prospective study and 250 for the retrospective one. Both prospective and the retrospective studies developed the methodology independently. Discussion: The psychological outcome of LDs has been mostly investigated using quality of life questionnaires. The recipient outcome has an important impact of the psychosocial outcome after donation for all LDs.

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(#171) EUROPEAN LIVING DONOR PSYCHOSOCIAL FOLLOW-UP (ELIPSY)

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Introduction: ELIPSY is a project co-funded by EAHC with the aim to develop a common methodology for all EU countries to assess/follow-up the psychosocial sphere of the Living donor (LD). Objective: To contribute guaranteeing a high quality of living organ donation programs by creating a follow-up model for the LD's psychosocial well-being and quality of life (QOL), including the impact of the recipient's outcome on the donor and the donor's perception of the donation process. Methodology: Working tasks: Current psychosocial follow-up practices: LD's assessment/follow-up methodology among partner's centers. Donor follow-up methodology: Evaluate the psychosocial well-being and the QOL of the donor before and after donation, as well as the impact of donation process. Recipient follow-up: Design a recipient follow-up methodology to correlate the recipient's outcome with the LDs psychosocial well-being. Studies: Prospective: compare the psychosocial well-being and QOL of the donors prior to donation and 1 year post-donation, including the impact of the recipient's outcome. Retrospective: evaluate the long-term (2005-2010) impact through evaluation of psychosocial well-being, QOL and impact of recipient's outcome in donors. Results:

Survey about current psychosocial assessment/follow-up practices was conducted in 52 centres from 10 countries. Results show no consensus while performing LD psychosocial assessment/follow-up practices. Post donation psychosocial wellbeing of LDs and their satisfaction one year after donation are linked to their psychosocial profile before donation. Psychosocial risk and protective factors for LDs are identified by making group comparison. The psychosocial wellbeing of LDs and their satisfaction up to 5 years after donation is presented. Links between the psychosocial donor outcome and the recipient outcome are examined. Similarities and differences in the outcome among the countries are described. Conclusions: ELIPSY project contributes for the harmonization of LD psychosocial follow-up among Europe to guarantee a high quality of LD programs.

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(#172) LIVING DONOR OBSERVATORY (LIDOBS)

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Introduction: LIDOBS is a living donor (LD) multidisciplinary community composed by international experts on Living Donation interested to join efforts to improve the quality of the procedures and to establish international consensus in order to protect LDs health and safety through the development of international registries and the follow-up of living donation impact on donors' life. Objective: To develop a scientific platform with the aim to assure the transparency, quality and safety of living donation programmes. Methods: Focused on: Protection: To guarantee LD's protection by providing the donors the detailed information about the process, detecting new ethical dilemmas and being in coherence with the legislation issues. Registry: Implementation of a database model for LD registration and data analysis. Follow-up: Detection of the key points for the outcome and mid to long term impact of donation process on donor's quality of life and their psychological well being. Research: Scientific researches to be carried out from the professionals in order to identify the best practices, to develop quality indicators and to make recommendation for LD safety. Results: On line data base registry: Expand the actual registry including data from other countries. The long term objective is to have a registry that would be available for all the centres with LD programs to assure the improvement of the research and the quality of the procedure. LDs satisfaction survey: A tool developed in the EULID project, available in 12 EU languages. LIDOBS helps the continuity of using the tool. Con-

clusion: Promoting LD follow-up and international registration practices through research and data analysis, and establishing a consensus among professionals will benefit transplant professionals and will provide better quality of LD programs. LDs themselves will be the ultimate beneficiaries as they will improve their safety and health.

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(#173) LIVING DONOR REGISTRY MODEL-LIDOBS

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Introduction: The number of living donor (LD) transplantations has increased during these last years. However, despite this success, there is no central database for these practices in European level. Thus, Living Donor Observatory (LIDOBS) a multidisciplinary team of international experts on Living Donation are concerned into developing such registry to ensure a rich resource for European transplant information. Objective: To develop an on-line simplified database registry model of Living Donor (LD) with central database reports in international level. Methods: During the elaboration of the EULID project (2007-2009), a special working group was in charge to investigate the registration practices in Europe and develop an on-line simplified database registry. The database created is available on the following webpage www.eulivingdonor.eu and was previously tested for EULID participating countries. It contains three levels of data: First level – mandatory to fill in and includes such data as: donor and recipient nationality, residency, donor recipient relationship, type of living organ allocation, type of organ, donor survival. Second level – recommended data of clinical pre and post donation parameters. These data are also called security data and include: weight, length, kidney/liver biochemical parameters, blood pressure, re-intervention, pain, and other complications. Third level – excellence data which include LD satisfaction and psychosocial follow-up; representing the quality of donation programs. Results: Currently there are 1410 registered LDs with mandatory data from 19 centers in 12 European countries. 1255 out of these are kidney LDs. Meanwhile a different profile is presented for the 155 registered liver LDs which belong to 5 centers in 5 EU countries. This divergence is due to the superiority in number as well as operative centers for kidney LDs programs. Conclusions: The preliminary data registration and database evaluation show the importance of centralizing data on EU level to secure the quality and safety of living donation.

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(#176) SUPPORTIVE PSYCHOLOGICAL CARE OF A LIVING LIVER DONOR AFTER EMERGENCY SURGERY: A CASE STUDY

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Objective: Beside organic risk factors, there are important psychosomatic complications to consider when evaluating a living donor. In [1], a classification scheme of potential complications in living liver donors was proposed. It is the task of a psychosomatic examination to identify such risk factors prior to surgery; however, in some cases it is not possible to do so. We describe a case of a 40-year old liver donor who required extended psychosomatic care after donating to his 9-year old son. Due to emergency circumstances, no psychosomatic assessment was possible prior to surgery. Throughout the entire psychosomatic treatment of the donor, the recipient had to be kept in intensive care unit, due to post-operative complications. **Methods:** As psychotherapeutic approach, elements mainly of systemic therapy were applied, in order to take advantage of resource-oriented and supportive techniques. A low entry point into treatment was established by providing therapy sessions on demand of the patient. The wife of the patient took part in one of the sessions. Self-rating psychological tests included PHQ-D, SKID, and PSQ. **Results:** Initially, the patient showed symptoms of a sub-syndromal posttraumatic stress disorder (PTSD) with flash backs, emotional blunting, and insomnia, requiring psychosomatic outpatient treatment (Nadalin stage 3b). During therapy, the symptoms improved to a mild depressive episode, even though the recipient (son) stayed critically ill during the entire psychotherapy. Interestingly, initial self-rating was substantially better than the clinical picture, and did not change much during the course. **Conclusion:** In this case study, after emergency surgery of a living liver donor, a short-term systemic psychotherapeutic approach was helpful to achieve stabilisation and reduction of PTSD symptoms.

[1] Nadalin et al.: Current trends in live liver donation. *Transpl Int.* 2007, 20 (4): 312-330.

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(#180) MULTIDISCIPLINARY TEAM CHALLENGES IN ADOLESCENT LIVER TRANSPLANTATION: WHAT TO DO? – A CASE REPORT

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Introduction: Liver transplantation (LT) has become standard treatment in adults and children with good long-term survival rates and emphasis now on improving quality of life after LT. Adolescence is a period of

significant change both neurologically and developmentally. Associated with a health condition this can be a challenging time for young people (YP) and health professionals (HP) looking after them. We would like to illustrate this with a case study. **Case presentation:** The case study describes a 16 year old female with Asian/Muslim background, known to the Paediatric and Adolescent Liver Service at King's College Hospital, who was assessed for LT following decompensation of her liver disease. She was known to have complex social circumstances, having lived abroad and residing in the UK with her sister, with limited parental support. The LT assessment was complex because of difficult engagement with HP, challenging behaviour with regards to adherence to treatment, language barrier and lack of social support from her family. Her mental status and development were assessed to ensure she had capacity to consent to treatment. She was an inpatient both in her local hospital (initially admitted to an adult ward) and on our unit whilst waiting for LT. Her LT educator took on the role of coordinating her care in a cohesive way including adapting the LT assessment to the patient's needs (eg education, use of interpreter), facilitating communication between various teams of HP including her local services (eg visiting local hospital) and encouraging engagement from family. **Conclusion:** This case study highlights the need for a multidisciplinary team member to lead on coordinating the care of YP with complex psychosocial circumstances and their relationship with HP and by identifying the individual's challenges improve patient outcome after LT.

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(#182) CAN WE IDENTIFY A PATIENT EMPOWERMENT AFTER HEART TRANSPLANTATION?

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Background: This research is being conducted in Brazil (2007-2013) and in Spain (2012-2013) in order to compare the social representation of heart transplantation recipients from both countries. Heart transplantation is necessary when a damaged or diseased heart needs to be replaced by a healthy and strong donor heart. This procedure is realized only when all other therapies or health treatments do not produce results and the only practicable way to guarantee the life of this patient is the heart transplantation. How can this patient explain us about his or her feelings about the process of low quality of life until a maybe near-death experience and the emotional and physical healing after heart transplantation? **Purpose:** In order to analyse the social representation of heart transplantation recipients we have been observing how the patients feel during all the

process of transplantation. The aim of this study is to identify the empowerment of the patients in their social representations about their feelings in social inclusion and social integration with their family and the society. Procedure: Interviews with objective and open questions have been applied in heart transplants patients after their return to home. The patients informed us about their feelings, and in the open questions they tell us about their lives before and after the transplantation. These data have been analysed in a qualitative manner. Results: Mainly, there are no significant differences between Brazilian and Spanish heart transplantation recipients. Patients' empowerments were found in many interviews and very clearly expressed whenever the heart transplantation recipients compared their situation before and after the transplantation. The patients told us not only how happy they feel after having the chance to return to life, but how they feel in having the opportunity to live a second life.

AUTONOMY AT THE END OF LIFE

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(#50) SHOULD WE ACCEPT ORGAN DONATION EUTHANASIA: THE VIEW OF PROFESSIONAL COMMUNITY IN SLOVENIA

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Increased demand for transplantable organs is provoking changes in the medical and legislative frameworks. One of the emerging sources for donor pool expansion is the procurement of organs from patients after euthanasia (with the patient's consent). Slovenija-Transplant is the central professional institution leading all transplant activities in Slovenia. A brain death protocol is the only possible criteria for the organ procurement. Euthanasia is prohibited by Slovene law and by Code of medical deontological practice. The Slovene National Medical Ethics Committee supports the view that euthanasia should not be legalized. However being part of the Eurotransplant network Slovenia is already faced and challenged with the practice existing in the Eurotransplant region (e.g. organs from life support withdrawal donors can be offered). No studies or systematic open debates on the stands of Slovene professionals about the changing medical practice have been conducted yet. The context serves as a background for the anthropological research on the opinion of the Slovene professional community concerning the emerging issues in transplant medicine. More specifically, the objective of the study is to hear and evaluate the professionals' view on new sources and eligibility criteria for organ donation, patients' autonomy, trust and fears of the general public, conflicting situations of the medical staff in cases of donation after euthanasia and life support withdrawal donors. Methods: open

interviews with key actors in the field of transplant medicine, ethical boards and relevant governmental institutions; questionnaire will be sent to medical doctors (ICU and surgical units), one debate forum will be held. The paper will present the survey results and statement of Slovenian professional community about organ donation after euthanasia. Possibilities and limitations for the redefinitions of law and medical framework in Slovenia will be discussed.

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(#65) THE ROLE OF THE SPECIALIST NURSE FOR ORGAN DONATION IN DECISION MAKING FOR ORGAN DONATION: AN INTEGRATIVE REVIEW OF THE LITERATURE

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Objective: To investigate the impact of the Specialist Nurse for Organ Donation on consent rates for organ donation at the time of decision making by families. Design: Integrative review of the literature. Data Sources: Databases including Medline, CINAHL, Pubmed, EBSCO and BNI with language restriction of English only publications were searched to April 2012. Review methods: The literature was assessed and studies that met the inclusion criteria were included. Studies that did not investigate influencing factors, including the presence of a specialist practitioner for organ donation, on consent rates were excluded. Data was systematically synthesized using the CASP framework. Themes identified are summarised and compared. Results: Eight studies including cohort, quantitative, qualitative and case studies, a systematic review, and a RCT were reviewed. Factors that can be influenced by healthcare practitioners and services to facilitate families' decision making for organ donation fall into six broad categories: Information given during the request, perceived quality of care, understanding of brain death, specific timing of request, approach and expertise of the person making the request (collaborative requesting) and time spent with the family. Conclusions: A number of factors influence the outcome of decision making at the moment of request for organ donation, the most significant being the skills and timing of the individual making the request for consent for organ donation. Various studies indicate that having a Specialist Nurse for Organ Donation embedded in the process results in well informed decision making by the family of the potential organ donor. This is more likely to result in a positive outcome for organ donation and ultimately transplantation.

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(#93) CONTROLLED DCD IN SPAIN AND THE ABSENCE OF A SUPPORTING LAW: DOES IT ENTAIL ANY ETHICAL/LEGAL CHALLENGE?

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Controlled DCD protocols are prevalent in the US/UK/Canada/the Netherlands—countries with an opt-in system for organ donation – and Belgium, with a long/well reported history of end-of-life decision-making. It has proven to be a promising source of organs for transplantation, even the main source of DCD. These protocols have been for long rejected in Spain due to ethical/legal/strategic reasons, with a moratorium on cDCD agreed upon by the ONT in 1996. In spite of this, since 2009 several hospitals are performing cDCD in Spain. Objective: To answer these questions: Why now? Does the legal/moral implications of performing cDCD without a law supporting such protocols deserve some discussion? Method: Review of the current law/ethical consensus and current practice of cDCD in Spain. Spanish transplant coordinators generally apply the opt-out law in a soft manner: families are always consulted and can refuse the donation. If the family expresses no opposition, there is no need of explicit authorization to donate for the patient to become an organ donor. What model of consent is appropriate in cDCD is an open question even intending to maintain high OD rates without losing ethical credibility and/or public trust. The current Spanish legal definition of deceased donor by the cardiocirculatory criteria requires the irreversible cessation of cardiorespiratory functions always following an adequate period of resuscitation attempts. Two main arguments have been appealed to supporting cDCD: 1. The decision to withdraw life support is always prior to any consideration of OD: the latter cannot unduly interfere in the former 2. The protocol respects donors' autonomy by honoring their formerly expressed wish to become organ donors. Spanish current law does not support such cDCD protocols. Should changes be addressed before starting/continuing cDCD?

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(#118) ROLE OF DIAGNOSTIC IMAGING METHODS IN CONFIRMATION OF BRAIN DEATH IN CLINICAL PRACTISE

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Introduction: The diagnosis of brain death (BD) was first defined by an Ad Hoc Committee of the Harvard Medical School. Most countries define brain death as irreversible loss of brain function, including the brain

stem. With regards to confirmatory tests legislation ranges from not necessary to obligatory. In Croatia confirmatory tests are obligatory and currently 7 ancillary tests (TCD, DSA, MSCTA, MRA, EEG, Tc-HMPAO, Evoked potentials) are equally accredited. In our hospital TCD, DSA, MSCTA and evoked potentials were used to demonstrate the cessation of cerebral circulation. TCD was preferred due to bedside evaluation. Methods: A retrospective research was conducted with insight into medical history of patients who in 2012 were treated for severe brain lesions, which finally led to BD. After the clinical diagnosis of brain death was made, the appropriate confirmatory test was chosen. Results: In 31 out of 36 patients clinical diagnosis of BD was confirmed with ancillary test. TCD was positive in 13 patients, MSCTA in 9, evoked potentials in 6 and DSA in 3 patients. MSCTA was repeated twice in 3 patients and three times in 1 patient. In 3 out of 11 patients, who underwent MSCTA, BD could not be confirmed because of residual brain flow. 2 patients died during the observational period. Conclusion: Although most countries agree upon the definition of BD, there is a discrepancy between the means by which it is determined. We find that using confirmatory tests helps in diagnosis and also shortens the time in which it is established. This is very important with regards to transplantation program. We would like to encourage the discussion that would help define more uniform guidelines and standardise the usage and interpretation of ancillary tests.

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(#144) 'ODISEAS' CONSENSUS PROJECT: ORGAN DONATION IN SPANISH EMERGENCY AMBULANCE SERVICES

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Objective: Uncontrolled donation after circulatory determination of death (uDCDD) protocols are currently performed in 6 regions in Spain, and provide 10% of all cadaveric organs. Emergency medical services (EMS) play a crucial role in donor identification, family information, transfer to the hospital, and organ preservation. Concern has been raised on whether these tasks collide with ordinary EMS responsibilities. The objective of the ODISEAS consensus project is to enable a medical and ethical deliberative process on current uDCDD programmes in Spain, and to collectively explore ways of improvement. This paper will summarize the results of this deliberative process. Material and methods: Stakeholders (EMS, ICU and transplant professionals, along with bioethicists) will participate in a workshop to be held in March 2013. The points of agreement and disagreement will be identified and summarized in a document that members of the group will have the

opportunity to review and comment. Results: Conclusions will be drawn on the following topics: irreversibility of cardiac arrest; death determination according to cardiac criteria; selection criteria for potential organ donors; information given to families of potential organ donors; objectives sought during transportation: ongoing resuscitation attempts vs organ preservation procedures; uDCDD programmes logistics; efficacy of uDCDD programmes; alternatives and ways for improvement.

PUBLIC ISSUES

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(#08) THE GABOIR-REGISTRY WILL HELP TO IMPROVE THE HEALTH AND RISK COMMUNICATION

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Introduction: Transplant institutions in Germany are facing a persistent and severe shortage in organ donors. This shortage forces these institutions to search for new ways to expand the donor pool and explore novel therapeutic options. Therefore the Transplant-Center Freiburg performed the first German ABO-incompatible Living-Kidney-Transplantation in 2004. Since that time, over 500 ABOi-Living-Kidney-Transplantations were realized at 32 German Transplant Centers. Method: The GABOiR-Registry was planned in order to establish a data registry which offers the possibility to pool data gathered in all patients undergoing ABO-incompatible kidney transplantation in Germany. The registry is intended to allow for medical-scientific data analyses as well as economical analyses, with the intention of increasing the rate of living donor kidney transplantations in Germany and to improve the health and risk communication. The design and development of the registry for ABO-incompatible kidney transplantation patients provide important insights into success rates and safety issues concerning this novel therapeutic option in Germany and will help to further establish this technique as being reliable and safe. Results: The aims of this registry were to insure transparency with regards to economical factors involving the medical procedure, to establish the safety of the therapeutic measure by recording outcome data and adverse events and provide a sound foundation for continued documentation of medical long term outcome data of a novel therapeutic intervention. Conclusion: The registry furthermore will allow to gather and access medical long term data for scientific analyses and will help to increase the rate of living donor kidney transplantations in Germany. Moreover the analysis of the registered data will help to establish that ABO-incompatible kidney transplantation in comparison to

maintenance dialysis is highly cost effective and carries a significant socioeconomic benefit (first model calculations have provided evidence for this hypothesis).

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(#123) CO-OPERATION IN THE FIELD OF TRANSPLANTATION BETWEEN COUNTRIES OF THE BLACK SEA AREA

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The Black Sea Area (BSA) cooperation project is built on the experience of Committee on organ transplantation (CD-P-TO) and Moldova with strong involvement of France and Italy, that resulted in the revision of the transplantation law in this country and the establishment of a transplantation agency. Based on Council of Europe recommendations and the experience gained during the implementation of the Moldova programme, the experts proposed a project through which a regional strategy can be channelled to promote organ donation and transplantation in the Council of Europe member states from the BSA. The initial development of organ transplantation in the countries of the BSA (Armenia, Azerbaijan, Bulgaria, Georgia, Moldova, Romania, Russia, Turkey and Ukraine) dates from the late 1970s; mainly in the form of kidney transplants from Non-Heart Beating Donors (NHBD). At present, transplantation medicine in the BSA countries is still lagging far behind other European countries, little data is available and few transplants are being performed. The countries in the network seem to lack in organisation and internal infrastructure necessary to support such high level programmes. At the same time, some of the BSA countries made a very intensive work in the regulatory and legal framework in the last couple of years. It is important to note that organ donation and transplantation raise ethical and legal issues that need to be addressed according to various cultural backgrounds. Nevertheless, it is necessary to identify and share experiences from local initiatives which could provide models for implementation. The main aim of this project is the exchange of knowledge between the partners of the project and the transfer of best available knowledge and good practices in the field of transplantation from the EU member countries.

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(#136) A PSYCHOMETRIC ANALYSIS OF THE ROTTERDAM RENAL REPLACEMENT KNOWLEDGE-TEST (R3K-T) USING MULTIDIMENSIONAL ITEM RESPONSE THEORY (MIRT)

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Objective: Knowledge is one of the strongest motivators for promoting well-informed (shared) decision making. Nevertheless, there is no validated and standardized test of the level of knowledge among renal patients regarding kidney disease and all treatment options. Therefore, the objective of this study was to investigate the psychometric properties of a questionnaire that assesses patients' knowledge on kidney disease and renal replacement therapies for use in research and practice. Methods: A 30-item list was validated in 187 patients on dialysis and in 83 patients who were undergoing living donor kidney transplantation the following day. Additionally, the test was administered to 2 representative reference groups from the general population of Dutch residents (n = 515) and North American residents (n = 550) using a web-based survey. The test is available in 9 languages. Firstly, using the 2PL model from Item Response Theory we assessed Differential Item Functioning (DIF) for all the groups. Secondly, we examined the difficulty and discriminative properties of the questionnaire by using Multi-dimensional IRT (MIRT). Thirdly, norm-references were calculated. Results: Almost all items showed good discrimination and threshold parameters based on the fitted 2PL model. DIF was found for 5 redundant items which would distort trait level estimates. MIRT analyses were subsequently employed for the remaining 25 items. Two stable dimensions with 21 items were retrieved for which norm-references for the dialysis and transplantation group were calculated. The first dimension 'Dialysis and Transplantation' contains 11 items and the second dimension 'Living Donation' contains 10 items. Conclusions: This study resulted in a questionnaire, the R3K-T, which enables reliable testing of patient's knowledge on kidney disease and treatment options. Further validation of the R3K-T in more specific groups, such as living kidney donors, for which subscale scores may contain clinically relevant information would increase practical rigor of this test.

CHILDREN AS DONORS AND RECIPIENTS

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(#28) ETHICAL ISSUES IN USING SIBLINGS AS BONE MARROW DONORS

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Background: Healthcare professionals are often challenged by the myriad of ethical issues in using siblings, particularly those who are minors, as bone marrow donors. In the paediatric environment these challenging ethical dilemmas often arise in the fields of oncology and immunology. Ethical tensions arise in both the traditional use of siblings as bone marrow donors and in the use of saviour siblings. I will provide an ethical analysis of the issues and recommendations for good practice. Objectives: 1) Examine ethical issues in using siblings as bone marrow donors (i.e. parental consent and conflict of interest, the impact on family dynamics, and challenges in determining best interests of the donor child), 2) Examine ethical issues in the practice of saviour siblings (i.e. general ethical soundness of the practice, and the responsibilities of healthcare practitioners in counseling families about the practice of savior siblings), 3) Review of relevant legislation, and 4) Discuss implications for practice. Conclusion: Both the use of children as bone marrow donors and the practice of saviour siblings is ethically defensible in some circumstances. Healthcare practitioners should be equipped to educate children and their families about the risks and benefits of these practices and provide support and counseling. Identification and analysis of the ethical issues inherent in using children as bone marrow donors and the practice of saviour siblings will provide good practices for managing the ensuing ethical dilemmas.

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(#73) CHILDREN AND ADOLESCENTS EXPERIENCE OF DONATING BONE MARROW / STEM CELLS TO SURVIVING SIBLINGS

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Family and sibling relationships are affected in both positive and negative ways when a child in the family is afflicted with a severe illness during a long period of time. There are few national studies conducted in Sweden on how siblings who were bone marrow/stem cell donors think and feel about their experience. The aim of this study was to describe children's and

adolescents' experiences of donating stem cells to a sick sibling in Sweden. Method: A descriptive interview study with an inductive approach was performed using qualitative content analysis. The six participants were of both sexes and between 11-21 years. They were recruited from three different children's transplant centers, had donated stem cells before the age of 17 and all had surviving siblings. Result: The theme proud heroes without a choice summarizes the results. The category proud but anxious to be a donor describes a desire and a joy to help, but also concerns how they would endure the procedures and a concern of not being good enough as a donor. They were very anxious for their sick sibling. The category heroes without real choices in need of support highlights the strong family ties make them not having a choice situation for the donation, but a need support from their environment, healthcare and from receiving information but also all of its weaknesses. Conclusion: These donors were happy to contribute to the sibling's recovery. They were proud and gained a positive view of life from this experience. However the questions remain who will consider the psychological risks of these children and adolescents and if it is right to expose young siblings to this risk.

alysis is more adapted? Here, this one utterance from a patient haunted the physician, amplifying the distance, the opposite objectives and the disparate representations of the physician and his patient.

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(#80) USE AND MISUSE OF NARRATIVES THREADS IN TRANSPLANTATION. DOCTOR'S NARRATIVES

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A patient known from her first day of life had chronic renal failure from congenital uropathy, multiple surgeries and hospitalisations, dialysis followed by renal transplant for up to 13 years. She returned to haemodialysis awaiting for a second transplant. Questioned by a dialysis nurse in front of her somewhat distracted physician she said quietly: "You know, I have been sick all my life". The doctor happened to be seized by this answer and haunted by it since. What did the patient mean? Did she say it knowing the doctor would hear it? All of her life the doctor had tried to bring her as close to normal health as possible and for some long periods she looked as if she was enjoying quite a normal life. Does that means she wants to be sickly? Will she not try to get better? Wasn't she taking her meds appropriately and caused herself the demise of her graft? Would she do the same for a second graft? Can we really put her on the list? What is worth for her and her parents that we tried so hard to keep her alive? Her mother had said that raising a sick child was very difficult for her. Is the patient just mirroring the thoughts of her mother? Did the mother entertain the idea of a sick child? Was she gaining anything by having a sick child? What will the physician tell the family of the next unborn children with uropathy? Knowing that times have changed, transplants are doing better, di-

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