

# Learning Workstream

**Combatting patients'  
uncertainty and fear**

**In  
collaboration  
with**



**Group  
members**

**Peter Carstedt**  
Sweden

**Pisana Ferrari**  
Italy

**Anna Forsberg**  
Sweden

**Nichon Jansen**  
The Netherlands

**Hannah Maple**  
UK

**Emma Massey**  
The Netherlands

**David Paredes  
Zapata**  
Spain

## LEARNING WORKSTREAM

### Combatting patients' uncertainty and fear

A major survey with the aim of grasping the lived experience and main concerns of 330 transplant recipients from more than 27 countries presented in the Learning Workstream Report showed they faced a life of uncertainty, with fear of graft rejection being the highest concern.

Anna Forsberg-R.N., Professor in Transplant Nursing at Lund University and Skane University Hospital, Sweden, presented the survey results which found infection risk — a live issue with COVID-19 — and striving to live a healthy life were key concerns, as well as worries about the donor's family and how the donor died.

While many seek support for these issues, some patients are not prepared to talk about them, the ESOT survey, carried out in collaboration with the European Transplant Patient Organization, found.

Prof Forsberg said the results demonstrated that health professionals should pay attention to the psychological aspects of the recipient, take the patient seriously and offer person-centred care.

Adopting well-known principles used in rehab medicine to develop and implement post-operative plans by transplant professionals would facilitate adaptation and help organ recipients regain a new, but different life, she said.

In the Focus session, two transplant recipients shared their inspirational and emotional stories about how they cope with these concerns on film and also in person in the Q&A session, moderated by Emma Massey who is a clinical psychologist from the Erasmus Medical Center in the Netherlands.

Emma Dalman, 34, from Sweden, received a heart in 2013 aged 27. She appeared live from hospital where she is being treated for an infection — one of the fears noted by the survey respondents.

She worries about rejection — sometimes more, sometimes less — made worse by the fact that two close friends Sophia and Martha died within months of each other following transplants.

This has made the former dietician at times scared to go to sleep at night for fear of dying like her friend, and worried about her future and therefore reluctant to save for her retirement.

She said: "I have time periods when I don't worry so much and everything is happy and golden, then there are times I'm convinced I will not live to see retirement. When I am more down, stressed, a lot is happening at once, or if someone I know passed away, it's tough."

#### Taking control

However in the last year she has taken control and started to save for her retirement and other plans, including become a student in environmental issues and sustainability. She said: "I realised I have to live life to the full and appreciate the second chance I have been given. My parents and friends mean the world to me, I have to live on for them as they have to live on for me."



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”

Emma Dalman, aged 34

Austrian airline pilot Klaus Granegger, aged 65, received a kidney in 2012 after being on dialysis for five years which had halted his career.

But within a year of receiving his 'perfect kidney,' keeping fit and active with Nordic walking, he was well enough to resume his job in the sky and worked as a pilot for an airline in Greece for a further six years.

He doesn't fear graft rejection. He prepared for his transplant with psychological support, seminars and meditation and keeps mentally positive now. He told the TLJ "For me, the kidney lasts as long as I will live. I'm sure about it. I feel perfect, I feel full of power, even more healthy than ever.



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*If I have to die now for any reason, I can say I had the best life. I think I will live for the next 20 years healthy and wealthy for the rest of my lifetime.*

”

Klaus Granegger, aged 65

Both Emma and Klaus have daily rituals where they give thanks to the donor who saved their life. For Klaus, this happens early. "Every morning I do a short prayer, thank you for being healthy, thank you the body, for the soul, thank you for my life, for this donor." He has even given his kidney a name, Lullaby.

For Emma, she has a notebook where, every evening, she writes down three things she is grateful for — and every day she includes that fact that her heart is still beating. "I don't take that for granted any more. It helps me see things more clearly, appreciate life and everything I have been given, it's a really awesome life."

### Seeking support in difficult times

Emma Massey said their stories confirmed the importance for patients of taking control, making plans, being positive, staying fit and seeking support in more difficult times.

In the Live Q&A, Pisana Ferrari, patient advocate, founding member of the Italian Pulmonary Hypertension Association and a double lung transplant recipient of 18 years, said it was a great presentation which resonated with her everyday life.

She is always concerned at having all her pills never running out, as they are not available over the counter, and she schedules check-ups months in advance.

After her transplant she feared she would never see her daughter grow up, but now she has watched her graduate and get married.

Pisana Ferrari said: "I commend ESOT for doing this initiative...There's a need for patients to have more information and guidance, things we can do and not do, there's a big gap there... patients are often quite lost and lacking vital information."

### Dealing with uncertainty

In the final session Matilda Almgren R.N., PhD presented a framework of uncertainty after organ transplantation involving the complex process of adaptation and how the organ recipients try to balance expectations and disappointments while adapting to a life with a transplant. Professor Forsberg then finally presented a different perception of graft rejection from the transplanted persons' perspective, an understanding quite different from the professionals' view. A platform was made for future discussions at the ESOT congress in Milan, 2021.

## SPECIALTY SESSIONS

EDTCO | ELPAT | ETAHP

LEARNING WORKSTREAM

UNCERTAINTY IN ILLNESS: IMPACT ON PATIENT

SELF-EFFICACY AND SELF-MANAGEMENT



In collaboration with the transplanted patient group

## Controlling the uncontrollable

Transplant patients view their body and its functioning in a very different way to the medical perspective so clinicians should ask questions to fully understand their mindset, and help them navigate their future around fear of graft rejection, the Learning Workstream session heard.

Anna Forsberg, Professor in Transplant Nursing Lund University and Skane University Hospital, Lund, Sweden, said clinicians talk about immune graft rejection on a cellular level but the patients view it in terms of the consequences for daily life.

Previous research has shown they experience a 'constant ever present perpetual threat.'<sup>12</sup>

Prof Forsberg interviewed 16 people aged 19–65 in a new study. She found they are constantly striving to control this 'invisible threat' with a variety of mechanisms, including relying on fate or luck, adhering to medicines and immunosuppressants and being healthy and avoiding alcohol.

Prof Forsberg suggested a new approach for clinicians. She said: "Ask the patient: 'when I say graft rejection, how do you perceive it?' Listen to the patient narrative, instead of giving all this medical info which does not make sense."

Matilda Almgren, a registered nurse specialising in intensive care, from the thoracic intensive care unit at Skane, said that patient follow up concentrates on survival and graft rejection, when the person receiving the follow up simply wants to return to normal healthy life.

### Expand follow-up

Her research showed there is uncertainty over survival and recovery — that it is not as much as expected and not as quickly as hoped — as well as struggles with performance and relationships, and expectations from family and friends.

She said some patients felt abandoned, missed healthcare support and that they are not taken seriously when they reveal uncertainty about the future, such as questions about 'will I be able to see my kids grow up.' She concluded that follow-up should be broadened and not focussed on medical issues only.

In the live Q&A, Ms Forsberg continued her theme. She advised clinicians to 'align with the patient' and admit their own lack of control. She added: "Patients have taught me almost everything I know about what it means to be a human and a recipient."

Angelika Widhalm, founder and president of the patient organization Hepatitis Aid Austria — Platform Healthy Liver (HAA), and a liver recipient, said she agreed a different approach was needed to give patients the right support.

She said: "Patients say, 'can you prepare me for what is coming up, what does this mean for my family?' These are coming to Patients' Associations — so we need to find a way to implement Patients Associations more into the whole system."

<sup>12</sup> Nilsson M, Persson L-O, Forsberg A. Perceptions of experiences of graft rejection among organ transplant recipients— striving to control the uncontrollable. J Clin Nurs 2008; 17: 2408–17.

## Join us at ESOT Congress 2021

This year, the ESOT Congress is being held in Milan from 29 August - 1 September 2021 and will be taking place online and in person.

Through a multidisciplinary approach, the congress will feature the latest research and innovation from the most prominent scientists and physicians in the field of organ transplantation.

Guaranteed to motivate and inspire, this landmark meeting will provide a unique opportunity to connect science and medicine.

## Share Your Research

The ESOT Congress serves as a premier platform for researchers from across the globe to present their organ transplantation research.

We invite clinicians, scientists, researchers, nurses and allied health professionals to submit abstracts and present their latest transplant research.

## Programme

The scientific programme has been developed based on five key domains that encompass the most relevant topics in organ transplantation.

To find out more, please visit:  
[esotcongress.org](http://esotcongress.org)

## About ESOT

### Objectives

The European Society for Organ Transplantation (ESOT) was founded over 30 years ago and is dedicated to the pursuit of excellence in organ transplantation. Facilitating a wealth of international clinical trials and research collaborations over the years, ESOT remains committed to its primary aim of improving patient outcomes in transplantation. With a community of over 8,000 members from around the world, ESOT is an influential international organisation and the facilitator of the biennial congress which hosts approximately 3,500 experts who come to meet to explore and discuss the latest scientific research. ESOT attracts the foremost transplantation experts to work in its committees and sections, and has an impressive track record in supporting research, supporting extensive education, and promoting changes in European policy.

### Mission, Vision and Values

ESOT is committed to advancing research and clinical practice in the field of organ transplantation to improve the lives of everyone affected. The combined efforts of all stakeholders in the public and private sectors, and civil society are essential to halting and reversing the need for organ transplantation. As such, ESOT acknowledges that every voice is valued.

To find out more about TLJ 2.0, please visit:  
[tlj-esot.org](http://tlj-esot.org)

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Contact us:  
[askme@esot.org](mailto:askme@esot.org)



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**ESCTJ2.0**  
TRANSPLANTATION LEARNING JOURNEY  
• online experience • 15-17 November 2020

**Thank you**