

PROGRAMME

Friday 26 April 2019 - Slowacki Theatre

17:00-19:00	Opening Moderators: Emma Massey (ELPAT chair) & ELPAT vice chair (TBA) Opening Welcome address	Slowacki Theatre Emma Massey (Netherlands) Piotr Przybyłowski, President of the Polish Society (Poland)
17:20	Keynote lecture Current and emerging challenges in transplantation ethics James Childress (University of Virginia, USA)	
	Plenary dialogue 1 Moderators: Willem Weimar (Netherlands) & Gabriel Oniscu (UK)	
	International kidney exchange: opportunity or exploitation?	
17:50	Global kidney exchange: the evidence to date Michael Rees (USA)	
18:10	Exploring international exchange from a European perspective: hurdles and opportunities Bernadette Haase (Netherlands)	
18:30	Dialogue	
19:00-21:00	Networking event	

Saturday 27 April 2019 - Auditorium Maximum

08:30-10:00 **Plenary Dialogue 2**

Moderators: Rutger Ploeg (UK) & Krzysztof Zieniewicz (Poland)

Is opting out the solution for the organ shortage?

Opting out in the UK: a matter of principles and pragmatism in public affairs

Antonia Cronin (United Kingdom)

The ethics of consent policies and the role of families in deceased organ procurement

David Rodríguez-Arias (Spain)

Dialogue



10:00-10:30 **Coffee break**

Focus sessions 1 – 2 – 3

10:30-12:00 **1. Public views, trust and (mis)understanding of death**

Moderators: Dale Gardiner (UK) & Michael Bos (Netherlands)

When are you dead enough to be an organ donor - the German experience

Axel Rahmel (Germany)

'They will finish me off before I am dead' - challenges & opportunities in organ donation from a multi-ethnic and multi-faith UK population

Gurch Randhawa (UK)

LB30 General trust and organ donation in Poland Krzysztof Pabisiak /Joanna Krotofil (Poland)

Dialogue

10:30-12:00 **2. Moral courage and distress in transplantation**

ETAHP @ ELPAT joint session

Moderators: Fabienne Dobbels (Belgium) & Marjo van Helden (Netherlands)

What do we struggle with ethically and morally in the pre-transplant phase? In this focus session Professor Leino-Kilpi will introduce the concept of moral courage

(the theory, prevalence and examples). Subsequently, transplant professionals will present and discuss clinical cases from daily practice.

Moral courage explained

Helena Leino-Kilpi (Finland)

Case study presentations:

Anna Forsberg (Sweden) & Marjo van Helden (Netherlands)

Dialogue



- 10:30-12:00 3. Getting more out of transplantation: addressing modifiable risk factors - EKITA @ ELPAT joint session**
Moderators: Tomasz Kruszyna (Poland) & Christina Papachristou (Germany)
- Obesity among transplant patients Diederik Kimenai (Netherlands)
- Immunological barriers in renal transplantation: how to get around them? Karine Hadaya (Switzerland)
- Dialogue

12:00-13:30 Lunch

12:15-13:15 Lunch Symposium – supported by SANDOZ A Novartis Division

Remote health after transplantation

Moderator: Emma Massey (Netherlands)

- 1. Remote Tx patient care: From a Psychosocial point of view**
Fabienne Dobbels (Belgium)
- 2. Remote health after transplantation: From a Practical point of view**
Mario Schiffer (Germany)
- 3. Remote Tx patient care: From a Legal point of view**
Gerhard Nitz (Germany)

Full oral sessions 1 –2 – 3

- 13:30-15:00 1. Developing dialogue on opting out**
Moderators: Bernadette Haase (Netherlands) & David Rodríguez-Arias (Spain)
- OP01 UK ICU / ED clinicians attitudes to deemed consent for organ donation (“opt out”) Dan Harvey (UK)
- OP03 Switching to an opt-out system in the Netherlands. Conclusions to be drawn Marina Morla (Spain)
- OP04 Legislative framework and attitudes of Greek health care professionals, students and general population about organ donation: a synthesis of studies Georgios Manomenidis (Greece)
- OP05 Opt-out donor legislation, quo vadis Belgica? Diethard Monbaliu (Belgium)
- LB01 Comprehensive study of an attitude of medical students towards organ donation in Russia: first results Aleksandr Reznik (Russia)

- LB02 Translation of “Western approach” to effectiveness of donation promotion strategies: identification of barriers and borders for societies with traditional beliefs Oleg Reznik (Russia)
- LB03 Allocation in The Netherlands: the law and practicalities Eline Schiks (Netherlands)

13:30-15:00 2. Living organ donation

Moderators: Frank Dor (UK) & Aisling Courtney (UK)

- OP06 Living kidney donor knowledge of provided information and informed consent – a prospective nationwide inventory study E.Q.W. Spoon (Netherlands)
- OP07 Cost-effectiveness of a home-based educational programme on renal replacement therapies: a proof-of-principle study Steef Redeker (Netherlands)
- OP08 Expanding live donor kidney transplantation through advocacy training and social media Macey Henderson (USA)
- OP09 Ethical evaluation before living kidney transplantation: a pilot study Karine Hadaya (Switzerland)
- OP10 The Swedish experience of anonymous living donors Annette Lennerling (Sweden)
- OP11 What lessons can be learned from the UK experience of (relinquishing) anonymity? A survey study among unspecified donors and recipients? Lisa Burnapp (UK)
- OP12 Unspecified (non-directed, altruistic) kidney donors in the UK are becoming younger and take longer to donate than specified kidney donors - results from the BOUnD study Hannah Maple (UK)
- LB04 Non-simultaneous kidney exchange cycles in resource restricted countries without non-directed donation Michael Rees (USA)

13:30-15:00 3. Organ trade and paid donation

Moderators: Frederike Ambagtsheer (Netherlands) & Farhan Navid Yousaf (Pakistan)

- OP13 How informed and voluntary is their "informed consent"? "informed consent" by commercial living donors (kidney vendors) insights from a single center in Iran Christina Papachristou (Germany)
- OP14 Pakistan’s kidney trade: a form of organized crime Athina Koufou (Greece)
- OP15 How to deal with unprovable suspicion of organ trade? Lada Zibar (Croatia)
- OP16 Lack of organized kidney transplant activity in the Balkans - real danger for organ trafficking! Ninoslav Ivanovski (F.Y.R. Macedonia)
- OP17 Organ transplantation for foreign nationals in Canada: a survey among transplant professionals Marie-Chantal Fortin (Canada)
- LB05 Recent developments in transplant tourism into China and transplant abuse in China David Matas (Canada)
- LB06 Organ trafficking: the Portuguese experience in developing a legal framework and a code of conduct for healthcare professionals for the management of patients and report suspected cases to law enforcement authorities Ana Pires Silva (Portugal)
- LB07 Procure to cure Antoine Estephan (Lebanon)

15:00-15:30 Coffee break

Workshops 1 – 2 – 3 – 4

- 15:30-17:30** **1. Lessons learned from the implementation of soft-opt out systems of organ donation**
Workshop facilitators: Antonia Cronin (UK), Jane Noyes (UK) & Pawel Luków (Poland)
- Learning objectives*
This workshop will explore issues related to the implementation of soft-opt out systems of organ donation across Europe.
- 15:30-15:40** Introductions and workshop overview Antonia Cronin
- 15:40-16:20** *Setting the context:*
Overview of organ donation and implementation of a new soft opt-out system of organ donation in:
- Poland Pawel Luków
 - Wales, UK Jane Noyes
- 16:20-16:30** Small group discussions: How does your system of organ donation compare with the old and new system in Poland and Wales, UK?
What do you think about the implementation strategies?
- 16:30-16:45** *Understanding the impact: What happened when the soft-opt out system was implemented in Wales?*
- Findings of first robust process evaluation including findings with family members Jane Noyes
 - Impact of media campaign on intended behavior
 - Donor consent rates
 - Number of transplants performed
- 16:45-16:55** Small group discussions: What do these findings say to you? Pawel Luków
Facilitator to invite sharing of key points with the main group. Jane Noyes
- 16:55-17:10** *What happened as a consequence: Changes to implementation strategies and practice in Wales?* Jane Noyes
- Overall lessons learned
 - New media campaign
 - New staff training and clinical protocols
 - Introduction of additional communication approaches derived from field of crises negotiation
 - Acknowledgement that change is complex and happens slowly
- 17:10-17:25** Small group discussions: Would you have done anything differently? Pawel Luków
Facilitator to invite sharing of key points with the main group. Jane Noyes
- 17:25-17:30** *Summary* Antonia Cronin
- 15:30-17:30** **2. Unspecified (anonymous/non-directed) donation – what is new on the horizon?**
Workshop facilitators: Annette Lennerling (Sweden) & Frank Dor (UK)
- Learning objectives*
This workshop will explore issues around unspecified kidney donation (UKD). Lectures will be given on what the primary motivations are to become an UKD and what the primary limitations to UKD are. Furthermore, we will learn that anonymous kidney donors wish to normalize anonymous donation and about mental health in donors post UKD. The discussion will pertain to the challenges and opportunities of UKD.

Summary of workshop

Frank Dor and Annette Lennerling will moderate the workshop and lead the discussions about challenges and opportunities of UKD that will take place after each talk. Nizam Mamode (UK) will share outcomes of the BOUND study, about understanding barriers and outcomes of UKD from different perspectives. How to raise awareness about unspecified donation will be presented by Lisa Burnapp (UK). A talk on normalizing UKD will be given by Cody Maynard (USA) and finally Willij Zuidema (Netherlands) will present the mental health among unspecified living kidney donors after donation (MEGA study). We will have a dialogue with all workshop participants in the end.

15:30-16:00	Understanding barriers and outcomes of unspecified kidney donation from different perspectives (outcomes BOUND Study)	Nizam Mamode (UK)
16:00-16:30	Raising awareness about unspecified donation	Lisa Burnapp (UK)
16:30-16:45	Dialogue	
16:45-16:53	OP18 Take us off your pedestal: normalizing anonymous kidney donation	Cody Maynard (USA)
16:53-17:01	OP19 Mental health among unspecified living kidney donors after donation: MEGA study	Willij Zuidema (Netherlands)
17:01-17:16	Dialogue	

15:30-17:30 3. Conflict organs: organ trade in times of forced migration
Workshop facilitators: Frederike Ambagtsheer (Netherlands) & Seán Columb (UK)

Background:

Over the past decade the organ trade has generated significant dialogue and discussion among medical professionals, policymakers and scholars. While much has been written about the threat of organ trafficking and the moral, ethical, and legal challenges that the organ trade presents, there is a deficit of empirical evidence into how the trade is facilitated within and between countries. Moreover, there is a lack of critical engagement with the implications of current legislative and policy mechanisms in response to the organ trade and the impact this can have on vulnerable populations, i.e. asylum seekers and refugees.

This workshop aims to address methodological issues in organ trade research and brings together empirical research from active scholars in the field to advance knowledge and understanding of the organ trade and the conditions behind it. The workshop starts with a methodological critique by Dr. Ana Manzano on organ trade research. Then, Dr. Farhan Navid Yousaf and Dr. Sean Columb will present their research findings on migrants, asylum seekers, and refugees who are being targeted for their organs. The extent to which this is happening, and the reasons why require further consideration, particularly from a comparative perspective(s). The empirical findings presented by the participants of this workshop explore the relationship between the organ trade, conflict and forced migration in different geo-political contexts.

15:30-15:50	OP20 Mythical numbers and the evidence for trafficking of human beings for the purpose of organ removal: a methodological critique	Ana Manzano (UK)
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15:50-16:15	Social world of organ trafficking: intersecting vulnerabilities and episodes of exploitation	Farhan Navid Yousaf (Pakistan)
16:15-16:40	People smuggling and the organ trade on the central Mediterranean route	Seán Columb (UK)
16:40-17:30	Panel dialogue with the 3 speakers	
15:30-17:30	<p>4. The child recipient and donor – life and death balance</p> <p>Workshop facilitators: Marion Siebelink (Netherlands) & Angie Scales (UK)</p> <p><i>Learning Objectives</i></p> <ul style="list-style-type: none"> • Consider and discuss ethical dilemmas that face families whose child waits for a transplant and the impact on the family. • Discuss decision making when a child is the donor, whose decision and how health care professionals may impact on this. • Consider the use of social media where a child is the donor, it's impact on donor and recipient families positive and negative. 	
15:35-16:05	<p>Introduction and welcome</p> <p>Child Recipient Story (James' Story)</p> <ul style="list-style-type: none"> • Coping with a child needing a transplant • How to manage feelings around the death of another child • Hopes and fears for the future 	<p>Marion Siebelink (Netherlands)</p> <p>Kate Lewis (UK)</p>
16:05-16:20	<p>Child Donor Story (Story of Erin who at 5yrs wanted to donate)</p> <ul style="list-style-type: none"> • Children's perception about what happens to them and how this affects decision making • Always mentioning the consideration of donation – research into parental perception of worthiness of child's life (research) • Dealing with not hearing from recipient families 	Angie Scales (UK)
16:20-17:20	<p>Group work – includes accepted abstracts</p> <p>1 hour (choice of topics, circulate round groups) pose an ethical dilemma for each topic.</p> <ul style="list-style-type: none"> • Group 1 Recipients and recipient families managing feelings around the death of another child. Psychological impact on families waiting for an organ. • Group 2 How to frame the subject of donation when a child is the donor – abstract presentation and discussion. Children making decisions regarding donation at a young age, consent, competence Should donation always be mentioned to families whether a possibility of not? • Group 3 Directed deceased donation in children – abstract presentation and discussion. How do we manage social media and donation when children are involved? Discuss differences between countries and if there are similar situations where adults are involved. 	
	OP21 Directed deceased organ donation in pediatrics in the era of social media	Laura Miller-Smith (USA)
	OP22 Re-framing the best interest standard of consent for paediatric organ donation	Anji Wall (USA)
17:20-17:30	Feedback and Conclude	Marion Siebelink & Angie Scales

Full oral sessions 4

17:30-18:45

4. Country perspectives

Moderators: Nichon Jansen (Netherlands) & Gurch Randhawa (UK)

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| OP23 | Transplant issues and organ donation in Nepal | Kiran Jang Kunwar (Nepal) |
| OP25 | Organ sharing program in Middle East countries: barriers and solution | Meysam Mojtabaee (Iran) |
| OP26 | Abuse of brain death definition in organ procurement in China | Huige Li (Germany) |
| OP27 | Psycho-social, ethical and legal training for transplant coordinators to improve capacity and enhance organ transplantation in Bulgaria and the region | Assya Pascalev (Bulgaria) |
| OP28 | 'Don't let them know he's going to be an organ donor.'
Collusion requests from donor families | Crystal Lim (Singapore) |
| LB08 | Transplantation legislation and practice in Turkey | Mehmet Haberal (Turkey) |

Brief oral sessions 1

17:30-18:45

1. Patients and professionals perspectives

Moderators: Karina Hadaya (Switzerland) & Nizam Mamode (UK)

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| OP29 | Factors influencing access to kidney transplantation (fiat): a protocol of a qualitative study on stakeholders' perspectives | Katja Kloss (Netherlands) |
| OP30 | Shared decision making in kidney patients: involvement in decisions regarding the quality of deceased donor kidneys | Lothar van Hoogdalem (Netherlands) |
| OP31 | Full body transplantation, is it allowed? | Kristof van Assche (Belgium) |
| OP32 | Professional ethics – a framework for nurse anaesthetists' participating in the organ donation process in the perioperative setting | Anne Flodén (Sweden) |
| OP33 | Canadian transplant nephrologists' perspectives on the decision making process of accepting or refusing a kidney from a deceased organ donor | Marie-Chantal Fortin (Canada) |
| OP34 | Transplant candidates' and transplant recipients' perspectives
On the decision to accept or refuse an offer for a deceased donor kidney | Marie-Chantal Fortin (Canada) |
| LB09 | Does people talk with the family about organ donation intentions? | Irena Milaniak (Poland) |
| LB10 | Listening music during arteriovenous fistula surgery decreases patient anxiety | Sanem Cimen (Turkey) |

Late breaking 1

17:30-18:45

1. Living donors & recipients

Moderators: Mirjam Tielen (Netherlands) & Sylvio Nadalin (Germany)

- LB11 Gender disparity between living donors and the recipients in kidney transplantation: results of a single center Sayin Burak (Turkey)
- LB12 Domino liver transplant: a different living organ donation Inés Mega (Portugal)
- LB13 Evaluation of compliance in young transplant patients Robin Weyts (Belgium)
- LB14 Psychological response to heart transplantation – single center experience Irena Milaniak (Poland)
- LB15 Long-term experiences and ethical views in families after bone marrow transplantation between siblings as children results of a retrospective qualitative study Christoph Rehmann-Sutter (Germany)
- LB16 Body sharing within the family. Philosophical aspects of bone marrow transplantation between siblings as children Christina Schües (Germany)

Sunday 28 April 2019

08:30-10:00 Plenary Dialogue 3

Moderators: Giuliano Testa (USA) & David Shaw (UK)

Challenges and opportunities in vascularized composite Allotransplantation

Achievements and challenges in VCA

Gerald Brandacher (USA)

Informed consent in VCA

Elisa Gordon (USA)

Dialogue



10:00-10:30 Coffee break

Focus sessions 4 – 5 – 6

10:30-12:00 4. Uterus transplantation versus surrogacy?

Moderators: Gerald Brandacher (USA) & Julian Koplin (Australia)

Informed consent in uterus transplantation

Giuliano Testa (USA)

Psychological aspects of uterus transplantation

Stina Järholm (Sweden)

Dialogue

10:30-12:00 5. Beyond survival? Determining outcomes that matter

Moderators: Lisa Burnapp (UK) & Marie Chantal Fortin (Canada)

What outcomes matter to kidney transplant recipients?

Allison Tong (Australia)

Living donor outcomes that matter (most): What can we learn from asking them directly?

Zeeshan Butt (USA)

OP36 Fatigue in kidney transplant recipients and patients on maintenance dialysis - using the promis-57 questionnaire

Sumaya Dano (Canada)

LB17 The effect of liver transplantation on patient-centred outcomes: a propensity-score matched analysis

Alessandro Sgrò (Italy)

Dialogue

- 10:30-12:00 6. Informed consent for research and ante-mortem interventions**
Moderators: Axel Rahmel (Germany) & Anne Flodén (Sweden)
- Bio-banking in organ donation – ethical limits to data collection Rutger Ploeg (UK)
- Ante-mortem interventions in DCDD: the use of ECMO Anne Dalle Ave (Switzerland)
- OP37 Examining the process of consent for interventional donation research Jesse Cooper (UK)
- OP38 Consent to research on organs and tissues retrieved from deceased donors: ethical and regulatory issues in Belarus Andrei Famenka (Belarus)
- OP39 The legitimacy of ante-mortem interventions when consent to donation is provided by third parties Henrietta Consolo (UK)
- Dialogue

12:00-13:30 Lunch

Full oral sessions 5 – 6 – 7

- 13:30-15:00 5. Psychology and behaviour**
Moderators: Anna Forsberg (Sweden) & Zeeshan Butt (USA)
- OP40 Living donor kidney transplantation and psychological assessment of donors-recipients in Greece Thalia Bellali (Greece)
- OP41 Living kidney donors' experience of their own bodies Katarzyna Kowal (Poland)
- OP42 E-health psychosocial care for living kidney donors: an implementation study Lieke Wirken (Netherlands)
- OP43 Creating an on-line transplant education hub for patients and frontline staff to promote kidney transplant education outside the transplant center – interim report Dmitri Belenko (Canada)
- OP44 Cannabis and alcohol use and access to organ transplantation: an ethical analysis Marie-Chantal Fortin (Canada)
- OP45 Evolving self-management networks: the psychosocial impact of sport-related communities Carl Bescoby (UK)
- OP46 Promoting medication adherence and self-management among kidney transplant recipients (mars-trial): development of an intervention protocol Mirjam Tielen (Netherlands)
- OP47 Improving understanding of health beliefs and immunosuppression adherence in long-term kidney transplant patients through pharmacist-led consultation and medicines optimisation Antonia Cronin (UK)
- 13:30-15:00 6. Deceased donation: the role of the family**
Moderators: Anne Dalle Ave (Switzerland) & Simon Messer (UK)
- OP48 The “disram” approach: a research-based model for family care in deceased organ donation Anja Marie Jensen (Denmark)
- OP49 ‘Actually i am totally pro-donation’: reasons, regret, and recommendations from Danish families who said no to organ donation Anja Marie Jensen (Denmark)
- OP50 Where quality counts: the perceived influence of in-hospital care on family donation decisions Wendy Walker (UK)

- OP51 Donation after circulatory death - an expanded opportunity for donation appreciated by families Marit Helen Andersen (Norway)
- OP52 Increasing consent and assent rate for organ and tissue donation: communication about donation-telephone advice by psychologist Safina Mahmood (Netherlands)
- OP53 Role of coordinator-donor conformity in success rate and quality of family consent Meysam Mojtbaee (Iran)
- OP54 Contextualising the ethics of organ donation after circulatory death in the UK: a qualitative study Jessie Cooper (UK)
- OP55 Healing from organ donation trauma Masoud Mazaheri, Iran)

13:30-15:00 7. Public issues and communication

Moderators: Gabriel Danovitch (USA) & Chris Papadopoulos (UK)

- OP56 Public knowledge and attitudes towards consent policies for organ donation in Europe. A systematic review Alberto Molina Pérez (Spain)
- OP57 The role of the family in deceased organ procurement Janet Delgado Rodríguez (Spain)
- OP58 To donate or not to donate: an empirical-ethical study of moral attitudes to organ donation posters Solveig Hansen (Germany)
- OP59 Values in the press regarding organ donation and transplantation María Victoria López (Spain)
- OP60 International student survey on knowledge and attitudes towards donation and transplantation of organs Sabine Wöhlke (Germany)
- OP61 Social media use among transplant professionals in Europe: a cross-sectional study from the European Society of Organ Transplantation Frank Dor (UK)
- OP62 Share your wishes: the role of social media in improving organ donation consent rates Bonnie Venter (South Africa)
- OP63 50 Shades of "no": how intensive care staffs handle family refusals for organ donation in Denmark Anja Marie Jensen (Denmark)

15:00-15:30 Coffee break

Workshops 5 – 6 – 7

15:30-17:30 5. Psychological and ethical challenges in pre-transplant screening: analysis of case studies

Workshop facilitators: Christina Papachristou (Germany), Inês Mega (Portugal) & Fabienne Dobbels (Belgium)

Background

Professionals involved in transplantation medicine are confronted on a regular basis with psychologically and ethically demanding situations. These involve questions of life and death, equity and fairness in the selection of transplant recipients and organ donors, management of feelings of guilt or anger, conflicts in the team and experiencing ones own boundaries. Individual professionals, but also teams and institutions have different ways in acknowledging and dealing with these situations. Guidelines or tools to assist teams in managing such situations are not always available or adequate. The workshop shall address in an interactive manner the above issues and engage participants to exchange knowledge and experiences.

Workshop goals

- Stimulate discussion and reflexion about the personal role and perspective in ethically and psychologically challenging situations in transplant medicine
- Promote awareness on decision-making styles and possibilities of dealing with difficult cases in the selection and treatment of transplant patients and organ donors
- Sharing knowledge on assessment and decision-making tools e.g. EPAT, TERS
- Encourage knowledge transfer and adaptation to needs to the own professional setting

Target group

All professionals involved in transplantation medicine (surgeons, nephrologists, hepatologists, nurses, mental health professionals, transplant coordinators, social workers, ethicists, policy makers, management professionals etc.) interested to reflect on their role regarding the selection and care of transplant patients and organ donors and to promote a climate of transparency and respect towards all parts involved in transplantation.

Methods

Case studies, debate, group discussion, invited speakers-oral presentation. Participants have the option to send in advance to the workshop coordinators a short summary of a case they wish to discuss in the group. There is limited number of cases that can be discussed. Priority will be given to those applying first.

Outline

15:30-15:50	Introduction and engagement of the group in participation	
15:50-16:50	Case presentations and team work/discussion	
16:50-17:00	OP64 The benefits of a systemic approach in psychosocial assessment of complex multicultural situations in paediatric liver transplantation with living donor	Laure Rougier (Belgium)
17:00-17:10	OP65 Succeeding in VCA: Mobilizing insights from partners and caregivers of hand transplant recipients	Emily Herrington (USA)
17:10-17:20	LB18 Alloplastic facial transplants: surgeons' role in informed consent	Hassan ElHawary (Canada)
17:20-17:30	End remarks	

- 15:30-17:30 6. Should we stop using the term 'brain death'?**
Workshop facilitators: Nichon Jansen (Netherlands), Dale Gardiner (UK), Anne Flodén (Sweden) & David Shaw (Switzerland)

Learning Objectives

- Understand the reasons for a shift away from use of the term 'brain death' in some countries.
- Reflect on how this shift might impact on family, legal and medical perspectives.
- If the term 'brain death' is abandoned, help propose what term should we use instead?

Summary

There seems to be a shift away from use of the term brain death in some countries. In 2008 the authority that gives the Code of Practice for the Diagnosis and Confirmation of death in the UK, abandoned the term 'brainstem death'? Instead, the Code simply talks about the diagnosis of death. In clinical practice more people are using the term 'death using neurological criteria' as can be seen in these new education videos <https://www.odt.nhs.uk/deceased-donation/best-practice-guidance/donation-after-brainstem-death/diagnosing-death-using-neurological-criteria/>.

In 2006 Canada adopted the term 'neurological determination of death' and Germany is proposing 'irreversible cessation of brain functions'. And of course, fifty years ago the ad hoc committee of the Harvard Medical school proposed 'irreversible coma', not 'brain death', as their preferred terminology for a new definition of death.

The shift is because there is a recognition that the term 'brain death' is a term that is widely misunderstood in the media and the public, difficult to explain and even among those who accept that 'brain death' is death many are concluding that the term is conceptually flawed. If the world adopts many different terms for the same clinical circumstance, as appears to be occurring, will this paradoxically increase confusion. So, if the term 'brain death' is abandoned, what term should be used instead?

The workshop is organised and led by Nichon Jansen (Dutch Transplant Foundation, Netherlands) and Dale Gardiner (NHS Blood and Transplant, UK) with workshop facilitators Anne Flodén (University of Gothenburg, Sweden) and David Shaw (University of Basel, Switzerland). It will include short presentations by Dale Gardiner, David Shaw, Anne Flodén and Tineke de Wind with plenty of time for dialogue and interactive voting. Two oral abstract presentations on related topics will close the session.

15:30-15:35	Welcome	Nichon Jansen (Netherlands)
15:35-15:50	Introduction – the problem	Dale Gardiner (UK)
15:50-16:05	Family perspective	David Shaw (Switzerland)
16:05-16:30	If we change what should we use instead and how would this change organ donation nomenclature and discussion with families?	Anne Flodén (Sweden) & Tineke Wind (Netherlands)
16:30-17:00	Dialogue & Vote	Nichon Jansen (Netherlands)
17:00-17:15	OP66 Withdrawal of therapy and do not resuscitate – is it available in all countries?	Eva Šteina (Latvia)
17:15-17:30	OP67 A pioneering initiative of intensive therapy till brain death to increase donation rates – what dialogues and with whom are needed?	Yie Roei Chee & Tong-Khee Tan (Singapore)

15:30-17:30 7. Public campaigns for organ donation

Workshop facilitators: Gurch Randhawa (UK) & David Rodríguez-Arias (Spain)

Learning objectives

This workshop aims to:

- a. provide an overview of the importance of promoting organ donation among the public
- b. examples of innovation in public engagement with organ donation.

Summary

The workshop benefits from 2 eminent researchers who are involved with organ donation and public engagement activities. Dr. Chris Papadopoulos is funded by NHS Blood and Transplant to lead the world's first study to explore the feasibility of utilizing primary healthcare settings to increase organ donation. The proposed intervention has the potential to benefit all sections of the UK's diverse population in terms of age, gender, ethnicity and religion.

Dr. Sinja Coz has been reviewing the evidence-base of interventions that seek to promote organ donation amongst the public. The workshop will enable researchers and policymakers to reflect upon the evidence-base to develop future public engagement interventions that can improve organ donation rates among diverse ethnic and faith populations from all age groups.

- The role of primary care in increasing organ donation Chris Papadopoulos (UK)
- OP68 What works best? Systematic literature review of interventions for promoting post-mortem organ donation Sinja Čož (Slovenia)
- LB19 Creating (good) reputation on Facebook: the case of Slovenija-transplant Jana Šimenc (Slovenia)

Full oral sessions 8

- 17:30-18:45** **8. Transplants throughout the lifespan**
Moderators: Diederik Kimenai (Netherlands) & Marion Siebelink (Netherlands)
- OP69 What attitude should we adopt with early graft failure in a recipient who participated in kidney paired donation? Marie-Chantal Fortin (Canada)
- OP70 Pre-emptive live donor kidney transplantation: moving barriers to opportunities. An ELPAT view David van Dellen (UK)
- OP71 Especially “elderly” patients should receive a living donor kidney transplant Mirjam Laging (Netherlands)
- OP72 How to predict psychosocial difficulties after paediatric liver transplantation with a living donor: the efficiency of clinical pre-transplant interviews Laure Rougier (Belgium)
- LB20 Social and psychological impacts of having a child with liver Transplant Ebru Ayvazoglu Soy (Turkey)
- LB21 UK young muslim’s view on organ donation Mikail Aktas (UK)

Brief oral sessions 2

- 17:30-18:45** **2. Living donation**
Moderators: Dirk Stippel (Germany) & Annette Lennerling (Sweden)
- OP73 Clinical utility of the Edmonton symptom assessment system to screen for depression and anxiety in kidney transplant recipients Evan Tang (Canada)
- OP74 The experience of people close to a person with kidney disease, of receiving a letter about living kidney donation (ld). Eva Lagging (Sweden)
- OP75 Can financial incentives improve patient compliance with living kidney donor follow-up? Macey Henderson (USA)
- OP76 Identifying risk severity using proposed ‘Wuhan chart (risk severity scale)’ in diseased donor kidney transplantation Kiran Jang Kunwar (Nepal)
- OP77 A survey towards xenotransplantation among Iranian transplantation professionals, religious experts, lawmakers and waiting list patients Mahdis Mojtabae (Iran)
- OP79 Family matters: comparative analysis on living organ donors in Germany and Israel Hagai Boas (Israel)
- LB22 Retroperitoneoscopic live donor nephrectomy Ivan Dymkov (Russia)
- OP87 Psychological indicants of the positive and negative effects of the organ transplantations Mateusz Zatorski (Poland)

Late breaking 2

17:30-18:45

2. Deceased donation

Moderators: Marina Berenguer (Spain) & Pawel Luków (Poland)

- LB23 Children, organ donation and Islam: a report of a multi-disciplinary day Mikail Aktas (UK)
- OP99 Deceased directed donation: examining the ethics in a multi-cultural setting Rebecca Greenberg (Canada)
- LB26 Deceased directed kidney donation: a recent case study from the London organ donation services team Lucy Dames (UK)
- LB27 Organs for deceased donation as resources, commodities and gifts in the history of the Russian transplantology Pavel Tishchenko (Russia)
- LB28 Emergency patient with sudden cardiac arrest as a source of organ Donation Andrey Skvortsov (Russia)

Monday 29 April 2019

Focus sessions 7 – 8



- 08:30-10:00 7. Increased risk donors: between a rock and a hard place?
ELITA @ ELPAT joint session**
Moderators: Wojciech Polak (NL) & Inês Mega (Portugal)
- Donors with viral infections Marina Berenguer (Spain)
- Extended criteria donors Krzysztof Zieniewicz (Poland)
- High risk living liver donors Silvio Nadalin (Germany)
- OP78 Outcome following donor hepatectomy in living donor liver transplantation at a high volume center Sujeet Saha (India)
- OP80 Should we split every suitable donor liver? Ethical arguments in favour of a mandatory splitting policy Nadia Primc (Germany)
- Dialogue

- 08:30-10:00 8. Social deprivation and access to transplantation**
Moderators: Allison Tong (Australia) & Elisa Gordon (USA)
- Findings from the ATTOM study Gabriel Oniscu (UK)
- OP81 Equity in organ allocation? A survey of psychosocial and lifestyle characteristics affecting listing in us solid organ transplant centers Anji Wall (USA)
- OP82 Living donor kidney transplantation in black, Asian and minority ethnic patients; a single centre cross sectional cohort study Antonia Cronin (UK)
- OP83 Social difficulties are independently associated with health-related quality of life in kidney transplant recipients Istvan Musci (Canada)
- Dialogue

Full oral sessions 9

- 08:30-10:00 9. Psychological adaptation among recipients**
Moderators: Hannah Maple (UK) & Sohal Ismail (Netherlands)
- OP84 Symptom burden is associated with multiple aspects of health related quality of life in kidney transplant recipients Istvan Musci (Canada)
- OP85 Quality of life assessment before and after kidney transplantation Roman Danielewicz (Poland)
- OP86 Peer mentoring as an avenue to explore in kidney transplantation: kidney transplant recipients' perspectives on peer mentoring Marie-Chantal Fortin (Canada)
- OP88 Resilience predicts health-related quality of life in Slovenian kidney transplant patients Bernarda Logar Zakrajsek (Slovenia)
- OP89 Adaptation after lung transplantation Anna Forsberg (Sweden)
- OP90 Exploring attitudes and factors influencing reproductive choices in renal transplant patients (expect-study) Marleen van Buren (NL)

10:00-10:30 Coffee break

Focus sessions 9 – 10

- 10:30-12:00 9. DCD heart transplantation: now a reality?**
Moderators: Undine Samuel (Netherlands) & Rutger Ploeg (UK)
- DCD heart transplantation - the science and practice Simon Messer (UK)
- DCD heart donation - the ethics and law Dale Gardiner(UK)
- OP91 Ethical considerations in relation to heart donation in the context of donation after cardio-circulatory death Marie-Chantal Fortin (Canada)
- Dialogue
- 10:30-12:00 10. Expanding live donation across Europe**
Moderators: Michael Rees (USA) & Frank Dor (UK)
- Lessons learnt in Cologne Dirk Stippel (Germany)
- Lessons learnt in Belfast: what's next? Aisling Courtney (UK)
- Successful strategies in the Netherlands Willem Weimar (Netherlands)
- OP92 Latter research results of the first in Poland paired donation, within chain kidney pair donation and the exchanges of pairs between two centers Rafal Kieszek (Poland)
- Dialogue

Full oral sessions 10

- 10:30-12:00 10. Euthanasia and legal boundaries of deceased donation**
Moderators: Angie Scales (UK) & Bernadette Haase (Netherlands)
- OP96 Should we accept directed organ donation after medical aid in dying? Quebec healthcare professionals' perspectives Julie Allard (Canada)
- OP94 Organ harvesting from donors killed by euthanasia may undermine public trust in transplantation Jadranka Buturovic-Ponikvar (Slovenia)
- OP95 Organ donation after euthanasia: an experience based ethical perspective Diethard Monbaliu (Belgium)
- OP93 Organ donation euthanasia (ODE) Jan Bollen (Netherlands)
- OP97 Organ scarcities, competing claims and the challenge of allocation R.R. Kishore (India)
- OP98 Mapping consent systems and family role de iure in Europe Marina Morla González (Spain)
- LB29 Sociocultural forms of organ donation and transplantation in the light of legal regulations in determining brain death Olga Papova (Russia)

12:00-13:30

Closing session

Plenary Dialogue 4

Moderators: Emma Massey & Willem Weimar (Netherlands)

Living donor organ banking: a worthwhile investment?

Vouchers for living donors kidneys: Ethics and implications

Gabriel Danovitch (USA)

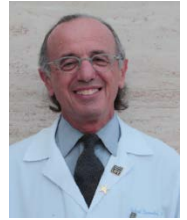
The body as gift, commodity, or something in between

Julian Koplin (Australia)

Keynote Lecture

The ethics of organoid transplantation:
how should one launch a first in human trial?

Annelien Bredenoord (University Medical Center Utrecht, Netherlands)



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