



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



2nd ELPAT CONGRESS
April 17 – 20, 2010
World Trade Center
Rotterdam, The Netherlands

Programme and Abstracts
www.ELPAT.org



Ministry of Health, Welfare and Sport





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| | <i>Guest Editor:</i> <i>Prof. Willem Weimar, MD, PhD</i> <i>Rotterdam</i> |

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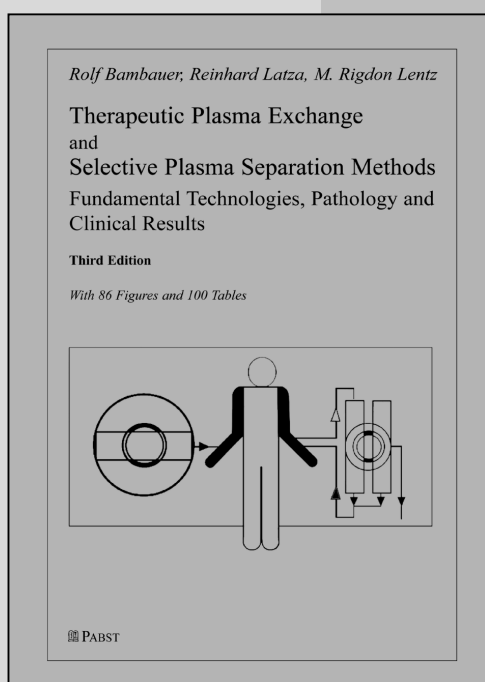
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Covered in EMBASE/Excerpta Medica

Rolf Bambauer, Reinhard Latza, M. Rigdon Lentz

Therapeutic Plasma Exchange & Selective Plasma Separation Method

Fundamental Technologies, Pathology and Clinical Results



Third Edition, 86 Figures and 100 Tables

428 pages, Price: 60,- Euro
ISBN 978-3-89967-458-3



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The third edition will give a new, complete overview of the therapeutic apheresis (TA) including all semi- and selective methods, which are available. All methods, their functions, indications, clinical results, criticisms, and future aspects are discussed. This edition contains 428 pages including 100 tables and 86 figures, and 2776 references. In 6 chapters historical highlights, methods of unselective and selective separation procedures, complications and side effects of TA and clinical results of different diseases will be mentioned. Possible indications of TA are shown in pediatric diseases. Selective separation methods like cascade-filtration, cryofiltration, plasmapheresis, fibrinogen-adsorption, different methods of Immunoabsorption, and LDL-apheresis, and other methods, like BioLogic-DTPP-system, Molecular Adsorbent Recycling system (MARS), Prometheus system etc., are discussed and their indications are shown.

Different clinical application committees have made a gradation of diseases, which are accepted for TA. All these new tendencies have influenced the clinical routine of treatments. The advantages are the elimination of pathologic substances and the interruption of pathogenic reactions. The disadvantages are the unselective elimination of all proteins by the unselective methods, the possible complications and the high costs. The authors try to define with regard to the literature the indications of different methods of TA. Especially in the present time, in which the resources in the health systems decrease enormously, a strong definition of indications for TA is necessary to save the health of our patients and to reduce the costs in future. This edition should be a teaching and working book for all physicians, nurses, scientists, and industries, who are interested in this field. The experiments of modern biotechnologies to try a better imitating of the organ functions will be more and more encouraging, and we understand the pathophysiology of different diseases better and this enables us a more effective therapy in patients with bad prognosis. Very important are different adsorption methods for plasma or blood for various diseases. This edition will give answers to different questions in this area.

Welcome!

It is with pleasure that I welcome you on behalf of the organizing committee to the 2nd ELPAT conference in Rotterdam. ELPAT stands for Ethical, Legal, and Psychosocial Aspects of Organ Transplantation. After its foundation during the first conference in Rotterdam it has become a permanent platform for the exchange of information, ideas and expertise in these fields.

Moreover, ELPAT also attempts to be the movement from which research groups can structure their efforts by working together. Especially the rapid expansion of the European Union creates vast opportunities for cooperation between the various nations, although at the same time it may create problems that we have to face e.g. equal access to health care.

The topics that will be discussed during the present 2nd ELPAT conference have been prepared in two ELPAT working group meetings held in Juan-les-Pins (France) in 2008 and 2009. These workshops were made possible by the generous support of the European Society for Organ Transplantation. This organization also embraced the ELPAT movement by giving room for special ELPAT sessions during their International congresses in Prague (2007) and in Paris (2009). We are fortunate that the Transplantation Society followed this initiative with ELPAT sessions during their conferences in Sydney (2008) and in Vancouver (2010). The European Transplant Coordinators Organization has also invited ELPAT for a joint session in their Cardiff meeting (2010).

The 2nd ELPAT conference has largely been funded by the European Commission. Therefore it is not surprising that the theme of this conference is "Borders in Transplantation".

You may think in terms of crossing borders between nations and the free movement of goods, services and people. You may also make interpretations in terms of the border between life and death, and even about the transition between our present and our future actions, ideas and convictions. During this conference the kick-off meeting of the ELPAT project "Living Organ Donation in Europe" will take place. This project has been funded under the Seventh Framework Programme of the European Commission and research groups from both new and old EU Member States will participate.

The structure of the present conference resembles that of the first conference and the two working group meetings: it is based on 6 main topics: 1. Organ Tourism and Paid Donation, 2. Deceased Donation, 3. Legal and Ethical Boundaries, 4. Diverse Populations, 5. Psychological Care for Living Donors and Recipients, and 6. Samaritan / Unrelated Donation.

There will be invited lectures during the plenary sessions, workshops, and 'walk-in sessions' covering the various Ethical, Legal, and Psychosocial 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,



Willem Weimar, Chair



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General Information

Congress Secretariat

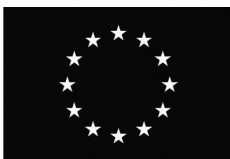
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This conference is supported by



Ministry of Health, Welfare and Sport



Venue

Beurs-World Trade Center (WTC)
 Beursplein 37
 3011 AA Rotterdam
 The Netherlands
 Website:
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, 17 April | 13:00 – 19:00 |
| Sunday, 18 April | 08:00 – 18:00 |
| Monday, 19 April | 08:00 – 18:00 |
| Tuesday, 20 April | 08:00 – 13:00 |

Accompanying Persons Policy

The fee for accompanying persons is € 50. Registered accompanying persons will be admitted to all social events. The appropriate badge will be essential for admittance.

Media

Contact

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

Ad van den Dool

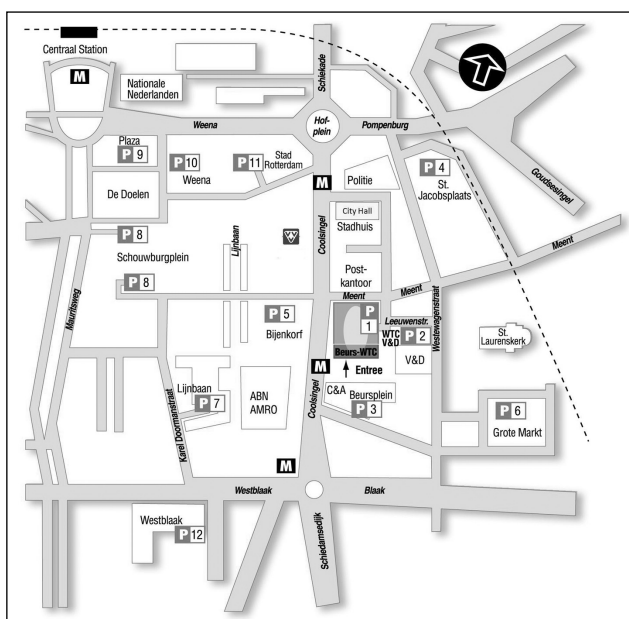
Email: secretariat@elpat.org
 Tel.: +31 (0) 627 14 37 31

Internet

Internet access is available in the *Veder Room*.

Travel Information

Map of city centre



Schiphol Airport (main airport) in Amsterdam has a direct train connection with Rotterdam Central Railway Station. Trains run every 30 minutes. The travel time is approximately one hour.

See: <http://www.ns.nl/cs/Satellite/travellers> for the timetable and prices.

Fyra is the high-speed train that connects Schiphol and Rotterdam and runs every hour, 17 times a day, Monday through Friday. The travel time is approximately half an hour.

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

Tram / metro

Within Rotterdam a network of buses, trams, water taxis and metro maintains excellent connections.

Public transport from Rotterdam Central Railway Station to the World Trade Center:

Metro: take the metro, get off at the second station, 'Beurs', and take the exit 'Beursplein'

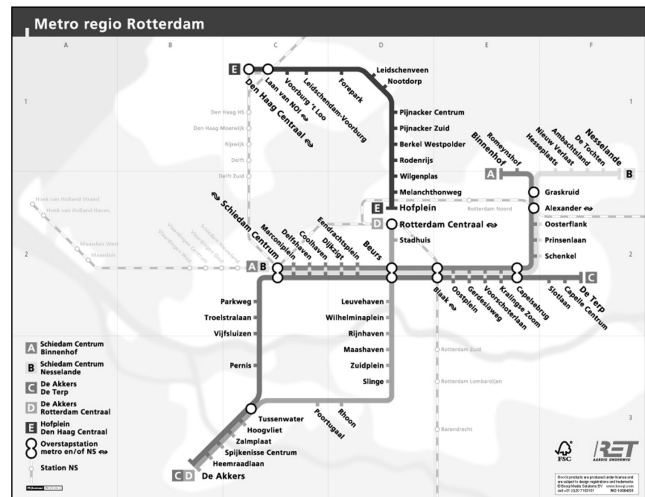
Tram: take tram 8, 20, 21, 23 or 25. Get off on stop 'Beurs', at the ABN-AMRO Bank.

For tram and metro an OV-chipkaart is needed

| Where can I purchase my OV-chipkaart and upload travel credit and travel products? | |
|---|---|
| Where? | Purchasing and uploading |
| RET Service Points At metro stations: Beurs, Capelsebrug, Rotterdam Centraal, Spijkenisse Centrum, Zuidplein | - Every OV-chipkaart - Travel credit - All travel products |
| RET Service Shop Coolsingel 141, above Beurs metro station | - Every OV-chipkaart - Travel credit - All travel products |
| Vending machines at RET metro stations | - Anonymous OV-chipkaart and disposable OV-chipkaart - Travel credit - All travel products (Star-subscriptions from beginning 2010) |
| RET bus and tram | - RET 2 hours - RET bus&tram 1 hour (can be bought on buses and trams from beginning 2010) |
| www.ov-chipkaart.nl / www.ret.nl | - Every OV-chipkaart - Travel credit - All travel products (Star-subscriptions from beginning 2010) |
| Primera, Tabac & Gifts and most of the TNT Service Points | - Anonymous OV-chipkaart - Travel credit |

Personalized OV-chipkaart:
 You need this if you are entitled to discount. This applies to children (age 4-11) and senior citizens (65+) who then receive 34% discount on the full rate when travelling on travel credit. The card has several advantages:

- Automatic uploading via your current account with € 10.-, € 20.- or € 50.-.
- You can order travel credit and travel products online.
- The possibility of blocking the card if lost/stolen.



| How often do you travel? | Which public transport company do you travel with? | Travel product we recommend | In combination with this OV-chipkaart |
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| | Only RET | RET Monthly Discount or Star-subscription | Personalized OV-chipkaart |
| Less frequently (3 or more times a year) | Various public transport companies | Travel credit | Personalized OV-chipkaart or anonymous OV-chipkaart |
| Hardly ever (less than 3 times a year) | Only RET | RET 2 hours RET bus&tram 1 hour* RET 2 metro trips RET 1, 2 or 3 days | Disposable OV-chipkaart |

*The recommendations only serve as a guide. For the current range and travel product conditions visit www.ret.nl. For more information, please ask our staff or call the RET OV-chipkaart Help desk: 0900-500 6010 (€ 0.10 p/m). *Can be bought on buses and trams from beginning 2010.*

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

Tourist Information

VVV Rotterdam Store
 Coolsingel 5, 3012 AA Rotterdam
 Website: www.rotterdam.info
 Email: info@rotterdam-store.com



Opening hours:

| | |
|-------------|---------------|
| Mon – Thurs | 09:00 – 17:30 |
| Friday | 09:00 – 21:00 |
| Saturday | 09:00 – 17:30 |
| Sunday | 10:00 – 17:00 |

**Abstracts**

Abstracts selected for the 2nd ELPAT Congress will be presented as oral and poster presentations.

Oral presentations

Abstracts selected for an oral presentation will be presented during the parallel sessions on Sunday 18 and Monday 19 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, Leeuwen 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 loaded 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). Please note that internet access is not available in the meeting rooms.

Speaker room / preview room

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

| | |
|-----------|------------------------|
| Saturday: | 17 April 11:30 – 17:00 |
| Sunday: | 18 April 07:30 – 17:00 |
| Monday: | 19 April 07:30 – 17:00 |
| Tuesday: | 20 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 ELPAT 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 2nd 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 expressly prohibited without the express 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.

Presenters are expected to attend the chaired poster viewings, during which discussions will be held. Please refer to the following schedule in order to identify your poster session:

Sunday 18 April – Posters P01 to P28

Posters 1 - 4: Organ Tourism And Paid Donation

Posters 5 - 11: Diverse Populations

Posters 12 - 17: Diverse Populations

Posters 18 - 23: Legal and Ethical Boundaries

Posters 24 - 28: Legal and Ethical Boundaries

Presenters' time schedule: 13:30 – 14:30 in the **Rotterdam Hall**

Monday 19 April – Posters P29 to P62

Posters 29 - 37: Deceased Donation

Posters 38 - 45: Deceased Donation

Posters 46 - 54: Psychological Care for Living Donors and Recipients

Posters 55 - 62: Psychological Care for Living Donors and Recipients

Presenters' time schedule: 13:30 – 14:30 in the **Rotterdam Hall**

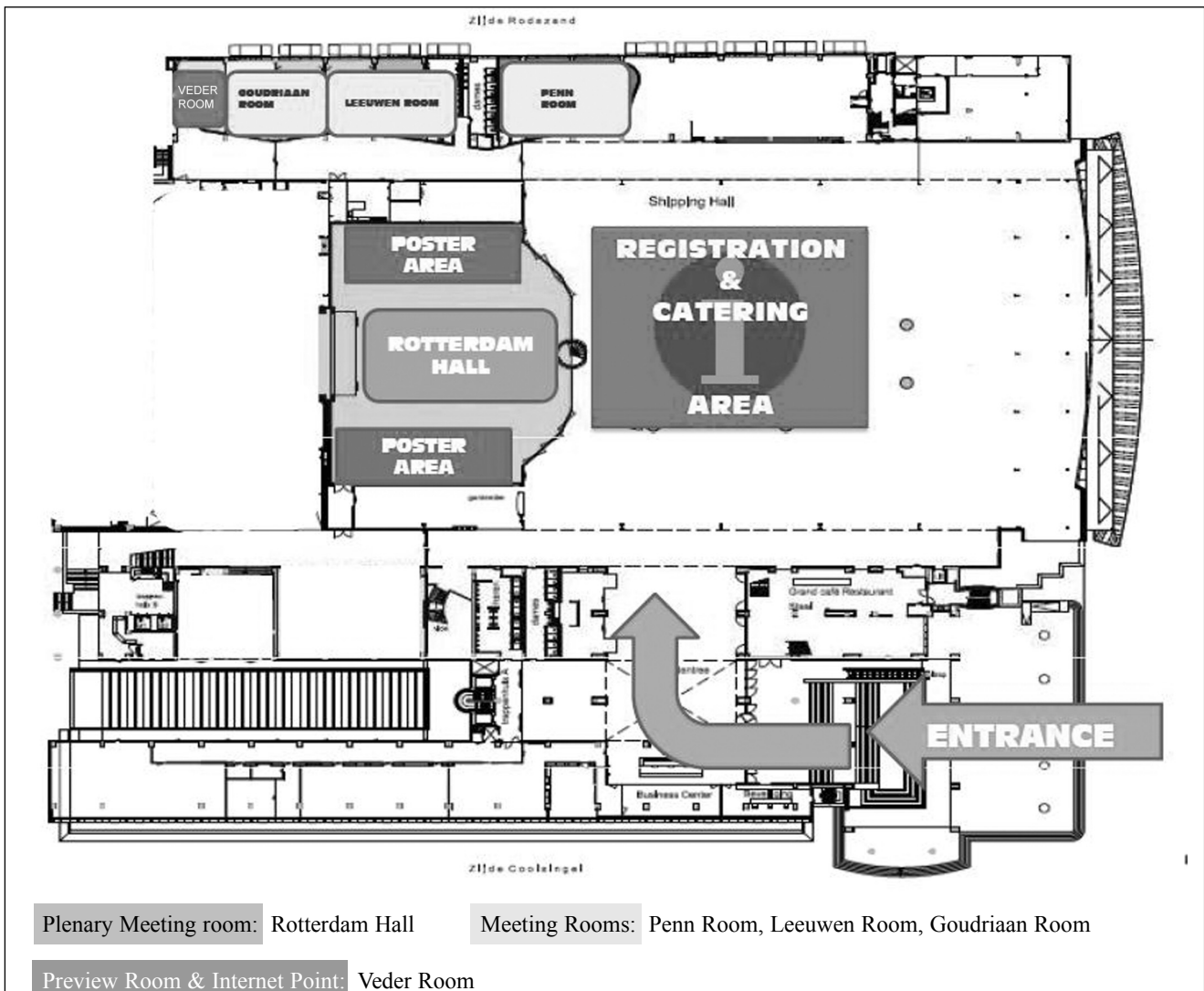
Posters not picked up by the author by the end of the congress will be discarded.

Posters should be put up on: April 17 from 13:00 – 15:00

Posters should be taken down on: April 20 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.



Social Programme

Saturday, 17 April

18:00 – 19:00 Welcome Drinks & Poster Opening

Beurs-World Trade Center Rotterdam / Shipping Hall



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

Admittance:

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

Sunday, 18 April

19:00 – 22:30 Museum Visit and Dinner

Wereldmuseum



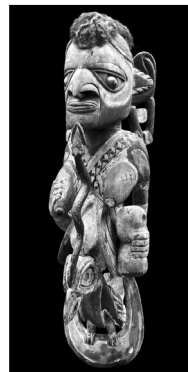
You are welcome to join us at the Wereldmuseum, located in one of Rotterdam's most authentic historic buildings, with a fantastic view on the river "Maas". Here you will enjoy a wonderful dinner in the 'ballroom' of Prins Hendrik's former Yacht Club, which has recently been restored to its former glory.



The dinner will be accompanied by live music.

Dinner entertainment: **The Ethics of Harp – from Heaven to Hip.**

You will be given the opportunity to visit the exhibition 'Oceania'.



Oceania, signs of rites, symbols of power takes us on a journey through Oceania, along the many islands spread throughout the southern Pacific Ocean. Dominated by the endless sea, this cultural region reveals itself through masks, shields, architectural objects, musical instruments, ornaments and clothing. In their original context, the works of art have a functional significance which weaves together social, economic and ritual elements. Originally they were a means of communicating with the supernatural. In the eyes of

the users, the statues and masks are imbued with spiritual power and must therefore be treated with caution and care. The Oceanic people use prayers and magic to try to influence the unpredictable supernatural powers.

This exhibition is open to registrants from 19.45 to 20.30.

Admittance:

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

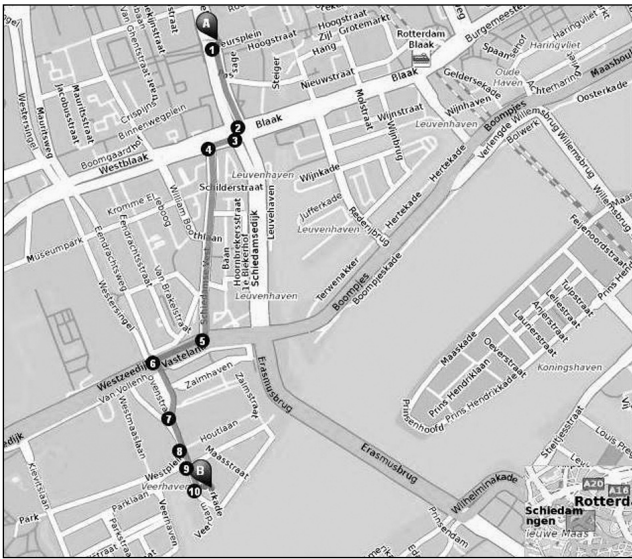
How to get there:

The **Wereldmuseum Rotterdam** is situated at the 'Willemsskade 25' in Rotterdam, right next to the picturesque 'Veerhaven' and alongside the river Maas.

From the World Trade Center you can get on **tram 23**, direction 'Beverwaard'. Get off tram 23 at stop 'Leuvehaven'. You can also take the metro from **underground** station 'Beurs' and get off at 'Leuvehaven'.

From 'Leuvehaven' you must cross the large connecting road 'Vasteland' and walk in the direction of the river Maas. When you arrive at the riverside, you turn to the right. You will find the Wereldmuseum at the corner of the 'Willemskade' and the 'Veerkade'.

On foot the distance from WTC is 1,61 km (± 20 minutes).



For more information about Wereldmuseum Rotterdam, please visit www.wereldmuseum.nl

Admittance:

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



The City Hall is within walking distance of the World Trade Center at the Coolingsel 40 (two blocks, approx. 5 min)

Monday, 19 April

18:00 – 19:30 ELPAT Congress Reception City Hall



The city of Rotterdam will organize 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.

Programme Overview

| | Saturday, April 17 | Sunday, April 18 | Monday, April 19 | Tuesday, April 20 |
|-------|--|----------------------------------|--|--------------------------|
| 8:00 | | | | |
| 8:30 | Registration | Plenary Session 2 | Plenary Session 3 | Plenary Session 4 |
| 9:30 | | | | Coffee Break |
| 10:00 | | Coffee Break | Coffee Break | Plenary Session 4 |
| 10:30 | | Walk-in sessions 1 - 3 | Walk-in sessions 4 - 6 | |
| 11:30 | | Free Communications 1 - 4 | Free Communications 5 - 8 | |
| 12:30 | | | | Snacks |
| 13:00 | | Lunch | Lunch | |
| 13:30 | | Poster Session 1 | Poster Session 2 | |
| 14:30 | | Workshops 1 - 3 | Workshops 4 - 6 | |
| 16:00 | | Coffee Break | Coffee Break | |
| 16:30 | Opening & Plenary Session 1 | Workshops 1 - 3 | Workshops 4 - 6 | |
| 18:00 | Welcome Drinks | | Congress Reception at City Hall | |
| 18:30 | | | | |
| 19:00 | | Museum Visit and Dinner | | |
| 19:30 | | | | |
| 22:30 | | | | |

| | |
|-------|--|
| | Saturday, April 17 |
| | |
| 12:30 | |
| 13:00 | Registration |
| 16:00 | Opening & Plenary Session 1 |
| | Rotterdam Hall |
| 18:00 | Welcome Drinks |
| 19:00 | |

16:00 – 18:00 Opening and Plenary Session 1 (Rotterdam Hall)
‘Crossing Borders in Organ Transplantation’

Chairs: Peter Morris, London, United Kingdom;
Herold Metselaar, Rotterdam, The Netherlands

- 16:00 Opening
Paul Huijts, Director-General of the Dutch Ministry of Health, Welfare and Sport
- 16:10 Borders in transplantation
Willem Weimar, Rotterdam, The Netherlands
- 16:30 The free movement of patients and organs in the European Union
Aart Hendriks, Leiden, The Netherlands
- 17:00 The boundary between life and death
Stuart Youngner, Cleveland, United States of America
- 17:30 Self-imposed boundaries
Janet Radcliffe Richards, Oxford, United Kingdom

18:00 – 19:00 Welcome Drinks Rotterdam Hall

| | | | | |
|-------|--|---|--|---|
| | Sunday, April 18 | | | |
| 8:00 | | | | |
| 8:30 | Plenary Session 2 | | | |
| | Rotterdam Hall | | | |
| 10:00 | Coffee Break | | | |
| 10:30 | Walk-in session 1 Children as Donors Penn Room | Walk-in session 2 Samaritan Donation and Altruism Leeuwen Room | Walk-in session 3 Euthanasia and Organ Donation Goudriaan Room | |
| 11:30 | Free Communications 1 Organ Tourism and Paid Donation Penn Room | Free Communications 2 Diverse Populations Leeuwen Room | Free Communications 3 Legal and Ethical Boundaries Goudriaan Room | Free Communications 4 Psychological Care of Living Donors Rotterdam Hall |
| 13:00 | | | | Lunch |
| 13:30 | Poster Session 1 - Rotterdam Hall | | | |
| | Organ Tourism and Paid Donation | Diverse Populations | Legal and Ethical Boundaries | |
| 14:30 | Workshop 1 Organ Tourism and Paid Donation | Workshop 2 Diverse Populations | Workshop 3 Legal and Ethical Boundaries | |
| 16:00 | Coffee Break | | | |
| 16:30 | Workshop 1 Organ Tourism and Paid Donation Penn Room | Workshop 2 Diverse Populations Leeuwen Room | Workshop 3 Legal and Ethical Boundaries Goudriaan Room | |
| 18:00 | | | | |
| 19:00 | Museum Visit and Dinner | | | |

08:30 – 10:00 Plenary Session 2 (Rotterdam Hall)

*Chairs: Assya Pascalev, Sofia, Bulgaria
Rutger Ploeg, Groningen, The Netherlands*

08:30 What happened after the Istanbul declaration?
Francis Delmonico, Boston, United States of America

09:00 Organ donation and transplantation through the lens of Muslim scholars
Farhat Moazam, Karachi, Pakistan

09:30 Organs wanted, but how to avoid commodification?
Judit Sándor, Budapest, Hungary

10:00 COFFEE BREAK

**10:30 – 11:30 Walk-In Session 1 (Penn Room)
Children as Donors**

Moderator: Bernadette Haase-Kromwijk, Leiden, The Netherlands

*Experts: Thalia Bellali, Thessaloniki, Greece;
Magi Sque, Southampton, United Kingdom;
Marion Siebelink, Groningen, The Netherlands*

How do grieving parents react to the request for organ donation from their child? (abstract #1)
Sabine Moos, Mainz, Germany

Adjusting to loss after donating a family member's organ (abstract #2)
Tamar Ashkenazi, Tel Aviv, Israel

**10:30 – 11:30 Walk-In Session 2 (Leeuwen Room)
Samaritan Donation and Altruism**

Moderator: Jan van Busschbach, Rotterdam, The Netherlands

*Experts: Annette Lennerling, Gothenburg, Sweden;
Sigrid Sterckx, Ghent, Belgium;
Govert den Hartogh, Haarlem, The Netherlands*

**10:30 – 11:30 Walk-In Session 3 (Goudriaan Room)
Euthanasia and Organ Donation**

Moderator: Michael Bos, The Hague, The Netherlands

*Experts: Paul Schotsmans, Leuven, Belgium;
Stuart Youngner, Cleveland, United States of America;
Dirk Ysebaert, Antwerp, Belgium*

Initial experience with transplantation of lungs recovered from donors after euthanasia (abstract #3)
Dirk van Raemdonck, Leuven, Belgium

**11:30 – 13:00 Free Communications 1 (Penn Room)
Organ Tourism and Paid Donation**

*Chairs: Francis Delmonico, Boston, United States of America;
Blanca Miranda, Barcelona, Spain*

11:30 Incentivizing organ donation: a Swedish priority setting perspective (abstract #4)
Faisal Omar, Linköping, Sweden

11:45 The paradox of prohibition and how potential adverse consequences of the Istanbul Declaration may be controlled (abstract #5)
Frederike Ambagtsheer, Rotterdam, The Netherlands

12:00 The outcome of commercial transplant tourism in Pakistan (abstract #6)
Ninoslav Ivanovski, Skopje, Macedonia

12:15 Access of non residents to transplantation medicine (abstract #7)
Daniela Norba, Frankfurt, Germany

12:30 European legislation prohibiting organ commerce (abstract #8)
Michael Bos, The Hague, The Netherlands

12:45 Sharing organs with foreign nationals (abstract #9)
Rebecca Bruni, Toronto, Canada

**11:30 – 13:00 Free Communications 2 (Leeuwen Room)
Diverse Populations**

*Chairs: Farhat Moazam, Karachi, Pakistan;
Chris Rudge, London, United Kingdom*

11:30 Racial disparities in kidney transplant: beyond medical factors (abstract #10)
Larissa Myaskovsky, Pittsburgh, United States of America

11:45 Studying the organ donation process within the immigrant population (abstract #11)
Teresa Pont Castellana, Barcelona, Spain

- 12:00 Ethnicity and access to kidney transplant programs (abstract #12)
Louise Maasdam, Rotterdam, The Netherlands
- 12:15 Is gifting a relevant concept to promote organ donation? The views of the UK's religious leaders (abstract #13)
Kulwinder Kaur-Bola, Luton, United Kingdom
- 12:30 UK students of Indian and Pakistani descent: what are the factors that influence their attitudes towards organ donation? (abstract #14)
Salman Gauher, London, United Kingdom
- 12:45 Comparative analysis about the knowledge of both organ donation and transplantation among Argentinian students (abstract #15)
Liliana Marta Martinez, Buenos Aires, Argentina
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- 11:30 – 13:00 Free Communications 3 (Goudriaan Room)
Legal and Ethical Boundaries**
- Chairs: Bijan Fateh-Moghadam, Muenster, Germany;
Hans Akveld, Bussum, The Netherlands*
- 11:30 Ethical and legal dimensions of the public discourse on transplantation. A media analysis (abstract #16)
Mihaela-Cornelia Frunza, Cluj, Romania
- 11:45 The Spanish model for organ donation. Success factors and ethical issues (abstract #17)
David Rodríguez-Arias, Salamanca, Spain
- 12:00 Euthanasia and organ transplant (abstract #18)
Karine Bréhaut, Paris, France
- 12:15 EULID: European Living Donation: Protection, health and safety (abstract #19)
Assumpta Ricart, Barcelona, Spain
- 12:30 The ethical equipoise in living and deceased donor liver transplantation: towards decision processes based on mathematical models (abstract #20)
Alessandro Vitale, Padova, Italy
- 12:45 Limited number of kidneys – who should get access to the waiting list? (abstract #21)
Marie Omnell-Persson, Malmö, Sweden
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- 11:30 – 13:00 Free Communications 4 (Rotterdam Hall)
Psychological Care for Living Donors**
- Chairs: Margareta Sanner, Uppsala, Sweden;
Leonieke Kranenburg, Rotterdam, The Netherlands*
- 11:30 Creation, validation and results of a living donors satisfaction survey (abstract #22)
Assumpta Ricart, Barcelona, Spain
- 11:45 Psychosocial characteristics predictive of post-operative mental health in living liver or kidney donors: a systematic literature review (abstract #23)
Johan van Gogh, Rotterdam, The Netherlands
- 12:00 Psychosocial outcome and reflections of donors undergoing living donor liver transplantation (ldlt) – results of a qualitative research study (abstract #24)
Christina Papachristou, Berlin, Germany
- 12:15 Patient reported outcome measures (proms) in living donor kidney transplantation: recipient expectations exceeded while concerns remain regarding initial donor recovery (abstract #25)
Luke Forster, London, United Kingdom
- 12:30 Development and validation of the living donation expectancies questionnaire (abstract #26)
James Rodrigue, Boston, United States of America
- 12:45 Is donating a kidney associated with changes in health habits? (abstract #27)
Larissa Myaskovsky, Pittsburgh, United States of America
- 13:00 – 14:30 LUNCH
-
- 13:00 – 14:30 Poster Session 1 (Rotterdam Hall)**
- Posters 1 - 4: Organ Tourism and Paid Donation**
Chair: Michael Bos, The Hague, The Netherlands
- Posters 5 - 11: Diverse Populations**
Chair: Marion Siebelink, Groningen, The Netherlands
- Posters 12 - 17: Diverse Populations**
Chair: Emma Massey, Rotterdam, The Netherlands
- Posters 18 - 23: Legal and Ethical Boundaries**
Chair: Frank Dor, Rotterdam, The Netherlands
- Posters 24 - 28: Legal and Ethical Boundaries**
Chair: Medard Hilhorst, Rotterdam, The Netherlands
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- 14:30 – 18:00 Workshop 1 (Penn Room)
Organ Tourism and Paid Donation**
- Chairs: Annika Tibell, Stockholm, Sweden;
Michael Bos, The Hague, The Netherlands*
- 14:30 Organ trafficking and transplant tourism: case of Moldova – first steps in identification and prevention
Igor Codreanu, Chisinau, Moldova
- 15:00 Organ economy: organ trafficking in Moldova and Israel
Susanne Lundin, Lund, Sweden

15:30 Solving the kidney transplant crisis for minority ethnic groups in the UK: is being transplanted overseas the answer? (abstract #28)
Antonia Cronin, Manchester, United Kingdom

15:45 Regulated living unrelated donation leads to commercialism (abstract #29)
Mustafa Al-Mousawi, Kuwait City, Kuwait

16:00 **COFFEE BREAK**

16:30 Living kidney donation: for love or money? Attitudes of 250 actual living donors (abstract #34)
Marleen van Buren, Rotterdam, The Netherlands

16:45 Workshop ‘offering incentives to promote organ donation: comparing three proposals’ (abstract #35)
Sigrid Sterckx, Ghent, Belgium; Stellan Welin, Linköping, Sweden; André Krom, Utrecht, The Netherlands

**14:30 – 18:00 Workshop 2 (Leeuwen Room)
Diverse Populations**

*Chairs: Gurch Randhawa, London, United Kingdom;
Emma Massey, Rotterdam, The Netherlands*

14:30 Introduction workshop by the chairs

14:40 Explaining low rates of organ donation among minority ethnic groups: a holistic approach
Myfanwy Morgan, London, United Kingdom

15:10 Unshakable egoist? A Swiss mixed methods research on the social and psychological aspects of the organ donation act (abstract #30)
Francesca Bosisio, Lausanne, Switzerland

15:25 Why is it that deceased transplant recipients’ families refuse to donate? (abstract #31)
Teresa Pont Castellana, Barcelona, Spain

16:00 **COFFEE BREAK**

16:30 Ethnically diverse populations and their participation in living kidney donation programs
Joke Roodnat, Rotterdam, The Netherlands

17:00 Living donation among ethnic minorities: a Dutch qualitative study on the attitudes, communication and needs of kidney patients (abstract #36)
Lily Claassens, Rotterdam, The Netherlands

17:15 Faith & organ donation: engaging with faith communities to address the UK organ donor crisis (abstract #37)
Komal Adris, Manchester, United Kingdom

17:30 Cultural barriers for setting up a kidney transplantation program in the indigenous population of Chiapas, Mexico (abstract #38)
David Terán-Escandón, Mexico City, Mexico

**14:30 – 18:00 Workshop 3 (Goudriaan Room)
Legal and Ethical Boundaries**

*Chairs: Thomas Gutmann, Muenster, Germany;
Medard Hilhorst, Rotterdam, The Netherlands*

14:30 The exclusion of organ transplantation from the cross border care directive: boundary or opportunity?
Herman Nys, Leuven, Belgium

15:00 Respect for the individual as a human right in relation to post-mortem use of the human body for transplantation (abstract #32)
Austen Garwood-Gowers, Nottingham, United Kingdom

15:15 Legal guidance on non-heart beating donation in England and Wales (abstract #33)
Chris Rudge, London, United Kingdom

15:30 Altruistic-directed living unrelated donation: a genuine gift of life or a Trojan horse of the market?
Miran Epstein, London, United Kingdom

16:00 **COFFEE BREAK**

16:30 Confidentiality in living donation: contradictions between donor and recipient autonomy (abstract #39)
Nizam Mamode, London, United Kingdom

16:45 Autonomy and paternalism in living donation (abstract #40)
Nizam Mamode, London, United Kingdom

17:00 Conflicts of values about definitions of equity in organ allocation in Switzerland (abstract #41)
Anne Kauffmann, Geneva, Switzerland

17:15 The allocation of organs: the need for fairness and transparency (abstract #42)
Sheelagh McGuinness, Keele, United Kingdom

19:00 – 19:45 Reception Wereldmuseum
19.45 – 20.30 Exhibition visit Willemskade 22
20.30 – 22.30 Dinner Rotterdam

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| | Monday, April 19 | | | |
| 8:00 | | | | |
| 8:30 | Plenary Session 3 | | | |
| | Rotterdam Hall | | | |
| 10:00 | Coffee Break | | | |
| 10:30 | Walk-in session 4 Incentives for Organ Donation | Walk-in session 5 Compliance | Walk-in session 6 Directed and Conditional Donation | |
| | Penn Room | Leeuwen Room | Goudriaan Room | |
| 11:30 | Free Communications 5 Deceased Donation | Free Communications 6 Psychological Care of Recipients | Free Communications 7 Samaritan / Unrelated Donation | Free Communications 8 Deceased Donation and Legal and Ethical Boundaries |
| | Penn Room | Leeuwen Room | Goudriaan Room | Rotterdam Hall |
| 13:00 | | | | Lunch |
| 13:30 | Poster Session 2 - Rotterdam Hall | | | |
| | Deceased Donation | Psychological Care | | |
| 14:30 | Workshop 4 Deceased Donation | Workshop 5 Psychological Care of Living Donors and Recipients | Workshop 6 Samaritan / Unrelated Donation | |
| | Penn Room | Leeuwen Room | Goudriaan Room | |
| 16:00 | Coffee Break | | | |
| 16:30 | Workshop 4 Deceased Donation | Workshop 5 Psychological Care of Living Donors and Recipients | Workshop 6 Samaritan / Unrelated Donation | |
| | Penn Room | Leeuwen Room | Goudriaan Room | |
| 18:00 | Congress Reception at City Hall | | | |

08:30 – 10:00 Plenary Session 3 (Rotterdam Hall)

*Chairs: Paolo Bruzzone, Rome, Italy;
Inez de Beaufort, Rotterdam, The Netherlands*

08:30 End of life care of potential organ donors
David Price, Leicester, United Kingdom

09:00 Making house calls: how a novel home-based program can increase live donor kidney transplantation
James Rodrigue, Boston, United States of America

09:30 Altruism: reciprocity/solidarity approach
Peter Šykora, Trnava, Slovak Republic

10:00 COFFEE BREAK**10:30 – 11:30 Walk-In Session 4 (Penn Room)
Incentives for Living Organ Donation**

Moderator: Rutger Ploeg, Groningen, The Netherlands

*Experts: Arthur Matas, Minneapolis, United States of America;
Judit Sándor, Budapest, Hungary;
Gert van Dijk, Rotterdam, The Netherlands*

**10:30 – 11:30 Walk-In Session 5 (Leeuwen Room)
Compliance**

Moderator: Emma Massey, Rotterdam, The Netherlands

*Experts: Mary Amanda Dew, Pittsburgh, United States of America;
Fabienne Dobbels, Leuven, Belgium*

Predictors of noncompliance in kidney transplantation (abstract #43)
Tetyana Ospanova, Kharkiv, Ukraine

**10:30 – 11:30 Walk-In Session 6 (Goudriaan Room)
Directed and Conditional Donation**

Moderator: Axel Rahmel, Leiden, The Netherlands

*Experts: Antonia Cronin, Manchester, United Kingdom;
Mark Murphy, Dublin, Ireland;
Hans Akveld, Bussum, The Netherlands*

Interviews with a group of transplant professionals about directed organ donations from deceased donors (abstract #44)
Kelley Ross, Toronto, Canada

**11:30 – 13:00 Free Communications 5 (Penn Room)
Deceased Donation**

*Chairs: John Forsythe, Edinburgh, United Kingdom;
Stellan Welin, Linköping, Sweden*

11:30 Influence of demographical and administrative factors on the rate of deceased organ donors in Latvia (abstract #45)
Janis Jushinskis, Riga, Latvia

11:45 Myths and facts – what should we know about neurocritical patient evolution and organ donation? (abstract #46)
Teresa Pont Castellana, Barcelona, Spain

12:00 Determination of death and organ retrieval in Spain, US and France. Knowledge, concepts and attitudes among health professionals (abstract #47)
David Rodríguez-Arias, Salamanca, Spain

12:15 Brain-based criteria for diagnosing death: what does it mean for family members approached about organ donation? (abstract #48)
Tracy Long-Sutehall, Southampton, United Kingdom

12:30 Discussing organ donation with next of kin (abstract #49)
Peter Desatnik, Helsingborg, Sweden

12:45 The role of intensive care unit doctors in organ donation procedures (abstract #50)
Danica Avsec-Letonja, Ljubljana, Slovenia

**11:30 – 13:00 Free Communications 6 (Leeuwen Room)
Psychological Care for Recipients**

*Chairs: Margareta Sanner, Uppsala, Sweden;
Leonieke Kranenburg, Rotterdam, The Netherlands*

11:30 Living kidney donor: integral donor protection (abstract #51)
David Paredes-Zapata, Barcelona, Spain

11:45 Predictors of quality of life in caregivers to cardiothoracic transplant recipients (abstract #52)
Larissa Myaskovsky, Pittsburgh, United States of America

12:00 Defining success in living donor kidney transplantation: should patient reported outcome measures (proms) influence the limits of living donation? (abstract #53)
Luke Forster, London, United Kingdom

- 12:15 Composite risk scores and depression as predictors of mortality, clinical improvement, and other waiting-list outcomes: the waiting for a new heart study (abstract # 54)
Gerdi Weidner, Tiburon, United States of America
- 12:30 Depression and anxiety in living kidney donation: evaluation of protagonists, donors and recipients (abstract #55)
Alice Soares, Porto, Portugal
- 12:45 Beliefs and attitudes to medication among kidney transplanted in Sweden (abstract #56)
Annette Lennerling, Gothenburg, Sweden
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- 11:30 – 13:00 Free Communications 7 (Goudriaan Room) Samaritan / Unrelated Donation**
- Chairs: Thomas Gutmann, Muenster, Germany; Govert den Hartogh, Haarlem, The Netherlands*
- 11:30 Paired living kidney donation in the UK (abstract #57)
Rachel Johnson, Bristol, United Kingdom
- 11:45 Review of ethical guidelines for the evaluation of living organ donors (abstract #58)
Linda Wright, Toronto, Canada
- 12:00 A retrospective analysis of living kidney donation at the Centre Hospitalier de l'Université de Montréal (CHUM): a rationale for paired-exchange programs (abstract #59)
Marie-Chantal Fortin, Montréal, Canada
- 12:15 Integration of a Good Samaritan and a kidney exchange program (abstract #60)
Willij Zuidema, Rotterdam, The Netherlands
- 12:30 Unbalanced kidney paired exchange (abstract #61)
Marry de Klerk, Rotterdam, The Netherlands
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- 11:30 – 13:00 Free Communications 8 (Rotterdam Hall) Deceased Donation / Legal and Ethical Boundaries**
- Chairs: Axel Rahmel, Leiden, The Netherlands; Medard Hilhorst, Rotterdam, The Netherlands*
- 11:30 An organ donation lesson in primary school; teacher's opinions (abstract #62)
Marion Siebelink, Groningen, The Netherlands
- 11:45 Just because we can, should we? An ethical approach to temporary alternatives as a bridge to paediatric transplant (abstract #63)
Núria Masnou Burralló, Barcelona, Spain
- 12:00 Current situation of non heart beating donation and transplantation in member states of the Council of Europe (abstract #64)
Beatriz Dominguez-Gil, Madrid, Spain
- 12:15 Index linked organs for transplants (abstract #65)
Antonia Cronin, Manchester, United Kingdom
- 12:30 Extended criteria liver donation and transplant recipient consent: the European experience (abstract #66)
Paolo Bruzzone, Rome, Italy
- 12:45 Even actual living kidney donors are not all registered in the donor register (abstract #67)
Mirjam Laging, Rotterdam, The Netherlands
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- 13:00 – 14:30 LUNCH
-
- 13:30 – 14:30 Poster Session 2 (Rotterdam Hall)**
- Posters 29 - 37: Deceased Donation**
Chair: Andries Hoitsma, Nijmegen, The Netherlands
- Posters 38 - 45: Deceased Donation**
Chair: Marion Siebelink, Groningen, The Netherlands
- Posters 46 - 54: Psychological Care for Living Donors and Recipients**
Chair: Frank Dor, Rotterdam, The Netherlands
- Posters 55 - 62: Psychological Care for Living Donors and Recipients**
Chair: Jan van Busschbach, Rotterdam, The Netherlands
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- 14:30 – 18:00 Workshop 4 (Penn Room) Deceased Donation**
- Chairs: Magi Sque, Southampton, United Kingdom; Bernadette Haase-Kromwijk, Leiden, The Netherlands*
- 14:30 Follow on introduction from plenary presentation 'Between Life and Death'
Stuart Youngner, Cleveland, United States of America
- 14:40 Organ donation: triggers and impact on health professionals
Peter Desatnik, Helsingborg, Sweden
- 15:15 Impact of donation on bereaved families
Magi Sque, Southampton, United Kingdom
- 16:00 **COFFEE BREAK**
- 16:30 The effect of the request for organ donation on grieving relatives (abstract #71)
Sabine Moos, Mainz, Germany

- 16:45 Deceased donation, culture and the objectivity of death (abstract #72)
Maryon McDonald, Cambridge, United Kingdom
- 17:00 Illustrative case study and discussion
Janet Radcliffe Richards, Oxford, United Kingdom
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- 14:30 – 18:00 Workshop 5 (Leeuwen Room)
Psychological Care for Living Donors and Recipients**
- Chairs: Fabienne Dobbels, Leuven, Belgium;
Jan van Busschbach, Rotterdam, The Netherlands*
- 14:30 Is your patient a good candidate for transplantation? The role of pre-transplant psychosocial screening
Christiane Kugler, Hannover, Germany
- 15:00 Psychological factors in living donors: do they matter?
Mary Amanda Dew, Pittsburgh, United States of America
- 16:00 **COFFEE BREAK**
- ‘Patient quality of life after transplantation: predictors’**
- 16:30 Depression, non-compliance, and survival in heart transplant candidates (abstract #73)
Pavla Notova, Bratislava, Slovakia
- 16:40 Which predictors of self-rated health in patients after kidney transplantation are important? (abstract #74)
Maria Majernikova, Kosice, Slovakia
- 16:50 Psychosocial determinants of quality of life 6 months after liver transplant: a longitudinal prospective study (abstract #75)
Inês Mega, Lisbon, Portugal
- 17:00 Psychological consequences of organ transplantation: a prospective study among liver transplant recipients (abstract #76)
Coby Annema, Groningen, The Netherlands
- ‘Acceptance of living transplantation among patients’**
- 17:10 Predictors of the willingness to consider living donor kidney transplantation in haemodialysis patients (abstract #77)
Daniela Mladenovska, Skopje, Macedonia
- 17:20 Group education of families and friends of CKD patients; the impact on living kidney donation (abstract #78)
Ton van Kooij, Rotterdam, The Netherlands
- 17:30 Three-part modelling of the decision to accept a live donation: certainty, refusal, questioning (abstract #79)
Deborah Ummel, Montréal, Canada
- 17:40 Living or deceased kidney transplants? Experiences of the donation process among kidney recipients in middle Sweden (abstract #80)
Margareta Sanner, Uppsala, Sweden
- 17:50 Living kidney donors who regret donation (abstract #81)
Gilbert Thiel, St. Gallen, Switzerland
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- 14:30 – 18:00 Workshop 6 (Goudriaan Room)
Samaritan / Unrelated Donation**
- Chairs: Annette Lennerling, Gothenburg, Sweden;
Willij Zuidema, Rotterdam, The Netherlands*
- 14:30 The promotion of living unrelated donation
Gabriel Danovitch, Los Angeles, United States of America
- 15:10 One donor, two Samaritan transplantations (abstract #68)
Medard Hilhorst, Rotterdam, The Netherlands
- 15:25 Psychosocial, educational and economic factors in living unrelated kidney donation: a single Brazilian center experience (abstract #69)
Gustavo Ferreira, Sao Paulo, Brazil
- 15:40 Psychosocial outcomes of Good Samaritan donors compared to a matched sample of traditional donors (abstract #70)
James Rodrigue, Boston, United States of America
- 16:00 **COFFEE BREAK**
- 16:30 Allocation of non-directed living donor organs
Antonia Cronin, Manchester, United Kingdom
- 17:05 The problem (?) of organ solicitation
Katrina Bramstedt, San Francisco, United States of America
- 17:35 Favourable psychological outcomes among good Samaritan donors: a follow-up study (abstract #82)
Emma Massey, Rotterdam, The Netherlands
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- 18:00 – 19:30 Reception City Hall** Coolsingel 40
Rotterdam
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| | Tuesday, April 20 |
| 8:00 | |
| 8:30 | Plenary Session 4 |
| | Rotterdam Hall |
| 9:30 | Coffee Break |
| 10:00 | Plenary Session 4 |
| | Rotterdam Hall |
| 12:30 | Snacks |
| 13:30 | |

**08:30 – 09:30 Plenary Session 4 (Rotterdam Hall)
‘Beyond Borders in Transplantation’**

*Chairs: John Forsythe, Edinburgh, United Kingdom;
Rutger Ploeg, Groningen, The Netherlands;
Willem Weimar, Rotterdam, The Netherlands*

08:30 Workshop Recommendations
*Michael Bos, The Hague, The Netherlands
Magi Sque, Southampton, United Kingdom
Jan van Busschbach, Rotterdam, The Netherlands
Gurch Randhawa, London, United Kingdom
Thomas Gutmann, Muenster, Germany
Annette Lennerling, Gothenburg, Sweden*

09:30 COFFEE BREAK

*Chairs: Hele Everaus, Tartu, Estonia;
Aggie Balk, Rotterdam, The Netherlands*

10:00 The new EU Member States
Assya Pascalev, Sofia, Bulgaria

10:30 Stem cell science and donation
Bobbie Farsides, Brighton, United Kingdom

11:00 New EU policies in transplantation
*Anna Pavlou, European Commission,
Directorate-General Health and Consumer Protection,
Public Health and Risk Assessment Directorate*

11:30 The future of transplantation: technological and/or moral innovation?
Tsjalling Swierstra, Enschede, The Netherlands

12:00 Closing remarks

12:30 – 13:30 Snacks

Plenary Sessions

Plenary Session 1

16:00 – 18:00 ‘**Crossing Borders in Organ Transplantation**’

The free movement of patients and organs in the European Union

Aart Hendriks, Leiden, The Netherlands

The entering into force of the Lisbon Treaty seems to have little impact on the free movement of patients and organs in the European Union. Patient mobility is, however, already a reality in Europe, also in response to long waiting times on the national level. Moreover, the Charter of Fundamental Rights bestows EU citizens with health care rights, whereas the EU is committed to counter organ trafficking and transplant tourism. The European Commission is known to be determined to take away (financial) barriers for patients seeking health care in another Member State, while guaranteeing safe and high quality health care as well as respect for patients’ rights. To this end, it issued a proposal for a directive on the application of patients’ rights in cross-border healthcare on 2 July 2008. This legal instrument potentially has significant importance for the free movement of patients in the European Union.

In my presentation, I will discuss the meaning of EU law and the proposed directive for the free movement of patients and organs in the European Union against the background of scarcity of organs, evidence of organ trafficking and transplant tourism, and the standards set by the Council of Europe. Special attention will be paid to the relationships between the European Union and the Council of Europe, an intergovernmental organisation with treaties and protocols in the field of biomedicine and human rights, as well as the position of Eurotransplant and the normative meaning of the Declaration of Istanbul.

Issues discussed include the (national) way of selecting patients for transplantation versus medical standards accepted at the international level, free movement of persons and goods, self-sufficiency, non-discrimination, justice and human rights.

The boundary between life and death

Stuart Youngner, Cleveland, United States of America

When one thinks of moral philosophy in general and bioethics in particular, the issue of boundaries is inevitable. Crossing or blurring boundaries can be unsettling, not just for philosophers and bioethicists, but for the societies in which they live. Boundary crossing can be considered immoral, profane, or even abominable. If boundaries are important, what methods might we employ to tell us where they are? For geographic boundaries we use surveyors’ instruments or GPS technology. For boundaries in bioethics, philosophy, religion and biology are the most likely methodologies. For example, the line between killing and letting die must be drawn by philosophy – carefully defining terms and weighing the role of intent, motive and so on.

For death, two methods come into play – philosophy and medical science. Religion has had a role – the line between life and death is where God says it is as revealed in sacred texts –

but I will not consider religion here. Life and death are understood in biological terms and, therefore, medical science certainly has a role in the determination of death. But that role is secondary because medical science can only show us how to identify the presence or absence of functions that philosophy has identified as the “critical” ones, critical here meaning function(s) that when irreversibly lost, mark the transition from living human person to corpse. Unfortunately, philosophers do not and never will agree upon just which functions are critical and exactly what is meant by irreversible. Thus, the definition of death and the determination of its exact moment remain social constructs, contextualized by particular cultures and politics. Today, the need for human organs is the most powerful contextual factor shaping when and how we say someone is dead.

Self-imposed boundaries

Janet Radcliffe Richards, Oxford, United Kingdom

The science and technology that have broken down the natural boundaries between individuals have produced confusion through wide swathes of medicine, because the possibilities they open keep running up against laws, conventions, habits of mind and institutions developed in a quite different world. In particular, transplanters have to contend with deeply ingrained feelings and traditions that protect the integrity of bodies, both living and dead, and as a result need to tread warily as they go about the business of organ procurement. Now that we are all potential sources of spare parts for other people, clinicians and politicians have responded to the breach of physical boundaries by reinforcing conventional ones, and assuring us that our organs are safe unless we choose to give them. However, some of the boundaries within which organ procurement have been constrained are of exactly the opposite kind. Many of the restrictions – such as, for instance, the ones that disallow directed donation and arrangements for reciprocity, as well as organ selling – take the form not of protecting potential donors from having organs taken without their consent, but of limiting the circumstances and ways in which donations may be made. Perhaps such restrictions may be justified, but the kinds of justification usually offered, such as ‘the fundamental principle that organs are given altruistically and must go to the person most in need’ cannot be made to justify the kinds of arrangement that are in place, and are anyway incompatible with the principles their advocates invoke in other contexts. It is interesting to speculate on the real motivations underlying these policies. In the meantime, there is reason to think that restrictions of these kinds may reduce the availability of organs by running against popular feeling, and even increasing distrust. At least they need serious rethinking.

Plenary Session 2

08:30 – 10:00

What happened after the Istanbul Declaration?

Francis Delmonico, Boston, United States of America

The Mission of the Declaration of Istanbul Custodian Group (DICG) is to promote, implement and uphold the Declaration of Istanbul so as to combat organ trafficking, transplant tourism and transplant commercialism and to encourage adoption of effective and ethical transplantation practices around the world.

On September 30, 2009, the Steering Committee of the Declaration of Istanbul met in Beirut, Lebanon, in conjunction with the Congress of the Asian Society of Transplantation, to formulate a strategy and plans for the continued implementation of the Declaration. Since the November 2008 Steering Committee meeting, there has been a reduction in organ trafficking and transplant tourism in China, the Philippines, and Pakistan. Israel has enacted legislation that impedes Israeli citizens from receiving insurance coverage for transplants performed outside of Israel if the destination country prohibits foreign patients from undergoing transplantation. There has been a recorded reduction in foreign transplants in Colombia from 12 % to 1 % of transplants performed. More than 80 professional organizations and societies have endorsed the Declaration of Istanbul and it has been translated into more than a dozen languages.

Task Forces have been established to interact with professional organizations, medical and scientific journals, pharmaceutical companies and other research sponsors, and a government and healthcare institutions. A task force has also been formed to address patient affairs – especially those that pertain to organ trafficking and transplant tourism.

On October 13, 2009 a Joint Report by the Council of Europe and the United Nations was presented in New York at the United Nations to launch a global effort in combating human organ trafficking.

In March 2010, the WHO will hold its 3rd Global Consultation on transplantation in Madrid, Spain (in collaboration with TTS and ONT) to foster the development of self sufficiency in each nation in providing organ transplants for its residents.

Organ donation and transplantation through the lens of Muslim scholars

Farhat Moazam, Karachi, Pakistan

Islam has no concept of a central authority akin to a church to formulate uniform policies and rules binding on all Muslims. Historically, Muslim *ulema* (scholars) and *muftis* (jurists) provide *fatawa* (religious opinions) regarding the permissibility or not of specific actions/practices including those connected to medical practices such as organ donation and transplantation. The opinions are based on their interpretation of Qur'anic verses, the Sunna (practices of the Prophet), and juridical principles including *qiyas* (analogy). An *ijma* (consensus) of prominent *muftis* important as it is, nevertheless, does not preclude other Muslim scholars from taking a different position utilizing the same religious sources.

My presentation will consist of two parts. I will begin with a brief overview of *ijma* statements from notable Islamic insti-

tutions supporting organ transplantation, and also provide dissenting opinions voiced by *ulema* from the Asian subcontinent particularly against cadaveric donations. In my experience, the latter are far better known, and quoted, by religious leaders in Pakistan who have significant influence over the population.

The second half of my talk will deal with the Transplantation of Organs and Tissues Ordinance of Pakistan, 2007 which, in order to stem kidney tourism, includes clauses prohibiting unrelated live organ donation to non-Pakistanis. I will focus on the challenge against Ordinance 2007 filed in the Federal Shariat Court (FSC) of Pakistan, the position of *muftis* appearing for and against the petition, and arguments offered by the FSC judges in support of their decision to dismiss the petition. Attempts to enhance organ donation require moving beyond standard “medical” discourse to a better understanding of the diversity of religious and cultural traditions that are critical to public willingness or resistance towards donating organs.

Organs wanted, but how to avoid commodification?

Judit Sándor, Budapest, Hungary

The Ovideo Convention states a categorical ban on the commercialization of organ donation in Article 21 by saying “The human body and its parts shall not, as such, give rise to financial gain.” The convention is based on broad consensus in Europe as more than twenty countries have ratified it so far. It follows from the text that both commercialization and commodification are covered by this prohibition. The prohibition is restated in the Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Transplantation of Organs and Tissues of Human Origin. The Protocol also prohibits advertising the need for, or availability of, organs or tissues, with a view to offering or seeking financial gain or comparable advantage.

In the Explanatory Note of the Convention it is clarified that under Article 21 of the Convention organs and tissues, including blood, should not be bought or sold or give rise to financial gain for the person from whom they have been removed or for a third party, whether an individual or a corporate entity such as, for example, a hospital. However, certain technical acts which are performed on the basis of these items may legitimately give rise to reasonable remuneration. For instance, this Article does not prohibit the sale of a medical device incorporating human tissue as long as the tissue is not sold as such. Further, this Article does not prevent a person from whom an organ or tissue has been taken from receiving compensation which, while not constituting remuneration, compensates that person equitably for expenses incurred or loss of income.

In the last decade one possible competitor to transplantation, stem cell therapy, in many respects has already entered in the commercial zone. While strict provisions to prevent commodification of organs are widely accepted in the public, in the field of stem cell treatment, people often look for commercial alternatives. The hard question of the future will be whether this thinking about cells could fundamentally alter our thinking about human organs and tissues as well, from something personal to something that serves therapeutic purposes. Furthermore, can we maintain the distinction between human cells and human tissues? The presentation explores the tendencies for commodification and describes some possible scenarios for regulation.

Plenary Session 3

08:30 – 10:00

End of life care of potential organ donors

David Price, Leicester, United Kingdom

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.

Making house calls: how a novel home-based program can increase live donor kidney transplantation

James Rodrigue, Boston, United States of America

Live donor kidney transplantation (LDKT) yields superior outcomes relative to chronic dialysis and deceased donor kidney transplantation. Therefore, kidney transplant programs provide patients with LDKT information in the context of transplant clinic visits, often combining informal discussions with members of the transplant team, written brochures, videotapes/DVDs, and educational seminars. While certainly beneficial and cost-effective, this clinic-based education may be limited by several factors. For example, this educational approach targets the patient primarily and it relies on them to disseminate information about LDKT and living donation to others. Moreover, the time constraints of a clinic-based approach may not allow for all of the patient’s primary concerns (i.e., imposing on others, uncertainty about how to discuss living donation with others, misinformation about donor eligibility criteria, donor outcomes, etc.) to be fully addressed. The precise numbers of patients who do not pursue LDKT and potential living donors who are never evaluated because of these factors are unknown, but are potentially high. We developed a psycho-educational LDKT program designed to overcome these clinic-based educational barriers by delivering such information to patients and their family members, friends, co-workers, and others in the patient’s home. This home-based LDKT approach has shown to be effective at increasing LDKT knowledge, reducing LDKT concerns, and increasing the

likelihood of eventual LDKT for the patient. This presentation will describe the key features and outcomes of this home-based approach, as well as highlight some of our observations and experiences in implementing this type of educational program.

Altruism: reciprocity/solidarity approach

Peter Sýkora, Trnava, Slovak Republic

The failure of the present system of altruistic donation to cope with the ever growing demand for human organs calls for more efficient alternatives. Within a traditional bipolar discourse on medical donation the only alternative to the Good Samaritan model on which organ procurement is based, is seen in some forms of legal, free or controlled organ markets. However, there is a wide-spread aversion to commodification of human body, not to mention that it is already illegal under current legislation in most countries. I try to show that there is a way out from the altruism/commerce deadlock dichotomy. We should replace a narrow concept of psychological altruism, based on unselfish motivation and charitable donation to strangers (Titmuss’s “gift relationship” paradigm), by a more general concept of altruism, in a sense, as used in behavioural sciences. Behaviour is said to be altruistic if an altruistic actor pays a cost for delivering a benefit to others, regardless of his/her motivation. Moreover, the behavioural concept of altruism, in contrast to a psychological concept, does not exclude reciprocity. Indirect reciprocity plays a crucial role in human societal solidarity and it is in fact behind many modern welfare state policies, such as tax, pension and health care system. The aim of this reconceptualization is to develop a new conceptual framework for organ procurement models to be based on reciprocity and solidarity principles in which donors will be reciprocated, although not directly paid, for donation.

Plenary Session 4

08:30 – 09:30 Workshop Recommendations

Organ Tourism and Paid Donation
Michael Bos, The Hague, The Netherlands

Diverse Populations
Gurch Randhawa, London, United Kingdom

Legal and Ethical Boundaries
Thomas Gutmann, Muenster, Germany

Deceased Donation
Magi Sque, Southampton, United Kingdom

Psychological Care for Living Donors and Recipients
Jan van Busschbach, Rotterdam, The Netherlands

Samaritan/Unrelated Donation
Annette Lennerling, Gothenburg, Sweden

10:00 – 12:00 ‘Beyond Borders in Transplantation’

Organ donation and transplantation in the new EU Member States

Assya Pascalev, Sofia, Bulgaria

Stem cell science and donation

Bobbie Farsides, Brighton, United Kingdom

It is regularly claimed that Stem Cell science holds great promise for people with a variety of serious life limiting and life threatening diseases. However, as yet, the future remains

uncertain in terms of how quickly and how effectively that promise can be realised. Part of the reason for this is the ethically challenging nature of the basic and translational research required to advance therapeutic interventions involving the use of human embryonic stem cells. Some of the ethical issues are clearly specific to these exciting new possibilities within regenerative and transplant medicine, others are new variants of ethical questions relating to donation, participant/patient selection, research and treatment already familiar to participants at this conference. Using data from a series of observational and interview/discussion based studies conducted at five specialist centres within the UK between 2004 and 2009 this paper will consider the experience of over 50 scientists and clinicians working in this ‘ethically contested’ field of biomedicine, and their reflections upon the ethical frameworks within which they operate.

New EU policies

Anna Pavlou, European Commission, Directorate-General Health and Consumer Protection, Public Health and Risk Assessment Directorate

The future of transplantation: technological and/or moral innovation?

Tsjalling Swierstra, Enschede, The Netherlands

Anticipations of the future of organ transplantation mostly evolve around the promises of technological innovation: xenotransplantation, tissue engineering, artificial organs, etc. And indeed, these promises are worth taking seriously. But the future of organ transplantation is not determined by technological innovation alone. Social, moral, innovation will play a major role too. It is impossible to think realistically about the future of organ transplantation without acknowledging the interplay of technology and morality in the past and present. Moral innovation should be taken as seriously as technological innovation.

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Walk-in Sessions

Walk-In Session 1

10:30 – 11:30 Children as Donors

Experts:

Thalia Bellali, Thessaloniki, Greece
Magi Sque, Southampton, United Kingdom
Marion Siebelink, Groningen, The Netherlands

Moderator:

Bernadette Haase-Kromwijk, Leiden, The Netherlands

Undeniably the death of child is one of the most distressing of bereavements as parents naturally expect to out live their children. Couple this bereavement with the request for organ donation and you have one of the most stressful and provocative emotional environments for both health professionals and the bereaved family. Supporting the bereaved and carrying out the organ donation discussion can thus be a highly sensitive encounter and requires a skilled and empathetic approach if the persons tasked with making decisions on behalf of the child are to make a decision that they will remain comfortable with and not regret later.

This Walk-in Session will give you an opportunity to network with other delegates who have a particular interest in this field and to meet experts in end of life decision-making and organ donation in the paediatric setting. Using current evidence you will have the opportunity to explore real life case studies and discuss the issues that would need to be resolved to enhance the probability of a positive agreement to donation. Issues that may well be relevant are: communication issues; conditions of the organ donation discussion (who, where, how and when); the decision-making process (different types of decision-making e.g. by consensus, de facto decision, by accommodation or deliberation, by rational/stepwise, by impulse – instantaneous decision); bereavement issues; meaning-making of organ donation; cultural-legal issues (in different European countries) and many more. We look forward to welcoming and meeting you.

How do grieving parents react to the request for organ donation from their child? (abstract #1)

Sabine Moos, Mainz, Germany

Adjusting to loss after donating a family member's organ (abstract #2)

Tamar Ashkenazi, Tel Aviv, Israel

Walk-In Session 2

10:30 – 11:30 Samaritan Donation and Altruism

Experts:

Annette Lennerling, Gothenburg, Sweden
Sigrid Sterckx, Ghent, Belgium
Govert den Hartogh, Haarlem, The Netherlands

Moderator:

Jan van Busschbach, Rotterdam, The Netherlands

Living donation is normally a matter of relatives, partners or, occasionally, friends. If the donor and the recipient don't know each other this is called Samaritan donation: donation between strangers. It is relatively new and in some countries still legally forbidden. For a long time it was suspected that the offer could not be properly voluntary. It is one of the paradoxes of the organ donation debate: we usually insist that donation must be altruistic, here comes the one person who really seems to be an altruist and we think (s)he must be mad. The consensus by now is that such an offer requires close scrutiny to determine whether it is well-considered, but it is very well possible that it is. In this session we will consider ethical aspects of Samaritan donation.

We begin with the general question of its moral acceptability. We approach that question from a specific perspective. As a medical act removing a living organ is at first sight problematic, because it doesn't seem to be in the interest of the donor. It doesn't turn a patient into a (more) healthy person, but a healthy person into a patient. Yet living donation is by now generally accepted. How do we justify it? There seem to be three options, and for each of these we will ask the question whether that justification is also available for Samaritan donation. The first option is to propose that the consent of the donor is enough. The second option is to suggest that donation really is in the interest of the donor after all, if only we take a sufficiently wide view of his/her interests. The third option is to refer to the special relation which exists between donor and recipient and the responsibilities involved in that relation. The first two of these justifications seem to be applicable to Samaritan donation as well, but the third seems to pose more of a problem.

The next question we will address is the following. If we accept Samaritan donation in principle, are there any kinds of donation we still have reason to object to? Actually two kinds of Samaritan donation have to be distinguished: directed and non-directed. In directed donation the donor specifies either the individual who, or the class of individuals which is to receive the organ (s)he donates. As for non-directed donation the question we will consider is whether, if we accept donation of a kidney, we also agree to allow donation of a globe of a lung or a liver, and, if so, if these donations can be made cumulatively. Finally we intend to consider the acceptability of directed donation. Some forms of it (e.g. donation to young children) seem relatively innocent, others (donation to people of a particular race or skin, or to a public figure, or on solicitation) seem much more problematic.

Both of the questions in this part of the session will be introduced by the presentation of a relevant case.

Walk-In Session 3

10:30 – 11:30 Euthanasia and Organ Donation

Experts:

Paul Schotsmans, Leuven, Belgium

Stuart Youngner, Cleveland, United States of America

Dirk Ysebaert, Antwerp, Belgium

Moderator:

Michael Bos, The Hague, The Netherlands

Around 1995, at a time when the possibility of legalizing euthanasia was actively debated in the Netherlands, the question was raised whether euthanasia and organ donation could be medically, legally and ethically consistent. At that time the Ethics Committee of the Dutch Transplant Association presented its opinion that, if the legal hurdles were overcome and a law decriminalising euthanasia was adopted, there should be no overriding legal and ethical arguments to deny patients who requested euthanasia (under the strict conditions formulated) the possibility of organ donation. However, some doubts were voiced that the actual method of euthanasia (medication) could perhaps preclude the use of these organs. Also, the procedure of determining the death of such patients, fully respecting the Dead Donor Rule, could present an obstacle. Therefore, this Ethics Committee recommended that, in anticipation of breakthrough legislation, only tissue donation was to be carried out in such patients. Finally, in 2001 a euthanasia law was adopted in the Netherlands, followed in 2002 by a similar law in Belgium. In these laws 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, and any external pressure must be ruled out. 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 caused by illness or accident and leaves the patient in a medically futile situation. This does not necessarily mean that euthanasia is only restricted to patients in a terminal phase of illness.

Between 2005 and 2007, in four Belgian patients whose request for euthanasia was granted and who had also expressed their willingness to donate organs, this combined procedure has been successfully performed for the first time. These patients were around 45 years of age and had a debilitating neurologic disease, resulting from severe cerebrovascular accident or primary progressive multiple sclerosis. The euthanasia procedure was performed in the hospital operating room, but the patient's and family wishes were fully respected. The actual donation procedure followed the method of donation after cardiac death (DCD) and resulted in procurement and transplantation of 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 procurement procedure.

Obviously, allocation of the thus procured organs - in this case performed by the Eurotransplant organization - could only be done to countries that had adopted euthanasia legislation: Bel-

gium and the Netherlands. The first Belgian cases were presented in a Eurotransplant meeting in 2006, and the allocation procedure was discussed. The Eurotransplant Ethics Committee was invited to develop recommendations on how to ethically integrate this procedure in the routine allocation. Final recommendations were accepted by the ET Board in May 2008 in Vienna. It seems important that the transplant community should further discuss the potential of this procedure, despite the fact that the World Medical Association considers both euthanasia and assisted suicide as conflicting with basic ethical principles of medical practice, and urges physicians to refrain from participating even if national law in a given country allows or decriminalizes euthanasia. The case will be presented of a Belgian patient with a deeply traumatic psychiatric history, who has requested euthanasia and at the same time made an explicit wish to donate organs after death.

Initial experience with transplantation of lungs recovered from donors after euthanasia

Dirk van Raemdonck, Leuven, Belgium

Walk-In Session 4

10:30 – 11:30 Incentives for Living Organ Donation

Experts:

Arthur Matas, Minnesota, United States of America

Judit Sándor, Budapest, Hungary

Gert van Dijk, Rotterdam, The Netherlands

Moderator:

Rutger Ploeg, Groningen, The Netherlands

Financial incentives for living kidney donation: free health care

Gert van Dijk, Rotterdam The Netherlands

In this statement it is argued that there are no decisive objections against financial incentives to living kidney donation. There are certainly a number of difficulties, but these can be addressed by attaching conditions to implementation. There are two fundamental principles that should be respected: equal access and the voluntariness of the donation. These principles are best respected by introducing an incentive in the form of a life-long payment of health insurance premiums for live donors. This option does most justice to the moral intuition of many people who do not see organs as something for which you should receive money. Another benefit of exempting donors from paying health insurance premiums is that it is not so evident that it would lead people in financial difficulties to decide to donate an organ. This is all the more so, because poor people pay less health care premiums than do rich people, and therefore benefit less.

A responsible system for incentives for living donation should meet several criteria, the most important of which is that only the government can obtain and distribute the organs, and pay for the incentive.

The ethical incentive

Judit Sándor, Budapest, Hungary

Love and care is probably the best and most powerful incentive for organ donation. If someone suffers from the prospect of losing a close relative, organ donation seems to be a sacrifice worth doing.

Therefore, if additional benefits are given to the organ donor in the form of health services, then it should be done in a manner that avoids foreclosing altruism. It should be considered unfair for organ donors if they are unable to receive the necessary health care service when they need it later in their lives and possibly die in the lack of financial support. Nevertheless, their future health care needs should be uncertain at the moment of donation, and should not be taken as a condition for the act of donation.

As I respect the principle of autonomy, I could also imagine organizing altruistic competitions as incentives. For example, two states, two provinces, two counties of approximately equal size of population could enter into a competition to see which group or society cares more for those who are in need of organs, and which one is willing to donate more organs. As a likely consequence, the more altruistic community would

benefit from a better concentration of health resources and from more lives saved there. Or is it just a dream?

A regulated system of incentives – Choosing life over death

Arthur Matas, Minnesota, United States of America

The discussion of transplant ethics is filled with nuances. Even bioethicists debate which are the primary principles to be used in resolving debates or discussion. But a simplistic view is that for individuals who prefer to be alive, *life is probably better than death*.

The discussion about incentives for organ donation does not occur in a vacuum. It is clear that for patients with end stage renal disease, a transplant provides a longer life and a better quality of life versus maintenance dialysis. Thus *the limited organ supply results in many candidates dying while waiting for a transplant*. It has been estimated that candidates ≥ 60 have a 50% chance of dying before being transplanted (1). Increasing the supply of organs will save lives.

A regulated system of incentives for living donation has the potential to increase donation and therefore save lives. While there are ethical concerns – which could be dealt with by an appropriate regulated system – opponents continue to debate the ethical nuances without proposing feasible alternatives.

In the United States – see table below – organ donation has plateaued (or slightly decreased) in spite of the introduction of ECDs, DCDs, paired exchanges, and chains. Incentives have the potential to markedly increase donation.

The opportunity for life should be given a priority in ethical debates. We should begin trials of incentives to determine whether incentives increase donation, shorten the waiting list, and decrease patient mortality.

Table: Donors in the United States 2001-2009

(www.UNOS.org)

| | To | Date | 2009 | 2008 | 2007 | 2006 | 2005 | 2004 | 2003 | 2002 | 2001 |
|-----------------|---------|--------|--------|--------|--------|--------|--------|--------|--------|--------|------|
| All Donor Types | 281,387 | 14,059 | 16,520 | 16,635 | 17,095 | 16,483 | 16,005 | 15,137 | 14,779 | 14,272 | |
| Deceased Donor | 183,499 | 8,812 | 10,552 | 10,592 | 10,661 | 9,913 | 9,358 | 8,667 | 8,539 | 8,233 | |
| Living Donor | 97,888 | 5,247 | 5,968 | 6,043 | 6,434 | 6,570 | 6,647 | 6,470 | 6,240 | 6,039 | |

1. Schold J, Srinivas TR, Sehgal AR, Meier-Kriesche HU. Half of kidney transplant candidates who are older than 60 years now placed on the waiting list will die before receiving a deceased-donor transplant. *Clin J Am Soc Nephrol.* 4:1239-45, 2009

Walk-In Session 5

10:30 – 11:30 Compliance

Experts:

Mary Amanda Dew, Pittsburgh, United States of America

Fabienne Dobbels, Leuven, Belgium

Moderator:

Emma Massey, Rotterdam, The Netherlands

This session is designed to generate ideas about novel approaches to take in future research and clinical practice in order to address nonadherence issues in organ transplant recipients. The session will begin with a brief overview of the state of the field of adherence research in transplantation. This overview will (a) summarize information on the prevalence of nonadherence to the multicomponent post-transplant medical regimen and (b) key issues and recommendations for work in this field, as delineated in a recent consensus conference. Discussion will then focus on Session participants' ideas regarding risk factors for nonadherence that deserve greater attention in research and clinical practice. Professor Ospanova will give a 5-minute presentation of her abstract related to this topic. The second half of the session will be devoted to discussion of the range of interventions that appear most promising for addressing nonadherence in transplant recipients – both interventions to address nonadherence when it is observed, and interventions to prevent the occurrence of nonadherence. Session participants will be asked to nominate intervention strategies deemed most important to test in clinical trials in transplant recipients. They will also be asked to delineate what they see as the chief barriers to mounting intervention studies in transplant populations as well as deploying interventions in routine clinical care of these patients. Products of the Session will therefore be a summary of intervention research ideas, a list of key barriers to intervention testing and implementation, and recommendations regarding strategies to overcome these barriers and advance intervention work in this field.

Predictors of noncompliance in kidney transplantation (abstract #43)

Tetyana Ospanova, Kharkiv, Ukraine

Walk-In Session 6

10:30 – 11:30 Directed and Conditional Donation

Experts:

Antonia Cronin, Manchester, United Kingdom

Mark Murphy, Dublin, Ireland

Hans Akveld, Bussum, The Netherlands

Moderator: Axel Rahmel, Leiden, The Netherlands

The issue of directed donation of organs from deceased donors for transplantation has recently risen to the fore, given greater significance perhaps by the relatively stagnant rate of deceased donor organ donation. Whilst its status and legitimacy is explicitly recognised across the United States, elsewhere a more cautious, if not entirely negative, stance has been taken.

Directed donation is when a donor organ (or organs) is (are) directed to a specific *person*, or a nominated individual is given priority. *Conditional* donation is when a donor organ (or organs) is (are) offered to (or possibly withheld from) a specific *class* of recipient. Despite this very clear distinction, at the present time public policy in a number of European countries imposes a blanket rejection of any deceased donor organ donation unless it is intended that the organ(s) be distributed through a system of impartial equitable allocation. Directedness of any sort is considered unacceptable.

Directed and conditional donations challenge the traditional construct of altruistic deceased donation and organ allocation based upon equity and impartial justice in a very immediate and striking way. They implicitly raise important questions as to whether the body or parts of the body are capable of being owned, and by whom. Further, they highlight the difficulty faced by those who administrate the transplant laws when individual authorisation amounts to placing restrictions or conditions upon a donation which will inevitably compromise the 'central principle' of equitable organ allocation in specific instances.

In marked contrast the rationale underpinning *living* donor organ donation and allocation is donor autonomy, and respect for an individual's wishes and informed decision. At their outset, living donor transplant programmes emphasized specifically *directed* donation. An individual was entitled to donate to another individual in whom he, or she, had a special interest, a brother say. Non-directed donation was to some extent mistrusted since it did not involve the personal bond considered necessary to overcome the reluctance of doctors to inflict surgical injury on one person for the benefit of another. The increasingly good outcome of living donor transplantation, not only to close genetic relatives but also to un-related recipients, combined with the ever-increasing demand for organs, has made altruistic or 'samaritan' living organ donation an altogether attractive model and has enhanced its ethical acceptability. This type of living donation is *non-directed* and for the most part entirely anonymous. Despite the emergence of this type of living donation, it remains the case that most living donations are directed. They usually involve a healthy person donating an organ (usually a kidney) or part organ (for example liver or lung lobe) to a specific recipient who is related to the donor either genetically or emotionally.

In this session, using clinical case-based presentations we will examine the ethical and legal implications of directed and conditional donation in the context of deceased donation and contrast the current position in living donation. Implications for current legal frameworks and public policy will be considered.

Interviews with a group of transplant professionals about directed organ donations from deceased donors (abstract #44)

Kelley Ross, Toronto, Canada

Workshops

Workshop 1

14:30 – 18:00 Organ Tourism and Paid Donation

Chairs:

Annika Tibell, Stockholm, Sweden;

Michael Bos, The Hague, The Netherlands

Introduction

The last 15 years have seen a sharp worldwide increase in the number of organ transplants where nationals of one country obtain kidneys or even livers in another country through the services of commercial organizations, and where the donors (vendors) are financially rewarded. The WHO has calculated that as much as 10% of all kidney transplants worldwide are performed on the basis of such commercial transactions, involving donors who – sometimes legally, but more often illegally – sell an organ. In a number of cases this organ tourism also involves human trafficking, where poor and desperate persons are coerced, deceived and exploited for the purpose of retrieving their organs for transplantation. According to the UN Protocol (2000) on human trafficking this should be considered as a (transnational organized) criminal offence. The Declaration of Istanbul (2008) has been instrumental in changing the scene in several countries that had become the hub of organ tourism and trafficking: e.g. Pakistan, India, the Philippines and China. New legislation, more strict oversight and prohibition of offering/selling organs to foreigners have positively influenced the situation there. However, there is concern that organ tourism and commercialism is now targeting other countries, such as Egypt, Colombia and some countries in Eastern Europe (Balkans). This workshop will discuss a number of issues that are related to organ tourism and paid donation. On the one hand it will focus on the negative consequences of commercial transplantation: the medical, social and psychological hardships of victims of commercialism (vendors); the way that illegal and criminal organizations operate in what is called the ‘organ economy’; and the medical risks that patients run when they resort to obtaining an overseas transplant. On the other hand we will explore how (living) organ donors in general view the idea of receiving (monetary) compensation or reward for their altruistic behaviour. Finally, it will be discussed if offering some sort of reward for donation can act as an ethically acceptable, legal and effective incentive to promote and increase donation.

Organ trafficking and transplant tourism: Case of Moldova – first steps in identification and prevention

Igor Codreanu, Chisinau, Moldova

The use of material derived from one human being for the treatment of others poses major ethical questions for those individuals and the societies in which they live. According to the data provided by the Global Observatory on Donation and Transplantation, almost 100 000 patients worldwide receive a solid organ transplant every year. Additionally, a large number of tissues and cells are implanted on a routine basis to treat a

wide range of pathologies. The current demand, particularly for organs but to a lesser extent for some tissues, far outweighs the supply. At the end of 2007, 58 182 patients were waiting for a kidney, liver or heart transplant in the European Union, while only 25 932 corresponding transplant procedures were performed during that year. As the result of this shortage, organ trafficking and transplant tourism have become global problems accounting for an estimated 10% of organ transplants that are performed annually around the world. The World Health Organisation, Council of Europe, United Nations and European Union as well as experts from professional societies TTS, ISN, ELPAT developed and implemented a wide range of consensus documents, recommendations and specific actions and activities aimed to address the growing problems of organ sales, transplant tourism and organ, tissue and cells trafficking. Nevertheless, there are yet a lot of places/countries in the world where transplant tourism and organ trafficking are continuing to be serious problems. In 2008, in an effort to collect reliable data on organ trafficking, as well as to implement specific measures to improve the identification, prevention and primary healthcare of victims the Renal Foundation of Moldova developed the project “Identification of the victims of trafficking of human beings with the purpose of organ retrieval and prevention of the human trafficking cases”. During the project medical workers were trained to identify and assist the victims of organ trafficking. Also, teams of youth volunteers capable to organize prevention activities based on peer-to-peer education approach have been established.

Organ economy: organ trafficking in Moldova and Israel

Susanne Lundin, Lund, Sweden

Organ trafficking is an illegal means of meeting the shortage of transplants. The activity flourishes for several interacting reasons, such as medical needs, poverty and criminality. Other factors are fundamental cultural conceptual structures such as the dream of the regenerative body as well as the view of the body as an object of utility and an object of value. One consequence of these views of the body and the individual is that, not only the criminality itself, but also the medical achievements of the med-twentieth century challenge the ethical principles of the individual’s integrity.

In my presentation I aim to go behind the normative discussions that usually surround organ trafficking (as well as organ transplantation in general). I discuss how organ sellers are viewed – by their surroundings and various NGOs – as revolving around morally loaded categorizations as “victim”, “donors” etc.

My material is collected from Moldova and Israel. It consists of observations and interviews together with reports from authorities in these countries. The focus is on, what the social anthropologist Caroline Nordstrom call, the shadow economies that govern existence and in which people, goods, weapons, money, bodies, etc. constitute components of the global market. Why this is happening, and what the societal consequences might be, or actually are, is examined through my ethnographic fieldwork.

Solving the kidney transplant crisis for minority ethnic groups in the UK: is being transplanted overseas the answer? (abstract #28)

Antonia Cronin, Manchester, United Kingdom

Regulated living unrelated donation leads to commercialism (abstract #29)

Mustafa Al-Mousawi, Safat, Kuwait

Living kidney donation: for love or money? Attitudes of 250 actual living donors (abstract #33)

Marleen van Buren, Rotterdam, The Netherlands

Mini-workshop ‘offering incentives to promote organ donation: comparing three proposals’ (abstract #34)

Sigrid Sterckx, Ghent, Belgium;

Stellan Welin, Linköping, Sweden;

André Krom, Utrecht, The Netherlands

Workshop 2

14:30 – 18:00 Diverse Populations

Chairs:

Gurch Randhawa, London, United Kingdom;

Emma Massey, Rotterdam, The Netherlands

Introduction: Demographics of living and deceased donation and recipient waiting lists: issues and challenges

Within Europe and beyond, disparities between ethnically and socially diverse groups in donor registration, family consent, living donation and transplantation rates have been demonstrated. Which factors contribute to these inequalities and what strategies can be employed to reduce them? In this workshop we will discuss the cultural, social and economic barriers to access to organ donation and transplantation as well as possible solutions to this problem. Invited speakers will present in-depth investigations of factors influencing donor registration, family consent rates and living donation. This analysis will consider not only individual and demographic factors but also organizational and societal influences. In addition several short presentations will examine various difficulties and issues within this field: Family consent rates and reasons for refusal among families of deceased transplantation patients (Pont, Spain); Social representation of organ donation among the French Swiss population (Bosisio, Switzerland); Faith based perspectives and concerns and possible recommendation for improving organ donation rates in ethnic minority communities (Adris, UK); Barriers to dialysis and transplantation among indigenous Mexican Chiapas (Teran, Mexico); Attitudes and communication on living kidney donation among ethnic minority kidney patients (Claassens, the Netherlands). Using the presentations as a spring board, we hope to generate an active and open debate on donation rates and access to transplantation as well as ideas on how to resolve these inequalities.

Explaining low rates of organ donation among minority ethnic groups: a holistic approach

Myfanwy Morgan, London, United Kingdom

Rates of deceased organ donation are generally low among Black and South Asian minority ethnic groups. This together with relatively high rates of end stage renal failure and requirements for HLA matching lead to long waiting times for kidney transplantation. Explanations of low donation rates among minority groups have focused on individual barriers to registration and consent, particularly the role of religion and faith, and generally assume the homogeneity of groups.

This paper first outlines a holistic and critical approach that represents a shift from the traditional emphasis on ‘problems’ of culture and portrayal of minority ethnic groups as relatively singular, static and enduring social categories. We regard barriers to donation as arising from the intersecting and changing influences of cultural and religious beliefs and feelings of marginalisation associated with low socio-economic status and perceived lack of acceptance. These multiple situational

factors may in turn reduce trust in doctors and the health system, shape notions of civic responsibility and reciprocity, and occasionally lead to the desire for burial in one's country of origin. Furthermore individualistic explanations of both donor registration and consent require to be complemented by analyses of the significance for donation rates of organisational factors and the assumptions and practices of health professionals. Secondly, the paper describes how we are implementing this approach in the DonaTE (Donation, Transplantation and Ethnicity) Programme. Initially a systematic review with narrative synthesis and community based study will examine the varying meanings of ethnic identities and experience of barriers to donation among different sections of ethnic communities. The next hospital phase employs ethnographic methods to study organisational and professional influences on the consent process. Both strands will inform the final stage of developing and evaluating a training package to increase health professionals' cultural competence and confidence in communicating with minority ethnic families.

Unshakable egoist? A Swiss mixed methods research on the social and psychological aspects of the organ donation act (abstract #30)

Francesca Bosisio, Lausanne, Switzerland

Why is it that deceased transplant recipients' families refuse to donate? (abstract #31)

Teresa Pont Castellana, Barcelona, Spain

Ethnically diverse populations and their participation in living kidney donation programs

Joke Roodnat, Rotterdam, The Netherlands

In the Rotterdam region 38% of inhabitants are non-Europeans and they represent about 44% of the patients on the waiting list for deceased donor kidney transplantation. During the past 30 years, the number of living donor kidney transplantations has increased steeply in our centre. However, Europeans gained most, whereas non-Europeans remained dependent on transplantation via the deceased donor waiting list. We wondered whether a low attendance or a high rejection of potential non-European donors could explain this difference. Between 2000 and 2007, 1059 potential living kidney donors attended the pre-transplant clinic. Potential donors were divided according to 8 countries of origin: African, Dutch Antillean, European, Indonesian, Moroccan, Surinamese, Turkish and Various Countries. In addition to direct living donation, participation in alternative living donation programs was studied: Kidney-exchange, Domino-paired, ABO-incompatible, and Anonymous donation.

European donors predominated in both the potential (79%) and in the actual donor populations (85%). Actual donors comprised 39% of non-European and 59% of the European potential donors ($p < 0.001$). In non-European compared to European donors participation in alternative living donation programs was significantly lower (3.6%, 12.6% respectively $p < 0.001$). In all non-European populations, genetically related donors predominated, whereas genetically related and unrelated donors were equally represented in the European potential donor population ($p < 0.001$). Partners were under-represented

in all non-European populations ($p < 0.001$). The attitude and behavior of non-Europeans with the longest duration of stay in the Netherlands was closest to that of the Europeans. The population with the shortest stay differed the most. This could possibly be attributed to integration and social factors that determine the possibilities for socioeconomic improvement. We wondered about the combination of ethnic factors and socioeconomic status on access to living donor transplantations. Presumed ethnic factors could possibly be the result of socioeconomic factors that prevail in the population studied. This will be studied in recipients of deceased versus living donor renal transplantations in our centre. Results will be presented and discussed.

Living donation among ethnic minorities: a Dutch qualitative study on the attitudes, communication and needs of kidney patients (abstract #38)

Lily Claassens, Rotterdam, The Netherlands

Faith & organ donation: engaging with faith communities to address the UK organ donor crisis (abstract #36)

Komal Adris, Manchester, United Kingdom

Cultural barriers for setting up a kidney transplantation program in the indigenous population of Chiapas, Mexico (abstract #37)

David Terán-Escandón, Mexico City, Mexico

Workshop 3

14:30 – 18:00 **Legal and Ethical Boundaries**

Chairs:

Thomas Gutmann, Muenster, Germany;

Medard Hilhorst, Rotterdam, The Netherlands

Introduction

“Workshop 3: Legal and Ethical Boundaries” will (almost) evenly deal with the three main fields of topical ethical and legal inquiry in transplantation. After an introductory survey on “recent developments in Europe to lift legal and ethical barriers” in organ transplantation, two presentations will focus on pressing questions concerning post mortem donation (“End-of-life care of potential organ donors” and “Respect for the individual as a human right in relation to post-mortem use of the human body for transplantation”). Another three presentations will be devoted to aspects of personal autonomy in living organ donation („Altruistic directed unrelated donation“, “Autonomy and paternalism in living donation” and “Confidentiality in living donation: contradictions between donor and recipient autonomy”). The workshop will conclude with two contributions on distributive justice (“The allocation of organs: the need for fairness and transparency” and “Conflicts of values about definitions of equity in organ allocation”, Switzerland taken as an example). Intense discussions are to be expected (to be continued in the ELPAT working groups).

The exclusion of organ transplantation from the Cross Border Care Directive: boundary or opportunity?

Herman Nys, Leuven, Belgium

On 2 July 2008, the European Commission presented a proposal for a Directive on the application of patients’ rights in cross-border health care. With the proposed Directive, the Commission establishes a general framework for the provision of safe, high quality and efficient cross-border health care in the European Union and to ensure freedom of movement of health services and patients and a high level of health protection. On 23 April 2009 the European Parliament has approved the report of rapporteur John Bowis on the proposed directive. The Parliament introduced an amendment to article 2. According to the amendment the Directive will not apply to organ transplantation. In recital 9a (new) this is justified as follows: ‘Due to their specific nature, they will be regulated by a separate directive’. This is a reference to another Directive proposed by the Commission on 8 december 2008 on standards of quality and safety of human organs intended for transplantation. This Directive aims to ensure that human organs used for transplantation in the EU comply with the same quality and safety requirements. In this way, the Directive will facilitate their exchange between Member States. Thus, instead of fostering the free movement of patients who need an organ transplantation the EU, at least the European Parliament wants to foster the exchange of organs. This is confirmed in a working document of rapporteur Frieda Brepoels on the proposed ‘organ directive’: ‘in view of the specific nature of transplantation and the delicate system of waiting lists, it would be wise to consider an exception for organs in the directive on cross-

border health care, which is currently being discussed’. I will deal with the questions whether this exclusion can be justified from the point of view of equal treatment of EU citizens and whether such an exclusion is creating a boundary or an opportunity for organ transplantation, also in light of national policies restricting the access to organ transplantation for non-residents as for instance in Belgium.

Respect for the individual as a human right in relation to post-mortem use of the human body for transplantation (abstract #31)

Austen Garwood-Gowers, Nottingham, United Kingdom

Legal guidance on non heartbeating donation in England and Wales (abstract #32)

Chris Rudge, London, United Kingdom

Altruistic-directed living unrelated donation: A genuine gift of life or a Trojan horse of the market?

Miran Epstein, London, United Kingdom

So far, the campaign against organ commercialism has been working on the assumption that commercialist practices could not pervade transplant medicine without being spotted as such. This explains why it has only targeted overt expressions of organ commercialism. But does this assumption really hold water? And what if it does not?

In attempt to answer these questions, I shall explore a widely acceptable category of donation – altruistic-directed living unrelated donation (LURD). I shall argue that (1) under certain conditions this category is indeed capable of concealing organ commerce behind false declarations of altruism, that (2) these conditions are likely to intensify in all societies, and that (3) the reluctance of the anti-market campaign to tackle this loophole is a sign of profound weakness.

I maintain that a robust anti-market case makes no concessions to or compromises with the market. It exposes, denounces and rejects its Trojan horses, no matter how alluring they seem. As far as altruistic-directed LURD is concerned, it insists on ultra-rigorous screening mechanisms to verify the donor’s sincerity. All in all, it prefers a screening system that risks lower procurement rates by wrongly turning down genuinely altruistic donors over one that achieves higher procurement rates by turning a blind eye to imposters.

Confidentiality in living donation: contradictions between donor and recipient autonomy (abstract #39)

Nizam Mamode, London, United Kingdom

Autonomy and paternalism in living donation (abstract #40)

Nizam Mamode, London, United Kingdom

Conflicts of values about definitions of equity in organ allocation in Switzerland (abstract #41)

Anne Kauffmann, Geneva, Switzerland

The allocation of organs: the need for fairness and transparency (abstract #42)

Sheelagh McGuinness, Keele, United Kingdom

Workshop 4

14:30 – 18:00 Deceased Donation

Chairs:

Magi Sque, Southampton, United Kingdom;

Bernadette Haase-Kromwijk, Leiden, The Netherlands

Introduction

Scientific advances, successful medical responses to critical injury and new laws that seek to promote the availability of donor organs touches the professional and social conscience of ethicists and health professionals, and indeed families who must make decisions about donation on behalf of their critically injured relative. These constraints raise the question: “In light of ethical controversy and scientific advances: How can deceased donation remain morally defensible?” This Workshop offers you the opportunity to engage with experts in the field in lively discussion around this question. Stuart Youngner building on his opening plenary address “Between life and death” will introduce the Workshop. Peter Desatnik will discuss the dilemmas for health professionals focusing on the use of clinical triggers, NHB and DCD donors; Magi Sque and Sabina Moos will offer a perspective on behalf of involved families; Maryon McDonald will provide a contemporary social context, while Janet Radcliffe-Richards will draw together the above issues through the use of illustrative case study. We look forward to welcoming you to what is anticipated to be an animated and informative discussion.

Follow on introduction from plenary presentation ‘between life and death’

Stuart Youngner, Cleveland, United States of America

Donation after cardiac death (DCD) protocol – both controlled and uncontrolled – offer the possibility of significantly increasing the number of organs procured for transplantation. However, they introduce three sets of problems. First, they involve significant deviations from usual clinical practice, deviations that may cause discomfort to health professionals and donor families. Second, they raise heretofore unasked (and potentially unanswerable) questions about the meaning of *irreversible* loss of function. Finally, while most countries’ laws treat cardiac death and brain death each as sufficient conditions for declaring death, experience with DCD protocols may reveal that health professionals consider neurological criteria for death the most important.

Organ donation: triggers and impact on health professionals

Peter Desatnik, Helsingborg, Sweden

There are four human sources for organ donation, brain dead patients, patients where CPR has failed, patients where intensive care has been withdrawn and donation from living persons. The latter won’t be discussed further.

Brain dead patients are patients admitted for intensive care but who cannot benefit from it; their brain damage being too extensive. An essential point to enhance organ donation in this category of patients is to identify when the treatment is no longer for the benefit of the patient but for organ function. The objective is to maintain advanced intensive care until the moment when death can be declared and to make organ retrieval possible, delicate mission.

Another category of patients where organs also can be retrieved are patients with cardiac arrest (DCD). CPR was initiated but failed, and the patients never recover blood circulation. The main factor for enabling organ donation in this group of patients is sustained blood circulation from the place of cardiac arrest, for example after a traffic accident, until the patients reach the hospital, where organs can be retrieved. If organs are to be retrieved under these circumstances the procedure has to be very strict with a well defined non touch time between the completion of CPR and the declaration of death. When the patients are declared dead procedures can be initiated to make organ retrieval possible.

To complete the categories in which organ donation could be optional are patients in-between the groups above, patients in intensive care units with futile prognosis. It is decided to withdraw the intensive care, the patients die of cardiac arrest and organ retrieval could be an option. In these patients known positive attitudes to organ donation are mandatory.

So far the intensive care speciality has regarded organ donation much as something mainly managed by the transplant side. However, it is not the transplant surgeons but the general public who wants the opportunity to receive new organs if necessary. Now it is time to realise that one of the major tasks for intensive care doctors and staff is organ donation. To enable organ donation from brain dead patients one has to either increase or maintain an advanced level of intensive care.

One must however understand how hard it can be for the intensive care staff to change perspective from curing one patient in the intensive care ward and instead carry on with intensive care although the patient’s prognosis is futile. Thereby enable nine other patients to receive new organs for transplantation.

When organ donation could be an option, except for medical treatment of the potential donor it also includes many psychological and ethical aspects. The challenge is not only to take care of the potential donor but also the relations to and care-taking of the next of kin.

A firm organisation within the intensive care, educated and skilled staff with the resources to inform and educate all hospital personnel in all aspects of organ donation, is a necessity. The results of such an organisation which is competent both in medical care of organ donors and handling of next of kin will be the retrieval of more organs for transplantation.

Donation after cardiac death =DCD, Cardiopulmonary resuscitation = CPR

Impact of Donation on Bereaved Families

Magi Sque, Southampton, United Kingdom

Families of potential organ donors are first, bereaved families, and need to be supported by health professionals educated to work with bereaved people. Specific issues might arise for these families and they may struggle with the enormity of events unfolding around them, as so few people die in circumstances that facilitate donation they are unlikely to have role models for their behaviour. Studies indicate that importance is attributed to bereaved families' need to consider organ and tissue donation. The family may not think about donation, and as most families aspire to honour the pre-mortem wishes of the dead, if this opportunity is denied, then the chance to fulfil that wish is lost. Family members therefore are most likely to be grateful that donation was discussed with them. These findings suggest that in situations of a donor's clinical suitability the organ and tissue donation discussion should form part of high quality end of life and bereavement care. Care that is focused on giving families: **Time** to realise the inevitability of death; time to understand and absorb the nature of the brain injury that killed their relative; time to discuss this with other family members and to seek reassurances for any concerns. **Attention** to the special role they had as next-of-kin; attention to their inner turmoil and the understanding that this will influence how they process information. **Care** in the way, and the where, that information is presented and the understanding that this will 'live' on in their minds for years to come. Some families report consolation in being associated with a donor who they regard as a 'hero'; whose remarkable achievement leaves a profound and poignant legacy of life, which can ripple out far beyond the recipient, their family and community. Such an association may affirm the status and worth of the bereaved and atone for their 'sacrifice'. Likewise, some families report that donation helped them to cope by giving meaning to death. Not offering the choice of donation to a family could therefore be considered unethical.

Discussion focused on two issues impact on health professionals and bereaved families

The effect of the request for organ donation on grieving relatives (abstract #71)

Sabine Moos, Mainz, Germany

Deceased donation, culture and the objectivity of death (abstract #72)

Maryon McDonald, Cambridge, United Kingdom

Illustrative case study and discussion

Janet Radcliffe Richards, Oxford, United Kingdom

The aim of this session is to begin a systematic identification and analysis of the legal, institutional, ethical, social and psychological obstacles to efficient deceased organ donation. We know that if we did everything technically possible to make organs available that were no longer of any use to their dead or dying owners, we could save far more lives through transplantation than we currently do. If we think it is important to save lives, as everyone here does, it is important to make sure

that all these obstacles are either unavoidable or justified. Much of the current work to maximize organ donation necessarily takes for granted the legal and institutional framework against which it takes place, but much of this was in place before the scientific and technical developments that made transplantation possible. It needs at least to be clearly recognized, and then questioned.

Because the session will be interactive it is impossible to say in advance exactly what ground it will cover, how much divergence of opinion and practice it will reveal, or how much substantive moral discussion will emerge. It should, however, be enlightening in many ways.

The session will be interactive, and centred round case studies. The aim will be to establish how much divergence of opinion there is among participants about the appropriate way to act in particular clinical situations, and then try to identify the causes of actions that result in a (technically) unnecessary loss of viable organs. This may well turn out to be more difficult than it sounds. Although the long-term aim will be to investigate the extent to which there can be agreement about morally acceptable ways of minimizing the loss of organs, the first step must be to establish what exactly the obstacles are.

Workshop 5

14:30 – 18:00 Psychological Care for Living Donors and Recipients

Chairs:

Fabienne Dobbels, Leuven, Belgium;

Jan van Busschbach, Rotterdam, The Netherlands

Introduction

The successes of transplantation in terms of survival and the use of more liberal medical selection criteria have led to an increasing number of patients being referred for evaluation of suitability for transplantation. However, organ shortage remains a limiting factor in the number of transplantations performed per year, resulting in prolonged waiting times, and a high mortality on the waiting list. Given the scarcity of donor organs, it is of utmost importance to select those patients with end-stage organ failure who will benefit most from transplantation.

Guidelines on pre-transplant selection of recipients state that careful pre-transplant screening should not only comprise a comprehensive medical evaluation, but should also involve a thorough psychological assessment. Yet, it is currently not clear what is meant by a thorough psychosocial assessment.

The use of living donors could be an alternative solution to overcome the problem of organ shortage, yet, concerns about donor safety and ethical considerations necessitate a careful evaluation, selection and follow-up of the donor as well. Protocols for pre-transplant medical evaluation of prospective donors are increasingly published. The adoption of protocols organizing the psychosocial screening and follow-up care is, however, less straightforward.

This workshop discusses the state-of-the-art on pre-transplant psychosocial screening for both recipients and donor candidates, and addresses the needs for psychological care as a cornerstone of effective chronic illness management.

Is your patient a good candidate for transplantation?

The role of pre-transplant psychosocial screening

Christiane Kugler, Hannover, Germany

Christiane Kugler will discuss which pre-transplant psychosocial and behavioral factors affect post-transplant outcomes, and will provide guidance on the content of pre-transplant psychosocial screening of transplant candidates.

Psychological factors in living donors: do they matter?

Mary Amanda Dew, Pittsburgh, United States of America

Mary Amanda Dew will summarize the available evidence regarding pre-transplant psychosocial functioning of potential living donors, and will provide some concrete recommendations on how screening and follow-up should be performed.

‘Patient quality of life after transplantation: predictors’

Depression, non-compliance, and survival in heart transplant candidates (abstract #70)

Pavla Notova, Bratislava, Slovakia

Which predictors of self-rated health in patients after kidney transplantation are important? (abstract #71)

Maria Majernikova, Kosice, Slovakia

Psychosocial determinants of quality of life 6 months after liver transplant: a longitudinal prospective study (abstract #72)

Inês Mega, Lisbon, Portugal

Psychological consequences of organ transplantation: a prospective study among liver transplant recipients (abstract #73)

Coby Annema, Groningen, The Netherlands

‘Acceptance of living transplantation among patients’

Predictors of the willingness to consider living donor kidney transplantation in haemodialysis patients (abstract #74)

Daniela Mladenovska, Skopje, Macedonia

Group education of families and friends of CKD patients; the impact on living kidney donation (abstract #75)

Ton van Kooij, Rotterdam, The Netherlands

Three-part modelling of the decision to accept a live donation: certainty, refusal, questioning (abstract #76)

Deborah Ummel, Montréal, Canada

Living or deceased kidney transplants? Experiences of the donation process among kidney recipients in middle Sweden (abstract #77)

Margareta Sanner, Uppsala, Sweden

Living kidney donors who regret donation (abstract #78)

Gilbert Thiel, St. Gallen, Switzerland

Workshop 6

14:30 – 18:00 Samaritan/Unrelated Donation

Chairs:

Annette Lennerling, Gothenburg, Sweden;

Willij Zuidema, Rotterdam, The Netherlands

Introduction

The lack of organs for transplantation is a world wide problem. This organ shortage has led professionals to explore new opportunities and technologies to increase the number of organs available for transplantation. Living organ donation is one of the most prominent but also controversial solutions that have been sought. One way to increase the number of living donors has been to expand donor criteria to also include living unrelated donation from other than first-degree family members. A second way has been the acceptance of Samaritan living donors (kidney and liver). In Europe Samaritan living donation remains very controversial and is only performed in the UK, Sweden and in the Netherlands.

In this workshop there are three guest speakers and four abstract presenters. The following topics will be presented and discussed by our guest speakers:

The problem of organ solicitation: at the moment in Europe and in the US we are confronted with donors and patients soliciting on websites and in newspapers.

Allocation of non-directed living organ donors: background and summary of the UK situation. Methods of allocation include: non-directed donation to a patient on the waiting list and domino paired procedures. In light of these methods – that touch on the issue of directed and conditional allocation of ‘anonymous’ donations – legitimacy and difficulties from a legal and ethical perspective are presented.

The final topic is the promotion of living unrelated donation. Abstract presentations focus on Samaritan kidney donors wishing to donate also a part of the liver. Secondly, psychological outcomes among Samaritan and living unrelated kidney donors will be presented. We look forward to an interesting workshop with fruitful discussions.

The promotion of living unrelated donation

Gabriel Danovitch, Los Angeles, United States of America

The last decade has seen a remarkable yet largely unheralded change in the nature of the relationship between living donors and their recipients in the United States. Spousal donation is common and biologically unrelated donation now accounts for approximately 50% of all living donor transplants. Our studies provide evidence to support the contention that this development has occurred in the absence of material gain (and often with financial loss) for both related and unrelated donors. Medical and psychosocial outcomes have been excellent. In this regard the US has taken a leading role. There are many opportunities for increasing living donation. At a time of increasing need for organ donors, both living and deceased, how can we best promote related and unrelated living donation both in the developed and developing world, while protecting the

health and welfare of living donors, and without risking transplant tourism, trafficking, and exploitation?

One donor, two Samaritan transplantations (abstract #68)

Medard Hilhorst, Rotterdam, The Netherlands

Psychosocial, educational and economic factors in living unrelated kidney donation: a single Brazilian center experience (abstract #69)

Gustavo Ferreira, Sao Paulo, Brazil

Psychosocial outcomes of good Samaritan donors compared to a matched sample of traditional donors (abstract #70)

James Rodrigue, Boston, United States of America

Allocation of non-directed living donor organs

Antonia Cronin, Manchester, United Kingdom

The non-directed altruistic living donor kidney scheme in the UK was implemented following enactment of the Human Tissue Act 2004 on 01 September 2006. Although such donations were not previously unlawful they were specifically legislated for in the 2004 Act and this, to some extent, provided the legitimacy for promoting and allowing such donations and transplantations to take place.

At the present time donor organs that become available through the non-directed living donor kidney scheme are allocated anonymously to the most suitable recipient waiting on the deceased donor transplant list. Since its implementation in the UK the non-directed living donor kidney scheme has resulted in 26 such transplants.

Allocation of donor organs made available through the non-directed living donor kidney scheme may usefully be allocated to start a ‘cascade’ of ‘paired’ living donations. In this instance the final ‘paired’ donor organ would be impartially allocated to the deceased donor transplant list. This cascade has also been referred to as ‘domino transplantation’. While this allocation model would undoubtedly result in a greater number of transplanted organs it is not entirely without ethical controversy. There is, for example, a certain irony in preferentially allocating a so-called ‘non-directed’ altruistic donation to a recipient (or set of recipients) who is (are) already in the fortunate position of having a potential living donor, particularly if this were to disadvantage others on the deceased donor waiting list. What makes a cascade attractive is the net effect of an increase in the total number of paired/pooled exchange transplants that take place, which at the same time removes paired recipients from the deceased donor transplant list, thus reducing the overall number of patients on the deceased donor waiting list, thereby increasing the chances of others on the list to receive an organ. But if those who administrate the organ allocation scheme are entitled to preferentially allocate an individual’s organ, why should individual donors themselves not be so entitled too?

This presentation summarizes the background and activity so far of the non-directed altruistic living donor kidney scheme in the UK. It examines the legitimacy of organ allocation models proposed and highlights the difficulties they might encounter from a legal and ethical perspective.

The problem (?) of organ solicitation*Katrina Bramstedt, San Francisco, United States of America*

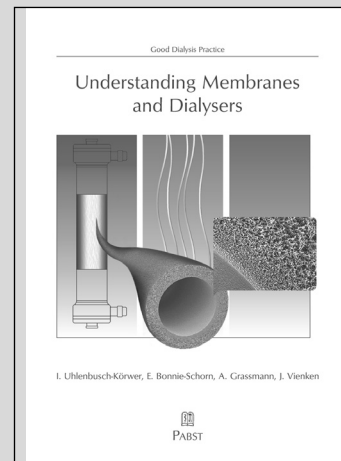
The active pursuit of a living organ donor (organ solicitation) can be considered problematic by some depending on the means, the setting, and the relationships involved. „Solicitation“ itself can seem an unsavory word, and it is often associated with organ vending (even when there is no cause for such). Transplant hospitals and their personnel have multiple ethical duties including, 1) protect the safety of their living donors and transplant recipients; 2) protect the integrity of living donation and transplantation as clinical practices. I will discuss arguments for the ethical permissibility of donor solicitation, as well as present a set of behavioral prompts for teams to probe with regard to organ vending when screening candidates about their suitability for participation as living donors.

Favourable psychological outcomes among good Samaritan donors: a follow-up study (abstract #82)

Emma Massey, Rotterdam, The Netherlands

*I. Uhlenbusch-Körwer, E. Bonnie-Schorn,
A. Grassmann, J. Vienken*

Understanding Membranes and Dialysers



The dialyser and its centrepiece, the membrane, play a central role in chronic renal replacement therapy. More than 1000 different types of dialysers are currently available on the market. How are these characterised and how do they differ? What are their special features and how do they contribute to acute and chronic effects in the patient? Is there a link between morbidity and mortality and the use of a particular type of dialyser? This book addresses these questions and attempts answers based on current scientific knowledge. In this context, dialyser development and the basics of filter performance and biocompatibility assessment are reviewed.

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Abstracts

Oral presentations

How do grieving parents react to the request for organ donation from their child? (Abstract #1)

Sabine Moos MD; Anne Bärbel Blaes Eise; Tom Breidenbach MD; Monika Schmid MD
DSO Region Mitte, DSO, Mainz, Rheinland-Pfalz, Germany

Background: Organ donation of children and adolescents mostly occurs in the context of an unexpected, sudden death. Since parents usually decide on behalf of their deceased children, the stability and comfort with the decision to donate is particularly important here. Based on survey data we gathered among relatives of child and adolescent organ donors, we evaluate the circumstances and quality of the donation request and thus help alleviate the reluctance of ICU staff to raise organ donation in an emotionally difficult situation.

Methodology: A survey was conducted with a standardized questionnaire from 2004 to 2008 of 279 relatives of an organ donor about a year after the donation. 39 of them were parents who had lost a child.

Results: 46% (n=18) of the respondents expected the request for organ donation when brain death diagnostics were brought up in the conversation. 13% (n=5) even brought up organ donation themselves. Asked whether they had felt pressure to consent to donation from the medical staff at the time, 92% (n=36) said no, 3 respondents (8 %) said yes. In retrospect, a majority of relatives felt good about their decision to donate: 89 percent (n=35) indicated they would do it again today, 8 percent (n=3) replied "I don't know," and only one surveyed family said they would decide against organ donation today.

Summary: Our data shows that the request for organ donation is legitimate and expected by relatives even in particularly difficult situations, such as the sudden and unexpected death of a child. Since 15 percent of the 12000 patients on wait lists are currently children and adolescents in need for a lifesaving transplant, medical staff should never hesitate to bring up organ donation with relatives.

Adjusting to loss after donating a family member's organ (Abstract #2)

Tamar Ashkenazi PhD candidate
Ministry of Health, Tel Aviv, Israel

Research Aims: (a) To explore the effect of donating an organ on the donating families. Does their consent to donate help them through their mourning or instead exacerbate their distress and make it harder for them to return to a satisfying, meaningful life?

(b) Does organ donation have an added value? Beyond the benefit to the sick people waiting for a transplant, is there a benefit to the donating family? Does it help or hinder their adjustment to their bereavement?

Methods: Parents of young or adolescent children who had been asked to donate an organ or tissue from their dead child, 216 parents in all: (a) 100 who agreed to donate an organ (46%), (b) 46 who agreed to donate tissue (21%), (c) 37 who refused to donate an organ (17%), (d) 33 who refused to donate tissue (15%).

The concept of 'adjustment to loss' was defined specifically for this study from four key factors: the mourning process, personal growth after loss, meaning of life after loss, and meaning to the donors of the donation of organ or tissue.

Findings: On three of the above four factors – the mourning process, personal growth after loss, the perceived meaning of life after loss – the parents who agreed to donate displayed a more adaptive response than the parents who declined. No statistically significant association was found between the method of determining death – brain death or heart death – and any of the factors in adjustment to loss, despite the fact that the experience of loss looked different in each of the two cases. The medical staff's intervention was found to exert a positive effect on adjustment to loss lasting months and even years after the event.

Initial experience with transplantation of lungs recovered from donors after euthanasia

(Abstract #3)

Dirk Van Raemdonck MD, PhD¹; Geert Verleden MD, PHD³; Lieven Dupont MD, PhD³; Dirk Ysebaert MD, PhD²; Walter Van Donink RN²; Gerda Van Beeumen RN²; Willy Coosemans MD, PhD¹; Herbert Decaluwe MD¹; Georges Decker MD¹; Paul De Leyn MD, PhD¹; Philippe Naftoux MD¹; Toni Lerut MD, PhD¹

¹Thoracic Surgery, University Hospitals Leuven, Leuven, Belgium; ²Transplant Surgery, University Hospital Antwerp, Edegem, Belgium; ³Pneumology, University Hospitals Leuven, Leuven, Belgium

Objectives: Donors-after-cardiac-death (DCD) have become an increasing source of lungs in recent years with reported good outcome. Experience with lung transplantation (LTx) from DCD after euthanasia has not been reported so far.

Methods: Between 01/2007 - 09/2009, 12/139 (8.6%) isolated LTx were performed from controlled DCD (Maastricht Category-III), including 3 (2.2%) after euthanasia (so-called Category-V). Donors expressed their will for organ donation after their request for euthanasia was granted according to the country's legislation. Permission to transplant organs recovered from these specific donors was approved by the Institutional Review Board.

Results: All 3 donors (M-F-M; 48-50-62 years) suffered from a debilitating neurological disease. Euthanasia procedure was carried out by three independent physicians in the operating room in the absence of the retrieval team. Heparine was administered to all donors. After death was certified, a quick sternotomy was performed and lungs were preserved by antegrade+retrograde cold Perfadex[®] flush following a warm ischemic interval since asystole of 14-10-13 min. Three recipients (M-F-M; 30-56-59 years) underwent DLTx for bronchiolitis obliterans/fibrosis/emphysema. Both lungs were implanted sequentially via anterior thoracotomies without extracorporeal support. Total ischemic time was 329-414-302 min for the first lung and 547-517-434 min for the second lung. The fibrotic recipient died in the ICU from multiple problems 3 months post-LTx with a good functioning lung. The other 2 patients were extubated on day 5-2 and discharged from ICU on day 8-8 and from hospital on day 33-23. No donor-related

complication was seen. FEV1 increased from 21%-16% pre-transplant to 61%-94% at discharge and 97%-92% at last follow up (52–2 months).

Conclusions: LTx from euthanasia donors is feasible with good early and late outcome. A larger experience is needed to compare their outcome with lung recipients from brain-dead and other cardiac-death donors.

Incentivizing organ donation:

A Swedish priority setting perspective (Abstract #4)

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Organ transplantation is the treatment of choice for end stage organ diseases; unfortunately needs for organs outstrip supply in nearly all parts of the world. This presentation explores the potential role of a diverse set of incentives, underpinned by incentive theory and empirical evidence, to increase rates of deceased organ donation in Swedish health care. Our aim is twofold, firstly to construct an incentive scheme that could potentially bridge the gap in transplantation needs, and secondly to examine the moral reasonableness of the scheme based on the Swedish priority setting ethical principles of: human dignity, needs and solidarity, and cost effectiveness which together represent the core values of Swedish health care and guide decision making at various levels of health care. We propose extrinsic incentives in the form of €5000 towards funeral expenses paid to the estate of the deceased or family. However in order to capture individuals motivated by intrinsic and signalling incentives we allow for all or part of the compensation to be diverted as a donation to a reputable charity of the deceased's or family's choice. Through the discussion we demonstrate the proposal to be compatible with the values of Swedish health care, and that it merits serious consideration.

The paradox of prohibition and how potential adverse consequences of the Istanbul Declaration may be controlled (Abstract #5)

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Introduction: The Declaration of Istanbul proclaims that organ trafficking, transplant tourism and transplant commercialism should be universally prohibited and punished. Since its establishment, the Declaration has been successful in various ways. It has been supported by numerous states and organizations who endorse its principles and definitions. The question arises however whether universal efforts to prohibit these phenomena are effective. Prohibition of other demand-driven phenomena such as drugs, alcohol and prostitution has illustrated that prohibition can have unintended, even harmful effects. We address this question from a criminological viewpoint by critically analyzing the potential consequences of prohibition.

Methods: First of all, we explain the concept of prohibition. Secondly, we go into implications of the prohibition of drugs, alcohol and prostitution. Thirdly, we focus on the possible ramifications of the universally endorsed prohibition of organ trafficking, transplant tourism and transplant commercialism.

Results: Prohibition means criminalization through legislation and enforcement. Criminalization of alcohol, drugs and prostitution tell us that prohibition may not always be a successful solution to achieve a decline and/or harm reduction. Prohibition without enforcement can have the effect of driving illegal trade, such as organ trafficking underground, making it more profitable and harmful to the people involved.

Conclusion: Professional care and expertise must be taken in promoting and establishing prohibition of organ trafficking. Implementing strict legislation only will have adverse effects and lead to an increase or displacement of illegal trafficking. In addition to anti-organ trafficking legislation, willingness, awareness and prioritization at the local, national and international enforcement level is a prerequisite for successful prohibition and prevention. If these conditions are not fulfilled, the universal prohibition of organ trafficking as promoted by the Declaration of Istanbul is likely to fail.

The outcome of commercial transplant tourism in Pakistan (Abstract #6)

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Underdeveloped cadaver renal transplantation and increase of organ shortage stimulate some patients to go in the Far East to buy a kidney. In the last years the promising place is Pakistan. We followed 36 transplanted patients in Lahore and Rawalpindi the last 16 months: 25 from Kosovo, 10 from Macedonia and one from Albania. The transplant team and the hospitals are identified and some data about the transplant procedure are sent. The immunosuppression included CyA, Pred and MMF. The patients did not pass the usual pretransplant work-up. 80% of them are HCV or HBsAg positive. Seven patients died, 16 had wound infections with postoperative hernias. Three perirenal hematomas, 6 abscesses, 4 lymphocelles, and 4 urinary fistulas are operated. Nephrectomy was done in 3 patients due to renal thrombosis. Nine have active hepatitis C, 4 CMV disease, 3 steroid diabetes and 3 acute myocardial infarction. Nine had one or more rejection episodes. Most of them have UTI with *Pseudomonas* or *Escherichia*. The one year patients and graft survival rate is 80% and 68%, respectively. The authors do not recommend this type of transplantation not only from the ethical point of view, but also from frequent medical and surgical complications.

Access of non residents to transplantation medicine

(Abstract #7)

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An examination of the existing regulations in Europe and the US dealing with the access of non-residents and the restriction of access to transplantation medicine, resp. allows two general approaches to be distinguished. The first one limits the access of non residents to the (national) waiting list. That means those who are denied access can not be transplanted, no matter how urgent the case might be. The alternative approach is to allow the registration on national waiting list for everybody who is suitable for a transplant but to consider certain groups of persons such as non residents subordinately in the actual allocation process. In this second category various differentiations are possible in particular with view to high urgency patients. This however leads to the consequence that due to the lack of organs there are few chances to receive an organ of good quality or to receive an organ at all. This approach was chosen by UK and Switzerland. It is however highly doubtful whether the existing regulations would stand the legal proof in the light of constitutional rights in particular human rights assigned to every person irrespective of nationality or residency. Human rights that are at stake are in particular the right to life and to physical integrity but also the prohibition of discrimination. Hence exceptions need to be made at least for high urgency patients. In Europe furthermore European community law needs to be taken into consideration as well, in particular the free movement of patients. Any regulation therefore should be in accordance with national constitutions as well as European law (e.g. Art. 12, 18, 39, 43, 49 TEC and Council Regulation (EC) no 1408/71).

European legislation prohibiting organ commerce (Abstract #8)

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In Europe some 50.000 patients are currently on the waiting list for kidney transplantation. Each year only 1 out of 3 patients actually gets transplanted, waiting 2-5 years on average. Desperation drives an unknown number of patients to consider obtaining a commercial transplant abroad. However, a long list of international/European resolutions, treaties and guidelines state that 'transplantation from deceased/living donors is only permitted on condition that the organ does not give rise to financial gain or valuable consideration'. Also, legislation in European countries without exception prohibits selling, buying or trading of human organs. We have analysed the legislation in 31 European countries to see to what extent these national laws follow international regulations, directives and guiding principles concerning prohibition of organ commerce. These rules include: prohibition of monetary payment or reward, of advertising the need or availability of organs (soliciting), and of brokering, and prohibition for health profession-

als to engage in or facilitate transplants with organs obtained by exploitation, coercion or payment (organ tourism or trafficking). We looked at quality and effectiveness of these laws, and also at penalties/sanctions imposed on persons who violate the law. Preliminary analysis showed that most countries (23) have legislation dealing only in a very general and restricted way with prohibiting organ commerce (concerning only cadaveric donor kidneys, sanctions only directed at physicians making profit, small fines, no regulations against organ tourism). A group of only 8 countries could be identified as having strict and comprehensive prohibition of organ commerce (including living donation, brokering, solicitation, trafficking, heavy sanctions): this includes Germany, Switzerland, UK, Finland, Romania, Croatia, and to a lesser extent France and Portugal. Overall conclusion is that the majority of European laws is not specific enough, and not effective against organ commerce. Examples of national legislation will be discussed.

Sharing organs with foreign nationals (Abstract #9)

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Throughout Canada, transplantable organs are an absolute scarcity, with significant wait times and deaths on the waiting lists in several provinces. Some Canadian hospitals receive requests to accept FNs to their waiting lists for organ transplantation from deceased donors. Currently Canada does not have a national policy, leaving each hospital to address the issue independently. In the context of a world encompassed by globalization, the question of whether or not foreign nationals (FN) should be listed for organ transplantation needs to be addressed. A national or provincial policy would allow each hospital to respond to such requests in a standardized manner, thus achieving a degree of equity. Development of a policy on transplantation for FNs must be justified by a thorough exploration of the issues. This paper will review: arguments for and against listing FNs for organ transplantation; relevant policies and position statements; practices in other countries and suggestions for viable policy options will be made. There are compelling arguments for and against listing of FNs. However, the tension is mainly between two arguments: organs are an absolute scarcity, yet humanitarian aid aligns with Canadian values.

Racial disparities in kidney transplant: Beyond medical factors (Abstract #10)

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End-stage kidney disease (ESKD) is more common in African Americans (AAs) than European Americans (EAs). AAs also wait longer to receive a kidney transplant (KT) for this disease; and are less likely to receive the optimal treatment, a living donor KT. Reasons for race disparities are poorly understood. This longitudinal study examined how cultural factors (e.g., perceived discrimination, medical mistrust), psychosocial factors (e.g., anxiety, depression), and KT knowledge contributed to race disparities in KT.

Patients being evaluated for KT completed telephone interviews after their first transplant clinic appointment, and again after they were accepted or found ineligible for KT. At baseline AA (n=25) and EA (n=79) patients were demographically similar, although AAs had lower incomes (t=2.4, p<.05). AAs reported experiencing significantly more healthcare discrimination, perceived more overall healthcare racism, had higher levels of medical mistrust, lower trust in their physician, greater family loyalty, and more religious objections to KT than EAs (t-tests range = 1.9 to 5.8, all ps<.05). AAs took significantly longer to complete transplant evaluation than EAs (t=2.1, p<.05). This difference appeared to be accounted for by other factors: linear regression indicated that more experience of healthcare discrimination, higher perceptions of healthcare racism, lower KT knowledge, more depression, and greater trust in their physician predicted longer time to complete evaluation (adjusted R²=0.3, p<.001). Logistic regression indicated that higher rates of medical mistrust was the only significant predictor of participants who had a living donor (OR=3.2, 95% CI=1.3, 8.3). Cultural and psychosocial factors associated with race contribute to disparities in the duration of KT evaluation. Transplant teams must pay particular attention to such factors in KT candidates in order to help ensure that AAs are not disadvantaged in proceeding through the transplantation process.

Studying the organ donation process within the immigrant population (Abstract #11)

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The increased immigrant population in Spain (10-16 % in recent years), has led to cultural complexity affecting end-of-life decisions and organ donation. AIM: To study organ donation interview protocol when dealing with immigrants. METHODS: To analyse family interview registers of all potential donors in University Hospital Vall d'Hebron (2002-2008) comparing native and immigrant populations. We consider: nationality, number/relationship of people at interviews, education, length and number of interviews. We also study: awareness of Spanish Transplant Law, donor card, knowledge about transplants, interviews outcome. RESULTS: 294 interviews were performed. 39 (13,2%) corresponding to immigrants: 13 Latin America, 10 Africa, 9 Asia, 7 Europe. The percentage of family refusals was slightly higher 9/39 (23%) vs. 45/255 (18%) ns. There were no significant differences regarding: length of ICU stay 1.9±5 vs. 2,3±4.9, number of people at interview, possession of donor card, knowledge of Spanish Transplant law. However, we found significant differences in: limited health literacy 20/39 (51%) in immigrants vs. 30/255 (11,7%) native population, length (114±97 vs. 40±35 minutes) and number (3,34±1,6 vs. 1,2±1,2 times) of interviews. Reason given for donation was reciprocity 24/30 (80%) vs. 72/255 (28,2%) followed by solidarity 17/30 (57%) vs. 164/255 (64%), corpse transfer financial assistance 25/30 (83%) vs 80/255 (31%). "Living will" organ donation in the immigrant population was 3 (7,6 %) vs. 35 (13, 7%). Reasons for refusals were (immigrants vs. native population): deceased's expressed refusal 4/9 (10%) vs. 37/45 (82,2%), concerns over corpse image 4/9 (55%) vs. 26/45 (57%), mistrust of Health System 2/9 (22%) vs. 4/45 (8,8%), religious convictions 4/9 (44%) vs. 6/45 (13,3%).

Conclusions: The immigrant population requires greater input in terms of time and resources. Moreover, further research into their specific needs is imperative.

Ethnicity and access to kidney transplant programs (Abstract #12)

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Introduction: As the Rotterdam population becomes more and more ethnically diverse, the number of non-Caucasians seeking renal replacement therapy rises accordingly. We wondered whether non-Caucasians had equal access to our kidney transplant programs.

Methods: All 1009 recipients of kidney transplants performed in a 8 year period from January 2000 to December 2008 were included in the present study. We gathered the following patient's characteristics: ethnicity (3% missing data), recipients of living vs. deceased donor kidneys, age and gender. Data were compared to those of patients on the waiting list.

Results: Among the patients on the waiting list 33 % were of non-Caucasian descent, which is significantly ($p=0.006$) higher than the proportion of non-Caucasian patients (24%) transplanted in the period study. During this period we performed 574 living donor and 398 deceased donor kidney transplants. In the group of recipients of deceased donor kidneys 150 (38 %) were non-Caucasian, not significantly different ($p=0.294$) from the proportion on the waiting list. However, in the living donation program we transplanted only 84 (15 %) non-Caucasians, which is significantly ($p<0.0001$) lower compared to the proportion on the waiting list.

Conclusion: Our living donor kidney transplant program primarily serves Caucasian patients, while non-Caucasian patients remain dependent on kidneys from deceased donors. This inequality in access to our living donation program might be explained by language barriers or cultural factors. Special programs for non-Caucasians to raise awareness of the possibilities of living donation are warranted.

Is gifting a relevant concept to promote organ donation?

The views of the UK's religious leaders

(Abstract #13)

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Background: The concept of 'gifting' has been considered as potentially relevant in promoting organ donation. This study aimed to explore this issue from a religious perspective.

Methods: A qualitative study involving eighteen one-to-one interviews with religious leaders based in the UK was carried out. The interviews sought to explore the views of religious leaders in relation to the concept of 'gifting' from a religious perspective, and the potential relevance that this may have to organ donation.

Results: 'Gifting' was seen as being a relevant concept for the religious leaders:

"... In the Gospels, feed the poor; visit the homeless; take people in, you know, visit those who are widowed and so forth; so the whole aspect the tangible, practical serving the community. We have a service, sort of, orientation, in terms of giving and empowering others and enhancing people's lives and it means for those who are less fortunate than we are..." (Sharon Platt-MacDonald, Seventh Day Adventists)"

"The concept to Sikhism is that you lose the "I" [for] individual and become part of the whole which is not just Sikhs, but the whole of humanity. In that charity is very, very important. ... In Punjab, blood donation is a big thing people sometimes go to a couple of the Gurdwaras, [it's] a huge movement. (Jasdev Singh Rai, British Sikh Consultative Forum)"

Conclusion: The findings revealed that all the participants were unanimous in their view: 'that to give a gift, which would save or enhance the quality of another's life', was important and in keeping with their religious beliefs. Religious leaders agreed that more needed to be done to promote the concept of 'gifting' and to encourage debate concerning organ donation among their lay congregation.

UK students of Indian and Pakistani descent: What are the factors that influence their attitudes towards organ donation? (Abstract #14)

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Introduction: The shortage of organs donated for transplantation in the UK is well documented particularly among ethnic minority groups. The UK Organ Donation Taskforce has highlighted the need to better understand why ethnic minorities have low donation rates. Existing work has often studied ethnic minorities in broad groups, focusing on older populations. We set out to investigate the factors which influence attitudes towards organ donation amongst younger generation ethnic minorities, focusing specifically on Indian and Pakistani students.

Methods: Two qualitative approaches were employed: nine focus groups followed by eight semi-structured interviews. A total of fifty-eight participants were interviewed. Focus groups were divided by ethnicity and gender. Interviews were conducted on each combination of ethnicity, gender and medical/non-medical background.

Results: A thematic analysis of transcripts identified six factors that influence Indian and Pakistani students: religion, culture, awareness of the importance of donation, treatment of donors and their organs, family attitudes and medical education impact. Islam was the most important factor identified for Pakistanis while for Indians all six were relevant. Medical education specifically influenced attitudes to donation as opposed to general level of education as found in previous studies. Cultural changes gave an insight into how the younger generation differs from older generations because they are adopting British culture which is more positively disposed towards donation. Family views remained important. Awareness of the importance of donation was very low in both groups.

Conclusion: Young Indian and Pakistanis are not against donation and in our study participants were generally open to considering donation after death. However the factors identified suggest there is no single obstacle to organ donation and all need to be addressed in a culturally relevant manner to improve donation rates.

Comparative analysis about the knowledge of both organ donation and transplantation among Argentinian students (Abstract #15)

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Introduction: During 1996, 2000, 2004 and 2008 surveys were conducted to learn about the knowledge of both organ donation and transplantation among students. Although the number of real donors increased from 7.4 (1996) to 13.1% per million inhabitants (2008), a large number of individuals still do not have access to transplantation due to organ shortage.

Objectives: To compare the changes as to the knowledge of organ donation and transplantation among students in Argentina from 1996 to 2008 in 4-year intervals.

Materials and methods: 4500 surveys were conducted using closed 12-item questionnaires distributed in educational centers.

Results: 56.80% women. 86.75 % students. 1996 2000 2004 2008 N892 N1564 N1181 N863. Does not know what brain death means 37.50% 22.60% 19.5% 32.6%. Did not receive information 69.10% 67.10% 54.2% 72%. Does not know when a person may be donor 31.4% 39.4% 24.5% 43.8%. Does not know which the body responsible for organ donation is 62.40% 47.76% 51.7% 76.3%. Does not know what organs may be donated. 34.20% 41.37% 25.5% 42.3%. There is no adequate educational campaign 76.80% 78.13% 49.1% 64.9%. Has not met any transplant patient 65.10% 57.67% 62.3% 71.6%. Does not know when a person must undergo transplantation 56.70% 58.24% 43.6% 48.3%. Does not know about the life of an individual before and after transplantation 66.60% 68.83% 58.5% 92.8%. Does not think his/her religious beliefs forbids organ donation 95.50% 86% 94.3% 92.8%. Would not be an organ donor 23.10% 32% 17.2% 39.6%. Is not afraid of donating 67.40% 58% 34.7% 61.5%

Conclusions: Although changes have been found in the 1996-2004 period, the 2008 survey shows a backward step as to this issue. A significant percentage of the students does not know about the essential aspects involved in both organ donation and transplantation. This successive results make us think about how important it will be to include this issue in the education system.

Ethical and legal dimensions of the public discourse on transplantation.

A media analysis (Abstract #16)

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The present study aims at investigating the role of traditional and non-traditional Romanian media in framing the ethical discussion on transplantation. During the year 2008, Romania faced a public debate on the issue of organ transplantation, due to an attempt to change the existing legislation on transplantation, from an opt-in to an opt-out system. Press monitoring of the articles on transplantation topics published in 2008 by two important newspapers, *Adevarul* and *Cotidianul*, has been conducted. Subsequently, in order to analyze the immediate perception of the articles, article rating and on-line comments posted by internet readers of those articles have also been examined. This paper shows that, although some differences between the two publications are significant, the ethical dimensions of transplantation are usually neglected. Thus, articles take into account various dimensions concerning the deontology of physicians, but only infrequently address the complex ethical dimensions of donors and recipients. Legislative aspects are summarized, but there is only weak or no connection between legislative and ethical aspects. An important ethical actor is represented by the Christian Orthodox Church, due to the fact that bioethical issues are frequently addressed in Romania through the theological moral frame. Church position is explored in order to propose an alternative, nondogmatic perspective on transplantation ethics. A conclusion of the study is that the ambiguous public opinion on transplantation is closely correlated with missing the complexity of an ethical approach.

The Spanish model for organ donation. Success factors and ethical issues (Abstract #17)

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Introduction: With a donor rate close to 35 donors pmp, Spain has the world's highest rate of organ donation. As a result of a progressive and almost uninterrupted increase of transplantation activity, Spain is regarded by many as a model to be followed. However, the recipe of the Spanish Model is complex and has not been completely analyzed.

Objective: To provide a better understanding of factors involved in the success of the Spanish Model of organ donation.

Outcomes: The Spanish Model involves legal, political, economic, medical, cultural, and communication ingredients as well as high doses of pragmatism. The first part of this talk will clarify some of the factors that plausibly explain this phenomenon. In the second part some tentative hypotheses for a complementary understanding of Spanish rates in organ donation and transplantation are proposed. Those hypothetical factors are not sufficiently supported by empirical evidence and give rise to ethically debatable issues.

Conclusions: The Spanish Model's success can be attributed to a pragmatic policy based on a sustained effort in exploring all strategies to promote organ donation without undermining citizens' trust in their health care system. For the goals of organ transplantation and its long-term success in Spain, a public discussion on some ethically debatable aspects of this model could be implemented and enlightened by sound empirical data. This could provide valuable lessons on additional success factors in organ donation for other countries.

Euthanasia and organ transplant (Abstract #18)

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Euthanasia and organ transplant, as objects of study for a political scientist, question the political practices and represent relations between society and state. It's not only the political question around euthanasia and organ transplant which are at stake, but moral behaviour that a society devotes to itself. It's necessary to ask the French society if it grants additional rights to people who compose it. According to classical sociology criteria (P. Birnbaum, J. Leca, 2000), society acts on people. Nevertheless, when it's a matter of rights of life or death, does not it come back to individual to act on its social environment? In this case, we could find another sociology founded on other criteria. Choices of society in the right to die and individual consent in organ donations show whether society recognizes or not citizens' wishes. During discussions about bodies' free disposition, we find conflicts of values and common ideological positioning set up by political control and medical institutions. It returns us then in ethical, moral, juridical and sociological representation of death in our liberal states. Where are we up to in France? Do health professionals agree with law and bodies the government set up in French society? In this talk, we differentiate ideological step of scientific step and analyse theoretical frames which guide our political analysis. Do expectations and practices of health professionals agree with legislation? If we legalize active euthanasia in France, what would happen in the field of organ harvesting?

EULID: European living donation: Protection, health and safety (Abstract #19)

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Objective: We present the EULID project which aims to establish a European common standard to guarantee LD (Living Donors) health and safety through common practices and regulations.

Methods: Twelve partners from European Countries work cooperatively to reach a consensus and recommendations on ethical, legal and protection practices related to LD. Project grant-aided by the European Commission.

Results:

- Legislation: Prohibition and penalization of organ trafficking, tourism, commercialism, and incentives. Prohibition of minors and persons unable to give consent. Authorization of transplant centres and LD registry controlled by authorities. Regulation of independent commission. Reimbursement of expenses. Protection of donors and their families from discrimination, permanent injury or death.
- Ethical: The altruism of LD should be object of the most elevated consideration by the community. The promotion of LD should not impede cadaveric donation. Organ trafficking, commercialism or incentives are ethically unacceptable. The autonomy of the donor doesn't surpass appropriate medical decision-making.
- Protection: There should be no cost to the donor. Sick-leave with 100% payment. Financial coverage in case of unforeseen events related with the donation process. LD should be protected of any form of physical, psychological, social or economical disadvantage. Medical follow up obligated and psychosocial support if needed. Homogenous protection systems within EU.
- Registration: Registration of all LD is obligated for safety and transparency. A regulatory audit is mandatory. Identification, countries of residency, nationality, type of donation, institutions and outcome are obligatory. A central database is obligatory and supported by national authority.

Conclusions:

- The project contributes to a European consensus that can lead to best practices.
- The protection of LD should be done through laws and regulations as well as giving information and performing a follow-up.
- Common registries are important improvements to be implemented.

The ethical equipoise in living and deceased donor liver transplantation: Towards decision processes based on mathematical models

(Abstract #20)

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Background: The decision process allocating a specific organ from a cadaveric or a living donor to a particular liver transplantation (LT) recipient is strongly influenced by ethical issues.

Aims: a) To effectively represent the potential equipoise achievable between the different ethical principles involved in LT. b) To construct a mathematical decision model able to objectify and quantify these ethical aspects.

Methods: The desirable LT ethical equipoise may be described by a triangle with the transplant benefit (life expectancy with LT minus that without LT) at its superior apex and, the potential harms to the waiting list and to the living donor at inferior apices. We then constructed a Markov model to objectify and quantify the ethical equipoise triangle. The data sources to construct and validate the model were: the online UNOS website, and a prospective database from Padua about a new allocation model.

Results: Although our centre was characterized by a higher proportion of HCC patients in the WL (25% versus 10%) and a lower proportion of high MELD score (> 20) non-HCC patients (17% versus 27%) than the average US centre, these proportions were similar among transplanted patients. By using several simulations of ethically critical scenarios, our model showed that it is possible to objectify, measure, and modulate the clinical-prognostic impact of the following ethical principles: the utilitarianism principles of benefit and of harm to the waiting list, the urgency and fair chances principles, the paternalistic and autonomy principles (living donor).

Conclusion: We constructed and validated the first prognostic-decisional model based on both clinical and ethical variables able to influence the efficacy and safety of liver transplantation.

Limited number of kidneys – Who should get access to the waiting list?

(Abstract #21)

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Background: The overall aim of this study is to survey and analyse the process of selection of patients to the kidney waiting list in the Nordic countries, collaborating within Scandia-

Methods: A questionnaire was sent to one senior physician of each of the ten centres within Scandia-transplant where deceased donor kidney transplantation is performed. The questions concerned evaluation of the patient for inclusion on the waiting list. The respondents were also asked to decide whether 12 borderline cases should be accepted for transplantation or not. Answers should be given with the policy at the centre in mind. The response rate was 100 %.

Results: Differences in criteria relate among others to some centres being stricter when it comes to limits for cardiac ejection fraction and some centres being prepared to accept older patients than others. Four centres have a policy not to include predialytic patients. In two out of 12 borderline cases the centres answered unanimously whether to accept the patient or not. All centres agreed that they would not refrain from acceptance of a patient due to the scarcity of organs if the patient were considered to benefit medically from transplantation, but in specific situations this is more doubtful. Only a few respondents were positive to common Nordic guidelines for investigations or limiting values.

Conclusion: We conclude that there are some differences in the Nordic countries regarding acceptance of the patients to the waiting list for kidney transplantation. This raises interesting ethical issues. A question, which needs further discussion, is how to balance utility and justice in this process.

Creation, validation and results of a living donors satisfaction survey (Abstract #22)

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Objective: To validate a Living Donor (LD) questionnaire to evaluate the satisfaction with the process, and the impact on the social, economical and psychological well-being spheres.

Methods:

Survey creation:

- Design of questions evaluating other previous questionnaires, considering using multiple choice answers according to Likert scales, and evaluation of the survey and methodology by the Sociology Department of University of Barcelona.
- Questions are addressed to explore 3 spheres:
 - Perception and acceptance of the donation process (information received, decision making and impact of donation on economics, life opportunities, job, and donor-recipient relationship)
 - Quality of life
 - Psychological well-being
- Survey is translated to 9 European languages.
- The study belongs to the EULID project, grant-aided by the European Commission. <http://eulivingdonor.eu/SurveyValidation>:

Use of the Delphi's methodology:

1. Evaluation of the importance, appropriateness and comprehension of each question, done by a group of national and international experts. Modification of the questions, considering by consensus the minimum score to be accepted 5 in percentile 10. Second round with the same experts with the modified survey.
2. Pilot test of the survey with a sample of LD to evaluate the comprehension, viability and reactions of the target population. Modification of the survey taking into account the information from the pilot test. Survey Collection: 220 satisfaction surveys from 9 European countries have been performed.

Results:

- We present a validated LD satisfaction survey that will allow to perform a mid-term and long-term living donor follow-up exploring spheres like satisfaction with the process, quality of life and socioeconomical impact.
- We present the analysis of 220 questionnaires performed in 9 European countries.
- Results show that the procedure is safe and the impact on donors is minimum.

Psychosocial characteristics predictive of post-operative mental health in living liver or kidney donors: A systematic literature review

(Abstract #23)

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Objective: Previous research has demonstrated that mental health outcomes following living donation are predominantly favorable. However, little is known about the factors at the time of donor screening that predict poor mental health in living liver and kidney donors after donation. A systematic literature review was conducted to identify empirical research on markers for post-donation vulnerability. The long-term objective is to produce evidence-based guidelines that may support clinicians in donor screening, monitoring and counseling.

Methods: Eligible studies include: assessments of psychosocial and mental health parameters, both pre- and post-donation, by means of objective measurement tools, in a population of living liver or kidney donors. Scientific reports, published in any language until September 2009, were searched for through PubMed, PsychInfo, and Embase. Two independent reviewers evaluated major outcomes, socio-demographic donor characteristics, and properties of design and measurement tools.

Results: Out of 227 abstracts screened, 123 full-text reports were selected for in-depth evaluation. Seven studies fully met the inclusion criteria. The mean sample size of donors enrolled was 44. Five of the seven studies were European. Main outcomes of interest were mood (N=6), quality of life (N=3) and DSM-IV disorders (N=2). For the most part, results indicated that mental health in terms of quality of life and mood was not

impaired after donation. Two studies identified that pre-operative higher levels of anger and fragile self-esteem were related to less favorable outcomes after donation.

Conclusions: The published evidence suggests that living donation does not affect mental health. However, small sample sizes may influence the low incidence of observed mental health problems, and their subsequent lack of predictive capacity. Conducting more research on predictors and pooling data in multi-center studies is encouraged.

Psychosocial outcome and reflections of donors undergoing living donor liver transplantation (LDLT) – Results of a qualitative research study (Abstract #24)

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Background: Living donor liver transplantation (LDLT) has been increasingly performed in recent years to overcome the shortage of organs raising various medical and ethical issues, due to the donor risk. Outcome studies are needed to improve our knowledge about the LDLT-experience, the donors' post-operative course and to develop our concept for the evaluation and support of the donors.

Methods: We conducted a study using qualitative research methods. Preoperative clinical semi-structured interviews and 6-month postoperative follow-up interviews with 47 liver donors were analysed using the method of Grounded Theory (Glaser & Strauss, 1967).

Results: LDLT presents an emotional and physical challenge even for carefully selected healthy donors. Donors experience rapid deterioration in their health, face changes in their social life and are confronted with issues, like loss of autonomy and uncertainty about their health. Physical and emotional/psychological difficulties are not rare and recovery can be a long process. Donors need to mobilise all available personal and social resources to cope with such demanding conditions and to integrate the donation into their lives. Donors usually do not regret donation and express overall well-being, joy or satisfaction, even when experiencing ongoing physical symptoms or the death of the recipient. Yet, a small percentage of donors are facing difficulties to integrate the donation experience expressing disappointment or regret.

Conclusions: For the medical personnel involved in the transplantation procedure it is important to keep such results in mind in order to prepare donors for the postoperative course, provide adequate care and be able to identify conflicting feelings. Thorough pre- and postoperative psychosocial evaluation and support should remain an integral part of every transplant program aiming at high quality standards.

Patient reported outcome measures (PROMS) in living donor kidney transplantation: Recipient expectations exceeded while concerns remain regarding initial donor recovery (Abstract #25)

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The aim of this study was to establish donor and recipient expectations and evaluate whether these are met following transplantation. 18 donors and 17 recipients underwent structured interview, and completed the Hospital Anxiety and Depression Scale (HADS) and SF-36 Quality of Life questionnaire before, 3 months post-transplant and 1 year post-transplant. Donors and recipients have similar overall expectations pre-transplantation (mean aggregate scores 35.1 and 32.6, $p=0.09$). Recipients expected to be less tired (4.6), and more able to work (4.2) and socialise (4.3). 3 months post-transplantation, recipient expectations were met in all 16 variables. Furthermore their HADS and SF-36 scores significantly improved ($p=0.04$ & $p < 0.02$); at 3 months recipients' SF36 scores were greater than donors' (94.2 v 41.7, $p=0.000$). Donor ability to work and financial position were worse than expected (2.8 & 3) with greater pain and a longer recovery period. 40% recipients and 33.3% donors reported qualitative concerns regarding donor support. 1 year post-transplantation donor expectations for their health and happiness were exceeded (3.3 v 3.2 & 4.1 v 3.9) and their HADS scores (1.3) improved to below the pre-transplant (2.0) and 3 month levels (2.6). Recipient pre-operative expectations of improved health, less pain and more happiness were exceeded one year post-transplant (4.6 v 4.2, 3.7 v 3.5, 4.3 v 4.0). In conclusion, expectations are high for both donors and recipients prior to living donor renal transplantation. 3 months posttransplantation recipients' expectations were exceeded, while donor outcome was poorer than expected. Despite this the majority of donors reported emotional benefits. One year post-transplantation recipients continue to report good outcome while donors have made full recoveries both physically and emotionally with many reporting benefits having donated. Further consideration of donor welfare may be required in the early post-operative period.

Development and validation of the living donation expectancies questionnaire (Abstract # 26)

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It is important to assess the motivations and expectations of potential living donors. In addition to expecting an improvement in the health and quality of life of the recipient, potential living donors may expect the donation experience to yield some personal, spiritual, or relationship benefits for themselves as well. We developed a questionnaire, the Living Donation Expectancies Questionnaire (LDEQ), to measure living donors' expectancies prior to surgery and to assess whether these expectations were met after surgery. The aim of the current presentation is to summarize LDEQ data we collected at

two U.S. transplant centers over the past several years. In addition to describing the development of the LDEQ, this presentation will highlight four primary findings: (1) there is strong internal consistency and factor analytic support for six scales: Interpersonal Benefit (IB), Personal Growth (PG), Spiritual Growth (SG), Quid Pro Quo (QPQ), Health Consequences (HC), and Miscellaneous Consequences (MC); (2) expected benefits of living donation are associated with higher optimism and lower mental health; (3) high LDEQ scores differentiate those living donors with relative or absolute psychosocial contraindications to donation from those with no psychosocial contraindications; and (4) 1 yr after donation, living donors report that their pre-donation expectancies were exceeded and that they achieved higher than anticipated interpersonal benefits, personal growth, and spiritual growth. Collectively, these studies have shown that the LDEQ is a well-validated clinical tool for measuring donor expectations and a useful research strategy for assessing whether donor expectations are met in the months and years after surgery.

Is donating a kidney associated with changes in health habits? (Abstract # 27)

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Donating a kidney is a helping act that may have short and long-term consequences to the donor's health. It also represents an opportunity for donors to re-evaluate their health habits. While previous studies have examined the effect of donation on health and financial outcomes, no studies have examined whether donating a kidney is related to changes in health habits. We conducted telephone interviews with 85 donors (47 females; 12 African Americans; 70 European Americans; 3 Other) who donated a kidney via laparoscopy between 10/02 and 12/04. Donors were asked to recall their health habits before and after donation. Overall rates of regular check-ups increased from 53% before to 80% after donation. Of those who had regular check-ups post-donation, 94% had their blood pressure checked, 74% had blood glucose checked, and 65% had their kidney function checked. While 23% of donors who smoked pre-donation quit smoking, there was no change in rates of heavy drinking (>14 drinks/week) pre- to post-donation. Before donation, 57% of donors reported exercising regularly (>3x/week); but postdonation, only 46% exercised regularly. While 18% of donors had a BMI in the obese to extremely obese range before donation, that percentage increased to 25% post-donation. Regression analyses

indicated that regular check-ups and exercise post-donation were associated with better physical quality of life (-4.1 and -5.6, respectively), all $p < .05$. Despite recommendations for annual testing in kidney donors, a substantial proportion of donors do not have their blood glucose or kidney function checked annually. This finding implies that typical pre-donation health education strategies are not having the desired impact. Future research should evaluate the reliability of these findings in a larger sample of kidney donors and seek to understand and promote better health habits among kidney donors.

Solving the kidney transplant crisis for minority ethnic groups in the UK: Is being transplanted overseas the answer? (Abstract #28)

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Nearly 1 in 4 UK patients waiting for a kidney transplant are from a minority ethnic group. Organ shortage has prompted patients to source organs from overseas. We report a summary of demographic information about UK residents who have travelled overseas to receive a kidney transplant and returned to the UK for follow-up. Methods: Follow-up data were obtained on 210 living-donor and 22 deceased-donor transplants undertaken overseas between 01 January 2000 and 28 April 2009. Unadjusted and risk adjusted analyses of five-year graft and patient survival were carried out. Findings: Transplant recipients overseas were predominantly of South Asian ethnicity (62%). Overseas transplants took place predominantly in Pakistan (49%) and India (20%). 58% of transplants were from living unrelated donors. 28% were from living related donors, most of whom were recorded as cousins. Their mean age was 459 years (range 13-83 years, $n=245$). For those patients who return and are reported, there were significant differences in terms of five-year graft and patient survival ($p < 0.01$ for both) for overseas transplants compared with patients transplanted in the UK. Discussion: Minority ethnic communities appear more likely to travel overseas for a kidney transplant. This is perhaps not surprising, given they are least likely to receive a kidney transplant in the UK due to their greater propensity of kidney failure and shortage of suitable donors. Our analyses demonstrate a statistically significant inferior five-year patient survival and graft outcome in those patients transplanted overseas compared to those transplanted in the UK. It is essential that these patients are fully informed that transplant outcome from organs sourced overseas is significantly inferior and may relate to the quality of the organ transplanted.

Regulated living unrelated donation leads to commercialism (Abstract #29)

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Worldwide demand for organs for transplantation, particularly kidneys, created an illegal market in which organs from poor donors are sold as a commodity. This has led to commercialism and transplant tourism in many countries in the world. In order to make more kidneys available for patients in Kuwait and to combat transplant tourism a regulated living unrelated (LUR) donor program was initiated in Kuwait in 1999 allowing unrelated donors to donate kidneys according to Kuwait Transplant Law of 1987, which prohibits organ sale but allows altruistic donation. All prospective LUR donors were interviewed by an official committee formed of transplant specialists, psychiatrist, social workers and a legal representative from the Ministry of Health. The requirements to be eligible for interview included a monthly salary of not less than 600USD and an official residency in Kuwait of at least 2 years. The aims of the interview were to explore the motives for donation, to assess the maturity and psychological state of the donors and to exclude possible coercion. Of 802 prospective LUR donors accepted for interview, between 1999 and 2008, only 75 were Kuwait nationals and the rest were expatriates living in Kuwait. 582 were accepted as possible donors. The majority (63.9%) claimed some sort of emotional relationship with patients or a member of their families. Only 250 actually donated their kidneys. In order to evaluate the program, we selected 50 recipients of LUR donor kidneys at random to interview. 48 accepted to participate. Most patients (72.8%) were on dialysis for less than one year before their transplant. 40.2% had children and 95.6% had from 1 to over 10 siblings who could be donors. Family offered donation in 85.4% of cases but 44% of patients refused due to availability of LUR donors while 44.1% claimed family was not medically suitable. All patients except two admitted paying the donor between 600-36000USD. Average price for the kidney: 17250USD.

Our **Conclusion**: Allowing LUR donation in any form opens the door to commercialism and should be prohibited.

Unshakable egoist?

A Swiss mixed methods research on the social and psychological aspects of the organ donation act (Abstract #30)

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Background: Due to organ shortage in the industrialized countries, a growing pressure is put on the social actors of transplantation to find solutions in order to increase the num-

ber of available organs, in accordance with the ethical and legal framework. Among the strategies adopted, in Switzerland national campaigns aim at raising the public awareness regarding the need to make one intention explicit about organ donation. However, the psychological conflicts and the ethical issues related to the act of donation are little explored.

Purpose: In this study we explore the organ donation social representations of the Swiss population (i.e. German, French and Italian speakers) and we analyse the way in which they raise and spread out within the social field, with particular attention to their cultural references. These results will foster the development of a broader project that aims at implementing a critical stance among the social stakeholders of the transplantation field.

Methods: Researches using both qualitative and quantitative methods have proven to be effective in the study of public health topics. In this work we associate a quantitative tool to qualitative methods in an embedded mixed method design. During the first phase of the study, a questionnaire explores the organ donation social representations of the Swiss French population. These data will be used during the second phase in order to create scripts for focus groups and semi-structured interviews.

Results: In this poster communication, we will argue that the use of a mixed methods approach is relevant to the interdisciplinary research field. Furthermore, we will introduce the process underlying the creation of our questionnaire and we will present the preliminary results of the first-phase survey.

Why is it that deceased transplant recipients' families refuse to donate? (Abstract #31)

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One would suppose that organ recipients' relatives are automatically favourable to donation. However, this does not appear to be the case.

Objective: Retrospective family interviews study (2002-2008) of all potential donors (organ and tissues) evaluated in the Vall d'Hebron University Hospital, who were previously candidates for transplant or underwent transplant, so as to know the outcome of donation interviews.

Methods: Comparative study of donor family interviews within the transplanted or waiting list population and non transplanted. Variables included were: Age, gender, level of education, donor card, interview length, and outcome, knowledge of Spanish transplant law, etc.

Results: 25 transplanted registers (6 for organs and 19 for tissues) of 3683 non transplanted family interviews were analysed. We compared the transplanted and non transplanted samples. The discussion results were; favourable to donation 8/25 (32%) cases (4 organs and 4 tissues) vs 2432/3683 (67%). Refusal to donate 17/25 (68%) (2 organs and 15 tissues) vs. 1251/3683 (34%) (44 organs and 1207 tissues). The arguments against donation were: Deceased's opposition in life 4/17 (23%) vs 121/1251 (9.6%), Extreme suffering (deceased's and family's) 14/17 (82%) vs 391/1251 (31.5%), Punishment of

Health System 5/17 (20%) vs 97/1251 (7.8%), Religious Beliefs 3/17 (12%) vs 65/1251 (5.2%), Deceased 's will unknown to family 7/17 (31%) vs 344/1251 (27,5%) (Multiple reasons).

Conclusions: Refusal to donate by families of deceased transplanted patients is higher than within the normal population. It would be necessary for the transplanted population to express their living will regarding organ and tissue donation in clear terms, as it appears that their families hold doubts. Family interviews often reveal unrealistic expectations and further studies are required to ascertain the true position of the transplanted patients and their families.

Respect for the individual as a human right in relation to post-mortem use of the human body for transplantation

(Abstract #32)

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In theory systems for post-mortem use of the human body for transplantation and other purposes can exist anywhere on a spectrum from allowing the individual total control over what happens to their body after death to treating the body as an object of state and/or medical control. In practice all systems have at least some features which are toward the middle or latter end of the spectrum. As such they raise human rights issues but these have received limited attention in the literature. Here the authors will argue that it is important to pay heed not just to general human rights instruments such as the European Convention on Human Rights 1950 (ECHR) but also medically oriented ones such as the Convention on Human Rights and Biomedicine 1997 (CHRB). Whilst the former are oriented toward protection of the individual and contain relevant specific provisions on issues such as private and family life and non-discrimination, the latter help to determine how this orientation and such specific provisions apply in medical contexts. The CHRB, for example, emphasises the primacy of the individual vis-à-vis the needs of science and society and asserts a range of related values linked to respect for the individual in medicine – such as dignity, identity, integrity and equality. Armed with this understanding one can more vigorously debate the human rights compatibility of systems of post-mortem use that deviate from full protection of the individual, questioning their underpinning philosophies rather than assuming that they can be defended by reference to the simple fact that they represent the norm. This presentation is prepared within cooperation established among members of European Association of Health Law (EAHL).

Legal guidance on non heart-beating donation in England and Wales (Abstract #33)

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The Department of Health published Guidance for clinicians caring for potential non-heartbeating donors in November 2009. Treatment of patients who are incapacitated – eg unconscious patients after a major brain injury – is governed by The Mental Capacity Act 2005, which requires that treatment may only be given that is „in the patient’s best interests“. The Guidance sets out the Department of Health’s view of the circumstances under which certain actions, necessary to facilitate or optimise non heart-beating donation after death, may be considered to be „in the patient’s best interests“ and it is hoped that this will support clinicians working in the field and allow them to develop more detailed professional guidance.

Living kidney donation: For love or money? Attitudes of 250 actual living donors (Abstract #34)

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Introduction: Due to lengthening wait lists for kidney transplantation a debate has emerged as to whether financial incentives should be used to stimulate live kidney donation. In recent surveys among the general public approximately 25% was in favour of financial incentives while the majority was opposed or undecided. In the present study we investigated the opinion of living kidney donors.

Methods: We asked 250 living kidney donors whether they, in retrospect, would have wanted a reward for their donation. We also investigated their attitude towards financial incentives for anonymous donation and what type of incentive would be deemed most appropriate.

Results: 250 donors underwent nephrectomy 0-26 (median 3) years prior to the study. Relationship with the recipient was 60% genetically related, 23% non-genetically related, 8% were Good Samaritans and 9% donated on an anonymous basis in a kidney exchange procedure. The vast majority (78%) was not in favour of any kind of reward for themselves as they had donated out of love for the recipient. Remarkably, 60% of the donors were in favour of a financial incentive for individuals donating anonymously. Relationship to the recipient had no influence on their opinion. A reduced or free health insurance premium was the preferred incentive.

Conclusion: We conclude that although living kidney donors in this study had donated their kidney out of love, one fifth would nevertheless have wanted a modest reward. To stimulate anonymous donation the majority is positive on using financial incentives. The little impact donation had on their life and the major positive effect on the recipients’ life may have convinced them that any means of promoting living kidney

donation, including financial incentives, should be tried to stimulate living kidney donation.

Workshop 'Offering incentives to promote organ donation: Comparing three proposals'

(Abstract #35)

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In order to address the current shortage of organs for transplantation, several commentators have recommended that trials be implemented to evaluate programs in which either donors or their families are ‘rewarded’ for consenting to donation. Such experiments would aim to investigate whether offering incentives would increase organ donation rates without violating important moral principles or generating undesirable social consequences.

In this workshop, each of the three convenors will outline a particular type of incentive that could be implemented:

- (1) Aimed at the next of kin in post mortem donation. Incentives can either be monetary (e.g. paying funeral costs directly to the undertaker) or non-monetary (e.g. presenting the next of kin with details on possible recipients and their needs);
- (2) Financial incentives aimed at the donor in post mortem donation (a “futures market”);
- (3) Financial incentives aimed at the donor in living donation (e.g. a lifelong free health insurance).

The social and moral acceptability of each model will first be discussed separately, with active involvement of the audience. Subsequently, a comparative analysis will be made of the different mechanisms’ potential drawbacks and promises, again actively inviting input from the attendees.

Living donation among ethnic minorities: A Dutch qualitative study on the attitudes, communication and needs of kidney patients

(Abstract #36)

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Objective: Living kidney transplantation rates have increased and exceed those of cadaveric kidney transplantation in The Netherlands. However, among ethnic minority patients the

percentage of living kidney transplantations has not developed equally. A qualitative study at the Erasmus Medical Centre (EMC) explores factors that underlie the relative lower frequency of minority patients who undergo transplantation with a living donor.

Methods: In an ongoing study, focus group interviews are planned at the EMC to investigate the attitudes and needs of ethnic minority patients regarding living kidney donation and subsequent communication with their family and friends. Eligible candidates were: kidney patients from Moroccan, Turkish, Antillean, Surinamese and Cape Verdean origin; without a living donor; identified through the Eurotransplant list; and seen by an EMC nephrologist. For purposes of comparison, focus groups are also planned with minority patients with a living donor and Dutch patients. Analysis of the interviews is based on the Grounded Theory.

Results: In September 2009, 93 eligible kidney patients out of 331 were identified. Of these 70 (75%) did not have a living donor. Approaching the Hindustani patient group (N=12) yielded an in-depth discussion with three patients. Living donation was considered appealing (N=3), although this was impossible due to family illness (N=2) or not desired out of fear bothering others (N=1). Religion was not an influencing factor (N=3). The participants reported they had discussed their disease with others, but felt that in the Hindustani community this was taboo (N=3). Education meetings would be welcomed (N=3).

Conclusions: Analysing attitudes, communication and needs in subgroups of ethnic minority patients may identify the barriers for living kidney donation. The outcomes will guide the development of a home-based education intervention.

Faith & organ donation: Engaging with faith communities to address the UK organ donor crisis (Abstract #37)

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Background: UK organ donation statistics highlight significant disparities between ethnic groups, empirical research illustrates the significance of cultural and religious factors on decisions relating to organ donation.

The Organ Donor Campaign (ODC) raises awareness through education, employing appropriate engagement strategies for different sections of UK communities. [To find out more, visit: www.organdonorcampaign.co.uk]

Aims & Objectives: Recognizing the significance and influence of faith to affect social change, the ODC launched its Faith and Organ Donation initiative in 2009.

Primary aims include:

- Explore faith based perspectives towards organ donation amongst the following UK faith communities: Christian, Muslim, Jewish, Hindu, Sikh and Buddhist.
- Create a unique platform for faith/community representatives, policy makers and healthcare professionals to engage and put forward their respective views, concerns and solutions on/around organ donation

- Harness faith community networks to disseminate knowledge and stimulate debate around organ donation within their respective communities.

Methodology: Phase I: Six seminars – one for each of the faith communities listed. Allow respective faith representatives to identify existing views, religious references and opinions around organ donation and generate recommendations as to how organ donation rates can be improved.

Phase II: Disseminate knowledge and generate debate through the respective faith community networks at local grassroots level.

Results:

Phase I concludes: Feb 2010.

Initial findings include:

- Significant need for more information and education around organ donation at the local grassroots level. Resources are an important concern.
- Participants happy to employ existing faith/community networks to disseminate knowledge and promote organ donation.
- Diverse views exist within and between the respective faith communities.
- Barriers to organ donation

Cultural barriers for setting up a kidney transplantation program in the indigenous population of Chiapas, Mexico (Abstract #38)

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Epidemiology: As in several other countries, Mexico has a growing waiting list for kidney transplantation, however, as reported elsewhere, indigenous patients, although more prone to have conditions that would eventually lead to end-stage kidney disease, their opportunities for having those diagnoses made or being included in the aforementioned list are much smaller than for their nonindigenous counterparts. On the other hand, the influence of western diet has increased the risk of diabetes, hypertension and obesity among these populations.

Social burdens: Chiapas is a state with roughly the extension of Benelux in which impoverished indigenous communities, that talk up to a dozen different languages, are located in remote places, and they lack of most of the commodities usually available with urbanization; additionally Chiapas' indigenous groups mistrust of white or mestizo government representatives amidst a background of centuries-old history of exploitation and rebellion. Concept of disease and reasons for avoiding treatment: Although basic medical services are almost universal in the region, and despite the recent inauguration of a hospital with dialysis and transplantation capabilities, indigenous chances for receiving such treatments remain scarce.

Proposal: Any intervention should consider beliefs and cultural framework of indigenous population, including themselves as much as possible in order to restore their trust in government-run healthcare providers.

Confidentiality in living donation: Contradictions between donor and recipient autonomy (Abstract #39)

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Current guidelines regarding the sharing of medical information between a potential living organ donor and their recipient are either unclear or may require one way disclosure of recipient data. It has been held that the donor requires sufficient information about the recipient to make an informed decision, but that the recipient should not be given access to the donor medical history, particularly when the donor does not proceed. It may be argued that donor autonomy is paramount, and that this is due to the voluntary act of donation. However, full disclosure of recipient information may not be appropriate. The recipient may be seen to be trading autonomy for an organ. Full disclosure may be seen as a condition of donation, when other conditions are not considered justifiable. Nondirected donors have no information about their recipient, nor do donors participating in paired exchange schemes. Donors also accrue benefit from donation, and it is questionable whether competing demands for autonomy between two individuals can be resolved by assessing the extent of selflessness involved. To make an informed choice, donors only require to know about the likely chance of success in the recipient. Grouping outcomes into broad categories would satisfy this requirement without compromising the autonomy of either donor or recipient and would save lives by allowing some recipients, such as those who are HIV positive, to proceed. HIV positive recipients, particularly from overseas, are often reluctant to disclose their diagnosis due to the associated stigma. This presentation argues that donors can give valid consent on this basis, and that limited, not full, disclosure of recipient information is appropriate.

Autonomy and paternalism in living donation

(Abstract #40)

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The 2006 UK Human Tissue Act introduced the notion of appropriate consent in living donor transplantation, and specifically stating that the donor should be competent to consent and do so voluntarily. A fundamental principle of the act is donor autonomy. However, the implication of this is that potential donors who are at risk from surgery, either due to a poor peri-operative outcome or a later risk of renal failure, should nevertheless be considered for donation if they meet the requirements for appropriate consent. Several objections can be raised to this perspective, although few are absolute. The transplant team can also be considered to have autonomous rights and may therefore refuse surgery; however, it is argued that there are limits on when and how this refusal might take place. Beneficence could be said to supersede the principle of autonomy, and transplant teams could then be acting in the patients' best interests; however, autonomy is the right to make the wrong decision. This presentation argues that autonomy is

not absolute; profound emotional and psychological pressures ('The tyranny of the gift') in living donation mean that decision making cannot be, nor should be, entirely objective or rational. Similarly, paternalism is inevitable, but should be limited, in the medical consultation. Donors may dismiss later consequences of donation (for example in those with renal calculi) due to immediate emotional pressures and transplant teams may need to take some of the responsibility for these decisions. In the context of compromised autonomy and limited paternalism, transplant teams should exercise a beneficent approach to potential donors, but should do this in a transparent and controlled manner.

Conflicts of values about definitions of equity in organ allocation in Switzerland (Abstract #41)

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Our study's aim is to identify the different concepts of equity as they are in practice in Switzerland nowadays. The ethical values which are implied in the concepts of equity are deduced from the law, from the way Swisstransplant applies it and from medical practice. We analyse these results through the conceptual means of bioethics and political philosophy. The allocating process is made through several levels of decisions, which involve important conflicts of ethical values: a. the explicit and implicit basic choices (concept of justice adopted, the best health care system and the purpose of transplantation); b. the types of criteria chosen and why (the swiss law only allows the use of medical criteria); c. the definition and the measures of these criteria; d. the balance between the criteria (defined on the one hand by the law and on the other hand by the doctors' judgement; marginal organs pose a lot of problems). It would be naive to believe that it is enough to use only medical criteria in order to avoid discriminations. Their use is never morally neutral. In our opinion, a more fair balance between urgency and efficiency, in Switzerland, would suppose: the reconsideration of the leeway given by the law to the doctors, the emphasis on the conditions of acceptance in the waiting list, dealing with the limits of the amount of retransplantation. In the case of marginal organs, when it is possible, the recipient should be given the possibility of voicing out his/her opinion in the allocation process. Furthermore, the swiss law should be given credit for not taking into account social criteria. However, it should be less indifferent to the voluntary health-risky behavior and to the deliberate absence of compliance.

The allocation of organs: The need for fairness and transparency (Abstract #42)

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We review the UK organ allocation system which has evolved to accommodate many of the conflicts which can arise. These include (but are by no means limited to) conflicts over biological incompatibility between a donor and a recipient, legal issues, ethical principles, competing claims between individuals, between individuals and society, the objectives of healthcare regulators, and resource issues. Do we aim for equity of access or maximising efficacy? Like healthcare allocation more generally, the organ allocation process is not perfect. A primary purpose of this paper is to examine whether the current imperfections are understandable and justifiable. We discuss the medical and biological constraints with which the organ allocation system must operate and then continue to consider the various trigger events which have impacted on the organ allocation system. These events act as important markers in how the system has evolved and provide depth of understanding to the process. We present a description of the current organ allocation algorithm, the development of the system, and examine its benefits and shortcomings. We also consider the politico-legal framework within which the system exists. We analyse the importance placed on concepts such as 'fairness', 'justice', and 'equity' within the allocation algorithm. The paper concludes with some challenges which future developments will have to overcome. Instituting an organ donation and allocation system raises a diversity of issues, which relate to ethics and public acceptability, and not mere scientific viability. The paper illustrates the fact that allocation decisions cannot be made on purely medical or scientific grounds. The criteria which are used involve some aspects of moral deliberation. Like any area of health care where resources are scarce morally justifiable reasons which are acceptable to society generally must be used to justify allocation.

Predictors of noncompliance in kidney transplantation (Abstract #43)

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Objective: To explore predictors of noncompliance in patients after kidney transplantation.

Methods: 38 adult kidney transplant patients at Kharkiv Nephro-Urological Center (mean age 39.3±7.2 years, 41.7% female, and 84.6% primary graft) who were at least 6 months post transplant were recruited from 2003 till 2009. Patients completed the Kidney Disease Quality of Life (KDQOL) questionnaire.

Results: Mean age at the onset of renal replacement therapy was 33.61 (SD 3.13) yrs, whereas the mean ages at placement on the list was 29.23 (SD 3.14) years. Three categories of variables that appear to be associated with noncompliance were explored: demographic characteristics, psychological variables, and social variables. Demographic predictors associated with noncompliance include age of transplantation more than 30 yrs and male gender. Psychological predictors of noncompliance include patient reports of depression, anxiety, anger-hostility, and substance abuse. Failed Mental Health Composite level was associated with older age, male gender, transplantation age less than 30 yrs, years of listing more than 2 yrs. Noncompliance with immunosuppressive therapy was found to be a major risk factor for late acute rejections. Patients who had a late acute rejection due to noncompliance were significantly more depressed, tended to perceive their overall health as poorer, experienced more symptom distress, and had lower levels of self-efficacy with medication intake compared with patients who did not experience a late acute rejection. Social variables that have been shown to predict noncompliance in kidney transplant recipients include poor relationships and a lack of social support. Poor family relationships were highly associated with noncompliant behavior involving poor diet, lack of exercise, failing to take medications correctly, and smoking cigarettes.

Conclusions: It is important to recognize predictors of non-compliance for improving long-term outcomes in patients undergoing kidney transplantation.

Interviews with a group of transplant professionals about directed organ donations from deceased donors (Abstract #44)

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Objective: In Ontario, Canada, the organs of deceased donors are usually allocated to those recipient candidates who are ranked highest on the province's waiting list. However, on rare occasion, a donor or the donor's family will request that an organ be given to a designated recipient or designated group of recipients. I conducted a study to elicit the views of a group of transplant professionals in Ontario on the question, "When, if ever, should a donor or the donor's family be allowed to choose the recipient of the organ?"

Methods: In-depth interviews were conducted with 14 transplant professionals from a range of clinical disciplines. The transplant professionals were asked questions about hypothetical scenarios involving different forms of directed donations. The interviews were analyzed using inductive coding procedures derived from grounded theory.

Results: An analysis of the interviews revealed, among other things, the transplant professionals' general acceptance of directed donations in which the donor or the donor's family has a close relationship with the designated recipient; opposition to directed donations in which the designated recipient is a member of a particular and identifiable group of recipients; opposition to directed donations that result from a public appeal for organs; belief that a medically urgent recipient should always be given priority over a designated recipient who is in

less critical need; and belief that upon any request to select the recipient the donor or the donor's family should be educated about the ethical basis of the standard allocation procedures.

Conclusion: The views of the transplant professionals interviewed were similar to, but also different from the considered views of authors on directed donations in the transplant literature.

Influence of demographical and administrative factors on the rate of deceased organ donors in Latvia (Abstract #45)

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Background: Organ transplantation is the most effective method of treatment regarding patient's benefits and also costs, especially transplantation from deceased donors. However, the number of deceased donors is influenced by various factors. The aim of this study was to analyse the impact of demographical and administrative factors on the rate of deceased organ donors in Latvia.

Material and methods: Analysis was performed based on data obtained from The Central Statistical Bureau of Latvia, The Office of Citizenship and Migration Affairs, and Latvian Transplantation Centre for the period from 1992 till 2009. Changes in the rate of deceased donations were analysed in association with demographical and economical situation, amendments of law, etc.

Results: Deceased organ donation was positively affected by the establishment of transplant co-ordination and legal basis for brain death diagnostics in Latvia (60% increase in the rate of donation within the next few years, $p < 0,001$) and initiation of a new donor registry through the State Population Registry (15% increase in the number of donations, $p < 0,01$). Decrease in the number of donations from deceased donors during the last two years for more than 30% ($p < 0,005$) was associated with economical and administrative reforms in medicine (decrease in the number of donor hospitals, resignation of medical personnel, etc.), however, an audit of the main donor hospitals did not reveal "unreported" donors by ICU personnel. Demographical situation didn't show significant impact on the rate of donations.

Conclusion: The rate of the deceased donations is influenced by general situation and tendencies in medicine and in society. In present situation the rate of deceased donations could be improved by expansion of donation criteria and by increased use of DCD donors, however, both processes need additional transplant co-ordination staff and investments.

Myths and facts – What should we know about neurocritical patient evolution and organ donation? (Abstract #46)

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Introduction: In hitherto published data there are no registers telling us how many neurocritical patients die in brain death. The follow up protocol of these patients is used by the transplant coordinator to avoid losses of potential organ donors in Catalonia, Spain.

Aim: A multicentric study, analysing evolution of neurocritical patients in Intensive Care Units in 4 university hospitals with donation programs.

Methods: These hospitals completed the following questionnaire:

1. Administrative data: n° of admissions, n° of neurocritical patients, survival, mortality and occupation rates.
2. Neurocritical pathologies: n° brain traumas, n° strokes (hemorrhagic and ischaemic), n° brain tumors, n° anoxic encephalopathy.
3. Evolution by pathology (alive or type of death: heart arrest or brain death), length of stay and number of donors. The study period was 2002-2008.

Results: We analysed 2472 neurocritical patients (GCS <8) out of 64.971 admitted in ICU. Of those analysed 30% (755/2472) died in brain death and 55% (416/755) became organ donors. 40% (984/2472) were released with good outcomes and 6% (151/2472) had poor results (GOS 2-3). Average length of stay for brain dead patients was 3,7 days (range 1-11) compared to 13,9 days (range 1-45) deaths in cardiac arrest. By pathologies, brain death occurred as follows: 1. Brain Trauma 18% (175/876). 2. Subarachnoidal Haemorrhage 34% (104/298) 3. Intracerebral Haemorrhage 50% (312/618) 4. Ischaemic stroke 30% (66 /225) 5. Brain Tumour 25% (25/88) 6. Anoxic Encephalopathy 40% (85/208).

Conclusions:

1. 30% of neurocritical patients in ICU died in Brain Death.
2. Brain Death occurred in first 3 days.
3. A standardised protocol of prudential observation time, including evaluation, prognosis and family information, would surely lead to improved results, family satisfaction and organ donation.

Determination of death and organ retrieval in Spain, US and France. Knowledge, concepts, and attitudes among health professionals (Abstract #47)

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Objectives:

- 1) We ask professionals related to organ donation in three countries – Spain, USA, and France – if they know (a) the legally accepted criteria for death in their own country and (b) the legal vital status of three clinical scenarios: Brain death (BD), donation after controlled cardiac death (cDCD) and donation after uncontrolled cardiac death (uDCD).
- 2) We assess and compare (a) their personal belief about the vital status of BD and DCD donors and (b) their underlying criteria and concepts of death.
- 3) We analyze professional's moral judgments on organ retrieval.

Methods: 587 Spanish, French and American professionals likely to be involved with organ donors were interviewed during a personal structured interview.

Results: In response to questions about the case scenarios, 551 study subjects (95%) had the personal belief that a brain-dead patient is dead, 497 (87%) believe that donor under a uDCD protocol is dead, and 331 (61%) believe that a donor under a cDCD protocol is dead. Regarding the scenario of uDCD, 248 study subjects (42%) were not satisfied with “cardiac death” but insisted on the need of a determination of “brain death” by neurological criteria (brain death). Regarding the scenario of cDCD, 194 study subjects (33,5%) believe that brain death must be demonstrated for this donor to be declared dead. Five hundred seventy-six (98%) study subjects considered it acceptable to take organs from a brain-dead donor; 430 (73%) considered it acceptable in the case of uDCD; and, 331 (59%) considered it acceptable in a protocol of cDCD.

Conclusion: Although brain death is still conceptually and practically problematic, a majority of professionals in all countries consider it as the gold standard for an individual to become an organ donor.

Brain-based criteria for diagnosing death: What does it mean for family members approached about organ donation? (Abstract #48)

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Despite attempts to separate the diagnosis of brain death from the process of organ donation and transplantation the introduc-

tion of the concept of brain death into legislation triggered a true revolution during the 1970s which was decisive in establishing transplantation programmes. However empirical work indicates that how individuals perceive death to have occurred is not always congruent with medico-legal definitions of death. The diagnosis of brain death is a difficult issue for bereaved family members, due in part to the questions that it raises about life and death: What is death? When does it happen? Does life linger on after a diagnosis of brain death? This presentation will discuss the answers to these questions from the perspective of bereaved family members in receipt of this diagnosis and the health professionals who aim to support them by drawing on results from both empirical work and literature, which suggests that for bereaved family members the diagnosis of brain stem death marks the beginning of the death process, whereas for health professionals it marks the end of the death process.

Discussing organ donation with next of kin

(Abstract #49)

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Introduction: There is increased demand for organs to treat patients with irreversible organ failure. Transplantation, however, continues to be restricted by lack of donor organs. Different strategies for improvements have been tested [1, 2]. It has been pointed out that anaesthesiologists and intensive care physicians are the ones most likely to be involved in the care of potential donors. At the same time focus for intensive care is the patient. When intensive care cannot save the patient however organ donation could be the result. One of the main questions regarding organ donation is when it is appropriate to discuss organ donation with the next of kin.

Material and methods: A questionnaire, presenting three different patients with severe brain damage, was sent to 1235 Anesthesiologists/Intensivists and 1000 persons from public in Sweden. The first patient was under intensive care just been declared brain dead. The second patient was in the ICU with ventilator treatment, dying. The third patient was not in the ICU, not ventilated. If organ donation should be possible this patient must be moved to the ICU, ventilator treatment initiated.

Results: 98% of the professionals and 78% of the public were prepared to discuss organ donation in the patient declared dead. In the dying patient under ICU treatment but not yet dead 65% of the professionals and 77% of the public accepted to discuss organ donation. Finally when the patient is dying but not in the ICU 25% of professionals and 66% of the public accepted to discuss organ donation.

Conclusion: Willingness to discuss organ donation in patients in futile situations is perhaps higher among the public than among professionals. It should however also be stressed that there might be a difference when answering a questionnaire compared to a real situation.

The role of intensive care unit doctors in organ donation procedures (Abstract #50)

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Summary: A survey was carried out among ICU doctors to determine their knowledge of and attitude towards brain death and organ donation procedures. The results show a positive attitude toward donation and good clinical knowledge of the issues. However, some results indicated a situation which is rather alarming and calls out for a better educational system for this group of professionals.

Objective: In order to increase the number of organ donors in Slovenia, which is a member of Eurotransplant, diagnostics of brain death and recognition of possible organ donors by intensive care unit (ICU) doctors play a key role.

Methods: A validated questionnaire using the Delphi method was sent to 80 intensive care unit doctors. The main purpose of the survey was firstly to evaluate how well doctors are acquainted with procedures for establishing brain death, and secondly how well they recognise potential donors.

Results: The number of returned questionnaires was 60 (75%). The analysis confirms a rather high level of clinical knowledge of the diagnostics of brain death and identification of potential donors. The overall attitude towards organ donation and the related procedures is very positive. However, results when doctors were asked specifically for the steps following deep apnoeic coma with enlarged pupils are no longer sufficiently precise. This is an alarming situation, since more than 25% of the ICU doctors do not know exactly how to proceed by means of the diagnostics.

In **conclusion:** our study shows that intensive care unit doctors who could have a positive effect on organ donor recognition would benefit from a special educational programme dealing with brain death diagnostics procedures and organ donation. This could increase the number of organ donations in Slovenia, where every donor counts.

Living kidney donor: Integral donor protection

(Abstract #51)

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Introduction: During last years, in spite of a high cadaver donor rate, the change in donor profile (43% >60 years old), has created the need to offer living kidney donation (LKD) to young recipients, preemptive transplantation, ABO incompatibility, or vascular complex retransplantation. In our centre LKD represents more than 35% of all donors. Additionally to the medical and surgical procedures LKD implies emotional, social and economical personal experiences that need to be evaluated to improve his protection.

Methods: A retrospective study of all Medical Charts of LKD from January 2006 to December 2008. All donors have been evaluated following the Multidisciplinary joint protocol of the hospital. Demographic, social and clinical characteristics of the donors are described and analyzed with the SPSS program.

Results: We reviewed 102 LKD (64,7% females), age 49,05 years old (24-75 years) with 55% of them >50 years. Our hospital is a National Reference Centre for LKD with 58% living in the Catalan region. All were related donors: siblings 36.3%, parents specially the mother 20.6%. For emotionally related the most common was wife 18.6% and husband 10.8%. The marital status of donors was 70.5% and 16.6% singles. The vast majority were actively working (62%) and 45% needed to ask for work leave to avoid difficulties. Economically, 12% have a mortgage with some economical difficulties, especially when LKD were between couples, specially in 44.1% that have people economically dependent.

Discussion: An independent role based in the Transplant Coordinator as the donor's advocate, favours an active donor protection to avoid social or economical risks to achieve the highest standards of care. The issue of the recognition of the value of living donation to achieve a protected situation requires a more wide participation of all responsible at a national level.

Predictors of quality of life in caregivers to cardiothoracic transplant recipients (Abstract #52)

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Current trends in medical treatment have resulted in shortened hospital stays, and extended life expectancies for chronically ill adults, thus placing increased responsibility for their care on the family. As hospitals rely more heavily on family caregivers (CGs) to assist with patient recovery, it is imperative to determine the effects that such burden may have on CGs. Previous research has focused on the burden of caregiving to adults whose health deteriorates over time. However, little attention has been paid to CGs of patients who undergo procedures to improve their health. We therefore examined such a population, CGs of transplant (TX) recipients, in order to determine the nature of change in CG quality of life (QOL) and psychosocial factors that may predict their QOL post-TX. Adult (aged 18+) CGs of 218 cardiothoracic TX recipients (lung n=120; heart n=98) participated in semi-structured interviews that included measures of demographics, social support, self image, coping, CG burden, and QOL at 2, 7 and 12 months post-TX. Mixed-model hierarchical analysis of variance (ANOVA) showed that QOL in CGs was high and remained so across the first year post-TX in emotional and so-

cial functioning. However, physical functioning [F(2,305)=5.8, $p<.01$] and bodily pain [F(2,336)=3.1, $p<.05$] worsened over the year. Linear regression analysis indicated that optimism was the most consistently important predictor of CG QOL across all domains. Greater caregiver burden predicted poorer QOL in physical and psychological domains. Higher family support predicted better QOL in social and psychological domains (adjusted R² range = 0.12 to 0.28, all $ps<.001$). There were no differences by type of TX recipients received. TX teams should identify CGs who may be at risk for QOL declines in order to maximize positive outcomes for the entire family after transplant.

Defining success in living donor kidney transplantation: Should patient reported outcome measures (PROMS) influence the limits of living donation? (Abstract #53)

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Aim: to establish individual donor and recipient criteria for success and evaluate whether these are met following transplantation. 18 donors and 17 recipients underwent structured interview, and completed the Hospital Anxiety and Depression Scale (HADS) and SF-36 Quality of Life questionnaire before, 3 months post-transplant and 1 year post-transplant. Both donors and recipients reported low thresholds for success, with minimum acceptable graft survival (1.68 and 4.3 years post-transplantation). Recipients were keen to avoid or escape dialysis (e.g. "It will be worthwhile if I have any time at all off dialysis"). Donors were happy to undergo transplantation even if the benefits were limited (e.g. "I would never feel the operation wasn't worthwhile because at least we would have tried."). 93% of donors stated that donation would be worthwhile even if the transplant failed within a month. Post-transplantation, all participants agreed their transplant was successful with expectations met or exceeded and numerous qualitative benefits reported. This was despite 55% of recipients experiencing clinical issues. 75% of donors report emotional benefits 3 months post-transplant and donor 1 year HADS scores were improved from pre-transplantation. Patient defined criteria for clinical success in living donor kidney transplantation differ vastly from actual rates, with reported minimum acceptable outcome surprisingly low. Patient perception of good outcome and acceptable risk may have clinical implications. Positive donor outcome suggests that the potential for emotional and psychological benefit (described by one donor as "the most fulfilling event of my life"), could influence decision making where donors are at higher clinical risk. This implies that patients may have a different understanding of the risks and benefits of transplantation compared to clinicians, with important consequences for decision making.

Composite risk scores and depression as predictors of mortality, clinical improvement, and other waiting-list outcomes: The waiting for a new heart study (Abstract # 54)

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Objective: To improve the prognosis of heart transplant (HTx) candidates, prediction of waiting-list outcomes is needed. The purpose of this study was to evaluate two composite risk scores (Heart Failure Survival Score; HFSS; German Transplant Society Score; GTSS), and depression as predictors of mortality and competing waiting-list outcomes [high-urgency transplantation (HU-HTx), elective transplantation, delisting due to clinical improvement] in newly listed HTx candidates.

Methods: A multi-center prospective study (17 hospitals in Germany and Austria) was conducted with 318 patients (18% female; aged 53±11) newly registered with Eurotransplant. Demographic variables and depression (HADS-D) were assessed by questionnaires. Variables to compute HFSS and GTSS, age, medications, and outcomes were provided by Eurotransplant.

Results: At 12 months, 33 patients died, 83 received urgent HTx, 30 elective HTx, and 17 were delisted due to improvement. Applying cause-specific Cox regressions, only the HFSS was significantly associated with 1-year mortality (HR=0.64 [0.43; 0.95], $P=0.029$). The GTSS was the strongest predictor of HU-HTx (HR=1.02 [1.01; 1.02], $P<0.001$) and was also related to clinical improvement (HR=0.99 [0.98; 1.00], $P=0.027$). Low depression contributed significantly to clinical improvement, even after adjusting for age and risk scores (HADS-D: HR=0.12 [0.02, 0.89], $P=0.039$).

Conclusions: These findings confirm the usefulness of composite risk scores for the prediction of waiting-list outcomes, validating both scores for their intended use. Depression among HTx candidates deserves further attention, as it appears to reduce the chance for clinical improvement independent of disease severity. Prediction of waiting-list outcomes may benefit from considering patients' psychological attributes in addition to their medical characteristics.

Depression and anxiety in living kidney donation: Evaluation of protagonists, donors and recipients (Abstract #55)

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Background: Psychosocial status of donors before and after transplantation has been an important concern in living donor kidney donation programs. Investigation of psychosocial issues of recipients is not as frequent. Since 2002 a protocol of psychosocial evaluation for donors and recipients was included in the living kidney donation program.

Aim: To evaluate psychopathologic dimensions in donors and recipients, before and after transplantation, as well as to compare two groups.

Methods: 34 recipients (mean age 37,34) and 45 donors (mean age 41,2) completed after a clinical interview, Zung Self-Rating Anxiety and Depression Scales, before and after surgery. Pearson Chi-Square, McNemar and Fisher's Test were applied.

Results: Total anxiety was positive in 35 recipients (100%) in pre transplant; 31 (88,6%) continued after transplant; cognitive and CNS dimensions had diminished in a statistically significant way ($p < 0.005$). 16 donors (35,6%) were positive for total anxiety before surgery; after, 30 (66,7%) were positive in total anxiety ($p > 0,005$). In all anxiety dimensions, recipients show higher symptomatology than donors, with statistically significant value ($p < 0.005$). Depression was absent or had light levels in the 35 (100%) recipients, before and after surgery. Moderate and severe depression was present in 7 donors (15,9%) before surgery, and in 10 (22,2%) after. Donors present more depressive symptoms than recipients in the two moments ($p < 0.005$). No other psychopathological diagnosis occurred from interviews.

Conclusions: Recipients don't present depressive symptoms before and after living donor transplantation and anxiety is important among this group. Surgery may have a positive impact in lowering anxiety. Donors present important depressive symptoms and also anxiety symptoms although in a less significant way than for recipients, before and after living kidney transplantation. Donors maintained psychopathologic symptoms after surgery. Donors must have psychosocial support before and after donation.

Beliefs and attitudes to medication among kidney transplanted in Sweden (Abstract #56)

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Background: Studies, mainly from the USA, show that non-adherence to medical regimen post kidney transplantation is not uncommon. Attitudes, experienced effect of treatment and social support are important factors for adherence to medication.

Objectives: To study beliefs and attitudes to medication in general as well as to immunosuppressive drugs specifically in a Swedish kidney transplant population. This has not previously been studied.

Methods: The instrument Beliefs about medicine questionnaire (BMQ) by Horne et al.1999, was included in a questionnaire that also contained 27 author constructed questions. In autumn 2008 the questionnaire was sent to all members in the Swedish kidney patient association i.e. 2800, 77.5% replied. Of those, 1114 were kidney transplanted with a functioning graft.

Results: 51% were male, 77% over 50 years, 39% working. Benefits of medication was greater than risks for most. The majority experienced good quality of life, social support, continuity and trust. The vast majority had different symptoms and side effects from immunosuppressive drugs. 12% considered immunosuppressive drugs disturbing in daily life, worried about becoming dependent or they were like a mystery. 6% forgot to take the immunosuppressive drugs often or rather often, 2% experienced the risks with immunosuppressive drugs greater than the benefits. A cluster analysis was also performed and clusters derived.

Conclusions: The responders who forget and experience risks greater than benefits may be nonadherent. A close follow-up and more education might be a solution. This study is made in a selected population. Beliefs and attitudes may differ in a younger population as well as in non-members of patient organizations. A questionnaire study among kidney transplanted non-members is planned. This questionnaire includes the BAASIS, an instrument measuring self-reported adherence. Preliminary results can hopefully be presented at the ELPAT conference.

Paired living kidney donation in the UK

(Abstract #57)

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A new legal framework for organ donation in the UK allowed paired living kidney donation from 2006. A national programme was agreed and initially only two-way exchanges were considered. Possible exchanges are prioritised according to scoring for each possible transplant based on: geographical

proximity to other pair, sensitisation level of recipient, HLA mismatch of transplant and, as a tie-breaker, donor-donor age difference. The first 'matching run' was possible in April 2007 (9 pairs), followed by three-monthly 'matching runs'. From April 2008, three-way exchanges were also considered. The programme has grown to 147 pairs listed in the October 2009 'matching run'. In total approximately 300 pairs have been listed. Almost 60% are HLA incompatible [HLAi] (including 13% also ABO incompatible [ABOi]), while the remainder are ABOi only. All 23 UK transplant centres are involved. 35% of patients have been identified for a transplant, although over half have not proceeded due to positive crossmatch results or late identification of donor issues or alternative transplants. In total, 41 paired donor transplants have been carried out in the UK by November 2009, including one three-way exchange. The pairs most likely to be transplanted are A donor / B recipient and vice-versa ABOi pairs, and HLAi pairs with only low or moderate levels of sensitisation. Last year paired donor transplants represented 1.8% of living kidney donor transplants in the UK. A protocol for domino paired donation has been agreed whereby altruistic non-directed (or Samaritan) donors will donate to the paired donation list rather than donating directly to the deceased donor (DD) list as currently. It was agreed, however, that if a high priority match was identified on the DD list, then the Samaritan donor kidney would still be allocated directly to that patient.

Review of ethical guidelines for the evaluation of living organ donors (Abstract #58)

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In 2005, the Multi Organ Transplant programme (MOT) of the Toronto General Hospital developed ethical guidelines for the evaluation of living organ donors (LDs) in order to establish substantive criteria and processes for LD evaluations. In 2007, nine new issues were reviewed to establish practice guidelines that reflect the values of staff, LDs and recipients. The issues were: unrelated non-directed LDs, unrelated directed LDs, use of unrelated non-directed donors (NDDs) in exchange programmes, foreign LDs, public solicitations, publicity, emergency transplants using LDs, the role of LDs' significant others and repeat LDs.

Objectives: To establish the programme's position on evaluation of potential LDs in nine new situations and the circumstances for acceptance.

Methods: Bioethics staff prepared and circulated to multidisciplinary staff a background document outlining each issue, possible responses, their potential consequences and the ethical values reflected by each response. Eight rounds were held where discussion on the issues was recorded and analyzed for agreement or disagreement about conditions for accepting LDs.

Results: Consensus emerged on issues including maintaining anonymity of NDDs for six months after donation and focus-

ing on beneficence rather than altruism among LDs. Staff disagreed on NDDs directing their organs to identified groups of recipients. Other recommendations included development of a protocol for the evaluation of LDs in emergency recipient situations and refusing donors where publicity is a primary reason for donation. Staff responses were presented to patients, the hospital community and external stakeholders for input, which was incorporated into practice guidelines.

Conclusions: This presentation will outline the review and outcomes of new clinical situations posing ethical challenges for staff of a transplant programme.

A retrospective analysis of living kidney donation at the Centre Hospitalier de l'Université de Montréal (CHUM): A rationale for paired-exchange programs (Abstract #59)

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Background: The shortage of organs, the excellent outcome of renal transplantation performed from living organ donors (LOD) and the low morbidity and mortality associated with living organ donation are incentives to increase renal transplantation from LOD.

Purpose: Before implementing an initiative to increase living organ donation it is important to better understand living organ donation practices in our transplant center.

Methods: We performed, from our electronic database, a retrospective analysis of all LOD who contacted our center from 01-01-2005 until 31-12-2008.

Results: During the study period, 189 individuals interested to donate a kidney to 151 recipients contacted our center. 58 (31%) potential donors were turned down. The main reasons were: medical contraindication (48%), ABO incompatibility or positive cross-match (40%), and donor age (5%). A total of 45 renal transplantations were performed from these living organ donors (24%). All donors were genetically or emotionally related to their recipients. In 51% of these transplantations, the donors and recipients were siblings. In 7/45 (16%) renal transplantations, the donor was O blood group whereas the recipient was a non O blood group.

Conclusion: Between January 2005 and December 2008, only 24% of all potential LOD effectively donated a kidney. A major reason for refusal was either ABO incompatibility or positive cross-match between donor and recipient. Moreover, 7 O blood group living organ donors could have been invited to participate in chain exchange if this kind of program would have been available in Canada, allowing 7 other potential renal transplantations to be performed. This supports an initiative to establish a paired-exchange and a list exchange program.

Integration of a Good Samaritan and a kidney exchange program (Abstract #60)

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Between January 2000 and July 2009, 132 individuals inquired about Good Samaritan kidney donation. These donors were willing to donate to genetically and emotionally unrelated patients. Some Good Samaritan donors (GSDs) wish to donate to a specific person, but most in an anonymous way to the wait list. Alternatively, they were offered to trigger a domino-paired procedure. In the latter program the GSD donates to the recipient of an incompatible couple provided the donor of that couple (domino-donor) donates to another couple or to a recipient on the wait list. In contrast to kidney-exchange donation where bilateral matching of couples is required, recipient and donor matching are unlinked in domino-paired donation. This facilitates matching for unsuccessful couples from the kidney-exchange program where blood type O prevails in recipients and is underrepresented in donors. Fifty-one GSDs donated their kidney (39%) and 35 domino-donors were involved. There were 29 domino procedures, 24 with one GSD and one domino-donor, 5 with more domino donors. In total 86 transplantations were performed. Donor and recipient blood type distribution in the couples limited allocation to wait list recipients with blood type non-O. The success rate of domino-paired donation is dependent on the composition of the pool of incompatible pairs, but it offers extra opportunities for difficult to match pairs that were unsuccessful in the kidney-exchange program.

Unbalanced kidney paired exchange (Abstract #61)

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Background: Kidney transplants with a living donor have excellent graft survival. To optimize transplants with a living donor, incompatible couples may participate in a kidney exchange. However, also compatible couples can be enrolled in this program by a so called unbalanced kidney exchange procedure. One donation can then result in multiple transplant procedures. We wondered if Dutch compatible pairs were willing to donate in a kidney exchange program.

Methods: We interviewed compatible couples who visit our out-patients clinic. We asked them about their willingness to help incompatible couples and about their motivation. We collected data e.g. gender, age, relationship, therapy and blood types.

Results: Most related donor-recipient pairs were not prepared to change from a directed to non-directed procedure. Howev-

er, one couple was very enthusiastic; they were unrelated, men in their middle thirties. The recipient was a 39 year old man, not on dialysis, not-immunized and with blood type A. The donor was a 33 year old man with blood type O. They participated in the match procedure of July 2009. The computer selected them in a match combination of four pairs. Surgical procedures took place in the beginning of November in collaboration with 4 hospitals. All recipients and donors are doing well. In conclusion, the strategy of allowing compatible pairs to participate in a kidney exchange program is a logical consequence of our kidney exchange program. The motivation of unbalanced kidney exchange donors is in part compatible to that of true Samaritan donors. They can help anonymous patients as well as their own directed recipient.

An organ donation lesson in primary school; teacher's opinions (Abstract #62)

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Introduction: Most families do not communicate freely about organ donation despite children being confronted with the topic through the media. It is important to provide children with information to help start home discussions. One way of reaching children and their parents is through educational programmes at school. The goal of this study: gain insight into the opinions and wishes of primary school teachers with regard to a lesson about organ and tissue donation. The main research question explored the social support in primary schools to develop a lesson about organ and tissue donation, and the best age to hold it.

Methods: Explorative qualitative and quantitative study of the opinions of head teachers. Interviews with key informants and a questionnaire sent to all 7452 primary schools in the Netherlands.

Results: The response rate was 1582 (23.6 %). Most teachers (80%) have no experience with lesson on organ donation in school, 72% would discuss the subject in school, 28% consider it a subject for home discussion. 10 years and up is the best age to start these lessons. 75% of the respondents reported having adequate knowledge but not enough teaching material on the subject. It is important to provide unbiased information. The respondents also advise incorporating a lesson on organ donation and transplantation into a biology lesson or social education class. Lessons can be instructive or can help children to form their own opinion.

Conclusion: The topic of organ donation is a subject that can be discussed last two years of primary school. School can play a role in the social responsibility to discuss organ donation and can then bridge the gap in information for youngsters so that they can start a discussion at home.

Just because we can, should we?

An ethical approach to temporary alternatives as a bridge to paediatric transplant (Abstract #63)

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Our Hospital, is one of three centres in Spain performing paediatric heart and lung transplants. Shortage of paediatric organs compared with adults obliges us to look for new, albeit temporary, strategies. Long waiting lists and progressive patient deterioration leads us to, occasionally, utilise temporary alternatives such as biventricular assistance (Berlin Heart-BH) with or without previous ECMO (Extra Corporeal Membrane Oxygenation) for cardiac and ECMO for lung transplants. However, even the final solution (transplant) is in reality temporary, as all paediatric transplants will require re-transplantation.

Results: Here we present our pioneering experience in mechanical device use in transplantation (2007-09). We have used BH in 3 patients: One died due to coagulation disturbances and became an organ donor. Two are still alive after cardiac transplant. We have used ECMO as a bridge to lung transplant in two patients, one is alive and the other died after transplant.

Discussion: The use of BH and ECMO, has proved to be effective in extending WL time until transplantation. Nevertheless, the use of this technique must be restricted to those cases where successful transplantation is the expected outcome, but never as a compassionate treatment. It is imperative that we make humane decisions based on ethical, as well as clinical, criteria. Just because we can, should we?

As paediatric patients are legally unable to make decisions and their parents and physicians are emotionally involved, limits need to be set and Advanced Care Planning discussed before arriving at theatre.

Conclusions: Stricter indications on life-sustaining techniques must be applied in the field of paediatric transplant. Common policies must be drawn up if we are to avoid futile suffering.

Current situation of non heart beating donation and transplantation in member states of the Council of Europe (Abstract #64)

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Introduction: Shortage of organs for transplantation has led to a renewed interest on non heart beating donation (NHBD). The aim of this project was to describe the current situation of NHBD in Member States of the Council of Europe (CoE).

Methods: A questionnaire was designed, agreed upon and distributed between representatives of Member States of the CoE at the CD-P-TO on the characteristics of NHBD programmes and related activity and on the short-term results of recipients transplanted from NHBD.

Results: Twenty six countries returned the questionnaire: 9 countries confirmed any NHBD activity, 10 were balancing the initiation of a programme and 7 were not. For countries with NHBD, non touch period ranged from 5 to 20 minutes. Countries with a higher NHBD activity were Belgium, the Netherlands and the UK (mainly controlled) and Spain (mainly uncontrolled). The number of organs recovered per donor (ORPD) as well as organs transplanted increased for NHBD along the years. During 2000-2008, 4,907 organs were transplanted from NHBD in the CoE (4,164 kidneys, 505 livers, 157 lungs and 81 pancreas). Short-term outcomes of 2,992 kidney recipients (controlled versus uncontrolled) from NHBD were analyzed, taking into account: primary non function, delayed graft function and 1 year graft survival.

Conclusions: NHBD is increasingly accepted and used in Europe, but still limited to a few countries. Although it represents a valuable source of organs for transplantation, it might negatively impact HBD activity in some countries. The degree of utilization of NHBD and ORPD and OTPD is lower as compared to HBD. Short-term results of NHBD are promising with some differences between recipients transplanted from controlled vs. uncontrolled NHBD. Further analysis will be required in this area.

Index linked organs for transplants (Abstract #65)

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The shortage of organs available for transplantation makes it likely that it will not always be possible to find an 'ideal' donor. Some donor organs are better than others. By using 'expanded criteria' and 'marginal' donors and accepting organs from those who might previously have been considered unsuitable donors, meaningful expansion of both the living and deceased donor pool has been made possible. Their acceptance and use has come to the fore along with a heightened awareness of the ever increasing shortfall of organs available for transplantation. This paper examines strategies that have been put in place in order to maximise the donor pool. It explores the legitimacy of using both 'expanded criteria' and 'marginal' donors, in order to help overcome the shortfall of organs available for transplantation, and challenges the arbitrariness and terminology that has thus far been utilised to evaluate the outcome of such transplants. Published empirical evidence is reviewed and outcomes assessed. It is argued that while these strategies may at first appear to be a straightforward solution to the problem of organ shortage, their implementation is not without ethical controversy and may even be a counter-intuitive solution to the problem of organ shortage. In the absence of real alternatives, it is argued that continuing to support their use is legitimate. It is proposed that the term 'index linked organs for transplants' may be a more meaningful way in which to capture the risks associated with the use and allocation of organs.

Extended criteria liver donation and transplant recipient consent: the European experience

(Abstract #66)

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ELPAT1 coordinated the distribution of an electronic questionnaire. Completed questionnaires were received from 30 centres in 13 countries. Twenty-eight centres accepted ECD liver donors. The percent estimate of ECD livers was 32%. The criteria for defining a liver donor as ECD were: steatosis in 24 centres (85%), age up to 80 years in 23 centres (82%), serum sodium >165 mmol/l in 17 centres (60%), ICU stay with ventilation > 7 days in 16 centres (57%), SGOT >90U/l in 12 centres (42%), BMI >30 in 10 centres (35%), SGPT >105U/l in 10 centres (35%), serum bilirubin > 3mg/dl in 10 centres (35%) and other criteria in 13 centres (46%). 23 centres informed the transplant candidate of the ECD status of the donor: 10 centres (43%) when the patient registered for transplantation, 3 centres (14%) when an ECD liver became available and 10 centres (43%) on both occasions above. 10 centres required the liver transplant candidate to sign a special consent form. Ten centres informed the potential recipient of the donor's serology. Only 3 centres informed the potential recipient of any 'high risk' behaviour of the donor. Potential recipients of ECD livers were: patients with previous cancer (21 centres), HBV+ patients (14 centres), HCV+ patients (12 centres), HIV+ patients (10 centres), critically ill patients (10 centres), patients > 65 years of age (7 centres), patients performing high risk sex practices (7 centres), drug users (5 centres), and patients < 65 years of age (1 centre). The majority of centres discussed with potential recipients that they may/will receive an ECD liver, usually when they were registered for transplant and were required to sign a special informed consent form. Some centres also informed the transplant candidate when an ECD liver became available.
ELPAT1 (Ethical, Legal and Psychological Aspects of Organ Transplantation)

Even actual living kidney donors are not all registered in the donor register (Abstract #67)

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In the Netherlands, individuals aged 12 years and older can register in the 'Donorregister'. Within the Dutch population, 5.327.835 citizens were registered up to and including 2008. That is, 37.7% of the Dutch population aged 12 years and older were registered by then. More women than men were registered (41.5% vs. 35.1%). We wondered whether living kidney donors had higher registration rates and whether the non-registered donors still registered after donation. When living kidney donors come to our center for the first time, they come in for screening. Three months after donation they have an evaluation interview. At both times they are asked whether they are registered or not. In total, 405 donors donated their kidney

from January 2004 until December 2008. We are analyzing their screening and evaluation results. 46.8% of the living kidney donors were registered in the Donorregister before donation. Only two non-registered donors still registered after donation. Proportionately more men than women were registered (55.2% vs. 41.7%). Compared to the Dutch population, more living kidney donors are registered in the Donorregister. Actual donation did not influence their registration. Most living donors are related, either blood related or through partnership, to the person they donate their kidney to. They are confronted with someone suffering from kidney failure who is in need for transplantation. Therefore they are more likely to recognize the importance of registration. In our sample, the sex ratio is different from the one seen in the Dutch population. While women in our sample were not more likely to be registered, men remarkably were. This finding is contrary to a previous study as well. Still, more than 50% of the actual donors were not registered. Apparently their altruism is confined to their inner circle.

One donor, two Samaritan transplantations

(Abstract #68)

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Purpose: Imagine a 'Samaritan' living donor, who has donated one of his kidneys to an anonymous patient. He again contacts the transplantation centre in order to donate part of his liver. The Centre startled by this idea, refers to the regular screening procedure. Suppose this potential living liver donor does not suffer from any psychiatric disorders nor is any psychological condition found that obstructs decision making or makes the wish to donate flawed. The patient is well-informed and well able to decide. Should the transplantation centre accept the offer?

Methods: We feel that a donor's wish should not be followed in all cases, even though this wish is a clear expression of free will. However, a refusal must be based on sound moral reasons (and should not be unduly paternalistic). It is unclear what reasons these might be. We outline the most common arguments for refusal and show which arguments, if any at all, are most promising.

Results: Arguments for non-acceptance can refer to various circumstances, e.g. transplantation risks, a doctor's conscience, the absence of a clear donor-recipient relationship, the undesirability of a two-fold donation in societal respect, or a fundamental professional norm. A comparative analysis to other medical practices helps to understand the relevance and substance of this latter, professional norm.

Conclusion: If we see transplantation practices as medicine, medical professional norms provide common ground. Given that the donor's well being should be given first priority, only good reasons and particular circumstances may provide exceptions to this rule. The ultimate question is whether the sheer wish of a potential donor provides us with sufficient reasons, given the risks of transplantation and a lacking donor-recipient relationship. When the answer is no, we should carefully develop more substantial criteria for donor refusal.

Psychosocial, educational and economic factors in living unrelated kidney donation: A single Brazilian center experience (Abstract #69)

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Background: The increased need for organs has led to greater acceptance of living kidney donation. This broadening of the donor pool introduces challenges to the evaluation of such donors. Questions are raised regarding the obligation of an evaluator to explore the depth of the donor's intentions. There are concerns about potential coercion of vulnerable individuals in a country where the income inequality rates are high.

Method: We prospectively applied a questionnaire on economic, educational and psychosocial aspects of 114 potential donors in the period of January 2008 to October 2009 in a Brazilian single center. They were divided in 2 groups: Living Related Donors (LRD; n= 73) and Living Unrelated Donors (LURD; n=41). Groups were categorized based on their relationship with the recipient.

Results: These groups were similar in female gender (LRD 57%; LURD 44%; p=0.24) and age (LRD 41.38±10.7; LURD 41.85±9.2 years; p=0.81) The groups were similar in religious belief (catholic: LURD 61%; LRD 43% p=0.07), non-home-owners (LURD 50.2%; LRD 41.67%; p=0.31), housing type (house: LURD 85%; LRD 87%; p=0.77), married marital status (LURD 48.8%; LRD 50%; p=0.074) and public transport as the major transportation (LURD 51.2%; LRD 62.5%; p=0.32). A high school education was observed in 56.9% of the LRD group and 46.3% in the LURD group (p=0.82). The family income was also similar in both groups (LURD 4.08±2.33; LRD 4.68±3.06 Brazilian minimum wage; p=0.30). The strongest motives to become a donor were: "wish to help" and "identification with the recipient" in both groups.

Conclusions: We couldn't find any difference in psychosocial, educational and economic characteristics in the unrelated kidney donation population when compared to the related donors candidates. Two major ethics principles were observed in both groups: autonomy and lack of coercion.

Psychosocial outcomes of Good Samaritan donors compared to a matched sample of traditional donors (Abstract #70)

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Aim: Relatively little is known about Good Samaritan Donors (GSDs), individuals with no relationship (genetic or emotional) to the transplant recipient. The aim of this ongoing study is to examine the psychosocial outcomes of GSDs compared to a matched group of more Traditional Donors (TDs).

Methods: All GSDs (n=36) at two U.S. transplant centers were mailed a packet containing the SF-36 Health Survey, the Living Donation Expectancies Questionnaire (LDEQ), and additional questions about the perceived benefits and adverse effects of donation. In addition, a matched (age, sex, and yr of donation) group of TDs (n=72) were mailed a similar questionnaire packet.

Preliminary Results: This is an ongoing study and findings will be updated at the time of the presentation. Based on a 60% response rate to date (24 GSDs, 41 TDs), there are no statistically significant differences between GSDs and TDs on quality of life indices, perceived benefits of living donation, or other psychosocial parameters measured (all p's>0.05). However, relative to GSDs, TDs have reported higher quid pro quo expectations (p<0.01) and more perceived health consequences (p<0.05) since donating a kidney. Both GSDs and TDs reported similarly high donation satisfaction and high decision stability.

Conclusion: Relative to a matched group of TDs, GSDs are not experiencing any decrements in quality of life or negative psychosocial issues secondary to living donation.

The effect of the request for organ donation on grieving relatives (Abstract #71)

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ICU staff often assume that a request for organ donation increases the emotional agony for grieving relatives. As a result, attending physicians and nursing staff often shy away from raising the issue of organ donation with relatives in the acute bedside bereavement situation. Our research suggests that this perception is largely mistaken. In a survey among 279 donor relatives conducted in Germany from 2004 to 2008, 119 (42,7 percent) of respondents indicate that they in fact expected a request for donation once the lack of brain activity was mentioned by attending physicians. 38 of them (13,6 percent) even raised the issue themselves. 223 (79,9 percent) further said that the request for (and their subsequent consent to) organ donation did not add to their grief at all.

Their sadness, they indicated, was due to the sudden loss of a beloved relative and not caused or deepened in any way by the subsequent organ donation. What is more, a remarkable 106 (38 percent) of respondents felt organ donation helped them deal with their grief. Remarks like: „His death was not in vain, he could at least still help others.“ or „I find comfort knowing that a part of her lives on in another person,“ were typical among respondents who felt this way.

Summary: The results of our survey among donor relatives suggests that they increasingly see the request for organ donation as a normal occurrence when the deceased are brain dead. Attending physicians and nursing staff should thus be encouraged to overcome their reluctance to raise the issue of organ donation with relatives in the acute bedside bereavement situation.

Deceased donation, culture and the objectivity of death (Abstract #72)

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Death is everywhere a matter of moral definition. The idea of ‘deceased donation’ underlines the inherently social nature of death and the return to NHBDS has raised new moral concerns. This paper addresses some of these concerns by placing death in a broader cultural and cross-cultural context. In the medicalised parts of Europe, scientific criteria have been introduced and death claimed as an event. This paper suggests, however, that death is still in these circumstances a moral process whatever the scientific criteria used in its declaration. The invention of ‘objectivity’ in Europe introduced epistemic virtue in decision-making, with an array of tests and timings and standardised technologies, but brain-deaths and cardio-respiratory death have still jostled each other in a way that some might see as worrying. This paper argues for recognition of the cultural moralities involved – and at the same time makes the case for a definitive and socially robust objectivity where it is badly needed.

Depression, non-compliance, and survival in heart transplant candidates (Abstract #73)

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Purpose: Non-compliance is associated with increased mortality and morbidity in chronic heart failure (HF) patients, heart transplant candidates. Several psychosocial factors are considered risk factors of non-compliance. They include persistent anxiety and depressive symptoms, alcohol and nicotine abuse, lack of social support, low socio-economic status, presence of the organic psychosyndrome, and maladaptation. To evaluate psychosocial parameters and survival related to compliance in patients (pts) with advanced HF.

Methods: 412 pts (360 males) admitted to HF centre, mean age 50.0±10.7 years, were included. In 60%, primary cause of HF was cardiomyopathy. 52% of pts were in functional class NYHA III, 15% in NYHA IV. Mean left ventricular ejection fraction was 21.0±4.5%. Median survival of all pts was 48.0±5.4 months (CI=37.4-58.6). We used Beck Depression Inventory (BDI) to assess depression, Spielberger Questionnaire of Anxiety (STAI) anxiety, Visual Analogue Scale (VAS) for socioeconomic status, and GTO and TMBM scores for organicity. Survival was evaluated using LogRank test.

Results: Mean BDI score of the whole group was 10.6±6.3. Depression was present in 214 (52%) of pts. Mean STAI score was 33.2. Anxiety was present in 53% of pts. 13% of pts had a lack of social support and 14% had low socio-economic status. 20% of pts were smokers and/or alcohol drinkers. Organic psychosyndrome was present in 14% of pts. Any degree of depression was significantly associated with worsened survival (LogRank=7.2, p=0.007). Although pts with high anxiety

(LogRank=0.11, p=0.74), low socio-economic status (LogRank=2.02, p=0.16), lack of social support (LogRank=0.53, p=0.47), alcohol and nicotine abuses (LogRank=0.05, p=0.83), presence of organicity (LogRank=0.05, p=0.82) had shorter survival, differences were not significant.

Conclusion: Prevalence of depression and anxiety among HF patients is high. Depression is the only psychosocial parameter of compliance that significantly predicts shorter survival of heart failure patients.

Which predictors of self-rated health in patients after kidney transplantation are important?

(Abstract #74)

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Purpose: Only a few studies into self-rated health (SRH) in patients after kidney transplantation (KT) have been performed using a longitudinal design. The aim of this study was to analyze the relationship between the graft function, psychological factors and SRH over time.

Methods: 63 patients (mean age 48±12 years, male 61%) were examined in the 3rd month (T1) and 12th month (T2) after KT. Sociodemographic data and data on glomerular function (Cockcroft-Gault equation) were collected. Patients completed the SF-36 questionnaire measuring SRH and the GHQ-28 measuring anxiety and depression. Linear regression was used to identify predictors of SRH at T2. Age, gender, SRH at T1, change in glomerular function and change in degrees of anxiety and depression were also set as independent variables.

Results: SRH and glomerular function slightly improved over time; on the other hand anxiety and depression slightly decreased over time. The regression model consisting of SRH at T1 ($\beta=0.578$, 95%CI 0.359;0.698, p<0.001), the change in glomerular function between T2 and T1 ($\beta=-0.299$, 95%CI 13.533;52.390, p<0.001) and the change in degree of anxiety between T2 and T1 ($\beta=-0.195$, 95%CI -36.587;-1.693, p<0.05) explained 55.4% of variance in SRH at T2.

Conclusions: SRH is significantly associated with a change in glomerular function as well as with a change in the degree of anxiety over time. Improvement of the graft function and relief from anxiety are connected with improvement in the well-being of patients after successful kidney transplantation over time. As a result, physical and psychological domains have consequences for patients' self-rated health; however, in our study the change in glomerular function over time showed slightly more involvement in self-rated health than the change in degree of anxiety over time.

Psychosocial determinants of quality of life 6 months after liver transplant: A longitudinal prospective study (Abstract #75)

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The aim of this study was to investigate the psychosocial determinants of quality of life 6 months after liver transplant. We studied a sample (n=60) of liver transplant candidates that attended outpatient clinics of the Transplant Unit Of the Hospital Curry Cabral in Lisbon, between March 2006 and March 2007, after informed agreement. The instruments used were MOS SF-36 (Quality of Life), HADS (anxiety and depression), NEO-FFI (personality traits) and BriefCOPE (coping strategies). Statistics were determined by SPSS 13.0 for Windows. As results, several psychosocial predictors were found using multiple regression. The physical component of quality of life 6 months after transplant was determined by coping strategies and physical quality of life in pre transplant period. The mental component of quality of life 6 months after transplant was determined by diagnosed depression in the transplant period and patients clinic diagnosis. The results suggest that coping strategies and depression in pre transplant period are important quality of life determinants 6 months after liver transplant. Further studies are needed to identify in what way continued psychotherapeutical interventions starting in an initial phase can improve mental and physical component of quality of life in patients at risk, such as those that have high indicators of depression and those that choose non-adaptive coping strategies in pre transplant period.

Psychological consequences of organ transplantation: A prospective study among liver transplant recipients (Abstract #76)

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Introduction: As clinical outcomes and survival of organ transplantation improve, outcomes as health related quality of life and psychosocial outcomes become increasingly important targets of evaluation. Generally, health related quality of life improves after transplantation, but meta-analysis shows that psychological health does not improve significantly after transplantation (1). Recent research shows that a subset of transplant recipients experience distress even a few years after transplantation (2,3), which may lead to poorer psychological health and poorer adjustment to life. To understand the impact of transplantation on peoples' lives a trauma model can be informative. A transplantation is a major life event and embodies elements of a traumatic experience: it is outside the usual human experience and involves multiple stressors. This experience

can have negative and positive consequences: posttraumatic stress or posttraumatic growth. Knowledge about posttraumatic stress and posttraumatic growth can contribute to a better understanding of psychological adjustment to transplantation.

Objective: To gain insight into prevalence, associated factors and impact on quality of life and psychological health of posttraumatic growth and posttraumatic stress in Dutch liver transplant recipients. **Design:** A prospective study in which 87 adult liver transplant recipients will be followed during the period they are enlisted on the waiting list till two years after transplantation. Data will be assessed by questionnaire before transplantation and 3, 6, 12 and 24 months after transplantation and by medical record review. All adult transplant candidates enlisted for a liver transplant between October 2009 and September 2012 and treated at the University Medical Centre Groningen are eligible to participate in the study.

Results: Inclusion started in October 2009, so far over 20 patients are included.

References: 1. Bravata DM et al, 1999.

2. Goetzmann L et al, 2008. 3. Dew MA et al, 2005.

Predictors of the willingness to consider living donor kidney transplantation in haemodialysis patients (Abstract #77)

Daniela Mladenovska psychologist, Aleksandar Sikole PhD, Vili Amitov MD, Lada Trajceska MD, Gjulsen Selim MD, Olivera Stojceva PhD, Ninoslav Ivanovski PhD University Clinic of Nephrology, Skopje, Macedonia

Background: Despite the confirmed benefit of living donor kidney transplantation (LDKT), many patients hesitate to pursue this treatment option. The possible reasons are: donor's health and wellbeing, fear of unknown, feeling of guilt, etc. The objective of the study was to examine predictors of willingness to consider LDKT in haemodialysis (HD) patients in our center.

Methods: One hundred and eighty HD patients were approached to participate in this cross-sectional study. Patients older than 70 years, those with psychiatric disorders and comorbid diseases were excluded, leaving 142 patients eligible. The psychosocial questionnaire was completed by 132 subjects. Multivariate statistical analysis was conducted to analyze sociodemographic factors, perceived health status, perceptions and information about living donation as the predictors of willingness to consider LDKT.

Results: Of 132 participants, 57 (43%) were willing to accept LDKT, 14 (10%) were unsure and 61 (46%) were unwilling. In univariate analysis, the willingness correlated with a lower perceived risk for the donor, higher perceived benefit, better perceived current health status, perception that it is appropriate to ask a family member to donate, and higher level of information received about LDKT (p<0.001, respectively for all the variables). Older age and lower education correlated with a lower acceptance (p=0.001 and p=0.003, respectively). No significant effects were seen for sex, ethnicity, socio-economic, marital and living status, dialysis vintage and spirituality. In multivariate analysis, willingness to accept LDKT independ-

ently and positively correlated with higher perceived benefit ($p < 0.001$), lower risk perception ($p = 0.02$) and with more favorable perception of the current health status ($p < 0.001$). In conclusion, the authors recommend the appropriate educational interventions for the patients and the potential donors.

Group education of families and friends of CKD patients: The impact on living kidney donation

(Abstract #78)

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Introduction: Previous studies have shown that comprehensive and timely education about future consequences of renal disease is highly appreciated by CKD patients, their families/friends. Most patients perceive dialysis as their first therapeutic option when ESRD develops, despite overwhelming evidence that renal transplantation has superior outcome. Living kidney donation is frequently overlooked and patients are often reluctant to discuss this option with relatives and friends. We hypothesized that timely education of family/friends of patients with ESRD improves understanding, prevents misconceptions about future health status, and stimulates discussion about living kidney donation.

Methods: We performed a pilot study in 10 consecutive families of patients (7M/3F, 53.8 9.3 yrs) with progressive renal failure. We organized a gathering of all relatives and friends of a patient, preferably at the patient's home, and engaged in an itemized discussion about current and future health status of the patient, and possible treatment modalities. The discussions were led by an hospital social worker. Data of patient survival on dialysis, after LKD and deceased donor transplantation were given. Risks and benefits of living kidney donation for both recipient and donor were presented. On average 5 individuals attended per patient.

Results: Participating patients, relatives and families unanimously welcomed the approach of family counseling. All felt improved mutual understanding and bonding within the family. All patients were relieved after the health care provider initiated discussion about living kidney donation. After a period of 3 months, potential kidney donors showed up in 10/10 families.

Conclusion: Group education of families, relatives and friends of patients with CKD leads to a better informed and understanding family, and to a improved family bonding. Relatives consider living kidney donation, thereby offering great potential benefit to patients.

Three-part modelling of the decision to accept a live donation: Certainty, refusal, questioning

(Abstract #79)

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Background: Living kidney donation implies important psychosocial issues for both donor and recipient. While much attention has been paid to donors and their motivation, less is understood in terms of the decision to accept a live donation.

Objective: Guided by Mauss' 3-part theory (giving, receiving, giving back) the present study examines how kidney recipients discuss living donation.

Methods: Secondary data from interviews conducted by a transplant psychologist with thirteen recipients of a live donation were analyzed. Cases analyzed were diversified in terms of gender (5 women and 8 men), age (aged 29 to 68), and relationship to donor. Coding was performed by two coders using a mixed grid approach. Use of N*Vivo (ver 8) permitted strategic analyses using: 1) matrices and 2) modeling.

Results: All offers to give were described by the recipient as spontaneous and voluntary, never solicited. While all offers were accepted, two patterns of attitudes toward accepting emerged:

1) prompt acceptance based on certainty; 2) acceptance preceded by a period of questioning. Those who engaged in initial questioning were also those who mentioned negative aspects of donation and transplantation (i.e., concerns for donor's health, fear of rejection). While the theme of giving back was less often mentioned, recipients described giving back in terms of a closer relationship with the donor or increased prosocial behavior toward others in general. Others wondered how to give back.

Conclusion: Accepting a live donation is a complex issue that needs to be discussed in depth prior to transplantation. Results from the present study highlight important points that may be discussed in psychosocial interviews with intended recipients prior to donation to help them prepare for the multiple steps involved in the process, including questioning regarding giving back post-donation.

Living or deceased kidney transplants? Experiences of the donation process among kidney recipients in middle Sweden (Abstract #80)

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Aim: The aim of the study was to explore how patients with end-stage renal disease (ESRD) recruited living-kidney donors and what factors were related to whether the actual donor of the recipients was living or deceased.

Method: A questionnaire constructed for this study was sent to 246 adult kidney recipients who had been transplanted at the Karolinska University Hospital in Stockholm, Sweden from Jan 2004 to July 2008. The response rate was 87%.

Results: The following eight conditions were identified as problem areas:

- The living-kidney recipients perceived the evaluation period as too long.
- Though they had a living donor, most living-donor recipients had to undergo dialysis for a relatively long period.
- The patients perceived requesting a donation as difficult; support for this task was missing.
- Deceased-donor recipients were least satisfied with the support offered in finding a donor.
- The suitability of donors was obscure to the patients, which might lead to potential donors being excluded for non-medically relevant reasons.
- The patients perceived fear as the main reason to refuse donation; information to possible donors might be incomplete.
- Relatively many recipients thought that the donors were abandoned by healthcare after nephrectomy.
- Older patients and singles were least likely to get a living donor.

Conclusions: The very high response rate indicates that the kidney recipients were eager to announce their views on organ donation and transplantation. Much remains to be done to facilitate the donation process for ESRD-patients; the problem areas outlined above should be scrutinized and improved. Checking these areas can be used in quality control when analysing living kidney donation at local and national levels.

Living kidney donors who regret donation

(Abstract #81)

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The question, whether living kidney donors remain satisfied about donation or regret it afterwards, is discussed controversially. The head of a patient organisation in Switzerland made the statement on the radio, that “most donors regret kidney donation later on”. In contrast I. Fehrman-Ekholm published in 2000 an analysis showing that “donors don’t regret” (Transplantation 2000, 69: 2067- 71). In order to analyze the situation in Switzerland in a systematic way, we included this question in the regular donor-follow up of SOL-DHR from 2002 on. SOL-DHR is registering and following life-long all living kidney donors in Switzerland prospectively and longitudinally since April 1993. Till October 2009 a total of 1190 kidney donors are registered and followed.

Method: From July 2002 on all kidney donors received in addition to the former questionnaire a SF-8-test including the following additional question: “Would you donate a kidney again if you still had two kidneys?” Possible answer: YES/NO/DON’T Know. Option 4 was NO ANSWER. We now analyze 1239 SF-8 questionnaires filled out by 847 living kidney donors not earlier than 9 months after nephrectomy but up to 16 years after donation. Since the questionnaire is sent every 5 years after donation, 694 donors have sent more than one questionnaire.

Results: Majority of donors (775 out of 847=91.5%) would donate a kidney again despite all experience made (post-oper-

ative pain, trouble with health insurance etc). Even a donor who almost died due to pulmonary embolism (necessitating thoracotomy, intensive care unit etc) wrote us to donate again. 28 donors (3.3%), however, would not donate again and regret donation. 4 other donors (0.5%) wrote that they don’t know whether they would do it again. Another 40 donors (4.7%) filled out the SF-8 form but left the specific question about donation unanswered (empty space). 22 of the 28 donors who regret donation are females (79%), clearly more than the ratio of females in the whole SOL-DHR (66% donors are females). The reason for regretting donation is in descending order: 1) Medical errors or inadequate psychological handling done by the transplant team (8/28=29%). Most were avoidable. 2) Long-lasting pain resulting from nephrectomy in 6 cases (21%). 3) Troubled relation with the kidney recipient after donation in 5 cases (18%); 4) Poor outcome of the transplant in 4 cases (14%) unavoidable. 5) Severe surgical complication during nephrectomy in 2 cases (7%); 6) Partial inability to work in the former job following nephrectomy (2 cases or 7%). 7) Unclear 1 case.

Conclusion: The vast majority of donors do not regret living kidney donation (91.5%). A small minority, however, does regret it. Analysing this small cohort more closely reveals that the reasons to regret would have been avoidable, a lesson to be learned.

Favourable psychological outcomes among Good Samaritan donors: A follow-up study

(Abstract #82)

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Objective: In a growing number of transplant centres Good Samaritan donors are accepted to donate anonymously to a genetically and emotionally unrelated person. The main aim of this study was to investigate the impact of living kidney donation on the psychological well-being of Good Samaritan donors.

Methods: Twenty-four Good Samaritan donors, who had donated between 2000 and 2008, participated in two separate semistructured interviews with a nurse and psychologist (96% response rate). Lifetime mental health history, pre and post donation psychological complaints, donation satisfaction and impact of the donation on well-being were measured.

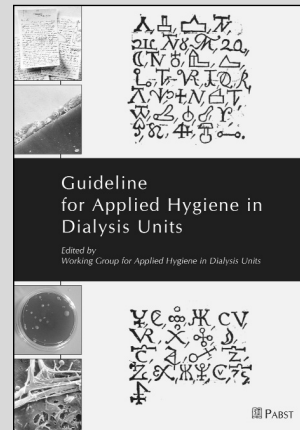
Results: Good Samaritan donors reported a considerable positive impact of donation on psychological well-being while the negative impact was almost negligible. Donors were exceedingly satisfied with the donation process and some personal benefits were also documented. Almost all would donate again if possible. Despite a lifetime history with a psychiatric diagnosis in almost half of the donors, psychological complaints both prior and subsequent to donation were comparable with

average norm scores. Factors indicating vulnerability for poorer outcomes after donation include pre-existing psychological problems and negative reactions from the social environment.

Conclusion: We conclude that among adequately screened and supervised donors, Good Samaritan donation does not appear to be detrimental to psychological well-being. When risk factors for poorer outcomes are identified extra supervision is recommended. Good Samaritan donors can make an important contribution to shortening the waiting list for transplantation, particularly via the Domino-paired kidney exchange programme.

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Abstracts

Poster presentations

Identification of the victims of trafficking in human beings (THB) with the purpose of organ retrieval and facilitation of the access to the medical and social assistance (Abstract P01)

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There is no specific methodology to identify victims of organ retrieval (VOR). We are presenting the project which aim is to help to elaborate the possible methodology to identify and assist the VOR.

Identified need:

- To elaborate and implement a specific methodology for the identification of VOR
- To facilitate the access of the victims to the medical and social assistance
- To sensitize the inhabitants from the participating localities regarding the phenomenon of THB

Proposed activities:

- Activities with the purpose of the identification of the VOR and facilitation of the access to the medical and social assistance
- Elaboration of the methodological scheme to identify the VOR
- Round tables with family doctors and social assistants from the localities where VOR were identified
- Individual work with the VOR
- Medical and social assistance for the VOR
- Campaigns to sensitize the society concerning the phenomenon of THB
- Informing seminars for the youth regarding the THB and the prevention of the organ trafficking
- Elaboration and outspreading of the informative materials regarding the VOR

Expected results:

- Identification of approximately 170 of the VOR in the 9 rural districts involved in the project
- Approximately 100 victims will benefit from the medical and social assistance
- The project will improve the collaboration between the medical and social domain for the identification and support of the VOR
- Involvement of approximately 300 family doctors in the process of identification of the VOR
- Approximately 2000 youth and teenagers will be informed regarding the risks and dramatic consequences of THB.

Adverse outcomes in recipients of commercial transplants (Abstract P02)

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Insufficient numbers of organs retrieved and increasing waiting times for transplantation have resulted in growing numbers of kidney patients from the US, Canada, Europe, the Middle East and Australia traveling abroad to obtain a commercial transplant, involving a paid donor. Reports on these commer-

cial transplants in the period 1980-1995 (although scarce) showed consistently that recipient outcomes were often considerably worse than for domestic transplants: graft and patient survival were less and peri- and postoperative complications higher than to be expected in experienced centers. Because of this information, commercial transplants were medically and ethically condemned by most transplant physicians in developed countries. However this caused no marked decrease in commercial transplantation, and in fact, since the late 1990's there has been a further increase in the number of commercial transplants, and countries offering these services. We have analysed recent reports on outcomes of commercial transplants (since 2003) to see if outcomes have lately improved in terms of patient mortality, graft survival and surgical complications. Although some reports (eg from Taiwan) show that outcomes of commercial transplants (in China) do not significantly differ from domestic transplants, the majority of reports still show inferior outcomes in patients transplanted abroad in commercial centers using paid donors. Furthermore, there is a disturbing lack of information on outcomes of commercial transplants within Europe (e.g. Moldova, Ukraine, Kosovo, Turkey). Another risk is the lack of proper screening procedures for paid donors, insufficient communication between commercial transplant centers and patients' home center, and underreporting of early peri- and postoperative complications. On the basis of recent information, patients considering the option of obtaining a transplant abroad should still be advised and warned of running increased risk in terms of inferior graft and patient survival.

Transplant tourism from Taiwan to China – Some reflection on professional ethics and regulation (Abstract P03)

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Biomedicine and Technology, Taiwan*

Transplant tourism is increasingly an international and domestic ethical and human right concern in recently years. It also happened from Taiwan to China fervently in the past decade. My research based on the Taiwan National Health Insurance Database shows there were 1919 domestic renal transplantation cases but 2284 overseas renal transplantation cases from 1998 to 2007. This medical and social practice was considered ethically problematic and doctors might be involved in the process of transplant tourism. The issue was discussed at the medical ethics committee of the Department of Health. The committee concluded that: doctors and healthcare professionals, if involved with 1. introducing patients to a broker agency without receiving payment, 2. introducing patients to a broker agency and receiving payment, 3. personal involvement with brokering, 4. bringing patients overseas and performing transplant surgery and receiving payment, would be considered medical practices violating medical ethics under the Physician's Act article 25, item 4, which could incur punishment including a warning, compulsory education programs, termination of medical practice, or revoking of medical licenses. At

about the same time (2008), the bioethics center of National Taiwan University also launched an “Asian Task Force on organ trafficking” and later announced the “Taipei recommendation on the prohibition, prevention and elimination of organ trafficking in Asia” which advocates the “national self-sufficiency” principle and “calls on all countries to adopt a policy which discourages their citizens to travel abroad in order to obtain organs for transplantation.” In June 2009, the Taiwanese government proposed a revision of the Transplantation Act to include a fine of up to 1 million NTD (30,000 USD) if doctors and hospitals are involved with organ brokering (Liberty Times 2009). I will introduce in this paper why international organ tourism is ethically wrong and how the ethics guidelines and legal regulations have been established to discourage transplant tourism in Taiwan in last 3 years.

Commercialization and reciprocity – Public and patients’ moralities toward organ donation (Abstract P04)

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We explored ideas and motives behind public attitudes toward organ donation and its commercialization in the context of recent academic and political debates on attempts to increase the number of donor organs by means of financial incentives. We analyzed 4 focus group discussions (FGs) conducted in Germany between 2005 and 2008 with various participants: (1) recipients of a cadaveric donation, (2) recipients of a living donation, (3) living organ donors, and (4) lay people (N(a – d) = 30). In our analysis we used the method of qualitative content analysis to extract the major argument classes and moral viewpoints about organ donation and its commercialization. We found a thorough concordance in the critical assessment of most commercial strategies over the 4 groups of participants. Slight deviations between groups were most likely due to different perspectives resulting from the various ways the groups were affected. Overall, we observed a strong tendency to assess the practice of organ procurement in terms of reciprocity. The current political and legal discourse neglects the central role of reciprocity for lay people and patients. Targeted legal and practical solutions should (re)consider strategies to integrate the highly valued idea of reciprocity in organ donation practice: for example, the club model and the paradigm of anonymity in cadaveric organ allocation.

Organ donation and ethnicity: Unpicking the formulation of a 'problem' (Abstract P05)

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UK transplant services are currently coping with huge shortages in the availability of donor organs, with transplant waiting lists increasing each year. This shortage is particularly acute amongst Black and Minority Ethnic communities (BME), who make up 23% of the waiting lists, yet represent only 8% of the population; and 3% of organ donors. As a result, individuals from BME communities have a reduced chance of receiving a transplant in comparison to the White population. Existing research has framed this ‘problem’ by largely exploring community attitudes towards donation. In this way, high donation refusal rates among BME communities are narrowly related to the ‘culture’ of these communities. As counter to such focus, this paper will unpick the ‘problem’ as it has been presented in UK research and policy. It will argue that by simply looking towards communities as the source of the problem, the ‘issue’ has been de-contextualised. Using anthropological approaches to ‘culture’; and initial findings from an ongoing multi-sited ethnography, the author will argue for an alternative perspective on the relationship between ethnicity and organ donation. This involves exploring the practices and processes of the donation ‘request encounter’ and the experiences of those involved (BME donor and non-donor families and health professionals), to enable a re-focusing of the subject. The paper will conclude that only by re-situating the ‘issue’ of ethnicity and organ donation away from a simple ‘problem’ of communities; and by implicating health institutions within ‘cultural’ practices, rather than in isolation of them, can alternative findings emerge. These include the emotional discomfort of Intensive Care staff in asking families for donation; donor-transplant coordinators’ struggles to get potential donor referrals; and the difficulties encountered by families in making decisions which go far beyond simple ideas about ‘cultural’ beliefs.

Nighttime toilet use as major reason for sleep disturbance in renal transplant recipients

(Abstract P06)

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Background: The aim of this study was to assess quality of sleep in a sample of community dwelling renal transplant recipients (RTx) using the Pittsburgh Sleep Quality Index (PSQI).

Methods: This cross-sectional study, included all patients (n = 135) having a renal transplant at a single transplant center in Switzerland in the last five years. Demographics were assessed using a structured questionnaire. Sleep quality was assessed with PSQI.

Results: Median post transplantation time was: 2 y (IQR:1-4y) in the sample. The prevalence of poor SQ using the one factor PSQI model was 47.4%. Subjects slept approximately 7 hours (\pm 1.5). It took 25 minutes (\pm 28) to go from full wakefulness to sleep. The most annoying sleep disturbance was the need for nighttime toilet use (Frequency: 96, Percentage: 81,1%).

Conclusion: Perceived poor SQ in RTx population is a serious issue, especially nocturia.

Uncertainty in the long-term follow up of adolescent liver transplant recipients:

The providers' perspective (Abstract P07)

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Purpose: Our study is the first step of a participatory action-research project aimed at enhancing patient education in the long-term follow-up of adolescent liver transplant recipients. In order to facilitate the development of long-term self-management skills in adolescent patients, healthcare providers (HCPs) need to discuss not only medical and treatment-related issues with their patients, but also general health and psychosocial concerns. Methods to enhance adherence include improved communication between patients and HCPs. However, patient-provider interactions are currently not sufficient-

ly addressed as a factor impacting on long-term adherence. The aim of our study was to explore how the healthcare providers in our programme understand non-adherence in adolescents and define their own role regarding self-management education.

Methods: We conducted a qualitative exploratory study through in-depth interviews (n=22), followed by a confirmatory descriptive study through self-administered questionnaires (n=31).

Results: Our results show a discrepancy between the HCPs understanding of the psychosocial factors which impact on long-term adherence, and their actual practice of patient education, which tends to address cognitive and behavioural factors only. A number of uncertainties were found to explain the HCPs' perceived difficulty to engage in comprehensive patient education activities: uncertainty regarding (i) the health status of transplant recipients; (ii) a shared operational definition of adherence and the cause of organ rejection in some cases; (iii) the extent to which adherence is a shared responsibility which involves the HCPs as patient educators; (iv) long-term psychosocial outcomes in living-related donations.

Conclusion: Clarity and congruence of messages are major factors of success in health education. In order to avoid the risk of conveying incongruent messages, interdisciplinary healthcare teams need to explicitly acknowledge and discuss the various areas of uncertainty, some of which are inherent to transplantation.

Prevalence and correlates of influenza vaccination among renal transplant recipients

(Abstract P08)

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Background: Immunosuppressive regimens increase kidney transplant patients' risk of contracting life-threatening influenza. However, little information exists about the prevalence and correlates of influenza vaccinations in this population.

Objective: The purpose of this study was to determine the prevalence and explore correlates of influenza vaccination in renal transplant (RTx) recipients.

Methods: This cross-sectional study used data of the Supporting Medication Adherence in Renal Transplantation (SMART) study. The convenience sample consisted of 356 adult RTx recipients (58.1% male; mean age 52.9 years (SD 13.53)) recruited from two Swiss transplant outpatient clinics. Influenza vaccination status was assessed by self-report (yes/no). Known correlates of vaccination in chronically ill patients (older age, cohabitation, higher education, higher socio-economic status, financial stability, more co-morbidities, negative smoking status, and clinical site where care is received) were entered into a multiple logistic regression model.

Results: Of the 356 patients, only 83 (23.3%) reported having been vaccinated against influenza in the previous year. Positive vaccination status was significantly related to older age (OR: 1.04; 95% CI: 1.02-1.06).

Conclusion: Despite national and international guidelines recommending influenza vaccination in RTx patients, influenza vaccination prevalence was low in this sample. This study's results suggest that transplant centers need to implement policies to maximize influenza vaccination of their patients.

'Gift-exchange' theory, religion and organ donation: How do they connect? (Abstract P09)

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Background: Data from many countries relating to organ donor waiting lists and organ donors highlights significant disparities between ethnic groups. Empirical studies have shown that religious issues may be important influencing factors when making a decision about organ donation. This study seeks to investigate the potential role and relationship between 'gift-exchange' theory and religion to engage society in cadaveric organ donation.

Methods: The study involves a critical literature review that examines the interaction between 'gift-exchange' theory, religion and cadaveric organ donation.

Results: The first strand is gift-exchange theory. Mauss' (1954) theory of gift-exchange will be a fundamental part of the proposed study. The theory rests on three main principles; obligation to give, receive and reciprocate. Titmuss (1971) made huge contributions in his analysis of the US market-based systems and the use of Mauss' work. The second strand is religious views. These are thought to be a barrier to organ transplantation however, no major religion strictly prohibits it although there are differences in attitude (Elliot, 1999; De Long, 1990). Within some faiths, the decision to donate is complex, there are different schools of thought on the subject and these complexities may act as barriers to organ donation. The third strand is cadaveric organ donation. The Organ Donation Taskforce Report outlines the fundamental need for organ donors and the UK have one of the lowest rates of donating organs in the developed world. Around 16 million people are registered on the NHS Organ Donor Register (NHS Blood and Transplant, 2009) however there is still a large gap between the supply meeting the demand.

Conclusion: Initial analysis indicates that there may be a potential for 'gift-exchange' theory and religion to be combined in an effort to better engage the public with organ donation.

The impact of health status on patient distress

(Abstract P10)

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Introduction: In the majority of cases, patients' perceived health status improves after renal transplantation. Still, in some cases patients report distress despite perceiving their health as good. Conversely, other patients do not report distress despite perceiving their health as compromised. The aim of this study is to identify personal characteristics of patients that make them either vulnerable to or buffer them from the impact of lowered health.

Method: 609 of 1013 eligible patients returned a self-report questionnaire. To identify differences between four groups based on dichotomization of health status and distress, correlations, analysis of variance and analysis of covariance were employed.

Results: Patients with lowered health and no distress showed higher scores on mastery ($F=4.017$; $df=23$; $p<.001$), acceptance ($F=5.924$; $df=18$; $p<.001$) and optimism ($F=2.857$; $df=26$; $p<.001$) than patients with good health and no distress. Furthermore, patients with lowered health and no distress scored lower on negative affect than patients with good health who were distressed ($F=2.251$; $df=25$; $p=.003$).

Discussion: Patients who are not distressed despite lower health have more feelings of control over life, better acceptance of the illness and are more optimistic. Patients who are distressed despite good health report more negative affect. The impact of lowered health on patient distress depends on personal characteristics of the patient.

How organ transplantation is represented in Québec newspapers? (Abstract P11)

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Background: News media are a key source of health information for the public. No study has examined how organ transplantation (OT) is depicted in the newspapers. Analysis of press coverage in transplantation will help us to understand how public perceive OT. This better understanding of press media coverage can help transplant professionals to address expectations, misconceptions, fears, etc. of patients seeking a transplant and open a dialogue with journalists and the public on OT.

Purpose: The aim of this study is to analyse Québec press coverage on OT.

Methods: Throughout Eureka database, we retrieved 948 Québec newspaper articles published between 01/01/95 and 31/12/2008. Only articles where OT was the main topic were analysed by content analysis (227/948 articles).

Results: Our analysis shows that articles about OT are predominantly short (94% are less than 1000 words). Liver transplantation is the most frequent organ transplantation cited (26%) in articles. This is explained by the important coverage of Mickey Mantle case in 1995. Also, OT is depicted in a banal way and superficially. Finally, the themes mostly found in the articles are: lack of resources in Québec healthcare system; life and death issue; political and organisational issues; costs of transplantations and medications; complications after the transplantation. Ethical issues related to OT are not mentioned or discussed in Québec newspapers.

Conclusion: OT is presented in Québec newspaper in a superficial way. There are no in-depth articles about OT. OT is depicted as a routine procedure and journalists say nothing about ethical issues related to this treatment. These OT representations might fuel patients' unrealistic expectations about OT and the views that there is a right to be transplanted.

Women's discourse on their professional concerns after organ transplantation:

A qualitative study (Abstract P12)

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Nowadays, little is known about women's professional concerns after an organ transplantation, as they constitute a minority among transplant recipients (40%). Despite this gender difference, most of existing studies focusing on psychosocial aspects of transplantation present undifferentiated results, in which women's concerns tend to wear off. The aim of this IRB-approved study was to highlight women's discourse concerning their own management of tensions between illness and work. Semi-structured interviews focusing on daily activity were conducted with nine women at home, hospital or university, according to the participants' will. The interviews were verbatim transcribed and a first qualitative thematic analysis was performed, based on an original developmental Embodied-Socio-Psychological Model. Preliminary results show that the announcement of transplantation represented a breaking point in these women's life, having their previous experiences of the world collapsed. At the time of the interview, each woman had started a reconstruction process, trying to make sense of her experience in light of her physical impairments, personal history and previous relationship to work. However, some of them were still blocked with their embodied emotions: as they had to fight daily with their bodies' needs they could hardly work anymore. Others seemed to give priority to the social aspects and tried to recover their previous life by working or having many activities, like „normal persons”. Fi-

nally, others had been able to find a special meaning to their experience and, whether they worked or not, had begun integrating their illness as a part of their body experience, their social mind, and their own historical and affective story. These preliminary results suggest that a thorough exploration of women's professional concerns is necessary to propose adapted support during the transplant process and improve positive employment outcomes after organ transplantation.

Moral obligation of the United States Federal Government in providing for post-transplantation medication (Abstract P13)

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Renal transplantation has become the benchmark treatment for End Stage Renal Disease (ESRD). After receiving a transplantation, the patient must take immunosuppressive medication to prevent organ rejection. Studies have shown that the patients with the best overall compliance and graft survival are patients with private insurance. However, the patients with private insurance only account for a minority number of the total number of renal transplant patients. The majority of the renal transplant patients are dependent on the Medicare system (federal medical insurance) to cover the cost of the surgery and the related immunosuppressant. In 1972, the US federal government made the treatment of ESRD a unique condition under Medicare coverage. Medicare initially covered hemodialysis, the transplant surgery, and immunosuppressive medicines for one year. In the 1990s, coverage for immunosuppressive medication was increased from one to three years. After three years, coverage for medication is terminated by the federal government. The average cost of immunosuppression is about \$12,000 per year. The termination of the benefit places an undo burden on the patient. If the patient becomes non-compliant and develops rejection and graft failure, Medicare will cover the cost of dialysis (a cost of \$47,000 per year) and re-transplantation. However, non-compliance makes the patient a less desirable candidate for transplantation. The current system potentially places patients in a vicious cycle. The government should be morally obligated to cover the cost of immunosuppression for the life of the patient. This presentation will address the moral obligation of the US federal government in covering immunosuppression for more than three years. The presentation will also address whether renal transplant should still be a special condition under Medicare funding.

Introduction of ethical workshop in transplantation unit of CHUV (Abstract P14)

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Introduction: Interdisciplinary health's care teams of transplantation unit are involved in difficult ethical situations, which occur as well at the time of evaluating a patient for transplantation as when the transplanted organ failed. It is about an interdisciplinary team made up of many physicians from different specialities, nurses, psychiatrists. We intend to study the usefulness of an ethical analytic workup in decision-making process to help the patient's care and to improve reflective capacities of the team's members.

Methods: Through the presentation of transplantation's ethical cases in teaching workshops, we will evaluate together the goals of each clinical situation and go through analytic and ethical process looking for ethical wisdom. All staff members of the transplantation unit will be invited to the workshop every six weeks, each session lasting 1h30. A health care professional involved in the care of the patient presents a problematic situation that is still on-going and raises ethical questions related to the transplantation process. The meeting is guided by a doctor of medicine and philosophy who is head of the ethics unit of the University hospital (CHUV) and by a physician of the transplant unit. This workshop will be evaluated by a written questionnaire at the beginning and the end of the 4 meetings.

Results: During these 4 workshops, the type of up-coming topics, recurrent problems, participation and the possible impact on present and future practice will be evaluated. We will analyze the way the workup is conducted and can be improved, its meaning for the professionals and the outcomes.

Conclusion: Depending on the impact of these first workshop series, we will consider an extension of the workshops to the other clinical units (intensive care unit, oncologic unit...).

Negotiating living kidney donation among migrant minorities (Abstract P15)

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Living pmp kidney donation rates have for decades been high among ethnic Norwegians (20.5 in 2008) whereas LKD from ethnic minority migrants to close relatives remain insignificant, according to National Transplantation Unit coordinators. At the largest municipal hospital in Oslo unofficial data communicated from physicians during anthropological fieldwork indicate that a third of all ESRD-patients on dialysis belong to ethnic minorities. Among the 30 000 Pakistani minority – (largest ethnic minority in Norway) – the number of patients who have received a kidney from a relative residing in Norway is negligible. Until 2008, some had imported a 'family' donor from their home country with travel, surgery and living expenses covered by the NHS; others were placed on the DD

waiting list. 'Imported' donors were sent back to their country of origin following post-donation follow-up. After the Istanbul-declaration, stating that the health authorities sanctioning transplantation are responsible for long-term post donation care, this protocol has been discontinued: Pakistan does not yet have a social welfare system which could guarantee required care. Prognoses indicate a demand for an annual increase in dialysis units of 5-10%. Considering the concurrent expected growth in renal replacement therapy, motivating living donation in the Pakistani-minority is all the more crucial, from a NHS perspective. No statistically valid comparison between ethnic minorities' and majority population' donation rates exists: ethnic background is considered irrelevant and not registered in patient records. Nor is there any systematic knowledge about reasons behind Pakistani-families' apparent unwillingness to donate a kidney to a close relative. Results from fieldwork suggest that the consensus among Norwegian nephrologists that the proper person to solicit donation from relatives is the patient's physician, i.e. not the patient himself/herself, is perhaps not the optimal method for selecting family donors among ethnic migrant minorities.

Employment status after lung transplantation in a developing country (Abstract P16)

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Introduction: Transplantation is an experience of disruptive character that hits in the patient's psyche and environment (family and work). The transplant allows recipients to eliminate the physical barrier for the performance of multiple labour activities, but in certain social contexts with high rates of unemployment it operates like a variable of exclusion in front of the employment selection.

Objective: To analyze changes of the recipients' pre and post lung transplantation employment status, and to evaluate if the impact of the transplant conditions the working bonds.

Material and Methods: Between 06/1994 and 10/2006, 123 lung transplantations were performed at a single institution in Argentina. For the present analysis, 79 adult patients (age > 18 years) with a 6 month conditional survival were included. Mean age was 38 years, and 31 were female.

Results: PRE-TRANSPLANT 51(64%) retired, not working 15 (19%) unemployed 3 (3.8%) formal work 3 (3.8%) students 7 (9.4%) housewives. POST TRANSPLANT 30/51 (38%) informal work 21/51 (26,5%) not working 11/15 (14%) 6 informal work/5 formal work 4/15 (4.5%) not working 3 (3.8%) formal work 3 (3.8%) students 7 (9.4%) housewives. Pre transplant: 3.8% (n=3) of the patients on the waiting list were working. This percentage reached to 55.8% (n=44) in the post-transplant follow-up. All three patients working pretransplant were formal work (100%) while only 8/44 (18%) had a formal work.

Conclusion: Although the increased number of patients who got up themselves into the labour market, the majority of them did it in informal conditions. Ignorance on the part of the em-

ployers, the little employ supply and the fear of the patients to lose their health insurance operates like important variables in the employment insertion of the patient. The task of education and information at community level is essential to improve this situation.

Analysis on the quality of life of patients undergoing intrathoracic transplantation in Argentina: Psycho-social approach (Abstract P17)

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Introduction: This study deals with the quality of life of patients on waiting list for transplantation and patients who have already undergone intrathoracic transplantation in our center, based on a questionnaire including psycho-social issues, and the patients' subjective and objective views.

Objective: The objective of this study was to learn about the views these patients have of their quality of life in these scenarios, in order to obtain answers useful to improve certain issues which are difficult to manage.

Results: During the year 2007, 48 patients, 24 on waiting list and 24 who had already undergone transplantation were given a closed, structured questionnaire. The purpose of this questionnaire was to look into the same variables both in the pre and post-transplant scenario. The analysis of the answers helped us identify the following issues:

DIFFICULTIES PRE-TRANSPLANT/POST-TRANSPLANT: Degree of mobility 62,5%/37,5%; Autonomy 37,5%/12,5%; Compliance with drug therapy 0%/29,1%; Hospitalization 12,5%/25%; Worry 62,5%/41,6%; Sadness 41,6%/29,1%; Anxiety 58,3%/25% Pts. who have a job 25%/50%; Integration 54,1%/45,8%.

Conclusions: The analysis of the difficulties in the pre-transplant period evidences that psychosocial rehabilitation should start during this period in order to provide patients with the emotional and social support.

Risks for living donors: A comparison with volunteer participation in clinical trials

(Abstract P18)

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Organ donation from living donors has been compared to the participation of healthy volunteers in clinical trials. Some authors consider both actions to be not only unselfish choices, but also social duties. Either way, living organ donation is rightly recognized as an altruistic act of high moral standards. The comparison of living donors with volunteer participants is subject to many ethical reflections. While some widely recog-

nized ethical criteria support the comparison, others do not. Assuming the comparison is legitimate, we can compare the informed consent procedures involved in each of the two situations. In dealing with informed consent, the concept of risk deserves special attention: risks are usually considered acceptable in clinical trials if they do not exceed a "minimal" level. According to the U.S. Code of Federal Regulations, a situation of "minimal risk" is when "the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests." Organ donation does not seem to fit this description. Clinical research ethics also makes frequent use of the notion of "acceptable risk," but the definition is highly subjective. Consequently, the notions of both "minimal risk" and "acceptable risk" cannot be easily applied to living organ donation. Recent studies suggest that the chances of dying from kidney donation are 1 in 4,000, and that long-term risks may be higher than previously imagined. The risk may become more significant in developing countries. Though demanding requirements for the validity of living donor informed consent are already in force in many countries, detailed and uniform procedures for living donor risk assessment are necessary.

Long-term results of living donors – Scandinavian experience (Abstract P19)

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Background: Kidney transplantation with organs from living donors has increased. We wanted to find out more about kidney function and donor experiences with focus on safety of long-term results.

Material and Methods: All living kidney donors from 1965-2005 undergoing surgery were included in a survey study. Questionnaires to the donors and medical analyses of kidney function, microalbuminuria, and blood pressure were analysed.

Results: Of 1112 donors 13% had died, 6% were lost for follow-up. Total 4% were living abroad and thus 824 former donors were available for the study. 661 accepted to participate answering the questionnaires and 571 to have blood tests analysed. The present mean age (SD) of the donors was 61 (13) years, range 24-92. Time since donation was 14 (9) years, range 2-43. Two have received a kidney transplant and one is in regular dialysis. The mean (SD) s-creatinine at follow-up was 94 (25) $\mu\text{mol/L}$, range 48-383. The mean s-urea was 6.8 (1.8) mmol/L , range 1.8 – 18, 4 (n= 535). Measured GFR with iohexolclearance or CrEDTA clearance (n = 182) showed a mean (SD) value of 68 (15) mL/min/1.73m^2 body surface, range 25-111. High blood pressure was found in 147/543 = 27% of the donors and 126 = 23% had anti-hypertensive medication. Microalbuminuria defined as urine albumin-creatinine ratio above 5 $\text{mg}/\mu\text{mol/L}$ was found in 63/474 = 13%. Estimating the GFR that the donor would have had with two kidneys and compared that with the actual kidney function

showed increasing kidney function with time. Thus, the normal ageing procedure of the kidneys is not found.

Conclusions: This large study of living kidney donors shows that the remnant kidney after donation has capacity to increase the kidney function for many years. One fourth have hypertension and 1/10 microalbuminuria.

Ethical, legal and social aspects of innovated organ transplantation program at developing country in South-America (Abstract P20)

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Specific objective: Show and analyse the social, ethics, politics and technical aspects concerning implementation of an organ transplantation program at developing country in Latin America supported by a new solidarity and equitable politic for catastrophic diseases.

Methods used: Obtain data base concerning the transplant activity in the country the last 20 years. Review of legal body existing to regulate the transplant activity. Identification of hard points and also irregular situations considered like a „modus operandi“ of our transplantation activity. Determination of social and ethics principles supported by constitution to regulate catastrophic situations for patients and their families. Effect of the exercise of politic power by health authority to start and change direction of transplant activity between several actors involving in transplants and diagnostic of support needs for hospitals equipments and professional training. Choice and analysis of financial mechanism to allocate resources by government for all citizens and residents in our country and regarding a better politic to stimulate this activity between accredited professionals and institutions.

Summarize results obtained:

1. Poor Statistics of transplant activity within the last 20 years.
2. New legal proposition to regulate organs, tissues and cells transplantation.
3. Description of new politics and implementation of management of catastrophics situations program at Public Health Ministry.
4. First results obtained by new programs of Liver transplantation, modified Renal transplant program, Heart transplantation, Bone marrow transplants and projected pancreas, lung and heart-lung transplantations.

State conclusions reached: Financial, social and quality of life impact of our own politic proposition.

Feasibility and ethicality of heart transplantation from non-heart beating donors (Abstract P21)

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Objectives: The non-heart beating donor (NHBD) is an increasing source of organs for transplantation. Cardiac donation from NHBD has been considered infeasible due to concerns that ischemic injury will lead to irreversible myocardial damage. Our aim was to determine whether hearts from NHBDs could be resuscitated and recover sufficient function for transplantation through investigation in animal models and human NHBDs.

Methods: A human NHBD suffered cardiac arrest after elective withdrawal of supportive therapy. Extracorporeal perfusion was established through cannulation of the great vessels twenty-three minutes after death. Load independent left ventricular (LV) contractility was measured in hearts resuscitated after circulatory arrest and 15 minutes of warm ischemia in rat and porcine models of NHBD heart resuscitation. For purposes of control, rat and porcine models of brainstem death (BD) were utilized to measure LV contractility 2 hours after BD.

Results: Extracorporeal coronary perfusion led to functional cardiac recovery in a human NHBD. Following resuscitation, extracorporeal support was withdrawn and the heart supported the circulation independently confirming effective cardiac function. In rat and porcine models of NHBD heart resuscitation LV contractility of resuscitated NHBD hearts was superior to that of brainstem dead hearts in our small and large animal model.

Conclusion: The world's first heart transplant in 1967 was performed using a heart from a NHBD. We have demonstrated that the NHBD heart can be resuscitated and recover adequate function to support the circulation. In-vivo resuscitation of the heart and re-establishment of cardiac function after circulatory arrest has raised ethical concerns. However, in view of removal of other organs from NHBDs should cardiac resuscitation and donation be precluded? These issues must be addressed before a clinical program of heart transplantation from NHBDs can be established.

Organ donation in infancy, childhood and adolescence in the northern region of Germany (Abstract P22)

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Introduction: Organ donation in children is always a great emotional challenge for all participants, but on the other side

because of an excellent organ quality and the size it is a great chance for pediatric recipients. Because of the still opened cranial sutures there are special conditions in infancy.

Methods: Retrospective electronic analysis of all donor advices up to 18 years of age the German federal states Bremen, Hamburg, Lower Saxony and Schleswig-Holstein from 1.1.2006 to 6.5.2009.

Results: All together there have been 1493 donor advices, 73 in childhood and adolescents. The most weighted age have been the first 12 months. 34 patients died because of an unnatural cause (23 craniocerebral trauma. The craniocerebral traumatized patients are, with four exceptions, pupils or adolescents. Of these 19 older children 18 died because of traffic accidents, one fell of a great height. In two young children child abuse had been evidenced. In 35 children a natural cause of death had been found. In one child there was an unclear cause, in 3 children the cause could not be identified retrospectively. In 37 children the donation had to be cancelled before listing at Eurotransplant (13 cardiovascular failures, 22 denegations, 1 cancellation of an acceptance, 1 complex systemic anomaly), in two children after listing at ET. In 34 patients organ donation succeeded. Of 11 infants, only in two patients a donation was performed, of the 7 children between 13 and 24 months in 3 patients. Altogether 158 organs had been transplanted, 4.6 organs per donator.

Summary: About 5% of all organ donators are up to 18 years of age. Often a donation of multiple organs is possible, especially hearts and lungs can often be transplanted.

Primum non nocere: How can we justify the use of living donors as long as deceased donation is not optimally exploited? (Abstract P23)

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Living donation is being promoted in most countries today as an alternative to challenge the organ shortage from deceased donors. Such approach can only be justified when the potential for deceased organ donation is fully exploited. We used the Donor Action Medical Record Review (MRR) methodology to measure whether and why potential deceased donors were missed in 5 European countries. MRR data was collected from 47,809 patients who died in 540 critical care units in 206 hospitals in Belgium, Finland, France, Poland and Switzerland between November 2006 and October 2009 and with an age limit of 75 years for heart-beating (HB) donation. On a total of 16,531 ventilated patients without contra-indications to HB donation, 4,139 (8.7% of all deaths) met criteria for brain death (BD) diagnosis and were considered potential HB donors. On average, 28.7±15.0% were not identified as potential donor, 45±16.1% of potential donors (22.7% of identified cases) were not referred as such to a procurement team and 35.2±12.3% of relatives were not approached with the option to donate. Average consent and retrieval rates as a % of potential were only 43±6.7% and 41.7±6.2% respectively. Retrieval rates (organs/potential donors) varied between 1.90 (Finland), 1.78 (Belgium), 1.66 (Switzerland), 1.38 (France) and 0.86 in

Poland. Organs/donor yields varied from 4.16 (Switzerland), 4.08 (Finland), 4.04 (Belgium), 3.00 (France) and 2.71 (Poland). Over 55% of deceased potential donors in 5 European countries with relatively high donation performance were missed along the donation pathway due to non-identification, no referral, no approach of relatives, and objections to donate. Efforts to increase the organ pool should therefore focus on optimizing clinical practices in deceased organ donation before starting to promote living organ donation.

Mother requests for brain-dead son's semen – A case study (Abstract P24)

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Objectives: A case of a 26 year old male, 6 years after kidney transplantation due to chronic renal failure and on immunosuppressive treatment, who developed brain death due to subarachnoid hemorrhage is presented. His mother and female partner were informed that he was brain dead and were asked for consent for organ donation. After medical evaluation the decision was made to retrieve the liver. However, his mother asked the intensive care physician, regional transplant coordinator and Poltransplant coordinator if semen could be posthumously collected so that his partner might be inseminated and have his child.

Methods: A case study and literature review. It was the first such case in Poland, therefore several legal, technical, medical, moral and ethical concerns have arisen. Even though it might be technically feasible to retrieve and store sperm from a brain dead man, the case raises questions concerning the respectful treatment of the dead body and the quality of the semen procured from the kidney recipient, but first of all it brings up a problem if he would want his partner to be a single mother after his death and finally, the problem of the welfare of the potential child.

Results: The sperm was not posthumously collected.

Conclusions: Presented case emphasizes that in Poland the gamete donation after brain death is not regulated. According to General Regulations of The Cell, Tissue and Organ Recovery, Storage and Transplantation Act of July 1st, 2005 its regulations “shall not apply to a recovery, transplantation of gametes, gonads, embryonal and fetal tissues, and reproductive organs or parts of these”. The standard for dealing with cases such as presented above is not established, therefore discussion about practice in such a situation is essential.

Impact of legal regulations in organ transplantation (Abstract P25)

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Based on the investigations of the Projects Alliance-O and DOPKI an overview about the relevance and impact of regulations in organ donation and transplantation shall be given. It is important to distinguish legal regulations related to post mortem organ donation that can be based either on Heart-Beating-Donation or Non-Heart-Beating-Donation on the one hand and legal restrictions to living donation. The two major prerequisites for post mortem heart beating organ donation are the brain death of the patient and the consent of the patient respectively his/her relatives. However the criteria for brain death and in particular the regulations for obtaining consent differ immensely. The most interesting finding of this examination was to find out that in the end in day to day practice those two concepts do not differ significantly since the wishes of the relatives of a deceased person are always respected no matter what the legal regulation says. Differences can be found in particular regarding the acceptance of Non-Heart-Beating Donation. Only in UK the law allows Non-heart-beating Donation in all four Maastricht Categories. In terms of living donation existing regulations always imply a restriction in order to protect the potential living donor or to prevent organ trafficking. Hence it is only consequent that those restrictions are regulated by law since they effect the right of the living donor do decide himself about his physical integrity and it also deprives the living donor recipient from a possibly lifesaving treatment. In all participating countries organ trafficking is penalized and living donation has to be altruistic. The majority of countries require a specially defined relationship between donor and recipient and 10 out of sixteen countries have installed ethical committees that need to approve of the planned donation or require an approval by court.

Misattributed paternity: To tell or not to tell (Abstract P26)

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Kidney transplantation from living donors involves an evaluation of potential living donors and their intended recipients. Ascertaining necessary medical information about the donor and recipient may uncover an incidental finding of misattributed paternity. This discovery introduces difficult ethical questions for the healthcare team i.e. to whom the information belongs; it's relevant to decision-making; the obligation to disclose it or not; if so, to whom; and what process should be used to resolve the issue?

Objectives: 1. To identify and discuss the ethical issues in the incidental discovery of misattributed paternity during evaluation of potential living kidney donors and recipients. 2. To

present a policy addressing this issue and discuss consequences of and reflections on, applying the policy.

Outcomes: This presentation outlines a case of an incidental finding that a prospective kidney donor and the intended recipient were not genetically related, but believed they were. The team was uncertain if they had a duty to disclose this information to the donor and/or the recipient and how disclosure would impact their future relationship or the decision to donate. The role of the mother in the disclosure raises issues as to whom the team has duties or obligations. The consultation process focused on issues including truth telling, autonomy, paternalism, confidentiality, and the nature of the relationship between patients and healthcare professionals. We will present the decision making process, its outcome, the development of a policy to address this issue proactively and reflections on use of the policy.

Conclusions: Incidental findings of misattributed paternity are best addressed proactively so patients are warned that such information may be uncovered and given an option for disclosure if these findings occur. The role of the mother raises additional issues of duties and communication.

Results of 1-year descriptive living donors registration study in partnering European countries (Abstract P27)

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Objective: Development of Living Donor (LD) on-line database registry model with central database reports at international level.

Methods: A survey on current registration practices on 11 European countries was performed. Based on these results, a database registry was developed. An on-line module was created and used by 8 countries, registering retrospectively their LD activity for a year. Donor and recipient nationality, residence, donor recipient relationship, organ allocation, organ donated, status were asked at an obligatory level. Clinical parameters (weight, length, kidney and liver laboratory parameters, blood pressure, complications such as surgical re-intervention, pain, wound complications, psychological complications) were specified at the recommended level. Database was tested in participating countries. Project grant-aided by the European Commission.

Results: As a result database objectives (user, validation, follow-up, data form, data consultation, technical specification)

and descriptive data input were measured and evaluated. In the test cases, 564 subjects were registered (111 Romania, 44 France, 130 Italy, 132 Spain, 136 UK, 2 Portugal, 8 Sweden and 1 Slovenia). Donor residence: known in 428 cases (421 within registering country, 7 outside) and 134 unknown. Recipient residence: known in 554 cases (3 outside registering country and 10 unknown). The relationship was: 453 cases genetically related, 62 non-genetically related (Spouse/partner), 24 non-genetically related (friends) and 25 non-related. 503 cases were directed-related, 55 were directed altruistic and 6 were non-directed pooled. 470 kidney and 94 liver donors were entered.

Conclusions: The preliminary data registration and database evaluation shows an immediate value of these data. Both residence, relationship and follow-up show critical missing data. These first reports of the EULID database for LD stress the importance of centralizing data on an EU level to secure the quality and safety of living donation.

The social construction of death as a decisional frame in organ donation (Abstract P28)

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Organ donation has been regulated in Spain in terms of presumed consent. This law states that every citizen is a potential donor if the contrary has not been officially declared. However, this law, in practical terms, is not being fully applied and this fact transforms the family of the dead as the 'natural' speaker of the dead person's wishes in relation to organ donation when health professionals ask for authorisation. In such situation, organ donation appears suddenly in family biography, what enacts conceptions about death which are socially constructed in the Catalan society. In this paper, it is argued that shared conceptions about death clearly determine individual decisions on organ donation. Drawing on 26 discussion groups and 17 interviews to health professionals and general population and the work on metaphors of Lackoff (1980) and Lizcano (2006), we analyse how social death conceptions configure the decisional frame of organ donation and how these conceptions position families to accept or reject to donate.

Requesting families of potential organ donors in the ICU: Preliminary results (Abstract P29)

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Introduction: Family refusal for organ donation is the main reason for the loss of potential donors in the Netherlands. Therefore the Dutch Transplant Foundation started a study to analyse the decision making process. This is the first time that also data of families who refused donation are analysed.

Methods: Within a time frame of 1.5 years (December 2007 – May 2009) three Dutch hospitals participated in our study, after approval of the local METC. Family members of potential organ and/or tissue donors were approached by letter 3 months after death to fill in a questionnaire.

Results: In total 98 out of 147 families (67%) returned the questionnaire. Mean age of the responders was 54 years (range 20-82) and 60% were women. The outcome of all donation requests was consent in 56% and refusal in 42% (2% missing). Almost all families were satisfied with the way the ICU staff took care of them at the moment of death of their loved one (96%), and with the way the physician requested families for organ donation (96%). When families were satisfied about 60% gave consent for donation. When donation was discussed in the past the consent rate was higher (62%) than when donation had never been mentioned (44%) (NS). In 5% religion played a role in the decision making process. Families would make the same decision on donation again in 95%.

Conclusion: Satisfaction of families with the care of the ICU and the way the doctor asked for donation was high, although some improvements can be made. Of the satisfied group around 40% refused donation. When donation was discussed in the past, the family consent rate was higher.

Do the transplantologists have a specific status? (Abstract P30)

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Organ transplants quite peculiarly challenge current representations about the body and the person, and that is felt as much by the patient as by the transplanting person that performs them. We suggest the hypothesis that the relationship arising between the transplanting and transplanted persons crystallizes the difficulties and ambiguities – as much personal as medical ones – that emerge when facing the various issues

confronting patients. As a result, the transplanting practitioner is conferred a specific status relatively to the other doctors. Our study aims at assessing the specific nature of the transplanting person's status in the context of the doctor-patient relationship, in order to, on one hand, better understand what is at stakes there, and the potential challenges that arise and, on the other hand, elaborate directions capable of making the doctor-patient relationship more satisfactory. We have conducted semi-directive interviews, whose respondents are 20 solid organ transplantologists. We have selected transplantologists distributed in representative fashion regarding the nature of transplants in France. The first results have yielded several elements of reflection: first, most respondents substantiate that the transplantologists' status is actually singular. On the other hand, the particular connection between the transplantologist and the general practitioner has proved worth exploring, both concerning the fact that transplantologists distance themselves from general practitioners, and regarding the similar nature of the way patients are taken care of (global type of care, lasting all along the lifespan of the graft, sometimes during the patient's whole life). Lastly, the symbolic facet of the transplantologist-transplanted relationship is also of great interest: indeed, several doctors use words like "magic" or "magical" when talking about the graft. The rest of the interview analysis should enable us to fine-tune those results and these could come with ethical and philosophical considerations.

Donation after cardiac death: A solution for organ shortage in Italy? (Abstract P31)

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Worldwide there is an ever-widening chasm between the supply and demand for organ donation. In many countries of Europe and United States organ donation after cardiac death (DCD) is viewed as a new source of organs. In Italy there are no DCD protocols and donors pool mainly consists of patients who died after brain arrest. We sought to determine how much donors pool in our hospital could be expanded introducing DCD. Retrospectively charts of all patients, aged from 18 to 55, deceased in the intensive care units of University Hospital A. Gemelli in Rome, from 2005 to 2007 were examined. Obtained data were compared with those gathered from donation registry, concerning same age and time range. Of 408 patients, 379 were excluded according to our selection criteria; 29 patients represent our potential DCD donors. Main cause of death was trauma; other causes included myocardial infarction, aorta dissection, brain haemorrhages and gun shot. 15 patients died less than 24 hours after recovery; 5 died in 72 hours and 9 were recovered for more than 3 days. In the same period, 11 patients were potential donors according to neurological criteria of death. DCD could have quadrupled potential donors pool in our hospital. Our data refers to II category of donors of Maastricht classification. In Italy, according to our law, no-touch time consists of 20 minutes. Literature data show warm ischemia time ≥ 25 minutes as an increased risk factor for primary non function and delayed graft function in

transplantation. Any assessment of an Italian DCD protocol cannot ignore what would be the WIT and has to take into account ethical, socio-economical and political issues. For instance, withdrawal of life sustaining treatment is not allowed, so Maastricht category III donors cannot expand pool.

Natural vs artificial organ perfusion: Proposal of a new classification for deceased organ donors

(Abstract P32)

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Organ perfusion before harvesting determines the warm ischemic time and consequently the quality of organs for transplantation. Whether death be declared by cardio-pulmonary or neurological criteria is less important, although deceased organ donors are currently classified according to persistence or absence of cardiac activity, respectively: 1) heart-beating donors (HBD) or donors after brain death (DBD); 2) non heart-beating donors (NHBD) or donors after cardiac death (DCD). Perfusion before harvesting clearly differentiates HBD from NHBD. In HBD organ perfusion is natural, due to spontaneous blood circulation; in NHBD perfusion is absent or artificial (blood circulation from cardio-pulmonary resuscitation, post-mortem extracorporeal membrane-oxygenation (ECMO), or in situ cold fluid perfusion). ECMO may be useful for advanced resuscitation in patients with severe cardio-pulmonary failure. If ECMO is ineffective or futile, death may occur with artificial circulation of blood in the absence of cardio-pulmonary activity. Consequently, death could be declared either by cardio-pulmonary or neurological criteria. In these cases the four existing definitions of donor, defective in organ perfusion specification, may be misleading and clinically inadequate. Thus, two new definitions may be suggested: type I - natural organ perfusion: deceased donor where organ perfusion before harvesting is obtained by the donor's own cardiac function even if sustained by drugs; type II - absent or artificial organ perfusion: deceased donor where organ perfusion before harvesting is absent or obtained by external artificial devices with no cardiac function. Type I donors are either HBD or DBD; type II donors can be NHBD and DCD, but also DBD. The new simple acronyms defining organ donors would be: DDNP (type I) i.e. deceased donor with natural perfusion; DDAP (type II) i.e. deceased donor with artificial (or absent) perfusion.

The role of moral counseling during decision making by proxies (Abstract P33)

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Introduction: Objection by relatives is the main cause of loss of potential donors. Little is known about the process of decision making by proxies at the time of organ donation. Our aim is to study this decision making process and to establish the need for additional moral counseling by an independent counselor.

Methods: We are conducting a prospective qualitative study by interviewing relatives of 10 cases in which permission was given, and 10 cases where organ donation was refused. The semi-structured interviews, taking place two months after death, are based on the following 5 themes: moral considerations for donation, the role of the Dutch donor register, the patient's opinion concerning donation, the need for additional support and peace with their decision.

Results: So far, we have interviewed 10 relatives who gave permission and 3 relatives who refused donation. The outspoken wish of the donor or his perceived values were moral considerations of relatives to give permission. The main reason for refusal was the supposed patient's wish. Registration in the donor register facilitates the decision in all cases. In case of no registration most donors had discussed their wishes with the relatives. All respondents had a positive attitude towards donation, although some of them refused consent based on an assumption of the patient's wish. Coaching around the time of the donation request would have been appreciated by most relatives. Moral counseling was considered especially useful, when proxies disagreed with each other. Nobody regretted the decision, although some were disappointed about the circumstances in which the decision had to be taken.

Conclusion: Moral counseling may support relatives and facilitate decision making during the donation process.

ETPOD – European training program on organ donation in Poland – A single centre study

(Abstract P34)

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Objectives: The aim of the ETPOD Project was to increase donation rates by blended learning and face-to-face training of 3125 Health Care Professionals from European Union countries (375 from Poland) involved in the donation process. The basis of the project was the existence of Target Area (TA), the area where donor and transplant hospitals are located. There were 25 TA's allocated in 16 participating countries, 1-3 TA's in each. The aim was to train 125 health professionals in each TA. The highest number (3) of TA's was established in Poland and in Germany.

Methods: In Bydgoszcz, one of the Polish TA's, 2 University Hospitals were involved in the project. According to the Program objectives, 144 health professionals were trained during Essentials on Organ Donation Seminar (EOD) held in November 2008 by previously trained 2 Senior Transplant Coordinators, 2 Junior Transplant Coordinators and the Transplant Area Manager. However, not more than 48 % EOD participants were employed in TA Bydgoszcz hospitals.

Results: The follow-up report revealed that the EOD Seminar has positively changed the attitude towards the donation process of vast majority (almost 90%) of surveyed participants. Furthermore, statistical analysis of data from 1st semester 2008, whole year 2008 and 1st semester 2009 has shown an increase of brain death diagnosis, potential donors, effective donors and procured organs in 2 University Hospitals in Bydgoszcz. Nevertheless, the number of refusals has also increased.

Conclusions: The ETPOD project allowed participating health professionals to develop a positive attitude and know-how knowledge required to lead organ donation process, resulting in an increase of the organ donation rate in TA Bydgoszcz. Education of health professionals from donor hospitals is essential for effective participation in the organ donation process.

Family approach – Retrospective analysis of family refusals (Abstract P35)

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Since January 2009 the DSO information system provides for a detailed documentation of the family approaches for analysis purposes in order to enhance and improve the professional family approach. 1627 family approaches have been analysed. Only in 6 % of the cases the deceased has documented his will to donate in written form. 24 % of the family decisions were based on the orally expressed will and 42,1 % on the assumed will of the deceased. In 26 % of the cases the family made up its own decision. Main reasons for refusal were a negative attitude of the deceased towards organ donation (35,6 %) and the lack of knowledge about the attitude (26,8 %). Further reasons for refusal were the disagreement between the relatives (10,4 %), the fear of violating the physical integrity (8,8 %) and not being able to accept the death of the relative (5,1 %). Religious reasons or doubts regarding the concept of brain death did not play a noteworthy role. 71,3 % of the 1627 families were approached by the attending physician only. In 28,7 % of the family approaches the DSO-coordinator was engaged. The consent rate was 57,4 % in the case the attending physician was not accompanied by a coordinator whereas it amounted to 74,5 % with the participation of a trained coordinator.

Conclusions: Further raise of public awareness is required in order to ensure the persons make up their mind during life time and thus take off the pressure from the relatives. The low consent rate is one of the mayor factors influencing organ donation rates in Germany. Apparently the participation of a coordinator who has profound knowledge about organ donation and enough time during the decision process but also afterwards, is an important factor.

Expanding the donor pool – Liver procurement from a brain-dead kidney transplant recipient – A case study (Abstract P36)

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Objectives: The goal of transplantation is to provide every patient on the waiting list with an opportunity to obtain an organ transplant. According to Polish Transplant Coordinating Centre 'Poltransplant' there were 2212 patients waiting for an organ in Poland on the last day of October 2009. The shortage of organ donors has led to new strategies to increase the availability of allografts for transplantation, such as organ procurement from brain-dead organ transplant recipients. In this

study, a case of a 26-yr-old male brain-dead donor who had received a kidney transplant 6 years before, is presented.

Methods: A case study and literature review. The potential donor was haemodynamically stable, although required positive inotropic medication. The echo study showed lesion typical for hypertonic myocardiopathy. Diuresis was normal although the creatinine level increased significantly. The hepatic function profile was normal and liver enzymes were within normal value range.

Results: The decision was made to retrieve the liver alone and it was successfully transplanted. The liver function remains still normal 5 months after transplantation.

Conclusions: Although transplant recipients represent an uncommon group of deceased organ donors, it is probable that situations when transplant recipients may be considered as potential organ donors will occur more often. This report suggests that brain-dead solid organs recipients should not be excluded a priori as organ donors and their both native and allografted organs may be harvested and successfully transplanted.

Opinion of healthcare workers in France about consent required for organ donation from deceased patient (Abstract P37)

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Objective: To assess what kind of consent for organ donation (brain-dead and donation after cardiac death) is preferred by French professionals working in intensive care unit and operating room.

Method: From November 2007 to April 2008, 221 professionals (on 635 physician or nurses) were interviewed in 6 hospitals (university or regional hospitals) from 6 towns: Créteil, Bicêtre, Suresnes, Evry, Lyon and Bron, during a personal structured interview.

Results: Forty-two percent of professionals (n=93) required donor's explicit consent (EC), 38% of professionals (n=85) considered family consent (FC) sufficient. Presumed consent (PC) was considered sufficient for 18% of professionals (n=39). Eighty-two percent of professionals (n=182) agreed with legal standard PC for organ preservation (femoral cannulation and abdominal cooling or use of extracorporeal membrane oxygenation) while contacting donor's family after determination of death in uncontrolled donation after cardiac death (u-DCD).

Conclusion: While a minority of French professionals agree with the standard PC model, most of them prefer EC or FC. There is no unanimity about which system of consent for or-

gan donation should be required. Nevertheless, there is some agreement on the belief that PC is sufficient for organ preservation in u-DCD protocols, before the family is contacted.

Ethical aspects for establishing of brain death in the ICU (Abstract P38)

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Critically ill patients with neurological disease or with head and brain injury may die in ICU, but death of ventilated patients with circulatory support is not easy to recognize. In these patients many ICU doctors are waiting for irreversible cessation of circulatory functions. They perform the brain death tests only if they believe that the critically ill patient may become the donor of organs for transplantation. In a study carried out by Slovenijatransplant in intensive care units only 53.3 percent of respondents considered that it is necessary to perform a brain death tests in a patient in apnoic unresponsive coma. Procedures for assessing brain death and organ donation for transplantation must be clearly defined professionally and ethically. Therefore, the sequential, regular neurologic examination of all patients is an extremely important part of assessing patient status. If we establish deep coma, the absence of spontaneous respiration and absence of motor responses it is statutory to perform brain death tests. It is our professional, ethical and legal obligation. When we certify brain death we must establish if the dead person is possible organ donor for transplantation. In this case we don't interrupt medical procedures and we continue with procedures to maintain organ functions. Diagnosis of brain death is the basis for reflection on the donation and withdrawal of organs for transplantation. If a dead person is not a possible organ donor we must stop all further life support interventions and we must interrupt all medical treatment and procedures. The determination of the brain death is not part of the donor and transplant program. The determination of the brain death must become a routine procedure at all apnoic patients in deep coma in ICU.

Seeking normality: Life on the kidney transplant list (Abstract P39)

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A study of the life world of individuals waiting for a kidney transplant aimed to provide a descriptive and conceptual understanding of how individuals experience their wait. Thirty qualitative interviews were undertaken with individuals on the UK deceased donor kidney transplant list. The study employed grounded theory methodology. Participants' experiences of waiting for a transplant can be described as, seeking

normality. On a daily basis participants sought to live as normal a life as possible, through the negotiation of symptoms and treatment into daily life, and through the processes of maintaining hope of a transplant and dealing with waiting. Certain contextual factors and resources, such as the ability to work, support of family and friends and information and support from health professionals, enabled or constrained participants in the process of seeking normality. Participants were undergoing a continued process of maintaining their hope of a transplant. They used knowledge of the transplant list and the system of allocation of donated kidneys to understand and rationalise their wait and to respond to challenges to their hope. Participants varied in how much they thought about their wait for a transplant. Some were able to 'bracket off' or 'contain' their hope, while others described frequent and regular thoughts of a transplant. Health professionals should offer personalised information about the allocation of donated kidneys, which takes account of the impact of such information on hope. Support should be available for individuals who are experiencing challenges to their hope.

Ethical issues raised by donation after cardiac death (DCD). Analysis of the ethical challenges according to the French, Spanish and American health care workers (Abstract P40)

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Objectives: The goal of this work is to identify and discuss the ethical concerns that DCD protocols give raise in these three countries. Two kinds of DCD protocols can be distinguished: controlled-DCD (c-DCD) and uncontrolled-DCD (u-DCD).

Methods: 587 French, Spanish and American professionals likely to be involved with organ donors were interviewed during a personal structured interview, in the frame of the «IN-CONFUSE» study performed between April 2007 and April 2008.

Results: 430 professionals (73%) considered acceptable the organ procurement in a protocol of u-DCD and 331 (59%) considered it acceptable in a protocol of c-DCD (no differences between countries for each protocol). 335 professionals (57,1%) considered that the u-DCD protocol raised ethical concern. Professionals from the USA were more concerned with absent family/patient consent for use of ECMO and compromising interest of patient who is a potential donor in favor of interest of potential organ recipients, while Spanish professionals were more concerned with no determination of death by neurological criteria. Organ preservation (femoral canula-

tion and abdominal cooling or use of ECMO) while contacting donor's family after determination of death is recognized as an ethical concern without difference between countries. 372 professionals (63,6%) considered that the c-DCD protocol raised ethical concern. Both French and Spanish professionals were more concerned with no determination of death by neurological criteria. Compromising interest of patient who is a potential donor was a concern for the professionals without difference between countries.

Conclusion: The lack of determination of death by neurological criteria, even if not legally required, as well as the potential of conflict of interest, are main ethical concern related to DCD according to health care workers.

Maintaining anonymity between organ donor's family and recipients (Abstract P41)

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Pressure from the media forced the ethics committee of Quebec's OPO to reexamine this question. OPO is the core organization linking nominative data of the donor to recipients. The question was revised from three viewpoints: values and legal foundations of the health care system, advantages and risks for parties involved: donor's families, recipients and OPO personnel, and risks and advantages for the donation system in itself. Historically, this rule imposed itself progressively based on difficult experiences, abuse and exploitation of parties involved. It rallies a large consensus in Europe, Australia and Canada. Many American OPO, but not all, offer organized meetings between donor's families and recipients. Our health system is founded on confidentiality of personal medical data even after death. Justice is maintained with equality of chance based on anonymous attribution of organs. Autonomy of the organ donor is maintained by not revealing his identity and recipients are protected by respect of this rule. For donor's families and recipients, psychosocial risks and advantages are difficult to establish. The organ is perceived differently by both parties. For the donor's next-of-kin, the organ may remain a living part, embodying survival of his loved one. Establishing contact may bring closure. On the other hand the recipient has to incorporate the organ and, although being grateful, do not want personal details. Demands on the part of recipients are rare. And beforehand, apprehending how both parties will react to the encounter and analysing the mourning process of the donor's family may demand specialized abilities mastered by mourning specialists but not coordinators. Therefore risks may prevail over advantages. Donation system operates on the basis of human solidarity and although data are rare, there is no evidence that anonymity is deleterious to the donation system.

The Eurodeath project on the definition of death

(Abstract P42)

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Introduction: Most European countries accept a dual standard for determining death: total brain failure and irreversible circulatory arrest. Nevertheless, their policies differ with regard to the specific tests and requirements to determine irreversible loss of brain and/or cardiac function. Some have questioned the conceptual validity of both standards in the context of organ donation (President's Council 2008). To better understand the extent to which these conceptual debates may have an impact in practice, some surveys have been performed within general public and health care workers involved in the determination of death and organ donation (Youngner et al. 1989; Siminoff et al. 2004; Dubois et al. 2004; Rodríguez-Arias and INCONFUSE study group 2008).

Methods: To complete these reflections and assess their impact in Europe, an ELPAT interdisciplinary workgroup of researchers including not only doctors but also philosophers, lawyers, anthropologists..., participated in the design of a questionnaire, which was drafted by the co-signatories. It will be tested in 8 European countries before using it in a larger number of European countries.

Objectives: This research aims at three objectives: 1. to analyze and compare health professionals' knowledge and beliefs regarding the dual standard; 2. to assess and compare their attitudes towards organ procurement, and 3. to elicit their underlying concepts of death and personhood. In this communication, the methodology of this research will be discussed. The procedure of the adaptation of the questionnaire and some methodological choices that have been done will be explained. The French pilot study results will be presented. Finally, the participation of new countries will be proposed.

Face transplantation: Ethical considerations of the donor side in the French experience

(Abstract P43)

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Face transplantation raises multiple questions with regard to the donor side. We analyzed the impact of such harvest on the deceased person, his/her family, and the well-being of the recipient. We first exposed the significance of the face in the common mind. Face transplantation is a biomedical research rigorously framed by the law. We used the four principles of

Beauchamp and Childress, which are relevant to clarify medicine questions, to study the consequences of the face harvest on the donor. The face is central to understand our identity and primordial for communication with other people. The Public Health Code assimilates face transplantation with other organ grafts. The National Consultative Ethics Committee for Health & Life Science states that full facial transplantation could not be recommended for the time being, only in research program. The Biomedical Agency and the French Agency for the Security of Health Products ensure the family consent, the body restoration and the medical protocol used. The first principle of Beauchamp and Childress insists on the respect of the autonomy of the individual. The donor can give his consent while alive; in other cases expressed consent of the family is required. Non-maleficence, the second principle, insists on the body donor restoration and the anonymity. The principle of benevolence needs to ensure the well-being of the recipient. The last principle of justice justifies the research for the future generations. Facial transplantation is a promising therapeutic research area, which demands a specific approach of the donation act. The personal history of the donor is involved. Legal laws are here to control this biomedical research procedure. Ethical approach would suggest that when deceased body respect and anonymity would be acquired, the balance would favor the face donation.

The ethics of extracorporeal support of donation after cardiac death (Abstract P44)

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In most countries of the world, it is considered ethical to recover organs from donors that are declared dead based on the absence of spontaneous circulation. This has been termed Donation after Cardiac Death (DCD). Extra-Corporeal Support (ECS) is a means of artificially assisting or replacing cardiovascular circulation. ECS can allow an individual to remain alive despite the absence of cardiac function and breathing. ECS is now used in some countries to assist circulation after the declaration of death by cardiac criteria. The ethical basis for this practice has not been clearly established. This study will review the ethical basis for organ donation, the "dead donor rule", and the impact of ECS on this rule. Conclusions and recommendations on ECS assisted DCDD will be given. It is now clear that DCD is a misleading term. It implies that the heart itself has died, yet hearts have been transplanted following cardiac arrest. A more accurate term for the practice of recovering organs following cessation of cardiac activity is Donation after Circulatory Determination of Death (DCDD). The key concept is that the donor is dead when circulation has ceased. ECS is used to assist DCDD in three circumstances: donors that fail resuscitation (Maastricht Type 1/2), donors that undergo planned withdrawal of life support (Type 3), and brain dead donors that develop cardiac arrest (Type 4). The appropriateness of ECS support, and the necessary components of ECS assisted DCD protocols in each scenario will be examined and discussed in detail. The overall conclusion will be that ECS supported DCDD can be done in an ethical manner

and to the extent that it can increase the utilization of organs from DCDD, it should be expanded.

Professional experience of critical care staff impacting on comfort levels with donation related tasks (Abstract P45)

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Critical Care (CC) staffs' confidence with the donation process is correlated with subsequent success rates in obtaining consent for donation. We investigated whether CC staffs' professional experience impacts on their self-reported confidence levels with donation related tasks. Donor Action (DA) Hospital Attitude Survey data was collected from 3,040 medical and 12,551 nursing staff involved with donation in 162 hospitals from 5 European countries between January 2005 and May 2009. Respondents were surveyed on their confidence in: notifying a transplant coordinator or OPO about a potential donor (Q1), explaining brain death to relatives (Q2), introducing the subject of organ donation (Q3), obtaining consent for donation (Q4). Results are expressed as % of staff feeling comfortable with individual tasks. Professional experience was categorized as < 1 yr, 1-5 yrs, 6-10 yrs, 11-20 yrs and > 20 yrs. Data was entered to the DA System Database for analysis. Self-reported confidence levels increased significantly with years of experience amongst medical staff, from 56.9 to 80.7% for Q1 (P<.0001), from 50.4 to 76% for Q2 (P<.0001), from 43.9 to 70.1% for Q3 (P<.0001) and from 39 to 59.8% for Q4 (P<.0001). On average, and irrespective of professional experience, nursing staff felt significantly less comfortable with each task compared to medical staff: Q1: 45.3 vs. 72.4% (P<.0001), Q2: 30.8% vs. 67.6 (P<.0001), Q3: 34.3% vs. 60.8% (P<.0001), Q4: 21.2 vs. 52.6% (P<.0001). Rather than excluding younger staff members from the donation process, these findings urge more experienced staff to coach and train their younger colleagues in donation related matters. Nursing staffs' inferior confidence levels demonstrate the need for customized training so as to impact on their skills and ultimately increase donation rates.

Donor age related conversion rates in 5 European countries: Donor action evidence based data demonstrating an unexploited potential (Abstract P46)

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Background: The conversion rate of potential into actual donors is accepted to be the gold standard to assess countries' performance in organ donation. The study investigated donor

age specific differences in conversion rates for organ donation between 5 European countries.

Methods: A total of 49,130 Donor Action (DA) Medical Record Review (MRR) files were collected from Critical Care deaths between January 2006 and June 2009 (Belgium: n=17,663, Finland: n=2,447, France: n=20,821, Poland: n=1,163, and Switzerland: n=7,036). According to DA's MRR algorithm, 'potential donors' are defined as medically suitable and ventilated patients meeting all criteria for brain death diagnosis. Donor age categories were < 30 yrs (potential: n=674), 30-49 yrs (potential: n=1,223), 50-69 yrs (potential: n=1,942) and 70+ yrs (potential: n=1,039).

Results: Average total conversion rates were 39.5% in Finland, 39.4% in France, 35.4% in Belgium, 34.8% in Switzerland and 28.9% in Poland (P=.0007). Aggregated conversion rates were highest in the < 30 yrs group ($41.3 \pm 6.4\%$), and 30-49 yrs (41.6 ± 3.5), to decrease to $36.5 \pm 9.5\%$ (50-69 yrs) and $18.4 \pm 8.4\%$ in the 70+ yrs group. In the age groups of < 30 and 30-49 yrs., conversion rates were highest in Belgium (48.5 and 46.5% respectively) and lowest in Poland (36.7%) and Switzerland (32%). In the age group 50-69, France scored highest (44.3%) and Poland lowest (20.1%, P<.0001). In the age group 70+, France scored highest with 30% and Finland lowest (12%, P<.0001).

Conclusions: DA's MRR methodology is a powerful and standardized tool to assess countries' conversion rates of potential into actual donors. Markedly different conversion rates between countries demonstrate a significant room for improvement of donation practices, particularly for older donors.

Psycho-social outcome in liver transplanted children: Be aware of emotional self assessment! (Abstract P47)

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Background: Psycho-social outcome in children after liver transplantation (LT) is known to be inferior to age-related peers. Yet, when children and their parents are questioned by their nurse or their physician about the child's psycho-social well-being, the answers usually are very positive. We hypothesised that patients and their parents after LT report their psycho-social well-being too enthusiastically when enquired by their personal care takers.

Patients and methods: Inclusion criteria: LT at the Children's University Hospital of Geneva 1992-2007, age >3 years, <16 years, time after LT >2 years. Children and their parents were questioned by their well-known nurse at the annual follow up visit about their personal well-being. To allow for evaluation of answers, scores (good, medium, bad) were attributed to the different standardized questions (see results). 46 children were included in this study. 27 (59%) were transplanted for biliary atresia, 13 (28%) for other cholestatic liver disease, 2 (4%) for fulminant hepatitis, 4 (9%) for metabolic disease.

Results: Mean age at enquiry was 9.7 years (SD 4 years), mean time after LT was 7.5 years (SD 4.2 years). The different themes were reported as good for: parent-child relation-

ship (83%), relationship with peers (98%), relation with siblings (39%), sport activities (54%), play activities (78%), school performance (87%), expression skills (67%), and general behaviour (89%).

Conclusion: Most of our LT children and their parents consider, during a personal interview with a closely related nurse, that the child's psycho-social outcome is good; only relationship with siblings seemed to be negatively affected. It is generally acknowledged that children after LT have negatively altered psycho-social outcomes. Emotionally influenced reports about psycho-social outcome in children after LT must be looked at with care.

Eating habits predict outcomes in patients awaiting heart transplantation: The waiting for a new heart study (Abstract P48)

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Objective: For patients with heart failure a diet rich in polyunsaturated fatty acids, but low in salt, and moderate alcohol consumption are beneficial. We investigated the role of these eating habits for the prognosis of patients awaiting heart transplantation (HTx).

Methods: A multi-site prospective study was conducted with 58 female and 260 male (51 ± 1 and 53 ± 5 years of age) new HTx candidates enrolled at 17 German-speaking hospitals. Baseline demographics, eating behavior and alcoholic beverage consumption were assessed by food frequency questionnaires. Eurotransplant provided medical characteristics to determine disease severity and 2 year waiting-list events (death, delisting due to clinical deterioration, high urgency HTx, elective HTx, delisting due to improvement). Applying cause-specific Cox Proportional Hazard regression, we investigated whether consumption of foods rich in polyunsaturated fatty acids, foods high in salt, and alcohol intake predicted death/deterioration and high-urgency HTx.

Results: After 2 years (median = 338 days, range 13-1394 days) 54 patients died, 15 were delisted due to deterioration, and 110 received high urgency HTx. Independent from age, sex, body mass index, and disease severity, frequent consumption of foods rich in polyunsaturated foods was associated with a lower risk for death/deterioration (hazard ratio [HR]=0.45, 95% confidence interval [CI] 0.23-0.89, p<.05). A positive effect of alcohol consumption for this outcome emerged only in men (HR=0.28, 95% CI 0.12-0.68, p<.01, interaction with gender p<.07). Consumption of salty foods did not affect death/deterioration, but was associated with a shorter time till high-urgency HTx (HR=2.62, 95% CI 1.45-4.73, p<.01).

Conclusion: Eating habits of HTx candidates appear to influence their prognosis while waiting for a new heart. This finding suggests that this patient group may benefit from dietary interventions that contribute to the stabilization of patients' health.

Dark side of the moon – Suicide after LVAD-implantation as a destination therapy (Abstract P49)

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Left ventricular assist devices (LVAD) are increasingly used in patients with end-stage heart failure as a destination therapy. Not all patients benefit durably from their improved quality of life under VAD-support. For some of them many psychological items might be a source of problems in their life far from normal. Depression and anxiety are well-documented in patients with end-stage heart failure and correlate with a higher risk of suicide. This case reports about a 69 yrs old, depressive patient, who committed suicide by disconnecting his driveline almost three years after implantation of a LVAD. We provide a medical, psychological and psychiatric background of this unique case. To the author's knowledge, a published report of suicidal attempts after LVAD implantation does not exist. The device itself might give depressive patients a new opportunity of committing suicide. The inhibition threshold seems to be dramatically decreased by an every day handling like changing the batteries or connecting/disconnecting the driveline of the controller in comparison to more rude suicidal attempts like hanging oneself or shooting oneself down. This report highlights the importance of pre-implant psychological screenings, the need for regular and long-term psychological support for this vulnerable patient population, and the need for more research on the patients' views on „living with an LVAD“ (qualitative research), together with research exploring risk profiles for depression/suicide. A debate about palliative care and end-of-life decisions after LVAD implantation as a destination therapy would be helpful as well.

Gender-specific differences in living donor liver transplantation – A review study (Abstract P50)

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Living donor liver transplantation (LDLT) has developed into an important therapeutic option for liver diseases. Regarding living donor kidney transplantation (LDKT), gender-specific differences have been observed concerning both donors (two-third women, one-third men) and recipients (two-thirds men, one-third women). Aim of this study is to examine whether there is a gender disparity for LDLT. We contacted 89 national and international transplantation registries, single transplant centers and coordinators. Additionally a sample of 274 articles dealing with LDLT and their outcome were reviewed and compared with registry data. The data include the gender of donors and recipients, the country of transplantation and the donor-recipient relationship. The investigation showed that overall there are slightly more male donors (53% male, 47%

female). Regarding to the recipients, 59% of the organs were distributed to men and 41% to women. Differences in the gender-distribution were observed regarding individual countries. Especially in Asiatic countries a lot more recipients (70%) and donors (59%) are males. Worldwide 80% of the donors are blood related, 11% are not blood related and 9% are spouses. In Europe and Asia there are more spouses than not blood related donors. The data acquired from the publications is similar to the registry data. Our research has shown that there are hardly any registry data published, a lot of countries don't have national registries or the access to these data is difficult. Therefore reviewing publications is important to acquire data for countries where numbers on LDLT aren't available. But even wide range published studies often don't give information on the gender distribution and the donor-recipient relationship. Further investigations are needed to understand the possible medical, psychosocial or cultural reasons regarding gender distribution in LDLT and the difference compared to LDKT.

Body-experience after liver transplantation – A body-grid examination (Abstract P51)

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Introduction: Living with a donated organ raises not only clinical aspects, as surgery risks and possible graft-rejection, but also questions regarding the psychological integration of the donor organ and the bodily experience of the recipients. From a surgical point of view a liver transplantation is considered a successful life saving therapy. Yet, the recipients are those asked to cope with the liver transplantation and its impact on their bodies and lives. This study presents findings concerning the psychological outcome of liver recipients and their body-experience after liver transplantation. Research questions:

1. How is the liver integrated in the body-experience of the recipients?
2. How is the donor liver described and experienced by the recipients?
3. Are there differences concerning the organ integration and the body-experience between recipients of a living donation (LDLT) and ones who received a deceased donation (LTx)?

Methods: To study the subjective body-experience and the integration of the donor organ we used the repertory grid technique by Kelly based on his theory of personal constructs (1955). This technique for eliciting and analyzing personal construct systems combines an individual questionnaire and a semi-structured interview and allows a qualitative and quantitative approach simultaneously regarding the data selection and analysis. Sample: Recipients of a LDLT and LTx were examined. The sample consists of 13-15 patients for each group. The two groups were matched for age, gender, year of transplantation and type of liver disease.

Results: The results depict the body-experience of recipients after a liver transplantation and how they perceive compared to each other the integration of the donor organ in their body.

Differences between the LDLT and LTx group are discussed, as well as implications of the results for improving the treatment and psychological counselling of the recipients.

Stressful events at the onset of type 1 diabetes in recipients of kidney-pancreas transplantation

(Abstract P52)

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Introduction: Events that are experienced as stressors can overwhelm the capacity of mental resources available to face them and, based on organic predisposition, result in the triggering of a variety of physiological responses. In type 1 diabetes, stress has been associated with the onset of the disease. **Objectives:** To study events experienced as stressful, associated with the onset of type 1 diabetes in patients who received kidney-pancreas transplantation (KPT).

Patients and Methods: Type 1 diabetic patients with end-stage renal disease who underwent simultaneous kidney-pancreas transplantation from October 1994 to April 2009 (n=78; female, 39; male, 39) were assessed by semistructured interviews of psychosocial evaluation. Quantitative and qualitative data were processed with the SPSS statistical programme.

Results: The average age of onset for type 1 diabetes was 11.5 years, rank: 2 years-28 years. Events which were considered as stressful and were associated with the onset of type 1 diabetes were referred by 52/78 patients, 11/78 did not refer related events while 15/78 had no data. No difference was observed according to the sex of the patient. Among patients referring stressful events, 55% were death of relatives, loss of relatives from diseases with risk of life, or rupture of significant liaison; 20% were accidents or risky situations; 12% were situations perceived as highly demanding; 8% diseases; 5% conflicts or discussions with significant relatives.

Conclusion: In this population, the loss of significant personal relationships has been associated with the onset of type 1 diabetes.

Evaluation of patient quality of life after simultaneous kidney-pancreas transplantation: A fifteen-year experience at a single center

(Abstract P53)

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Introduction: Kidney-pancreas transplantation (KPT) not only restores renal function and eliminates the need for exogenous supply of insulin but also improves the quality of life

(QOL) of patients. However, no uniform criteria are accepted regarding how to evaluate this latter issue.

Objective: To describe the socioeconomic profile, the results of satisfaction according to previous expectations, and the subjective perception of quality of life in KPT.

Patients and Methods: Psychosocial semi-structured interviews before KPT n= 78, from 10/94 to 4/2009. In 6/2009 n= 57 were interviewed after KPT. Mean time between TX and interview 55 months (rank 161 m- 3m). SPSS quantitative/qualitative analyses.

Results: Actuarial patient survival rate at 1 year and 5 years were 92% and 86%. Pre-transplant: 39m/39f, mean age at transplant, 31.7 years, D.S. 6,05; married, 49.5%; capable of working, 40.5%; high school, 63%. With regards to the family support subjective perception, 43% "Very good". The most frequent (47%) expectation was improving QOL. The emotional affective state was good in 52%. Post-KPT: 31m/26f; mean age, 37.5, D.S. 6,83; married 39%, capable of working, 55%. Satisfaction with transplantation was "Very satisfied" in 91.22%; while 94.73% referred that "I would decide to transplant again". Matching with expectations built at the pre-transplant period was "Very much matched" in 47%. The QOL was perceived as "Much improved" in 86%. QOL improvement in psychological aspects (mood improvement) was seen in 89%, labour aspects, 49%, and social-familiar environment, 42%.

Conclusions: This series of patients studied reported satisfaction with KPT, fulfilling previous expectations, and improving QOL. Improvement was perceived both in the physical as well as the psychological status, and by a better capacity for working. Moreover, almost all patients concluded that, given the necessity, they would get transplanted again.

Psychological evaluation of family and social support and health care compliance in patients with kidney-pancreas transplantation (Abstract P54)

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Introduction: The importance of the role of family support and compliance of health care is highlighted by numerous investigations in different transplant (TX) programmes.

Objectives: In relation to family and social support, a) To describe the characteristics observed, b) To identify factors in the subjective perception of the patient, c) To analyse changes in perception during the post-TX, and d) To analyse relationships between perception and implementation of health care.

Patients and methods: Type 1 diabetic patients with end-stage renal disease receiving kidney-pancreas TX (n= 78) between 10/94 and 4/09 were evaluated with semi-structured psychosocial assessment interviews pre- and post-TX. SPSS quantitative/qualitative analysis.

Results: Pre-transplant (n=78) 39 male/39 female. Mean age 31,7 years, D.S. 6,05; 49,05 % married, 50% had children, 40,5% were working. The subjective perception of family relationships 61,5% good/very good, 27% regular/conflicts, 11,5% no data. Less satisfactory relations were observed in

patients younger than <45 years, female gender, and those with greater financial dependence. As conflictive situations, men were associated with work problems and reliance on others for care while in women it was related with family and partner relationships. Family conflicts, non-family partnerships and deaths were referred to as obstacles to implementing health care. The subjective perception of having good family support tended to match attitudes of better compliance with care. Post-TX interview (n=57) 31 male/26 female; mean age 37,5, D.S. 6,8; 39% married; 50% had children; 55% capable of working. The subjective perception of family relationships were observed as Good/Very good in 85% of patients.

Conclusions: This population had mostly a subjective good or very good perception of family support, improving at the post-transplant period. Good family support tended to match attitudes of better compliance with health care.

Evaluation of effectiveness of information for the candidate to kidney donation (Abstract P55)

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Living donation has been attracting a growing interest among patients, relatives and friends, shown by the greater demand for information as well as the involvement of more and more professionals. We have created an information sheet (SICADR) that summarises the essential information in simple sentences with the best balance of scientific precision and comprehensibility. Purposes are to standardise the information given by different professionals, improving the completeness of the information itself, as well as verifying and documenting the awareness of the potential donors. Aim of this study is to determine the effectiveness of SICADR in facilitating the knowledge process in the potential donor: subjects living the experience of being kidney donors were consulted; all these latter were in a psycho-physically good state, even after a few years from the surgery. Another aim was to assess the existence of a link between personality characteristics and motivation to donate, and whether this link can affect the learning process. All Italian subjects donating a kidney 1993 to 2004 at the Niguarda Ca 'Granda Hospital-Milan, were sent a letter making the proposal of a telephone interview, those who agreed were interviewed, respecting the confidentiality of data collected. The interview was made by four parts: assessment of psycho-physical wellbeing, personality traits (BIG-FIVE), evaluation of SICADR; motivations to donate. The data analysis has allowed a first evaluation of SICADR and highlighted the links between motivations to donate and some personality factors: open-mindedness and emotional stability.

Coping strategies and self efficacy as a mediator of quality of life in renal transplant patients

(Abstract P56)

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Background: Although renal transplantation brings many benefits to patients, it is potentially associated with a number of drawbacks, which include constant risk of rejection, the need to comply with a complex medication regimen capable of producing pronounced side effects, and the need for ongoing medical supervision.

These drawbacks are considered as stressors for patients (Fallon, 1997).

Purpose: The purpose of this study is to investigate the relationships among transplant-related clinical factors, cognitive appraisal of health, perceived self-efficacy, coping, and health-related quality of life in renal transplant patients using a theoretically derived mode in Middle East population.

Methodology: A descriptive, correlational, cross-sectional design with a sample that includes patients at two distinct periods post-transplant (less than 1 year) and later (1-5 Years post transplant) will be used to examine coping and HRQOL in renal transplant patients. In this study, cognitive appraisal of health, perceived self-efficacy, coping strategies, will be measured. This study will be conducted at our transplant center located in KSA (Eastern Province).

Sample Characteristics: Targeted population is adult renal transplant recipients. Accessible population is renal transplant recipients who are managed at our center and meet the inclusion and exclusion criteria.

Sample Size: Using a descriptive cross-sectional design, a convenience sample of 70 participants post renal transplantation will be recruited N=30 < 1 yr post transplant; N=40 1-5 yrs post transplant.

Instruments: The Cognitive Appraisal of Health Scale (Kessler, 1998), The Brief COPE (Carver, 1997), Quality of Life Index (QLI)-Transplant Version, Brief Symptom Inventory (BSI). Kidney Transplant Questionnaire Statistical Analyses Data will be analyzed using SPSS computer software. Statistical significance will be considered at P<0.05.

Expected Conclusion: Our study will shed light on the significance of applying coping strategies in patients and the holistic and dynamic interventions including physical and psychosocial components, that are needed to help renal transplant patients cope with transplantation and improve their QOL.

Donors and recipients perceptions after living kidney donation (Abstract P57)

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Perceptions of donation have been evaluated in several living organ donation programs for donors; evaluation of associated recipients is not as frequent.

Aim: To evaluate perceptions of donation in formal and emotional aspects, in donors and recipients after transplantation; compare two groups.

Methods: 34 recipients (mean age 37,34) and 45 donors (mean age 41,2), completed a Sociodemographic and a Donation Perception Questionnaire after transplantation.

Results: Donors were: female 57,8%. Recipients were: 62,9% male. Siblings were 53,3% and parents 44,4%. 65,7 % recipients thought that the motivation for donation was self determined and 20% that it was suggested by medical team; 77,1% responded it was donor's wish; 51,4% had serious or some doubts in accepting and for 48,6% it was an easy decision. 100% classified as special the relationship with donor and 80% thought that after donation it was the same; 17,1% declared it was "a little better". Among donors: 88,9% decided by themselves, 8,9% were asked for donation. When there was donor's initiative, his wish was the main reason (91,1%), 8,9% felt a moral obligation, 77,8% felt it was an easy decision; 17,8% hesitated a little. 84,4% were not worried about their future health. 86,7% classified as special the relationship with recipient and 71,2% thought that after donation it was the same; and for 17,8% was "very much better". 97,8% stated that they would donate again if it was possible. Recipients: emotions towards donor (34%): gratitude (26%), feelings of joy, feelings about themselves (74%): better QoL (37%), positive life changes (46%), positive emotions, joy and elation (23%). Donors: positive feelings towards recipients: improvement of emotional life (56%), and QoL/giving life; towards themselves: self valorisation (31%).

Conclusions: Donors and recipients had very positive perceptions about donation (specially QoL and emotional improvement).

Quality of life in living kidney donation: Donors and recipients evaluation (Abstract P58)

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Background: Quality of Life (QoL) of donors has been an important concern in living donor kidney donation programs. Investigation of QoL in associated recipients is not as frequent. Since 2002 a protocol of psychosocial evaluation which included QoL evaluation for donors and recipients was performed in the living kidney donation program.

Aim: To evaluate QoL dimensions in donors and recipients, before and after transplantation; compare two groups.

Methods: 34 recipients (mean age 37,34) and 45 donors (mean age 41,2), completed before and after surgery a Sociodemographic Questionnaire and Short-Form 36 Health Survey (SF-36). Wilcoxon test was used to analyse SF-36 for each group, considering the two moments. Mann-Whitney Test was performed to verify differences between the two groups.

Results: Donors sociodemographic characteristics were: 26 female (57,8%) and 19 male (42,2%); 77,8% were married. They were siblings (53,3%), parents (44,4%) and a daughter. 42 were active (93,3%) and 3 were retired from profession. Recipients sociodemographics: 37,1% were female and 62,9% male. 71,4% were married; 48,6% were active, and remaining were retired and not working because of renal disease; 3 were unemployed. Recipients had higher values ($p < 0,001$) for every dimensions with exception for Health Change after surgery. In donors, no change was important ($p > 0,005$). Before surgery, recipients had lower values in all dimensions ($p < 0,005$) with the exceptions of Health Change and Mental Health that were not significant. After surgery, only Social Function was poorer ($p < 0,005$).

Conclusions: More females are donors and less are recipients. Most of donors were siblings and parents. All donors were related (Portuguese law of unrelated donation appeared in 2007). After surgery, QoL significantly improved in recipients and was not poorer in donors. QoL was significantly poorer in recipients before surgery.

Relationship between social and psychological diagnoses in assessments for intrathoracic transplantation (Abstract P59)

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Introduction: Both psychological and social evaluations are part of interdisciplinary studies that candidates for intratho-

racic transplant usually undergo. In our experience, we have proved that an isolated evaluation dichotomizes patient's reality, and provides a partial view of the patient's situation.

Objectives: 1. To find out dependence between the psychological and social diagnoses in transplant assessments. 2. To analyze whether social variables condition psychological variables or vice versa.

Materials and methods: Between January 2, 2001 and March 1st, 2005, 331 psychosocial evaluations obtained after both individual and family interviews, social visits and self-administered diagnostic techniques (Zung's depression test and STAI anxiety test) were assessed. CATEGORIES: SOCIAL CATEGORIES: Apt; conditionally apt (CA), aspects to be figured out in the short and long term; Social risk (SR). Several variables to be dealt with in the middle and long term; temporarily non apt (TNA), structural problems calling for a social structural change.

Psychological categories: C1 without contraindication, C2 needs follow up. Anxiety and depression high levels C2HPR, high psychological risk. Severe neurosis, lack of adherence personality disorders, history of psychiatric disorders and addictions; C3: inclusion not recommended. Overt Psychosis. Addictions. Psychopathic personalities.

Results: Diagnoses were as follows C1: 75 (22.6%); C2: 186 (56%); C2HPR: 50 (15%); C3: 20 (6%); Apt: 191 (57.7%); CA: 99 (29.9%); SR: 29 (8.7%); TNA 12 (3.6%) Variable crossover showed that: 40% (8) of C3 were either RS or NAT 20% (10) of C2HPR were TNA/SR 31% (9) of SR were either C2HPR or C3, 75% (9) of TNA were either C2 HPR or C3.

Conclusions: Dynamic dependence was observed among the psychosocial variables. It becomes necessary to work together to improve the patients' conditions in order to apply for transplant programs. Also, marked social difficulties trigger psychological symptoms such as depression, anxiety, both distress and stress and vice versa.

Quality of life after living kidney donation

(Abstract P60)

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Kidney transplantation is the best treatment of end-stage renal disease. The benefits for recipients are obvious. The consequences for living kidney donors appear to be not so clear. The objective of the study was to evaluate the quality of life after living kidney donation. Patients and methods: A total of 66 living donor open nephrectomies were performed in our centre between 1995 and 2005. The quality of life was assessed in 40 donors after nephrectomy. The study applied The Satisfaction

With Life Scale (SWLS), the Situation Assessment Questionnaire, the Health Behaviours Survey and our own questionnaire. Donor mean age was 46.14 years. Mean observation period was 65.6 months.

Results: The mean SWLS score in the investigated group was 22.25. There was a trend towards better life satisfaction in living kidney donors compared to Polish adults. The mean SWLS score in living kidney donors was significantly higher than in dialyzed patients in Poland. The donor life satisfaction was significantly lower when the recipient was dead than when they were alive. Most donors perceived the kidney donation as a challenge in cognitive judgement. Mean score of the Health Behaviours Survey was not significantly different than in general population in Poland. Mean pain score after donation was 3.2 in 5-item scale (1- severe pain, 5-mild pain). Mean time of return to work was 3.5 months. Living kidney donation in Poland has a positive impact on donors' quality of life except when the recipient died.

Influence of psychosocial variables in the outcome of intestinal transplant recipients

(Abstract P61)

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Introduction: The psychosocial assessment is an important part of the pre transplant (TX) interdisciplinary evaluation. Previous studies done at our institution showed that in the intrathoracic pre TX evaluation the psychological items were independent factors that conditioned social variables and the post transplant evolution.

Aim: To observe the relationship between psychosocial variables and the clinical prognosis in intestine transplant pediatric patients.

Material and Methods: From March 2006 to March 2009, 30 patients were evaluated for intestinal TX, 24 psychosocial evaluations were pediatric. The diagnosis (D) was obtained through both individual and family interviews, social visits and self-administered diagnostic techniques.

Social categories: Apt (A); conditionally apt (CA); Social risk (SR).

Psychological categories: C1 without contraindication, C2 needs follow up, C2HPR, high psychological risk.; C3: inclusion not recommended. 4 young patients who presented severe social difficulties and different psychological diagnosis at the pre TX assessment have been analyzed. L; D; H and S 16, 1, 5 and 11 years old respectively, all of them men, mean age 8.2 yrs.

Results: Diagnosis / Tx (12)/ No Tx (12) A-C1 / 3 / 1 A-C2 / - / 2 AC-C1 / 3 / 3 AC-C2 / - / - AC-C2HPR / 1 / 1 AC-C3 / - / 1 SR-C1 / 2 / 1 SR-C2 / 3 / 2 SR-C3 / - / 1 Pte./Years/TX/Time in list/SocialD/PsychologicalD /Evolution Pos tx L/ 15/ 11-10-06/ 88 d/ CA/ C2HPR/ Chronic rejection H/ 7/ 12-07-09/ 322d/ SR/ C1 /OK S/ 12/ 6-11-08 / 28 / SR/ C1 /OK D/ 1/ - / - / SR / C3 /non list

Conclusions: The personality, the way of behaving and the capacity of resilience and adaptation together with the social

support, affective and the good family functioning may condition the abilities to improve the basic social difficulties that allow access to the transplant program and have an impact on the prognosis.

Non-compliant teenage transplant recipients

(Abstract P62)

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St. Joseph's University, Philadelphia, United States

Organ transplant recipients make a life-long, life saving commitment to themselves, their families, and society. For teenage transplant patients, they have multiple issues that affect them. Not only are they in a chronic state of sickness, they are going through a state of rapid physical and psychological growth. Teenagers must deal with not only „adult“ medical problems, but also the normal pains of growing. When a teenager receives a transplant, the decision is generally made by a parent. When the teenager receives the age of 18, they are now considered an adult. What happens when the „adult“ teenager becomes noncompliant? This presentation will discuss the ethical implications of the new adult (autonomy versus social justice) but also the ethics of re-transplantation due to non-compliance.

*K. Conrad, E. K. L. Chan, M. J. Fritzler,
R.L. Humbel, P. von Landenberg, Y. Shoenfeld
(Eds.)*

From Pathogenesis to Therapy of Autoimmune Diseases

In the spectrum of immunological diseases affecting various organs by inflammation and/or fibrosis, autoimmune reactions play an important role. Based on different studies both in humans as well as in animal models it becomes obvious that there is a broad range of pathologies that involve not only "primary" autoimmune reactions but also other pathogenic mechanisms such as postinfectious and autoinflammatory processes. The heterogeneity within the immunological diseases may reflect the variable expression of autoinflammatory, autoimmune, and up to now unknown factors in disease development and manifestation. Based on histological and immunohistochemical examinations, IgG4-related sclerosing disease has been proposed as a novel clinicopathological entity with autoimmune phenomena but unknown etiology (chapter 1). The clarification of the etiopathological mechanisms is required to optimize prophylaxis, diagnostics and therapy. Especially, the application of novel and designer biological therapies (chapter 8) requires a better understanding of the processes that are involved in the genesis of immunological diseases. In chapter 2, some aspects of the role of epigenetic mechanisms and innate immunity in the pathogenesis of autoimmune diseases are described. Regardless of the underlying pathology, disease-associated autoantibodies are important biomarkers for the vast majority of non-organ and organ specific autoimmune diseases. However, to improve our understanding of these diseases and serological diagnostics it is necessary to search for novel autoantibodies, to further evaluate the real clinical relevance of known autoantibodies and to further develop and standardize the detection methods (chapters 3-5). Pathogenetic aspects as well as aspects of the serological diagnostics, including novel autoantibody specificities, novel methodologies and evaluation studies are presented for rheumatoid arthritis, systemic lupus erythematosus, antiphospholipid syndrome, systemic vasculitides, systemic sclerosis (chapter 6) and various organ specific diseases (chapter 7). In summary, the present volume highlights novel insights into the immune dysregulation, pathogenesis, serological diagnostics and biological therapies of autoimmune diseases.

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G. Kirste (Hrsg.)

Nieren-Lebendspende - Rechtsfragen und Versicherungs-Regelungen für Mediziner

Angesichts der Diskrepanz zwischen dem Bedarf und der Anzahl der für eine Transplantation zur Verfügung stehenden Organe toter Spender ist in den letzten Jahren der Anteil der Nieren-Lebendspende-Transplantationen deutlich gestiegen. Die Ergebnisse nach Lebendspende-Transplantation sind teilweise sogar besser als nach Transplantation von Organen toter Spender. Dank zahlreicher medizinischer Fortschritte eröffnen sich auch in diesem Bereich zunehmend neue Möglichkeiten. So können heute auch Organe zwischen nicht verwandten Spendern und Empfängern erfolgreich transplantiert werden. Doch die neuen Möglichkeiten werfen auch neue Fragestellungen und Probleme auf, die es erfordern, neue Grenzen zu ziehen. Dabei ist nicht nur die Medizin gefordert, sondern auch Psychologie, Ethik und Rechtswissenschaften. Nicht zuletzt sind auch vielfältige sozialversicherungsrechtliche Aspekte zu berücksichtigen.

Im Mai 1999 fand in Hinterzarten unter Vorsitz von Prof. Dr. Günter Kirste und Dr. Joachim Böhler, Freiburg, ein Workshop zum Thema Nieren-Lebendspende statt, an dem zahlreiche Fachleute aus dem In- und Ausland teilnahmen. In einer Reihe von Referaten erläuterten verschiedene Experten die vielfältigen Aspekte der Lebendspende aus ethischer, juristischer und medizinischer Sicht. Darüber hinaus wurden zahlreiche Fragen und Probleme in angeregten und teilweise sehr kontroversen Diskussionen aufgegriffen und erörtert, an denen sich neben den Referenten auch viele Anwesende aus dem Auditorium beteiligten.

Einen Themenschwerpunkt bildete die psychologische Evaluation beim Spendewilligen und beim potentiellen Empfänger einer Lebendspende. Aus ethischer und psychologischer Sicht wurden verschiedene Entscheidungskriterien vorgestellt und erläutert, die teilweise bereits praktische Anwendung finden. Anhand von Fallbeispielen wurden besondere Probleme und Fragestellungen dargestellt, wie z.B. die Anonymität zwischen Spender und Empfänger.

Mehrere Referate befaßten sich mit rechtlichen Grundlagen und Voraussetzungen zur Lebendspende. Dabei wurde auch auf aktuelle Rechtsfragen und die mögliche weitere Entwicklung auf diesem Gebiet eingegangen. Die Beiträge wurden durch die Stellungnahme eines Vertreters des Bundesgesundheitsministeriums ergänzt. Eine zentrale Frage betrifft die Interpretation des gültigen Transplantationsgesetzes hinsichtlich der Beziehung zwischen Spender und Empfänger, die insbesondere auch für die (für Deutschland nicht gültige) Zulässigkeit einer Cross-over-Spende von Bedeutung ist. Einen weiteren Schwerpunkt bildeten versicherungsrechtliche Aspekte, wie die finanzielle Absicherung für den Spender bei später auftretenden Folgeerscheinungen oder Komplikationen.

In mehreren Beiträgen wurden Grenzen und Möglichkeiten der Lebendspende aus medizinischer Sicht erläutert. Sie wurden durch Berichte über Studienergebnisse und aktuelle Daten zum Patienten- und Transplantat-Überleben ergänzt. Ein weiteres Referat gab einen Überblick über die besonderen Aspekte der Lebendspende bei Kindern.

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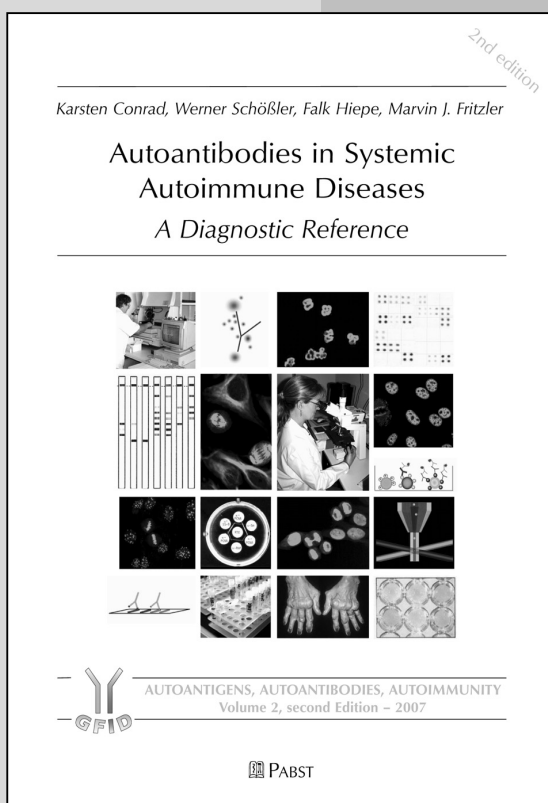
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Autoantibodies in Systemic Autoimmune Diseases - A Diagnostic Reference



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Autoantibodies are a very heterogeneous group of antibodies with respect to their specificity, induction, effects, and clinical significance. Testing for autoantibodies can be helpful or necessary for the diagnosis, differential diagnosis, prognostication, or monitoring of autoimmune diseases. In case of limited (forme fruste) disease or a single disease manifestation, the detection of serum autoantibodies can play an important role in raising the suspicion of evolving disease and forecasting prognosis. This book and reference guide is intended to assist the physician in understanding and interpreting the variety of autoantibodies that are being used as diagnostic and prognostic tools for patients with systemic rheumatic diseases. Autoantibodies observed in systemic autoimmune diseases are described in alphabetical order in Part 1 of this reference guide. In Part 2, systemic autoimmune disorders as well as symptoms that indicate the possible presence of an autoimmune disease are listed. Systemic manifestations of organ-specific autoimmune diseases will not be covered in this volume. Guide marks were inserted to ensure fast and easy cross-reference between symptoms, a given autoimmune disease and associated autoantibodies. Although the landscape of autoantibody testing continues to change, this information will be a useful and valuable reference for many years to come.

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