



These recommendations on best practice for living organ donation were developed by the Living Donor Observatory (LIDOBS). LIDOBS is a group of international experts who agreed to improve the quality of living donation, and to foster research and international consensus on strategies to protect living donors' health and safety.

This informative leaflet describes the final recommendations agreed during the International Conference on Living Donation-High Quality Practices (LIDOBS.) held in Barcelona, Spain on November 6-7th, 2014. This Conference brought together more than 100 participants representing greater than 30 countries from Europe, Asia, the Americas and Africa who discussed and defined consensus on the safety, transparency and quality of Living Organ Donation programmes.



### LIDOBS CONSENSUS ON LIVING ORGAN DONATION PROGRAMMES TO GUARANTEE QUALITY, SAFETY AND TRANSPARENCY IN LIVING ORGAN DONATION

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# ETHICAL AND LEGAL ASPECTS

**1.** Commitment to non-commercialization of living organ donation.





Compulsory

 Development of binding guidelines for transplant centres and professionals regarding the selection and follow-up of living organ donors.





**3.** Development and provision of quality indicators for transplant centres regarding living organ donation.





Excellence

 Empowerment and training of transplant professionals and students from all involved disciplines in the ethics of living organ donation.





**5.** Legislation and policy to protect non-resident living organ donors.





 Legislation and policy to protect living organ donors from discrimination in issues related to employment and health insurance.





# LIVING DONOR PROTECTION

7. It is highly recommended that donors undergo psychosocial evaluation prior to selection and donation. After donation, healthcare services should always be available and regular evaluations should be performed.





8. Valid written informed consent should be given after the donor has been interviewed and approved by an independent donor advocate who is not involved in the recipient care.





 Living organ donation should be costneutral. The living organ donor should not be subjected to any prejudice detrimental to employment, insurance coverage, or obtaining of credit, loans or mortgages.





### KIDNEY LIVING DONOR FOLLOW-UP

10. Donor education should be performed by transplant institutions that provide high quality educational resources and tools. Harmonizing tools between different centres is recommended.





11. Short- and long-term donor medical follow-up is mandatory after living kidney donation.





**12.** Psychosocial follow-up is mandatory in the short-term, and long-term followup is recommended for donors and/ or recipients with high medical or psychological stress levels.







Compulsory

### LIVER LIVING DONOR FOLLOW-UP

13. The most important factor for good living liver organ donor outcomes is the preoperative evaluation. A thorough psycho-social, anatomical and medical evaluation of each potential donor by an impartial team is essential.





14. In the immediate post-operative period, frequent laboratory analyses and imaging of the remnant liver should be performed to ensure appropriate recovery and the absence of early biliary and vascular complications.





**15.** The minimum period for medical follow-up of living liver donors should be one year. Follow-up should be performed at 1, 3, 6 and 12 months, and include patient interviews, physical examinations, laboratory tests and ultrasounds, and psychological examinations. These resources should also be available if needed by living organ donors after the first post-donation year. In particular, psychosocial follow-up should be available for life.







#### LIDOBS RECOMMENDATIONS | BARCELONA 2014

### LIVING DONOR REGISTRY

16. Registration of all living organ donors is mandatory, and adequate donor follow-up is necessary for the purposes of traceability, safety, and transparency of activities and outcomes of living donor procedures performed within all EU member states. A donor follow-up registry can help to protect living organ donors, and be a mechanism through which the scientific community can learn more about living organ donation.





**17.** Collection of living organ donor data must be through a central database system that is accessible to appropriately authorized persons, and compliant with legal requirements for data protection.





 Regulatory audits are mandatory and data should be monitored on both national and institutional levels.







19. A specifically purposed, carefully designed registry of living kidney and liver donors is recommended to foster accurate assessments of the living donor experience.





### QUALITY INDICATORS AND CERTIFICATION

**20.** A quality management system in living organ donation to provide more efficient and standardized care; ensure detection of safety issues; and improve outcomes is recommended.





21. Written, up-to-date, protocols to evaluate health status, donor-recipient immunology and organ compatibility, surgery, and short- and long-term follow-up after donation should be available.





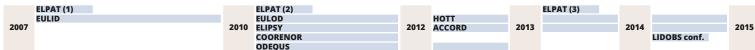
22. All living organ donor transplant programmes should maintain an up-todate donor registry, and collect, analyse and report data on short- and long-term outcomes and complications of living organ donation.







## EXAMPLES OF EU-FUNDED PROJECTS ON LIVING DONATION



#### **EULID (2007-2010)**

Analysed the current European situation regarding legal, ethical, protection and registration practices related to living organ donation, in order to set standards and recommendations that guarantee the living donor health and safety.

### **ELPAT Congresses (2007, 2010 and 2013)**

ELPAT Congresses bring continuity and progress in European research and dialogue on Ethical, Legal and Psychosocial Aspects of organ Transplantation of the European Society for Organ Transplantation (ESOT). It aims to integrate and structure this field of science by bringing together European professionals from different disciplines.

### **EULOD (2010-2012)**

Aimed to establish an inventory of living donation practices in Europe, explore and promote living donation as a way to increase organ availability, and write recommendations that improve the quality and safety of living organ donations in Europe.

### **ELIPSY (2010-2012)**

Aimed to contribute in guaranteeing the good quality of organ living donation for transplant through a living donor long-term psychosocial and quality of life follow-up. The recipient's outcome was correlated to these aspects and a follow-up methodology was created.

#### **COORENOR (2010-2012)**

The objective was to establish a coordinated network between national programmes existing in the participating European Member States in the field of organ transplantation. It coordinated efforts of countries from Eastern and Western Europe, all having different approaches and programmes to tackle the issues of organ procurement and transplantation.

#### **ODEQUS (2010-2013)**

ODEQUS specific objectives were to identify Quality Criteria (QC) and to develop Quality Indicators (QI) for hospital level, in three types of organ donation: after Brain Death (DBD), after Circulatory Death (DCD) and Living Donation. Those tools are useful for hospitals self-assessment, external evaluation as well as for developing a European auditing model.

### **LIDOBS Conference (2014)**

Exchange experience and knowledge on Living Donation programmes in order to assure safety, quality and transparency of the procedures and high quality standards. The conference intended to set up a community of experts in Living Donation Programmes named LIDOBS that will continue to expand and increase the knowledge on the donation and transplantation procedures.

#### **HOTT project (2012-2015)**

Combating trafficking in persons for the purpose of organ removal: an international research project aims to increase knowledge and information, raise awareness about the crime and to improve the non-legislative response to such a crime.

### **ACCORD (2012-2015)**

ACCORD intends to improve the potential of Member States in the field of organ donation and transplantation and to contribute to the effective implementation of the EU Directive 2010/53/EU and the EU Action Plan on Organ Donation and Transplantation (2009-2015). The work on living donation helps creating a common methodology for registers of living donors.

## **OUR GRATITUDE** IS EXTENDED TO THE PARTICIPANTS WHO WERE INVOLVED IN ALL STAGES OF LIDOBS CONFERENCE

More than 100 professionals participated from more than 50 institutions linked to living donation transplant programmes in 31 countries. A very special thanks goes out to all the living donors and recipients who support and participate in this initiative.

Agence de la Biomédecine- France

Antalya Medicalpark Hospital- Turkey

Beaumont Hospital-Ireland

Bulgarian Center for Bioethics- Bulgaria

Centro Hospitalar do Porto- Portugal

Centro Nazionale Trapianti- Italy

Charité Universtiätsmedizin Berlin- Germany

Complexo Hospitalario Universitário A Coruña-Spain

Council of Europe-France

Dutch Transplantation Foundation- The Netherlands

ELPAT- Ethical, Legal and Psychosocial Aspects of Organ Transplantation

Erasmus MC University Hospital Rotterdam- The Netherlands

Foundation for Transplant - Romania

Fundació Puigvert- Spain

Gesundheit Österreich GmbH- Austria

Hôpital Foch-France

Hospital 12 de Octubre-Spain

Hospital Clínic de Barcelona- Spain

Hospital de Bellvitge-Spain

Hospital del Mar- Spain

Hospital Fernando Fonseca- Portugal

Hospital Germans Trias i Pujol- Spain

Hospital Sant Joan de Deú- Spain

Hospital Vall d'Hebron-Spain

Institute for Clinical and Experimental Medicine-Czech Republic

Instituto Português do Sangue e da Transplantaçao- Portugal

Instituto Português do Sangue e da Transplantação- Portugal

Irish Kidney Association-Ireland

Italian National Transplant Centre- Italy Karolinska University Hospital- Sweden

Kidney and Pancreas Transplantation, University of Wisconsin-USA

King Faisal Specialist Hospital Riyadh-Kingdom of Saudi Arabia

Kobe University Hospital-Japan

Medicalpark Antalya Hastanesi- Turkey

Ministry of Health of Cyprus- Cyprus

Mount Sinai Hospital-USA

National Liver Transplant Program- Egypt

National Organ Donation and Transplantation Office- Ireland

Nederlandse Transplantatie Stichting-The Netherlands

Nephrology S.A. -Instituto de Nefrología de Buenos Aires- Argentina

New York Presbyterian-Weill Cornell Transplant Program- USA

NHS Blood and Transplant- United Kingdom Nicosia General Hospital- Cyprus

Organització Catalana de Trasplantaments-Spain

Organización Nacional de Trasplantes- Spain

Oslo University Hospital- Norway

Poltransplant-Poland

Sahlgrenska University Hospital- Sweden

Slovenija Transplant-Slovenia

Turkish Transplant Foundation- Turkey

UK Transplant- United Kingdom

University Hospital Duisburg Essen-Germany

University Multiprofile Hospital for Active Treatment "Alexandrovska" -Bulgaria

University of Michigan Medical School- USA

University of Wisconsin-USA

World Health Organization



### Experience, research and consensus

LIDOBS Conference also provided a valuable networking opportunity and set the stage for further cooperation among transplant centres in Europe and beyond, including countries at different levels of living donation activities.

LIDOBS shall function as a platform where international professionals, actively working in the clinical practice of living donation, can exchange knowledge, network, engage in discussions, and set priorities following the values of safety, quality and transparency in living organ donation.

As a multidisciplinary network our thematic area of interest is focused on six main areas, represented in the Conference by the six working groups (WG).



- WG1: ETHICAL AND LEGAL ASPECTS WG2: LIVING DONOR PROTECTION WG3: KIDNEY LIVING DONOR
- FOLLOW-UP WG4: LIVER LIVING DONOR FOLLOW-UP
- WG5: LIVING DONOR REGISTRY WG6: QUALITY INDICATORS AND CERTIFICATION

The LIDOBS Network is characterized by territorial representation and is open to all stakeholders involved in living donation process.

JOIN US! http://lidobs.eulivingdonor.eu lidobs@eulivingdonor.eu ORGANIZED BY:



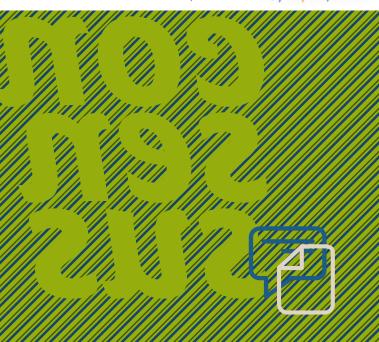












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**European Union**