

2019 ADVISORY BOARD MEETING



EUROPEAN TRANSPLANT PATIENTS ORGANIZATION

14 September, 2019
Copenhagen, Denmark

ESOT is thankful for the generosity of the following supporters for making this meeting possible



FACTS & FIGURES

ORGANIZING SCIENTIFIC COMMITTEE

Anna Forsberg
ESOT, ETAHP Vice-Chair, Sweden

Juan Fuertes
MD for Advocacy, Awareness
and Communication, Spain

Nichon Jansen
ESOT, EDTCO Vice-Chair, Netherlands

Fiona Loud
Kidney Care UK, Policy Director, UK

Hannah Maple
ESOT, ELPAT Vice-Chair, UK

Lone McColaugh
Lever Foreningen, President, Denmark

Mark Murphy
Irish Kidney Association, Chief
Executive, Ireland

David Paredes
ESOT, EDTCO Chair, Spain - Catalonia

Luca Segantini
ESOT, CEO, Belgium



WHEN: 14 SEPTEMBER 2019

WHERE: COPENHAGEN,
DENMARK

27

Participants

19

Patients Organizations/ Societies Represented

13

European Countries

3

ESOT Sections & Committees



ASSOCIATIONS AND ORGANIZATIONS REPRESENTED

- Transplant Sweden - Sports Association, Sweden
- Mer organdonation, Sweden
- Transplantoux, Belgium
- Pulmonary Hypertension Association of Hungary, Hungary
- Spanish Association for the Fight against Kidney, Spain
- Pulmonary Hypertension Association of Slovakia, Slovakia
- CFA Espluguenc Sport Barcelona, Spain - Catalonia
- University of Barcelona, Spain - Catalonia
- Donation and Transplantation Institute (DTI Foundation), Spain - Catalonia
- Hellenic Cystic Fibrosis Association, Greece
- Associacao Portuguesa de Insuficientes Renais (APIR), Portugal
- National Federation of Liver Transplanted Patients, Spain
- Stanford Medicine X
- Landsforeningen for Nyrepasienter og Transplanterte (LNT)
Norwegian Kidney Patients Organization
- European Kidney Patients Federation (EKPF), Norway
- Association of Kidney Patients of Catalonia, Spain - Catalonia
- European Kidney Patients Federation
- NVN - Dutch Kidney Society (Nierpatiënten Vereniging Nederland),
Netherlands
- European Transplant & Dialysis Sports Federation (ETDSF) & Irish Kidney
Association, Ireland



Group Photo of the participants to the Advisory Board Meeting of the European Transplant Patients Organization - Copenhagen, 14 September 2019

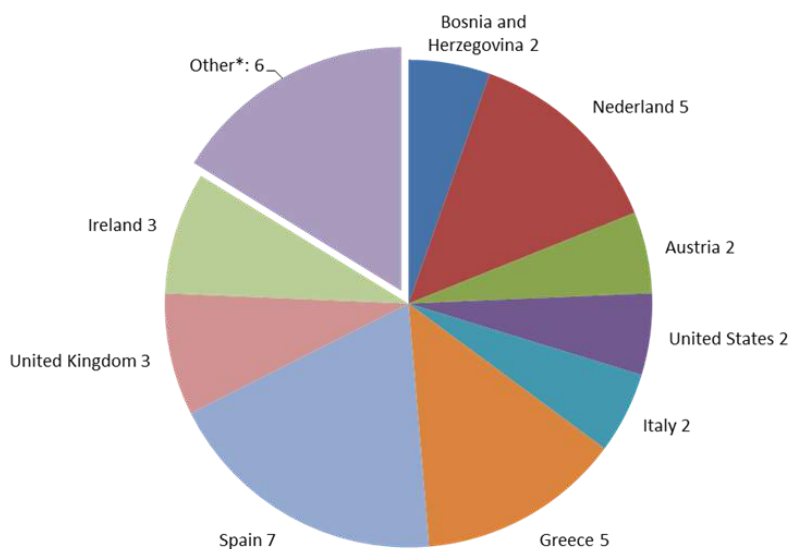
THE SURVEY

During Summer 2019, a questionnaire was submitted to Patients Organization and Societies to collect their feedback on the following topics:

- Transplant Accessibility
- Patients and waiting list criteria
- Informed consent : who protects the recipient?
- The Empowered Patient: patient wellbeing, physical condition, self-care for treatment adherence and better Quality of Life
- Patients Empowerment: The patient as partner
 - The role of patients in clinical trials development and digital health (development of new tools)
 - The Patient as a coach and a teacher for other patients



[CLICK HERE TO DONWLOAD THE SURVEY RESULTS](#)



Other*: Belgium, Denmark, Hungary, Russia, Slovakia, Sweden



15

Countries

37

Complete Surveys

TAKEAWAY MESSAGES AND KEY POINTS OF THE 2019 ADVISORY BOARD MEETING



- Transplantation needs to be treated as a chronic condition
- Very few issues are organ-specific and efficiency in conveying the message can be reached by focusing on commonalities
- For this purpose a cross-organ patient group is needed
- The Advisory board that met in Copenhagen strongly feels and supports the urge to **create an alliance and a forum**, to facilitate discussion groups among patients and patient organizations.

The aim is:

To **contribute**

To **research**

To support the development of a **person-centered approach**

To encourage and support **self-management**

- This network should and must be used to share concrete ideas to improve the situation across countries borders and to create a common ground to reinforce messages
- **Education is empowerment** – it is necessary to understand and to build a plan on how to disseminate and give access to knowledge as this is key for the participation of the patient to their own personal journey
- **Self-care and self-management are key factors**, nowadays this is facilitated and possible also through digital solutions
- To empower and increase the voice of patients at European level, it is now a necessary condition to work together and to join forces across Europe. The objective is not only to **create awareness** around organ donation, but also to **put a focus on fostering quality and enduring outcomes**.
- It is recognized by all participants the potential to create an alliance and network among patient organizations and to **connect the group with health care professionals and researchers (EU)**
- **Patients representation as equals** needs to be guaranteed in committees, policy-making bodies, etc.
- **Multidisciplinarity is a key factor** – there is a need to work across specializations
- Informed consent needs to be treated and recognized as an ongoing, dynamic process, which should start as early as possible
- It is important to learn how to manage expectations and convey the right message to patients
- Human touch is an important factor in the process
- An holistic perspective should be applied
- Connection with and among donor associations needs to be enhanced, supported and developed further
- Transparency and accessibility (e.g. infographics, online) of data should be guaranteed at the national level (mortality rates, etc.)
- Data from EUDONOR should be widely shared and dissemination should be supported
- **It's all about dignity!**



THE VIDEO SUMMARY

Watch a brief video summary of the Meeting that was held in Copenhagen on www.ESOTTransplantlive.org



CLICK ON THE IMAGE
to watch the video on YouTube



www.ESOTTransplantlive.org is #PoweredByESOT