

REPORT OF THE ADVISORY BOARD MEETING OF THE ESOT-ETPO ALLIANCE

In-person, Milan, and online 28th August 2021

The advisory board of the European Society for Organ Transplantation (ESOT) - European Transplant Patient Organisations (ETPO) Alliance met the day before the opening of the ESOT Congress 2021 in Milan. Attending were 38 representatives from 24 organisations and 19 countries, 59% online and 41% in the room at the Enterprise Hotel. This is part of ESOT's [Patient Inclusion Initiative](#).

The meeting was divided into three sessions:

- Welcome and Introduction
- The ESOT-ETPO Alliance – where we are
- The future of the ESOT - ETPO alliance and network

Session 1 Welcome and introduction

David Paredes, past chair of EDTCO, a transplant coordinator from Spain, opened the event explaining the background to the Alliance. It began its life in Copenhagen 2019 with a meeting of 17 patient organisations and societies from 13 countries along with 3 ESOT sections and committees: ETAHP (allied health care professionals); EDTCO (transplant coordinators); and ELPAT (ethical, legal and psycho-social aspects of transplantation). The Alliance has 10 founding partners.

Paredes said the aim of today's event was to establish, as a collaborative Alliance, 'where do we want to go, what do we want to be?' He introduced Italian cardiologist and President-elect of ESOT Luciano Potena to the room, who said it was important that, as a scientific society, ESOT tries to engage effectively with patient organisations, particularly around value based care. He welcomed the TransplantouX representatives who had cycled from Belgium.

Peter Carstedt, from More Organ Donation (MOD) Sweden, then described the event as a 'meeting among friends' bridging gaps between patient organisations, the profession and the ESOT community. He said the aim of today was to hear attendees' opinions on what we should do more or less of, to better understand our passions and goals and build the alliance so that it is 'all it can be.' "I'm very excited about it. There's a tremendous potential," he said.

Who is in the (virtual) room - David Paredes

Current attendees were patient associations representatives, individual patients, including those on waiting lists, those with chronic disease and those who had received transplants, as well as social workers, rehabilitation professionals and physicians, and three ESOT sections. He called for these numbers to grow and represent more areas of transplantation and other geographical areas. "We need more people – everyone is welcome."

There followed an open discussion: *Who is not in the room (but should be)?*

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It was suggested that the Alliance needs more NGOs working with patients as founding partners, which will be essential to survive, as well as EU representatives.

Other patient associations which are underrepresented include heart, pancreas, hidden organ, intestine, paediatrics, composite tissue. Care givers should also be invited. "They are very important and they are not given the importance they deserve," he said.

Carstedt appealed to attendees to identify key collaborators. "We have done some mapping but we really want your help in who should be invited." Attendees were directed to make suggestions in the chat and to visit the ESOT Congress webpages with dedicated area for patients.

SESSION 2 - ESOT ETPO alliance: where we are

1. What has happened since the last meeting: The Copenhagen meeting legacy

Nichon Jansen, past chair of EDTCO and a senior policy maker / researcher at the Dutch Transplant Foundation, summarised what has happened since Copenhagen.

A survey was carried out before that meeting, completed by 41 people/organisations from 15 countries, on six topics including patient empowerment, informed consent and waiting list criteria. Off the back of this a proposal was formulated to establish ETPO with an online platform or hub for European patient organizations, promoting exercise and ongoing communication .

A series of activities was put in train which have been very successful:

1. A second survey of patient asking, 'what are your main concerns with everyday life.'
2. A webinar for patients on 'Coping with uncertainty during the COVID-19 pandemic' with 248 participants from 48 countries and 510 standalone views.
3. TLJ 2.0 (ESOT's educational meeting) in November 2020 had a Learning Workstream concentrating on understanding uncertainty and fear of graft rejection from a patient perspective.
4. 2 Opinion papers have been submitted to Transplant International as a result.
5. In January a joint EPITA EDTCO / ETAHP symposium included a Patient Inclusion Initiative (PII) session.
6. ESOT's [Hesperis](#), a foundational course for young transplant professionals involved three patient/recipient speakers
7. The ESOT social media Twitter ambassadors including patient advocates/patients to support the promotion of dialogue and mutual learning.
8. A roundtable discussion on "Waiting list informed consent and patient self-care teaching" for Transplant Live, ESOT's online education platform, with Fiona Loud.
9. The Hackathon challenge to develop tools to serve transplant community is currently underway (June to October).
10. Patient-centred sessions at ESOT 2021 Congress and the Patient Inclusion Initiative mission statement highlighted on the ESOT website

In the discussion Kevin Fowler from the US, praised the 'amazing job' and suggested contacting the American Transplant Association. It was confirmed that the Alliance is interested in reaching outside Europe, but as a voluntary initiative had not had the capacity.

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2. Connecting people who had a transplant and healthcare professionals: examples of participation and co-production

Pisana Ferrari, from the Italian Pulmonary Hypertension Association AIPI, and Colin White, Irish Kidney Association, gave moving personal testimonies. Ms Ferrari had a double lung transplant in Vienna 19 years ago due to her idiopathic pulmonary hypertension. Last May she spoke at the HESPERIS online course on 'recipient management' for clinicians – the first time a patient representative had been involved.

She told them that a transplant is the start of a new journey that greatly impacts the recipient and their family but there are lots of things they are unaware of.

In her case:

- She didn't know that one can have hallucinations in ICU (she thought she was losing her mind) and that very high doses of cortisone can cause severe insomnia, euphoria and even, as in her case, manic behaviour.
- As an Italian treated in Austria, she was given a leaflet in German which she could not read
- Has had several skin cancers and has diabetes type 2
- The fact that you need to reorganise your life around the transplant and how it can affect personal relationships and work issues
- In the Q&A, she realised that not all transplant centres offer psychological support – this is an unmet need which is 'crucial' for patients and caregivers, she said.

Ms Ferrari said all these things would not overly frighten or put people off having the transplant if they were well communicated. She said it is essential that patients should be involved in understanding their care. "Mostly they are on their own at home they need to know what to worry about and what not to worry about." She concluded by saying that in order to improve the transplant experience there is great added value in including patients in any communication plans and patient education initiatives.

Co-chair Fiona Loud agreed and added that things that may seem small to clinicians are enormous to patients – 'their thinking is on the right lines but often the act of execution is not.'

Colin White, an #ESOT Twitter ambassador, is married to Chikoyo who has had end stage kidney disease since 2001, with less than 5% kidney function. He said they were 'absolutely in the dark' initially.

Since then he has worked for the Irish Kidney Association on the frontline with patients, as well as World Transplant Games Federation, and others. He said there was lots of pockets of great work around the world but it was really important to bring it all together, as sharing experience makes everyone stronger.

As a Twitter ambassador he is able to learn from leading experts and has great opportunities to network, promote collaboration, break down barriers and improve patient care. He said: "We are all strongly pushing for the same thing...and I strongly believe this will help."

3. Open Discussion - What has not happened yet?

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The wide-ranging Q/A covered the lack of research into physio for kidney transplants; telehealth and whether it was permanent post-pandemic; and the need to collaborate to create a global real-time map of access to organs in different countries.

SESSION 3 – The future of the ESOT - ETPO alliance and network

1. The ESOT - ETPO alliance: official presentation of the mission statement

Hannah Maple, a UK transplant surgeon and chair of ELPAT, and Pisana Ferrari shared a new mission statement, being unveiled at the Advisory Board, to encourage dialogue between ESOT and ETPO, which was widely welcomed by the speakers and attendees.

The mission statement is: **To promote realistic medicine** in organ donation and transplantation by **empowering people with transplants**, and **encouraging and facilitating a meaningful dialogue** between, patients, organ donors and their families, caregivers, transplant professionals **to ensure that their views and experiences are represented.**

Ms Maple further spelled out the [five core principles](#) informing the alliance and its activities, and Pisana Ferrari set out the [objectives](#) which can be viewed on the ESOT website.

Chair of session 3, Anna Forsberg, a professor of transplant nursing and an advocate of person centred care, said this mission statement is a big step forward - a team effort with the patient an equal member of that team.

2. The link to the future (ESOT Congress 2023 and Athens)

Transplant surgeon Gabriel Oniscu, ESOT President-elect said this is culmination of a huge effort by everyone involved. He said that trusted care can't happen without partnership and that shared decision making and shared care was the way forward.

Disruptive innovation was happening in many areas and within ESOT with discussions on digital transformation, greater patient inclusion as well as realistic medicine within the Congress.

"Patient involvement will enable doctors to deliver better care and that's it full-stop," he said. Realistic medicine, he added, could be described as 'it's my life, your care: let's discuss together.' Ongoing policy and public health initiatives include making the patient voice stronger so increased lobbying on legislation and European initiatives are likely. He concluded by saying he hoped 2023 – the next ESOT Congress in Athens - will be a landmark in this regard, with more positive steps forward.

3. The ETPO alliance network: how to grow and organise the collaborations within societies. The strategy and the results from the survey

Colin White and Peter Carstedt presented the results from the latest survey of 18 countries evaluating nine different activities organised since Copenhagen 2019. They were considered useful or extremely useful in most evaluations. The findings showed:

- Educational: Respondents liked personal meetings and information in different languages
- Policy: More interactions between patients and professionals, working together
- Co-production: More co-production and participation in existing activities, with a patient voice editor as well as a professional editor
- Networking & collaboration: working groups on issues, more communication about the value of this alliance

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Finally, the Advisory board addressed the future and next steps – how to grow and how organise ETPO activity alone and ETPO/ESOT Alliance activity.

Colin White suggested that the issues to collaborate on included:

- Promoting physical activity – not just competitive sport
- Patient education – deficits can be highlighted by patients
- Awareness/public education – using stories from patients and living donors as ‘they are the ones that get you heard’
- Paediatric transition to adult services – this is ‘a challenging time, as you go from being a big fish in a small pond to very, very small fish in a very big pond. There is not always a bridge to facilitate that changeover’
- Identity of ETPO – what is important to us, what are our goals as patients representatives and patients

Mr White said a two year gap gives ETPO time to put words into actions, with patient leaders collecting opinions and best practice, with agreed goals to reach by Athens. He continued ETPO must agree its priorities, agree a schedule of reporting between patient organisations and ESOT-ETPO must agree a work plan. The Advisory Board is in place: now the patient organisations must need step up, draw up an agenda and take it back to ESOT, he said.

4. Open Discussion

In the discussion, it was noted that the health related sphere is very busy and Covid has made things difficult but if the network is bigger, then it will be easier to make change and progress. Kevin Fowler in the US offered help as did Dimitris Kontopidis in Greece. Peter Carstedt said more basic funding was required in addition to support from ESOT.

Colin White advised people to talk to their own organisations and ask, ‘how can you contribute, what are shared topics for interest?’ Peter Carstedt said these topics needed to align with the top priorities in the organisation. “This is an invitation – we want to play. We have done some proof of concept. We are eager to take next steps but it’s going to be difficult without more people.”

In the closing remarks David Paredes said now we have a roadmap. “It will take time to put together and we need to do it step by step. During the pandemic we have been working, there is a changing relationship between patients, care givers and healthcare professionals.” He concluded: “Every small step is a step forward for the future.”

Do you wish to join the Alliance?

Visit <https://esot.org/network/> and get in touch!

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