



# Welcome to the ESOT- ETPO Network Alliance Meeting, London 2025

**Anna Forsberg, ESOT Councillor**  
ETPO Steering Group Member

# Agenda

12:30	Welcome	5 min	Anna Forsberg (Sweden)
12:35	ESOT–ETPO Alliance: what does it mean and how was it developed?	10 min	Daniel Gallego (European Kidney Patient’s Federation)
12:45	An overview of all the current and future activities of the ESOT – ETPO Alliance <ul style="list-style-type: none"> <li>Including activities where members of the ETPO Alliance have taken part in/helped ESOT Projects related to Patient Engagement</li> </ul>	10 min	Fiona Loud (Kidney Care UK)
12:55	Introducing ETPO’s new Terms of Reference – Paving a new way forward	10 min	Pisana Ferrari (Italian Pulmonary Hypertension Association)
13:05	My Life - My Scar	10 min	Jasmina Drolc (Slovenian Transplant Association)
13:15	How to tell your story - Empathy and the promotion of organ donation	10 min	Colin White (Patient Advocate)
13:25	Closing and Wrap Up	5 min	



# ESOT – ETPO Alliance what does it mean and how was it developed?

**Daniel Gallego, European Kidney Patients' Federation**

Member of the ETPO Steering Group

# It all started in 2019... in Copenhagen



To create a bridge between ESOT, the  
Council of Europe, Patient Associations,  
and Patient Advocates.

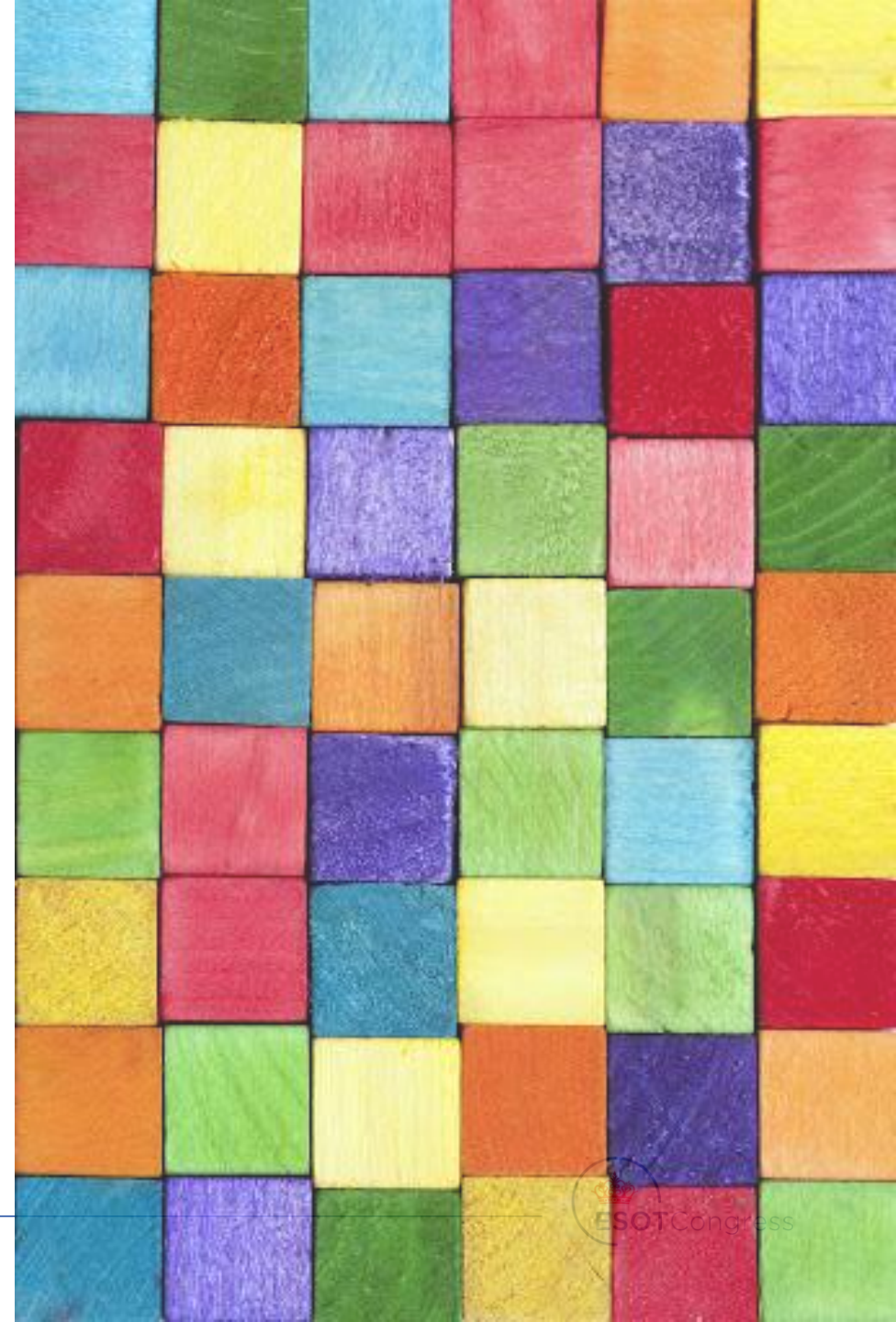
# What is our mission?

- **Bringing together healthcare professionals and people with transplants.**
- **To promote realistic medicine in organ donation and transplantation**
- **Empowering the people throughout their transplant journey**
- **Encouraging and facilitating a meaningful dialogue between patients, organ donors and their families, caregivers and transplant professionals**
- **To ensure their views and experiences are represented and amplified**



# Our core principles continue to be...

- **Transplant care** should be holistic and person-centred
- People with transplants should participate as **equals** in healthcare decisions and in the development of guidelines and policies that concern them
- The knowledge and experience that people with transplants have of their own health can **complement** that of healthcare professionals
- People with transplants should be involved in activities aimed at the **education** of fellow patients, organ donors and their families, caregivers, and transplant professionals
- **Information and data** should be transparent, accessible, and easily available to the patient community.



# Our Objectives

- Create an **open and trusting environment** that facilitates meaningful conversations between people with transplants and transplant professionals
- Reduce unwarranted variation in healthcare and **improve outcomes** throughout Europe
- Bring added value to the **health and quality of life** of the transplant population
- Implement realistic medicine by ensuring that people with transplants are equal partners in the decision-making process through the appropriate provision of information and consideration of available treatment choices. In this sense, **informed consent** should be understood as an ongoing, dynamic process, commencing as early as possible in the transplant journey
- Acknowledge that **person-centred care** and **self-management support** are essential to successful transplant care, and that digital solutions that enhance these aspects safely, should be developed and promoted
- Ensure that **research findings and data** regarding health-related quality of life, self-management, adaptation, and everyday life issues are rapidly disseminated to people with transplants in a transparent and easily accessible way, for example by promoting and stimulating open-access publications and open events
- Create **partnerships** with patient organisations to promote a healthy lifestyle in transplant recipients



# At the time of inception, the ESOT-ETPO Alliance was made up of -

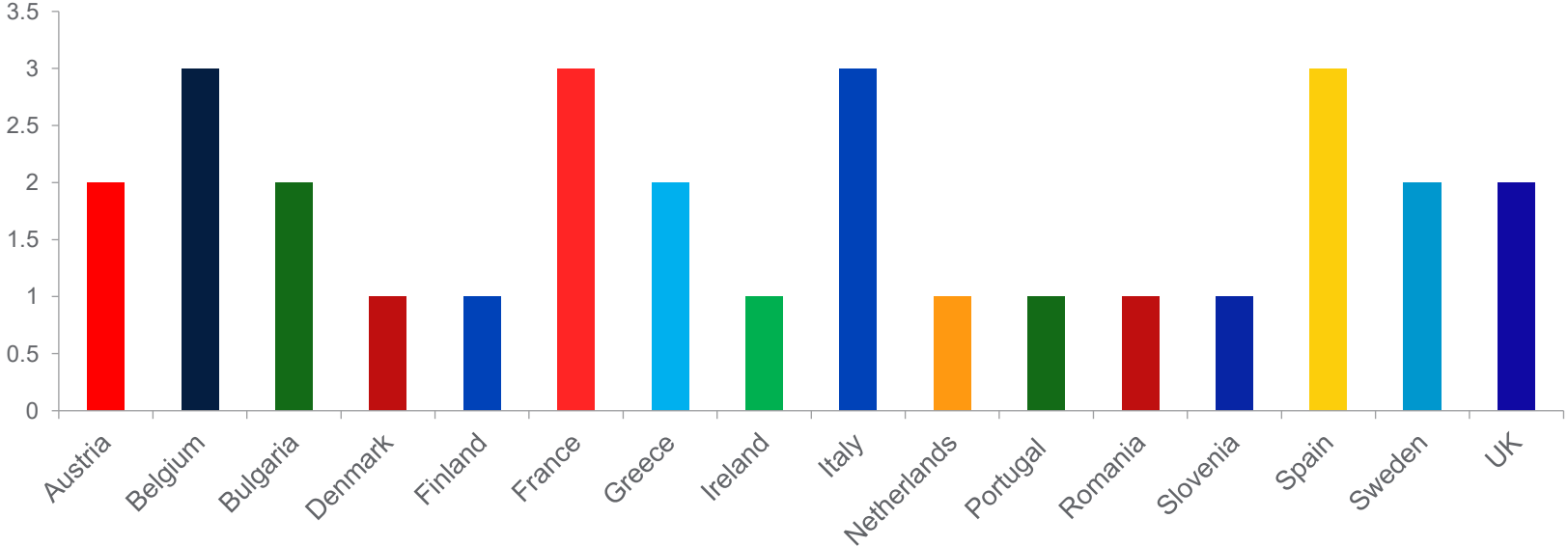
- **17 Patient Organisations**
- **13 Countries**
- **3 ESOT Sections and Committees**
  - EDTCO
  - ETAHP
  - ELPAT

# And now ... 30 member strong

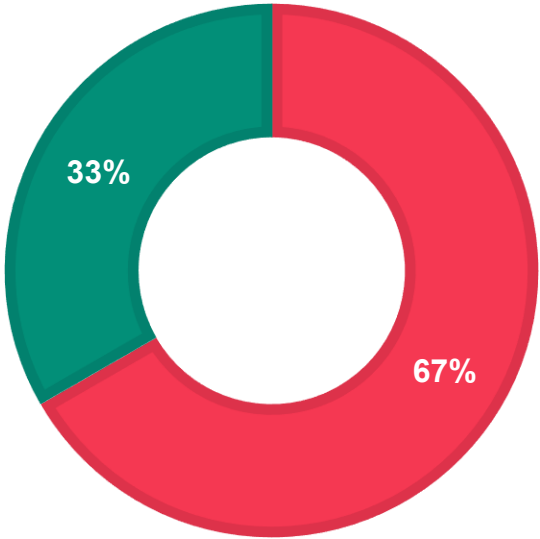


# ETPO Members' Distribution

## ETPO Alliance Network by Countries (16 countries)

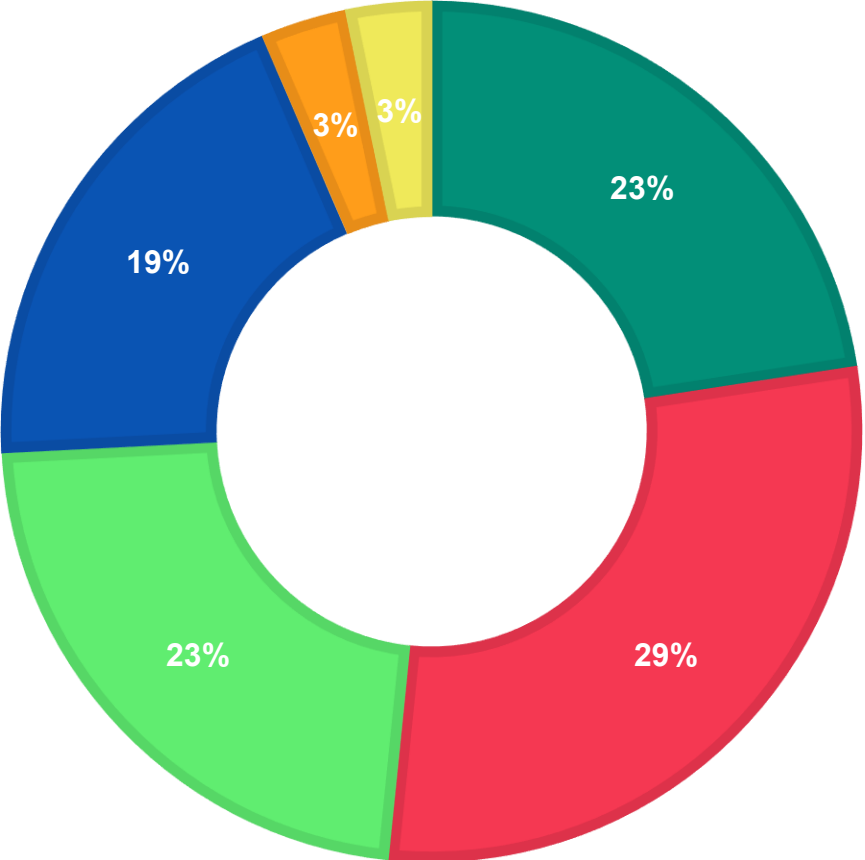


■ Country specific outreach  
■ International Outreach



# By organ

■ All organs ■ Heart & Lung ■ Kidney ■ Liver ■ VCA ■ Bone Marrow



# ETPO Outreach

- ETPO Newsletter – subscribers grew from 148 to **161**
- Through the ETPO Alliance Network, ESOT is able to in-directly reach approx. 50,000+ members across Europe
- Ad-hoc communications to invite members to participate in ETPO Activities
- A kind reminder to everyone: if you would like to promote any of your association/society's activities, please let us know, and it will be shared on the ESOT Patient Inclusion Initiative Page and through the quarterly newsletter

# Welcome to ESOT Congress 2025!



## After this session:

- Lunch break – 13:30 – 14:00
- ESOT Patient Inclusion Initiative Workshop – 14:00 – 16:30

# A quick note about the UK's ABPI code and the ESOT Congress 2025

The ESOT Congress relies on the support and sponsorship of Pharmaceutical Companies. These Companies are governed by the Associated Board of Pharmaceutical Industries (ABPI). According to **Clause 26.1 of the 2024 ABPI Code**: "*Prescription only medicines must not be advertised to the public. This prohibition does not apply to vaccination and other campaigns carried out by companies and approved by the health ministers.*"

To adhere to this guidance and maintain future ESOT Congress sponsorship, the Main Exhibition Area and the Industry Sponsored Symposia will be strictly restricted to Healthcare Professionals **ONLY**.

To be compliant with the code, the patients and patient advocates will need to be identified as such on their congress badge to ensure pharmaceutical companies can easily recognise you and avoid any deviation from the ABPI standards. The next slide highlights the sessions patients are allowed to attend in accordance with the ABPI code.

Patients will be able to access the Poster Area only via entrance **N8**

# Sessions you can attend

Sunday 29 June	Monday 30 June	Tuesday 1 July	Wednesday 2 July
<b>09:00 - 10:30</b> Specialty Update Symposium: The family voice in deceased donation	<b>16:00 - 17:30</b> Promoting equitable access to transplantation – real solutions to old problems	<b>09:00 - 10:30</b> New technology fuels sustainable post transplant care	<b>10:00 - 11:30</b> The case I learnt most
<b>09:00 - 10:30</b> Optimising living donor kidney transplantation in Europe	<b>16:00 - 17:30</b> ESOT & BTS Joint session: Equity without wastage in abdominal organ transplantation	<b>16:00 - 17:30</b> Can AI improve access to transplantation?	
<b>11:00 - 12:30</b> I, Robot: Serving cardio-thoracic transplantation between machines and human-beings – the European Cardio Thoracic Transplant Association (ECTTA) in collaboration with the European Association for Cardio-Thoracic Surgery (EACTS)			
<b>11:00 - 12:30</b> Specialty Update Symposium: Supporting transplant recipients in optimising their health: Needs and preferences			

# A big thanks to our Corporate Members for 2025

We truly appreciate the continued support of our Corporate Members for  
ESOT's Patient Inclusion Initiative





# Thank you

From the ESOT ETPO Steering Group



# An overview of the past, current, and future activities of the ESOT – ETPO Alliance

Fiona Loud, Kidney Care UK [www.kidneycareuk.org](http://www.kidneycareuk.org)

Member of the ETPO Steering Group

ETPO = European Transplant Patient Organisations

# What constitutes an ESOT ETPO Activity?

Any ESOT project, event, and activity  
where any member of the ESOT ETPO  
Alliance Network is involved

# Where it began...

## ESOT Congress Meetings and Workshops

- **Copenhagen 2019**
  - Advisory Board Meeting
- **Milan 2021**
  - Advisory Board Meeting
  - Online Symposium
- **Athens 2023**
  - ETPO Alliance Meeting
  - Workshop ' Staying Healthy'
  - Workshop ' Living your life after transplantation. Patient-centred approach and peer support network'
- **London 2025**
  - ETPO Alliance Meeting
  - Workshop 'Challenges to a practical approach to 'Staying healthy' for a transplant'



# ETPO participation in the ESOT Congress 2023

- **Membership of Programme Committee**
- **Speakers at opening and final plenary session**
- **Co-chaired sessions and workshops**
- **Lots of opportunity to get involved in planning**
- **Range of interesting patient-centred events**
- **The steering committee of the ESOT patient inclusion initiative endorsed a call for a European effort to collect follow-up data on transplant recipients and living donors.**

<https://esot.org/category/patients/page/2/>



# Sponsored Projects

**ESOT gets funding from pharmaceutical companies to carry out projects on varying topics. Either –**

- ESOT is approached by the pharmaceutical company OR
- ESOT pitches a project to the company who share the mission of patient empowerment

**How are these projects aimed at patient empowerment?**

**There are 2 types of projects -**

1. Projects designed to conduct clinical studies, and aimed at doctors, surgeons, and other HCPs. ESOT recommends including an element dedicate to Patient Empowerment/Awareness. For e.g. webinars, surveys, etc.
2. Projects designed with the primary goal of patient empowerment

Find out about events of interest <https://esot.org/esot-patient-inclusion-initiative/>

# ECP Project – The Patients’ Journey Around Immunomodulation and Rejection

This workshop addressed the patient experience of immunomodulation and rejection. How the patients and their family experience and feel about rejection.

**Moderator:** Pisana Ferrari

A graphic for a workshop. It features a large blue circular arc on the left side. In the top left corner is the ESOT logo with the tagline "Leading the way in transplantation". The main text reads "Workshop The Patients’ Journey Around Immunomodulation and Rejection". Below this, it says "This workshop is possible thanks to the unrestricted grant support from" followed by the Mallinckrodt Pharmaceuticals logo. At the bottom right is the ESOT logo and the website "esot.org".

**Workshop**  
**The Patients’ Journey  
Around Immunomodulation  
and Rejection**

This workshop is possible  
thanks to the unrestricted  
grant support from

**Mallinckrodt  
Pharmaceuticals**

esot.org 

Workshop is available for playback on the ESOT Virtual website – <https://virtual.esot.org/esot/>

# Patient advocacy and Literacy: Transplant Patient Journey around Infectious Diseases

A Webinar aimed at increasing patient awareness against the risks of infectious diseases through talks by experienced patient advocates and empower them to address their concerns with their healthcare professionals.

**Moderator:** Penilla Gunther (FOKUS)

**Speaker:** Fiona Loud (Kidney Care UK)

**Panellist:** Liz Schick (WTGF)



A promotional graphic for the webinar. It features the ESOT logo (Leading the way in transplantation) in the top left. The text in the center reads: "Webinar", "Transplant Patient Journey Around Infectious Diseases", "Thursday, 24 April 2025", and "17:30 - 18:30 CEST". In the bottom left, it says "This activity is kindly supported by" above the Takeda logo. The graphic is framed by a large blue arc.

Workshop is available for playback on the ESOT Virtual website – <https://virtual.esot.org/esot/>

# Quality of Life after Liver Transplantation: Transplant Patient Journey around Infectious Diseases

A project aimed at enhancing the understanding of the needs of individuals who require or have undergone liver transplantation. The main objectives of this project were: **to acquire greater knowledge of the needs** of people who need or received a liver transplant and **to provide** the patient community with curated, **easily accessible educational resources** that will meet their needs and contribute to improving their quality of life after transplantation.

Survey results: **947** completed surveys

**Steering committee Member:** Liz Schick (WTGF)



Workshop is available for playback on the ESOT Virtual website – <https://virtual.esot.org/esot/>

# Enhancing post-transplant care: Patient advocacy and Literacy

Mission: to focus on the person with an organ, not the organ in the person, with the aim of achieving person-centred transplant care.

In pursuit of this vision, the project **My Life – my Health** (MLMH) and all activities developed under this collaboration aim to accomplish three main objectives:

1. supporting patient literacy and the adaptation process
2. raising healthcare professionals' awareness and capacity building
3. empowering transplant nurses.

These efforts are geared towards ensuring holistic care and support for individuals undergoing organ transplantation.

**Steering Group members:** Anna Forsberg, Colin White, Hannah Maple, David Paredes, Bernadette Davis



You can read more about this project on the ESOT Website <https://esot.org/enhancing-post-transplant-care/>

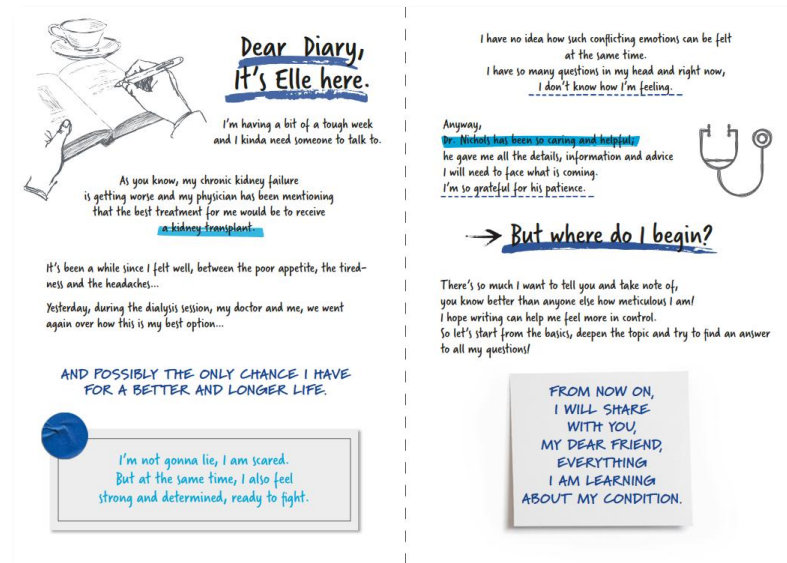
# The Patient Diary

Creation of an educational tool, the 'Patient Diary', which aims at fostering patient literacy and empowering the community.

It actively involved healthcare professionals and people with a transplant experience, ensuring a collaborative and comprehensive approach. The diary aims at providing guidance to prospective and current transplanted individuals, their families and dear ones, by offering valuable insights and reliable information to help them understanding and navigating the transplant journey.

## Steering committee members:

Fiona Loud, Colin White,  
Daniel Gallego, Peter Carsted



You can find more information on this project on the ESOT website – <https://esot.org/patient-diary/>



# Desensitisation in kidney transplantation: Improving Patient Awareness

Aimed at gaining an understanding of HLA sensitisation and desensitisation protocols, learn to identify which patients could benefit from these interventions, and appreciate the experiences of patients navigating this complex journey. A dialogue between a patient and a nurse provided an authentic perspective on the impact of desensitisation on patient care and outcomes.



The graphic features a white background with a large blue circular arc on the left and right sides. In the top left corner is the ESOT logo, which consists of a circle containing two hands shaking, with the text 'ESOT' and 'Leading the way in transplantation' below it. The main text is centered and reads: 'Webinar' in blue, followed by 'Desensitisation in kidney transplantation: Improving Patient Awareness' in bold black. Below this, the date and time are listed: 'Thursday 23 January 2025' and '17:30 - 18:30 CET'. In the bottom left corner, there is a small text block: 'This project is possible thanks to unrestricted grants from HANSA BIOPHARMA', with the HANSA BIOPHARMA logo to the right.

**ESOT**  
Leading the way  
in transplantation

**Webinar**  
**Desensitisation in kidney  
transplantation: Improving  
Patient Awareness**

Thursday 23 January 2025  
17:30 - 18:30 CET

This project is possible  
thanks to unrestricted  
grants from **HANSA**  
BIOPHARMA

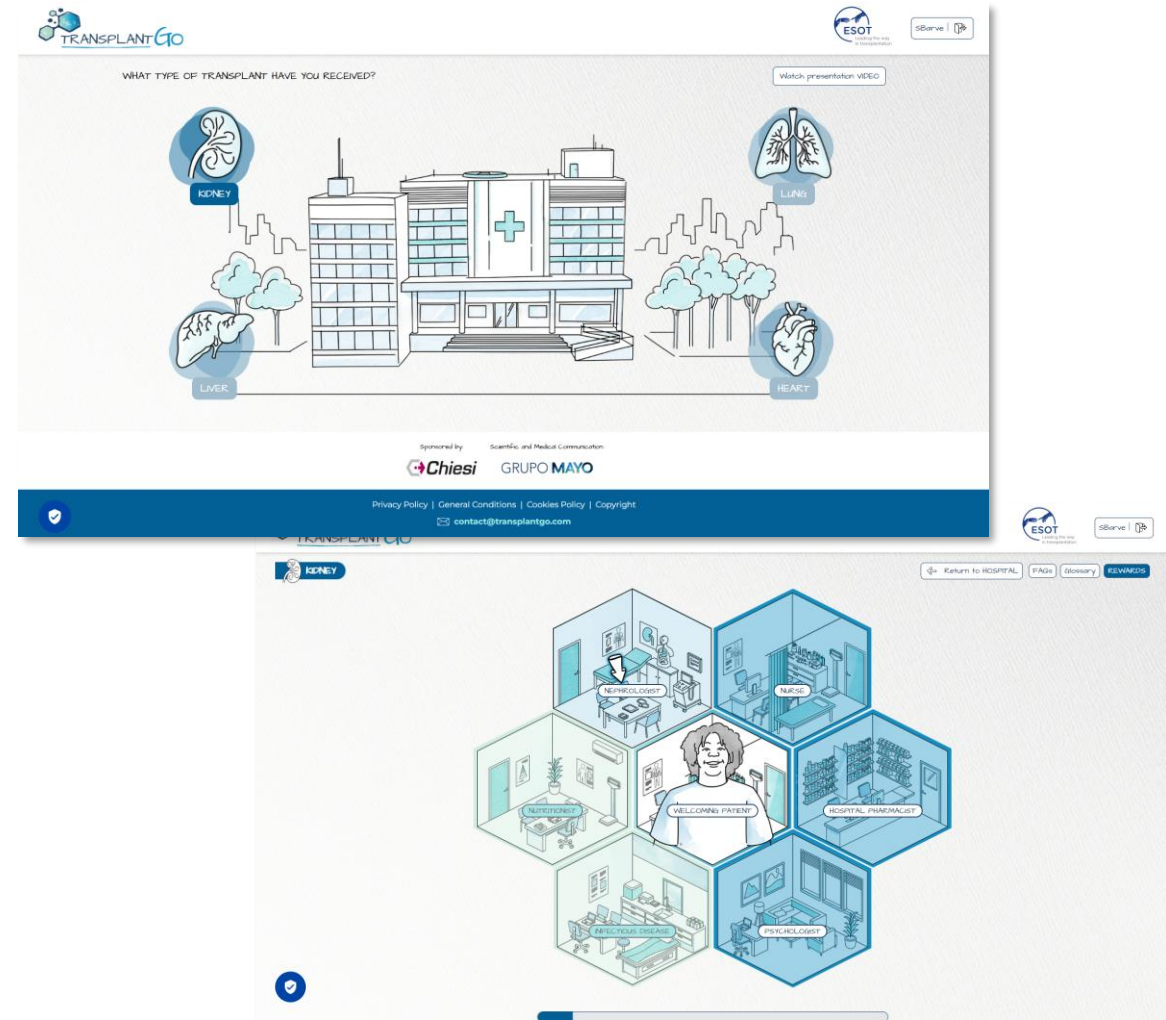
You can find more information on this project on the ESOT website – <https://esot.org/patient-diary/>

# Coming soon: TransplantGO!

Building on the success of the ESOT 'Patient Diary' initiative, we present **TransplantGO**, a new digital platform designed to support and empower transplant recipients across kidney, heart, liver, and lung transplants.

This next phase of the project aims to deliver reliable, evidence-based information in a user-friendly, gamified format, helping patients feel informed, confident, and connected throughout their post-transplant journey.

**ETPO Patients:** Bernadette Davis (Kidney) & Pisana Ferrari (Lung)



# Patient/ETPO perspective on a position paper on Xenotransplantation

To provide a patient perspective on –

- **Ethics and Public Engagement**
- **Promoting animal welfare**
- **Patient safety, equity, and transparency**
- **Balancing risks and benefits**
- **Learning from Europe's past experience in innovation with a strong ethical basis**
- **Public Opinion – What do people think? How can it be measured?**
- **Understanding why public trust is essential**



**Committee Member:** Peter Carstedt

# What's the future for ETPO Activities?

**With the new Terms of Reference, we invite members of the ETPO Alliance Network to suggest webinar/project ideas**



# Thank you

[Fiona.loud@kidneycareuk.org](mailto:Fiona.loud@kidneycareuk.org)

<https://esot.org/network/>



# MY SCAR, MY LIFE

Exhibition of art photographs – persons with transplanted organs



# MOJA BRAZGOTINA, MOJE ŽIVLJENJE *MY SCAR, MY LIFE*

RAZSTAVA FOTOGRAFIJ –  
UMETNIŠKIH AKTOV OSEB S PRESADENIMI ORGANI  
*EXHIBITION OF ART PHOTOGRAPHS –  
PERSONS WITH TRANSPLANTED ORGANS*



# Exhibition

## Cooperation:

Slovenija transplant (The Institute of the Republic of Slovenia for the Transplantation of Organs and Tissues) and Slovensko društvo Transplant (Slovenian Transplant Association - patient organisation)

## Models:

11

## Photographer:

Miran Juršič

## First opening:

7 October 2022 – University Medical Centre Ljubljana



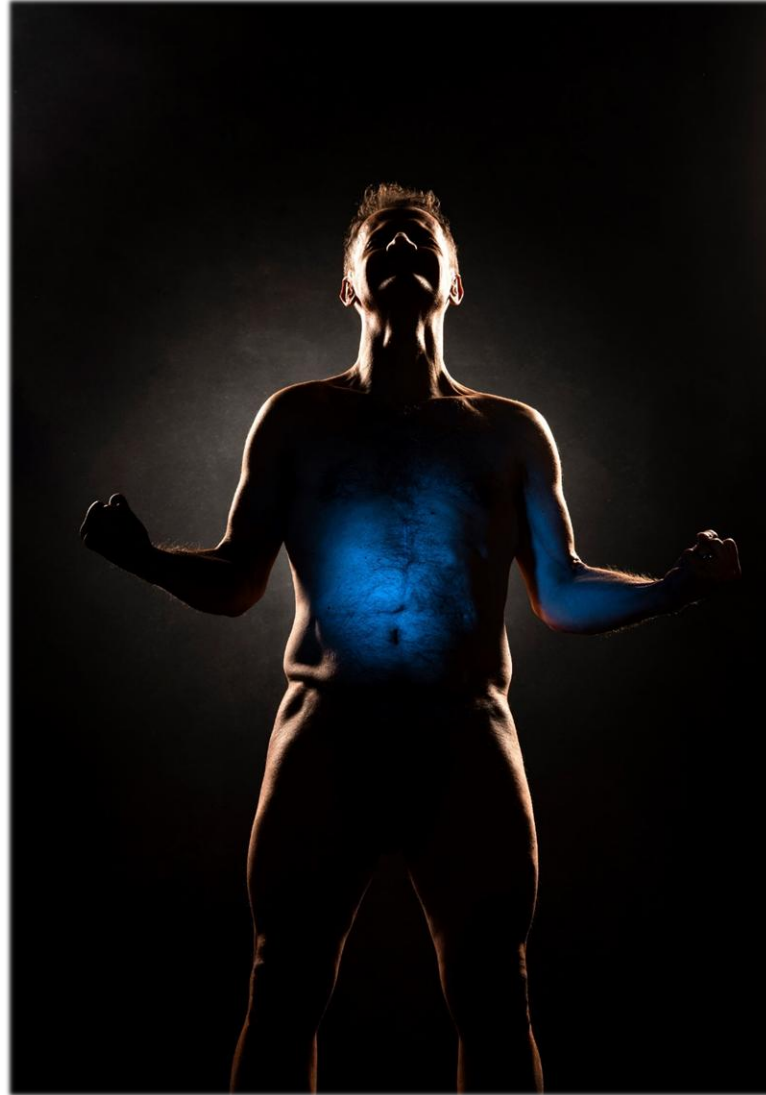
# Since then...

## **Exhibition:**

- Different locations (medical facilities, libraries, town halls, National Assembly of Slovenia, galleries...)
- Accompanied by press conferences, round tables, discussions...

## **Success:**

- The highest number of declarations in the donor register in the month of the first exhibition (566; average monthly declarations 80)
- Media invitations to events
- Numerous appearances: TV shows, newspapers, social media...
- Awareness, breaking stereotypes, get people talking...



# Therefore... new project: CIRCLE OF GRATITUDE AND COOPERATION

## **Campaign:**

- To express deep gratitude to organ donors and medical experts

## **Cooperation:**

- Slovenia – transplant, Association for pulmonary hypertension Slovenia and Federation of kidney patients of Slovenia

## **Central concept:**

- A circle - symbolising cooperation in a network of support.

## **Artists:**

- BKBF Artistic Group and Visual Voice (Robert Jurak, Izidor Zadavec from Slovenia and Nedim Hadži Ahmetović – Mafa from Serbia)





# Message

**#itstimetoconsent**

**#defineyourselfnow**

**#giftsgiving**

**#thankful**



**Thank you**



# Empathy, the key to inspiring others

**Using your story to promote public action**

Colin White | European Transplant & Dialysis Sports Federation

# Disclosure of conflicts of interest

I have nothing to declare

# Bring your audience into YOUR world

Personal stories resonate deeply with people and can inspire action /confidence in a way statistics alone often cannot.



# Bring your audience into YOUR world

## Chikoyo & Colin

Kidney Disease and us...

(The value of the lived experience)





# Bring your audience into YOUR world

A picture tells a thousand words. But you get a thousand pictures from someone's voice.

Paul Fleischman

# Bring your audience into **YOUR** world

- You are telling the audience **YOUR** story
- The facts of your story give it **structure**
- However, it's the emotions of your story that give it **impact**



# Bring your audience into YOUR world

## Make It Personal but Universal

- Speak from your lived experience, but do not lose sight of the broader message:

“I’m alive today because someone said YES to organ donation...

YOU could be that person for someone else.”



# Bring your audience into YOUR world

- Ensure that your take-away message for the audience is impactful
- This story highlights the realities of end stage kidney disease and life on dialysis
- The take-away message can be adapted to suit the audience





# Thank you

## Partnership matters

- Health care professionals bring their skills
- Patients, and their families, bring their lived experience

## #StrongerTogether