



How long will I wait?
Understanding uncertainty on the
waiting list

29 Oct | 18:00-19:00 CET



WEBINAR SCIENTIFIC PROGRAMME

29 October 2020 - 18:00 – 19:00 CEST (Amsterdam)

How long will I wait? Understanding uncertainty on the waiting list

Moderated by Fiona Loud and Irena Milaniak

Description and Rationale:

Dealing with the uncertainty associated with transplantation has recently been identified as a key priority for those awaiting a transplant, those who have received a transplant and for transplant professionals. This webinar will consider the issues surrounding uncertainty whilst on a transplant waiting list. The first part of the webinar will include talks by a transplant professional and a transplant recipient, presenting their perspectives on waitlist-related uncertainty. The discussion will then be opened to the audience for questions and answers.

Learning objectives:

- To understand uncertainty whilst waiting for an organ, from the perspective of both patients and transplant professionals
- To explore specific issues related to being on the waiting list and how these can be addressed
- To discuss experiences and management strategies for patients to use whilst waiting

Target audience

Physicians, transplant donor coordinators, nurses, allied healthcare professionals, professionals focusing on the ethical, legal and psychosocial aspects of organ transplantation, representatives of patient organizations, individual patients and their significant others.

Programme

18:00-18:05	Welcome and introduction (F. Loud, I. Milaniak)
18:05-18:20	Uncertainty from the clinician's perspective (H. Maple)
18:20-18:35	Uncertainty from the patient's perspective (P. Ferrari)
18:35-18:55	Q&A session
18:55-19:00	Concluding remarks (F. Loud, I. Milaniak)



PANELLISTS:



Pisana Ferrari
Italian Pulmonary Hypertension
Association (AIPI)
Udine, Italy

Pisana Ferrari's background is in Political Sciences and International Relations. She worked for a few years in EU Affairs in Brussels, and in Public Affairs for an agro-industrial group in Italy. The turning point in her career, and life, came about with the diagnosis, at age 32, of a life-threatening lung/heart condition, pulmonary arterial hypertension. Since then she has been actively involved in patient advocacy in her own country, Italy, and at EU level. In parallel, since her diagnosis, she has been working in the communication and event management field. She underwent a double lung transplant 18 years ago.



Fiona Loud
Kidney Care UK
UK

Fiona Loud has been policy director of Kidney Care UK since 2013. Previously Director of the Kidney Alliance, she led and co-authored a kidney community review of kidney care, *Kidney Health: Delivering Excellence*. She is involved with numerous other groups, working to improve standards of care for kidney patients. She set up and chairs the UK Renal Registry patient council and has contributed as a lay representative to many of the kidney guidelines produced by NICE (the National Institute of Health and Social Care). She is lay chair of a local hospital organ donation committee and vice chair of her local kidney patient association at another local hospital. Fiona spent 5 years on dialysis after her kidneys failed, before receiving a transplant from her husband in late 2006. She has a genetic condition called tuberous sclerosis which alongside 2 episodes of kidney cancer led to her kidneys failing. She is a Fellow of the British Renal Society and was one of the Health Service Journal Top 50 patient leaders. She was profiled in the [Lancet](#).



Irena Milaniak
John Paul II Hospital
Krakow, Poland

Irena Milaniak became a registered nurse in 1991 and made her clinical career at John Paul II Hospital, Cardiovascular Surgery and Transplantology Dpt. in Krakow, Poland. She has mainly performed her organ donation and organ transplantation training and research at the transplant unit of this hospital and at the Polish Transplant Coordinating Center Poltransplant. In 2014 she defended her doctoral thesis entitled "Evaluation of selected determinants of quality of life of patients after heart transplantation" at the Jagiellonian University Collegium Medicum in Krakow. In 2020 she was promoted to professor in health science at the Andrzej Frycz Modrzewski Krakow University. Her scientific achievement was concerning "The biopsychosocial functioning of heart transplant recipients". She currently focuses on thoracic transplant recipients and mechanical cardiac support in both research and the clinic as well as the psychosocial model of decision about organ donation. She has been an ESOT member since 2016 and an ETAHP board member since 2018.



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Hannah Maple
Guy's Hospital
London, UK

Hannah is a transplant and general surgeon in the final year of her training at Guy's Hospital, London. She is also a clinical lecturer research interests in health psychology as applied to healthcare and transplantation. She has a specific interest in unspecified living kidney donation and the prehabilitation of patients who are on the waiting list for a transplant. She is vice-chair and chair elect of ELPAT – the section of ESOT dedicated to the ethics, legal and psychological aspects of Transplantation.