



'Stichting' EUPATI Foundation – Board

(updated September 2020)

Chair



Anders Olauson (EPF)

Co-chair



Kay Warner (GSK)

Patient Representatives



Brian West
EATG



Derick Mitchell
IPPOSI

Industry Representatives



Donatella Decise
Novartis



Lasse F. Jacobsen
LEO Pharma

Academia/Non-Profit
representatives



**Ingrid
Klingmann**
EFGCP



**Anne-Charlotte
Fauvel**
EATRIS

ENP representatives



**Sandrine
Lavallé**
Luxembourg



**Filippo
Buccella**
Italy

Chair – Anders Olauson, European Patients' Forum (EPF) – 2 years

Anders is particularly concerned with the impact of rare conditions on children and their families. His work involves contact with both national and regional legislative bodies about rare disorders. He is also in contact with representatives of hospitals, education and labor unions as well as other key players in the field of rare diseases. Anders is past member of the board of EURORDIS and was president from 1999 to 2001. He represented it as a member of the board of the European Patients' Forum (EPF) until 2016. He has been president of EPF since June 2005 until 2016, when he was appointed Honorary President for EPF.



Co-Chair – Kay Warner, GSK – 2 years

Kay Warner is a Senior Director within the Patient Focused Development team at GlaxoSmithKline Research and Development. Kay moved to her current role as Patient Engagement Lead in January 2017 and is patient engagement subject matter expert at GSK. With her passion to make a difference in research and development, Kay has spent the last 16 years of her career working to strengthen the patient voice in medicines development and research at key decision timepoints. Her work has included interaction with individual patients, caregivers, patient advocates, patient advocacy organisations and health care providers. She represents GSK in the European Patients' Academy (EUPATI) project. She is also supporting the IMI2 project Patients Active in Research and Dialogues for an Improved Generation of Medicines (PARADIGM).



Patient Organisations - Brian West, European Aids Treatment Group (EATG) – 2 years

Brian has been involved in HIV activism since 1986. He lives in Edinburgh, Scotland, and has been living with HIV since 1983. He has been a member of the European AIDS Treatment Group, (EATG) since 2008, and has previously served on the Board of the EATG. He has in the past served 4 years on the Board of the European Patients Forum, part of that time as Vice-President. He served on the Trustees Board of Scottish service provider, Waverley Care for over 10 years. He now sits on the Board of Directors of HIV Scotland – a policy and advocacy organisation.



Patient Organisations - Derick Mitchell, Irish Platform for Patients' Organisations, Science & Industry (IPPOSI) – 1 year

Derick Mitchell, PhD is the Chief Executive Officer of (IPPOSI). Derick has a strong background in research, strategy, and advocacy from over 12 years' experience spanning several leadership roles in research and multi-stakeholder engagement in Ireland and at the EU-level. Derick has a strong track record in collaborating to influence healthcare policy with the goals of enhancing research infrastructure, increasing patient involvement, and improving access to treatments. Derick believes in the power of a united voice when it comes to patient advocacy and the central role of patients and their representative organisations in healthcare and research. Derick leads IPPOSI's involvement EUPATI and was instrumental in the development of the IPPOSI (EUPATI-based) patient education programme in Ireland.



Industry - Lasse Funch Jacobsen, LEO Pharma A/S – 2 years

Lasse holds a master's degree in international business communication from Copenhagen Business School and has completed leadership programmes at both Harvard Business School and INSEAD.

He brings 10 years of experience from working in pharma across the value chain from early stage Research and Development, to Communications, Corporate-and Medical Affairs to Marketing. Hence, he has vertical and horizontal understanding at operational, strategic, and management level from a pharma company. About half of his professional lift, he has worked in Patient Engagement teams across two different global pharma companies. Lasse has helped establish functions that ensures the patient's voice is heard and implemented from early research to end product in the value chain of a pharma company. He has been part of numerous initiatives and coalitions across Academia, Patient Organisations and Industry working together to help improve the lives of people living with chronic diseases. This includes EUPATI, PARADIGM, HYPO-RESOLVE and many more.



Industry– Donatella Decise, Novartis – 1 year

Starting 1996 I worked five years for the National Cancer Institute of Milan as a PET Radiochemistry Researcher (Nuclear Medicine Department), before joining the Pharma setting in year 2000 covering different roles, including Clinical Trial Manager, Medical Affairs Manager, Product Business Manager and Brand Manager for Schering-Plough, Astra-Zeneca and Novartis in the areas of Oncology, Haematology, Hepatology, Cardiovascular and Respiratory.



Since 2008 I am working for the Headquarters of Novartis Oncology Region Europe, entering the Patient Relations world in January 2014. In this role I cooperated with several Patient Associations, contributed to -and led -disease awareness campaigns, played the patient advocate internally and attended courses besides organizing/cocreating with Patients several events/initiatives over the years in cooperation with other internal functions (e.g. Market Access, Medical, Public Affairs...).

Academia/Non-Profit - Ingrid Klingmann, European Forum for Good Clinical Practice (EFGCP) – 2 years

Since January 2003 she has her own pharmaceutical development and site management support consulting company.

Dr Klingmann is Chairman of the Board of the European Forum for Good Clinical Practice (EFGCP). On behalf of EFGCP she was and is involved in different FP7-and IMI-funded projects (ICREL, PharmaTrain, EUPATI, PARADIGM, etc) and with her company in the FP7-funded paediatric LENA project. Her broad professional background as physician with experience in patient care, clinical development, site management and patient engagement enables Dr Klingmann to bridge the gaps between the interests and skills of all different stakeholders in medicines development with the aim to develop new patient-relevant treatments more efficiently. She also teaches on different clinical research and regulatory affairs topics in diploma and master courses at the University of Bonn, Germany, University of Basel, Switzerland, and the Université Libre de Bruxelles, Belgium.



Academia/Non-Profit – Anne-Charlotte Fauvel, European Infrastructure for Translational Medicine (EATRIS) – 1 year

Anne-Charlotte Fauvel is Head of European Affairs for the European Research Infrastructure for Translational Medicine (EATRIS), a non-profit organization composed of 110 academic research institutes and medical centres. Based in Amsterdam, EATRIS' mission is to accelerate the translation of research discoveries into patient benefit.

Anne-Charlotte is responsible for EATRIS' advocacy and partnerships strategy and oversees the infrastructure's portfolio of European collaborative projects. Anne-Charlotte has recently been leading EATRIS' increased efforts to liaise with the patient community and build bridges between academic researchers and patients. Prior to joining EATRIS, she worked as EU funding expert and Head of International Relations for a non-profit organisation based in France.



ENPs – Sandrine Lavalle, ENP Luxembourg – 1 year

Sandrine Lavallé received a Master of Communication degree and a Master of Sociology degree from the University of Louvain-la-Neuve in Belgium. She has a genuine passion for communication. She worked for 11 years at Alzheimer Europe, a non-governmental organisation, aiming at promoting the voice of people with dementia and their careers.

In 2007, she joined the Luxembourg Institute of Health (LIH), where she mainly deals with the popularization of scientific information to the public. In 2015, she voluntarily committed herself with EUPATI Luxembourg to give a voice to patients and try to help them to play an active role in the world of research at the national level. In 2017, she was diagnosed with a breast cancer. To be a patient reinforced her strong believe that integrating the patient's experience and expertise into research will result in a breakthrough in public health.



ENPs – Filippo Buccella, ENP Italy – 2 years

Filippo has been active since 2012 in the Italian national Liaison team as the patient member, and since 2012 I have been collaborating with EUPATI on an international level. In 2014, he participated in the foundation of the Italian EUPATI non-profit organization; since 2014, he is seating on its board as a patient member and president. He collaborated with board members from industry and academia to manage the first EUPATI training in Italian in 2018. He is still active today with EUPATI Italy.

Before starting his collaboration with EUPATI, he volunteered for more than 20 years in the non-profit association Parent Project. Parent Project fights to end Duchenne, accelerate research, raise patients' voices to impact policy, demand optimal care for every single family, and strive to ensure access to approved therapies. He founded this association in 1996 after discovering that my first child was affected with Duchenne Muscular Dystrophy, a rare genetic disease; he was its president until a few years ago. He is currently still on the board and actively collaborate, and also participated in DMD Drug Evaluations and EMA meetings and advisory boards. He works as a Pharmacist in my Pharmacy and is also active in the trade union association of Italian Pharmacists (Federfarma).

