



EUPATI Foundation 10-Year-Anniversary Event Brussels, Belgium 19-20 May 2022

Objectives of the meeting:

- To reflect on the progress and achievements of EUPATI since its launch
- To discuss EUPATI's role in patient education today
- To strengthen the EUPATI Partnership and create networking opportunities
- To explore key topics in the current workplan
- To reflect on the future focus for EUPATI and the next 10 years

Thursday 19 May 2022

Time	Session	Item	Moderator(s)	Speaker(s)
12.00	Arrivals and networking lunch for all participants (registration open from 11:30)			
14.00	Welcome addresses	Opening of EUPATI 10-Year-Anniversary Event	Kay Warner and Anders Olauson	Kay Warner and Anders Olauson
		Message from a EUPATI Fellow		Lara Bloom
		Message from EPF		Marco Greco, Anca Toma
		Message from IHI		Pierre Meulien
		Message from EFPIA		Nathalie Moll
		Message from EMA		Nathalie Bere
14.45		Group activity: Quiz	Secretariat	
14.55	Initial stages of EUPATI	Keynote presentation: The launch and early stages	Ingrid Klingmann	Jan Geissler
15.05		Keynote presentation: The challenges and evolving landscape of patient education		Nicola Bedlington
15.15		Moderated discussion		
15.25	Ensuring the continuation of EUPATI	Keynote presentation: Bridging phase - Strengthening the partnership and Achieving sustainability	Brian West	Matthew May & Matthias Gottwald
15.45		Moderated Discussion		
15.55		Group activity	Secretariat	
16.00	Coffee Break			
16.30	EUPATI today	EUPATI National Platforms: Experiences and challenges	Daniel de Schryver	Sandrine Lavallé, Filippo Buccella and EUPATI National Platform representatives
17.00		Keynote presentation: Where are we now?		Maria Dutarte
17.10		Message from Alumni		Mitchell Silva
17.20	Future of EUPATI	Keynote presentation: Vision for the future	Kay Warner and Anders Olauson	Vytenis Andriukaitis
17.35		Moderated discussion		
17.50		Call for action		Kay Warner and Anders Olauson
18.00	Reception			
19.00	Dinner			

Friday 20 May 2022

Time	Item	Facilitator/Presenter
9.30	Coffee	
10.00	Parallel workshops Workshop 1: Diversity & inclusion in health literacy Workshop 2: Changing role of patient experts and needs for further training & education	Ankita Batla, Caitlin Rich, Alexandra Lewis and Gry Wester
12.00	Lunch & departures	

Workshop 1: Diversity & inclusion in health literacy

This workshop will discuss diversity, inclusion and accessibility in the context of health literacy and EUPATI educational programmes.

The objective is to identify key considerations and recommendations for EUPATI to maximise accessibility to its educational platforms and resources, by identifying the key patient groups to be targeted.

Key questions for the participatory exercises are:

What is EUPATI's role in this context and what is its target audience? How is this related to the different types of patient profiles (e.g. patient advocates, patient experts, patient representatives etc)

- What do we mean by diversity and inclusion in the context of health literacy and EUPATI? What is the current reach of EUPATI in terms of different types of patients and patient groups? Are we excluding any groups?
- What does EUPATI need to do to make the educational content more accessible? What are the best practices around accessibility?

Workshop 2: Changing role of patient experts and needs for further training & education

This workshop will discuss the evolution of the role of patient experts within the patient engagement landscape, their engagement with the different stakeholders, and the related emerging needs for further education.

The objective is to identify key considerations and recommendations for EUPATI to expand its trainings and educational materials based on the identified new needs, by listing emerging topics and materials required in order to enable patients to be involved in future opportunities.

The key questions for the participatory exercises are:

- What do you see are the emerging opportunities for patients in medicines R&D and beyond (for you as a representative of patients/industry/academia)? Why this changing and how, where is this being driven from?
- What is the implication of these considerations in terms of needs for EUPATI patient education? Does the EUPATI training offer need to be expanded and if so, how and what are the key new areas?

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Speaker bios (in the order of the programme)



Speakers

Lara Bloom



Lara Bloom is the President and CEO of The Ehlers-Danlos Society and responsible for globally raising awareness of rare, chronic, and invisible diseases, specializing in the Ehlers-Danlos syndromes, hypermobility spectrum disorders (HSD), and related conditions.

Lara manages coordinated medical collaboration, raising funds for research, and focusing on the global progression of EDS and HSD. She speaks at conferences all over the world, lecturing to medical students and professionals, and supports specialists in the field by offering her experience as a leading Patient Expert. Commemorating ten years in the field of patient advocacy, Lara was officially appointed a Professor of Practice in Patient Engagement and Global Collaboration at Penn State College of Medicine, USA, on

March 11, 2020.

Marco Greco



Marco Greco has been President of the European Patients' Forum since 2014.

He was chairman of the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) from 2008 to 2014. He was the founder of the EFCCA Youth Group, and its leader from 2003 till 2007.

He was appointed as patient representative by the European Commission in the Pharmacovigilance Risk Assessment Committee at the European Medicines Agency

(EMA) from 2013 to February 2019. He has recently been selected as patient representative to EMA's Management Board for a three-year term starting on 15 June 2019.

He holds a degree in Law from UCSC MILAN and a Ph.D. in Law and Religious Freedom. He is currently working as an attorney in his law firm.

Anca Toma



Anca Toma joined EPF as Executive Director in March 2022. Her career started in the Romanian EU accession negotiations team, continued as a consultant in a public affairs and communications agency in Brussels, followed by ten years in Smoke Free Partnership, a European coalition of NGOs working to advance tobacco control for cancer and NCD prevention. Anca has over 15 years of experience in European health policy working in policy advocacy, strategic communications, developing and coordinating successful pan-European advocacy campaigns, and leading her team and organisation. Anca is a political science graduate of the University of Bucharest and holds a masters in European politics and administration from the College of Europe.

Pierre Meulien



Dr Pierre Meulien is Executive Director of the Innovative Health Initiative (IHI) and has decades of experience in the life science sector. Dr Meulien has a PhD in molecular biology from the University of Edinburgh and has carried out a post-doctoral fellowship at the Institut Pasteur in Paris. From 2002 to 2007, Dr Meulien served as founding CEO of the Dublin Molecular Medicine Centre. From 2007 to 2010, he was Chief Scientific Officer at Genome British Columbia. In 2010 he became President and CEO of Genome Canada. In 2015 he took up the post of Executive Director of the Innovative Medicines Initiative (IMI), the fore

runner of IHI.”

Nathalie Moll



Nathalie Moll joined the European Federation of Pharmaceutical Industries and Associations (EFPIA) as Director General in April 2017. Prior to joining EFPIA, Nathalie was the Secretary General of EuropaBio (2010-2017). She spent over 20 years working for the biotech industry at EU and national level in associations and corporate positions and held the position of Chair and Vice Chair of the International Council of Biotech Associations (ICBA). In 2013, Nathalie won the Technovisionaries Women Innovation Award organised by Women & Technologies® and was also named one of the 15 leading women in biotech in Europe in 2017. Nathalie holds an Honours Degree in Biochemistry and Biotechnology from St Andrews University, Scotland.

Nathalie Bere



Nathalie has been working at the EMA since 1998 and is responsible for engagement with patients and consumers. Over the years, Nathalie has been testing and implementing various methodologies to include the patient's voice in all aspects of the regulatory lifecycle of a medicine.

Patients bring specific knowledge and expertise to the scientific discussions from their real-life experience of living with a condition and their contributions lead to better regulatory outcomes.

As a steady increase in patient engagement at EMA has been observed, Nathalie continues to further strengthen and diversify these activities and ensure they are fit for purpose in an evolving health landscape.

Nathalie holds a Master in Public Health and a Bachelor of Science in Psychology.

Jan Geissler



As a CML patient since 2001, Jan co-founded the patient advocacy organisations LeukaNET, European Cancer Patient Coalition, CML Advocates Network, Acute Leukemia Advocates Network and Workgroup of European Cancer Patient Advocacy Networks (WECAN). He was Director of the European Patients' Academy (EUPATI) and manages the German EUPATI platform. Jan represents patient perspectives in committees e.g. in the European Cancer Organisation, EHA, EuroBloodNET, iCMLf, German National Decade Against Cancer and the Ethics Committee of the Bavarian Chamber of Physicians. He is CEO of Patvocates, a think

tank, consultancy and social enterprise on patient advocacy, health policy and patient engagement in research. He is work package leader in the IMI big data projects HARMONY and HARMONY-PLUS.

Nicola Bedlington



Nicola Bedlington was the first Secretary General of the European Patients Forum (2006-2019). During her tenure, she helped build the organisation to be the leading umbrella voice of patients in Europe, uniting 75 umbrella member organisations, and a key interlocutor with the EU Institutions, WHO and OECD.

She co- led the European Patients Academy on Therapeutic Innovation (EUPATI) 2012-2020), which now a Foundation providing education and training to patients on the A to Z of medicines. She also co-led PARADIGM, an IMI project dedicated to making patient engagement in the life cycle of medicines easier for all (2017-2020).

Nicola represented EPF as a founding board member of PFMD and has been advisor to several global organisations (ISPOR, DIA, ICHOM, WEF Health Future Group, HTAi) supporting their strategies on patient engagement.

Prior to her work with EPF, she led the European Disability Forum and served as an external expert for the European Commission. Nicola co-founded a consultancy – Millwater Partners in 2020, specialising in health, engagement and sustainability.

Matthew May



Matthew studied chemistry but quickly became disenchanted by the lack of personal contact in the lab search for the next successful medicine. He spent the early years of his career at DIA mostly working on the IMI-EUPATI project in ever expanding roles, as the project concluded he moved to EPF and led EUPATI during the bridging period initiating IMI2 EFOEUPATI and EIT Health EUPATI Reload, and setting the programme on the path to become a

foundation. In the end he was only able to witness the birth of the foundation from afar, having taken an opportunity to lead patient engagement in rare neurodegenerative diseases and later also Parkinson's disease at Roche at the start of 2020 where he is still today.

Matthias Gottwald



Matthias Gottwald is the former Head of R&D Policy and Networking at Bayer Pharma AG (2007-2021), being responsible for the interaction with the political environment on R&D related issues, consortia management and publicly funded activities.

He studied in Goettingen, where he gained a diploma in biology and a PhD in microbiology. Since 1986 he had worked with Schering AG and Bayer Pharma AG in several management positions in R&D. Since 2007 he was actively involved in the planning and implementation of the Innovative Medicines Initiative IMI and supported the initiative as chair of the IMI Operations Group of the EFPIA until 2020.

He was the Co-Chair of the EUPATI Steering Committee until the establishment of the EUPATI Foundation in 2020. In 2020-2021 he was actively involved in the EUPATI Reload project (EIT Health) designing the new EUPATI Open Classroom.

Sandrine Lavallé



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 belief that integrating the patient's experience and expertise into research will result in a breakthrough in public health.

Filippo Buccella



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).

Maria Dutarte



Maria joined EUPATI in 2020 and is the Executive Director of the EUPATI Foundation. She oversees the EUPATI Secretariat and the different workstreams. She has previously worked as a Project Manager at the European AIDS Treatment Group (EATG) coordinating patient involvement in a number of training initiatives and scientific projects. Maria has also worked for different scientific and international organisations. Her educational background is in International Education and Communications.

Mitchell Silva



Mitchell is a patient entrepreneur. He is co-founder of Patient-Centrics Esperity, a start-up aiming to deliver patient empowerment tools to increase quality of life of patients. Based on his experience by working with various stakeholders in the health system, Mitchell co-authored a book on patient engagement for the life science industry. He has also played the foundations of the Patient Expert Center in Belgium and is the chair of the Belgian EUPATI national platform. Mitchell has a PhD in bio-engineering from the KULeuven and an EUPATI-fellow. He was also one of the first HIMSS future50 patient leaders.

Vytenis Povilas Andriukaitis



Outstanding Lithuanian politician, EU Commissioner for Health and Food Safety (2014-2019).

V.P. Andriukaitis was born on 9th August 1951 in Kyusyur, Siberia. His parents were deported in 1941 and he returned to Lithuania in 1957. He is co-author and a signatory of the Independence Act of Lithuania (March 1990), also one of the co-authors of the Constitution of the Republic of Lithuania adopted in 1992. V. Andriukaitis is one of the founders of the Lithuanian Social Democratic Party and later on Chairman of the party (1999-2001), currently having the position of honorable chairman of LSDP. Member of the Lithuanian

Parliament for six terms, from 1990 to 2004 and from 2008 to 2012. During that time he served as a Chairman of the Committee on European Affairs, including during the accession to the EU in 2004; as a member of the Foreign Affairs Committee; as a Deputy Speaker of the Parliament (2001- 2004). The same years he served as the Head of the Lithuanian Delegation to the European Convention. Having background of professional doctor, V. Andriukaitis had been a practicing surgeon with specialization in cardiovascular surgery (more than 20 years). He also holds a degree in History from Vilnius University acquired in 1984. From 2012 to 2014 Vytenis Andriukaitis was a Minister for Health in the Lithuanian Government.

From 2014 to 2019 he served as European Commissioner for Health and Food Safety. From 2020 - Special Envoy of the WHO for Universal Health Coverage for the European region and Member of the Political Advisory Panel of the UHC 2030 Movement. V.P. Andriukaitis is an author of multiple articles and books, more than 140 legislative proposals and amendments on national and the EU level; among them Amendments to European Treaties.

Moderators

Anders Olauson, EUPATI Board Chair



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.

Kay Warner, EUPATI Board Co-Chair



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 half 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 and was elected industry co-lead of EUPATI in September 2020 and has been active in many patient engagement initiatives including PARADIGM and PFMD.

Ingrid Klingmann, EUPATI Board Member



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, ConcePTION, PharmaLedger, 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.

Brian West, EUPATI Board Member



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 served 3 terms on the Board of the European Patients Forum, where he is currently Vice-President. He has previously served on the Trustees Board of Scottish service provider, Waverley Care, and on the Board of Directors of HIVScotland – a policy and advocacy organisation.

Daniel De Schryver, EUPATI Board Member



Daniel De Schryver is Patient Engagement & Advocacy Lead, Europe, Middle-East and Africa, at Janssen, the pharmaceutical companies of Johnson & Johnson. He is part of a global multi-functional leadership team that helps the company to engage with patients in a systematic way, and helps to build partnerships in developing solutions that better meet the existing needs. In the EMEA region, Daniel leads a Center of Excellence as well as a group of individuals who function as single points of contact per country and therapeutic areas and who play a crucial role in working towards a more collaborative approach in innovation. Daniel joined Johnson & Johnson in 2001 as

Director Corporate Communications and initially worked in the field of oncology. In 2006 he moved to Infectious Diseases where he helped to maintain and enhance the company's relationships with the HIV Patient Community, before becoming the Global Therapeutic Area Communications Leader Infectious Diseases and Vaccines and Global Public Health. Daniel has a Master in Romance Philology (Literature) and he started his career as a teacher. After having worked in communications roles in the car industry for several years, he joined the non-profit sector and became country manager for Médecins Sans Frontières in Bosnia, Croatia and Angola. Back in Europe, he headed the Communications department for the organization. Before joining Johnson & Johnson, he worked at Burson-Marsteller as a consultant on corporate communications.

Workshop Facilitators

Ankita Batla, Medical Strategy & Patient Partnerships, Medical Strategy and Patient Partnerships VMLY&R HEALTH



I head up Medical Strategy and Patient Partnerships at VMLY&R HEALTH. I am a EUPATI trained professional and provides consultation for upskilling PAGs and pharma teams on patient engagement. Patient advocacy and health equity are my passions. I work very closely with a number of patient groups and organisations to further the cause of person-centred healthcare.

Alexandra Lewis, Associate Director, Medical Consulting at VMLY&R HEALTH



I have 10 years' experience in life science consulting and specialise in the communication of product value to multi-stakeholder audiences, including patients, policymakers, payers & physicians. I am passionate about health equity and for the past three years have had a particular focus on reducing disparities in access to care for underserved patient populations with metastatic breast cancer. At VMLY&R HEALTH, I lead cross-functional teams to deliver projects for pharma and biotech clients, across a range of therapy areas. I am an experienced facilitator having run numerous advisory boards and workshops for a variety of audiences.

Gry Wester, Associate Management Consultant, Medical Consulting at VMLY&R HEALTH



I am a highly experienced health science researcher with an interdisciplinary, international background. I am passionate about health equity and improving access to health care and patient outcomes. At VMLY&R HEALTH, I work on market access and business strategy, supporting clients in the creative transformation of science to value. I'm a strategic and creative thinker and bring a methodical and systematic approach to project work.

Prior to joining VMLY&R HEALTH, I was an academic researcher and lecturer at King's College London. I have 15 years' research experience in health and health care research, specialising in health inequality and public health policy.

Caitlin Rich, Research Associate in Consulting and Patient Partnerships, Medical Consulting at VMLY&R HEALTH



I run VMLY&R HEALTH's Patient Partnership Program, whereby patient groups share their experiences with our teams in return for expert support and training to meet their communication needs. Through this program, we have delivered a series of sessions for EUPATI patient experts, and most recently I delivered a training on communicating with people with low health literacy.

I am also a patient myself, so through my role and personal experience, I have an in-depth understanding of patient needs, their evolving role in the healthcare system, and the importance of patient activation to improve outcomes and experiences of care.