

Towards a Patient-Centred EU Mandate: Health Policy with and for Patients

16 October 2024, Renaissance Hotel, Brussels

Opening remarks



Moderator Katrina Sichel

London-born and bred, now Brussels-based moderator with an MA in Modern Languages from Oxford University. Her eclectic career path spans steel-trading in West Africa to business development in the post-Soviet states; co-managing an award-winning broadcast PR company (producing news packages for BBC, Sky News, Channel 4, Reuters etc.) to delivering presentation and media training for public and private sector clients at an international radio, film and television facility.

Since 2011, Katrina moderates events for all sorts of clients on diverse topics from technology and digitalisation, to agriculture, fisheries and maritime affairs; from environment, climate change and biodiversity issues to energy, mobility and transport topics; from financial governance to health(care). Alongside, until 2017, she managed the design and roll-out of EU multimedia communications campaigns for big agencies in Brussels. She speaks French, rusty Russian and a smattering of German.



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.



Stella Kyriakides

European Commissioner for Health and Food Safety, Stella Kyriakides has been leading the Commission's work in the area of health to establish a strong European Health Union. It includes Europe's Beating Cancer Plan, the implementation of the EU Pharmaceutical Strategy, the European Health Data Space, overseeing the work of the new European Health Preparedness and Response Authority and the operationalisation of the EU4Health funding Programme. She is also leading the Commission's new comprehensive approach to mental health.

During the COVID-19 pandemic, Commissioner Kyriakides led the EU's public health response.

Commissioner Kyriakides is also responsible for upholding and strengthening EU food safety and sustainability standards, covering every step in the food chain from production to consumption. Her responsibilities include animal welfare, as well as leading the work to protect animal and plant health. In 2006-2019, she was elected to the Cyprus Parliament for the Democratic Rally party, of which she was the Vice-President for ten years.

In 2011, she was appointed Head of the Cyprus Delegation to the Parliamentary Assembly of the Council of Europe (PACE).

In 2017, she was elected President of the PACE, the fourth woman to hold this position in the history of the Assembly.

A psychologist by profession, she has been an active advocate on children and patients' rights.

Following her own breast cancer diagnosis, she founded the breast cancer organisation in Cyprus Europa Donna Cyprus, for which she served as President for over 15 years. She was elected President to the European Breast Cancer Coalition Europa Donna and served on numerous European patient advocacy and scientific boards.

She is the recipient of numerous awards from her community service in Cyprus and globally.



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Dr Hans Henri P. Kluge began his term as WHO Regional Director for Europe on 1 February 2020, following his nomination by the WHO Regional Committee for Europe and appointment by the WHO Executive Board. He has 25 years of experience in medical practice and public health in numerous settings around the world. Having qualified in medicine, surgery and obstetrics from the Catholic University of Leuven in 1994, he began his career as a family doctor in Belgium. On assignment with Médecins Sans Frontières (MSF) Belgium from 1995, his international experience started in emergencies, working in Liberia and Somalia, coordinating a tuberculosis (TB) control programme and providing medical and public health services in conflict zones. Dr Kluge's work for MSF in the area of TB control continued with a posting coordinating programmes in prisons in Siberia, and then as the Regional TB Advisor for former Soviet Union countries in Moscow, Russian Federation. Dr Kluge joined WHO in 1999, as TB and TB-HIV Project Manager at the WHO Country Office in the Russian Federation.

During 2004–2009 his focus expanded, as Medical Officer for TB and then becoming Team Leader for the 3 diseases unit (HIV, TB and malaria) at the WHO Country Office in Myanmar, as well as working as a consultant to the Democratic People's Republic of Korea on TB. In 2009, Dr Kluge moved to the WHO Regional Office for Europe, and the following year was appointed Director of the Division of Health Systems and Public Health, and Special Representative of the Regional Director to Combat Multi/Extensively Drug-Resistant Tuberculosis. As division director, he led the development of a new WHO European Region vision on health systems for prosperity and solidarity; drove work on a regional study on universal health coverage and financial protection; prioritized a focus on service delivery including integrated and primary health care; and built strong partnerships on health system performance and reforms with the European Commission, Organisation for Economic Co-operation and Development (OECD), World Bank, GAVI, the Global Fund to Fight AIDS, Tuberculosis and Malaria, the European Observatory on Health Systems and Policies, civil society and donors. A Belgian national, Dr Kluge is fluent in English, French, German and Russian, as well as Dutch. He is married and has two daughters. He enjoys running, cycling and gardening.



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Session 1: Patient involvement across the healthcare continuum



Moderated by Anca Toma

Anca 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.



Melanie Carr is Head of the Stakeholders and Communication Division and a member of the Executive Board at the European Medicines Agency (EMA). She joined EMA in 1996 and has held various roles in pharmacovigilance, the centralised procedure for marketing authorisation, orphan medicines, the SME office and corporate stakeholders department. In her current role she is responsible for stakeholder relations management, communication, and crisis management. She has a degree in Pharmacy from the University of Nottingham in the UK and worked as a regulatory professional in the pharmaceutical industry prior to joining EMA.



Marko Korenjak is the President of the European Liver Patient Association (ELPA), representing 39 liver patient associations from 29 countries in the WHO European region. Marko is the co-chair of the Patient and Consumer Working Party and a member of the Pharmacovigilance Risk Assessment Committee (PRAC) at the European Medicines Agency. He was a member of the ECDC Advisory Forum, still actively participating in the working group on monitoring hepatitis B and C in the EU, and at the WHO EURO Collaborating Committee on TB, HIV, and viral hepatitis. Additionally, he serves as a member of the HERA Civil Society Advisory Forum and is a member of the Advisory Council for Europe, Middle East & Africa (ACEMEA) at DIA. He holds Master's degrees in Business and Economy, International Relations Diplomacy, and a third in International Patient Advocacy.

His work is dedicated to patient advocacy at the highest European levels. At ELPA, Marko leads a team that collaborates on 20 EU Horizon projects, managing over 200 million EUR in high-level liver research across more than 180 collaborating partners within the European Union. His influence in the field of hepatitis elimination was recognised in 2017 by The Economist's Research Unit, which named him one of the 18 most influential individuals globally in this domain. In 2024, Marko was honored with the prestigious "Made with Patients" award from Patient Focused Medicines Development (PFMD), the highest accolade for patient engagement worldwide, recognizing his significant contributions to patient advocacy and engagement in healthcare.



Maya Matthews has worked in public health for over 20 years. She is currently Head of Unit in the European Commission's Health and Food Safety Directorate General responsible for State of Health in the EU, European Semester and Health Technology Assessment. She was previously Deputy Head of Unit in the Strategy and Coordination unit. From 2013-2016, Maya worked in the European Union's Delegation to the United Nations in Geneva where she covered health issues and relations with the World Health Organisation.

Before joining the European Commission in 2008, Maya worked in Brussels for Eurohealthnet and consulted on reproductive health, HIV prevention and Tuberculosis. Maya holds a BA in Human Sciences from Oxford University and a Masters in Health Promotion Sciences from the London School of Hygiene and Tropical Medicine where she also worked as a researcher from 1993-1995.



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Frederico Guanais is Deputy Head of the OECD Health Division, where he leads the development of the Patient-Reported Indicators Survey (PaRIS), a multi-country initiative benchmarking the performance of health systems from the patient's perspective. He also oversees the Division's work on health statistics, health reforms, climate-health links, and the work in the Latin American region. Previously, he worked at the Inter-American Development Bank and at the Federal Government of Brazil. He has an extensive record of academic publications on primary care, health systems strengthening, and integration of health and social policies. He is a dual citizen of Brazil and Italy and holds a Ph.D. in Public Policy from New York University.



Nathalie Moll joined the European Federation of Pharmaceutical Industries and Associations (EFPIA) as Director General in April 2017. EFPIA represents the pharmaceutical industry operating in Europe. Together with its direct membership 40 leading pharmaceutical companies, 33 national associations representing over 1900 companies and in collaboration with health and research players, EFPIA's mission is to create an environment that enables our members to innovate, discover, develop and deliver new therapies and vaccines for people across Europe, as well as contribute to the European economy. EFPIA was named Best Business EU Trade Association in Brussels in 2022. Prior to joining EFPIA, between 2010 and 2017 Nathalie was the Secretary General of EuropaBio ranked as the most effective European Trade Association in Brussels in 2013.

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® while in 2009, Nathalie and the Green Biotech Team of EuropaBio were presented with the Leadership and Excellence in Advancing Ag-Biotech and Food Issues Award. Nathalie was also named one of the 15 leading women in biotech in Europe in 2017, recognised as one of the "20 Women Who Shape Brussels" by POLITICO Europe in 2020 and Among the Women who advance associations in 2021. Nathalie holds an Honours Degree in Biochemistry and Biotechnology from St Andrews University, Scotland.



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Fireside chats with MEPs



Adam Jarubas, Ph.D - Member of the European Parliament, re-elected as the Chairman of the EP Public Health Subcommittee (SANT) in 2024. In previous term, he worked also in the EP Special Committee on Beating Cancer (BECA). This term he continuous his work in the EP, working in the Committee on Industry, Research and Energy (ITRE) and Committee on the Environment, Public Health and Food Safety (ENVI). A graduate of the Świętokrzyska Academy in Kielce.

In 2018, at the Jan Kochanowski University in Kielce, he obtained a PhD in social sciences and regional policies. Assistant professor at the Institute of International Policy and Security. In the years 2006-2018, Marshal of the Świętokrzyskie Voivodeship. In the EP, he focuses on public health, green transformation and digital transformation in the EU, coordinating the work of the Polish delegation in the Group of the European People's Party in these areas.



András Tivadar Kulja is a Hungarian surgeon, accomplished digital health expert, and politician of the Tisza Party, elected as member of the European Parliament in June 2024. His social media posts and videos on health education in several platforms, especially on TikTok, prevailed during the Covid-19 pandemic, in an attempt to fight disinformation. Former Professor of Health and Science Communication at Semmelweis University, András is now serving as the Vice-Chair in the Committee of Environment, Health and Food Safety (ENVI) of the European Parliament, and Vice-Coordinator for the biggest political group, European People's Party (EPP), in the Public Health Committee (SANT).



Ondřej Dostál is a Czech lawyer and expert in health policy, bioethics, patients rights and medical law. He was elected to the European Parliament in June 2024, and serves as a member of the committee on Environment, Public Health and Food Safety (ENVI) and the delegation for relations with Southeast Asia (DASE).



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Session 2: Supporting an effective patient movement: challenges and opportunities



Moderated by Elisabeth Kasilingam

Elisabeth is a distinguished leader in the European health advocacy community, currently serving as the Chief Executive Officer of the European Multiple Sclerosis Platform (EMSP) and EPF Vice President. With a career spanning over 15 years, she has been instrumental in advancing the quality of life for patients with multiple sclerosis (MS) and other chronic conditions through strategic, impactful projects and policy initiatives. Elisabeth's journey with EMSP began in 2008 when she joined as a member of the Secretariat. Her dedication and expertise led to her appointment as Managing Director in 2016, and later as CEO. She has been pivotal in capacity-building developing programs strengthen national MS patient organisations, advocating for health and social policies, and nurturing young patient advocates.

Her efforts include leading the influential MS Barometer and related surveys, which provide critical data to shape policies that improve the lives of those affected by MS across Europe. In addition to her role at EMSP, Elisabeth has been actively involved with the European Patients' Forum since 2018, where she started as a Board member and later took on the role of Treasurer. Her background in law and European affairs, coupled with a deep commitment to human rights, has been a driving force in her work with Brussels-based NGOs such as Eurochild and EPF. Elisabeth's leadership is marked by a clear mandate to enhance access to care, employment opportunities, and overall quality of life for people with MS, demonstrating a steadfast commitment to the members and goals of these organisations.



Baiba Ziemele is a passionate patient advocate from Latvia. Living with inherited bleeding disorder, von Willebrand disease, she has been heavily involved in patient advocacy, becoming President of Latvia Hemophilia Society in 2009, representing European community with bleeding disorders as ePAG in EuroBloodNet, European Reference Network for rare hematological diseases, engaging in various committees at European Haemophilia Consortium and World Federation of Hemophilia. She has helped shaping rare disease policy nationally and internationally.

Since 2018, Baiba is also building Latvian Network of Patient Organizations to bring united patient voice and represent patient interests at various tables. In 2022, Baiba received Human Development award for outstanding contribution to health from Civic Alliance Latvia and US Embassy in Latvia and was awarded Person of the Year 2023 in Medicine by Latvian Medical Association. Magazine "Pastaiga" announced her one of most influential women in Latvia in 2024.



Dr Martin Danner is a lawyer and Federal Managing Director of BAG SELBSTHILFE e.V. After completing his studies in Heidelberg, he worked for several years as a lawyer specialising in health law before becoming head of the Health Policy and Self-Help Promotion Department at BAG SELBSTHILFE. Dr Martin Danner is the spokesperson for patient representation at the Federal Joint Committee.



Konstantina Boumaki is a medical doctor with 19 years of experience in patient advocacy. Since her diagnosis with type 1 diabetes in 2005, she has been a passionate advocate, leading numerous projects to improve patient engagement and health outcomes. Currently, she holds the position of Development Executive at Global Heart Hub, where she is responsible for patient engagement and advocacy within the cardiovascular disease space.

Konstantina is a board member of the European Patients' Forum Youth Group and the Youth Group representative in the European Patients' Forum Board of Directors. She also serves as a Board Treasurer for the Hellenic Diabetes Federation. She is also an active member of the International Diabetes Federation, both globally and in Europe, where she continues to lead impactful initiatives and collaborations. She holds an active role as a mentor in the International Diabetes Federation's Young Leaders in Diabetes Program and she is an active member in Yourah project of IDF Europe.



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Ildikó Vajda holds a PhD in neurophysiology and has worked for more than 8 years in the field of fundamental scientific research on neuronal plasticity. She then continued in the field of applied research and was modeling biological knowledge to be reasoned with by AI- agents for predicting eating behavioral patterns. From 2011 she is working together with patient organizations, healthcare professionals, IT-experts to make healthcare more patient-centric also in the digital era. She is working since 2020 at the Dutch umbrella organisation of patient organisations (the Netherlands Patient Federation). There she works on topics like AI, secondary use of data, ethics, all in relation to digital health from national en European health policy perspective. Her expertise is at the intersection of (digital) health innovations, co-creation methods and AI-ethics and health policy.

Fireside chats with MEPs



Tilly Metz is a Member of the European Parliament from Luxembourg since 2018. She is the 1st Vice-Chair of the Subcommittee on Public Health and a member of the ENVI, TRAN and AGRI Committees. In the previous mandate of the European Parliament she represented Greens/EFA in the Special Committee on the COVID-19 pandemic. Her focus in EU health policy is on One Health, healthcare workforce, women's health, access to medicines and rare diseases.



Vytenis Povilas Andriukaitis was born on 9 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.



Kateřina Konečná is a Czech MEP from Communist Party of Bohemia and Moravia. She has been elected as a member of the European Parliament in 2014, in 2019 and in 2024 (new left coalition Enough! (Stačilo!)). She is a substitute member of the ENVI committee, the SANT subcommittee and full member in the IMCO committee. She focuses on the topic of access to healthcare, deals with public health issues and cooperates very closely with patients and their organisations.

For 5 years, she was EP's contact person responsible for the ECDC agency. During her two mandates, she worked on the HTA regulation, medical devices and in-vitro medical devices regulations, EU4health program, health union package (EMA, ECDC and cross-border health threats) as weel as the Pharmaceutical package (both regulation and directive). She was a vice chair of the PEST special committee and from September 2020 she was also the group's coordinator in the BECA special committee.



Stine Bosse is a newly elected Danish MEP for Moderaterne (Renew Europe). Prior to going into politics, MEP Bosse was a board member in the insurance and financial services industries and a business leader most known for her work as a former CEO of Tryg, a major Nordic insurance firm, and long-time board member of Allianz. She has also served on the boards of NGOs including PlanBørnefonden (part of Plan International).

Stine Bosse is known for her focus on digitalisation and innovation within the insurance sector, as well as her commitment to promoting equality and diversity in the workplace. Bosse has received several awards for her leadership and contributions to the industry.



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Closing Remarks



Dr Natasha Azzopardi Muscat has been Director of the Division of Country Health Policies and Systems at WHO/Europe since 2020. A medical doctor by training and a specialist in public health, she has worked in various areas in the health sector in her native Malta, including maternal and child health, mental health, and primary care. Before joining WHO, Dr Azzopardi Muscat occupied various senior positions in the Ministry of Health in Malta, including that of Chief Medical Officer.

From 2016 to 2020, she was President of the European Public Health Association (EUPHA), where she was actively involved in health advocacy at the European level.



Anca Toma

Anca 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.