



## EUROPEAN PATIENTS' RIGHTS DAY 2025

### *Exploring the benefits of health data sharing for patients, healthcare systems, and medical research at the EU level*

15 May 2025 | 14:30 – 16:30  
Room 3H1 | European Parliament, Brussels

**Jakub Adamski, Head of the Co-operation Department, The Office of the Commissioner for Patients' Rights**



Jakub Adamski – health system expert, lawyer, and manager with many years of experience in public administration and consultancy. He specializes in the financing of healthcare services, including the reimbursement of medicines and medical devices. He is the Head of the Co-operation Department at the Office of the Commissioner for Patients' Rights, where he is involved in implementing solutions that support and guide patients within the healthcare system.

**MEP Vytenis Povilas Andriukaitis, S&D Group, Lithuania**



Outstanding Lithuanian politician, EU Commissioner for Health and Food Safety (2014-2019). Having a background as a professional doctor, V. Andriukaitis had been a practicing surgeon with specialization in cardiovascular surgery (more than 20 years). He is a 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 holding the position of Honorary Chairman of LSDP. He served as the Head of the Lithuanian Delegation to the European Convention. 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. From 2024 – Member of European Parliament. Member of ENVI, SANT, and AFCO committees, a coordinator of the S&D group in the SANT committee. He is the author of multiple articles and books, more than 140 legislative proposals and amendments on the national and EU level; among them, Amendments to European Treaties.

### **Birgit Bauer, Digital Health and Social Media Expert, Patient Expert, and Coordinator of Data Saves Lives Germany**



She is an internationally recognized expert in digital health, patient advocacy, and health communication. As founder of *Data Saves Lives Germany* (DSL DE), she leads a patient-driven initiative promoting responsible health data use and strengthening health literacy. DSL DE develops tools like the *DSL DE Kompass*, a magazine on effective communication, and “Fachgedöns,” which explains digital health terms. Birgit also advises international stakeholders on strategy, communication, and patient engagement in digital health.

### **MEP Brando Benifei, S&D Group, Italy; Co-Chair of the MEPs Interest Group "European Patients' Rights & Cross-Border Healthcare"**



Brando Benifei is an Italian MEP serving his third term in the European Parliament. During the previous mandate he was co-Rapporteur for the Artificial Intelligence Act and thanks to this work in March 2024 he won the prize for the Best MEP of the Mandate assigned by The Parliament Magazine.

Now he is the Coordinator in the Committee on International Trade for the Socialists and Democrats Group and Chair of the European Parliament's D-US delegation. He is a member of the Committee on Constitutional Affairs and he works also as a substitute member on the EU internal market and consumer protection and on legal affairs, always following closely digital issues.

**Johanna MC Blom, Professor of Psychobiology, Pediatric & Behavioral Neuroscience - University of Modena, and IHI FACILITATE Coordinator**



Dr. Johanna MC Blom, Associate Professor in Psychobiology and Pediatric and Behavioral Neuroscience, University of Modena. Coordinator of the long-term follow-up of children with cancer and the use of psychotropic drugs, AIEOP; Member of PANCARE, SIOP, and the International Guideline Harmonization Group (IGHG) for the development of Psychosocial and Neurocognitive surveillance guidelines for survivors of childhood cancer. She is the Deputy-Coordinator of the IMI-JU project FACILITATE. She is the Chair of the Ethical Committee for Research of the University of Modena and, currently, she is heading the initiative to develop guidelines for a common legal and ethical framework for receiving consent from minors. She is working, among others, on innovative data-driven network analysis as a tool to detect and predict the driving forces of disability using digital data.

**Sara Farina, Resident in Hygiene, Preventive Medicine, and Public Health- Università Cattolica del Sacro Cuore, PROPHET Project team**



Sara Farina is a medical doctor, currently in the last year of residency in Hygiene and Preventive Medicine and a PhD candidate in Public Health at the Catholic University of the Sacred Heart in Rome, Italy. Primary areas of interest include personalized medicine and genomics from a public health perspective, with a focus on population risk stratification and chronic disease prevention. National Coordinator of the working group on “Personalized Medicine and Genomics in Public Health” within the Resident Council of the Italian Society of Hygiene, promoting innovation in public health through the application of omics sciences. Currently involved in international research projects funded by the European Commission, including the PROPHET project coordinated by the Catholic University and focused on personalized prevention in Europe, contributing significantly to health policies and prevention strategies.

### **Marko Korenjak, President - European Liver Patients' Association (ELPA)**



Marko Korenjak is the President of the European Liver Patients' Association (ELPA), representing 39 patient associations across 29 countries. He is a leading patient advocate at the European level, with three Master's degrees in International Relations, Business and Economy, and International Patient Advocacy. He is a member of the EMA Pharmacovigilance Risk Assessment Committee (PRAC), the HERA Civil Society Forum, and the Advisory Council at DIA. Recognized globally for his work in hepatitis elimination, he was named one of the world's most influential voices in the field by The Economist's Research Unit. In 2024, he received the "Made With Patients" award by PFMD for his commitment to meaningful patient engagement. Marko actively leads ELPA's involvement in over 20 EU-funded projects focusing on health innovation, digital health, and personalized medicine. Recently, he was appointed as Acting Director of the Public Agency of the Republic of Slovenia for Quality in Healthcare: the agency responsible for monitoring the quality of healthcare in Slovenia, managing several national healthcare databases, certifying all public and private healthcare providers, and ensuring that minimum standards in care delivery are met.

### **Fulvia Raffaelli, Head of Unit C1 Digital Health, DG SANTE, European Commission**



She joined the Commission in 2002. Since September 2022, she has been working at the Director-General for Health and Food Safety (DG SANTE), where she is Head of the Digital Health unit.

## MEP Tomislav Sokol, EPP Group, Croatia; Co-Chair of the MEPs Interest Group "European Patients' Rights & Cross-Border Healthcare"



Tomislav Sokol was born in Zagreb in 1982. He obtained his first degree in law at the Faculty of Law, University of Zagreb, in 2006, magna cum laude. He then obtained a Masters of Law (LL.M.) specialising in European Union Law at the Katholieke Universiteit Leuven (KUL), Belgium, in 2009, magna cum laude. He defended his PhD at KUL, dealing with free movement of cross-border health care services in the EU and its impact on national health insurance systems in 2014. He was a Member of the Croatian Parliament until July 2019, when he became a Member of the European Parliament. He is Member and EPP Coordinator in the Committee on Public Health (SANT), Member of the Committee on the Internal Market and Consumer Protection (IMCO), and also Member of the Delegation to the EU-Turkey Joint Parliamentary Committee (D-TR), and the Delegation for relations with Serbia (D-RS). He is also a Substitute Member of the Committee on the Environment, Public Health and Food Safety (ENVI), the Committee on Constitutional Affairs (AFCO), and the Delegation for relations with Montenegro (D-ME) in the European Parliament.

## Aneta Tyszkiewicz, Director Digital and Data - European Federation of Pharmaceutical Industries and Associations (EFPIA)



Aneta is Director Data and Digital at European Federation of Pharmaceutical Industries and Associations (EFPIA), representing the R&D-based pharmaceutical industry in Europe. She leads EFPIA's policy and advocacy activities about data, RWE, and new technologies. Her main goal is to support the digital transformation of European healthcare systems to enhance the discovery and development of innovative and trusted healthcare solutions that can bring tangible and meaningful benefits to patients. She has previously worked for the Council of European Dentists, the International Diabetes Federation, and a consulting agency.

## Mariano Votta, Responsible for EU Affairs – Cittadinanzattiva APS-Active Citizenship Network



Mariano Votta graduated in Political Science from the University of Rome. He has a Master's in European Public Relations and a Master's in Corporate Social Responsibility. In July 2013, he was nominated as the Responsible of EU Affairs at Cittadinanzattiva and Director of Active Citizenship Network, the European interface of the Italian civic organization Cittadinanzattiva. He is responsible for international relations with public and private stakeholders such as the European Commission, EU Parliament, EESC, and companies. He is a freelance journalist and programme manager too, with more than 10 years working in the field of citizens' rights, civic information, evaluation of quality standards in services provided by Public Administration and public companies. Between 2011 and 2012, he worked as a consultant for the United Nations Development Programme in Colombia, to assert a new governance in the management of Public Services and Health. In that Country, Cittadinanzattiva opened several Citizen Advisory Centres on Public Services and Health. In 2015, he took the initiative to encourage and promote the MEPs Interest Group focused on patients' rights called "European Patients' Rights and Cross-border Healthcare" inside the EU Parliament.

## Mariam Zaidi, journalist



Mariam Zaidi is an international news and EU politics specialist working as a presenter for TRT World, CNBC and Euronews. For TRT World she presents the news from both London and at their HQ in Istanbul where she steers hours of breaking news on the world's biggest stories. At CNBC she has fronted an energy series and moderates and MC's at the World Economic Forum in Davos. Previously BBC, ITV, CGTN, Euractiv, APTN and AFP she also moderates and MCs for a raft of corporate clients across tech, business, trade, sport, health, sustainability, agri-food, security, AI, trade, crypto and more. Specifically in the field of health, she has moderated events for ACN, Pfizer, Sanofi, Angelini Pharma, MEP Vytenis Andriukaitis covering issues such as medical deserts, rare diseases, ATMPs, non-communicable diseases, food safety and food supplements. You can find her on LinkedIn or on Instagram [mariam\\_zaidi\\_journalist](#).

**The initiative is realized under the patronage of:**



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and  
the Polish Commissioner for Patients' Rights, also known as the Patient Ombudsman, gave the honorary patronage to the event.

**In the framework of:**



The [FACILITATE project](#) has received funding from the Innovative Medicines Initiative 2 Joint Undertaking (JU) under grant agreement No 101034366. The JU receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA.

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