



EUROPEAN PATIENTS' RIGHTS DAY 2023

Advanced Therapy Medicinal Products in Europe: combining sustainability, innovation and respect for patients' rights

26 April 2023 | 15:00 – 17:00 CEST
Room 3H1 European | Parliament, Brussels

SPEAKERS' LIST

Thomas Allvin



Thomas Allvin is Executive Director for Strategy and Healthcare Systems at the European Federation of Pharmaceutical Industries and Associations (EFPIA), where his responsibilities include overall strategic coordination and leading EFPIA's work on health systems policies, including value-based healthcare and strengthening health system resilience. Thomas is also co-chair of the European Alliance for Value in Health, of which EFPIA is a partner. Before joining EFPIA in 2015, Thomas was Health Counsellor at the Permanent Representation of Sweden to the European Union, representing Sweden in the Council working parties for public health and pharmaceuticals & medical devices, and previously worked in several positions in the Swedish Ministry of Health and the Swedish Parliament.

Eleni Antoniou



Eleni Antoniou joined the team of the Thalassaemia International Federation in 2017 as a Policy Officer, with a focus on European and International Relations. Since August 2022, she serves as the Federation's Senior International Affairs Officer, collaborating closely with the World Health Organization, the European Commission and other health-related bodies. An expert public policy advocate, linguist and researcher, Mrs. Antoniou has designed and implemented many activities aimed at bringing thalassaemia to the forefront of international bodies' agendas. She is a co-author of the Global Thalassaemia Review 2021 and has published articles on the cost of thalassaemia care and the unmet needs and challenges of haemoglobin disorders in Europe.

Brando Benifei



Brando Benifei is an Italian MEP in his second term of office, currently Head of Delegation of the Democratic Party in the European Parliament. He has been working on health issues since the last legislature and is currently Vice-President of the European Parliament's Heart Group. Member of the interest group on Kidney Health and Antibiotic Resistance. Since its establishment in 2015, he has also been a member of the MEPs' interest group on "Patients' Rights and Cross-Border Healthcare", of which he is Co-Chair since 2019.

Stefania Bettinelli



Stefania Bettinelli is the President of Le ali di Camilla (Camilla's wings), an Italian association founded in 2019 to promote research and treatment of rare diseases affecting the skin and other stratified epithelia potentially treatable with advanced therapies based on epithelial stem cells, such as Epidermolysis Bullosa. She has been dealing with rare diseases since 2006 and headed external relations of the Centre for Regenerative Medicine "Stefano Ferrari" of the University of Modena and Reggio Emilia and the university spin-off Holostem Terapie Avanzate until January 2023.

Silvio Brusaferrò



President of the Italian National Institute of Health – Rome; Full Professor of Hygiene and Public Health at the University of Udine. Member of the EU Scientific Advice Platform on Covid-19 and Co-chair of the Global Health Summit Scientific Panel. Member and Coordinator of the OECD Bureau of Expert Group on the economics of Public Health. His professional experiences, at national and international level, have been focused on Public Health. Research and education issues of specific interest include: quality in healthcare, clinical risk and patient safety, infection prevention and control, antimicrobial resistance, best practices and core competences in public health, development of social networks to support health care systems and to orient the evolution of complex organizations in Public Health.

Jo De Cock



Jo De Cock, class of 1955, is a lawyer by background.

During his professional career he held the position of Social Counsellor to the Prime Minister of Belgium for eight years, from 1985 to 1993. Then, from 1995 to 2021, he was Chief Executive Officer of the Belgian National Institute for Health and Disability Insurance (INAMI - RIZIV).

Since 2021, he has been Chair of the Joint Network of Senior Budget and Health Officials at the Organisation for Economic Co-operation and Development (OECD) and advisor for the WHO European Region's Novel Medicines Platform.

Thanos Kosmidis



Thanos Kosmidis is cofounder and CEO of CareAcross, a digital health company focusing on cancer. CareAcross is a member of All.Can International, a multi-stakeholder not-for-profit organisation working to improve the efficiency of cancer care by focusing on what matters to patients. Thanos' role at CareAcross includes shaping personalised services to cancer patients and clinicians, and the company's partnerships with industry, researchers, academia and non-profit organisations, including All.Can.

Beyond the contributions to several digital health and entrepreneurship communities, he has been supporting several European Commission initiatives to enhance healthcare in cancer and beyond.

Stella Kyriakides



Stella Kyriakides is the European Commissioner for Health and Food Safety. She has been leading the Commission's work to coordinate the EU's health response to COVID-19. She is responsible for the establishment of a strong European Health Union and Europe's Beating Cancer Plan. She is leading the new 'Farm to Fork' strategy for sustainable food. Her responsibilities include enforcing EU food, animal welfare, animal and plant health laws. Previously, she was a clinical psychologist for the Cyprus Ministry of Health. In 2006-2019, she served in the Cyprus Parliament for the Democratic Rally party, of which she was the Vice-President. 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.

Anna Lisa Mandorino



Anna Lisa Mandorino is, since 2021, the Secretary General of Cittadinanzattiva. With a master's degree in Literature, she specialised in European Public Relations and Corporate Social Responsibility. At Cittadinanzattiva she was first in charge of Communication, then of General Management through the coordination of activities and projects for the promotion of civic activism and participation. She works with particular attention to public policies on health, services, education and training, human and civil rights, in order to affirm new forms of civic action and governance of public processes, especially related to the empowerment of local communities, stakeholder involvement and institutional dialogue. In addition to other roles, in 2022 she was also appointed as member of the National Ethics Committee for clinical trials related to ATMPs at AIFA (Italian Medicines Agency).

Francesco Saverio Mennini



Francesco Saverio Mennini, is currently Professor for Health Economics and Microeconomics (Business Administration Course) at University of Rome "Tor Vergata", (Faculty of Economics). He is also Professor for Political Economics at University of Rome "Tor Vergata", Faculty of Science. Visiting Professor, Institute of Leadership and Management in Health, Kingston University, London , UK (from 2011) and the President of SiHTA (Italian Society of Health Technology Assessment). In February 2023 he has been appointed as Expert in Health Economics to the Minister of Health and, since 2017 is a member, as an Expert in Economics, of Consiglio Superiore di Sanità and a member of the Working Group "Vaccines and anti-COVID-19 vaccinations" at Ministry of Health since 2020. He works also as Research Director at the Centre for Economic Evaluation and HTA (EEHTA), CEIS - Faculty of Economics, University of Rome "Tor Vergata". He is author of numerous publications (more than 150), national and international, of Health Economics, HTA and Economic Evaluation.

Paolo Morgese



Paolo Morgese leads European public affairs activities at ARM. A patient access, healthcare policy and investment professional with more than 20 years of experience in both assessing and supporting access to innovative healthcare technologies. Before joining ARM in 2017, Paolo worked for 5 years at Deerfield Management, a healthcare investment company. Prior to that, he worked at Merck Serono, Kyphon (which became Medtronic) and also spent several years with the Italian HTA Agency AGENAS. Paolo's interests and expertise are centred on cell and gene therapy value assessment, healthcare system modernization and financing healthcare innovation.

Attila Németh



Vice President of HUFERDIS (RIROSZ), educated as an economist for foreign affairs, working as an international marketing and communication leader in Hungary, has a daughter with Turner syndrome. Turner syndrome, a condition that affects only females, results when one of the X chromosomes (sex chromosomes) is missing or partially missing. This syndrome can cause a variety of medical and developmental problems, including short height, failure of the ovaries to develop and heart defects. He fights to end the disadvantage of rare disease patients compared to other patients and to make their lives easier and better. He also fights to ensure that rare disease patients receive the best possible social and health care, and that the demands of Hungarian rare disease patients are heard by the highest levels of public authorities.

Alessandra Renieri



Alessandra Renieri is Full Professor of Medical Genetics at the University of Siena and Director of Medical Genetics at Azienda Ospedaliero-Universitaria Senese. Her main research interest is the study of the genetic basis of rare diseases, especially Rett syndrome and other conditions with intellectual disability, Alport syndrome and rare cancers. Since 2017 she focused on the translation of gene editing using CRISPR/Cas9 to clinical practice. She is running different gene editing projects related to Rett syndrome, Parkinson and Alport syndrome. Since 2019 she is Member of the EMA Committee for Advanced Therapies (CAT).

Tomislav Sokol



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 a Member of the Committee on the Internal Market and Consumer Protection (IMCO), Special Committee on the COVID-19 pandemic: lessons learned and recommendations for the future (COVI) and also EPP Vice Coordinator in COVI Committee, and a Substitute Member of the Committee on the Environment, Public Health and Food Safety (ENVI) and Committee on Regional Development (REGI) in the European Parliament.

Domenica Taruscio



Domenica Taruscio, MD, is the former Director of the National Center for Rare Diseases at the Istituto Superiore di Sanità (Rome, Italy) and President of ICORD from 2010 to 2012 and from 2021 to date (<http://icord.es/main-menu/board>). Dr. Taruscio is an active contributor to the development of the European scientific and institutional framework on rare diseases and orphan medicinal products. She has been the Italian representative at the Committee for Orphan Medicinal Products (COMP, EMA) (2000 – 2009); scientific coordinator of several national and European projects; member of the Funders Constituent Committee of IRDiRC (<https://irdirc.org>); she has been the Italian Representative at the Board of Member States for European Reference Networks at the EU Commission; co-founder of the Undiagnosed Diseases Network International (UDNI <https://www.udninternational.org/>). She organized several International Conferences, Congresses, Courses and Webinars on rare diseases and orphan drugs. She is co-author of more than 210 publications listed in PubMed.

Mariano Votta



Mariano Votta is responsible for EU Affairs of the Italian NGO Cittadinanzattiva and the Director of its EU branch called "Active Citizenship Network" (ACN). Mariano has over 20 years of experience in advocacy, stakeholder engagement, European projects, communication, and civic information. In 2015 he led the launch of the MEP Interest Group "EU Patients' Rights & Cross-Border Healthcare," endorsed by nearly 100 organisations across Europe, and the MEP Interest Group "SDGs for wellbeing and consumer protection" in 2021. In 2016 Mariano has won the Efhre International University Excellence Awards on patients' rights and in 2017 he was appointed as Secretary-General at European Consumer Union. Along the mandate 2016/2019, he was also appointed by the EU Commission to represent Italian Consumer Associations in the EU Consumer Consultative Group. Mariano holds an MSc in Political Science and two post-graduate courses in EU Public Relations and Corporate Social Responsibility.

Mariam Zaidi



Mariam Zaidi is an international news presenter, reporter and expert on the EU. Also specialising in politics and foreign affairs she has more recently steered coverage on the Ukraine war and the energy crisis for Euronews. As a seasoned moderator and master of ceremonies for Euractiv, EU institutions and global corporate clients she is a master of many trades. A law grad with an MA in Journalism she has worked for the BBC, ITV, CGTN, APTN and CNBC.

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