




## Cross-border healthcare and centres of excellence to enhance patients' rights: access, information and innovation

27 February 2018, 15.00-17.00

Room (ASP 3H1)

European Parliament, Brussels

### Panelists

	<p><b>Giuseppe Banfi</b></p> <p>He works in Milan (Italy) as Director of Scientific Research programs at IRCCS, (Scientific and Teaching Hospital) Galeazzi Orthopaedic Institute, Director of Scientific Research programs at Gruppo Ospedaliero San Donato Foundation, General Director of Fondazione Centro San Raffaele. Full Professor of Clinical Laboratory Medicine at School of Medicine, University Vita –Salute San Raffaele and Vice Rector for Research University Vita-Salute San Raffaele. He is also member of the Board of Directors of Fondazione Istituto Insubrico Ricerca per La Vita Foundation.</p>
	<p><b>Beatrice De Schepper</b></p> <p>She was a co-founder of the Huntington Liga vzw, Flanders Belgium. She has been a very active member in all aspects of care for the Huntington's Disease community. In 2002 became a board member of the European Federation of Neurological Association, EFNA. From 2004 she was President of the European Huntington Association EHA and has remained as a Member at large as development officer. In 1990 she became a Member of the International Huntington Association IHA and in 2016 became the International development officer. She understands very well the many challenges facing Huntington's families with 8 members of her family with this disease.</p>
	<p><b>Pascal Garel</b></p> <p>He is since September 2005 Chief Executive of HOPE, the European Hospital and Healthcare Federation. Educated in political science and European law, he became Hospital Manager in 1989 with the diploma of the French National School of Public Health. His main professional background is healthcare management, with a twelve year experience in France in two Teaching Hospital Centres, Nantes and Rouen. Previous posts also include director of the Eu and International Department of the French Hospital Federation and responsibilities for Central and Eastern Europe at the French Ministry of Health. Associated lecturer at the University Paris Dauphine, he also teaches at the Alexandria University Senghor and at the French National School of Public Health.</p>



### **Nora Kajtar**

She works as policy officer at the European Commission's Directorate General for Health and Food Safety (DG SANTE). She is in charge of implementing the European Reference Networks under the framework of the Directive of Cross-border healthcare. She has been trained as a health economist and held various health policy positions in national and European administrations. She had worked at the Hungarian Ministry of Health, served as health attaché at the Hungarian Permanent Representation to the EU and was the coordinator of the area of health under the Hungarian Presidency. Since 2011, she has been working for the Commission and prior to joining the ERN team she dealt with macroeconomic analysis of health systems to inform policies at national and European levels.



### **Jasna Karacic**

President of the Croatian Association for the Promotion of the of Patients Rights since January 2016. She is a member of the Croatian Cochrane and a scientific researcher of the project "ProHealth". She graduated in Forensic Sciences (Forensic Psychiatry). She is specialist in psychoanalytic and integrative psychotherapy. In international collaboration with the Human Rights Center in Italy, where she is a member of the organization for the safety of patients. She is member of the Health Council of Zagreb and member of the Working Group on Health Protection Act and the Commission of the Ministry of Health for establishing the criteria for the development of the hospital health network institution. From 2017 she became part of the Council of the Croatian Government for Croats abroad.



### **Brian Kennedy**

Executive Director of the Alliance for Patient Access, and the affiliated Institute for Patient Access and Global Alliance for Patient Access (GAFPA.) As an international network of clinicians and patient advocates, GAFPA's mission is to promote health policies that ensure patient access to appropriate clinical care and approved therapies. In his capacity as Executive Director, he has overseen the development of dozens of educational and advocacy initiatives including those relating to biologic therapies, cardiovascular health, balance pain management, infant health, clinical trials awareness, and cancer care. His professional career has spanned the practice of law, campaign politics, government relations and corporate public affairs consulting. He is also the President of Arena Therapeutics, a medical research firm focused on advancing Deep Brain Stimulation for the treatment of patients recently diagnosed with Parkinson's disease.



### **Stephen McMahon**

Co-Founder of Irish Patients' Association. Experienced Patient Advocate with 15 years' experience as Chairman and CEO of IPA and Interim CEO and Board Member of a Global Patient Advocacy group. Has a demonstrated history of working in the NGO Health Sector. Skilled in Healthcare Advocacy, Management, Strategic Planning, Public Relations, Public Speaking, Patient Safety. Wide range of regulatory experience as a patient advocate, invited patient perspective reviewer BMJ. Graduated from Trinity college, Dublin, and Blackrock College.



### **Scott Pescatore**

He has dedicated the past 20 years of his career to the field of oncology across a broad range of medical and commercial activities in the US and EU. He has a passion for innovation and improving and extending patient's lives, particularly in the area of rare diseases. He has worked for Novartis Oncology since 2001 across roles of increasing responsibility and is currently the European general manager for the rare disease business unit where he is responsible for a portfolio of products focused on providing solutions to patients suffering from rare and difficult to treat conditions. Dr. Pescatore holds a Doctoral degree in Pharmacology and was a Post-Doctoral Fellow in Drug Development at the University of North Carolina Chapel Hill.



### **Gábor Pogány**

He holds a Ph.D. in Biochemistry with 3 years of research experience in the USA. He participated in the establishment of the Hungarian Williams Syndrome Association (HWSA) in 1998 (his middle daughter is affected with Williams Syndrome). He also initiated the foundation of the European Federation of Williams Syndrome Association (FEWS) as well as the Hungarian Rare Diseases Federation (HUFERDIS)/Hungarian Alliance of Patient Organizations (HAPO). He is a member of Hungarian Expert Committee on Rare Diseases from 2009. He was a member of the European Conference on Rare Diseases & Orphan Products (ECRD) Programme Committee (PC). He also was an alternative patient representative of EURORDIS in the European Union Committee of Experts on Rare Diseases (EUCERD) and he is a member of Orphanet International Advisory Board. Recently, he is involved in the formation of European Reference Networks, participating in EURORDIS Patient Advocacy Group (E-PAG).



### **Luca Sangiorgi**

MD, PHD in Clinical Genetics at "La Sapienza" University of Rome and a Master Degree in Research Promotion and Governance in Hospital Trusts and Local Health Units at the University of Modena and Reggio Emilia. He is coordinator of the Rizzoli Rare Disease Center and responsible of four National Registers of Rare Disease (Multiple Hereditary Exostoses, Osteogenesis Imperfecta, Ehler Danlos and Ollier Disease). He also coordinates the Emilia Romagna Region Hub and Spoke Network on Rare Bone Disorders. Since March 2017 he is the coordinator of BOND ERN that includes 38 Centres of Excellence for the treatment of Rare Bone Disorders in 10 EU Member States. As member of many different medical and scientific societies, he has been appointed President of Connective Tissue Oncology Society and International Skeletal Dysplasia Society.



### **Maurizio Scarpa**

MD PhD, paediatrician, is the Director of the Centre for Rare Diseases at the Helios Dr Horst Schmidt Kliniken GmbH in Wiesbaden, Germany. He is Professor of Paediatrics at the Dept. for the Woman and Child Health, University of Padova, Italy, and the Co-Founder of the Brains For Brain Foundation, Kings College of London, London, UK. He is the Coordinator of the European DGSANTE Project, INNERMED.

He is the Coordinator of the European Reference Network for Hereditary Metabolic Diseases, MetabERN, formed by 69HCPs in 18 EU countries and treating 43000 metabolic patients, and he is the Chair of the ERN Coordinators Working Group.



### **MEP Patrizia Toia**

She is graduated in Political Science at the University of Milan. She worked as Director of the Planning Service at Lombardy Region. She was regional councillor in Lombardy, with different responsibilities (Health, Budget)

She was Member of the Chamber of Deputies and in 1996 she was elected at the Senate of the Republic. In 2004 she was elected at the European Parliament, confirmed in 2009 and 2014. Member of the Group of the Progressive Alliance of Socialists and Democrats (S & D), she is Vice-Chair of the Committee on Industry, Research and Energy. She is also member of the Delegation for relations with Belarus and the Delegation to the Euronest Parliamentary Assembly and substitute member of the Committee on Development. She is Head of the Italian delegation of the S&D Group, Partito Democratico.



### **Mariano Votta**

Public affairs professional and journalist, is the Director of Active Citizenship Network (ACN), the international branch of the Italian NGO Cittadinanzattiva, where he is responsible for European Affairs. Since 2013, he has been actively involved as ACN stepped up its advocacy activities at the European Institutions, which in 2015 led to the opening of a representative office in Brussels and - above all - to the launch of the MEP Interest Group "European Patients' Rights & Cross-Border Healthcare", promoted with the endorsement of almost 100 organizations across Europe. Furthermore, in 2016, Mariano won the Efhre International University Excellence Awards on patients' rights. Passionate about healthcare and consumer issues, he has more than 17 years of experience in the field of advocacy, stakeholder engagement, European projects, communication and civic information.

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