Rare 2030
Foresight in Rare Disease Policy

FINAL POLICY CONFERENCE

The future of rare diseases starts today

Recommendations from the Rare 2030 Foresight Study

Speaker biographies

Co-hosting MEPs

Frédérique Ries

Frédérique Ries has been a Member of the European Parliament since 1999 and represents the Belgian Mouvement Reformateur in the Renew Europe Group. She is part of the the Committee on the Environment, Public Health and Food Safety (ENVI) sector and is Vice-Chair of Renew Europe.

A journalist and former Secretary of State for European and Foreign Affairs, she has been a pioneer in the implementation of patient-centric health policies that focus on European Union-added value, especially in the field of rare diseases.

She is a sponsor of the pilot project Rare 2030 (initiated by the European Parliament and co-funded by the European Commission), a foresight study that gathers the input of a large group of patients, practitioners and key opinion leaders to propose policy recommendations that will lead to improved policy and a better future for people living with a rare disease in Europe. Frédérique Ries is also the recipient of the 2017 EURORDIS Policy Maker of the Year Award.

Cristian-Silviu Bușoi

Cristian-Silviu Bușoi is a Member of the European Parliament and Chair of the Industry, Research and Energy Committee. He is also Member of the Delegation for Southeast Asia, as well as substitute Member of the Environment, Public Health and Food Safety (ENVI), Committee on Economic and Monetary Affairs (ECON) and the Delegation for the Arab Peninsula.

Mr. Busoi studied Medicine at Carol Davila University in Bucharest, Law from Titu Maiorescu University in Bucharest, and Diplomacy from the Romanian Diplomatic Institute in Bucharest. His political career started in 1996 when, as a student, he became a member of the National Liberal Party. Eight years later, he entered the Romanian Parliament and, in 2013, became President of the Romanian National Health Insurance House. Since 2007, he has been elected to the European Parliament for three consecutive terms.

Speaker biographies

Alphabetical order

Terkel Andersen

Terkel Andersen was elected President of EURORDIS-Rare Diseases Europe in May 2003 and has been a member of the EURORDIS Board of Directors since 1997, when the organisation was founded.

A person with haemophilia himself, Terkel has broad experience in disability and health issues becoming involved in the rare disease field in 1983 when he joined a Nordic project on the mapping of problems related to rare diseases. Terkel served as president of the Danish Haemophilia Society 1985-2017. He was one of the founders of the Danish Alliance of Rare Disorders in 1986 and worked as the first Executive Director of the Centre for Rare Diseases and Disabilities of the Ministry of Social Affairs in Denmark from 1990 to 2001. From 1992 to 2002, he served on the executive board of the World Federation of Hemophilia; and from 1993 to 1999, he was chairman of the European Haemophilia Consortium.In his professional capacity Terkel worked with the Danish National Council for Volunteering until October 2018.

Terkel represents EURORDIS at International Conferences throughout Europe and beyond.

Diego Ardigò

Diego is currently the Global Head of Research & Development in Rare Diseases at Chiesi Group. Before this role, he was leading Chiesi's development projects in rare diseases and advanced therapies and has more than 20 years experience in medical research and more than 10 in drug development, spanning from pre-clinical to commercial phase.

Diego is an MD with a specialization in Internal Medicine. He obtained a PhD at the University of Parma (Italy) in cardiovascular pathophysiology and a post-doctoral fellowship in cardiovascular genomics at Stanford University (California, US).

Before joining the industry, he worked at the University of Parma (Italy) in the field of cardiovascular and metabolic genomics, and as free-lance consultant for various academic institutions. He joined Chiesi in 2010, where he acted as Clinical Lead in the registration of the first stem cell therapy in EU and led the cross-company team (with uniQure BV) treating the first patient with a commercial gene therapy in EU.

Diego is serving as chairman of the Therapies Scientific Committee of IRDiRC (International Rare Diseases Research Consortium), where he led the Orphan Drug Development Guidebook initiative, and is a board member of the European Confederation of Pharmaceutical Entrepreneurs (EUCOPE). He is author of 50+ indexed papers and frequent speaker at international medical and industrial congresses.

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Inês Alves

Patient expert in rare bone diseases. Degree in veterinary medicine, post-graduated in surgery. 2 years of Ph.D. studies in veterinary sciences, incomplete degree. Creator of Beyond Achondroplasia in 2013, founder and president of ANDO Portugal, the Skeletal Dysplasia National Association. Vice-president of EUPATI Portugal. EUPATI fellow and Fundamentals trainer. Patient representative at ERN BOND, the European Reference Network for Rare Bone disorders, and member of the Steering committee.

Lecturer on patient involvement in R&D. Health Parliament Portugal Deputy at Technology and Care Integration Committee. Co-chair of Patient Outcomes for EuRR-Bone, the European Registry for rare bone and mineral disorders. Patient expert for EMA and IMI; Member of the management committee and communication co-leader of COST action Gemstone, Genomics of musculoskeletal traits EURORDIS volunteer evaluator in European Joint Program for rare diseases, EJP RD, and member in the E-rare and Rare 2030 expert panel. Founder and chair of the European Rare Bone Forum (ERFB). Based in Évora, south of Portugal. Mother of 3 children, one has achondroplasia, a rare bone condition.

Catherine Berens

Dr Catherine Berens was trained as a pharmacist and obtained her PhD in Pharmaceutical Sciences from the Catholic University of Louvain in Belgium. After having worked for the European Directorate for the Quality of Medicines & HealthCare (European Pharmacopoeia, Council of Europe, Strasbourg), she joined the European Commission in Brussels in 2002, as a Scientific Officer in charge of Rare Diseases in the Health Directorate of Directorate-General for Research and Innovation (DG RTD). From 2012, she worked as a Policy Officer for Pharmaceuticals in then-DG Enterprise and Industry, dealing with pricing and reimbursement of pharmaceuticals, and access to medicines. In 2014 she was appointed Head of Sector Neuroscience in DG RTD, and from September 2016, worked as the Assistant to DG RTD's Deputy Director-General in charge of Research Programmes. She was appointed Deputy Head of Unit 'Strategy' in DG RTD's Health Directorate in 2018, and became Deputy Head of Unit 'Healthy Lives' in 2019.

Jan Blatný

Jan Blatný M.D., Ph.D., Minister of Health of the Czech Republic studied general medicine at the Faculty of Medicine of Masaryk University in Brno, where he graduated in 1994 and where he also received his Ph.D, and in 2018 he was appointed as Associate professor of pediatrics at his home university. After his studies he spent various lengths of time at internships in Switzerland and the UK. From 2006 to 2008, he worked as a physician at the Primary at the Children's University Hospital in Dublin, Ireland, being registered both in Czechia, the UK and Ireland. However, he spent most of his professional life in the University Hospital Brno, especially at its children's hospital.

His main fields of interest have always been haemophilia, life threatening bleeding, and thrombosis in children. In this regard, he has been the Coordinator of the Czech National Haemophilia Programme (the authority managing and overseeing haemophilia care in the country). He co-operates with the Perinatal/Paediatric Scientific and Standardization Committee (SSC) of the ISTH, serves on the Executive Committee of EAHAD, on the Working Group for Pharmacokinetics and Population Pharmacokinetics of Factor Concentrates at SSC for Factor VIII, Factor IX and Rare Coagulation Disorders of the ISTH, on the Working Group on Paediatric Haematology of the Czech Paediatric Society, as well as on the Steering Committee of the Czech Society for Thrombosis and Haemostasis. He is a member of Medical Advisory Group (MAG) of EHC (European Haemophilia Consortium). He has authored and/or contributed to over 90 scientific papers and books and serves as a reviewer of several scientific journals, including Haemophilia Journal. He is a member of the committees of a number of national and international professional societies with this focus.

Stefano Benvenuti

Stefano Benvenuti is Global Partnership Manager at Fondazione Telethon since 2018. He is an experienced manager of an EU funded project and an expert of EU research policy. Since 2019 he represents Fondazione Telethon in the Executive Committee of the European Joint Programme on Rare Disease (EJP-RD). After graduating in International Cooperation for Development at the University of Bologna in 2007 he started as a consultant project manager of EU funded projects. In 2010 he joined the healthcare department of Regione Veneto working as EU project specialist where he contributed to re-design the regional system of participation in EU funded programs. During this period he also completed a master degree in Health Technology Assessment at Università Cattolica in Rome. Finally, in 2016, he joined Fondazione Telethon to set-up the EU affairs office and coordinate the participation of Fondazione Telethon in European and International initiatives.

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Virginie Bros-Facer

Virginie joined EURORDIS in 2015 as Research Infrastructure Project Manager, later becoming Scientific Director. Her responsibilities include managing all EURORDIS activities related to infrastructures and technologies facilitating rare disease research. Activities include fostering patient engagement in RD research projects, registries, clinical bioinformatics, genetics and genomics as well as ethical issues surrounding this pre-clinical research.

Prior to joining EURORDIS, Virginie worked for several research funding organisations in the UK, including as Director of Medical Research for Sparks, a children's medical research charity based in London.

Virginie holds an MSc and a PhD in Neuroscience from King's College London and also worked at the UCL Institute of Neurology on several research projects aiming to develop new therapeutic strategies for motor neuron disease and other neuromuscular disorders.

Simone Boselli

A member of the European and International Advocacy team, Simone has contributed to European policy development since 2017. Specifically, he represents EURORDIS in policy discussions on access to therapies, with a focus on reducing delays and inequalities, on the underlying challenges in the field of the value assessment, pricing and reimbursement of orphan medicines, and on current initiatives towards improved access. He has contributed to the finalisation of the paper on 'Breaking the Access Deadlock to Leave No One Behind' and is engaged in finding new policy solutions for improving access to innovative therapies for people with rare diseases in the context of the European Pharmaceutical Strategy.

Simone has almost 15 years of experience in the European public affairs arena, having previously worked for two leading consultancies in Brussels and specialised in health advocacy and government affairs in particular. He has expertise in healthcare having devised and implemented advocacy campaigns at EU and national level on a range of global health issues.With a view to advance rare diseases as a public health priority at a global level, Simone also supports advocacy activities at Rare Diseases International and the further development of NGO Committee for Rare Diseases.

Kate Bushby

Professor Kate Bushby joined the pioneering department of Human Genetics at the University of Newcastle in 1989. She built on the strong tradition of neuromuscular disease research there to develop a world leading team in patient care and clinical trial design and execution including leading the TREAT-NMD network of excellence for translational research in neuromuscular diseases.

Professor Bushby subsequently worked in rare disease policy development as a Vice President of the EU Committee of Experts on Rare Diseases and via a series of Joint Actions worked on development of the policy underpinning European Reference Networks for Rare Diseases.

Following the diagnosis of her husband with a glioblastoma, Prof Bushby stood back from her career, though she is now working in a voluntary capacity with the brain tumour community, specifically the strategic programme of the Tessa Jowell Brain Cancer Mission on the development of centres of excellence for brain tumour care in the UK.

Anne Charlet

Anne Charlet is Lupus Europe's Vice-Chair and a Lupus France board member. When Anne's daughter was diagnosed with Lupus at the early age of 16, it was a natural step to get involved, which led her to these patient representative organisations.

Anne is a trilingual American, with a deep interest in the subject of cultural intelligence. She has worked in the USA, UK and Germany before settling with her family in France, where she now provides Global Marketing support for Europe's largest IT service provider. As a member of the Lupus Europe Board of Directors and representing the European Lupus community, Anne is actively involved in several work-groups, specifically in the Digital Health area, for EPF, and the Patient Think Tank for EFPIA. Living in France, Anne has taken part in several initiatives by Lupus France such a crowd-funding for lupus research, online "meet the doctor" sessions with French experts, but obviously also the broader reaching Telethon.

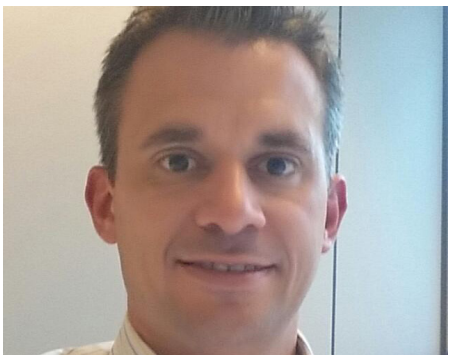
One of her main drives is to achieve better recognition of lupus throughout the world, and shorter time to diagnosis for lupus patients until we can one day live in a world without lupus.

Dorica Dan

Dorica Dan was elected to the Board of Officers in 2011 and has been a member of the EURORDIS Board of Directors since 2007.

Dorica initiated RPWA (Romanian Prader Willi Association) in 2003, established RONARD (Romanian National Alliance for Rare Diseases) through a project funded by CEE Trust in 2007 and Romanian Rare Cancers Association in 2011. She has opened the first Centre for Information about Rare Genetic Diseases in Romania and initiated the National Plan for Rare Diseases in Romania. In June 2011 she opened the Pilot Reference Center for Rare Diseases "NoRo" through a project implemented in partnership with Frambu Norway and funded by Norway Grants. She became an Ashoka Fellow in 2018.

Today she is the chair of the Romanian Prader Willi Association, Romania (RPWA); president of the Romanian National Alliance for Rare Diseases(RONARD); president of the Romanian Association for Rare Cancers and the coordinator of NoRo Center. She is also an ePAG co-chair in ITHACA.



Martin Dorazil

Martin Dorazil works since September 2019 as the Deputy Head of the Unit "European Reference Networks and Digital Health" in the European Commission's Directorate-General for Health and Food Safety. He has a background in law. He joined the European Commission in 2004 and since then he has worked on issues related to patients' rights in cross-border healthcare (DG SANCO), antitrust issues in the pharmaceutical sector (DG COMP) and legal, regulatory and policy issues related to marketing authorisations of medicinal products (DG SANTE).

Ilaria Galetti

I am vice president of FESCA, the Federation of European Sclero-derma Associations, Systemic Sclerosis ePAG representative in ERN (European Reference Network) ReCONNET, member of the DITA Task Force and member of the Panel of experts of Rare 2030, where I participated in the development of the Recommendations that aspire to improve the lives of RD patients in the next decade. I was part of the core group of Rare 2030 Italian stage that involved different stakeholders and policy makers.

I always try to collect the needs of the wider community and to interact with clinicians to improve the cure and the QoL of rare disease patients. As patient representative, I often participate in consensus meetings aiming at creating diagnostic recommendations and risk scores or in CABs for the research and the development of new potential therapies for SSc.

In ERN ReCONNET I have been involved in several activities such as in the State of the Art of CPGs and in SSc patient's care pathways, always collecting the voice of the European SSc community and giving back the outcomes of the activities.

Giovanna Giuffrè

Giovanna Giuffrè has worked with ISINNOVA since 2008, and has been a partner since 2010. Giovanna has been involved on the management of several IEE, FP7 and Horizon 2020 projects in the research and innovation, sustainability and health fields.

Through her work on scenario-building research projects, Giovanna has gained experience analysing trends and policies, facilitating workshops, and redacting policy recommendations. These projects include Foresight on Demand (FoD), BOHEMIA - "Foresight in support of future EU Research and Innovation Policy; RARE2030 - Foresight in Rare Disease Policy"; FRESHER– Foresight and modelling for European Health policy and regulation; FLAGSHIP - Forward Looking analysis of grand societal challenges and innovative policies; PASHMINA - Paradigm Shift Modelling and Innovative approaches.

In the framework of EU projects, Giovanna has researched and analysed policies in order to evaluate their impacts and effectiveness and has offered support to European and national authorities in planning and managing sustainable policies. Previous experience has included working for networks of local authorities (EUROCITIES and ICLEI) and for a network of non-governmental organisations (Medlink - Mediterranean links). Giovanna holds a Law degree from La Sapienza University, Rome, Italy and has a Masters in European Studies, College of Europe, Warsaw.

Holm Graessner

Holm Graessner has graduated in Biomedical Engineering, Electrical Engineering, German Language and Literature, Philosophy as well as Business Administration. He received his PhD "Summa cum laude" in 2004 and, then, he obtained his MBA degree in 2008.

He has been Managing Director of the Rare Disease Centre, since 2010, at the University and University Hospital Tübingen, Germany. He is Coordinator of the European Reference Network for Rare Neurological Diseases (ERN-RND). Together with Olaf Riess, he coordinates the H2020 Solve-RD project on "Solving the unsolved rare diseases". www.solve-rd.eu

From 2003 until now, he has been coordinating and managing more than 10 EU funded collaborative projects. The main focus of these projects are rare and neurological diseases, among them EUROSCA, MEFOPA, SENSE-PARK, MULTISYN, NEUROMICS and PROOF.

He has been co-leading one of the four working groups of the German Action Plan for Rare Diseases. Since 2020, as a fellow of the European Academy of Neurology (EAN) and in his function as the coordinator of ERN-RND, he is a personal member of the Rare Disease Coordinating Panel of the EAN.

Victoria Hedley

Victoria has been an active participant in the generation of rare disease (RD) policies and policy-related outputs for a decade. She currently leads the knowledge-base activities of the Rare 2030 foresight project and previously led the policy arm of RD-ACTION, the EU Joint Action for RD.

She has experience and understanding of a wide range of topics under the RD 'umbrella' and has contributed to the development of EU-level Recommendations around topics such as Cross-Border Genetic Testing; the Incorporation of RD into Social Services and Policies; Patient Registration and data collection; National Plans and Strategies; and, most prominently, European Reference Networks.

She led RD-ACTION support for the conceptualisation and implementation of ERNs and is now co-lead of the new Newcastle Centre for Rare Diseases, which she brought to fruition in 2020, and which is now consolidating the broad range of disease-focused and methodological expertise in the Newcastle region, to optimise patient-centred research and innovation.

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Clara Hervás

Clara Hervás is a Public Affairs Manager within the European and International Advocacy team of EURORDIS. In this role, she is responsible for developing and coordinating policy activities on issues that affect people living with a rare disease, such as respect for human rights, universal health coverage or the rights of people with disabilities.

Clara Hervas is also public affairs manager within Rare Diseases International (RDI) and policy coordinator at the NGO Committee for Rare Diseases, established as a platform to exchange with the United Nations. As such, she is responsible for institutional relations with the UN, its Member States, and its agencies, such as the World Health Organization (WHO).

A Spanish national, Clara Hervás holds a Bachelor of Arts in Human Geography from the University of Cambridge and a Master of Science in Global Politics from the London School of Economics (LSE) in the UK.

Kaja Kantorska

Kaja is a Policy Officer in Unit B5 dealing with Medicines: policy, authorization and monitoring at the Directorate General Health and Food Safety. Her work centers around the development of the pharmaceutical legislation and policies concerning authorization and manufacturing and use of medicinal products in the European Union, in particular with respect to orphan medicinal products.

She worked previously as Policy Officer in the Biotechnology field developing policy and legislation, as well as managing existing legislation, in relation to genetically modified organisms.

She has a university degree in Master Engineer in Biotechnology field from Lodz University of Technology in Poland.

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Kateřina Konečná

Kateřina Konečná, Member of the European Parliament. In the year 2009, she successfully graduated from Masaryk University and received an engineer's degree in the Public Administration field. She also has a bachelor's degree from Masaryk University, Faculty of Law. Her interest in the world surrounding us brought her to politics and resulted in her candidacy to the Czech Chamber of Deputies in 2002. As the youngest member of the Chamber of Deputies, she became a member of the Foreign Affairs Committee. She became a member of the Environment Committee after the elections to the Chamber of Deputies in 2006. She led the list of Communist candidates for elections in May 2010. After her re-election, she continued the promotion of practical and effective protection of the environment that will help people and will not take their jobs.

She also led the list of Communist candidates in the elections to the European Parliament in May 2014 as well as in May 2019. As a member of the European Parliament, she continues to engage in the Environmental Protection Policy and Public Health Policy as a member of the ENVI Committee. She focuses on the topic of Access to Healthcare, deals with the Public Health issues and cooperates very closely with patients and their organizations. She also supports the development of the Patients Academy project in the Czech Republic. During her mandate, she worked on the HTA regulation, Medical devices and In-vitro medical devices regulations or EU4health program. In the term 2014-2019, she was the European Parliament's sole contact person responsible for the ECDC agency, group's coordinator in the ENVI Committee and vice-chair of the EMIS Inquiry committee and PEST Special Committee. From September 2020 she is also a group's coordinator in the IMCO Committee and BECA Special Committee.

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Stella Kyriakides

On 1 December 2019, Ms. Kyriakides became the European Commissioner for Health and Food Safety. During the COVID-19 crisis, she has been leading the Commission's work to coordinate the EU's health response and support Member States to tackle the pandemic. She is responsible for the EU's Vaccine Strategy in order to procure safe and effective vaccines for all EU Member States and Europe's broader neighbourhood.

She is also responsible for the establishment of a strong European Health Union and supporting Member States to strengthen healthcare systems and deliver better patient outcomes for all EU citizens. This includes leading the reinforcement of EU health agencies, putting in place a stronger framework of cooperation against health threats, setting up a Health Emergency Preparedness and Response authority, rolling out Europe's Beating Cancer Plan to help improve cancer prevention and care, the new Pharmaceutical Strategy to ensure that Europe has enough affordable medicines to meet its needs, creating a European Health Data Space and the implementation of the new and ambitious EU4Health Programme.

On food safety, Commissioner Kyriakides is leading the new 'Farm to Fork' strategy for sustainable food, covering every step in the food chain from production to consumption. Her responsibilities also include ensuring enforcement of animal welfare laws and promoting European standards globally, as well as ensuring enforcement of EU laws on food safety and animal and plant health and leading the work to protect plant health, reduce dependency on pesticides and support low-risk and non-chemical alternatives.

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Yann Le Cam

Yann was one of the founders of EURORDIS-Rare Diseases Europe in 1997. He has been the organisation's Chief Executive Officer since 2000.

Yann initiated Rare Diseases International (RDI) in 2009. He is an elected member of the RDI Council and Chair of the RDI Advocacy Committee. He is a founding member of the NGO Committee for Rare Diseases (United Nations, New York) in 2014 and its Vice-Chair. Yann is a Co-Chair of the Global Commission to End the Diagnostic Odyssey of Children with Rare Diseases since its launch in 2018. Yann is a member of the World Economic Forum's Health Stewards Board from 2020 and of its Global Precision Medicine Council since 2019.

Recent past positions include: member of the Management Board of the European Medicines Agency (EMA) 2017-2019; Chair of the Therapies Scientific Committee of the International Rare Diseases Research Consortium (IRDiRC), 2013-2017; Vice-Chairman of the EU Committee of Experts on Rare Diseases (EUCERD), 2011 – 2013; and a member of the Commission Expert Group on Rare Diseases, 2014 – 2017; member of the Committee for Orphan Medicinal Products (COMP) at the EMA, served 9 years, two elected mandate as vice-chair for 6 years. Yann holds an MBA from HEC Paris. He has three daughters, the eldest of whom is living with cystic fibrosis.

Milan Macek

Professor Milan Macek Jr. MD, DSc is the chairman of the Department of Biology and Medical Genetics at the Charles University in Prague – the largest academic medical and molecular genetics institution in the Czech Republic. He was a past President of the European Society of Human Genetics (ESHG), currently a board member of the European Society for Human Reproduction and Embryology and of the European Cystic Fibrosis Society (ECFS).

His institute contributes to dissemination of knowledge in genetics gathered within various international European projects, such as CF Network, EuroGentest, EuroCareCF or Techgene, to Central and Eastern Europe. Prof. Macek did his postdoctorates at the Institut of Human Genetics in Berlin and at the McKusick-Nathans Centre for Genetic Medicine, Johns Hopkins University in Baltimore. During that time, he was also a fellow at Harvard School of Medicine in Boston. Prof. Macek is national coordinator of Orphanet, active member of Eurogentest, has been the chief advisor of the Czech EU Council Presidency under which the "EU Council recommendation on an action in the field of rare diseases was adopted in June 2009.

He also serves at the EUCERD committee on rare diseases and is involved in the rare disease-focused initiatives EURenOmics and RD-Action.

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Fanni-Laura Mäntylä

Fanni-Laura Mäntylä is a Mental Health Activist, a Patient Advocate and Mental Health and Substance Abuse Work Professional. Mäntyla was Chair of the 5th Edition of European Health Parliament: Committee on Mental Health and Healthy Workforce.

Speaking openly about her personal experience of work related burnout and young adulthood with severe depression, Mäntylä in her 30s is now an active influencer about mental health in her native country Finland as well as in the EU.

Being a type-1 diabetic, Mäntylä urges for more discussion about health in a holistic manner and calls for all stakeholders together on the agenda. Mäntylä is a strong voice for young people affected by mental ill-health and a living proof that issues with health do not define a person.

Nikolaos Milionis

Nikolaos Milionis has been a Member of the European Court of Auditors since the 1st of January 2014. He graduated from the Hellenic National School of Public Administration and entered the Hellenic Court of Audit as a First Instance Judge (Auditor) in 1989. He was appointed Appellate Judge (Conseiller Référendaire) in 1997 and Councillor (Conseiller-Maître) in 2004. He now holds the position of Vice-President of the Hellenic Court of Audit.

He acquired a PhD in Public Finance Law in 1998 (University of Athens), writing his thesis on 'The Institutional Role of the Hellenic Court of Audit'. He has taught at the Hellenic National School of Public Administration (1997-1998) and at the Hellenic National School for the Judiciary (1998-2012). Since 2013 he has been an Assistant Professor in Public Finance Law in Panteion University of Social and Political Sciences.

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Lucia Monaco

Lucia Monaco is the current Consortium Assembly Chair of the International Rare Diseases Research Consortium (IRDiRC), where she represents Fondazione Telethon, a charity committed to rare genetic diseases research. She is the head of Research Impact and Strategic Analysis and former Chief Scientific Officer of the foundation. She previously worked as a researcher at the San Raffaele Scientific Institute in Milan and earlier at Farmitalia Carlo Erba in Milan, Italy. She graduated in chemistry at the University of Pavia, Italy and received her training in biochemistry at the University of Iowa in Iowa City, USA and in molecular biology at the European Molecular Biology Laboratory in Heidelberg, Germany.

She is/has been member of several international committees and boards, among which: the Policy Board of the European Joint Program on Rare Diseases (EJP RD) and the Horizon 2020 Advisory Group for Societal Challenge 1 – Health, demographic change and well-being.

Antoni Montserrat Moliner

Antoni Montserrat Moliner (born in Barcelona and living in Luxembourg. Having both nationalities). He has been the Policy Officer in charge of the EU Rare Diseases policy and the EU Cancer policy in the Directorate of Public Health in the DG SANTE of the European Commission during 2005 and 2018. In the origin of the Commission Communication 2008 and the Council Recommendation 2009 on rare diseases as well as from many other EU initiatives in the fields of rare disease and cancer.

From 2018 he's a member of the Board of Directors of ALAN Maladies Rares in Luxembourg. Member of the Luxembourg Comité National Maladies Rares where he's the supervisor of the Working Group in charge of the creation of the National Register of Rare Diseases. He's also member of the Scientific Advisory Committee of the Spanish FEDER, a member of the EURORDIS Working Group on Newborn Screening, as well as a consultant for several public and private organisations on rare disease affairs.

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Christine Mundlos

After finishing medical school at the University of Mainz in 1989 Christine Mundlos first worked in cytogenetics (diagnostics) and later in molecular genetics (research). During this period (1989-1996) she spent several years living and working abroad in Australia and the USA. She moved to Berlin in 2000 with her family and was first involved in a project introducing the German DRGs (patient classification system) by Lohmann & Birkner Health Care Consulting at the Charité.

From 2005 to 2007, she completed the master's degree program on "Science Marketing and Science Communication" at the Technical University of Berlin. Since the end of 2008, she has been working for the Alliance for Chronic Rare Diseases Germany (ACHSE e.V.) at the interface between patient-organisations, medicine and research. She is the head of the ACHSE counselling service, and meanwhile the deputy managing director for the Alliance of Chronic Rare Diseases (ACHSE) e.V..

Fani Petridis

Fani is a Senior Director at the Global Patient Partnership team at Roche, which is responsible for facilitating early and systematic engagement with patients across the product lifecycle through industry-leading partnerships with patients. In this role, she leads the patient partnership strategy and engagement across rare neuromuscular diseases.

She is strongly committed to ensuring that the patient and caregiver voice is fully embedded in decision-making starting from the earliest stages of a medicine's development and throughout the whole lifecycle.

A trained economist, Fani has nearly 10 years of experience in patient engagement at a country level and internationally.

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Inmaculada Placencia Porrero

Inmaculada Placencia Porrero is a Senior Expert in Disability and Inclusion at Directorate-General Employment, Social Affairs and Inclusion at the European Commission. Her unit is responsible for the coordination of European policies for persons with disabilities. She works on European disability policies including the European Disability Strategy 2010-2020, and the EU implementation of the UNCRPD. Inmaculada holds a degree in Physics and Computer Science and worked in research and development before joining The European Commission in 1991. She has worked on research programmes addressing accessibility as well as assistive technologies and was Deputy Head of Unit for various disability-related units in the Commission.

Her work in the "e-Inclusion" unit of the Directorate-General for Information Society and Media addressed accessibility policy. While at the Directorate-General for Justice she contributed to disability-related antidiscrimination legislation. She was responsible for the Task Force for the preparation of the European Accessibility Act and remains responsible since its adoption in 2015. Currently under the Directorate General for Employment, Social Affairs and Inclusion, she is also working on the preparation of the post 2020 European Disability Strategy.

Ana Rath

Ana Rath is a medical doctor with a background in general surgery and a Masters degree in Philosophy. She oriented her career to medical information and terminologies in 1997 and joined Orphanet in 2005, where she was Manager of the Orphanet Encyclopaedia, then Scientific Director, and Director of Orphanet and Coordinator of the Orphanet network since 2014.

Ana was the coordinator of RD-ACTION, the EU Joint Action for rare diseases (2015-2018) and of the IRDiRC's Scientific secretariat until 2017. She chairs the Orphanet Rare Disease Ontology (ORDO), and was member of the WHO's ICD11 Revision Steering Committee. She currently coordinates the RD-CODE on implementation of RD codification in EU member states project and co-chairs the EJP RD Pillar 2 on data and resources ecosystem for RD research in Europe.

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Tamsin Rose

Tamsin Rose is Senior Fellow at Friends of Europe. Having studied international relations, she has 25 years of experience working across the European continent from Ireland to Mongolia.

A natural communicator, Tamsin has been a radio reporter, worked on press for the EU Delegation in Moscow and is currently a member of the external speaker team for the European Commission Directorate General for Communication, describing how the EU works and key policies to visitor groups from around the world.

Since 2002 she has specialised in public health and public participation issues, serving as Secretary General of the European Public Health Alliance (EPHA), and providing strategic advice for health groups on how to engage successfully with the EU.

Andrzej Ryś

Dr. Andrzej Ryś is a medical doctor specialised in radiology and public health, graduated from Jagiellonian University, Krakow, Poland. He founded in 1991 and ran as Director until 1997 the School of Public Health at the Jagiellonian University. Thereafter, from 1997 -1999, he served as Director of the Krakow's City Health Department. Between 1999 -2002, he continued his career as Deputy Minister of Health in Poland where he was member of the Polish EU accession negotiators team for the harmonisation of the Polish Health Care Law with the EU's Acquis Communautaire.

After becoming Senior Consultant of "Health and Management Ltd" for the World Bank (WHO) and EAR in Serbia (2002), he founded (2003) the "Center for Innovation, Technology Transfer and University Development" (CITTRU) at the Jagiellonian University, where he was Director until 2006.

In 2006, he became Director for Public Health and Risk Assessment at the Directorate-General for Health and Consumers (DG SANCO), in the European Commission. From 2011-2014, he assumed the position of Director for Health Systems and Products in DG SANCO. Since 2014, Dr. Andrzej Rys is the Director responsible for Health Systems, Medical Products and Innovation in DG SANTE.

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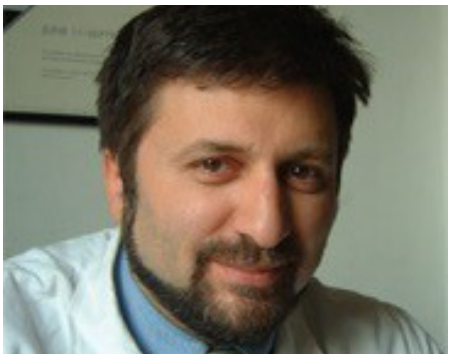

Luca Sangiorgi

Luca Sangiorgi, Director of Department of Rare Skeletal Diseases, is the coordinator of the Rare Diseases Centre of Rizzoli Ortopaedic Institute and responsible of 4 National Registers of Rare Disease (Multiple Hereditary Exostoses, Osteogenesis Imperfecta, Ehlers-Danlos Syndrome, Ollier Disease and Maffucci Syndrome).

He's the coordinator of BIOGEN, diagnos-tic and research genetic biobank, and of Telethon Network of Genetic Biobanks. He's been nominated Delegate for the European Research Infrastructure BBMRI working on Rare Dis-ease Biobanks. From March 2017, is the coordinator of the European Reference Network on Rare Bone Disorders - ERN-BOND.

He's the first author who has contributed to more than 60 articles published in impacted journals such as Nature Genetics, American Journal of Human Genetics, PLOS Genetics, Hu-man Mutation, Orphanet Journal of Rare Diseases (Index H: Scopus 25 Google Scholar 27).

David Sassoli

David Sassoli was born in Florence in 1956. During the 1970s, he graduated in political science at the University of Florence. He began his journalistic career by collaborating with small local newspapers and news agencies, before moving on to the Roman editorial office of the newspaper Il Giorno. He worked for several years as news reporter and then anchorman for TG3 and TG1, becoming one of the most notable and popular journalists in Italy. In 2007, he became deputy director of TG1.

In 2009, Sassoli joined the centre-left Italian Democratic Party. He became a Member of the European Parliament a few months later, was elected Vice President in 2014 and then President in 2019.

Rebecca T. Skarberg

Rebecca Tvedt Skarberg, (45) lives in Oslo, Norway. Her personal experience living with a rare condition comes from being born with osteogenesis imperfecta (OI), type 3. OI is a rare bone condition that affects the production of collagen. Rebecca has had approx. 100+ fractures, is short statured and uses a powered wheelchair to get around. She lives independently with her husband Knut Erik and their two cats.

Rebecca started volunteering from an early age. In the 90's she served on the board of the Norwegian OI Organization (NFOI) and also on the board of the first resource center for OI and other similar conditions in Norway (TRS). From 2007 - 2015 she served on the board of The Norwegian Federation of Organizations of Disabled People (FFO) and had many other commitments tied to that role. One of the most meaningful tasks was serving on the panel of experts for the Norwegian Directorate for Children, Youth and Family Affairs (BUFDIR) and also the project group that led to the establishment of the Norwegian National Advisory Unit on Rare Disorders (NKSD). From 2017-2019 she served on the patient board of Sunnaas Rehabilitation Hospital in Norway.

From 2014 Rebecca has worked for the Norwegian National Advisory Unit on Rare Disorders (NKSD). In 2020 she was head of the programme committee for the Rare Disease Day Norway.

Ceri Thompson

Ceri Thompson is Deputy Head of the eHealth, Well-Being and Ageing Unit in DG CNECT and working on the digital transformation of health and care, and the development of a European Health Data Space.

Prior to working on digital health policy within the Commission, Ceri worked for Eurostat, and for DG SANTE. Before joining the EU institutions in 2002, Ceri worked on global health policy at the UK's Department for International Development, for KPMG's international healthcare practice, and on epidemiological research projects in the UK and Brazil.

She has a degree in Mathematics from Durham University, UK and a Doctor of Public Health (DrPH) from the London School of Hygiene and Tropical Medicine.

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Olivier Véran

Olivier Véran is a French neurologist and politician who has been serving as Minister of Solidarity and Health in the governments of successive Prime Ministers Édouard Philippe and Jean Castex since 2020. A member of La République En Marche! (REM), he previously was the member of the National Assembly for the first constituency of the Isère department from 2017 until 2020.

Véran worked as a neurologist at the Grenoble-Alpes University Hospital. He has served as president of the Association of Hospital Assistants in Grenoble, spokesperson for the National Intersyncal of Hospital Interns, and advisor to the Departmental Order of Physicians of Isère.

Véran was first elected to the National Assembly in the 2012 elections, as a member of the Socialist Party. During his time in parliament, he was mandated by Prime Minister Jean-Marc Ayrault with a government inquiry into the regulatory framework for blood products.

In 2015, Véran resigned as an MP to compete in the 2015 departmental elections where he became a member of the regional council of Auvergne-Rhône-Alpes. In 2016, the Minister of Health Marisol Touraine appointed him to steer a committee in charge of drafting reform proposals for France's hospital financing.