



Mr Terkel Andersen, Denmark

Terkel Andersen was elected President of EURORDIS 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. Terkel is President of the Danish Haemophilia Society (since 1985). Terkel represents EURORDIS at international conferences throughout Europe and beyond.



Dr Christopher P Austin, USA

Christopher Austin is director of the National Center for Advancing Translational Sciences (NCATS) at the National Institutes of Health (NIH). Before joining NIH in 2002, Austin directed research and drug development programs at Merck, with a focus on schizophrenia. He earned his M.D. from Harvard Medical School, and completed clinical training at Massachusetts General Hospital and a research fellowship in genetics at Harvard.



Mr Tenu Avafia, Namibia

Tenu Avafia is a policy adviser on law, human rights and treatment access issues in the HIV, Health and Development Group in the United Nations Development Programme's Bureau for Development Policy. Prior to joining the UNDP in 2006, Tenu worked as a lawyer at the Legal Assistance Centre in Namibia.



Ms Lauren Barredo, USA

Lauren Barredo joined the Sustainable Development Solutions Network in 2012 and works to support the UN processes on Sustainable Development Goals (SDGs) there. Before joining this group, Lauren worked as the Special Assistant to the Director at Columbia University's Earth Institute.



Ms Daniela Bas, Italy

Daniel Bas is the Director of the Division for Social Policy and Development (DSPD), UN Department of Economic and Social Affairs (DESA). DSPD hosts the focal points for the UN system on youth, older persons, family, indigenous peoples, persons with disabilities, cooperatives.



Mr Lieven Bauwens, Belgium

Lieven Bauwens is the Secretary General of the International Federation for Spina Bifida and Hydrocephalus. He is a founding member of Child Help, a development cooperation organization and a board member of the Belgian Platform Disability and Development Cooperation.



Ms Avril Daly, Ireland

Avril Daly was elected to the EURORDIS Board of Directors in 2009, and has been Vice-President of EURORDIS since 2012. She is CEO of Retina. She was diagnosed with the rare retinal condition Retinitis Pigmentosa in 1998.



Ms Migdalia Denis, Venezuela

Migdalia Denis is the founder of the Venezuelan Society for Pulmonary Hypertension and the President of the Latin American society for Pulmonary Hypertension. Migdalia lives with Pulmonary Hypertension.



Ms Hawa Dramé, Guinea

Hawa Dramé is a biochemist who worked in the field of Rare Diseases for AFM (French Neuromuscular Association), Alliance des Maladies Rares and EURORDIS. Hawa founded FITIMA (Fondation Internationale Tierno et Miriam) in 2003, and there are now two centres, in Burkina Faso and in Guinea. Hawa is also a consultant in the field of health strategy for UNICEF and the WHO.



Mr John Forman, New Zealand

John Forman is the past-President of the International Conference on Rare Diseases and Orphan Drugs (ICORD). He served as the Executive Director of NZORD (New Zealand Organization for Rare Disorders) from 2000 to 2015 and has a personal connection with rare diseases, being father to twin adults living with a rare condition.



Ms Megan Fookes, Australia

Megan Fookes is a co-founder of Rare Voices Australia and founding Executive Director. Megan is the Managing Director of Fabry Australia and is a Fabry patient and mother of a son living with Fabry Disease. She is a member of the Council of Rare Diseases International and has been working in the rare disease sector since 2009.



Ms Vidhya Ganesh, India

Vidhya Ganesh was appointed as Deputy Director of Programme Division for UNICEF Headquarters New York in January 2016. Previously, Vidhya worked at the UNICEF Botswana Office where she served as Representative from 2014 to 2016, prior to which she served as the Deputy Representative in Afghanistan from November 2011 to July 2014 and Sierra Leone from March 2009 to November 2011.



Dr Gustavo Gonzalez-Canali, Uruguay

Dr Gustavo Gonzalez-Canali, since November 2013 has served as a Senior Advisor at the UN Coordination Division in IN Women in New York. Prior to this, Gustavo worked as the Head of the Health and Human Development Department at the French Ministry of Foreign Affairs.



Mr Navid Hanif, Pakistan

Navid Hanif is the Director of the Office for ECOSOC Support and Coordination, he has been in the role since 2012. He was posted to the Permanent Mission to the United Nations in New York in 1995. Navid joined the United Nations Department for Economic and Social Affairs (UNDESA) in 2001.



Ms Gunilla Jaeger, Sweden

Gunilla Jaeger has been working at the Ågrenska Foundation since 1989 and has a special interest in educational and everyday consequences of rare diseases. Gunilla has also taken part in the development of data gathering methods at Ågrenska. She is also a licensed psychologist.



Mr Yann Le Cam, France

Yann Le Cam was one of the founders of EURORDIS in 1997 and has been the organisation's Chief Executive Officer since 2001. He was the Vice Chairman of the EU Committee of Experts on Rare Diseases (EUCERD) from 2011 to July 2013, and he is also a nominated member of the current Commission Expert Group on Rare Diseases. In June 2016, Yann was elected to the Management Board of the EMA.



Mr Paul Melmeyer, USA

Paul Melmeyer currently serves as the Associate Director of Public Policy at the National Organisation for Rare Diseases (NORD). Paul has been in the role since February 2013. He is also currently studying for a Master's in Public Policy from George Washington University.



Dr Nata Menabde, Georgia

Dr Nata Menabde is Executive Director of WHO Office at the United Nations, New York since May 2015. Prior to her current role, since 2010, Nata Menabde was WHO Representative to India, and before that was the Deputy Regional Director of WHO's European Regional Office.



Ms Abbey S Meyers, USA

Abbey Meyers founded the National Organization of Rare Disorders (NORD) in 1982; and in January of 1983, largely due to the efforts of NORD, the Orphan Drug Act was passed by Congress.



Ms Maria Montefusco, Sweden

Maria Montefusco is since 2013 the Secretary of the Council of Nordic Cooperation on Disability, an advisory board to the Nordic Council of Ministers. Maria is employed at the Nordic Center for Welfare and Social Issues (NVC) where the secretariat of the Nordic Disability Council is positioned. NVC manages all projects initiated by the Disability Council.



Ms Irina Myasnikova, Russia

Irina Myasnikova is the Co-Chairman of the Russian Patients Association, President of Help to Cystic Fibrosis Patients, and CEO of the Russian Association for Rare Diseases. Irina is also the mother of a son with Cystic Fibrosis.



Ms Yukiko Nishimura, Japan

Yukiko Nishimura is an Assistant Professor at the Department of Intellectual Property and Social Application of Technology, part of the Research Centre for Advanced Science and Technology at the University of Tokyo. Yukiko is also Chief Secretariat of International Relations for the Japan Patients Association, and a Founder of ASrid (Advocacy Service for Rare and Intractable Disease Stakeholders).



Mr Anders Olauson, Sweden

Anders Olauson is founder, chairman and chief executive officer of the Ågrenska Foundation. In September 2008, Mr Olauson was appointed by the Swedish government to be a member of the Advisory Council at The National Board of Health and Welfare. He is also chairperson of the Patient Access Partnership and honorary president of the European Patients Forum.



Mr Marek Plura, Poland

Marek Plura served as a Member of the Polish Parliament between 2007 and 2014, before being elected to serve as a Member of the European Parliament. Marek is also a Member of the Committee on Employment and Social Affairs. Marek has suffered from progressive muscle dystrophy since birth.



Ms Ana Rath, Argentina

Ana Rath is a medical doctor with a background in general surgery and a Masters degree in Philosophy. Ana joined Orphanet in 2005, and serves there as a Director. She also acts as Managing Editor of the Topic Advisory Group on rare diseases at the World Health Organisation (WHO).



Mr Cyril Ritchie, Switzerland

Cyril Ritchie served five separate terms as Secretary of the CoNGO Conference and Board and Vice-President. He is currently serving his second term as President, after being re-elected to the position in 2014. Cyril has also since 1998 served as Vice-President of the Union of International Associations. He is also currently President of the Expert Council on NGO Law, as well as a Senior Policy Advisor for the World Future Council.



Mr Jean-Louis Roux, Belgium

Jean-Louis Roux joined EURORDIS-Rare Diseases Europe in 2015 as Public Affairs Director, responsible for European and international advocacy. In this role, he represents the voice of persons living with a rare disease in major policy platforms and initiatives aiming at expanding the recognition of rare diseases and improving patients' access to orphan medicines, in the EU and beyond. A patient himself, Jean-Louis brings to EURORDIS years of professional experience in the healthcare industry and consultancy sectors.



Mr Lee Yee Seng, Malaysia

Lee Yee Seng is the President and founder of the Malaysia Lysosomal Diseases (MLDA). Lee is the father of three children, two of whom are afflicted by POMPE disease, which is a rare disorder in the Lysosomal Storage Disease group.



Prof Min-Chieh Tseng, Taiwan, Province of China

Professor Min-Chieh received his Ph.D. in Sociology from the University of Wisconsin-Madison in 1997. Since then, he has acted as a professor of social work, a parent of a child with a rare disease, and a CEO of Taiwan Foundation for Rare Disorders (TFRD), to advocate for the privilege of patients who suffered from rare diseases in the region. Together with Serena Wu, also a mother of a child with a rare disease, they founded the TFRD in 1999.



Dr Philip Vickers, USA

Dr Philip Vickers joined Shire in 2010 and is Shire's Head of Research and Development. He is also a member of the Executive Committee. Philip previously led Research and Development for the Rare Disease Business. Prior to that, he held various roles at Boehringer Ingelheim Pharmaceuticals, Pfizer, and Merck & Co.



Dr Hassan Vahidnezhad, Iran

Hassan Vahidnezhad is a visiting scholar and research assistant at Thomas Jefferson University, in the Department of Dermatology and Cutaneous Biology. Hassan is currently studying for a PhD in Medical Genetics, having completed a B.Sc in Biology and an M.Sc in Human Genetics.



Mr Alain Weill, France

Alain Weill has been the elected President of the World Federation of Hemophilia since 2012. He was selected to be a Representative at the EUCERD, European Committee of Experts in Rare Diseases, in 2010.



Ms Durhane Wong-Rieger, Canada

Durhane Wong-Rieger is the President and CEO of the Canadian Organization for Rare Disorders (CORD); Council Member of Rare Diseases International. She is a member of the Advisory Board for the Canadian Institute of Health, Research Institute of Genetics and the Patient Liaison Forum for the Canadian Drugs and Technologies in Health.



Ms Rachel Yang, China

Rachel Yang is currently the General Manager of Phoebus Medical, a start-up company focusing on diabetic patient management. Since September 2015, Rachel has been in charge of International Affairs for the Chinese Organization for Rare Disorders (CORD), and has been instrumental in bridging the gaps between CORD and the international rare disease communities, and bringing China into the centre stage of the rare diseases world.