RARE DISEASES INTERNATIONAL

Rare Diseases International Policy Event
Friday 10 February 2017, Geneva

RARE DISEASE DAY®

Speakers at a Glance

Dr Christopher P Austin, USA

Christopher Austin, MD, 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.

Dr Peter Beyer

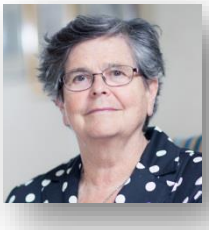
Peter Beyer, a trained lawyer, is a Senior Advisor with the World Health Organization (WHO) in Geneva where he is responsible for all issues related to public health, trade and intellectual property as well as funding of research and development. Peter was instrumental in setting up a sustainable cooperation on health and intellectual property related issues among the WHO, the World Intellectual Property and the World Trade Organization.

Professor Hugh Dawkins, Australia

Professor Hugh Dawkins leads the Office of Population Health Genomics (OPHG) in the development and management of policies, plans and statewide services to minimise the impact of genetic and rare diseases within Western Australia. Professor Dawkins is the nominated Australian contact for Orphanet and for the International Rare Disease Research Consortium (IRDiRC).

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.



Ms Ruth Dreifuss, Switzerland

Ms Dreifuss is Co-Chair of the UN SG's High-Level Panel on Access to Medicines. She became the first woman President of the Swiss Confederation in 1999. Between 1993 and 2002, she was a member of the Swiss Government and Federal Minister of Interior, where her responsibilities included public health and scientific research. Ms. Dreifuss was also Chairperson of the Commission on Intellectual Property Rights, Innovation, and Public Health, an entity established by the World Health Assembly.

Speakers at a Glance

Ms Christina Fasser, Switzerland

Christina Fasser is the Vice-President of ProRaris, the National Alliance for Rare Diseases in Switzerland and President of Retina International. As a patient with a rare eye disease herself, she has served as president and CEO of Retina Suisse from 1986 to 2015 and has been been a leading voice in the effort to focus attention on the need for scientific research to find a cure or treatment for retinal blindness world-wide.

Prof. Antoine Flahault, France

Antoine Flahault MD, PhD in biomathematics. He has been appointed as full professor of public health at Paris in 2002. He was the founding director of the French School of Public Health (EHESP, Rennes, 2007-2012). He is co-director of Centre Virchow-Villermé for Public Health Paris-Berlin (Université Descartes, Sorbonne Paris Cité), co-director of the European Academic Global Health Alliance (EAGHA), president of the Agency for Public Health Education Accreditation (APHEA). In January 2014, he has been appointed as professor of public health at School of Medicine, University of Geneva where he is the founding director of the Institute of Global Health.

Mr Jim Green, United Kingdom

Jim Green is the President of the International Niemann-Pick Disease Alliance. The INPDA, established in 2009, is a networking organisation for Niemann-pick patient organisations from around the world. He is the father of two adults affected by this very rare disease. Jim founded the Niemann-Pick Disease Group (UK) in 1991 and was Chairman of that organisation until 2012. Jim was also an original member of the NNPDF Board when it was formed in the USA in 1992. He continued to serve on that board until 2004. In the last 26 years, Jim has witnessed many advances in research and understanding of NP issues.

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 is also member of the Council of Rare Diseases International. Yann was the Vice Chairman of the EU Committee of Experts on Rare Diseases (EUCERD) from 2011 to July 2013, and he is 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.

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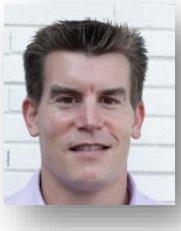

Dr Kevin Loth, United Kingdom

Kevin Loth, PhD, is responsible for leading Celgene's Corporate Affairs Department, encompassing the functions of Communications, Government Relations and Patient Advocacy. Kevin is a member of the EMEA Management Team and Global Corporate Affairs Leadership Team. Kevin's role is to lead the EMEA Corporate Affairs Community of Practice; ensuring patients remain at the centre of decision making, supporting Celgene's growth, and promoting the value of innovation.
Kevin is a member of the EFPIA Healthcare Systems Working Group and Chair of the IFPMA Working Group on Rare Diseases

Dr Ramaiah Muthyala, India

Ramaiah Muthyala, Ph.D. is founder of Indian Organization for Rare Diseases, (IORD) .Ramaiah serves as co-chair of Working Group on Chemically-Derived Products including Repurposing, Therapies scientific committee of IRDiRC. Ramaiah was founding member of "In need of Diagnosis" whose mission is to assist patients who need diagnosis of rare diseases; and has over 25 years of experience in orphan drug discovery and development in pharma as well as academic institutions.

Dr Olivier Menzel, Switzerland

Olivier Menzel is the chair and founder of the Blackswan Foundation. He has long been interested in research. Doctor of Science (UNIL, EPFL) from the Swiss Institute for Experimental Research Against Cancer in 2006, he led the Paediatric Surgery Laboratory of the University Hospitals of Geneva for seven years and worked for two years in the Management Team of the Swiss Medical Network, second largest group of private clinics in Switzerland. He also holds an Executive MBA in Health Management (HEC Lausanne). Olivier Menzel created the BLACKSWAN Foundation in 2010, to respond to the lack of interest and resources devoted to rare and orphan diseases.

Mr Anders Olauson, Sweden

Anders Olauson is one of the founding members of the NGO Committee for Rare Diseases. He is founder, chair 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.

Ms Valerie Paris, France

Ms. Valérie PARIS, Economist - Health Division, Organisation for Economic Co-operation and Development (OECD). Valérie Paris joined the OECD Secretariat in September 2005 to contribute to the work undertaken by the Health Division. Since then, she has contributed to several projects on health systems' characteristics and performance and on pharmaceutical policies.

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Mr Dainius Puras, Lithuania

Mr. Dainius Pūras is the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. Dainius Pūras is a Professor and the Head of the Centre for Child psychiatry social paediatrics at Vilnius University, and teaches at the Faculty of Medicine, Institute of International relations and political science and Faculty of Philosophy of Vilnius University, Lithuania.

Dr Ana Rath, Argentina

Ana Rath is a medical doctor with a background in general surgery and a Master's degree in Philosophy. Ana joined Orphanet in 2005, and serves there as a Director. She is Coordinator of RD-ACTION, European Joint Action on Rare Diseases 2015-2018 and of HIPBI-RD - Harmonizing information on phenomics for a better interoperability in the rare diseases field. She is a Member of the Revision Steering Committee of the WHO's International Classification of Diseases (ICD11) and Scientific coordinator of Support-IRDiRC, Scientific secretariat of the International Rare Diseases Research Consortium.

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.

Professor Dr Huub Schellekens, Netherlands

Dr. Huub Schellekens MD, PhD is professor of Pharmaceutical Biotechnology at Utrecht University in the Netherlands. He teaches Medical Biotechnology at the Department of Innovation Studies and has a research position at the Faculty of Pharmaceutical Sciences at the same university. He is a medical microbiologist by training and works on the preclinical development of biopharmaceuticals. He published more than 400 papers in peer reviewed international journals concerning many aspects of the development of therapeutic proteins. During the last years his work has included the immunogenicity of protein drugs and the problem of biosimilars and non-biologic complex drugs.

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Ms Maria Luisa Silva, Spain

Maria Luisa Silva is the Director of the United Nations Development Programme (UNDP) Office in Geneva. She has over 25 years' experience in UNDP and the UN system, most recently as UN Resident Coordinator/UNDP Resident Representative in Peru (2014-2015).

Mr. Oliver Timmis, United Kingdom

Oliver Timmis is the CEO of the AKU Society. Alongside working at the AKU Society, Oliver is a member of the Drug Information Transparency and Access (DITA) taskforce at EURORDIS, the RD Connect Patient Advisory Council, the ASTERIX Patient Think Tank, and the ISPOR Patient Centred Special Interest Group. He also volunteers at Findacure, the Fundamental Diseases Partnership.

Ms Durhane Wong-Rieger, Canada

Durhane Wong-Rieger is the President and CEO of the Canadian Organization for Rare Disorders (CORD); Chair of the Council 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.