

A **RARE DISEASE DAY®** EVENT

International Policy Event

THE RIGHT TO HEALTH: THE RARE DISEASE PERSPECTIVE

Friday, February 10, 2017
Campus Biotech, H8-Auditoire
Geneva, Switzerland



RARE
DISEASES
INTERNATIONAL



In partnership and with the support of:



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THE RIGHT TO HEALTH: THE RARE DISEASE PERSPECTIVE

09:00 - 09:30 REGISTRATION

09:30 - 10:00

WELCOME ADDRESSES

Christina Fasser, Vice-Chair, ProRaris, Swiss Rare Disease Alliance

Message from Cyril Ritchie, President of the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO)

10:00 - 10:20

LEAVE NO ONE BEHIND: WHY RARE DISEASES ARE IMPORTANT FOR THE GLOBAL HEALTH AGENDA

Introduction: Yann Le Cam, Chief Executive Officer of EURORDIS–Rare Diseases Europe, Member of the Council of Rare Diseases International

Universal Health Coverage is an ambitious new target for Sustainable Development Goals (SDGs), but as recently stated by Helen Clark, Administrator of the UN Development Program “**No country can claim to have achieved universal healthcare if it has not adequately and equitably met the needs of those with rare diseases**”. Despite important gains rare disease patients are a particularly vulnerable population that continues to experience serious violations of their health and health-related human rights, including discrimination in access to quality healthcare. Rare diseases are a global public health priority and need to be considered as part of the 2030 Sustainable Development Agenda and Goals.

10:20 - 10:40

THE RIGHT TO HEALTH

Dainius Pūras, United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, The Office of the United Nations High Commissioner for Human Rights

10:40-10:55 COFFEE BREAK

10:55 – 12:30

PANEL 1: THE RIGHT TO HEALTH OF PEOPLE LIVING WITH A RARE DISEASE

Moderator: Durhane Wong-Rieger, President and CEO, Canadian Organization for Rare Disorders (CORD); **Chair, Rare Diseases International**

Hawa Dramé, Founder, Fondation Internationale Tierno et Mariam (FITIMA), Burkina Faso and Guinea

Ruth Dreifuss, Co-Chair of the United Nations Secretary General’s High-level Panel on Access to Medicines, former President of the Swiss Confederation

Anders Olauson, Chair, NGO Committee for Rare Diseases, United Nations, New York

Dainius Pūras, United Nations Special Rapporteur on the Right to Health

Maria Luisa Silva, Director of United Nations Development Program (UNDP) Office in Geneva

12:30 - 13:30 LUNCH H8-Hall

13:30 - 13:45

INNOVATION AND RESEARCH ON RARE DISEASES AND THE IMPLEMENTATION OF SUSTAINABLE DEVELOPMENT GOALS (SDGS)

Introduction: **Durhane Wong-Rieger**, President and CEO, Canadian Organization for Rare Disorders (CORD); Chair, Rare Diseases International

In accordance with the principle of universality that underpins the 2030 Agenda and its aspiration to leave no one behind, innovation and access to health technologies for rare diseases will help nations accelerate implementation of SDGs. Ways of incentivising research and increasing access to medicines and treatment is needed where the market does not provide sufficient return on investments. No one country, no one continent, can solve alone the problems posed by rare diseases. Increased collaboration can lead to more data, more research, more treatments, greater awareness and an improved global understanding of rare diseases and good care practices.

13:45-14:05

TRANSFORMING RARE DISEASE RESEARCH: IRDiRC GOALS 2017-2027

Christopher P. Austin, Director, National Centre for Advancing Translational Sciences (NCATS – NIH); Chair, International Rare Disease Research Consortium (IRDiRC)

14:05-15:30

PANEL 2: INTERNATIONAL RESEARCH: EVERYONE BENEFITS WHEN EVERYONE PARTICIPATES

*Sharing the benefits of
scientific advancements:
Why international
collaboration in Rare Disease
Research makes sense.*

Moderator: **Yann Le Cam**, Chief Executive Officer of EURORDIS–Rare Diseases Europe, Member of the Council of Rare Diseases International

Christopher P. Austin, Chair, International Rare Disease Research Consortium (IRDiRC), National Institutes of Health, USA

Hugh Dawkins, Vice Chair, International Rare Disease Research Consortium (IRDiRC), West Australian Department of Health

Christina Fasser, President, Retina International & Vice-Chair, ProRaris

Jim Green, President, International Niemann–Pick Disease Alliance

Olivier Menzel, President BLACKSWAN Foundation and Coordinator of Rare Diseases International Working Group on Research

Ramaiah Muthyala, Founder and President of the Indian Organization for Rare Diseases, (I-ORD)

Ana Rath, Director, Orphanet

15:30 - 15:45 COFFEE BREAK

15:45-17:00

PANEL 3: LEAVE NO ONE BEHIND – A WORTHWHILE AND ACHIEVABLE ACCESS GOAL

*Improving Access to
Diagnostics and Therapies*

Moderator: **Durhane Wong-Rieger**, President and CEO, Canadian Organization for Rare Disorders (CORD); Chair, Rare Diseases International

Peter Beyer, Senior Advisor, Public Health, Innovation and Intellectual Property, Department of Essential Medicines and Health Products, World Health Organization

Antoine Flahault, Director of the Institute of Global Health, Université de Genève

Kevin Loth, Chair of IFPMA Rare Diseases Working Group and Vice President, Corporate Affairs and Policy, EMEA, Celgene

Yann Le Cam, Chief Executive Officer of EURORDIS–Rare Diseases Europe, Member of the Council of Rare Diseases International

Valérie Paris, Senior Health Policy Analyst, Organisation for Economic Co-operation and Development (OECD)

Huub Schellekens, Founder WHO Utrecht Centre of Excellence for Affordable Biopharmaceuticals in LMICs (UCAB)

Oliver Timmis, Chief Executive Officer, AKU Society

17:00 - 17:15

CLOSING REMARKS

Olivier Menzel, Chair and Founder, BLACKSWAN Foundation, Swiss Foundation for Research on Orphan Diseases

17:15 - 18:00 COCKTAIL



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