



## **A Rare Disease Day Event**

### **International Policy Event**

## **The Right to Health: The Rare Diseases Perspective**

Friday, February 10, 2017

Campus Biotech  
Geneva, Switzerland

Organised by:



In partnership and with the support of:



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## A Rare Disease Day Event

### Agenda

#### 09:00 - 09:30, Registrations

#### 09:30 - 10:00, Welcome messages

- **Christina Fasser**, Vice-Chair, ProRaris, Swiss Rare Disease Alliance
- **Cyril Ritchie**, President of the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO)
- **Ruth Dreifuss**, Chair of United Nations Secretary General's High-level Panel on Access to Medicines, former President of the Swiss Confederation

#### 10:00 - 10:15, 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.

#### 10:15 - 10:20, Video message

- **Philippe Douste-Blazy**, Candidate to the WHO Director-General position, Under-Secretary-General of the United Nations and Special Advisor to the United Nations Secretary-General former French Minister of Health and of Foreign Affairs



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### 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 (OHCHR)

### 10:40 - 11:00, 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

#### Introductions and Opening Statements:

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

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

**Ilona Kickbusch**, Director of the Global Health Centre and Adjunct Professor, Interdisciplinary Programmes, Graduate Institute, Geneva (To be confirmed)

**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

### 11:00-11:15 Coffee Break

### 11:15 – 12:30, Panel 1 Discussion

### 12:30 - 13:30 Lunch



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### **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 on rare diseases will help nations accelerate implementation of SDGs. Ways of incentivizing 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 Center 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**

**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



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### 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**

**Peter Beyer**, Essential Medicines and Health Products, World Health Organization (To be confirmed)

**Suzanne Hill**, Essential Medicines and Health Products, World Health Organization (To be confirmed)

**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

**Nicola Magrini**, Essential Medicines and Health Products, World Health Organization (To be confirmed)

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

**Huub Schellekens**, Founder WHO Utrecht Center 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 Cocktail