



RARE  
DISEASES  
INTERNATIONAL

Side Event  
World Health Organization  
72<sup>nd</sup> World Health Assembly


# UNIVERSAL HEALTH COVERAGE: INCLUDING RARE DISEASES TO LEAVE NO ONE BEHIND

THURSDAY 23 MAY 2019 - 18.00 - 20.00  
International Red Cross and Red Crescent Museum  
Avenue de la Paix, 1202 Geneva  
Salle Henry Dunant

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**Dr Tedros Adhanom  
Ghebreyesus, WHO**  
28 February 2018

The vision of the Sustainable Development Goals is a world in which no one is left behind, including people who suffer from rare diseases. Just because a disease affects a small number of people does not make it irrelevant or less important than diseases that affect millions. WHO's top priority is to support countries on the path towards universal health coverage, with the aim of ensuring that all people can access the health services they need. [...] This includes access to diagnosis and treatment for people who suffer from rare diseases. »

#WHA72RareDiseases



Advancing Universal Health Coverage (UHC) delivers on the right to health and broader human rights agenda. It also contributes to achieving the Sustainable Development Goals by ensuring that no one is left behind from accessing health and the underlying determinants of health. This presents a historic opportunity to address the challenges of people living with a rare disease and to scale up innovative approaches from the field of rare diseases on the road to UHC.

This informal side event will serve to promote awareness and knowledge on the topic and to unite the international community, the patient community and all relevant stakeholders to address the unmet needs of this largely ignored and vulnerable population.

## PROGRAMME

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### 17.30 WELCOME DRINKS

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### 18.00-18.30

**OPENING REMARKS** – **Dr Durhane Wong-Rieger**, Chair, Rare Diseases International and President & CEO, Canadian Organization for Rare Disorders

**KEYNOTE ADDRESS** – **Mr Todd Howland**, Chief of the Development and Economic and Social Issues Branch, Office of the United Nations High Commissioner for Human Rights

**GLOBAL FIGURES, DEFINITION AND VISIBILITY** – Video presentation by **Dr Ana Rath**, Director, Orphanet INSERM

**HOPES AND CHALLENGES OF PEOPLE LIVING WITH A RARE DISEASE** – **Mr Yann Le Cam**, Chief Executive Officer, EURORDIS-Rare Diseases Europe and Treasurer of the Council of Rare Diseases International

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### 18.30 -19.30

#### STRATEGIES TO ADDRESS RARE DISEASES WITHIN UNIVERSAL HEALTH COVERAGE

Panel Discussion moderated by Durhane Wong-Rieger

**INCLUDING RARE DISEASES IN THE NATIONAL HEALTH SYSTEM - THE CASE OF THE PHILIPPINES** - **Dr Carmencita Padilla**, Professor of Paediatrics at the College of Medicine and Chancellor of University of the Philippines Manila

**PREVENTION AND EARLY INTERVENTIONS - THE CASE OF SPINA BIFIDA AND HYDROCEPHALUS** - **Mr Lieven Bauwens**, Secretary General, International Federation for Spina Bifida and Hydrocephalus

**IMPROVING DIAGNOSIS, REDUCING MISDIAGNOSIS - THE CASE OF THALASSAEMIA**  
**Dr Androulla Eleftheriou**, Executive Director, Thalassaemia International Federation

**ACCESS TO TREATMENTS PROGRAMMES - THE CASE OF HAEMOPHILIA**  
**Mr Alain Weill**, President, World Federation of Hemophilia

#### Q&A AND DISCUSSION

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### 19.30- 19.45

**CLOSING REMARKS: THE WAY FORWARD** - **Dr Rüdiger Krech**, Director, Universal Health Coverage and Health Systems, Office of the Assistant Director-General, World Health Organization

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## ABOUT RARE DISEASES

There are over 6,000 identified rare diseases. Even though one disease may be rare, the number of people affected by rare diseases is extremely large, with an estimated 300 million worldwide. Rare diseases are often chronic, highly complex, progressive and severely disabling, frequently affecting life expectancy and generating specific care needs.

While rare diseases share the impacts and challenges of common severe conditions, because each affects very small numbers scattered across the globe, they are often misdiagnosed or undiagnosed. In addition, rare diseases receive little research, attention and funding, resulting in limited knowledge about causes, natural progression, and effective intervention. Fewer than 5% of diseases have any known treatment. Rare diseases impact not only a person's health, but also their socio-economic status, family, education and labour opportunities. Difficulties such as poverty, unemployment, stigmatisation and social exclusion are a daily reality for most people affected.

### A rare disease affects...



HEALTH



FAMILY



EDUCATION



WORK



ECONOMY



SOCIETY



SCIENCE

Rare diseases is a global policy priority demanding common solutions within the Sustainable Development Goals 2030 Agenda. Persons living with a rare disease need to be seen as more than just patients or their disease, but as human beings with rights to health and well-being.

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## ABOUT RARE DISEASES INTERNATIONAL

Rare Diseases International (RDI) is the global alliance of people living with a rare disease of all nationalities across all rare diseases. RDI's mission is to be a strong common voice on behalf of rare disease patients around the world, to advocate for rare diseases as an international public health priority and to represent its members and enhance their capacities. RDI has more than 50 member organisations from over 30 countries, that in turn represent rare disease patient groups in more than 100 countries worldwide.

RDI is a member of the NGO Committee for Rare Diseases, a Substantive Committee of the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO). The NGO Committee is a multi-stakeholder, inclusive, global ecosystem, which works towards making rare diseases a global health priority on the UN's agenda and within public health, research, medical and social care policies and structures around the world.



Event organised by



**RARE  
DISEASES  
INTERNATIONAL**

In collaboration with the NGO  
Committee for Rare Diseases



**NGO COMMITTEE FOR  
RARE DISEASES**



A Substantive Committee of  
The Conference of NGOs in Consultative Relationship  
with the United Nations

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