RARE
DISEASES
INTERNATIONAL

In collaboration with
NGO COMMITTEE FOR
RARE DISEASES

Informal Side Event

World Health Organisation 72nd World Health Assembly

Universal Health Coverage: Including rare diseases to leave no one behind

Thursday 23 May
18.00-20.00

Room Henry Dunant

International Red Cross and Red Crescent Museum
Avenue de la Paix, Geneva

This informal side event will promote awareness and knowledge on the topic Rare Diseases and serve to unite the international community, patients and all relevant stakeholders to address the unmet needs of this vulnerable population within Universal Health Coverage.

PROGRAMME

Welcome drinks from 17.30

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 (OHCHR)

Global figures,definition and visibility – (TBC) Ms Deborah Lambert, Orphanet Ireland

Hopes and challenges of people living with a rare disease – Mr Yann Le Cam, Chief Executive Officer, EURORDIS-Rare Diseases Europe

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

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

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.

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.