

5TH RARE DISEASES INTERNATIONAL ANNUAL MEETING

20th February 2019
Microsoft Global Headquarters
11 Times Square
New York

ROOM: CENTRAL PARK EAST

08:00 - 08:30 REGISTRATION AND VOTING BALLOTS

08:30 - 10:30 RDI GENERAL ASSEMBLY & MEMBERSHIP MEETING

*(closed session
for RDI Members only)*

Welcome Speech & Adoption of Agenda - Durhane Wong-Rieger, Chair of the Council of Rare Diseases International and President & CEO, Canadian Organization for Rare Disorders

Presentation of annual Activity Report and Financial Report 2018 - Paloma Tejada, Director, Rare Diseases International

Presentation and adoption of annual Work Programme: Action Plan and Budget 2019 - Paloma Tejada

Discussion of RDI's strategy and activities

Vote of resolutions on Annual Report 2018 and Work Programme 2019

Self-introduction of the newly-elected Council members

Announcement of results of votes on resolutions

10:30-10:45 BREAK

ROOM: CENTRAL PARK WEST

11:00 - 12:30 GLOBAL COMMISSION REPORT LAUNCH

Official launch of the Global Commission to End the Diagnostic Odyssey of Children with a Rare Disease's ("The Global Commission") digital roadmap for shortening the time to diagnosis for children with rare diseases worldwide.

13:00 - 14:00 LUNCH

#RAREDISEASESINTERNATIONAL

Follow the event LIVE on
<https://www.rarediseasesinternational.org/live>

ROOM: CENTRAL PARK WEST

14:00 - 17:45 RDI GLOBAL MEETING

*(open to non RDI Members,
Partners and Stakeholders)*

Interactive session to understand, discuss, and get further involved in RDI's advocacy. Opportunity to learn from and share with other patient advocates and rare disease stakeholders from around the world

13:30-14:00 REGISTRATION

WELCOME

14:00 - 14:10 Where we started, Where we are - Durhane Wong-Rieger, Chair of the Council of Rare Diseases International and President & Chief Executive Officer of The Canadian Organization for Rare Disorders

LEAVING NO ONE BEHIND: THE SUSTAINABLE DEVELOPMENT GOALS 2030 AGENDA

14:10 - 14:20 Why and How to advocate the UN? Overview of High-Level Event of the NGO Committee for Rare Diseases at the United Nations, New York on the occasion of Rare Disease Day 2019, **Anders Olsson**, Chair of NGO Committee for Rare Diseases

14:20 - 14:40 Towards a United Nations Resolution on Rare Diseases: Objectives, Progress and Coordination of our Action, **Yann Le Cam**, Chief Executive Officer of EURORDIS - Rare Diseases Europe and Member of the Council of Rare Diseases International

14:40 - 15:00 Q&A and open discussion

HEALTH FOR ALL: UNIVERSAL HEALTH COVERAGE

15:00 - 15:15 The Universal Health Coverage Political Declaration: an opportunity for rare diseases, **Durhane Wong-Rieger**

15:15 - 15:30 Case study - How Rare Diseases are being integrated in the Philippine National Health System, **Cynthia Madaraog**, President of Philippines Society for Orphan Disorders

15:30 - 15:45 Q&A and open discussion

15:45-16:15 COFFEE BREAK

HUMAN RIGHTS & DISABILITY

16:15 - 16:30 Including Rare Diseases in the Disability agenda using the UN Convention on the Rights of People with Disability (CRPD), **Lieven Bauwens**, Secretary-General, International Federation for Spina Bifida and Hydrocephalus

16:30 - 16:45 Q&A and open discussion

REGIONAL MOBILIZATION TO SUPPORT PATIENTS LOCALLY

16:45 - 17:00 Asia Pacific Alliance of Rare Disease Organizations (APARDO), **Durhane Wong-Rieger**

17:00 - 17:15 Rare Disease African Alliance (Africa-Rare.org), **Kelly du Plessis**, Rare Diseases South Africa

17:15 - 17:30 Iberoamerican Rare Disease Alliance (ALIBER), **Jesús Navarro**, Organización Mexicana de Enfermedades Raras

17:30 CLOSING REMARKS