



RARE  
DISEASES  
INTERNATIONAL



# 5<sup>TH</sup> | RARE DISEASES INTERNATIONAL ANNUAL MEETING

20<sup>th</sup> February 2019  
Microsoft Global Headquarters  
11 Times Square  
New York

**#RareDiseasesInternational**





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## ROOM: CENTRAL PARK EAST

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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

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**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

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**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 Olauson**, 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**





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