



RARE  
DISEASES  
INTERNATIONAL

**RDI Membership Meeting 2017 Barcelona  
(3<sup>rd</sup> Annual Meeting)  
June 4th, 2017  
Barcelona, Spain**

Hotel SB Bcn Events Castelldefels  
Room: Calma 1 & 2

***Programme***

***9:00 -10:30 Business Agenda***

***(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 and adoption of 2016 Activity Report

Presentation and adoption of 2017 Work Programme: Action Plan and Budget - *Paloma Tejada, Senior Manager, Rare Diseases International*

Discussion with members on how to raise awareness about RDI in their respective organisations and settings, as well as on a membership recruitment plan - *Lisa Phelps, Secretary of the Council of Rare Diseases International and Director of Marketing and Community Relations, National Organization for Rare Disorders*

Presentation of the newly-elected members of the Council - *Durhane Wong-Rieger*

***10:30- 11:00 COFFEE BREAK***

***11:00 – 19:00 Program Agenda***

***(Open session for RDI Members and non-Members)***

**11:00- 12:15 Global Environment: Advances and Opportunities**

RDI Joint Declaration: Rare Diseases: An International Public Health Priority – *Lisa Phelps*

Understanding the UN system and UN SDGs 2030 – *Clara Hervás, Public Affairs Junior Manager, EURORDIS-Rare Diseases Europe*

NGO Committee for Rare Diseases, New York – *Yann Le Cam, Chief Executive Officer of EURORDIS – Rare Diseases Europe and Member of the Council of Rare Diseases International*

RDI Rare Disease Day Policy Event Geneva – *Paloma Tejada*

A United Nations General Assembly Resolution: an introduction to the concept – *Clara Hervás*

Strategy towards a UN Resolution on rare diseases – *Yann Le Cam*

Q&A Discussion

**12:15- 12:30 Review of 11 national policies for rare diseases in the context of key patient needs**, Safiyya Dharssi, Director - International Public Affairs, Rare Disease & Inflammation/Immunology, Pfizer Inc

*This paper published in March 2017 in the Orphanet Journal of Rare Diseases is co-authored by Pfizer, the Canadian Organization for Rare Disorders and Genetic Alliance*

**12:30- 13:00 Presentation of the Report on the State of the Art of Rare Disease Activities in Europe, and pilot project to extend beyond the European Union**, Victoria Hedley, RD ACTION, Newcastle University, UK

*The survey that feeds this report is part of the activities of the Joint Action for Rare Diseases (RD – ACTION) and is co-funded by the Health Programme of the European Union*

Q&A Discussion

**13:00 – 14:00 LUNCH**

**14:00- 16:00 Environmental Scan of Rare Diseases Around the World: Advances and opportunities**

Regional developments with country specific examples and regional themes

Moderator: *Durhane Wong-Rieger*

14:00 – 14:45 Asia and Africa

*Dato' Hatijah Ayob, Malaysian Rare Disorders Society*

*Megan Hunter, Rare Diseases South Africa*

*Ritu Jain, DEBRA Singapore*

*Sanaullah Syed, Indian Organization for Rare Diseases*

*Kin Ping Tsang, Hong Kong Alliance for Rare Diseases*

Discussion: Regional and international developments, influences, barriers, opportunities

14:45- 15:30 Latin America

Moderator: *Durhane Wong-Rieger*

*Angela Chaves, Federación Colombiana de Enfermedades Raras (Colombia)*

*Migdalia Denis, Alianza Iberoamericana de Enfermedades Raras (ALIBER)*

*Paulina Peña, Federación Mexicana de Enfermedades Raras (Mexico)*

Discussion: Regional and international developments, influences, barriers, opportunities

15:30 – 16:00 Europe and North America

Moderator: Yann Le Cam

*Victoria Hedley, RD ACTION, New Castle University, UK*

*Lisa Phelps, National Organization for Rare Disorders*

*Rosa Sánchez, Federación Española de Enfermedades Raras*

*Durhane Wong-Rieger, Canadian Organization for Rare Disorders*

Discussion: Regional and international developments, influences, barriers, opportunities

**16:00- 16:30 COFFEE BREAK**

**16:30 -18:00 Advocacy Opportunities: Where and How Do We Go Forward?**

Building on Grassroots successes and initiatives

Moderator: *Yann Le Cam*

Panelists:

*Christoph Poincilit, International Niemann-Pick Disease Alliance (INPDA)*

*Chiara Ciriminna, BLACKWSAN Foundation*

*Mark Brooker, World Federation of Hemophilia (WHF)*

*Angela Chaves Restrepo, Federación Colombiana de Enfermedades Raras (FECOER)*

*Luciana Escati Peñalosa, Federación Argentina de Enfermedades Poco Frecuentes (FADEPOF)*

Discussion: Identifying Global and International Advocacy Opportunities

- Are there advocacy initiatives that RDI could build upon or contribute to, help promote for possible adaptation across borders?

Conclusions – *Durhane Wong-Rieger*

**18:00 -19:00 Rare Connect and RDI**

*Denis Costello, EURORDIS – Rare Diseases Europe and Mike Brudno, Sick Children's Hospital of Toronto*