RDI Membership Meeting 2017 Barcelona  
(3rd 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 Peñaloza, 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