



RARE
DISEASES
INTERNATIONAL

**Second Annual RDI Meeting
May 25, 2016
Edinburgh International Conference Centre
Agenda**

13.30- 14.30 Closed session for RDI Members Only

Introductions from 7 members of the Council

Tour de table of Member Organisations present

14.30- 14.45 Opening Speech – Durhane Wong-Rieger, President of the Canadian Organization for Rare Disorders

14.45 - 15.15 RDI Progress so far and first achievements – Paloma Tejada, Senior Manager, Rare Diseases International

15.15 – 16.15 Advocating for rare diseases at the international level

Panel introduced by John Dart, Senior Advisor to the Executive Committee, DEBRA International

Joint Declaration “Rare Diseases: Making Rare Diseases an International Public Health Priority”– John Dart, Senior Advisor to the Executive Committee, DEBRA International

The United Nations Committee for Rare Diseases – Anders Olauson, Founder and Chairman, AGRENSKA Foundation

“Treatment for all: the challenges of tackling a rare global disease” - Alain Baumann, Chief Executive Officer, World Federation of Hemophilia

Discussion

16.15 – 16.30 Coffee break

16.30 – 17.30 Rare Diseases International – next steps

Panel introduced by Lisa Phelps, Director of Marketing and Community Relations, National Organization for Rare Disorders

Introduction of 7 Members of newly-elected Council

Priorities, Strategy and Actions – Yann Le Cam, Chief Executive Director, EURORDIS

Discussion

17.30 – 18.30 Joining forces with other RD stakeholders – shaping the RD ecosystem

Panel introduced by Yann Le Cam, Chief Executive Director, EURORDIS

International Conferences on Rare Diseases and Orphan Drugs: “Supporting countries emerging to rare diseases” – John Forman, President of ICORD and former Executive Director of New Zealand Organisation for Rare Disorders

International Federation of Pharmaceutical Manufacturers & Associations: “Exploring synergies and common objectives between the patient community and industry” – Emmanuel Chantelot, Head of International Government Relations and Public Affairs, Shire and Chair of IFPMA Rare Disease Working Group

International Rare Diseases Research Consortium: “Fostering patient engagement in Rare Disease Research funding” – Dr. Iiro Eerola, Scientific Project Officer in the European Commission, DG Research and Innovation, Directorate for Health in the Unit for Innovative and Personalised Medicine

Discussion

18h20-18h30 Take home message

Cocktail