



RARE
DISEASES
INTERNATIONAL

4th RDI Annual Meeting

May 10, 2018

Business Suite 1&2

Messe Wien Congress Center

Vienna, Austria

Agenda

8.30 – 9.30 Registration

9.00 – 9.30 WELCOME COFFEE

9.30 -13.00 RDI Membership Meeting (closed session for RDI Members only)

9.30 – 10.30 Extraordinary General Assembly

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 Statutes for legal incorporation of RDI - Zoe Alahouzou, Deputy to Chief Executive Officer, EURORDIS- Rare Diseases Europe

Presentation of Memorandum of Understanding with EURORDIS to provide support to RDI - Zoe Alahouzou

Presentation and adoption of annual Activity Report and Financial Report 2017 - Paloma Tejada, Director, Rare Diseases International

Presentation and adoption of annual Work Programme: Action Plan and Budget 2018 – Paloma Tejada

Self-introduction of the newly-elected members of the Council

Angela Chaves Restrepo – Federacion Colombiana de Enfermedades Raras (Colombia)

Ritu Jain – DEBRA Internationala (Singapore)

Lisa Phelps – National Organization for Rare Disorders (United States)

Vote of resolutions

10.30 – 11.00 Topics to discuss with RDI Members

Towards an RDI Conference Programme - *Lisa Phelps, Member of the Council of Rare Diseases International and Director of Strategic Planning and Project Development, National Organization for Rare Disorders*

The Role of RDI in the International Rare Disease Research Consortium (IRDiRC) - *Durhane Wong-Rieger*

11.00 – 11.30 *COFFEE BREAK*

11.30 – 12.15

The Role of RDI in supporting RD Patient Advocacy Organisations – *Ritu Jain, Member of the Council of Rare Diseases International and Board Member of DEBRA International*

Rare Barometer Voices: Rare Barometer Voices: Extending the survey panel outside of Europe – *Sandra Courbier, Rare Barometer survey programme Senior Manager*

State of the Art of Rare Disease Activities: How to collect and benchmark rare disease policy information beyond the EU – *Paloma Tejada*

12.15 – 13.00

Open Forum

Moderators: Durhane Wong-Rieger and Lisa Phelps

- What is happening in Members' countries, regions or at the level for their disease that would be of keen interest to the other members to know;
- Activities that Members would like support on from RDI or that their members can contribute to or collaborate on;
- Global issues or actions that Members think RDI needs to bring back to its Advocacy Committee for consideration;
- Topics of interest for future education at the global level - to inform potential programs that RDI could run next to conferences and/or via web conferences.

13.00- 14.00 LUNCH

14.00- 16.00 RDI Open Meeting (for RDI Members and non RDI Members)

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

14.10 – 15.00 Means to advocate at the international level

RDI Advocacy Committee and RDI Policy to develop, recommend and adopt positions – *Ritu Jain, Member of the Council of Rare Diseases International and Board Member of DEBRA International*

The NGO Committee for Rare Diseases – *Durhane Wong-Rieger*

15.00 – 16.00 Advocating for Rare Diseases in the United Nations system

Actions to place rare diseases in the UN Sustainable Development Goals 2030 Agenda

Yann Le Cam, Chief Executive Officer of EURORDIS – Rare Diseases Europe and Member of the Council of Rare Diseases International

- Human Rights Council
- UN General Assembly – Third Committee (Social, Humanitarian & Cultural Issues)
- World Health Organization

Discussion

16.00 – 16.30 NETWORKING COFFEE (with EPAGs)

EURORDIS General Assembly