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)

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EURORDIS General Assembly