

RDI MEMBERSHIP MEETING

Agenda

Thursday 16 June 2022,

14:00 – 14:10

Opening Remarks and Message from the RDI Chair

Durhane Wong-Rieger, Council Chair, Rare Diseases International

14:10 – 15:00

Strategic Engagement of RDI Members: Consultation and Work in Progress

Consultation on New RDI Strategic Engagement Programme

Trial run and feedback

Flaminia Macchia, Executive Director, Rare Disease International

Hlawulani Mkhabela, Strategic Engagement Manager, Rare Disease International

Lisa Sarfaty, Vice President, Community Engagement NORD

15:00 – 15:10

Break (10 minutes)

15:10 – 15:55

Advocacy Priorities

UN Resolution – Impact & Implementation

Next steps – UHC & Health Equity, the WHO and beyond

Advocacy toolkits and resources

Flaminia Macchia, Executive Director, Rare Disease International

Dolores Cvitičanin, Public Affairs Manager, Rare Disease International

RDI Members, Share advocacy success and current priority

15:55 – 16:05

Break (10 minutes)

16:05 – 16:50

Global Access

Operational Description of Rare Diseases

IRDiRC/RDI Access Task Force

Essential Medicines Lists & Essential Diagnostics List

Mary Wang, Science Policy Manager, Rare Disease International

RDI Members, Share success and current priority to support access

16.50 – 17.00

Closing Remarks



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