RDI ADVOCACY COMMITTEE

Dr Ritu Jain

Council RDI
President Debra Singapore
Treasurer, DEBRA International
TERMS OF REFERENCE OF ADVOCACY COMMITTEE

General Objective

• To be the voice of people living with rare diseases worldwide
• In line with RDI’s Joint Declaration Rare Diseases an International Public Health Priority

Purpose

• Developing and recommending priorities, initiatives and policies
• Preparing position papers or statements or declarations
• Reviewing any position, statement, declaration or petition considered for adoption by the Council

Composition: 2 members of the RDI Council (Yann Le Cam as Chair and Ritu Jain) +13 patient advocates from RDI member organisations + advisor from IAPO (all volunteers and staff members of umbrella patient groups)
# MEMBERS OF THE ADVOCACY COMMITTEE

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<th><strong>Chair:</strong> Yann Le Cam</th>
<th>EURORDIS – Rare Diseases Europe</th>
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<td>2</td>
<td>Paul Melmeyer</td>
<td>National Organization for Rare Disorders NORD</td>
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<td>Maureen Smith</td>
<td>Canadian Organization for Rare Disorders CORD</td>
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<td>Angela Chaves</td>
<td>Federación Colombiana de Enfermedades Raras</td>
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<td>Migdalia Denis</td>
<td>Pulmonary Hypertension Latin Society</td>
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<td>Ramaiah Muthyala</td>
<td>Indian Organization for Rare Diseases IORD</td>
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<td>Chiara Ciriminna</td>
<td>BLACKSWAN Foundation</td>
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<td>Ritu Jain</td>
<td>DEBRA International</td>
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<td>9</td>
<td>Antonio Ciaglia</td>
<td>International Alliance of Patient Organisations –IAPO</td>
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<td>10</td>
<td>Lara Bloom</td>
<td>Ehlers-Danlos Society</td>
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<td>Simone Boselli</td>
<td>EURORDIS - Rare Diseases Europe</td>
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<td>12</td>
<td>Sanja Peric</td>
<td>Rare Diseases Croatia</td>
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<td>Kelly du Plessis</td>
<td>Rare Diseases South Africa</td>
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<td>Mark Brooker</td>
<td>World Federation of Hemophilia</td>
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<td>Lieven Bauwens</td>
<td>International Federation for Spina Bifida &amp; Hydrocephalus</td>
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<td>16</td>
<td>Alba Ancochea</td>
<td>Federación Española de Enfermedades Raras</td>
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CORE DRAFTING GROUP

• Yann Le Cam - Chief Executive Officer of EURORDIS
• Simone Boselli - Public Affairs Director, EURORDIS
• Mark Brooker - Senior Public Policy Officer, World Federation of Hemophilia
• Antonio Ciaglia - Policy Manager, International Alliance of Patients’ Organizations (replaced by Kawaldip Sehmi, CEO, IAPO)
• Chiara Ciriminna - Project Coordinator and External Relations, BLACKSWAN FOUNDATION, Swiss Foundation for Research on Orphan Diseases
• Paul Melmeyer - Director of Federal Policy, National Organization for Rare Disorders
FRAMEWORK FOR THE COMMITTEE TO OPERATE

RDI Policy on developing, recommending and adopting advocacy initiatives (available on the website)

Contains:

1. CRITERIA to recommend advocacy priorities and initiatives
2. Type of advocacy INITIATIVES RDI generates
3. METHODS used to develop advocacy positions
RDI advocacy priorities focus on areas of potential maximum impact using the criteria:

- **Relevance**: to patients and families living with a RD?
- Is it an advocacy priority best addressed at the international level?
- **Consistent** with the RDI Joint Declaration Recommendations?
- potential high impact
- priority across a large number of RDs and countries
- informed by knowledge base, advocacy materials, in-house expertise, and financial resources
2. TYPE OF ADVOCACY INITIATIVES

- Contribution or **Comment** and **Response** to Public Consultation (comment on report produced by a UN institution or international stakeholders like IRDiRC, IFPMA, ISPOR, IHGS)

- **Statement** or **Recommendation**, Position Paper, Petition, Discussion Paper, etc.

- State of the Art of **Rare Disease Activities Report**

- Policy **briefings** or Advocacy **tools** provided to RDI members and RDI Volunteers

- Oral/written **statement** and/or **side Meetings** in UN sessions (eg. Human Rights Council, Disability Convention), WHO World Health Assembly

- **RDI Policy Event** (eg. on Rare Diseases Day)
3. PROCESS FOR ENDORSING POSITIONS

Advocacy Committee (AC) reviews an existing position, adopts and recommends for adoption by the Council.

The AC either asks the Core Drafting Group or appoints an ad hoc group to initiative the first draft, and have these reviewed by the members of AC.

The AC develops a final draft submitted to the Council with recommendations for adoption.
PROCESS for ADOPTION

1. RDI generates a position paper or statement and adopts it independently

2. RDI contributes to a position proposed by a member or external stakeholder and adopts jointly, co-signing

3. RDI adopts an existing position without contributing to the content and provide its official support to the producer of this position. Adopted by majority of RDI members

Members are consulted on adoption (with an opt out option of 10 days).

The lack of opt out automatically indicates support or agreement.
Response to the Consultation on WHO’s Draft Note 13th General Programme of Work 2019-2023 - submitted on October 13th, 2017

Response to the 2nd round of Consultation on WHO draft 13th General Programme of Work (GPW13) - submitted on November 14th, 2017

Ongoing: basis for statement at WHO World Health Assembly side event in Geneva -21 to 26 May

Proposal Diseases High Level Meeting in New York in 2019

Contributions to “Health as a Human Right” and on “Rare Disability” through the NGO Committee for Rare Diseases

(more on that in next presentations)

of Framework of Collaboration with WHO (on-going)

UN Resolution Outline (rationale, scope and objectives) RDI Contribution to NGO Committee for Rare
EXISTING POSITIONS TO BE CONSIDERED

The following international position papers are currently being considered by RDI Advocacy Committee:

- **INTERNATIONAL JOINT RECOMMENDATIONS TO ADDRESS SPECIFIC NEEDS OF UNDIAGNOSED RARE DISEASE PATIENTS**

- **EURORDIS-NORD-CORD Joint Declaration of 10 Key Principles for Rare Disease Patient Registries**