



RARE  
DISEASES  
INTERNATIONAL

# RDI ADVOCACY COMMITTEE

**Dr Ritu Jain**

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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)



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**ADVOCACY COMMITTEE**



Yan Lee Cam  
Eurordis  
Chair



Maureen Smith  
CORD-Canada



Angela Chaves  
FECOER-  
Colombia



Kelly du Plessis  
RDSA-South Africa



Ramaiah  
Muthyala  
IORD-India



Paul  
Melmeyer  
NORD-EEUU



Ritu Jain  
DEBRA  
International



Lara Bloom  
EDS-UK



Sanja Peric  
RD-Croatia



Migdalia Denis  
PHLS



Lieven  
Bauwens  
IFSBH



Alba  
Ancochea  
FEDER-Spain



Mark Brooker  
WFH



Chiara  
Ciriminna  
BLACKSWAN  
FOUNDATION



Kawaldip  
Sehmi  
IAPO



Simone  
Boselli  
EURORDIS –  
Rare  
Diseases  
Europe



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# MEMBERS OF THE ADVOCACY COMMITTEE

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



# 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



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# 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



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# 1. CRITERIA FOR ADVOCACY PRIORITIES

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 **initiate** 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.



# ADVOCACY INITIATIVES OF THE COMMITTEE 2017-2018-2019

- ▶ 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



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# 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](#)

