Rare Diseases International
Activity & Financial Report 2019

A strong common voice for people living with a rare disease around the world
2019 Highlights

January
Legal Incorporation

February
RDI 5th Annual Meeting
RDI met with Dr Tedros, Director-General of the WHO, to discuss future collaboration

March
Rare Disease Side Events at WHO 72 World Health Assembly

May
Campaign with National Alliances to include RD in UN Political Declaration

September
RDI met with Dr Tedros, Director-General of the WHO, to discuss future collaboration

December
RDI signs an Memorandum of Understanding with WHO

February
RDI participated in Rare Disease Day policy event at the United Nations

March
RDI –IFPMA Round Table on Access in LMICs
Governance and Membership
RDI was incorporated under French law as an Association Loi 1901 on December 7, 2018.

RDI has been operating as a legally-registered organisation since January 2019.

The Statutes (constitution) of the organisation can be found on the website: https://www.rarediseasesinternational.org/governance/

Governance: RDI council

Durhane Wong-Rieger
CORD
Canada

Lisa Sarfaty
NORD

Yann Le Cam
EURORDIS

Ritu Jain
DEBRA
International

Kin Ping Tsang
Retina International

Rachel Yang
CORD
China

Jesús Navarro
ALIBER
Governance: RDI Advocacy Committee

Yan Lee Cam
EURORDIS
Chair

Maureen Smith
CORD-Canada

Ritu Jain
DEBRA International

Kelly du Plessis
RDSA-South Africa

Ramaiah Muthyala
IORD-India

Lara Bloom
EDS-UK

Leire Solis
IPOPI

Luciana Escati
FADEPOF

Eleni Antoniou
Thalassaemia International

Sanja Peric
RD-Croatia

Migdalia Denis
PHLS

Lieven Bauwens
IFSBH

Alba Ancochea
FEDER-Spain

Heather Richards
WFH

Simone Boselli
EURORDIS

Kawaldip Sehmi
IAPO

Roberta Anido de Pena
FADEPOF
Membership in 2019

62 member organisations, present in over 100 countries

- 35 national alliances
- 17 international federations
- 3 regional networks
- 7 other rare disease organisations

Europe 32
Africa 4
Asia 11
North America 6
South America 5
Oceania 3
RDI 6th Annual Meeting

February 20th at the Microsoft Global Headquarters in New York, USA
First time outside Europe
Launch of the Recommendations Report of the Global Commission to End the Diagnosis Odyssey of Children with a Rare Disease
NGO Committee for Rare Diseases High Level Event Rare Disease Day at the UN Event
32 member organisations from 26 countries at General Assembly and Membership Meeting
119 delegates at RDI Global Meeting
Communication & Engagement

Outreach and Engagement Manager
- Hlawulani Mkhabela

Monthly RDI e-newsletter
- sharing news, events, calls for input and action

Launch Facebook Workplace group
- online community for RDI members to connect with each other, share news and best practice and ask for guidance

Social media – Twitter +2000 followers

RDI National Alliance involvement in Rare Disease Day
Funding and Programmes
RDI Alliance of Companies

A platform for companies across different sectors to support the rare disease cause internationally and to increase mutual understanding of issues that are important for rare disease patients and different industries.

In 2019:

- 9 companies joined the Alliance
- Met for first on-line meeting on August 29 to learn more about RDI Advocacy strategy and inclusion of rare disease in UN Political Declaration on UHC
RDI Conference Programme

1. Rare Disease Day at the UN Event, Global Commission Report Launch, New York, Feb 20-21 level 3

2. World Orphan Drug Congress, Washington DC, April level 2

3. Canadian Organization for Rare Disorders/ReACT Conference, Toronto, Canada, May 9-13 level 3

4. ‘Rare Diseases: A global challenge, a holistic challenge’ Conference at the National Rare Disease Centre (CREER), Burgos, Spain, September 19-20 level 2

5. APARDO Summit ‘Regional Collaboration for Global Change’, Taipei, Taiwan, October 19-21 level 3

6. XIV International Conference on Rare Diseases and Orphan Drugs” (ICORD), Tel Aviv, Israel, November 11-13 level 2

7. World Orphan Drug Congress, Barcelona, Spain, November 12-14 level 2

8. VI Encuentro Iberoamericano de Enfermedades Raras (ALIBER 6th Conference) Murcia, Spain, November 13-15 level 4
RDI Fellowship Programme

Rare Disease Day at the UN Event / Global Commission Report Launch, New York, Feb 20-21 level 3

► RDI financial support for patient representatives to participate (17 fellowships)

Canadian Organization for Rare Disorders ‘A Rare International Dialogue” Conference, Toronto, Canada, May 9-13 level 3

► RDI financial support for patient representatives to participate (9 fellowships)

APARDO Summit ‘Regional Collaboration for Global Change’, Taipei, Taiwan, October 19-21 level 3

► RDI financial support for patient representatives to participate (16 fellowships)
Advocacy
Rare Disease Day at UN Event

Rare Disease Day Policy Event at the United Nations Headquarters

Co-organisers NGO Committee for Rare Diseases, EURORDIS – Rare Diseases Europe and RDI

21 February 2019, United Nations Headquarters, New York

15 countries co-hosted the event at UN Headquarters building in New York
Over 100 participants from the international NGO community, UN agencies, national governments, academic institutions, the private sector and the rare disease patient community came together at the United Nations Headquarters in New York.

40 patient advocates from RDI member organisations were invited to participate and represent the rare disease patient community.

17 RDI fellowships for patient advocates to attend
RDI and WHO Secretariat identified areas of collaboration to shape a partnership, which will be formalised in a Memorandum of Understanding.

Collaboration based on ambitious goals that contribute to WHO’s 13th General Programme of Work

Prepare the ground for RDI to be NSA in official relations with WHO

Will enable RDI to carry our programmes and shape the agenda from within (as NSA official relations)
Position of RD patient community on UHC

- Paper released in April 2019 adopted by RDI Council in consultation with RDI Advocacy Committee

- Input and case studies from RDI members

- Important advocacy tool in inclusion of RDs in UHC campaign

- Paper available on RDI website:
  www.rarediseasesinternational.org
Rare Disease Side events at WHO 72nd World Health Assembly

UNIVERSAL HEALTH COVERAGE: INCLUDING RARE DISEASES TO LEAVE NO ONE BEHIND

THURSDAY 23 MAY 2019 • 18.00 – 20.00
International Red Cross and Red Crescent Museum
Salle Henry Dunant
Avenue de la Paix, 1209 Geneva
(opposite Palais des Nations)

This informal side event will promote awareness and knowledge on the topic Rare Diseases and serve to unite the International community, patients and all relevant stakeholders to address the unmet needs of this vulnerable population within Universal Health Coverage.

PROGRAMME

18.30 - 18.40
OPENING REMARKS - Dr. Daphne Magee, Director, Rare Diseases International and President & CEO, Canadian Organisation for Rare Disorders

18.40 - 18.50
KEYNOTE ADDRESS - Mr. David Mawdsley, Chief of the Development and Economic Social Issues Branch, Office of the Special Rapporteur on the Right to Adequate Housing
GLOBAL FRAMEWORKS, DEFINITION AND PREVAILING VIEWS – Video presentation by Dr. Daphne Magee, Director, Rare Diseases International

19.00 - 19.10
HOUSES AND CHALLENGES OF PEOPLE LIVING WITH A RARE DISEASE – Mr. Yves Le Calvez, Chief Executive Officer, European Rare Diseases Europe and Treasurer of the Council of Rare Diseases International

19.10 - 19.20
STRATEGIES TO ADDRESS RARE DISEASES WITHIN UNIVERSAL HEALTH COVERAGE
Panel Discussion moderated by Dr. Yves Le Calvez

19.20 - 19.30
INCLUDING RARE DISEASES IN THE NATIONAL HEALTH SYSTEM – THE CASE OF THE PHILIPPINES – Dr. Ronaldo Baylima, Professor of Pediatrics at the College of Medicine and Chancellor of the University of the Philippines Manila
PREVENTION AND EARLY INTERVENTIONS – THE CASE OF SPINA BIFIDA AND HYDROCEPHALUS – Mr. Louis Khazad, Deputy Director, International Federation for Spina Bifida and Hydrocephalus
IMPROVING DIAGNOSIS, FILING MORGANISMS – THE CASE OF PROGRESSIVE SUPRANUCLEAR PALSYS – Mr. Edward Spence, Director, Global Foundation for Progressive Supranuclear Palsy
IMPROVING ACCESS TO TREATMENT – THE CASE OF MARFAN SYNDROME – Ms. Asian Wolf, President, World Federation for Marfan Syndrome

19.30 - 19.40
Q&A AND DISCUSSION

19.40 - 19.50
CLOSING REMARKS: THE WAY FORWARD – Dr. Daphne Magee, Director, Universal Health Coverage and Health Systems, Office of the Special Rapporteur on the Right to Adequate Housing
Side event to the 72nd World Health Assembly
Thursday, May 23 2019
12:30-14:00
Geneva, Palais des Nations, Room XXIII

Rare diseases are at the forefront of digital health and exemplify high added value of regional and global approaches. New digital tools are already being used to address the challenges of the 300 million people living with a rare disease to connect highly isolated patients, enable access and speed up diagnosis, refer to specialized medical expertise, to gather and share expertise on highly complex care, and accelerate clinical research. This side event will serve to show the potential of digital health to achieve Universal Health Coverage, using rare diseases as an example.

Opening remarks:
Ambassador Walter Stevens
Head of the EU Delegation to the UN in Geneva
Dr. Soumya Swaminathan
Chief Scientist, WHO

Keynote speeches:
Dr. Cristian Grasu
Secretary of State, Ministry of Health, Romania
Prof. Dr. Ildikó Horváth
Minister of State for Health
Ministry of Human Capacities, Hungary

Dr. Chieko Ikeda, Senior Assistant Minister for Global Health, Minister’s Secretariat, Ministry of Health, Labour and Welfare of Japan
Martin Seychell, Deputy Director-General DG SANTE, European Commission
Yann Le Cam, Founder and Chief Executive Officer of EURORDIS – Rare Diseases Europe

Closing Remarks: Dr. Soumya Swaminathan - Chief Scientist, WHO
Moderator: Durhane Wong-Rieger - Chair of Rare Diseases International and CEO of Canadian Organization for Rare Disorders

Sandwiches will be served prior to the event.
Formal Side Event: First time RD at WHA

Tweet by Soumya Swaminathan:
Rare diseases need more collaborative action and research. Digital tools can help families connect, provide information, assist doctors in diagnosis and create a global database. @eurordis @RareDiseases @WHO @EU_Commission

Tweet by ngorarediseases:
Encouraging words from @doctorsoumya Chief Scientist at @WHO about the relevance of current debates on knowledge and data sharing for rare diseases #WHAM2017#RareDiseases
Inclusion of Rare Diseases in the UN Political Declaration on UHC

Toolkit for National Alliances to advocate to Ministries of Health and Foreign Affairs; and to Permanent Missions to the United Nations

13 National alliances participated!
Argentina, Austria, China, Colombia, Germany, Greece, India, Luxembourg, Malaysia, New Zealand, Romania, Serbia, Spain.
UN Political Declaration on UHC adopted at High-Level Meeting on UHC during UNGA 74th Session (23 September 2019)
Adopted by 193 Member States and endorsed by all Heads of State
First time rare diseases included in a text adopted by UN General Assembly

Page 4: We therefore commit to scale up our efforts and further implement the following actions:

24. Accelerate efforts towards the achievement of universal health coverage by 2030 to ensure healthy lives and promote well-being for all throughout the life course, and in this regard reemphasize our resolve to:
   a. progressively cover one billion additional people by 2030 with quality essential health services and quality, safe, effective, affordable and essential medicines, vaccines, diagnostics and health technologies, with a view to cover all people by 2030;
   b. stop the rise and reverse the trend of catastrophic out-of-pocket health expenditure by providing measures to assure financial risk protection and eliminate impoverishment due to health-related expenses by 2030, with special emphasis on the poor as well as those who are vulnerable or in vulnerable situations;

34. Also strengthen efforts to address eye health conditions and oral health, as well as rare diseases and neglected tropical diseases, as part of universal health coverage;
MEMORANDUM OF UNDERTAKING

BETWEEN

THE WORLD HEALTH ORGANIZATION

AND

RARE DISEASES INTERNATIONAL

Introduction

WHEREAS WHO, having its headquarters in Geneva, Switzerland, is the directing and coordinating authority for health within the United Nations system. It is responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries, and monitoring and assessing health trends.

WHEREAS RDI is an international non-governmental organization, based in Paris, France, bringing together national and regional rare disease patient alliances from around the world as well as international rare disease-specific institutions to be the global alliance of rare disease patients and families of all nationalities across all rare diseases. RDI’s mission is to be a strong common voice on behalf of the 300 million people living with a rare disease around the world. RDI advocates for rare diseases as an international public health priority and represents the interest of people living with a rare disease worldwide.

WHEREAS RDI and WHO (hereinafter each referred to as a “Party”, and together, the “Parties”) wish to enter into this Memorandum of Understanding to set forth the terms of which they agree to collaborate on activities relating to improve the health and well-being of people living with rare disease worldwide:

Now, therefore, the Parties decide as follows:

Article 1

Objectives and Areas of Cooperation

1. Pursuant to the WHO General Programme of Work 2019-2021 (GPW11), and its strategic priorities to promote healthier populations and so serve the most vulnerable, the objectives of this Memorandum of Understanding is to assist in addressing public health issues related to rare diseases, to ensure that in the global move to achieve Universal Health Coverage, no one is left behind, in line with the ambitions to:

a. Increase awareness of rare diseases and their visibility in healthcare systems;

b. Strengthen healthcare systems, including improving access to accurate diagnoses, prevention of co-morbidities, and provision of multidisciplinary healthcare care;

c. Improve access to affordable and quality treatments and care; and

d. Encourage Member States to adopt strategies to address rare diseases challenges at
Collaborations
RDI-IFPMA Round Table on Access

First Round Table on Access to rare disease therapies in LMICs to explore barriers to access, discuss opportunities to overcome these challenges and identify what factors have helped to address them

- Co-organised with the International Federation of Pharmaceutical Manufacturers & Associations (IFPMA)
- International Union for Cancer Control, Geneva, December 4, 2019
- 15 patient representatives
- 14 company representatives from the biopharmaceutical industry

Patient advocates from Mexico, Guatemala, Uganda, Malaysia, US, UK, France, Cyprus and Portugal from disease areas including: haemophilia, SMA, thalassemia, rare cancers, Gaucher and other lysosomal storage disorders, described the expanded programmes that exist for their diseases at international level and more specifically about how they are carried out in their countries and the obstacles they encounter on the ground.
NGO Committee for Rare Diseases

Promotes rare diseases as a priority in global health, research, and social and medical care as part of the UN 2030 Agenda: the Sustainable Development Goals (SDGs)

RDI is a member and has a seat on the executive board

RDI contributed to UN submissions and statements on:
- The right to health and SDGs
- The right of people living with disability

RDI co-organised NGO Committee 2\textsuperscript{nd} high level meeting in February 2019

RDI 5\textsuperscript{th} Membership Meeting organised back to back in New York
Global Commission

- **High-level expert panel** led by Takeda, Microsoft and EURORDIS

- **Purpose** is to **build road map to improve diagnostic pathways for children with rare diseases**

- **Four RDI Members in the Commission:** Yann Le Cam (EURORDIS), Durhane Wong-Rieger (CORD Canada), Kevin Huang (CORD China), Pamela Gavin (NORD)

- **Involve RDI members through consultations on recommendations**

- **RDI participated in the launch and promotion of the recommendations and pilots in February 2019**
International Rare Disease Research Consortium

Unites national and international governmental and non-profit funding bodies, companies, umbrella patient advocacy organizations, and scientific researchers to promote international collaboration and advance rare diseases research worldwide

RDI in IRDiRC’s Consortium Assembly and Patient Advocates Constituency Committee (PACC).

13 of the 15 members organisations on the Patient Advocates Constituent Committee are RDI members

Ritu Jain represented RDI
- IRDiRC Meeting, Leiden, Netherlands, May 22-23
- IRDiRC Meeting, Paris, France, November 21-22
In 2019 RDI and its members participated in:

• APEC Rare Disease Policy Dialogue focused on Latin America, Santiago, Chile, July 10-11

• APEC Workshop ‘Using APEC Rare Disease Framework to develop National and Local Action’, Taipei, Taiwan, October 21

back to back to APARDO Summit and Taiwan Foundation for Rare Disorders 20th Anniversary celebrations.
# 2019 Financial report
## VS 2019 budget
### (Profit and Loss including in kind contributions)

<table>
<thead>
<tr>
<th>Revenue</th>
<th>Budget</th>
<th>Actual</th>
<th>Ratio</th>
<th>Δ in euros</th>
<th>Δ in %</th>
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<td>227 876</td>
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<td>2 126</td>
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<td>40 105</td>
<td>39%</td>
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<td>Volunteers</td>
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<td>24%</td>
<td>40 105</td>
<td>39%</td>
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<td>34%</td>
<td>-65 000</td>
<td>-25%</td>
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<td>Pharma. and Biotech Companies</td>
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<td>200 000</td>
<td>34%</td>
<td>-65 000</td>
<td>-25%</td>
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<td>Other Health Sector Corporates</td>
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<td>200 000</td>
<td>34%</td>
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<td>-25%</td>
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<td>Other for Profit Organisations</td>
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<td>15 000</td>
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<td>Outside Health Sector NPOs</td>
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<td>Event Fees</td>
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<td>Others</td>
<td>94 750</td>
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<td>-20%</td>
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<td>Sub-total</td>
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<td>Recovery of provisions</td>
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<td>Report of non-used income</td>
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<td>Total Revenue</td>
<td>593 840</td>
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<table>
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<th>Expenses</th>
<th>Budget</th>
<th>Actual</th>
<th>Ratio</th>
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<td>Wages and charges</td>
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<td>Other salaries</td>
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<td>Training and other costs</td>
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<td>Volunteers</td>
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<td>143 195</td>
<td>24%</td>
<td>40 105</td>
<td>39%</td>
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<td>Representatives and task forces</td>
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<td>Projects, office and translators</td>
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<td>Communications, Publications</td>
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<td>17%</td>
<td>-20 663</td>
<td>-21%</td>
</tr>
<tr>
<td>Financial expenses, Insurance, Tax</td>
<td>3 350</td>
<td>2 171</td>
<td>1%</td>
<td>-1 179</td>
<td>-35%</td>
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<tr>
<td>In kind overheads</td>
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<td>75 267</td>
<td>1%</td>
<td>-19 483</td>
<td>-20%</td>
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<td>Exceptional expenses</td>
<td>500</td>
<td>116</td>
<td>0%</td>
<td>-384</td>
<td>-77%</td>
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<tr>
<td>Sub-total</td>
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<td>568 144</td>
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<td>Contingency and loss provisions</td>
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<td>Commitment on assigned income</td>
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<td>Total Expenses</td>
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<td>568 144</td>
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<tr>
<td>Result</td>
<td>17 927</td>
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</table>
Breakdown of RDI's revenues - 2019

- 34% Patient Organisations and Volunteers
- 3% Health Corporations
- 63% Health NPOs
Thank you!