



RARE
DISEASES
INTERNATIONAL

ACTION PLAN 2019

1. STRENGTHEN RDI AS A WELL-GOVERNED AND SUSTAINABLE ORGANISATION

Governance

Legal incorporation in France, as Association Loi 1901, as an NGO, official publication based on Statutes

Council to adjust and adapt By-Laws

Council to meet via teleconference every other month

Officers to meet via teleconference every other month

Two Face-to-Face Meetings of Council

Online Council Elections: 7 members renewed by third every year

Policy of Relations with Commercial Companies

Annual General Assembly 20 Feb 2019:

- Adoption Annual Activity & Financial Report 2018
- Adoption Work Programme: Action Plan & Budget 2019

RDI Open Meeting (open to non-members and other stakeholders to attract new members and develop synergies with other actors in the RD ecosystem)

Secretariat

1 FTE Director Paloma Tejada, based in Geneva

1 FTE Manager (to be recruited 1S2019)

1 Part-time Public Affairs Manager, Clara Hervas, based in Brussels office

1 Part-time Consultant Corporate Relations Advisor, Jill Bonjean, based in Paris

RDI offices established in Brussels on 11 rue D'Egmont Brussels 1050 (in-kind EURORDIS, addendum MoU) and in New York on 521 5th Avenue New York NY 10175 (in-kind corporate VOZ)

Communications

- Website updates
- Communication material



Pending recruitment of Programme Manager :

- New visual identity
- New Brochure
- New PPT Presentation Template
- New Kakemonos
- Active Social Media on Twitter and Instagram

Financial sustainability: EURORDIS

EURORDIS Support: MoU signed for 5 years (2019-2023)

EURORDIS will continue to provide professional services:

- a) employ 1 FTE staff (RDI Director)
- b) provide 0.5 FTE public affairs staff for advocacy dedicated to RDI and related international activities
- c) provide financial & administrative services for management of accounts
- d) provide hosting, maintenance and update of website
- e) Provide official Office in Brussels

Financial Sustainability: Resource Development

RDI secures revenue to:

- cover its own external expenses
- hire the Programme Manager (1 FT)
- hire the Consultant in Resource Development (90 days)

RDI to raise unrestricted funds by setting up a Corporate Group: RDI Alliance of Companies for Patient-Centred Action

RDI to raise restricted targeted funds for Specific Programmes: Conferences, Fellowships

In-kind corporate contributions

Set up the “Alliance of Companies for Patient-centred Action”

- Made of commercial companies
- Includes different industry sectors from the beginning: pharma, biotech, diagnostic, devices, digital, CRO, distribution, PR & Law firms, other



- Membership Fees: 20 000 EUR /year, looking for a long term commitment
- Provides unrestricted resources for core activities
- Commitments : a) invited to the Annual RDI Open Meeting, b) invited to RDI Policy events, c) invited to all Level-3 RDI Conferences; d) invited to attend 2 dedicated Webinars per year
- Code of Conduct to be signed by all members
- Policy on Relations with Commercial Companies

2. BUILDING A LEGITIMATE RARE DISEASE PATIENT GLOBAL ALLIANCE

Membership

- 56 Members as end 2018: 33 National Alliance and 14 International Federations and 4 Regional Networks
- Expand membership base > +10, toward 70 members as end 2019
- Actively recruit more International Federations
 - PHA International, Tuberous Sclerosis, CF Worldwide, Duchenne World, Dravet Foundation, Rett Syndrome International, FOP, IPWSO, OIFE
 - Target US based international federations at NY events
- Recruit National Alliances in following countries:
 - Peru, Brazil, Chile, Philippines, Turkey, Algeria
 - Maintain informal relations with TFRD, KORD
 - Bring in regional networks: APARDO, Africa-Rare.org
- Call for Membership Fees

Strategic Partnerships

- NGO Committee for Rare Diseases – Executive Board
- International Rare Diseases Research Consortium (IRDiRC) - Patient Advocates Constituency Committee (PACC)
- Orphanet – Global figures on RDs+ ICD-11 and OrphaCode + promote Orphanet in new languages eg Arabic, Persian



- ▶ International Federation of Pharmaceutical Manufacturers & Associations (IFPMA) Working Group on RD
- ▶ Asia Pacific Economic Cooperation (APEC) LSIF Rare Disease Network – patient input in APEC Rare Disease Action Plan – 21 countries
- ▶ Global Commission on Ending the Odyssey for the Diagnosis of Children with Rare Diseases – patient input in the recommendations and support in promotion of recommendations and implementation of 2 out of 4 pilot projects

3.ADOULATE FOR RARE DISEASES TO BE AN INTERNATIONAL PUBLIC HEALTH PRIORITY & RAISE AWARENESS

Building up our capacities in Advocacy actions

Reach out to a critical mass of countries Permanent Missions (20) in Geneva and New York, select future country champions in each region of the G77 in close collaboration with RDI Member National Alliances

Establish an informal network “Friends of Rare Diseases” in Geneva and New York; organise briefings, breakfast meetings and small awareness or education conferences

Invite TIF and FADEPOF to join the RDI Advocacy Committee

Ad hoc Drafting Groups on UHC and UN Resolution

Add part time Staff : Clara Hervas, International Public Affairs, EURORDIS

Promoting RDs as a priority within UN Sustainable Development 2030 Agenda and towards a UN Resolution on RDs

Co-organise with NGO Committee for Rare Diseases’ Second High Level Policy Event in New York on February 21st

Develop a first draft of UN Resolution on RDs with Ad Hoc Drafting Group, Advocacy Committee, Permanent Missions from 3 to 5 countries, consult UN experts

Possible High Level Conference of Perm Reps from G77+ China on RDs – sponsored and organised by one Member State (tbc)

Placing RDs in the Universal Health Coverage Agenda

- RDI Contribution to UN Political Declaration on UHC
- WHO 72nd World Health Assembly Informal Side Event on RD & UHC (May)



- Outreach and briefings to co-facilitator countries (Hungary and Thailand) and to drafting countries (France, Japan) and champion countries (EU Delegation, Philippines, Kuwait)
- High Level Meeting on UN Political Declaration on UHC in New York & UN Plenary General Assembly (Sept)
- Possible side meetings with Perm Reps, small briefing meetings before the HLM
- RDI Members to advocate to their MoH and MoFA and Perm Reps to attend the WHO WHA Side event in May and support inclusion of RDs in the Declaration

Establishing WHO-RDI Collaborative Framework

Draft and sign Memorandum of Understanding WHO-RDI Collaborative Framework 2019- 2021 on 5 ambitions

WHO 72nd WHA informal side event and secure MS and NSA support

Mobilise Perm Reps in Geneva with "Friends of RDs", small meetings, breakfast briefings

Explore the feasibility of a "light Resolution" on RDs at WHO Executive Board of January 2020

Towards an evidence-based Advocacy

Advocacy Fact Sheet on rare disease global figures

Advocacy Fact Sheets on surveys on social impact of rare diseases

Explore partnership to perform the International State of the Art of RDs in a standard, progressive and sustainable way

4. ADVOCATE FOR PEOPLE LIVING WITH RARE DISEASES IN KEY AREAS

Engagement in Research: IRDiRC and ReACT

- RDI is a member of the International Rare Disease Research Consortium (IRDiRC) represented by Ritu Jain
- Take part in IRDiRC's Consortium Assembly
- Contribute to IRDiRC's goals and mission
- Promote membership amongst new countries
- RDI supports all patient representatives members of RDI in IRDiRC PACC (11 out of 13)
- Contribute to PACC's policy work and contribute to design and dissemination to RDI members of survey on patient engagement in research
- Partner with ReACT Conference, Toronto, Canada (May 5 -8)



Access to Diagnosis: Global Commission to end the diagnosis Odyssey of Children with a Rare Disease

The Global Commission initiated and co-chaired by EURORDIS, Microsoft and Shire. Members of the Global Commission include patient reps from RDI members: CORD Canada, NORD, CORD China and EURORDIS.

Support and involve all RDI members in Launch events on 20 February at Microsoft Global Headquarters, simultaneous 2nd launch in Brussels at Friends of Europe and 3rd launch event in Beijing on Feb 28 by CORD China

RDI will take part in 2 out of 4 pilots

Use the Recommendations as basis to develop RDI position on diagnosis

Bring the recommendations from Global Commission experts into Collaborative Framework with WHO

Access to Medicines: World Health Organization (WHO) and the International Federation of Pharmaceutical Manufacturers Associations (IFPMA)

Propose a Collaborative Framework with WHO that includes actions to improve access to medicines in LMIC

Mobilise political support of Member States through Perm Reps in Geneva to include access to medicines for rare diseases in WHO Fair Pricing agenda

Organise a Roundtable on barriers to Expanded Access Programmes in Lower and Middle Income Countries with IFPMA Rare Disease Working Group in Geneva

5. BUILD CAPACITIES OF MEMBERS & PATIENT ADVOCATES

RDI 5th Annual Meeting, Feb 20, New York

- Annual General Assembly (Members only)
- RDI Global Meeting (open to non-members, partners and stakeholders)
 - *Placing RDs in Sustainable Development 2030 Agenda – leave no one behind – Rare Disease Day at the United Nations, New York 2nd High level event of NGO Committee for Rare Diseases*
 - *Towards a UN Resolution for Rare Diseases*
 - *UN Political Declaration on Universal Health Coverage*
 - *Human Rights & Disability*



- *Regional mobilisation*
 - Asia Pacific Alliance of Rare Disease Organizations (APARDO)
 - Rare Disease African Alliance (Africa-Rare.org)
 - Iberoamerican Rare Disease Alliance (ALIBER)

RDI Conference Programme

Level 3 - "Conference co-organised with RDI"

- Level 1 support + RDI in Programme Committee; RDI covers RDI speakers, Fellowships
- Content aligned with RDI's overall strategy + advocacy topics

Ex. Canadian Organization for Rare Disorders / ReACT Conference, Toronto, May 8-11, 2019

Level 2 - "Conference in Partnership with RDI"

- Level 1 support + RDI in Programme Committee; RDI sometimes covers some RDI speakers, No Fellowships
- RDI objective: to build capacities on specific topics of need (national plans, registries, etc.)

Ex. ECRD, NORD Summit, WODC, IRDiRC, ISPOR, APARDO, ALIBER

Level 1 - "Conference supported by RDI"

- RDI logo, communication and promotion, link in RDI website

Ex. Conferences organised by Member National Alliances or International Federations

RDI Fellowship Programme

Objectives:

- To build capacities of patient advocates and organisations
- To support networking, exchange of experience, dissemination of patient advocacy knowledge and best practices
- To identify and train leader patient advocates
- To enable RDI members and other patient advocates who cannot afford to take part into RDI events
- Available for:
 - ✓ Annual RDI Membership Meeting NY Feb 20



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- ✓ NGO CfRD High Level Policy Event at UN NY Feb 21
- ✓ all RDI Level 3 Conferences
- ✓ WHO WHA side event
- ✓ Training seminars

RDI Experts Faculty

- ✓ Individuals acting in their own capacity
- ✓ Leaders from different horizons: patient advocates, academics, reps of learned societies, reps of industry, experts by themselves (retired or active)
- ✓ Appointed by RDI Council
- ✓ Fixed 3-year terms
- ✓ Signed Declaration of Conflict of Interest

To provide RDI with a pool of quality speakers for all conferences, workshops, meetings, to serve as speakers customized to local or regional event specific needs

Expert resource to RDI Advocacy Committee and members at large, for specific activities

Cultivate committed individuals to link back to their organisations and foster international collaborations and partnerships and multi-stakeholder engagement

To produce scientific or opinion papers for publication

RDI Peer to Peer Exchange & Networking Virtual Platform

Pending recruitment of Programme Manager:

- Create an RDI community, as a virtual forum for members eg. Facebook Workplace
- Create a profile of basic information about each member and its activities of potential interest to other members
- Organise one Webinar each month to present one member, or two members on same topic and discuss their activities and interests in common

Advocacy & Educational training tool kits

- Generate Advocacy training tool kits to support patient advocates on international and national policy-making
- Generate Educational Tool kit on complex research topic