



RARE
DISEASES
INTERNATIONAL

DRAFT
**STRATEGIC APPROACH &
ACTION PLAN 2016- 2018**

For consultation at RDI Annual Meeting
Edinburgh, Scotland
May 25, 2016

STRATEGIC PRIORITIES

1. Build a legitimate Global RD Patient Alliance to be the Voice of PLWRD around the world

2. Strengthen RDI as a well-governed and sustainable organisation

3. Advocate for RDs to be an International Public Health Priority and Raise Awareness of RDs worldwide

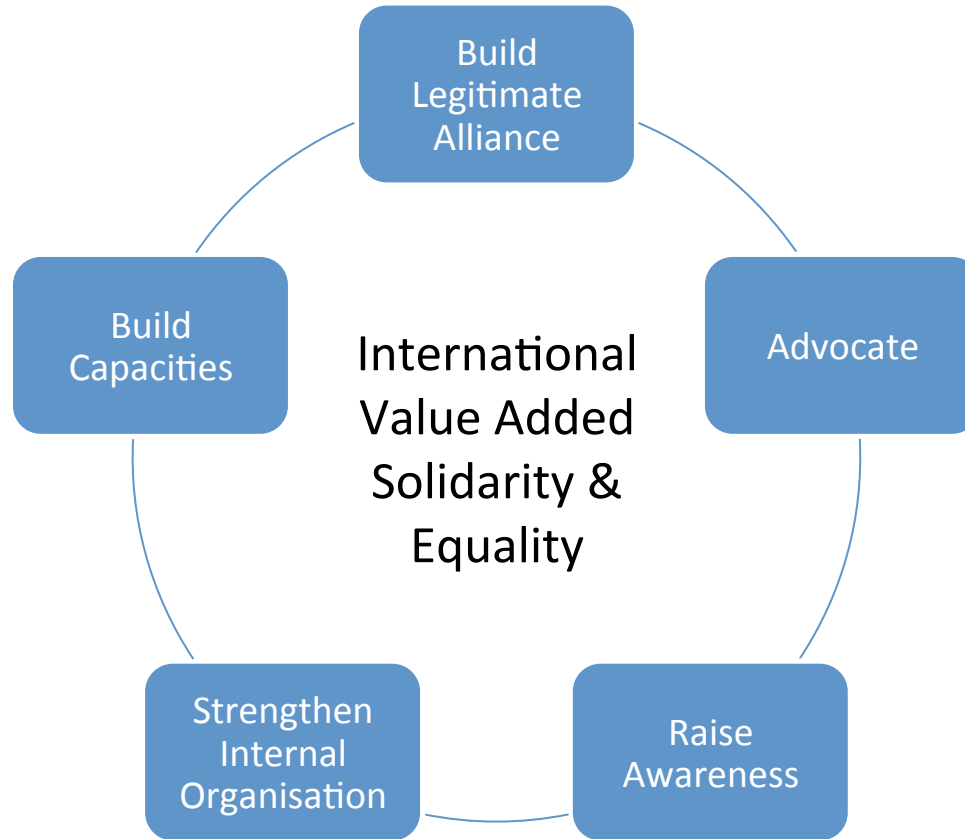
4. Advocate in favour of PLWRD worldwide in key areas

5. Build Capacities of Members and Patient Advocates



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STRATEGIC APPROACH



1. BUILDING A LEGITIMATE GLOBAL ALLIANCE

- Expand Membership base
- Engage existing and new members
- Engage with other stakeholders/ partners
- Communication and Outreach of RDI
- Create spaces for community to interact



ACTION PLAN X 3 YEARS

BUILD A LEGITIMATE ALLIANCE

- Recruit more members (35 at present /target 70 total - May 2018)
- Target solid and experienced International Federations and National Alliances
- Give visibility to and engage with members of members
- Delegate outreach work
- Attend conferences in places where there is little RD patient mobilisation



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ACTION PLAN X 3 YEARS

BUILD A LEGITIMATE ALLIANCE

- Create Online Int'l Patient Advocates Community using *RareConnect*
- Organise Webinars for members and potential members
- Send out news mailings to members
- Organise RDI Annual Meeting and RDI satellite meetings
- Improve and produce more Communication tools



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2. STRENGTHEN RDI AS AN ORGANISATION

- Refine membership and partnership criteria
- Set up a solid internal governance structure
- Adopt viable internal rules and a transparent decision-making process
- Achieve sustainable and diversified funding
- Evaluate impact



ACTION PLAN X 3 YEARS

STRENGTHEN ORGANISATION

- In 3-5 years re evaluate the legal status of RDI
- Develop By-Laws to be adopted by the Council
- Define internal rules and decision-making process (to be captured in By-Laws) → adoption of positions and set up of Working Groups
- Draft Terms of Reference for Working Groups
- Refine Membership eligibility criteria, partnerships and other forms of engagement
- Produce an Annual Work Plan, Activities & Financial Reports



ADOPTION OF POSITIONS

- RDI Position Statements adopted by all
- RDI Positions adopted with diverging views
- RDI Positions adopted by sub groups
- Co-Sign/Endorse existing Position Statements in order to give patient input or an international scope
- Give visibility to members political positions/ petitions
- Adopt joint statements with international professional alliances or learned societies



3. ADVOCATE FOR RD TO BE AN INT'L PUBLIC HEALTH PRIORITY & RAISE AWARENESS

- Move towards branding 'World' Rare Disease Day
- Promotion of the *Joint Declaration "Rare Diseases: an International Public Health Priority"*
- Draw RD landscape/ Collect data from patients on the ground
 - International State of the Art of Rare Diseases
- Carve out RD space in Universal Health Coverage via Health Technology Assessment
- Put RDs in Global Health Agenda – *Sustainable Development Goals*
 - UN Committee for Rare Diseases
 - World Health Organization



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UNITED NATIONS COMMITTEE FOR RARE DISEASES

- RDI to represent patients in UN Committee for Rare Diseases and be the engine behind it
- Apply for ECOSOC Consultative Status
- Recruit members from research, industry, academia, scientific and learned societies, other NGOs, government agencies and Member State Reps



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WORLD HEALTH ORGANISATION

- ▶ Engage with WHO using Regional, technical and topic approach
 - Attend yearly WHO Executive Committee in January and World Health Assembly in May as part of IAPO delegation
 - Organise meeting with IFPMA to meet WHO officials
 - Partner with Orphanet to use ICD 11 RD Task Force as springboard to raise visibility of RD at WHO
 - Give visibility to RDs at Human Rights Convention and Disability Convention meetings in Geneva
 - Organise an RD side event to WHA



3. ADVOCATE FOR RD TO BE AN INT'L PUBLIC HEALTH PRIORITY & RAISE AWARENESS

- Adopt new or existing Positions
- Create Work Groups to reflect on specific topics
- Promote the concept of National Plans and Policies for RDs in LMICs
 - Share lessons from existing RD policies and strategies
 - International Conference on NPRDs to be hosted by French Alliance at the time of the adoption of the French 3rd NPRD (end 2017)



3. ADVOCATE FOR RD TO BE AN INT'L PUBLIC HEALTH PRIORITY & RAISE AWARENESS

- Obtain official recognition of 'World' Rare Disease Day
- Organise International Policy event in Geneva/ NY for RDD 2018
- PSA in relevant events to explain RD as an international public health priority
- Participate in other relevant awareness campaigns (Patient Solidarity Day, Disability Day)



4. ADVOCATE FOR PLWRD WORLDWIDE IN KEY AREAS - ACCESS

- Ensure Access includes LMIC
- Promote National Pricing & Reimbursement policies for all RDs
- Promote better OD Legislation and Regulatory Framework
- Promote Patient Access Schemes across the globe
- Facilitate patient – industry dialogue in emerging markets
- Stress Prevention and Rehabilitation over Treatments in LDCs



ACTION PLAN X 3 YEARS

ACCESS

- Create RDI WG on Access
- Submit Contribution to UNSG high-level panel on access to medicines
- Work with IFPMA RD WG to
 - Facilitate dialogue between NA and Industry associations in +5 countries emerging to RDs
 - Promote better OD Legislation and Regulatory Framework
 - Promote Patient Access Schemes



4. ADVOCATE FOR PLWRD IN KEY AREAS - RESEARCH

- Advocate and Raise Awareness about the need to coordinate and increase support for RD Research internationally
- Leverage global funding through IRDiRC
- Promote more patient involvement and a broader representation of patient groups in research
- Adopt common positions linked to research eg Joint Declaration – expand item -; Petition RarEvolution; Patient engagement in research; patient registration and data collection; etc
- Build alliances with the scientific community



ACTION PLAN X 3 YEARS

RESEARCH

- Map out POs that are funding research and/or managing their own registries and natural history studies from RDI membership and beyond
- Create an RDI WG on Research
- Involve RDI representatives into IRDiRC
- WG on Research to reflect on Research part of State of the Art, Position, Contribute to RarEvolution Project
- Invite IRDiRC to be part of UN Committee for Rare Diseases
- Organise a patient track at the next IRDiRC Conference. Fellowships for umbrella POs to attend IRDiRC



5. BUILD CAPACITIES OF MEMBERS & PATIENT ADVOCATES

- Facilitate networking and information exchange between members and other interested patient groups
- Foster the emergency of common advocacy positions
- Build Capacities at National and Regional level



ACTION PLAN X 3 YEARS

BUILD CAPACITIES

Sharing Profiles & Best Practice

- Profiles of Member Organisation and Patient Representatives
- Identify and showcase programs / best practice
- Organise programs/best practice into Thematic Clusters
- Organise monthly Webinars

Knowledge Exchange & Training

- Open access to existing training seminars (ie Summer School)
- Supporting new training initiatives
- Fellowships to attend Annual Conference, Regional Meetings & other relevant meetings

Supporting the creation of new umbrella organisations

- Facilitate contacts between members
- Twinning / Mentoring Program



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