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Rare Diseases International

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EURORDIS Membership Meeting 2015 Madrid

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What is RDI?

The Global Alliance of People Living with Rare Diseases of all Nationalities across all Rare Diseases

It is an informal network that will eventually be registered and have a legal identity – a later decision by its members. Initial focus is on taking action and gaining experience of working together.

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Mission Statement

To be a strong common voice on behalf of people living with rare diseases around the world

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Vision

- RDI is patient-centric, patient-driven, patient-led
- RDI recognises patients with Rare Diseases are all linked and most are genetically related
- As the voice of all people living with rare diseases around the world today RDI will work to give visibility to rare diseases in the global health agenda
- As a result of RDI, people living with a rare disease worldwide and their families will experience increased public health services and support

General Objectives

- To promote rare diseases as an international public health and research priority through public awareness and policy-making
- To represent members and people living with rare diseases at large, in international institutions and forums
- To enhance the capacities of members through information, exchange, networking, mutual support and potentially joint actions

Why is RDI needed?

- To **unite, expand and reinforce the RD movement** of patient organisations and patient advocates
- To enable the **emergence of RD as a public health & research priority internationally**
- To enable the rare disease **patient groups to act at local, national, regional, international levels** and to interact with other RD areas
- Most international initiatives are ad hoc and linked to a particular diseases. RDI is an opportunity to work globally and to **create a global RD community through advocacy** and exchange of experience.
- To **influence the debate in international organisations** (UN, WHO, OECD)

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RDI: Global Inspiration for All

- RDI provides international platform for rare diseases along with more common ones
- RDI can serve as a portal for RD patients and families, regardless of where they live, to a global community with resources and support
- RDI provides opportunity for RD patients in countries and regions where RD not yet meaningfully recognised to feel empowered and connected

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RDI: Benefits for ex-Europe POs & NAs

- RDI presents opportunity for POs to leverage international voice to raise awareness, support, and action in their countries
- RDI provides opportunity for NAs to collaborate on regional issues and insure RDs included in health and economic polices, e.g., UHC
- RDI can highlight RD challenges endemic to LMIC's and encourage international attention to address them

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RD activities that are already international

- *Rare Disease Day* + 80 countries in 2015
- *RareConnect* Online Platform + 60 communities
- International Rare Diseases Research Consortium (IRDiRC)
- The European Conference on Rare Diseases & Orphan Products (ECRD)
- NORD's Rare Diseases and Orphan Products Breakthrough Summit
- International Conferences for Rare Diseases and Orphan Drugs (ICORD)
- Orphanet (present in 10 countries outside Europe)
- Pharma & Biotech companies (RD units organised at the global level)

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Background

- In March 2012, the EURORDIS Board of Directors adopted the orientation to create an informal network to expand the movement of rare diseases internationally, provide mutual support between patient organisations and be able to speak with one voice.
- RDI was also a clear expectation at ICORD Tokyo 2012, where participants shared a strong sense that it was time to take action at the international level.
- Survey carried out in Sept 2013 to evaluate level of interest

RDI Survey

64 respondents from 37 countries around the world were overwhelmingly in favour of the creation of a global rare disease patient alliance with 98% replying that they would be interested in joining.

Governance

The preliminary phase of the initiative has been steered by a Pre-Formation Group composed of EURORDIS and national rare disease alliances from the US (NORD), Canada (CORD), Japan (JPA), China (CORD), India (I-ORD), the Ibero-American pan-regional alliance (ALIBER) and the International Federation for Epidermolysis Bullosa (DEBRA International).

Governance

- Pre Formation Group is acting as interim Council of RDI until elections are organised
- Validated founding documents
  - Vision & Mission Statement
  - General Objectives & Action Plan
  - Membership Criteria & Common Goals
  - 10 Recommendations of the Joint Declaration
- PFG reviewed & approved Membership Applications received so far

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Who can be a member?

- Umbrella organisations representing several rare diseases in one country
- Umbrella organisations representing the same disease or family of diseases in several countries
- Umbrella organisations representing national alliances or other patient groups in several countries across a geographical region

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Membership Criteria

- Rare disease organisation, according to EU prevalence criteria (5 / 10 000)
- The Governing Boards should be usually made up of a majority of rare disease patients or family of patients.
- Financial transparency and diversified funding showing independence and minimisation of risk of conflict of interest
- Non-profit status
- Proven activities such as patient support and/or advocacy activities and/or research

Waivers possible

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Associate Membership

- Patient organisations or any other entity contributing to the objectives of RDI by their mission and work.
- Associate members cannot be elected to or vote at the Council of RDI
- To apply, go to:

http://www.eurordis.org/content/rare-diseases-international#membershipapp

Members so far

20 full members:

Argentina, Australia, Brazil, Canada, China, DEBRA International, EURORDIS, France, Hong Kong, IberoAmerican RD Alliance, India, IPOPI, Japan, Malaysia, Mexico, New Zealand, Retina International, Russia, Spain, USA

…Just received another application from the Arabic Organization of Rare Diseases!

What will RDI do?

Advocacy

- Development and adoption of a **Joint Declaration "Rare Diseases: an International Public Health Challenge"**
- Introduce *Rare Diseases International* to **UN's ECOSOC, WHO, OECD**
- Partnership and coordinated liaison with the **International Association of Patient Organisations (IAPO)** for conferences, policy and WHO liaison
- Potential **surveys** to members

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Action Plan

Information

- Creation of a ***Rare Diseases International* website** + listing of members
  - The domain name rarediseasesinternational.org is currently owned by EURORDIS and the website is under development
- Promotional Brochure
- Distinctive Visual Identity

Awareness

- Promotion of Rare Disease awareness worldwide through active participation in and the promotion and expansion of

  Rare Disease Day

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Action Plan

Networking

- RareConnect Online Discussion Group /mailing list
- Annual RDI Conference
- Organisation of regular ***RDI* Meetings**, back to back with existing conferences
- Encourage and facilitate **regional networking** e.g. IberoAmerican Alliance; Asia Pacific Alliance and others
- Possible development of a **Short-Term Exchange & Internship Capacity Building Programme** between member organisations

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Action Plan

Research

- Coordination with and encourage participation in the **International Rare Diseases Research Consortium (IRDiRC)** in order to broaden patient representation worldwide

Partnerships

Join forces with other relevant stakeholders

Seek common ground

Coordinate efforts

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Gaining recognition at the UN level

- UN Committee on Rare Diseases (through the Conference of NGOs with Consultative Status to the United Nations' Economic and Social Council ECOSOC)
- Starting discussions with IAPO, IFPMA and others who have experience reaching out to WHO
- Put rare diseases on the WHO Agenda
- Rare Disease Day recognised by the WHO
- A Report on RD presented to the WHO WHA
- Why not …a UN Resolution on Rare Diseases!

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Building bridges with other stakeholders: shaping RD eco-system

- International Alliance of Patients' Organizations (IAPO)
- International Conference on Rare Diseases & Orphan Drugs (ICORD)
- International Federation of Pharmaceutical Manufacturers & Associations (IFPMA)
- International Rare Diseases Research Consortium (IRDiRC)
- International Society of Human Genetics (ISHG)
- Orphanet International

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What are we doing here today?

- Marking the launch of the Global Alliance
- Showing support. Your presence (+ 60 organisations) is a good sign
- Agreeing on common principles
  - Adopting the Joint Declaration
- Calling to join the initiative
  - Applying for full or associate membership
- Start the process to elect the Council of RDI
  - Call for expressions of interest
- Elections to be held at the next RDI Annual Meeting

Opportunities to meet again

- ALIBER 3rd Congress in Guadalajara,

Mexico in June 2015

- ICORD Mexico City in October 2015
- NORD CBI in Washington DC in October 2015
- ECRD in Edinburgh in May 2016
- World Orphan Drug Congress in Geneva, Washington DC and Singapore every year
- Next IRDiRC Conference