



Rare Diseases International CNA Meeting - 14 October 2014



What is Rare Diseases International?

In its first phase,
RDI will be an informal network of
rare disease patient organisations
interested in building
the global alliance representing patients & families
of all nationalities
across all rare diseases.

What is Rare Diseases International?

- Brings together:
 - 1) National and regional patient alliances or lead organisations from around the world and
 - 2) International disease-specific federations or networks (no disease specific national group)
- Aims at:
 - 1) Being the global voice of PLWRD
 - 2) Promoting rare diseases as an international public health priority
 - 3) Building exchange of information & networking & capacities of its members
- Rare Diseases International is a EURORDIS Initiative

Mission Statement

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

Why RDI?

- To **unite, expand and reinforce** the RD movement of POs and patient advocates
- To enable the local RDs **patient groups to act at local, national, regional, global levels**
- To enable the **emergence of RD as a PH & research priority internationally**
- To enable the emergence of a strong **common voice on behalf of the +280 million PLWRD** around the world
- To **influence international organisations** (UN, WHO, OECD)
- To **create a global RD community through advocacy** and exchange of experience (not ad hoc, permanently).

Why a EURORDIS Initiative?

- To enable the 30 million PLWRD in Europe and EURORDIS to be actors in worldwide processes having an in Europe
- EURORDIS attracts POs outside of Europe and gains traction on promoting RDs at the international level
- 36 POs from outside Europe have joined EURORDIS
- EURORDIS CNA (National Alliances inside Europe) is very supportive of the initiative and National Alliances outside Europe (CORD, NZORD, RVA, JPA...) support the initiative
- EURORDIS CEF (European Federations) is also supportive. Currently International Networks & Federations are not talking to each other. No global dialogue across diseases.

Why a EURORDIS Initiative?

- EURORDIS survey (Nov 2013, 64 respondent, 37 countries) revealed that there is an overwhelming desire for a international RD patient alliance.
- RDI was a clear expectation at ICORD Tokyo 2013
- Strong sense that it is time to take action at the international level. Many countries have expressed their desire for Europe though EURORDIS to take the initiative (Canada, Asia, Latin America)
- As a Pan-European Alliance, EURORDIS has over 15 years experience in working with 48 countries in Europe with difference cultures, health systems and languages

What are the international activities of EURORDIS?

- **RDD:** +80 participating countries in 2014
- **RareConnect:** multilingual platform with 56 global communities, +500 POs from around the world
- **European Conference on Rare Diseases and Orphan Products (ECRD)** in partnership with NORD every 2 years in Europe with over 700 participants from a large number of countries
- **RDI** is a key aim in the **MoU partnerships** signed with **NORD, CORD, JPA** and soon with **RPU & RVA**

In which other international activities is EURORDIS engaged?

- **IRDiRC:** 1 of 3 POs represented at the executive Committee of the International RD Research Consortium
- **ICORD:** International Conference on RD
- **Orphanet:** present in 10 countries outside Europe
- **Pharma & Biotech companies:** RD units increasingly organised at the global level

What would be the role of EURORDIS in initiating RDI?

- RDI started as an initiative of EURORDIS
- → an **independent - legally registered** organisation within 3-5 years.

Before formal organisation, EURORDIS will:

- Bring together global POs for the launch of RDI
- Organise RDI meetings, facilitate creation of & participate in the governing **Council of RDI**
- Provide resources & office support in order to manage the initial RDI Action Plan

General Objectives:

- To enhance capacities of RDI members through information, exchange, networking, mutual support, potentially joint actions
- To represent its members and PLWRD at global level
- To promote RDs as an International Public Health priority through public awareness and policy

Initial Action Plan - 2014

- Start with a "Pre-Formation Period": bringing together key initial partners (founding members) having signed an MoU: NORD, CORD, JPA and ALIBER.
- ConfCalls and F2F meetings:
 - to develop and adopt internal rules (kind of by-laws)
 - to organise the governance and membership
 - to develop a revised action plan
 - to agree on co-funding of the initiative for next 3 years
 - to recruit first strategic members with joint letters
 - to develop a document "RDI Common Goals"
- Align common vision with others: Australia, China, Taiwan, New Zealand, Russia, South Africa

Initial Action Plan 2014

- Start communication on the international section of eurordis.org and on the websites of founding members – coordinated eNews
- Send Joint Declaration before Shenzhen & present it in Shenzhen. Public Consultation of 2 months. Finalisation.
- Organise a touch base meeting with founding members and other patient reps present at IRDIRC conference in Shenzhen
- Agree on RDI visual identity
- Draft joint invitation letter to eligible POs or RDI letter with distinctive visual identity.

Initial Action Plan 2014-15

- Actively recruit members from Dec to April
- Official launch in May, back to back EURORDIS Membership Meeting (Madrid) and CNA: launch of RDI + announcement of Declaration + press release
- Launching of www.rareiseaseinternational.org with list of members
- Launching of RareConnect RDI Discussion Group
- Printing and distribution of RDI brochure

Action Plan 2015-16

Information

- Creation of a **RDI website** with basic information about the initiative and a listing of all member associations including their logo, website and contact person/details (only English for now)
 - The domain name rarediseasesinternational.org is currently owned by EURORDIS and the website is under development by Paloma & Jean-Marc
- Production of a **brochure on RDI**, to also be available for download and printing online
- Distinctive visual identity

Awareness

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

Action Plan 2015-16

Networking

- Initial creation of a **RDI mailing list** to include all contacts in member organisations for an efficient exchange of information
 - This will eventually be moved to RareConnect as a Discussion group
- Possible organisation of regular **RDI Meetings**, back to back with existing conferences such as the IRDiRC conference or ICORD
- Encourage and facilitate **regional networking** e.g. IberoAmerican Alliance; potential Asian-Pacific Alliance; potential African Alliance
- Possible development of a **Short-Term Exchange & Internship Capacity Building Programme** between member organisations

Action Plan 2015-2016

Advocacy

- Development and adoption of a **Joint Declaration “Rare Diseases: an International Public Health Challenge”**
 - Present it at Shenzhen and launch 2-month public consultation
 - Official adoption at EURORDIS Membership Meeting in Madrid 2015
- Potential drafting of **position papers** at the initiative of any member organisation
- Introduce *RDI* 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 **survey** to members

Action Plan 2015-16

Research

- Coordination between *RDI* member organisations with respect to participation in the **International Rare Diseases Research Consortium (IRDiRC)**

Partnership

- Partnership with **Orphanet**
- Coordination between *RDI* member organisations with respect to the participation in **International Conference on Rare Diseases and Orphan Drugs (ICORD)**
- Introduce *Rare Diseases International* to IFPMA, ESHG

Action Plan 2015-16

Governance

- In the 1st year an interim group will be set up. A Steering Committee of the informal network, known as the **Council of RDI** will be composed of:
 - Involved Staff
 - 1 EURORDIS representative
 - 1 NORD representative
 - 1 CORD representative
 - 1 JPA representative
 - 1 National Alliance
 - 1 International Federation
 - 1 rep of regional alliance

Action Plan 2015-2016

Governance

- In year 2 of RDI, an expression of interest can be launched for the purpose of composing a new Steering Committee.
- When RDI becomes a formal entity, a BoD will be elected.
- Within the first months of its existence, the Council of RDI will:
 - Develop internal rules on membership, governance and public affairs
 - Establish a specific budget for direct costs

All members will be expected:

- To adhere to the Mission Statement, sign the 'Mutual Understanding' and submit a well-informed membership application
- To provide a contact person & provide the list of their members (for information purposes only and in order to determine the overall reach of RDI)
- To be listed on RDI website
- To contribute, review & sign up to policy documents
- To take part in RDD
- To add the RDI logo on their website
- To be active in communication exchange and other actions from the beginning

Medium & Long-term vision

After 3 to 5 years the situation & structure will be assessed to revise objectives and action plan and establish the necessity of:

- Creating a more stable and long-term organisation with a more formal and legal incorporation
- Developing a more formal membership structure
- Developing a formal governance structure

The Spirit of RDI: ‘Policy and actions is all of us’

In its **initial phase** RDI will be “under construction” while commencing actions and allowing its members to liaise and get to know each other. This will subsequently result in a more formal organisation with a new governance structure.

RDI needs to be a **multi-party initiative**, operated by all or several of its members. Anyone should be willing to take the lead in an action.

Membership

- Until RDI becomes a formal body with a legal identity, patient groups that fulfill the eligibility criteria express their will to join RDI by **applying for membership** to RDI and giving a voluntary financial contribution to RDI proportionate to their financial capacity.
- In the initial phase, **RDI secretariat** (membership and financial administration) will be embedded in EURORDIS with regular reporting to the Council of RDI
- The **Council of RDI** will review and approve membership applications.

Membership → Who can apply?

- **National Alliances** for Rare Diseases worldwide
- **International Federations for Rare Diseases** worldwide
- **Pan-regional networks** for Rare Diseases worldwide

Pan-regional networks can gather national Rare Disease Alliances organisations from a given region, for ex: IberoAmerican Alliance (ALIBER), Asia-Pacific Alliance (APARD) or Nordic Alliance.

As a general rule RDI will not accept membership applications from local patient groups. However, very different organisation structures may exist worldwide and it is up to the **Council of RDI to decide upon membership on a case-by-case basis**. In certain instances it may be deemed pertinent to include local organisations that may not be linked to a regional or international federation.

Membership → How can POs apply?

- To apply for RDI membership, POs are required to:
 - Sign a “Mutual Understanding” that contains RDI Mission Statement
 - Fill out an RDI Membership Application Form and send it to the RDI Secretariat
 - Share the list of their members* with the RDI Secretariat
- The Council of RDI will process applications and approve new members

The members of the organisations applying for RDI membership will not be members of RDI directly but their names will be used by RDI for communication purposes.

Visual Identity

- RDI will have its own distinct logo and visual identity that can later change when it becomes a legally incorporated body. The 'rebranding' of RDI can be decided and directed by the future governing body.
- In the meantime, the following logos are proposed to be used during the Phase I of the initiative.



Visual Identity : Option 1

Aspect graphique organique et cellulaire fort avec la représentation d'entités hétérogènes, grandes et petites, qui fusionnent. Une fois rassemblées, elles forment un tout cohérent, soudé et compact.

La forme circulaire évoque le monde, mais également le rassemblement « Rare Diseases International ».

Reprise des couleurs du logo EURORDIS.

Reprise de la typographie du logo EURORDIS (Frutiger). Mise en italique de cette typographie et en gris pour rappel du logo « Rare Diseases Day ».



*Rare
Diseases
International*

Couleurs



Déclinaisons



*Rare
Diseases
International*



*Rare
Diseases
International*



EURORDIS INITIATIVE

Typographies

*abcdefghijklmnopqrstuvwxy
z
ABCDEFGHIJKLMN
OPQRSTUVWXYZ*



Visual Identity: Option 2

Evocation d'un rassemblement de multiples entités hétérogènes (tailles et couleurs différentes). Ces entités sont petites et isolées au départ, mais fortes une fois rassemblées.

Evocation de l'entraide internationale de patients comme une constellation spatiale.

Référence à la charte graphique créé pour l'Activity Report 2013.

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Reprise des couleurs du logo EURORDIS.

Reprise de la typographie du logo EURORDIS (Frutiger).



**RARE DISEASES
INTERNATIONAL**

Couleurs



Déclinaisons



Typographies

abcdefghijklmnopqrstuvwxy
ABCDEFGHIJKLMNPOQRSTUVWXYZ



RDI Survey

A first survey was carried out in September 2013 in order to:

- Gather more information regarding the international situation of the RD field
- Assess interest in the Rare Diseases International initiative
- Use data to prepare a Joint Declaration “Rare Diseases: an International Public Health Challenge”
 - 64 respondents from 34 countries