



RARE
DISEASES
INTERNATIONAL

GENERAL PRESENTATION

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Name

Event

Date

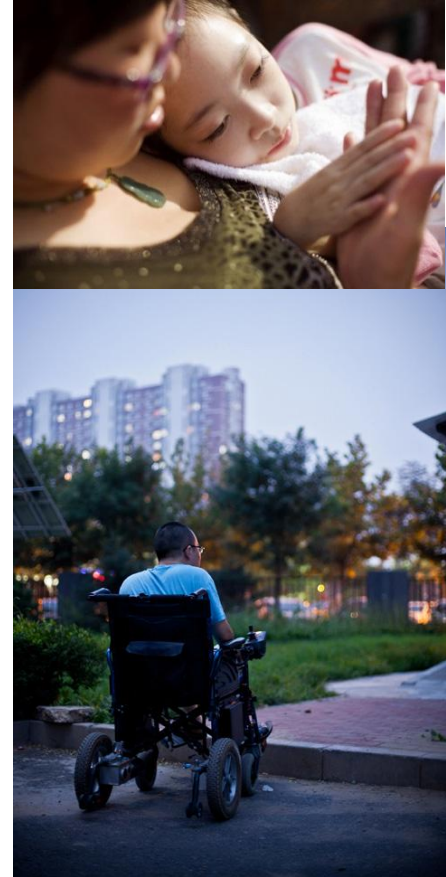
City, Country

WHAT IS RDI?

A EURORDIS Initiative aimed at building the first **Global Alliance of People Living with Rare Diseases of all Nationalities across all Rare Diseases**

For the time being RDI has no legal incorporation and is embedded in EURORDIS. It is expected to be registered as a separate entity in a few years according to the decision of its members

Initial focus is on taking action and gaining experience of working together.



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WHY IS RDI NEEDED?

- To **unite, expand and reinforce** the RD movement of patient organisations and patient advocates
- 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**
- To enable the emergence of a strong **common voice on behalf of the estimated 500 million people** living with rare diseases (PLWRDs) around the world
- To **influence international organisations** (UN, WHO)
- To enable the **emergence of RD as a public health & research priority internationally**
- To enable the local rare disease **patient groups to act at national, regional, international levels through advocacy and exchange** of experience.



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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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BENEFITS FOR PATIENT GROUPS IN DEVELOPING WORLD

- RDI presents opportunity for patient groups to **leverage international voice** to raise awareness, support, and action locally
- RDI provides opportunity for patient networks to **collaborate on regional issues** and insure RDs included in health and economic policies, e.g., UHC
- RDI can **highlight RD challenges endemic to LMIC's** and encourage international attention to address them
- RDI provides opportunity for RD patients in countries emerging to rare diseases to **get support from countries that are further down the line**
- RDI provides opportunity for RD patients in regions where RD not yet meaningfully recognised **to feel empowered and connected**



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GENERAL OBJECTIVES

- 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
- To promote rare diseases as an international public health and research priority through public awareness and policy-making



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ADVOCACY

► Joint Declaration “Rare Diseases: an International Public Health Priority” – Recommendations:

1. Enhanced Visibility of RDs
2. Patient Empowerment
3. Creation and Dissemination of Information
4. International cooperation in services to patients
5. Improve prevention, screening and timely diagnosis
6. The right to Universal Access to Healthcare
7. National and international networking of specialised expertise
8. Promotion of mobility of experts and patients to access adequate care
9. International coordination of Research
10. Shaping Policy at international level based on common values



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BUILDING BLOCKS TO FORM AN INTERNATIONAL PATIENT MOVEMENT

Since 2009, EURORDIS has signed agreements, with national rare disease alliances around the world that included common objective to create an international movement of rare disease patients, with:

- National Organisation for Rare Disorders (NORD, USA) in 2009
- Canadian Organisation for Rare Disorders (CORD, Canada) in 2012
- Japanese Patient Association (JPA, Japan) in 2013
- Russian Patients Union (RPU, Russia) in 2015
- Rare Voices Australia (RVA, Australia) in 2015



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HISTORY

- EURORDIS adopt international orientation in EURORDIS Strategy 2010-2015
- EURORDIS Partnerships with NORD, CORD, JPA, RVA, RPU included the creation of RDI
- RDI preliminary at ICORD Tokyo 2012
- EURORDIS with IAPO Survey carried out in Sept 2013 to evaluate level of interest = 64 respondents from 37 countries = 98% replied that they would be interested in joining RDI
- RDI “concept” presented and tested at conferences in 2014 including NORD Regional Meeting in Alexandria VA in Nov 2014
- RDI Pre-Formation Group & 1st Business Meeting at IRDiRC Conference in Shenzhen China in Oct 2014
- EURORDIS Round Table of Companies in Brussels in Feb 2015
- Official Launch & Inaugural Meeting in Madrid in May 2015



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RDI LAUNCH EVENT

MAY 28, 2015

MADRID, SPAIN



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WHO CAN BE A FULL MEMBER?

- Patient Umbrella organisations representing several rare diseases in one country
 - National Alliances
- Patient Umbrella organisations representing the same disease or family of diseases in several countries
 - International Federations
- Patient Umbrella organisations representing national alliances or other patient groups in several countries across a geographical region
 - Pan regional Networks



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MEMBERSHIP CRITERIA

- Rare disease organisation, according to US or EU definition or the definition of the country
- Non-profit status
- Patient-driven
- Legal incorporation
- Must demonstrate political independence and minimize the risk of conflict of interest through transparency of financial information and diversified funding

RDI recognises organisational set-ups may vary from country to country.

Waivers possible



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ASSOCIATE MEMBERSHIP

- Non patient-driven organisations or professional organizations or other type of entity active in the rare disease field and contributing to the objectives of RDI by their mission and work
- Very young patient organisations
- Certain patient groups that do not meet the criteria i.e. single-disease group in countries where there is no National Alliance yet
- Pharmaceutical or biotech companies cannot be Associate members but other for-profit organisations might be eligible
- Associate members cannot be elected to the Council of RDI



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38 MEMBERS TO DATE

1. Alliance Maladies Rares
2. ALIBER-Alianza Iberoamericana de Enfermedades Raras
3. Arabic Organisation for Rare Diseases (Associate)
4. Associacao Brasileira de Enfermedades Raras
5. Botswana Organisation for Rare Diseases
6. Canadian Organization for Rare Disorders
7. Chinese Organization for Rare Disorders
8. Croatian Alliance for Rare Diseases
9. Cyprus Alliance for Rare Disorders
10. Debra International
11. EAT - Federation of Esophageal Atresia and Tracheo-Esophageal Fistula
12. EURORDIS



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MEMBERS

13. Federación Argentina de Enfermedades Poco Frecuentes
14. Federación Colombiana de Enfermedades Raras
15. Federación Española de Enfermedades Raras
16. Federacion Mexicana de Enfermedades Raras
17. Findacure (Associate)
18. German Rare Disease Alliance (ACHSE)
19. Greek Alliance for Rare Diseases
20. Indian Organization for Rare Diseases
21. International Federation for Spina Bifida & Hydrocephalus
22. International Patient Organization for Primary Immunodeficiencies (IPOPI)
23. Japan Patients' Association (JPA/ ASRID)
24. Malaysian Rare Disorders Society



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MEMBERS

25. Naevus Global
26. New Zealand Organization for Rare Disorders (NZORD)
27. National Organization for Rare Disorders (NORD)
28. Pro Rare Austria
29. Rare Diseases South Africa (RVA)
30. Rare Voices Australia
31. Retina International
32. Romanian National Alliance for Rare Diseases (RONARD)
33. Hongkong Alliance for Rare Disorders (KHARD)
34. Genetic Alliance Australia
35. Pulmonary Hypertension Latin Society
36. Blackswan Foundation (Associate)
37. International Niemann Pick Disease Association
38. World Federation of Hemophilia



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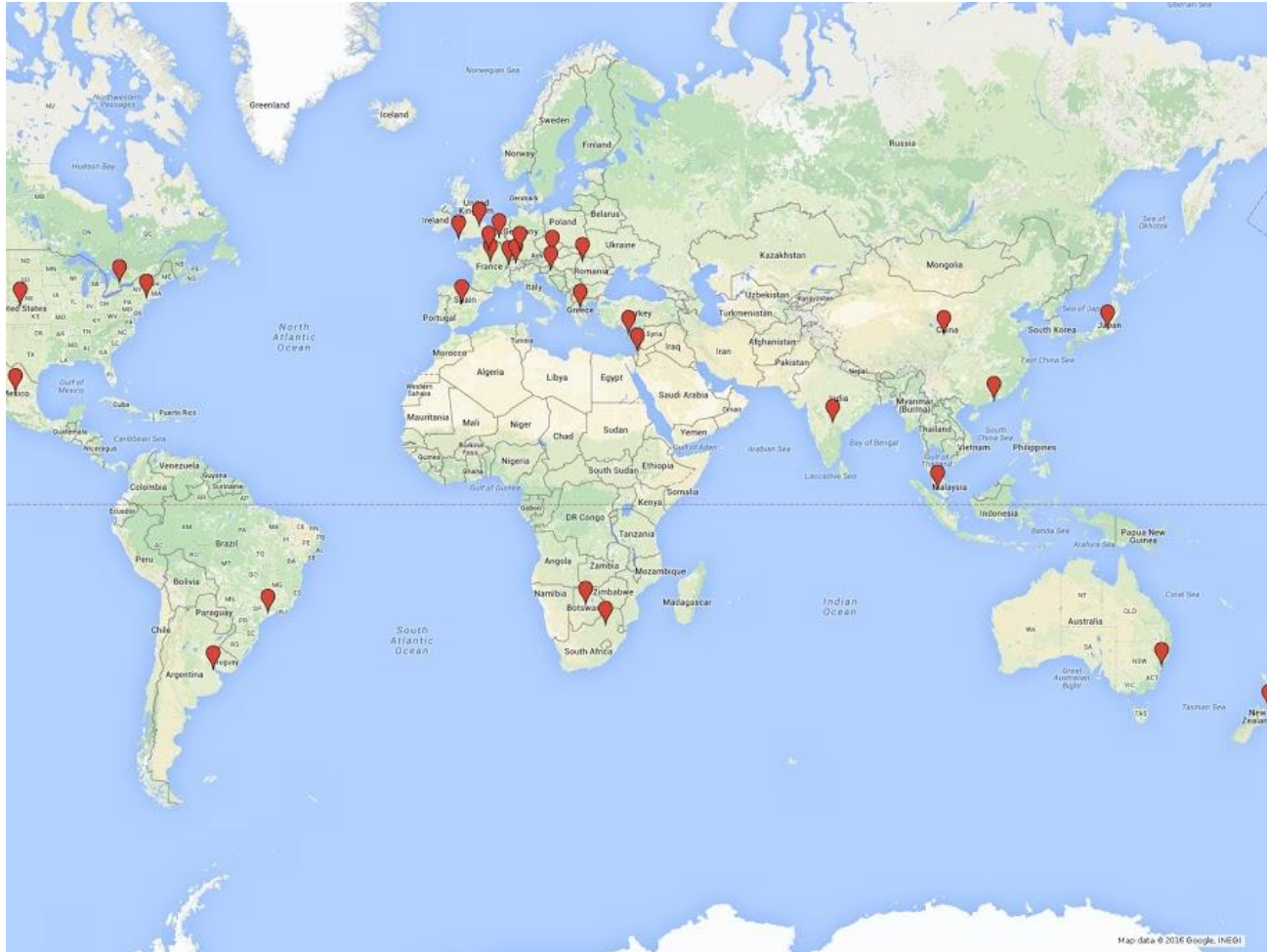
MEMBERSHIP BREAKDOWN

- 15 Non European National Alliances
- 8 European National Alliances
- 8 International Federations
- 3 Regional Networks
- 4 Associate Members



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RARE DISEASE NATIONAL ALLIANCES OF 23 COUNTRIES



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MEMBERS OF MEMBERS IN 67 COUNTRIES

Argentina, Australia, Belarus, Belgium, Bosnia & Herzegovina, Bulgaria, Brazil, Canada, Chile, Columbia, Costa Rica, Cyprus, Denmark, Dominican Republic, Egypt, El Salvador, Estonia, Finland, France, Germany, Greece, Guatemala, Hong Kong, Hungary, Iceland, India, Indonesia, Iran, Ireland, Italy, Japan, Malaysia, Mexico, Moldova, Morocco, Netherlands, New-Zeland, Norway, Pakistan, Panama, Paraguay, Peru, Poland, Portugal, Puerto Rico, Romania, Russia, Senegal, Serbia, Singapore, Slovakia, Slovenia, South Africa, Sweden, South Korea, Spain, Switzerland, Taiwan, Thailand, Turkey, Uganda, Ukraine, UK, U.S, Uruguay, Venezuela, Vietnam



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FUNDING

► EURORDIS, AFM Telethon, EC DG SANCO

► Members' Voluntary Contributions

- Alliance Maladies Rares
- Australian Genetic Alliance
- Blackswan Foundation
- Debra International
- IPOPI
- Hong Kong Alliance for Rare Diseases
- Malaysian Rare Diseases Society
- Pro Rare Austria
- Retina International

► Corporate Donors

- Biogen
- Genzyme
- Novartis
- Pfizer
- Shire
- Vertex



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GOVERNANCE

The preliminary phase of the initiative (until March 2016)

has been steered by a **Pre-Formation Group**

1. Ibero-American pan-regional alliance (ALIBER)
2. France (AMR)
3. Canada (CORD)
4. China (CORD)
5. International Fed. Epidermolysis Bullosa (DEBRA)
6. Europe (EURORDIS)
7. India (I-ORD)
8. International Fed. Primary Immunodeficiencies (IPOPI)
9. Japan (JPA)
10. USA (NORD)



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NEW COUNCIL OF RDI

John Dart
DEBRA
INTERNATIONAL



Ramaiah Muthyala,
I-ORD INDIA



Durhane Wong-
Rieger CORD
CANADA



Megan Fookes
RVA AUSTRALIA



Lisa Phelps
NORD USA



Yann Le Cam
EURORDIS
EUROPE



Alfredo Toledo
ALIBER
IBEROAMERICA



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OUTREACH & CONFERENCES

In 2014

- › IRDiRC Shenzhen
- › NORD Regional Meeting
Alexandria VA

In 2015

- › ALIBER Guadalajara, June
- › ERTC Brussels, February
- › EURORDIS Membership Meeting –
RDI first Annual Meeting Madrid
May
- › ICORD Mexico, October
- › 4th Latin American Patient Summit
Mexico, October
- › EURORDIS Council of European
Federations, October
- › WOD Congress Geneva,
November

In 2016

- › ReACT Barcelona, March
- › IAPO Patient Congress London,
April
- › WB and IMF Civil Society Policy
Forum, Lima –Peru April
- › BIO Conferences San Francisco,
June (booth in Patient Pavilion)
- › ALIBER Montevideo, September
- › ICORD Cape Town, October
- › NORD Summit, October
- › UN Committee for Rare
Diseases NY Launch, November



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REACT COMMUNITY
@react_community



Following

@rarediseasesint #RareDisease a public
#health and #research priority @eurordis
@BLACKSWANFound @WHO



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MAILING LIST – SIGN UP!

Rare Diseases International



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A EURORDIS INITIATIVE

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First Name

Last Name

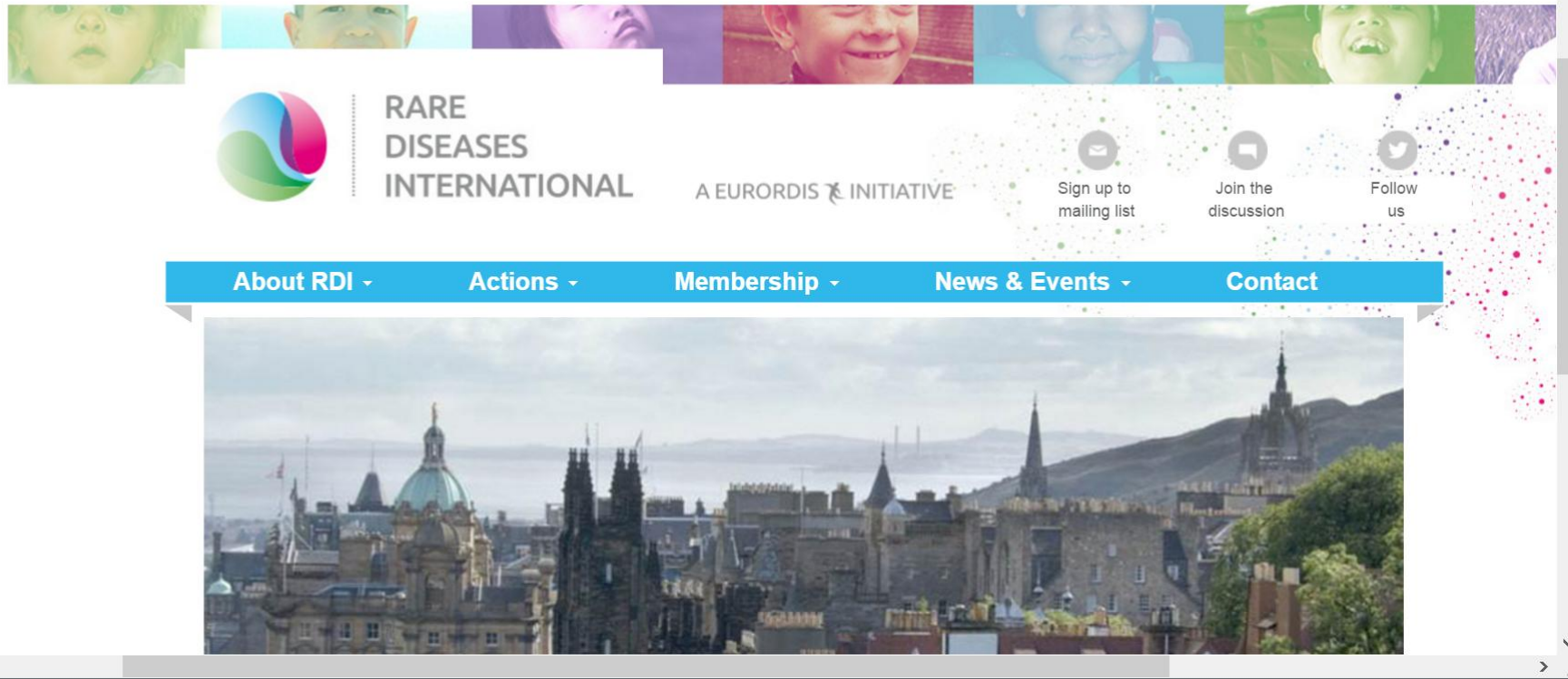
Organisation

Sign up to receive RDI information




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WEBSITE





www.rarediseasesinternational.org


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RDI @rarediseasesint · May 20
Feedback needed on Strategic Approach and Action Plan for Rare Diseases International rareconnect.org/topics/questionnaire

  1  

 You Retweeted **RareConnect** @RareConnect · Apr 25

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RDI ONLINE DISCUSSION GROUP



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Rare Diseases International

RELATED TOPICS

 EURORDIS

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www.rareconnect.org/rdi



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RARE DISEASES IN THE UN AGENDA

The ambition is to:

- Introduce concept and foster understanding of rare diseases in international institutions (UN, ECOSOC, WHO, PAHO, OECD)
- Rare Disease Day recognised by the WHO
 - Eg. World Hepatitis Day , World Day AIDS Day
- A Report on RD presented to the WHO World Health Assembly
- A Position Paper on RD presented at the UN General Assembly
- Why not ...a UN Resolution on Rare Diseases!



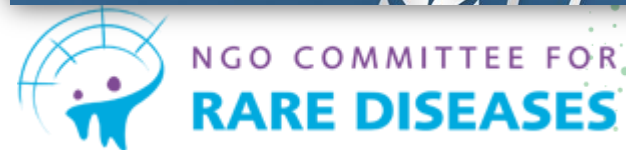
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GAINING RECOGNITION AT THE UNITED NATIONS

- The NGO Committee for Rare Diseases at United Nations, New York

through the Conference of NGOs in Consultative Relationship with the United Nations' Economic and Social Council (CoNGO)

- In line with RDI objective: Turning RD into an International public health priority
- Introduce concept, foster understanding of rare diseases in UN system
- Put rare diseases on the global health & development agenda
- Multi-stakeholder Committee
- RDI will represent patients
- Official launch – November 11, 2016 – New York



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www.ngocommitteerarediseases.org

BUILDING BRIDGES WITH OTHER STAKEHOLDERS: SHAPING RD ECO-SYSTEM



- ▶ **International Alliance of Patients' Organizations** – supporting RD patient groups and guide to WHO



- ▶ **International Federation of Pharmaceutical Manufacturers & Associations** – exploiting synergies with industry



- ▶ **International Rare Diseases Research Consortium** - fostering patient involvement



- ▶ **Blackswan Foundation/ ReACT Congress** – Advocacy and Awareness to support RD research



- ▶ **International Conference on Rare Diseases & Orphan Drugs** – strengthening collaboration, streamlining conferences and reinforcing patient dimension

South Africa 2016, China 2017, India 2018?



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THANK YOU!



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