



RARE DISEASES INTERNATIONAL

A EURORDIS INITIATIVE

Rare Diseases International is the global alliance of people living with a rare disease of all nationalities across all rare diseases.

RDI's mission is to be a strong common voice on behalf of the people living with a rare disease around the world.

www.rarediseasesinternational.org

Background

RDI is a EURORDIS (European Organisation for Rare Diseases) initiative. It stems from bilateral agreements between EURORDIS and the National Rare Disease Alliances of the US (National Organization for Rare Disorders), Canada (Canadian Organization for Rare Disorders) Japan (Japan Patients' Association), Russia (Russian Patient Union) and Australia (Rare Voices Australia) that include the establishment of RDI as one objective.

In 2013, with the support of the International Alliance of Patients' Organizations (IAPO), EURORDIS developed a survey to test the idea of creating a global alliance. 64 respondents from 37 countries around the world were overwhelmingly in favour of the creation of a global patient alliance, with 97.62% replying that they would be interested in joining.

The results of this international survey were used to draft the Joint Declaration: Rare Diseases as an International Public Health Priority, which encapsulates the main advocacy messages of RDI.

RDI was formally launched on May 28, 2015 alongside the annual EURORDIS Membership Meeting in Madrid, Spain.

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 a rare disease at large, in international institutions and forums
- ▶ To enhance the capacities of members through information, exchange, networking, mutual support and joint actions

CONTACT

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Join the discussion on
www.rareconnect.org/rdi

Actions

ADVOCACY

- ▶ Adopt and promote **RDI Joint Declaration: Rare Diseases as an International Public Health Priority**
- ▶ Introduce the concept and foster understanding of rare diseases in international institutions and forums, such as the **World Health Organization and the United Nations Economic and Social Council**
- ▶ Put rare diseases in the international and national policy agendas through expert consultative bodies such as the **NGO Substantive Committee for Rare Diseases at the United Nations, New York**
- ▶ Participate in international **position papers and surveys**

INFORMATION, NETWORKING & COMMUNITY BUILDING

- ▶ **Recruit members** from national and regional rare disease patient organisations from around the world as well as international rare disease-specific federations
- ▶ Organise an **annual meeting** to build a community of patients and other stakeholders interested in advancing the cause of people living with rare diseases internationally
- ▶ Encourage and facilitate **regional networking**
- ▶ Organise a **capacity-building exchange programme** to share know how between countries and diseases
- ▶ Provide an **information hub** for rare disease patient international affairs through a dedicated website, a RareConnect.org online community, a Twitter account and mailing list.

AWARENESS

- ▶ Participate actively in **Rare Disease Day**
- ▶ Organise specific international awareness campaigns

PARTNERSHIPS

Join forces with other rare diseases stakeholders:

- ▶ International Federation of Pharmaceutical Manufacturers & Associations (ifpma.org)
- ▶ International Rare Disease Research Consortium (irdirc.org)
- ▶ Orphanet International (orpha.net)
- ▶ International Alliance of Patients' Organizations (iaipo.org.uk)
- ▶ International Conference on Rare Diseases and Orphan Drugs (icord.se)
- ▶ International Federation of Human Genetics Societies (ifhgs.org)

Members*

- ▶ ACHSE – German Rare Disease Patient Alliance
- ▶ Alianza Iberoamericana de Enfermedades Raras
- ▶ Alliance Maladies Rares
- ▶ Arabic Organisation for Rare Diseases
- ▶ Associacao Brasileira de Enfermedades Raras
- ▶ Blackswan Foundation
- ▶ Botswana Organisation for Rare Diseases
- ▶ Canadian Organization for Rare Disorders
- ▶ Chinese Organization for Rare Disorders
- ▶ Croatian Alliance for Rare Diseases
- ▶ Cyprus Alliance for Rare Disorders
- ▶ Debra International
- ▶ EURORDIS
- ▶ Federación Argentina de Enfermedades Poco Frecuentes
- ▶ Federación Española de Enfermedades Raras
- ▶ Federacion Mexicana de Enfermedades Raras
- ▶ Federation of Esophageal Atresia and Tracheo-Esophageal Fistula
- ▶ Findacure
- ▶ Genetic Alliance Australia
- ▶ Greek Alliance for Rare Diseases
- ▶ Hong Kong Alliance for Rare Disorders
- ▶ Indian Organization for Rare Diseases
- ▶ International Federation for Spina Bifida and Hydrocephalus
- ▶ International Patient Organization for Primary Immunodeficiencies
- ▶ Japan Patient Association
- ▶ Malaysian Rare Disorders Society
- ▶ Naevus Global
- ▶ National Organization for Rare Disorders
- ▶ New Zealand Organization for Rare Disorders
- ▶ Pro Rare Austria
- ▶ Pulmonary Hypertension Latin Society
- ▶ Rare Diseases South Africa
- ▶ Rare Voices Australia
- ▶ Retina International
- ▶ Romanian National Alliance for Rare Diseases

**as of 31/03/2016*