



PRESS RELEASE

Launch of Global Voice for Rare Disease Patients: Rare Diseases International

May 28 2015, Madrid - The global voice for rare disease patients launches today. Over 60 patient representatives from 30 countries are gathering in Madrid, Spain for the inauguration of **Rare Diseases International** and to adopt a joint declaration to advocate for rare diseases as an international public health priority.

Rare Diseases International (RDI) represents patients and families of all nationalities across all rare diseases. It will be the voice of all people living with a rare disease around the world today and will work to give visibility to rare diseases in the global health agenda.

"RDI creates a united global patient voice for all people living with a rare disease around the world, including those who don't have a voice today, and works to turn ignorance, isolation and exclusion into knowledge, solidarity and hope." says Yann Le Cam, Chief Executive Officer of EURORDIS, the European Organisation for Rare Diseases.

The main objectives of RDI are:

- To promote rare diseases as an international public health and research priority by raising public awareness and influencing policy-making;
- To represent members and people living with a rare disease at large, in international institutions and forums, such as the World Health Organisation (WHO) and the United Nations Economic and Social Council (ECOSOC); and
- To enhance the capacities of members to improve the lives of those living with or affected by a rare disease through information exchange, networking, mutual support and joint actions.

RDI brings together umbrella patient organisations representing patient groups at the national and regional level, as well as international rare disease-specific federations from around the world. To date, 20 such groups have formally signed up to be a member of RDI and another fifty are expected to join the initiative before the end of the year.

RDI is a EURORDIS initiative, created in partnership with national alliances with which EURORDIS has signed agreements that include the establishment of RDI as one of the common objectives. The preliminary phase of the initiative has been steered by 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).

The launch meeting is also the opportunity for patients to hear from other stakeholders and potential partners, namely the International Federation of Pharmaceutical Manufacturers Associations (IFPMA), the International Conference on Rare Diseases and Orphan Drugs

(ICORD) and the International Rare Disease Research Consortium (IRDiRC). In the coming years, RDI aims to structure dialogue with industry, streamline the organisation of international conferences, increase patient representation in research funding bodies and promote rare diseases within the UN system.

The next annual meeting of RDI will take place in May 2016 in Edinburgh, UK alongside the the European Conference on Rare Diseases & Orphan Products (ECRD 2016 Edinburgh). Until then, members and those interested in the initiative, will be able to meet at other relevant international conferences including ICORD Mexico, NORD CBI, IRDiRC and the World Orphan Drug Congress.

For more information visit: <http://www.eurordis.org/content/rare-diseases-international>

[Photos of the event launch on flickr.](#)

Venue of launch:

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Rare Diseases

The European Union considers a disease as rare when it affects fewer than 1 in 2,000 citizens. Over 6000 different rare diseases have been identified to date, affecting over 60 million people in Europe and the USA alone. Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offering inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.

EURORDIS

EURORDIS, the European Organisation for Rare Diseases, is a non-governmental patient-driven alliance of patient organisations representing over 600 rare disease patient organisations in more than 60 countries. EURORDIS represents the voice of an estimated 30 million people living with a rare disease in Europe. Follow [@eurordis](#) or see the EURORDIS [Facebook page](#). For more information visit: www.eurordis.org.