



RARE  
DISEASES  
INTERNATIONAL



## Major rare disease stakeholders announce new collaboration to streamline efforts

**October 15, 2015, Mexico City** - Rare Diseases International (RDI), the European Organisation for Rare Diseases (EURORDIS) and the International Conference on Rare Diseases and Orphan Drugs (ICORD) today jointly announce a significant new collaboration to boost progress on rare disease policy worldwide at ICORD 2015, the [10<sup>th</sup> ICORD Conference](#).

The collaboration is based on the key common strategic objective **to promote rare diseases as an international public health priority**, will focus on partnering for the development and organisation of the annual International Conference on Rare Diseases and aims to:

- Enhance international discussion, cooperation and coordination of research, policies and actions of all bodies active in the field of rare diseases and orphan medicines, especially in regions of the world which are not yet advanced in this field
- Exchange best practices amongst their members and other existing bodies and develop international approaches and tools to address common issues in rare diseases and orphan products.

“This agreement is part of the continued effort to stress the international dimension of the rare disease movement and the benefits to be gained by global collaboration in this field,” said **Yann Le Cam, Chief Executive Officer of EURORDIS**. He added, “It stems from a need to streamline efforts and exploit existing synergies in a field where a multitude of separate initiatives and conferences are filling out the yearly calendar.”

**John Forman, President of ICORD and former Executive Director of the New Zealand Organisation for Rare Disorders (NZORD)**, commented “Significant developments in rare disease legislation and policy drug discovery in some parts of the world, especially North America and Europe, need collaborative efforts to ensure they are effectively translated into actions that improve outcomes for rare disease patients in the rest of the world. This will be a major priority for the future collaboration between our organisations and a task made easier by this agreement.”

The agreement adds a major new stream to the annual ICORD Conference through the active participation of patients worldwide represented by RDI, a EURORDIS-led initiative [launched in May this year](#).

RDI will partner with ICORD in order to support the existing ICORD Conference and provide a global forum for all stakeholders for effective communication and public debate around rare diseases and orphan medicines.

RDI will be included in the Programme Committee of the ICORD Conference. Sessions on themes that are stated priorities of RDI and ICORD will be included in the programme and an RDI satellite meeting will be held alongside the Conference.

EURORDIS, RDI and ICORD will bring the experience and commitment of key leaders in the field of rare diseases and orphan medicines. All three organisations will join forces to promote the event more widely and partner financially to ensure its success.

The next ICORD Conference takes place in October 2016 in Cape Town, South Africa and will be the first major event to showcase this joint initiative.

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**About ICORD**

The ICORD (International Conferences for Rare Diseases and Orphan Drugs) Society was formed on September 13, 2007 in Brussels. Its mission is to improve the welfare of patients with rare diseases and their families world-wide through better knowledge, research, care, information, education and awareness.

ICORD arranges annual Conferences on Rare Diseases and Orphan Drugs in different parts of the world, until now in Stockholm 2005, Madrid 2006, Brussels 2007, Washington DC 2008, Rome 2009, Buenos Aires 2010, Tokyo 2011- 2012, St Petersburg 2013, Ede 2014.

**About EURORDIS**

EURORDIS, the European Organisation for Rare Diseases, is a non-governmental patient-driven alliance of patient organisations representing 692 rare disease patient organisations in 63 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](http://www.eurordis.org).

EURORDIS has a track record of leading international activities, including [Rare Disease Day](#), [RareConnect.org](#) and the European Conference on Rare Diseases and Orphan Products (ECRD), which attracts a large number of participants outside of Europe.

**About RDI**

Rare Diseases International (RDI) is a EURORDIS-led initiative, in partnership with the National Organization for Rare Disorders (US), the Canadian Organization for Rare Disorders, the Japanese Patient Association, the Chinese Organization for Rare Disorders, the Indian Organization for Rare Diseases, the Ibero-American Alliance for Rare Diseases (ALIBER), the French Alliance for Rare Diseases (Alliance Maladies Rares), the International Patient Organization for Primary Immunodeficiencies (IPOPI), Dystrophic Epidermolysis Bullosa Research Association International (DEBRA International), among other groups.

RDI brings together national and regional rare disease patient organisations from around the world as well as international rare disease-specific federations to create the global alliance of rare disease patients and families. RDI's mission statement is to be a strong common voice on behalf of the people living with a rare disease around the world, to advocate for rare diseases as an international public health priority, and to represent/ enhance the capacities of its members.