ICORD

International Conference on
Rare Diseases & Orphan Drugs

Manuel Posada

President-elect of ICORD

“Defining relations between ICORD and Rare Diseases International”

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On behalf of John Forman – ICORD President

With Judith, Timothy and Hollie, age 40

Twins, Alpha-Mannosidosis, a Lysosomal storage disease

Involved in many rare disease groups in NZ and world-wide

Current President of ICORD

Introducing ICORD

ICORD

International Conference on
Rare Diseases & Orphan Drugs

- Society set up in 2007 (first ICORD conference 2005 in Stockholm)
- A multi-stakeholder society focused on rare diseases and orphan drugs
- Members include health officials, regulators, researchers, clinicians, industry, academics, patients, advocacy group leaders
- Has held 9 international conferences
- Sweden, Spain, Belgium, USA, Italy, Argentina, Japan, Russia, the Netherlands
- Next meeting in Mexico, October 2015
- 2016 – South Africa or New Zealand?

ICORD Board 2014-2016

President John Forman, New Zealand

Past-President Virginia Llera, Argentina

President-Elect Manuel Posada, Spain

Secretary Yukiko Nishimura, Japan

Treasurer Catharina Edfjäll, Switzerland

Members-at-Large

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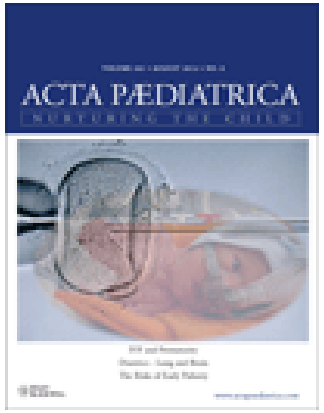
Stephen Groft, USA
Marlene Haffner, USA
Ann Nordgren, Sweden
Fernando Royo, Spain
Rumen Stefanov, Bulgaria
Maja Stolijkovic, Serbia
Domenica Taruscio, Italy
Barbara Wuebbels, USA

ICORD’s policy statement

- The Yukiwariso Declaration



- Published in Acta Paediatrica Vol 101, Issue 8, pp 805-807, August 2012 (summary version) - Also at [*www.icord.se*](http://www.icord.se) (full version)
- The declaration provides a rationale and framework for legislation, policies, action plans

The Declaration's 6 Principles

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- 1. RDs are a significant public health issue – 6 to 8%
- 2. Human rights and government duties are involved
- 3. RD research and product development should be supported
- 4. A comprehensive approach to rare diseases should be adopted
- 5. The importance of patient autonomy, consent and information needs
- 6. Include patient groups in policy and services

There are 12 guidance points to assist implementation of these principles

Working together for rare diseases

ICORD
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- ICORD welcomes efforts based on international collaboration
  - Rare Disease International – the patient voices
  - IRDiRC – research collaboration
  - Rare Disease Day – international awareness building
  - Global RD registry program
  - and more
- ICORD adds the multi-stakeholder and global perspective
- The more voices with consistent messages, the better chance of impact

ICORD and RDI

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- ICORD welcomes the establishment of RDI and looks forward to strong collaboration in the future
- We are already discussing a partnership in annual conference events
- Our policies closely align and together we can do more than if we act alone
- We look forward to a strong and fruitful collaboration with RDI

Thank you

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