



ICORD

International Conference on
Rare Diseases & Orphan Drugs

Manuel Posada

President-elect of ICORD

“Defining relations between ICORD and Rare Diseases International”

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

- 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

Simon Day, UK

Stephen Groft, USA

Marlene Haffner, USA

Ann Nordgren, Sweden

Fernando Royo, Spain

Rumen Stefanov, Bulgaria

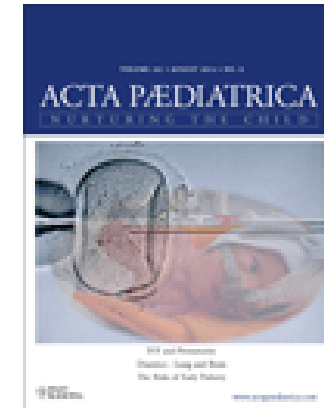
Maja Stolicjkovic, Serbia

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 (full version)
- The declaration provides a rationale and framework for legislation, policies, action plans



The Declaration's 6 Principles

- 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 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

- 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

- ICORD website www.icord.se
- Email icord@karolinska.se
- **ICORD Secretariat**
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