



INTERNATIONAL CONFERENCE ON RARE DISEASES & ORPHAN DRUGS 2014

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MISSION

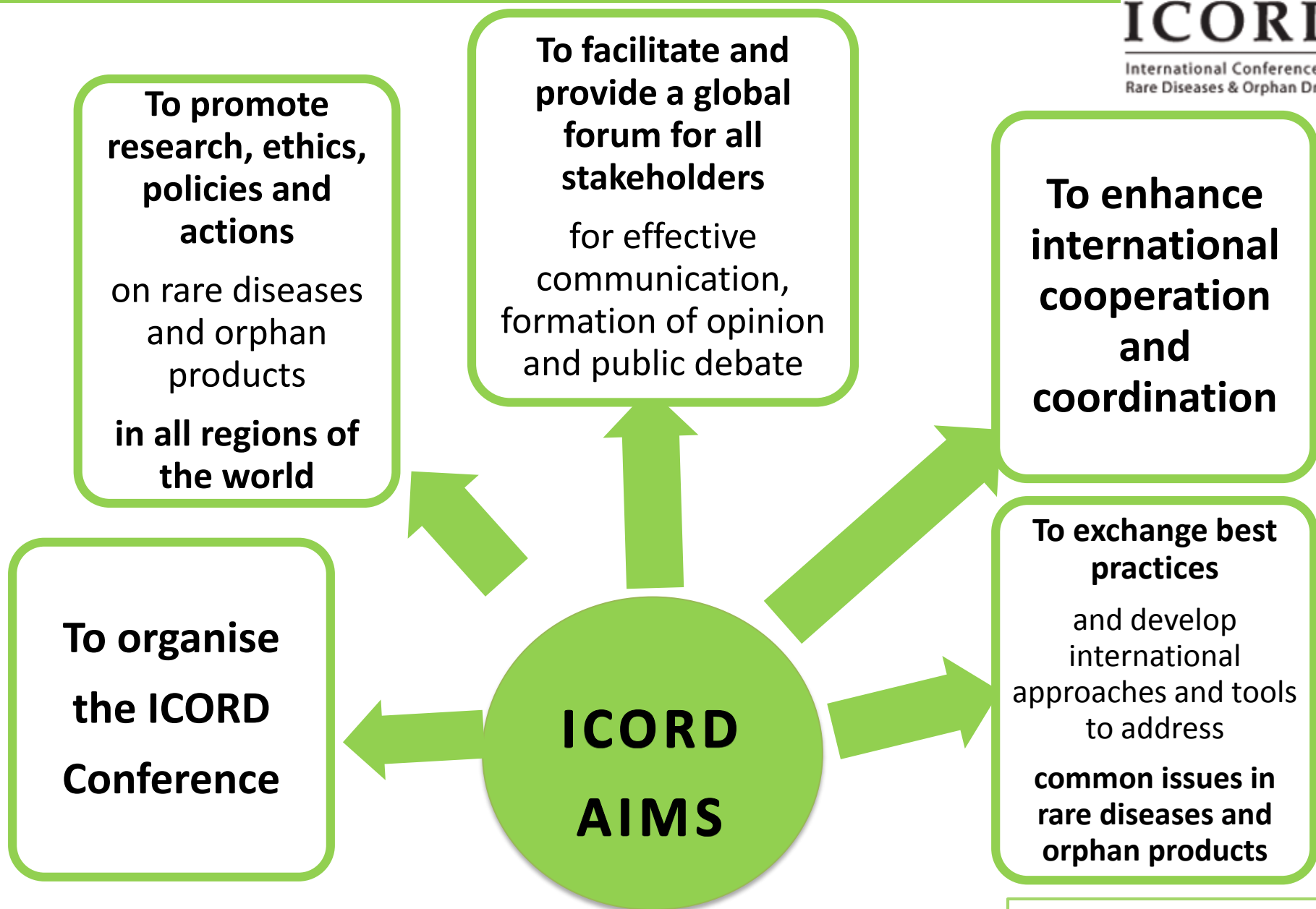


ICORD is an **International Society** for all individuals ***active in rare diseases and/or orphan drugs***, including health care, research, academic, industry, patient organizations, regulatory authorities, health authorities, and public policy professionals.

The ICORD 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 is an **open** organization in which academy, governments, industry and patient groups leaders work in an **equal level** of participation
- ICORD creates a **global environment** for rare disease policies developments
- A platform for bridging and empowering the **local initiatives** from the less developed Regions (an enzymatic process)

AIMS



WHY ICORD IS DIFFERENT ?

- A **pioneer** experience
- 10 years **sustaining** a global vision
- ICORD has been **inclusive** since its beginning
- ICORD **flexible** promotes “cultural changes” as requested by the different regional diversities

<http://icord.se>



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ICORD Position statement

The Yukiwariso Declaration

From the International Conference on Rare Diseases and Orphan Drugs (ICORD)

The need for world-wide policy and action plans for rare diseases

This declaration, adopted by the Board of ICORD in November 2011, was launched at Komaba research campus, University of Tokyo.



ICORD Yukiwariso Declaration

Declaration for worldwide policy and action plans for rare diseases

1. Action plans
2. Specific programs and policies
3. Allocation of resources
4. Specific counterbalancing policies
5. Cost effectiveness assessment should consider wider factors
6. Specific benefits of research into rare diseases.
7. Recognition of gaining knowledge to aid prevention
8. Encouragement of industry to contribute to rare disease knowledge



The Yukiwariso Declaration

9. Patient advocacy groups participation in advisory groups and expert panels
10. Development of information networks and support group capacity
11. Criteria for antenatal and newborn screening and ethical controls
12. Recognition of specific problems of rare diseases in developing nations

**Forman et al., Acta Pædiatrica
2012. 101, pp. 805–807**



HOW TO FAVOUR A GLOBAL IMPACT

- Including more Regions into the international cooperation in rare disease

MORE COUNTRIES

- In a given country favouring links between experts, patients and institutions interested in rare diseases

MORE INTERDISCIPLINARY WORKING GROUPS

- Building bridges of cooperation in research and public health

RESEARCH and PUBLIC HEALTH

- Empowering initiatives in awareness, research, regulations and education in rare diseases and orphan drugs.

ICORD STARTS AN ACTIVE PROCESS

not just making events, it's an enzymatic process



- WORKING GROUPS IN SPECIFIC ACTIVITIES: PATIENT GROUPS, REGULATORY, RESEARCH, BIOETHICS...
- PUBLICATIONS...

<http://icord.se>

PAST CONFERENCES



ICORD 2005 in Stockholm



ICORD 2006 in Madrid



ICORD 2007 in Brussels



ICORD 2008 in Washington DC



ICORD 2009 in Rome



ICORD 2010 in Buenos Aires



ICORD 2012 in Tokyo



ICORD 2013 in S.Petersburg



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ICORD 2014

IX Annual meeting of ICORD

- The Societal value of Prevention, Diagnosis and Treatments of Rare Diseases



<http://icord.se>

A banner image showing a row of traditional Dutch windmills along a canal at sunset. The sky is a warm orange-pink color, and the water reflects the light. A green semi-transparent box is overlaid on the left side of the image, containing the text 'ICORD 2014 The Netherlands'.

ICORD 2014 The Netherlands

HOME

Online registration is closed

It is not longer possible to register online. Though, you can participate during the Annual ICORD Meeting . You can come to the ReeHorst, and register on site. We are looking forward to welcome you!

The ICORD 2014 Annual Meeting will be held on October 7-9, 2014 in Ede, The Netherlands.

This year's meeting will be entitled: "**Societal value of Prevention, Diagnosis and Treatment of Rare Diseases**"

The overall aim of the ICORD meeting is to continue developing the constructive international partnership that will globally result in true advantages for patients with rare diseases.

The meeting is a global open forum for all stakeholders who share the mission and vision to improve the lives and welfare of patients and families with rare diseases through better knowledge, research, care, information, education and awareness.

We invite professionals acting in healthcare, research, academia, pharmaceutical industry, regulatory authorities, health authorities, policy makers, patient representatives and media to ICORD 2014. Meet, exchange knowledge and build global networks in the field of rare diseases and orphan drugs!

We look forward to welcoming you!

Virginia Llera, ICORD President

Désirée Gavhed, ICORD Secretariat

HAVE A VERY FRUITFUL CONFERENCE

<http://icord.se>