

ICORD's immediate challenges

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Ede – 7 October 2014



ICORD

International Conference on
Rare Diseases & Orphan Drugs

To build on 10 years of work done so far

- Establish better funding streams
- Confirm the annual meeting as a “business-as-usual” event
- Free up board time for liaison with governments, industry, academia, WHO, UN, World Bank, and more



Establish rare disorders on the international development agenda and universal healthcare agenda

- Spread rare disease policies and action plans beyond Europe, US and a small number of Asian countries
- Use ICORD's Yukiwariso Declaration as the flagship for the international Rare disease agenda
- Build regional alliances of Rare diseases groups such as those emerging in Asia/Pacific and Latin America



More liaison and educational opportunities

- ACCORD meetings with industry and academic groups
- Summer schools with Italian Rare Diseases Institute



Issues for rare diseases go well beyond drug discovery, regulation and reimbursement

They include:

Primary prevention, screening programmes, early and accurate diagnosis, best clinical care, and social and education support

Rare diseases need a womb-to-tomb approach



ICORD's challenge for the future is to bring the agenda and people together to make progress on these issues.



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