



E-RARE-3

*presentation, role of EURORDIS
& opportunities for members*

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E-Rare

ERA-Net for research programmes on rare diseases

ERA-Net

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European Research Area Network

- To accelerate the Cooperation and Coordination of Research Activities carried out at National/Regional level
- To contribute to the development of European Research Area by improving coherence and coordination across Europe of such research programmes
- To enable national systems to take on tasks collectively that they would not have been able to tackle independently
- ERA-Net consortium is composed of **funding bodies/ministries**

Austrian Science Fund FWF Austria
The Austrian Research Promotion Agency FFG Austria
Fund for Scientific Research F.R.S.-FNRS Belgium
Research Foundation Flanders FWO Belgium
Canadian Institutes for Health Research CIHR Canada
Quebec Health Research Fund FRQS Canada
Genome Canada GC Canada
National Funding Agency for Research ANR France
Programme Management Agency in the German Aerospace Centre DLR Germany
Federal Ministry for Education and Research BMBF Germany
German Research Foundation DFG Germany
The General Secretariat for Research and Technology-Ministry of Education and Religious Affairs GSRT Greece
Hellenic Centre for Disease Control & Prevention, Ministry of Health KEELPNO Greece
University of Pecs UNI PECS Hungary
Chief Scientist Office, Ministry of Health CSO/MOH Israel
National Institute of Health ISS Italy
Ministry of Health MoH Italy
Emilia Romagna Region ASSR Italy
Latvian Academy of Sciences LAS Latvia
National Centre for Research and Development NCBR Poland
Foundation for Science and Technology FCT Portugal
Institute of Health Carlos III ISCIII Spain
The Netherlands Organization for Health Research and Development ZonMw The Netherlands
The Executive Agency for Higher Education, Research, Development and Innovation Funding UEFISCDI
Romania
Swiss National Fund SNSF Switzerland
The Scientific and Technological Research Council TUBITAK Turkey

List of partners
(alphabetic order)

Today
E-Rare-3

Horizon 2020

E-Rare-3: 25 partners in
17 countries

E-Rare-1
2006-2010
FP6

E-Rare-2
2010-2014
FP7

Coordination & support activities

- Harmonization of national research programmes
- Development of strategic agenda
- Development of common funding mechanisms

Launch every year
Joint Transnational Calls

Objective

To enable scientists in different countries to build an effective collaboration on a common interdisciplinary research project based on complementarities and sharing of expertise, with a clear translational research approach.

Scope of the E-Rare Joint Transnational Calls

Clinical studies

Natural history of diseases, registries, databases, genotype/phenotype, correlation studies, diagnosis

Pre-clinical Therapeutic Research

Development of new therapeutic tools, proof-of-concept, innovative biotechnology research, drug toxicology / pharmacology.

Physiopathology

Gene identification, epigenetics, molecular mechanisms, new animal models, -omics, biomarkers

Role of EURORDIS

1. EURORDIS represents patients' organisations in the consortium
2. POs show a high interest in and a strong commitment to research and a strong willingness to collaborate with researchers, including logistical and financial support. *(PO devoted a minimum of 13M€ (w/o AFM) to research in 2009 and funded mostly basic research, but are also interested in and concerned by all areas of research).*
3. In alliance with EURORDIS the consortium will develop a model of collaborative funding with patients' organisations
4. The participation of EURORDIS in E-Rare-3 opens the possibility for **patients' organisations to foster their engagement in funding of research on rare disease at the transnational level. EURORDIS will coordinate a network of scientific officers from funding research patient organisations to find an innovative funding schema with patient organisations**

Opportunities for patient's organisations

1. Finance excellent research
2. Reach out and access international research projects for a specific RD/group of RD
3. Leverage significant funds for research dedicated to a specific disease
4. Navigate through, and integrate in, the complicate space of research funding

How is the cooperation with PO foreseen?

1. Pilot phase for the Joint Transnational Call 2016 (launch in December 2015)
2. Come to an agreement on the mechanism of involvement
3. Expansion phase of the Call 2017
4. Full speed => horizon 2018

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