BUILDING AN OPEN AND RESPECTED MOVEMENT OF PATIENT ORGANISATIONS AND ADVOCATES

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Retina International & EURORDIS, Ireland

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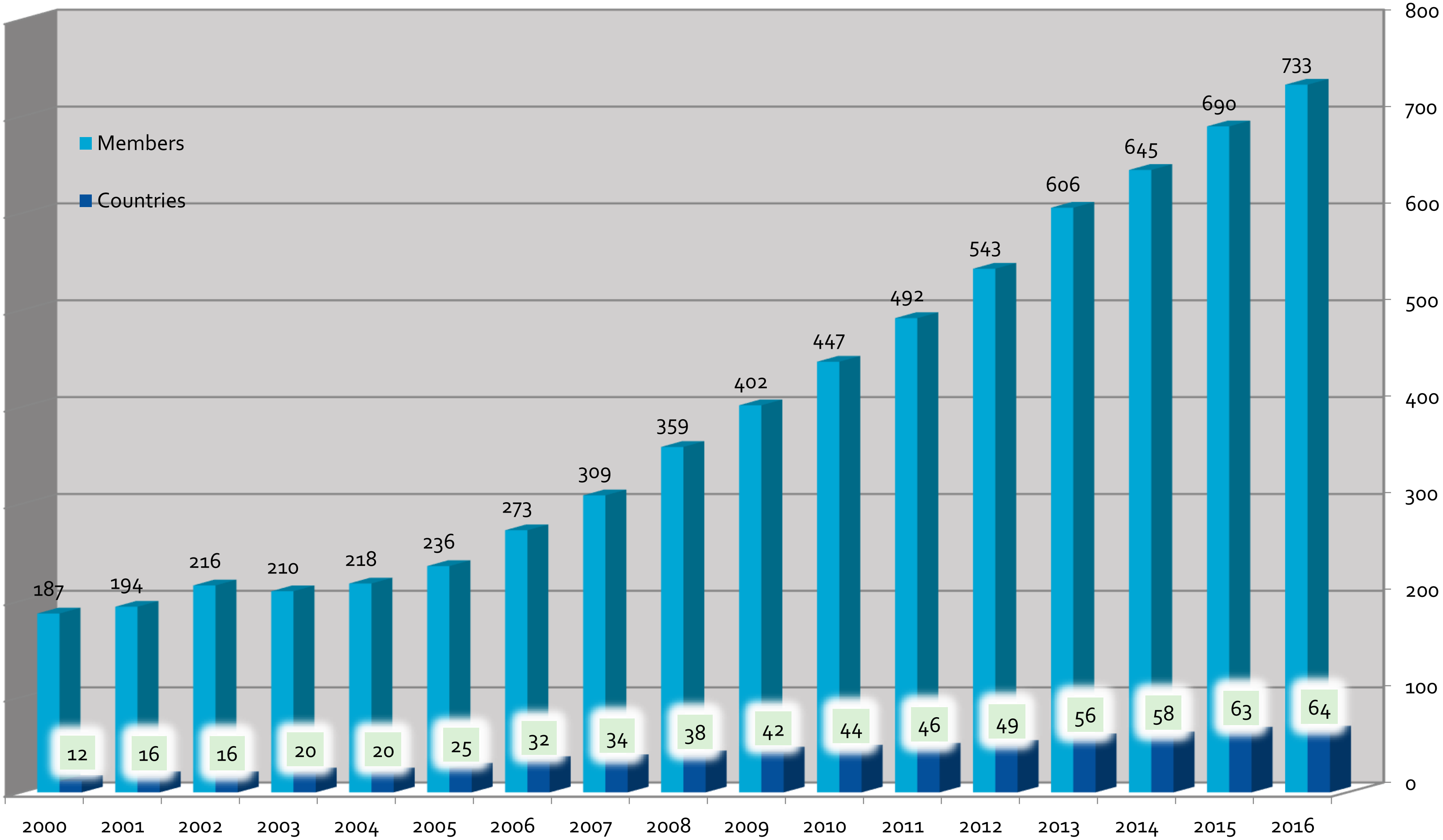
EURORDIS Membership 2000 - 2016



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EURORDIS member patient organisations in Europe & beyond

🟥 Associate Member

🟦 Full Member

European Reference Networks (ERNs)

ERNs aim to improve access to diagnosis and treatment by providing high-quality healthcare to patients who have conditions requiring a particular concentration of resources or expertise, such as rare diseases.

ERNs are networks of centres of expertise, healthcare providers and laboratories that are organised across borders

Expertise travels across borders, rather than the patient

- Patient-centred, involving patients from the start and as equal partners in all ERNs
- Optimal framework for multisystem rare diseases, every patient with a rare disease has a home under an ERN, leaving no one behind
- Anchored into national health systems
- Vehicle that will pave the way for faster diagnosis and access to expert care

ERNs are a game changer for Rare Diseases: There will be "before" and "after"

- European wide collaboration with nearly 1000 HCP from 26 Member States in 24 ERNs
- Magnetise patients needs to the right expert, leading to faster diagnosis and treatment
- Transparency on patient health outcomes from care received as a driver for clinical excellence
- Create a critical mass of patients and data, push the pace of research and clinical practice
- Connect and implement existing knowledge and experience of leading clinicians, researchers and patients
- Generate new knowledge

European Patient Advocacy Groups (ePAGs)

European Reference Networks (ERNs) created on founding principles of patient-centred care, patient advocate empowerment and patient engagement

ePAGs:

- **24 forums** for dialogue, unity & solidarity to optimise involvement of patients
- **Represent** patients to engage in application process & governance of RD ERNs
- **Open** to members & non-member patient groups in EU
- **Aligned** with RD ERN scope
- **Composed** of **84 elected ePAG representatives** & **934 ePAG member organisations**
- **Established** where there is an ERN application & progressively expanded
    - Terms of Reference
    - Call for Expression of Interest (16 March 2016) & Elections of ePAG representatives (21 April – 4 May 2016)
- Process **launched** in May 2015 & ePAGs **announced** in May 2016

ERNs & ePAGs

ERNs	ePAGs
ERN BOND	Rare Bone dis.
ERN CRANIO	Cranofacial anomalies
Endo-ERN	Endocrine dis.
ERN EpiCARE	Rare Epilespsies
ERKNet	Renal diseases
ERN RND	Neurological dis.
ERNICA	GastroIntestinal dis.
ERN LUNG	Pulmonary dis.
ERN Skin	Skin diseases
ERN EURACAN	Solid Tumours
ERN EuroBloodNet	Haemato. Diseases & malignancies
ERN EURO-NMD	Neuromuscular
ERN EYE	Eye diseases

ERNs	ePAGs
ERN GENTURIS	Genetic Tumour Risk Syndromes
ERN GUARD-HEART	Rare Cardiac
ERN ITHACA	Congenital malformations/ intellect. disabilities
MetabERN	Metabolic disorders
ERN PaedCan	Paediatric cancers
ERN RARE-LIVER	Hepatic disorders
ERN ReCONNET	Connective Tissue / Musculoskeletal dis
ERN RITA	Immunodeficiency, Autoinflammatory / Autoimmune dis.
VASCERN	Mutli-systemic vascular dis.
UROGENITAL	Urogenital diseases
TRANSPLANT-CHILD	

EURORDIS' role in ERNs

- Develop EUCERD Recommendations/ Addendum to ensure that **RD ERNs are patient-centred** with patient representation structured in the formal governance & operational delivery of ERNs
- Create **European Patient Advocacy Groups,** structured around the thematic ERN groupings outlined in the EUCERD Addendum & representative of rare diseases/ the associated patient organisations
- Lead Partnership for Assessment of Clinical Excellence in ERN (PACE-ERN) Consortium with HOPE and Accreditation Canada International to develop the technical proposal for the **Assessment Manual & Technical Toolbox** for ERN applications, on behalf of the European Commission

Patient expectations from ERNs: Clinical excellence & Improved Patient Health Outcomes

Our hope is that 30 million lives affected by rare diseases in the EU will be improved through:

- **National healthcare system coverage** of all rare diseases and across all EU countries
- **Open access** to expert advice for timely, accurate diagnosis and treatment
- **Increased evidence and adherence** to clinical guidelines
- **Accelerated pace of research**, integration healthcare and research infrastructures
- **Linked patient data** that are 'Findable, Accessible, Interoperable and Reusable'
- **Increased access to better therapies**, with faster development of new therapies for ALL RD

Rare Diseases International

RARE
DISEASES
INTERNATIONAL

A EURORDIS INITIATIVE

- What is Rare Diseases International (RDI)?

RDI is the global alliance of people living with a rare disease of all nationalities across all rare diseases. It counts 40 member organisations at the end of 2016.

- Who is involved?

RDI is a EURORDIS initiative set up with National Alliances around the world with whom we have signed partnership agreements (MoUs).

- Why Rare Diseases International?
  - To enhance capacities of Rare Diseases International members through information, exchange, networking, mutual support, joint actions
  - To represent its members & people living with rare diseases internationally
  - To promote RDs as an International Public Health & Research priority through public awareness and policy

www.rarediseasesinternational.org