



European Reference Networks and European Advocacy Patient Groups 101

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WHAT ARE THE EUROPEAN REFERENCE NETWORKS

European Reference Networks (ERNs) are healthcare networks that connect clinicians, researchers and patient representatives working on the same group of rare diseases, complex conditions or highly specialized surgery.

There are 24 Networks, that bring together nearly 1,500 Expert centres located in the 27 EU Member States and Norway.

Each Network focuses on a different group of diseases (e.g. Rare bone diseases).



WHAT ARE THE OBJECTIVES OF THE EUROPEAN REFERENCE NETWORKS



1. Facilitate sharing of knowledge and clinical best practice, inside and outside the Networks
2. Foster training of professionals and increase experts' mobility
3. Accelerate rare disease research and contribute to build reliable epidemiological data on the burden of rare diseases

... all this with the overall aim of improving access to timely, accurate diagnosis and adequate care and treatments for the 30 million people living with a rare disease in Europe.

WHAT IS THE ROLE OF ...



European Reference Network Coordinators (x 24)

Strategic direction, clinical leadership and coordination of Network activities.

All ERN Coordinators are members of the ERN Coordinators Group where they discuss matters that are of common interest to the 24 ERNs.

European Patient Advocacy Groups (x 24)

Represent the voice and interests of patients in the European Reference Networks' strategic planning and activities.

EU Member States + Norway

Lead role in the designation, development of European Reference Networks and their integration in national health systems.

All countries have a representative in the ERNs Board of Member States.

European Commission

Main source of public funding

Provide technical support, including IT infrastructure and services to all 24 ERNs.

Oversee and manage the designation of new healthcare providers that want to join the Networks (via public calls).

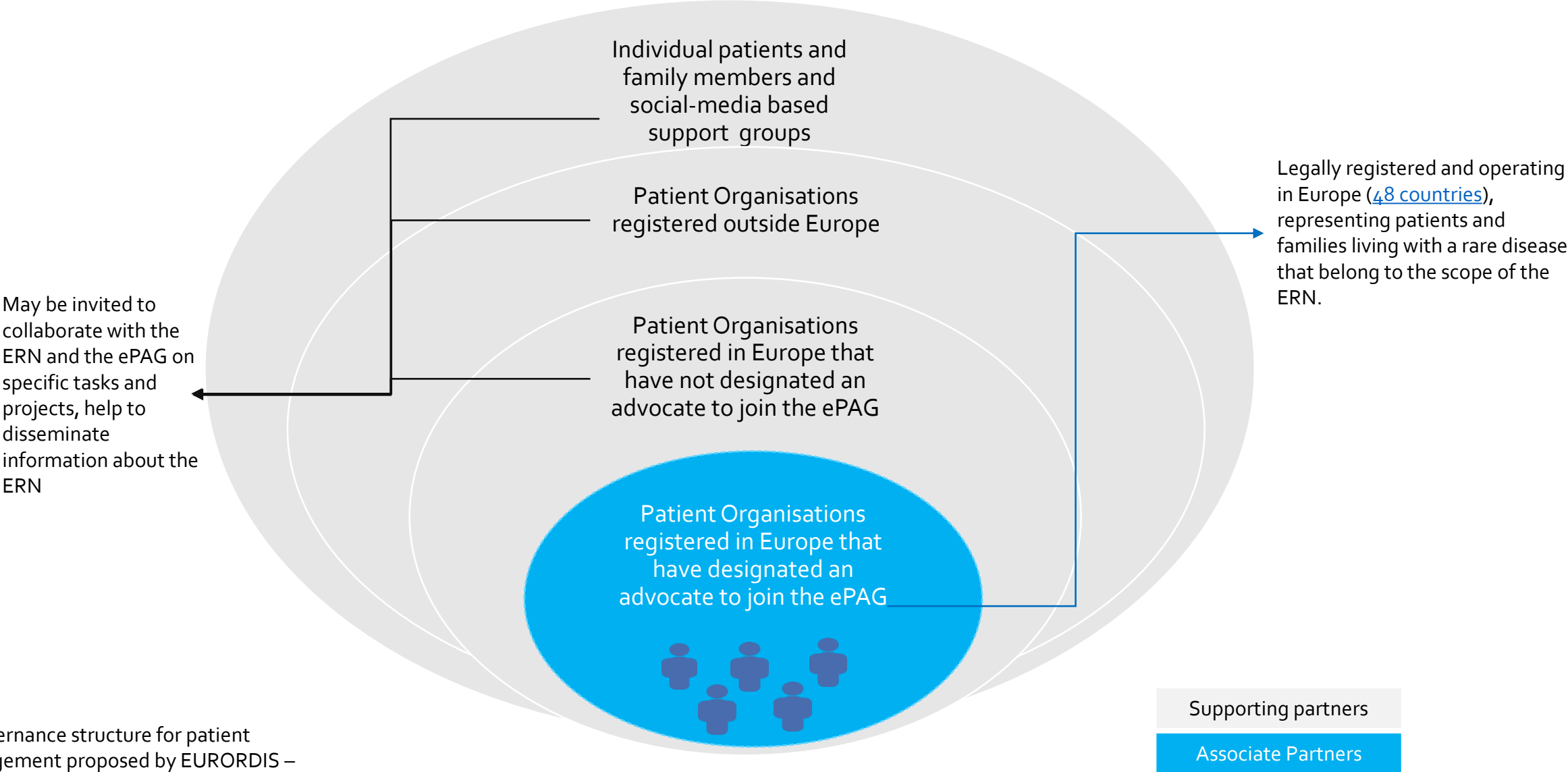
*Some ERNs use a different terms to designate their patient group

HOW ARE PATIENTS AND PATIENT ORGANISATIONS INVOLVED IN THE EUROPEAN REFERENCE NETWORKS

European Patient Advocacy Groups (ePAGs) are patient groups that bring together rare disease patient advocates who are actively involved in the 24 European Reference Networks, working in partnership with clinicians and researchers.



TWO LEVELS OF PATIENT ENGAGEMENT IN THE EUROPEAN REFERENCE NETWORKS*



*Governance structure for patient engagement proposed by EURORDIS – Not all ERNs have fully implemented it

What is the role of the European Patient Advocacy Groups advocates...

- ensure that the needs of people living with a rare disease drive the activities of each European Reference Network.
- champion the diversity of views of the wider patient community relevant for each ERN, and not just of their own disease area.
- work with their national and European networks to facilitate two-way communication between the European Reference Networks and the patient community.
- work in partnership with the clinicians to support the development of standards of care, clinical decision support tools and contribute to research, education, information and awareness activities.



The position of an ePAG advocate is a voluntary position and does not involve any financial compensation.

HOW IS EURORDIS SUPPORTING THE ADVOCATES INVOLVED IN THE ERNs

- EURORDIS supports advocates involved in European Patient Advocacy Groups by developing tools and processes to fulfil their mission and role in the European Reference Networks.
- EURORDIS facilitates the engagement of advocates in different areas of work: clinical practice guidelines, clinical decision support tools, research, evaluation, training and communication.
- EURORDIS facilitates peer learning and exchange of good practices between ePAG advocates on a regular basis.
- EURORDIS supports the overall governance of ePAGs and recruitment of new advocates and help identify new candidates.



HOW IS EURORDIS SUPPORTING THE ADVOCATES INVOLVED IN THE ERNs

EURORDIS manages working groups to favour peer learning and support advocates in the following areas



Clinical
Practice
Guidelines

Training and
Education

Consolidation
of ERNs

Research and
Registries

Connecting
patients with
ERNs

Quality
Improvement

WHERE TO FIND MORE RESOURCES

Patient organisations as well as individual patients or family members interested in receiving updates and information on the ERNs activities or willing to collaborate on specific projects and activities to support the Networks, may contact ePAG advocates to find out more: [ePAG Factsheet: here](#).

ePAGs

ePAG Section EURORDIS website: [here](#)

ePAG Good Practices: These are examples of activities that ePAG advocates have developed in the ERNs: [here](#)

ERNs (24 Networks)

European Commission website: [here](#)

Legislation

- [Directive 2011/24/EU](#) on patients' rights in cross-border healthcare
- Commission [delegated decision \(annex\)](#) defining the criteria and conditions that healthcare providers and the ERNs should fulfil
- Commission [implementing decision \(annex\)](#) defining criteria for establishing and evaluating ERNs
- Commission [Implementing Decision](#) (EU) 2019/1269 of 26 July 2019 amending Implementing Decision 2014/287/EU