EURORDIS
RARE DISEASES EUROPE

European
Patient
Advocacy
Group

THE INVOLVEMENT OF PATIENT ORGANISATIONS AND PATIENTS IN THE EUROPEAN REFERENCE NETWORKS

What are the European Reference Networks?

European Reference Networks (ERNs) are networks of Centres of Expertise that connect experts and researchers, who share the same interests in a specific rare disease or highly specialised treatment, across the European Union and the countries of the European Economic Area region. ERNs are first and foremost healthcare networks that aim to improve access to diagnosis, care and treatment by sharing their expertise, knowledge and resources, guiding care and treatment.

It is therefore of utmost importance that ERNs remain centred on patients' needs. **ERNs give clinicians and patient organisations from different countries the opportunity to co-design better healthcare services for people living with rare diseases.**

What are the European Patient Advocacy Groups?

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. Each of the 24 Networks focuses on a particular disease area and has its own ePAG.

What is the role of ePAG advocates?

They represent the interests and needs of the patient community:

- to ensure that the needs of people living with a rare disease drive the activities of each European Reference Network.

- to champion the diversity of views of the wider patient community relevant for each ERN, and not just of their own disease area.

- to work with their national and European networks in order to facilitate two-way communication between the European Reference Networks and the patient community.

- to work in partnership with the clinicians to support the development of clinical practice guidelines and other 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. Individuals must be endorsed by a patient organization based in a European country to join as an ePAG advocate and be involved in ERN working groups.

How can patient organisations and patients get involved in the ERNs?

Submit an application to designate an ePAG advocate!

Patient organisations that wish to designate a representative to join a European Patient Advocacy Group and be involved in the ERN working groups may contact lenja.wiehe@eurordis.org to ask for further information.

Receive updates or support specific projects and activities of the ERNs!

This type of lighter engagement has not yet been organised in all ERNs. 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.

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