

Thinking of getting involved in the ERNs as an ePAG advocate?

This short guide can help you to decide whether to apply

What are the European Reference Networks (ERNs)?

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 (ePAGs)?

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 an ePAG Advocate?

ePAG advocates represent the interests and needs of the patient community:

- to ensure that the needs of people living with a rare or complex condition 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 Network and the patient community.
- to work in **partnership with the clinicians and other patient representatives** to support the development of clinical practice guidelines and other clinical decision support tools, and the development of other ERN core activities in the areas of research, education, information and awareness raising.

The key role of ePAG advocates is to be a bridge between the ERN and the patient community



What do you need to ace as an ePAG Advocate?

To fulfil your role, you will need to bring some **skills, experience and motivation** to the table:

- Have **knowledge** of, or **experience of living** with, one of the rare and complex conditions included in the scope of the ERN.
- Willingness and **motivation** to get involved, contribute actively to the discussions and work of the ePAG and the ERN working groups.
- Ability to work **effectively and constructively** with other patient representatives and clinicians from different EU countries.
- **Ability to represent the interests** of people living with any of the diseases under the scope of the ERN, beyond your own disease.
- Ability to bring **independent judgement** from a patient representative perspective.
- Have an awareness of, and commitment to, **equality, diversity and inclusiveness**.
- High level of organisation and **self-motivation**.
- Understand the need for **confidentiality**.
- Fluency in **English** to be able to follow and contribute to meetings.
- Have **computer skills** and equipment to communicate through email, webinars, and videoconferences.
- Have knowledge or be willing to acquire **new knowledge** about the rare disease policy environment.

Having previous experience working in a committee setting with clinicians and other patient representatives is extremely helpful!

EURORDIS and ERNs value the time and contribution of ePAG advocates and the crucial role you play to deliver the Networks' vision and objectives. Your ERN Coordinating team and EURORDIS **will offer support and guidance** to help you fulfil your role as a patient representative in the ERN (for more information on EURORDIS support please read this [document](#)).

Benefits of becoming an ePAG advocate

ePAG advocates role and position in the ERNs give these representatives the possibility to:

- Work closely with clinicians, researchers, and other patient representatives to transform healthcare services and accelerate research to improve the health outcomes of people living with a rare disease in Europe.
- Participate firsthand in the development of the ERN objectives and infrastructure to ensure that it remains driven by patients' needs.
- Increase their international exposure and expand their international network, specifically across Europe.
- Improve their understanding of healthcare models across Europe and European Reference Networks.
- Further develop soft skills such as communication, public speaking, conflict resolution, etc. acquired through trainings such as the ones provided by EURORDIS through its Open Academy, EUPATI and others, and through active participation in the ePAG.
- Share and learn from other ePAG advocates and build their own capacities as patient representatives, broadening knowledge both within their own field of rare diseases and beyond.

What would be your responsibilities as an ePAG Advocate?

Being proactive and accountable

- Participate in and contribute to ERN working groups and attend the ERN annual meetings, when invited.
- Participate in ePAG calls.
- Report regularly in the ePAG calls and meetings on the progress of the work and projects in which you are directly involved in the ERN.
- Contribute to identify & develop the ePAG annual objectives and work programme.

Having a collaborative and team spirit

- Work constructively with other patient representatives and clinicians.
- Contribute to the assessment of new ePAG membership applications.
- Welcome and help with the training and integration of new ePAG advocates.

Being respectful and compliant

- Respect the confidential nature of the discussions.
- Comply with the ERN conflict of interest policy.
- Comply with the ERN's Terms of Reference and the ePAGs Terms of Reference. Adhere to the terms of a mediation agreement in the case you're involved in a mediation process.

Depending on your time, interests, expertise and skills you may engage in a variety of activities and projects, such as:

- contributing to develop a clinical practice guideline and other clinical decision support tools.

- developing patient journeys or other tools to identify the needs and expectations of the patient community in the care pathway.
- supporting ERN-awareness raising activities, including webinars, delivering presentations in external events, social media campaigns, etc.
- contributing to connect local medical and patient community with the ERNs and other actions to integrate the ERN into national health systems
- helping to develop educational activities for clinicians.
- supporting the development of materials for families and people living with a rare or complex condition.
- contributing to identify and develop relevant outcome measures.
- contributing to the development and management of the ERN registry.

In the fulfilment of your role as an ePAG advocates you must commit to adhering to the following **core values**:

- Respect the mission of the ERN and its governance structure.
- Listen to the opinions and requests of others.
- Show solidarity, mutual respect and support.
- Adhere to the principles of equity and social justice.
- Conduct yourself with professionalism in engaging with the clinical, research leads and fellow patient advocates.

How much time would you need to commit?

ePAG advocates time commitment to work on ERN-related matters varies widely. This a voluntary position, so it really depends on your availability to engage in the Network's activities. A rough estimate of the time required is presented in the table below.

Task	Periodicity	Time commitment
Regular ePAG meeting (within your ERN)	Approx. every two months	1h to 1h 30 min
ERN working groups calls	Variable, depending on the groups you'd like to be involved in	Time to prepare: 30 min-1h Duration of calls: 1h to 1h 30 min
ERN annual meeting* and ePAG annual meeting	Once a year	1-2 days meeting
Document writing, review and reading	Highly variable	Typically, 2 days per month but can increase to 5 days per month

*Attendance will be subject to the ERN budget availability

Interested in applying?

Individuals must be endorsed by a patient organisation based in a European country listed [here](#) to join as an ePAG advocate and be involved in ERN working groups.

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

compensation. Travel and accommodation expenses will be reimbursed according to the ERN policy on reimbursement for travel expenses.

You may contact the contact persons in each ePAG – go [here](#) and click on **“get involved in the ePAG”** to see the list. You may also drop an email to PEM-ePAGs@eurordis.org to ask for further information