

## 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?

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.

## 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!

## 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 and develop the ePAG annual objectives and work programme.

### Having a collaborative and team spirit

- Work constructively with other patient representatives and clinicians involved in the ERN.
- 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.

Also, 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. Regardless of this, a rough estimate is presented in the table below.

Task	Periodicity	Time commitment
Regular ePAG meeting (within your ERN)	Approximately every two months	1h to 1h 30 min
ERN working groups calls	Variable, depending on the groups you’d like to be involved in	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?

You would need the endorsement of a patient organization based in one of the 48 European countries listed [here](#). You may contact [PEM-ePAGs@eurordis.org](mailto:PEM-ePAGs@eurordis.org) to ask for further information.