

Process for establishing EURORDIS Patient Advocacy Groups (E-PAGs)

EURORDIS is pleased to invite rare disease patient organisations (EURORDIS members and non-members) across Europe to collaborate in the creation and development of EURORDIS Patient Advocacy Groups (E-PAGs).

[E-PAG Terms of Reference](#) have been developed in consultation with EURORDIS members outlining the governance structure and working procedures of E-PAGs.

EURORDIS Patient Advocacy Groups

E-PAGs are formed of **member organisations** and **elected representatives**. Membership of E-PAGs is open to all rare disease patient organisations, EURORDIS members and non-members, based in the European Union. E-PAG **member organisations** are aligned to the [grouping](#) of the rare diseases covered by the respective ERNs. To become a member organisation in a particular E-PAG, the patient organisation must represent diseases included in a specific ERN grouping.

E-PAG representatives are elected by the E-PAG members to be their voice at the ERN Board and ensure rare disease patient organisations are consulted by the ERNs for disease-specific discussions, project and activities.

Time Commitment

E-PAG representatives should consider the following workload/time commitment for their work for E-PAGs and ERN:

- Approximately 2 days per month (travel, meetings, etc.)
- 6 days per year for ERN Board meetings, plus preparation and debriefing time

Profile

E-PAG representatives should have significant experience in:

- Patient engagement and representation (in meetings, committees and boards)
- Patient advocacy
- National or European activities or projects

E-PAG representatives must:

- Speak fluent English (spoken and written)
- Live in one of the European Union's Member States



E-PAG member organisation registration

Registration is open to all European rare disease patient organisations. To register the interest of your patient organisation in becoming an E-PAG member organisation, and to collaborate, consult and be kept informed of developing ERNs, please email lenja.wiehe@eurordis.org indicating which [ERN](#) you wish to be affiliated to.

E-PAG representative elections

EURORDIS invites representatives of rare disease patient organisations (EURORDIS members or non-members) to step forward and voice interest in being a candidate for the E-PAG representative elections.

If you wish to apply to become an elected E-PAG representative, please return the [application form](#) to lenja.wiehe@eurordis.org, **before 24 March 2016**.

Please complete the application form, including a short biography and a personal statement why you wish to be considered for this role, and how your experience meets the expectations of the role. Please provide written endorsement from your respective patient organisations for support of your candidacy for the E-PAG representative elections.

All applications will be posted on an online voting platform. **Elections will take place from March 24 to 31**. Each patient organisation has 1 vote, inside their ERN Group. Ideally, each E-PAG will have 2 – 6 elected representatives.

Timeline

The process will consist of two stages:

- Raise awareness and consult with members and non-members requested for confirmation of alignment with ERN groups of diseases
 - EURORDIS members: Written consultation in **January 2016**
 - EURORDIS non-member: Engagement of National Alliance and European Federations to reach out to their members from **February 2016 to March 2016**
- Expressions of interest & elections for elected EPAG patient representatives
 - Email your expressions of interest to lenja.wiehe@eurordis.org **before 24 of March**, indicating which [ERN](#) you wish to be affiliated to.
 - Elections will be organised online **between the 24 and 31 March 2016**
 - Election results will be send on the **4 April 2016**

Appendix1

Brief on European Reference Networks

Why and what are ERNs

European Reference Networks (ERNs) create a clear governance structure for knowledge sharing and care coordination across the EU. They are networks of centres of expertise, Healthcare Providers (HCP) and laboratories that are organised across borders.

Due to the low prevalence and complexity of rare diseases, as well as to the nature of small and scattered patient populations, the system of ERNs that is being established can **bring real added value to rare disease patients**. ERNs aim to provide healthcare professionals with access to expertise that they may not have in their country.

ERNs and Groupings

It is unfeasible to create a separate ERN for every one of the over 6000 rare diseases that exist; ERNs will therefore be organised according to disease groupings. This grouping of diseases does not prevent a patient from being able to go to a disease-specific centre of expertise, nor from benefiting from the expertise of several ERNs.

EURORDIS aims to ensure that every rare disease patient, including the undiagnosed, will be covered by one ERN so that every person living with a rare disease finds a home within the European system of ERNs.

The current proposed list of groupings is below, and included on page 7 of the [Addendum to EUCERD Recommendations of January 2013](#).

Bone	Immunological & auto inflammatory
Cardiac	Malformation/dev. Anomalies/intellectual disabilities
Connective tissue & musculoskeletal	Metabolic diseases
Craniofacial & ENT	Multisystem vascular
Rare Cancer	Neurological diseases
Endocrine	Neuromuscular
Eye diseases	Pulmonary diseases
Gastrointestinal	Renal diseases
Gynaecological & obstetric	Skin disorders
Haematological	Urogenital diseases
Hepatic disorders	

EURORDIS is establishing a EURORDIS Patient Advocacy Group (E-PAG) for each emerging and established RD ERN, gathering elected patient representatives who will ensure that the patient voice is heard throughout the development of ERNs.

Patient centred-care and empowerment (Commission Expert Group on Rare Diseases Addendum to EUCERD Recommendations)

Patient organisations are not legally required to participate in the governance and evaluation of ERNs, but ERNs *are* required to demonstrate patient-centric care and patient empowerment.

Due to the complexity and low prevalence of rare diseases, as well as to the limited body of knowledge, experience and expertise in the field of rare diseases, the role of rare disease patients (as experts in their diseases) in the development of ERNs is more fundamental.

Therefore, a higher level of involvement of patients in the decision and opinion-making processes is essential to ensure the successful development of ERNs. The [Addendum to EUCERD Recommendations of January 2013](#) outlines detailed recommendations on how patient representatives can fully participate in the application, operational delivery and governance of ERNs. This strategic approach is fully endorsed by Member States and the European Commission.

Phased development and expansion of ERNs scope and functions

ERNs will, over the course of their five-year licensing, expand the scope of rare and complex diseases or highly specialized interventions under their grouped RD ERN. The E-PAG will also expand to ensure a continuous alignment of patient group representation with the scope of their affiliated RD ERN.

Member States will also designate Collaborative and Associated Centres to be affiliated to the RD ERNs. This is a Member State competency which will be formally undertaken in 2017. The Board of Member States has not yet agreed on the functions of these two types of affiliated centres to date.

Evaluation of ERNs

ERNs will be approved for a five year period, when they will be evaluated by an independent body and recommended for a renewal of their status.

Assessment of Centres of Expert and Healthcare Providers into an existing ERN

ERNs will also expand to increase their geographical spread and representation with new HCPs applying to join the network. These new HCP will be assessed against the same criteria and through the same process the original ERN was independently assessed.