

# EURORDIS Patient Advocacy Groups (E-PAGs)

## Term of References

### Introduction

European Reference Networks (ERNs) are created on the founding principle that they should be patient centered and empower patients. Patient organisations are integral to European Reference Networks in rare diseases (RD ERN). Patient organisation participation enhances the capacity of ERNs to improve patient health outcomes and patient satisfaction.

EURORDIS and its members understand the need and value of creating forums for dialogue, unity and solidarity amongst patient organisations, the need to optimise the involvement of patient and ensure equitable representation of all rare diseases covered in the scope of the [ERN disease grouping](#).

EURORDIS and its Council of European Federations promote the innovative approach of Patient Advocacy Groups (E-PAGs) to facilitate a structured patient engagement process in the decision and opinion forming process of RD ERNs, and to ensure that they are involved and contribute actively to the mission, services and network activities of ERNS.

E-PAGs are formed of patient organisations (both members and non-members of EURORDIS) within the scope of the specific grouping of each ERN. Each E-PAG mirrors the ERN grouping of rare diseases. E-PAGs will work collaboratively with ERN Healthcare Providers (HCPs) (full, associate and collaborative members) based on the operational criteria to be fulfilled to be an ERN and a HCP.

### Mandate

E-PAG representatives are full members of their respective ERN Boards and they participate in the decision making process as agreed on in every network.

E-PAG representatives have an official permanent mandate to represent EURORDIS and the affiliated patient organisations. They will liaise with their affiliated patient organisations to ensure true and equitable representation of the patient voice in their respective ERN.

### Objective

E-PAG representatives provide the patient perspective to the ERN Boards on the organisation and management of the network, specifically to<sup>1</sup>:

- Ensure care is patient-centred and respects patients' rights and choice;
- Promote and encourage a patient-centric approach in both delivery of clinical care, service improvement and strategic development and decision-making;
- Ensure transparency in quality of care, safety standards, clinical outcomes and treatment options,

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<sup>1</sup> Commission Expert Group for Rare Diseases, Rare Disease European Reference Networks: *Addendum to EUCERD Recommendations*, 10 June 2015

- Ensure all ethical issues and concerns for patients are addressed, balancing patient and clinical needs appropriately;
- Ensure feedback and evaluation of patient experience;
- Contribute to the development of patient information, policy, good practice, care pathways and guidelines;
- Ensure the application of personal data rules, compliance of information consent and management of complaints;
- Advise on planning, assessment and evaluation of the ERN; and
- Ensure the needs of all people living with a rare disease are considered and included in the ERN discussions and activities, specific to the scope of their respective ERN.

**E-PAG representatives** collaborate with **E-PAG members** to participate in the specific activities above.

### Composition

Membership of E-PAGs is open to all rare disease patient organisations, EURORDIS members and non-members, based in the European Union. Patient organisations based outside the European Union, in Europe at large or based in other countries relevant to the specific ERN, will progressively be included, on a case-by-case basis, in conjunction with the collaboration of ERNs with HCPs beyond the EU.

E-PAG membership is voluntary and structured as follows:

- **E-PAG members** are patient organisations aligned to the grouping of the rare diseases covered by the respective ERNs.
- **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, projects and activities. E-PAG representatives are all based in the European Union.

### Commitment

E-PAG representatives commit to:

- Reflect patients' viewpoints through proper internal consultation with their respective E-PAG's members to the best of their ability;
- Share important news and send a brief report of any ERN meeting attended to their respective E-PAG affiliated members and EURORDIS;
- Inform EURORDIS when representing the EPAG at a conference, workshop, or any meeting of public importance;
- Travel to meetings when required<sup>2</sup>; and
- Declare their potential Conflicts of Interests in formal meetings or activities.

E-PAG representatives are appointed for a two year term renewable by agreement for a further 3 year period. There is no remuneration for this role at present.

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<sup>2</sup> Travel related to ERN functions should be covered by the ERN. Travel related to E-PAG coordination and capacity building activities will be covered by members or shared costs between EURORDIS and members.



E-PAG representatives adhere to the [EURORDIS Charter of Volunteers](#) and declare their potential Conflict of Interest at time of election.

EURORDIS commits to:

- Support the creation of E-PAGs and the democratic election process of E-PAG representatives;
- Support the work processes of E-PAGs, mostly to be conducted through emails, RareConnect discussion groups and conference calls as well as the occasional face-to-face meeting;
- Provide staff support to E-PAG activities through the permanent interaction with EURORDIS leads for patient organisation relationships, healthcare and research;
- Provide specific support, when required, from EURORDIS managers and teams in research infrastructures, therapeutic development, information & access, survey, social policy and public affairs;
- Coordinate direct involvement and integrated action from EURORDIS activities, where appropriate in the Joint Action Rare Diseases, Joint Action Rare Cancers, Joint Research Centre platform for Rare Disease Registries, RD-Connect, Best Practices of Diagnostic and Care and other projects relevant to ERN, in a transversal and servicing manner;
- Facilitate the exchange of experience and knowledge across E-PAGs; and
- Provide consolidation of views across E-PAGs and the capacity for joint positions.

#### **Adoption, Implementation and Revision**

E-PAG Terms of Reference have been developed with contributions from European Federations and adopted by the EURORDIS Board of Directors in March 2016.

These terms of reference will be implemented in a flexible manner adapting to the specific situation of each rare disease grouping and reality of the actual networking of patient groups in this disease area. They will be revised based on experience gained and in line with the developing needs, specificity and functions of ERNs.