

NETWORK AGREEMENT REGARDING THE RULES FOR THE EUROPEAN PATIENT ADVOCACY GROUPS (EPAGS)

European Reference Network on Rare Bone Diseases

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

Share. Care. Cure.



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NETWORK AGREEMENT REGARDING THE RULES FOR THE EUROPEAN PATIENT ADVOCACY GROUP

European Reference Network on Rare Bone Diseases

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Short description:

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 fundamental. Therefore, this document establishes the ERN BOND internal procedure to become an ERN BOND ePAG member for a higher level of involvement of patients in the decision and opinion-making processes is essential to ensure the successful development of ERNs.

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INTRODUCTION

Patient representation and partnership with clinicians are vital tools for the ERN BOND to reach the goal of making expertise accessible and improving health outcomes to rare bone disease patients all over Europe.

The rules for organising the Patient Advocacy Group within the ERN BOND are based on the constitution of the ERN. It is stated: “patient advocates and patient organisations are recognised by the European Commission Expert Group for Rare Disease, as integral to the strategic and operational delivery of European Reference Networks in rare diseases (RD ERN) and should play an active role in the networks’ decision and opinion-making structures”.

From EURORDIS European Patient Advocacy Group (ePAG) Constitution and Rules of Procedure (May 2019).

ERN BOND EUROPEAN PATIENT ADVOCACY GROUPS (ePAG)

ERN BOND ePAG group represents patients with rare bone diseases currently covered by ERN BOND ([Rare Bone Diseases – ERN BOND](#)). The ePAGs are involved in decision-making processes and all activities of ERN BOND. ePAGs collaborate within the ERN on equal terms as other members of the network. The ePAG group ensures the needs of patients and their families are heard and has the important role of being a communication and information link between the patient community and the clinical community.

ERN BOND ePAG APPLICATION PROCESS AND SELECTION CRITERIA

Applying to become an ERN BOND is done through a written application sent to the ERN BOND coordination team (info@ernbond.eu).

The written application should provide a brief bio, the motivation behind becoming an ePAG and an endorsement letter from a formally recognised rare bone disease patient organization. In case of ultra rare bone diseases, where patients are unrepresented by organizations, an endorsement letter provided by a BOND HCP member is welcome.

The recruitment of ePAGs is ongoing to ensure a sufficient coverage of patient involvement within the network at all times. All applications are reviewed and processed by the coordination team in close collaboration with the ePAG group based on the eligibility criteria.

New ePAGs are appointed through agreement with the ePAG group and formally by ERN BOND coordination. ePAGs are appointed for the current grant period, between 2023 and 2027, and can be reappointed for the next period

Essential criteria for new ePAG applicants

ePAGs are expected to have:

- High level of understanding, writing and speaking in English.
- Be over 18 years old.



- ❁ First-hand experience of living with one or more of the rare bone diseases covered by ERN BOND, as a patient or family member of a patient.
- ❁ Be endorsed by a formal national patient organisation in Europe.
- ❁ Have availability to participate in ERN BOND meetings and activities throughout the grant period. Most meetings are held online during office hours. ePAGs are expected to attend 75% of working group meetings, in addition to ePAG meetings and annual meetings in BOND.
- ❁ Have computer skills and virtual technology understanding for effective communication.

Desiderable criteria for new ePAG applicants

- ❁ Minimum understanding of medical, psychosocial and disability issues relevant for the rare bone patient community.
- ❁ Minimum understanding of the regulatory framework and issues relevant to health and social care in the field of rare disease.
- ❁ Have completed EURORDIS Open Academy, EUPATI training or equivalent, or be willing to undertake such training.
- ❁ Skills, experience and geographic areas not currently represented by the ePAG group will be preferred.

Check current ePAGs dedicated rare bone diseases here [Patient advocates – ePAGs – ERN BOND](#).

ROLE AND RESPONSIBILITIES OF ERN BOND ePAG

- ❁ Represent the patients with rare bone diseases covered by ERN BOND and adhere to principles of equity within healthcare.
- ❁ Work in partnership with all members of ERN BOND strengthening patient involvement throughout the network.
- ❁ Be an active member in at least one (1) working group in ERN BOND.
- ❁ Support ERN BOND to build and disseminate information, primarily to the patient community, and to other relevant communities (e.g., healthcare providers, health authorities, clinicians and medical professionals and their professional bodies).
- ❁ Support and participate in ongoing planning and activities in ERN BOND in a timely and constructive manner.
- ❁ Respect the mission of ERN BOND and its governance structure.
- ❁ Show mutual respect, solidarity and support within the network.
- ❁ ePAGs must declare conflicts of interest in formal meetings in order to maintain transparency within the network.
- ❁ When speaking at conferences or other events, the ePAG can present individual perspectives. Whenever speaking on behalf of the ePAG group, the ePAG should align to the current Network Agreement document, present the joint group views and perspectives and respect the values of the ePAG group.

ROLE AND RESPONSIBILITIES OF CO-CHAIRS AND SECRETARY

When ERN BOND has approved six (6) ePAGs or more, the ePAG group elects two Co-Chairs for 1 year mandate. The ePAG Co-Chairs can have a maximum of 2 consecutive mandates and could also take on the role of Secretary. The role and responsibilities of the two Co-Chairs include:

- Representation of the ePAG group in the ERN BOND Steering Committee, if otherwise is not decided;
- Representation of the ePAG group in the EURORDIS ePAG steering committee, if otherwise is not decided;
- Share information from the ERN BOND Steering Committee and ePAG Steering committee of EURORDIS.

The ePAG group also appoints a Secretary to help coordinate the group's activities. Such activities can include:

- Scheduling ePAGs meetings and other arenas of communication;
- Handling email requests and matters of concern for the ePAG group.

The Secretary can delegate duties, with prior notice to the ePAG group, if unable to attend meetings and/or complete tasks, if necessary.

The role of Secretary will rotate between all members of the ePAG group, in alphabetical order, and will execute activities for 3 months, if otherwise is not decided. These decisions are made by simple majority voting.

These designations are made by simple majority voting.

TERMINATION OF ROLE OF ePAG

An ePAG appointment in ERN BOND comes to an end if:

- The ePAG sends a notice of resignation to the ERN BOND coordinator.

or

- The ePAG does not respond to BOND related communication (coordination, working groups or ePAG group) nor participates in ERN BOND activities (coordination, ePAGs emails, working groups activities) for a period of 3 months without prior notice.

Before an appointment is terminated, the ePAG needs to be contacted and made aware of concerns to find a solution. All decisions of termination are made by joint agreement between the ePAG group and ERN BOND coordinator.

This document should be revised at the end of the current grant period.

COVERAGE OF EXPENSES






ePAGs collaborate with ERN BOND on a volunteer basis.

Expenses due to travel, accommodation and necessary assistance are covered by ERN BOND, in individual agreement with the ERN BOND coordinator. The ePAG sends a notice of resignation to the ERN BOND coordinator.

AUTHORITY OF THE ERN BOND BOARD

Nothing in this document removes the rights of the ERN BOND Network Coordinator and/or Steering Committee to interpret and/or amend the contents of this agreement in the best interests of the Network or to comply with relevant directives or guidance from the European Commission.

LINKS

-  [ERN BOND – European Reference Network on Rare Bone Diseases](#)
-  [About ERN – ERN BOND](#)
-  [About ERN BOND – ERN BOND](#)
-  [Rare Bone Diseases – ERN BOND](#)
-  [Patient advocates – ePAGs – ERN BOND](#)

NEXT STEPS

This document should be revised in conjunction with the next grant period from 2027.





https://ec.europa.eu/health/ern_en



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