

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

ERN BOND - European Reference Network on rare BONE Diseases

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

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DOCUMENT INFORMATION

NETWORK AGREEMENT REGARDING THE RULES FOR THE EUROPEAN PATIENT ADVOCACY GROUP

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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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1. INTRODUCTION

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

The rules for organizing the Patient advocacy group within the ERN BOND is based on the constitution of the ERN. It is stated: “Patient advocates and patient organizations are recognized 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)*

2. ERN BOND REPRESENTATION IN THE EUROPEAN PATIENT ADVOCACY GROUP (EPAG)

ERN BOND European Patient Advocacy Group (ePAG) is a patient forum comprised of Patient Organizations (POs) wishing to engage in ERN BOND. All ePAG Patient Advocates have been endorsed by their respective POs to be active in ERN BOND activities and governance board and committees.

ERN BOND ePAG aims to represent the voice of patients within all the disease groups included in the ERN BOND to ensure that the needs of people living with a rare bone disease are included in the strategic and operational delivery of the network. We strive to represent a diversity of patient organizations and geographical coverage.

In 2020, the current ERN BOND ePAGs have an advocacy background in: achondroplasia, Osteogeneses Imperfecta, XLH and Ollier-Maffucci syndrome. It would be ideal for new ePAGs to have knowledgeable on other rare bone disease areas.

3. ERN BOND ePAG ADVOCATES CRITERIA AND APPLICATION PROCESS

Anyone, including sitting members of the ePAG, can actively encourage new patient representatives to apply for membership in the group.

Enrollment and approval of new ERN BOND ePAG Advocates should be through a written application (the applicant should include an endorsement letter from his or her Patient Organization and a bio sketch). The application can be sent to the BOND coordinator who will routinely inform the ePAG in BOND about new applications.

The current ePAGs will subsequently consider applications and approve or reject new members. Applicants are evaluated based on the agreed eligibility criteria and the need for new/more members.

Approval of new ePAG Advocates is through agreement in the BOND ePAG and in consultation with the BOND SC.

ESSENTIAL ELIGIBLE CRITERIA

- High level of understanding, writing and speaking English;
- Knowledge of one or more of the diseases represented by ERN BOND, either as a patient, close family member of a patient, carer. All must be over 18 years old;
- Applicants will have to be officially endorsed by one (or more) National Patient Organization(s) and/or European Federation(s), which is registered in Europe and operates in Europe. If an association does not yet exist for a disease (is the case for most ultra-rare diseases) the applicant will be evaluated on an ad-hoc basis and can be accepted as ePAG member, given agreement between ePAG, Network Coordinator and EURORDIS Patient Engagement Manager;
- Minimum understanding of technical and medical issues
- Willingness and motivation to commit to a minimum of 20 days per year to BOND ERN work, ideally more;
- Computer skills and equipment to communicate through email, webinars and videoconferences.

DESIRABLE CRITERIA:

- Have attended EURORDIS Summer/Winter School or EUPATI training or equivalent, or be willing to undertake such training either online or face-to-face;
- Skills or experience in disease areas not currently represented in ERN BOND ePAG;

- Willingness to learn and comprehend regulatory issues regarding health care systems;
- Geographic affiliation and experience not currently represented in BOND ePAG.

4. STRUCTURE

When BOND has 6 approved ePAG, the group elects a coordinator and an alternate. The coordinator and alternate represent the group in the BOND Steering Committee. The group also elects a representative and an alternate for EURORDIS ePAG steering committee. These designations are made by simple majority voting.

The coordinator is responsible for coordinating the group activities and must work closely with the ERN BOND coordinator.

5. COVERAGE OF EXPENSES

All duties as an ePAG advocate are unpaid. Travel costs are handled between each ePAG and the network coordinator. The network coordinator will strive to financially support all activities that are important for fulfilling the role of ePAGs.

6. ROLE AND RESPONSIBILITIES OF ERN BOND ePAG ADVOCATES

All ePAG Advocates agree to represent the wider patient community and perform the following role and responsibilities:

- Work in partnership with the clinicians and researchers within ERN BOND
- Represent the voice of all patients from the rare disease(s) for which they are a Patient Advocate, provide feedback from that rare disease community, and create a bridge between ERN BOND and the community to improve access to high quality diagnosis, care and treatment
- Support ERN BOND to disseminate information, primarily to the patient community, but as appropriate to other communities (e.g., healthcare providers, health authorities, clinicians and medical professionals and their professional bodies)
- Contribute to the development of patient information, treatment policies, good practice guidelines and care pathways;
- Contribute to the development of research priorities and ensure they are informed by the needs of patients and families;
- Provide advice on ethical issues, and balance patient and clinical needs appropriately.

All ePAG Advocates also commit to adhering to the following set of core values:

- Respecting the mission of the ERN BOND network and its governance structure;
- Listening to the opinions and requests of others;
- Showing solidarity, mutual respect and support;
- Adhering to the principles of equity and social justice;
- Conducting themselves with professionalism in engaging with the clinical, research leads and fellow patient advocates;
- Having the capacity to be active in ERN BOND and report regularly on their activities.

Additionally, all ePAG Advocates must also declare any potential Conflict of Interest in formal meetings or activities and remain independent, irrespective of their personal situation, pathology, and/or association and pharmaceutical industries or other commercial organizations.

Should there be disputes involving clinicians and ePAGs, the ERN BOND Coordinator and the ePAG can jointly ask EURORDIS to mediate, if the dispute cannot be settled within the ERN.

7. TERMINATION OF ROLE OF ePAG PATIENT ADVOCATES

A Patient Advocate appointment in ERN BOND comes to an end if:

- The Patient Advocate sends a notice of resignation to the ERN BOND coordinator, or;
- The ePAG does not respond to emails and does not contact the group in a period of 3 months, or;
- The ePAG group decides, in discussion with EURORDIS, and the ERN BOND Coordinator, that it is in the best interests of ERN BOND that the representative in question should be removed.

Before any decision is finalized to remove someone from being an ePAG Patient Advocate:

- both the ePAG Patient Advocate and EURORDIS must be informed of the reasons why it is proposed to remove them;

- at least one month should be allowed for mediation and any concerns raised to be addressed;
- Reshuffling of ePAG should be considered each time new members are accepted in the BOND or at least every 10 years.

8. 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.



European Reference Networks

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