European Reference Network | ERN eUROGEN
Rare Uro-Recto-Genital Diseases & Complex Conditions

European Reference Network
for rare or low prevalence complex diseases
Network Urogenital Diseases (ERN eUROGEN)

ERN eUROGEN Rules for Patient Engagement

v. 2026-11-09

TABLE OF CONTENTS

1. Introduction 3
   1.1. History 3
   1.2. Purpose of Rules of Engagement 3
   1.3. Amendments 3
   1.4. Authority of the ERN eUROGEN Strategic Board 3
2. European Patient Advocacy Group (ePAG) 3
   2.1. Role 3
   2.2. Composition 3
   2.3. Meetings 3
   2.4. Decision-Making 4
   2.5. Administrative Support 4
3. ePAG Chair 4
   3.1. Role and Responsibilities 4
   3.2. Mandate 4
4. ePAG Representatives 4
   4.1. Core Values 4
   4.2. Roles and Responsibilities 5
   4.3. Mandate 5
   4.4. Skills and Experience 5
   4.5. Benefits 6
   4.6. Time Commitment 6
   4.7. Reimbursement 6
   4.8. Substitutes 6
5. ePAG Application Process 6
   5.1. Deciding Whether to Apply 7
   5.2. How to Apply 7
   5.3. How Applications Are Assessed 7
6. Induction 8
   6.1. EURORDIS 8
   6.2. ERN eUROGEN 8
7. Suspension and Termination 8
   7.1. Voluntary Suspension 8
   7.2. Termination 8

Funded by the European Union

7.3. Evaluation Process 8
8. Other Patient Engagement 8

ABBREVIATIONS

AGM	Annual General Meeting (of the ePAG)
BoMS	ERN Board of Member States
EC	European Commission
ePAG	European Patient Advocacy Group
ERN	European Reference Network
ERN eUROGEN	European Reference Network for Rare Uro-Recto-Genital Diseases and Complex Conditions
EUCERD	European Union Committee of Experts on Rare Diseases
EUPATI	European Patients' Academy on Therapeutic Innovation
EURORDIS	EURORDIS-Rare Diseases Europe, the European alliance of rare disease patient organisations
PAO	Patient advocacy organisation
SBM	Strategic Board Meeting

Funded by the European Union

1. INTRODUCTION

1.1. History

According to the European Union Committee of Experts on Rare Diseases (EUCERD), patients and patient representatives should play an active role in the decision-making and opinion-making process of the European Reference Networks (ERNs) and be involved in structural and clinical network activities. EUCERD recommended that ERNs demonstrate meaningful patient involvement, patient-centeredness, and empowerment by recognising patients' role (as experts by experience and co-producers of knowledge) in the ERNs' structural and clinical activities, thereby meeting the legal requirements in the Delegated Acts.

1.2. Purpose of Rules of Engagement

These rules aim at facilitating the effective involvement of patient representatives in the activities of ERN eUROGEN. They are based on the framework EURORDIS developed for patient engagement in the ERNs and include specific provisions to adapt them to the ERN eUROGEN Governance Statutes.

1.3. Amendments

The ePAG will review the rules annually at its Annual General Meeting (AGM) to ensure they remain fit for purpose and make any necessary amendments (see 2.3).

1.4. Authority of the ERN eUROGEN Strategic Board

Nothing in this document removes the ERN eUROGEN Strategic Board's right to interpret and/or amend its content in the best interest of the ERN or to comply with relevant directives or guidance from the EC.

2. EUROPEAN PATIENT ADVOCACY GROUP (EPAG)

2.1. Role

ERN eUROGEN's aim is that patient perspectives and the needs of people living with rare diseases and complex conditions covered by ERN eUROGEN are integrated into all aspects of the network's activities. To achieve this goal, the ePAG's role is to:

- Represent the voice and interests of patients and families within ERN eUROGEN.
- Ensure a patient-centric approach in the collaborative activities of ERN eUROGEN in the areas of care, education and training, knowledge sharing and research.
- Support the identification of ERN eUROGEN strategic priorities.
- Provide input on ethical issues.
- Support ERN eUROGEN in the dissemination of its activities and information to the wider patient community to ensure transparency.

2.2. Composition

The ERN eUROGEN European Patient Advocacy Group (ePAG) consists of ePAG Representatives from patient advocacy organisations (PAOs) and/or individuals/parents/carers affected by rare uro-recto-genital diseases and complex conditions under ERN eUROGEN's scope. The ePAG Chair is responsible for coordinating the ePAG.

2.3. Meetings

The ePAG meets approximately every two months for approximately 1 hour during working hours. ePAG Representatives also attend meetings of the ERN Workstreams and Working Groups in which they decide to be involved, and the annual Strategic Board Meeting (SBM), which is usually at least a full-day meeting.

Funded by the European Union

The ePAG meeting preceding the SBM is used as the ePAG's Annual General Meeting (AGM), where procedural items and governance matters can be dealt with ahead of the SBM, such as amendments to these Rules for Patient Engagement (see 1.3) and renewal of mandates (see 3.2 and 4.3).

2.3.1 Housekeeping Rules to Facilitate Effective Meetings

1. Participants should aim to join meetings from a private location where members of the public cannot overhear them and where there is no background noise.
2. Any items not on the agenda ('Any Other Business') should be declared at the start of the meeting so appropriate time can be allotted.
3. The Chair will raise the agenda items in order and will introduce anyone covering the items.
4. Anyone wishing to comment on/discuss the agenda items should use the meeting's "raise hand" feature and wait for the Chair to call them to speak in turn.

2.4. Decision-Making

Decisions in the ePAG are taken by consensus, but voting is possible if necessary. In the event of non-consensus, the voice of the ePAG Chair is predominant. The ePAG Chair casts two votes on behalf of the ERN eUROGEN ePAG on the ERN eUROGEN Strategic Board.

2.5. Administrative Support

The ERN eUROGEN Business Support Manager is responsible for supporting the administrative tasks of the ePAG group, including welcoming new ePAG Representatives or other members of the patient community, setting up the regular ePAG meetings (agenda, minutes, follow-up actions) and disseminating any relevant information to the ePAG.

3. EPAG CHAIR

3.1. Role and Responsibilities

In addition to the core values and role and responsibilities of the ePAG Representatives mentioned below, the ePAG Chair has the following responsibilities:

- Ensuring the sustainability of the ePAG.
- Coordinating the activities of the ePAG and reporting shared vision to the ERN Coordinator/Strategic Board and the EURORDIS Steering Committee/Transversal Group, etc.
- Sharing important news and updating the ERN eUROGEN ePAG and the wider patient community on ERN eUROGEN activities as appropriate.
- Consulting with the ERN eUROGEN ePAG and the wider patient community on relevant issues and feeding back information to the ERN eUROGEN Coordinator.
- Assigning ePAG Representatives to Working Groups.
- Monitoring ePAG Representatives' activities in the Working Groups
- Representing the voice of ERN eUROGEN ePAG and the wider patient community on the ERN eUROGEN Strategic Board, including casting two votes for the ERN eUROGEN ePAG on the ERN eUROGEN Strategic Board.

3.2. Mandate

The ePAG Chair is appointed for a period of three years. Their mandate may be renewed with the agreement of the ePAG and in consultation with the ERN eUROGEN Coordinator. When transitioning to a new Chair, where possible, they should represent a different Workstream and country than the previous Chair.

4. EPAG REPRESENTATIVES

4.1. Core Values

- Contribute to the overall strategy and mission of the ERN in all its aspects.

- Champion the diversity of views of the ERN eUROGEN community, and not just represent one's own disease area or experience.
- Respect the confidential nature of the discussions when it is made clear that this is a requirement by the person who is chairing a meeting.
- Conduct oneself with professionalism in engaging with clinicians and fellow patient representatives.
- Listen to the opinions and requests of others and show solidarity, mutual respect and support.
- Adhere to the principles of equity and social justice.
- Convey opinions and input while being respectful of the viewpoints and opinions of others, ensuring criticism is constructive to allow open and collaborative debate where all individuals can feel respected and valued.

4.2. Roles and Responsibilities

The role of all ePAG Representatives is to:

- Respect and comply with ERN eUROGEN's mission and Governance Statutes, including the ERN eUROGEN Conflict of Interest policy, and adhere to the decisions of the ERN Strategic Board.
- Work in partnership with other patient representatives, clinicians and researchers involved in ERN eUROGEN.
- Be active in the ERN eUROGEN organisational structure (see the organisational structure chart on the network's website), including the Strategic Board, Workstreams, Expertise Areas, Work Packages and Working Groups (depending on interests, expertise and availability).
- Participate regularly in the majority of the ePAG meetings and send apologies in advance if unable to attend.
- Report regularly in the ePAG meetings on the progress of ERN eUROGEN work and projects in which they are directly involved. If unable to attend, the update should be sent by email ahead of the meeting.
- Participate in the ERN eUROGEN annual Strategic Board Meeting and other relevant network meetings (when face-to-face, subject to budget availability).
- Contribute to identifying and developing the ePAG annual objectives and work programme.
- Contribute, where needed, to ERN registry-related activities, training and education, and the development of patient information, clinical practice guidelines, clinical decision support tools, and referral pathways.
- Contribute to reporting activity, as requested in the ERN eUROGEN monitoring procedures.
- Contribute to the development of research priorities and ensure the needs of patients and families are taken into consideration.
- Support the ERN to disseminate information, primarily to the patient community, but as appropriate to other communities (e.g. healthcare providers, health authorities, clinicians medical professionals and their professional bodies).
- Contribute to other ERN eUROGEN collaborative activities where patient involvement is required, as appropriate.
- Provide input on ethical issues, and balance patient and clinical needs appropriately.
- Scout for or make recommendations for new ePAG Representatives to cover under-represented Expertise Areas.
- Contribute to the assessment of new ePAG Representative applications.

4.3. Mandate

The appointment of new ePAG Representatives is initially for a six-month period. During this period, new ePAG Representatives will have the opportunity to familiarise themselves with the activities and their role and responsibilities. After this period, the ePAG Chair, in consultation with the ERN eUROGEN Coordinator, will validate the appointment of the ePAG Representative.

The mandate of ePAG Representatives lasts for three years and may be renewed. Before the mandate ends, ePAG Representatives will be asked whether they wish to continue. If an ePAG Representative represents a PAO, the PAO will also be asked to confirm that it still endorses them by sending a new letter of endorsement. Renewals are confirmed at the ePAG AGM.

4.4. Skills and Experience

4.4.1 Required

ePAG Representatives should have:

- A knowledge of, or experience of living with, one of the rare and complex conditions included in the scope of ERN eUROGEN.
- Willingness and motivation to get involved and contribute actively to the discussions and work of the ePAG and the ERN Working Groups.

- The ability to work effectively and constructively with other patient representatives and clinicians from different EU countries.
- The ability to represent the interests of all Expertise Areas under the scope of ERN eUROGEN beyond their own Expertise Areas.
- The ability to bring independent judgement from a patient-representative perspective.
- An awareness of, and commitment to, equality, diversity and inclusiveness.
- A high level of organisation and self-motivation.
- An understanding of the need for confidentiality.
- The ability to communicate in English to be able to follow and contribute to meetings.
- Computer skills and equipment to communicate through email, webinars, and videoconferences.
- Knowledge, or are willing to acquire knowledge, on the rare disease policy environment.

4.4.2 Desirable

It is desirable to have experience working in a committee setting with clinicians and patient representatives.

4.5. Benefits

Their role in ERN eUROGEN gives all ePAG Representatives the possibility to:

- Work closely with clinicians, researchers, and other patient representatives to transform healthcare services and accelerate research to improve the health outcomes of people living with a rare disease in Europe.
- Participate firsthand in the development of the ERN objectives and infrastructure to ensure that it remains driven by patients' needs.
- Increase their international exposure and expand their international network, specifically across Europe.
- Improve their understanding of healthcare models across Europe and European Reference Networks.
- Further develop soft skills such as communication, public speaking, conflict resolution, etc., acquired through trainings such as the ones provided by EURORDIS through its Open Academy, EUPATI and others, and through active participation in the ePAG.
- Share and learn from other ePAG Representatives and build their own capacities as patient representatives, broadening knowledge both within their own field of rare diseases and beyond.

4.6. Time Commitment

As stated above ('Meetings'), ePAG Representatives will be required to attend ePAG calls approximately every two months, which will generally take place for approximately 1 hour during working hours. They will also need to attend the calls of the ERN Workstreams and Working Groups in which they decide to be involved, as well as the annual Strategic Board Meeting, which is usually at least a full-day meeting. In addition, they will need to dedicate time to reviewing and reading documents, if necessary, ahead of the meetings and calls. This implies a commitment of typically two days per month, depending on projects and activities, and can increase to approximately five days per month in the case of the ePAG Chair.

4.7. Reimbursement

The position of ePAG Representative is a voluntary position and does not involve any financial compensation. However, as outlined in the ERN eUROGEN Reimbursement Factsheet (v.2023-11-06), ERN eUROGEN will reimburse expenses for ePAG Representatives when participating in official ERN duty. In accordance with EC regulations, ERN eUROGEN will reimburse claimants the maximum EC Unit Costs for travel, accommodation, and (for non-catered events) subsistence, unless actual costs are agreed by the ERN Coordinator.

4.8. Substitutes

ePAG Representatives may nominate a substitute from their own PAO, where applicable, to attend specific ePAG or other network meetings if adequately briefed beforehand on the topic area. The ePAG Chair shall validate the participation of such substitutes in the ePAG or ERN meetings, respectively. Substitutes must comply with the ERN eUROGEN Conflict of Interest policy (see Governance Statutes) and with the core principles laid down above when attending ePAG or ERN meetings.

5. EPAG APPLICATION PROCESS

5.1. Deciding Whether to Apply

The following information may be helpful:

- EURORDIS Guide: 'Thinking of getting involved in the ERNs as an ePAG advocate?'
- EURORDIS Video: 'European Reference Networks and European Advocacy Patient Groups 101'
- EURORDIS Podcast: ERNs on AIR (particularly episodes 1-4 of ERNs on AIR, not RARE ON AIR episodes, which are different)

5.2. How to Apply

All applications to join the ERN eUROGEN ePAG are made directly to the ERN eUROGEN Coordination Team. From 1 January 2027, EURORDIS will no longer handle ePAG applications and will refer any enquiries it receives to the ERN eUROGEN Coordination Team.

5.2.1 Who Can Apply

Patients living with a condition within the scope of ERN eUROGEN, their family members (including parents and carers), and others with knowledge of these conditions who represent a PAO can apply to become ePAG Representatives. Applicants may represent a PAO or apply as independent representatives.

5.2.2 Application Package

Anyone who contacts the ERN eUROGEN Coordination Team about becoming an ePAG Representative will be sent:

- the ERN eUROGEN Rules for Patient Engagement
- the ERN eUROGEN Governance Statutes
- the ERN eUROGEN ePAG Application Form
- the ERN eUROGEN Conflict of Interest Disclosure Form
- the ERN eUROGEN ePAG Endorsement Letter Template (for applicants who represent a PAO).

5.2.3 Documents to Submit

All applicants should send the ERN eUROGEN Coordination Team:

1. A completed application form.
2. A completed ERN eUROGEN Conflict of Interest Disclosure Form, if they have anything to declare (the application form includes a screening question to help applicants decide).
3. Where an applicant represents a PAO, a letter of endorsement signed by the head of their PAO.

5.3. How Applications Are Assessed

1. The Coordination Team shares the application with an ERN eUROGEN Evaluation Committee made up of the ePAG Chair, the relevant Workstream Lead, the relevant Expertise Area Coordinator and the Programme Manager.
2. The Evaluation Committee reviews and discusses the application against the required skills and experience in Section 4.4. Selection is based on the documents submitted.
3. The Coordination Team or Evaluation Committee may ask for more information or arrange an informal call with the applicant to learn more about their skills, experience and motivation.
4. Priority is given to applicants who represent a country or a disease not currently represented in the ePAG.
5. New ePAG Representatives are approved through agreement in the ePAG and in consultation with the ERN eUROGEN Coordinator.
6. All applicants are told whether their application has been successful.
7. Successful applicants receive a Patient Engagement Agreement from the Coordination Team. Once the ERN eUROGEN Coordinator and the applicant have signed it, the applicant becomes an ePAG Representative and can attend ePAG and ERN meetings.

The ERN eUROGEN Coordination Team will let EURORDIS know who has joined the ePAG, so that EURORDIS's overview of patient representation across the ERNs stays up to date.

Funded by the European Union

6. INDUCTION

6.1. EURORDIS

All new ePAG Representatives should complete an interactive online induction session. EURORDIS delivers these webinars quarterly. They last an hour and a half and provide some background information about the ERNs and ePAGs and the work that they do.

6.2. ERN eUROGEN

In addition, new ePAG Representatives will also receive an information pack about the work of ERN eUROGEN and have a meeting with the ePAG Chair and ERN eUROGEN Programme Manager.

7. SUSPENSION AND TERMINATION

7.1. Voluntary Suspension

At any time, an ePAG Representative can send a notice of temporary suspension to the ERN eUROGEN Coordination Team if they would like to voluntarily step down for a period of time.

7.2. Termination

The mandate of an ePAG Representative shall terminate in any of the following cases:

1. The ePAG Representative sends a notice of resignation to the ERN eUROGEN Coordination Team explaining the reasons for the resignation.
2. The PAO (where applicable) withdraws the endorsement given to the ePAG Representative and sends a notice to the ERN eUROGEN Coordination Team explaining the reasons for the withdrawal.
3. The ePAG Representative does not respond to emails, attend meetings or does not contact the ePAG group for a period of three months.
4. The ePAG Representative is unable to fulfil the roles and responsibilities listed above.
5. The ePAG Representative is unable to respect the core values listed above and/or engages in unethical or unprofessional conduct prejudicial to ERN eUROGEN's reputation and purpose.

7.3. Evaluation Process

In the circumstances referred to in points 3-5 above, before any decision is made to remove someone from being an ePAG Representative, an Evaluation Committee composed of the ePAG Chair, the relevant ERN eUROGEN Workstream Lead, the relevant Expertise Area Coordinator, and the ERN eUROGEN Programme Manager will examine the case and establish if there are reasons for termination. The Evaluation Committee may seek advice from other clinicians, ePAG Representatives, and project managers involved in other ERNs. The ePAG Representative (and, where applicable, their endorsing PAO) must be informed of the reasons why it is proposed to remove them, including an opportunity for open discussion. At least one month should be allowed for mediation and for any concerns raised to be addressed. If the decision is made to terminate, a final letter confirming the end of the collaboration will be sent to the ePAG Representative (and, where applicable, their endorsing PAO).

8. OTHER PATIENT ENGAGEMENT

PAOs, individual patients or family members, and social media-based patient support groups both inside and outside of Europe may be invited to collaborate with the ERN and the ePAG without being formally involved in ERN eUROGEN as ePAG Representatives. They may be willing to collaborate on specific tasks (e.g., advise on guidelines, respond to surveys), help to disseminate information and/or materials about the ERN across their wider patient community, be consulted occasionally for feedback, and be kept informed on the development of the ERN activities.

Where it is felt necessary by the ePAG and the ERN eUROGEN Coordination Team, Memorandums of Understanding will be signed to outline and formalise the collaboration.



Funded by
the European Union

ERN eUROGEN is a European Reference Network (ERN) approved by the ERN Board of Member States (BoMS). For more information about the ERNs and the EU health strategy, please click here. The ERNs are funded by the European Union.



Funded by
the European Union