Welcome Guide for New ERN eUROGEN European Patient Advocacy Group (ePAG) Representatives

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WELCOME TO THE ERN EUROGEN TEAM!

As an ERN eUROGEN European Patient Advocacy Group (ePAG) representative, you play a vital role in improving the lives of patients with rare uro-recto-genital diseases and complex conditions. This guide will help you understand the network, your role, and how to contribute effectively.

1. ABOUT ERNS, EPAGS, AND ERN EUROGEN

What is an ERN?

European Reference Networks (ERNs) are virtual networks of centres of expertise, connecting healthcare providers, researchers, and patient representatives across the European Union (EU) and European Economic Area (EEA). The networks are fully funded by the EU to improve the diagnosis, treatment, and care of patients with rare or complex diseases. There are 24 networks, each focusing on a particular medical field. All the networks aim to ensure that expertise and knowledge are shared efficiently, providing faster and fairer access to high-quality care for conditions that require specialised knowledge and resources, regardless of where a patient or specialist is located.

What are European Patient Advocacy Groups (ePAGs)?

It is of utmost importance that ERNs remain centred on patient's needs. Therefore, ePAGs are patient groups that bring together rare disease patient representatives to actively participate in the 24 ERNs, working in partnership with clinicians and researchers. They are supported in their activities by EURORDIS (Rare Diseases Europe) (see more in Section 4).

What is ERN eUROGEN?

ERN eUROGEN is the European Reference Network dedicated to improving care for patients with rare uro-recto-genital diseases and complex conditions.

ERN eUROGEN Focus Areas

ERN eUROGEN is organised into three Workstreams (WS), which are further subdivided into 19 different Expertise Areas (EAs)[1] that cover over 60 specific codes that classify rare diseases and conditions (called ORPHAcodes). For areas involving complex surgeries that don't fit neatly into these classifications, broader medical coding systems (like ICD-10) are used instead.

Workstream 1 (WS1): Rare congenital uro-recto-genital anomalies (paediatrics)

Expertise Areas (EAs):

- 1.1 Complex genital reconstructions (DSDs)
- 1.2 Bladder exstrophy/epispadias

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[1] Note: ERN eUROGEN prefers to use the term 'Expertise Areas' rather than 'disease areas' to align with EU principles of equality, diversity, and inclusiveness. This terminology respects individuals whose needs relate to identity, such as differences in sex development (DSDs) or surgery for transgender patients, ensuring their lived experience is not framed as a disease or disorder.

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- 1.3 Rare urological stone and kidney diseases
- 1.4 Non-syndromic urogenital tract malformation
- 1.5 Posterior urethral valve
- 1.6 Posterior hypospadias
- 1.7 Urorectal/anorectal malformations

Workstream 2 (WS2): Functional uro-recto-genital conditions requiring highly specialised surgery (adults)

Expertise Areas (EAs):

- 2.1 Complicated & complex pelvic floor disorders
- 2.2 Rare diseases & conditions affecting the female urethra
- 2.3 Urethral reconstruction in rare diseases & conditions
- 2.4 Rare retroperitoneal diseases & conditions
- 2.5 Interstitial cystitis
- 2.6 Adult urogenital reconstructive surgery (transition from WS1)
- 2.7 Surgery for transgender patients

Workstream 3 (WS3): Rare uro-recto-genital tumours

Expertise Areas (EAs):

- 3.1 Penile cancer
- 3.2 Testicular cancer
- 3.3 Adrenal tumours
- 3.4 Abdomino-pelvic sarcoma
- 3.5 Rare renal tumour surgery

Collaboration with the European Association of Urology (EAU)

The ERN eUROGEN ePAG works in close cooperation with the European Association of Urology (EAU) to enhance patient-centred care for rare and complex uro-recto-genital conditions, promote awareness of patient needs, and advocate for better integration of patient-centred practices in clinical and research activities. Key areas of collaboration include:

- **Educational Resources**: ERN eUROGEN ePAG representatives assist the EAU Patient Office in creating or reviewing patient-friendly materials, including brochures, leaflets, and videos. The EAU Patient Information website is a key platform for making these resources widely available to patients and healthcare professionals.
- **Guidelines Development**: ERN eUROGEN ePAG representatives provide input within guideline development groups facilitated by the EAU Guidelines Office. The EAU Guidelines are supplied to all EAU members annually.
- **Conferences and Events**: ERN eUROGEN ePAG representatives regularly attend the Annual EAU Congress, participating in thematic sessions and roundtable discussions on rare and complex urology. The EAU provides a platform for ePAG advocates to highlight the patient perspective in clinical discussions.
- **Dissemination of Information**: The EAU supports the dissemination of ERN eUROGEN activities through its extensive network, reaching thousands of healthcare providers globally.

2. YOUR ROLE AS AN EPAG REPRESENTATIVE

As outlined in the ERN eUROGEN Rules for Patient Engagement, your role as an ePAG representative is to amplify the patient voice within the network and ensure patient-centricity across all activities. As an ePAG representative, you represent the patient's voice. Your input helps shape healthcare services, training, and research to better address patient needs.

Key responsibilities (see the Rules for Patient Engagement for full details) include:

- **Advocating for Patients**: Ensuring the network's activities align with patient needs and perspectives.
- **Participating in Decision-Making**: Joining strategic board, workstreams, and other meetings.
- **Developing Resources**: Collaborating on creating patient-friendly materials.
- **Disseminating Information**: Sharing updates, guidelines, and resources with patient communities.
- **Feedback and Monitoring**: Providing feedback on initiatives and monitoring their impact.

3. KEY WORK PACKAGES (WPS) AND ACTIVITIES

The activities of ERN eUROGEN are divided into specific Work Packages (WPs). Here's how they relate to your role:

- **WP1 – Coordination:** Ensures smooth operation and management of the network. It involves monitoring performance, supporting member hospitals, involving patients, and expanding the network across Europe.
    - **Your Role**: Participating in discussions about patient engagement, including presenting the patient perspective at Strategic Board meetings.
- **WP2 – Dissemination:** Focuses on sharing information about the network's work widely, including with medical professionals, patients, and their families.
    - **Your Role**: Helping create, review, and distribute resources to ensure they meet patient needs and reach a wide audience.
- **WP3 – Evaluation:** Monitors and evaluates how well the network is performing. This involves tracking key indicators, implementing quality improvements, and preparing detailed evaluation reports.
    - **Your Role**: Providing feedback and contributing to network quality improvement initiatives, ensuring evaluations reflect patient experiences.
- **WP4 – Healthcare and CPMS:** Uses and improves the Clinical Patient Management System (CPMS), a secure IT platform that helps doctors across Europe collaborate and seek expert advice for complex and rare cases.
    - **Your Role**: Advocating for the effective use of this tool within patient communities and organisations.
- **WP5 – Registries, Data Management, and Analysis:** Develops a database to collect and analyse information about patients with rare diseases, helping to improve treatments and long-term care.
    - **Your Role**: Participating in governance discussions and providing input on ethical and practical concerns regarding data use.
- **WP6 – Training and Education:** Provides training for doctors and surgeons to improve their skills in treating rare and complex conditions. This includes workshops, webinars, educational videos and books.
    - **Your Role**: Providing input based on patient needs.
- **WP7 – Clinical Guidelines and Clinical Decision Support Tools:** Develops and updates medical guidelines and patient-friendly resources like leaflets and videos to ensure patients receive the best possible care based on the latest research and expert advice.
    - **Your Role**: Ensuring patient perspectives are included and helping to create and review materials to ensure they meet patient needs.
- **WP8 & WP9 – Support for Ukraine:** Supports healthcare professionals in Ukraine by sharing knowledge and training to improve care for patients with rare conditions.
    - **Your Role**: Advocating for patient-focused approaches in these activities.

4. SUPPORT AND RESOURCES

ERN eUROGEN Contact Points

For any queries about your role or network activities, contact these members of the ERN eUROGEN Coordination Team:

- Jen Tidman, ERN eUROGEN Business Support Manager, Jen.Tidman@radboudumc.nl
- Michelle Battye, ERN eUROGEN Programme Manager, Michelle.Battye@radboudumc.nl

EURORDIS (Rare Diseases Europe)

EURORDIS is a non-governmental, patient-driven alliance of patient organisations representing individuals and families affected by rare diseases across Europe. It is a key player in advocating for improved healthcare, research, and policies for rare diseases at the European and international levels. EURORDIS was instrumental in establishing ePAGs and continues to oversee their activities, ensuring alignment with patient advocacy goals. EURORDIS supports patient advocates across all ERNs through:

- Training and Guidance (e.g., the Open Academy) to develop advocacy skills and clarify responsibilities.
- Facilitating the ePAG Steering Committee and transversal working groups to share experiences and foster collaboration.
- Resources and Tools: FAQs, guides, and podcasts to empower advocates and promote best practices.
- Unified Representation: Amplifying the ePAG voice at the EU level, influencing rare disease policies and decisions.

Specific EURORDIS Resources

- **Induction Calls**: Every six months, EURORDIS hosts an induction call for new patient advocates or those interested in learning more about joining an ERN. During these sessions, they comprehensively introduce the ERNs and patient representation within the networks. This is an excellent opportunity for newcomers to learn about their role as ePAG advocates, ask questions, clarify doubts, and connect with others from different ERNs. If you or someone you know would like to join, please send an email to pem-epags@eurordis.org
- **ERNs 101 Video**: This is a 15-minute video in which experienced ePAGs explain their role. Watch it on YouTube here.
- **ERNs on AIR Podcast**: Episode 1 provides valuable insights into the ePAG experience. Available on Spotify here.
- **Patient Partnership Hub**: This hub hosts resources to help you plan and implement patient partnership in healthcare networks. It includes best practices, guides, tools and resources to build partnership skills. Access it here.
- **Open Academy**: The academy offers rare disease-specific comprehensive training programmes to empower patient advocates with the knowledge, skills and confidence they need to engage with different stakeholders as equal partners. See what courses are available here.

5. GLOSSARY

Here is a list of terms you may see in ERN eUROGEN documents or hear mentioned during ERN eUROGEN meetings:

Term	Definition
Assessment, Monitoring, Evaluation and Quality Improvement System for the European Reference Networks (AMEQUIS)	A framework designed to assess and enhance the performance and quality of ERNs.
Board of Member States (BoMs)	A governing body with representatives from EU Member States and the European Economic Area. BoMs approve and oversee the designation of European Reference Networks (ERNs).
Clinical Decision Support Tools (CDSTs)	Digital or manual tools designed to assist healthcare professionals in making evidence-based clinical decisions for patient care.
Clinical Patient Management System (CPMS)	A secure IT platform facilitating virtual consultations among ERN healthcare providers across Europe.
Clinical Practice Guidelines (CPGs)	Evidence-based recommendations to guide healthcare providers in managing specific conditions. ePAG representatives often contribute to their development.
Conflict of Interest (COI)	Situations where personal or organisational interests could potentially influence professional judgment or actions.
Declaration of Interest (DOI)	A formal statement disclosing any personal or financial interests that could influence one's professional responsibilities.
ePAG Representative	A patient representative who actively participates in ERN governance and activities. ePAG representatives contribute to decision-making and collaboration within the network.
ePAG Steering Committee	A strategic advisory group managed by EURORDIS, comprising advocates from all ePAGs to share experiences and provide guidance across ERNs.
ePAG Transversal Topic-Based Groups	Working groups managed by EURORDIS, focused on specific topics such as clinical guidelines, communication, research, and evaluation, allowing cross-ERN collaboration and learning.

ERN Affiliated Partner	A healthcare provider with a special link to an ERN, designated by Member States lacking full ERN members. They support either healthcare provision, knowledge production, or coordination.
ERN Collaborative Platform (ECP)	A digital platform facilitating collaboration and information sharing among ERN members.
ERN Coordinator	The person responsible for overseeing the operations and governance of an ERN, ensuring collaboration among members and compliance with regulations.
ERN Coordinators' Group (ERN CG)	A collective of ERN coordinators working together to ensure effective network operations and collaboration.
ERN Healthcare Provider (HCP) Member	A recognised centre of expertise for rare and complex diseases, endorsed by their Member State and meeting ERN criteria.
ERN Project Manager	A professional responsible for coordinating ERN activities, managing resources, and overseeing financial and technical reporting.
ERN Supporting Partner	Healthcare providers, medical societies, or other entities contributing to an ERN's work without being formal members or affiliated partners.
European Commission (EC)	The executive branch of the European Union, responsible for proposing legislation and implementing decisions.
European Health and Digital Executive Agency (HaDEA)	An agency managing European programs and initiatives in health, digital, and related fields.
European Patient Advocacy Group (ePAG)	A dedicated group of patient advocates for each ERN, formed to ensure patient needs are central to the network's strategic and operational activities.
European Rare Disease research Coordination and support Action (ERICA)	A project supporting the integration and coordination of rare disease research activities across Europe.
European Rare Diseases Research Alliance (ERDERA)	A collaborative network focused on advancing research in rare diseases.
European Reference Network (ERN)	A group of highly specialised healthcare providers that form a network to address rare, low-prevalence, or complex diseases and conditions.
European Union (EU)	A political and economic union of 27 European countries, operating through a system of supranational institutions and intergovernmental decisions.
EURORDIS	A European organisation representing patient advocacy groups and supporting patient involvement in rare disease research and healthcare, including the management of ePAGs.
Expertise Area (EA)	Specific fields of expertise within ERNs, focusing on particular conditions or procedures.
Joint Action on integration of ERNs into national healthcare systems (JARDIN)	An initiative aimed at integrating ERN activities into national healthcare frameworks.
Member State (MS)	Countries that are members of the European Union.
Multi-Disciplinary Team (MDT)	A group of healthcare professionals from various specialities collaborating to provide comprehensive patient care.

Patient Organisations (PO)	Non-profit organisations legally registered in Europe that represent patients and families affected by rare diseases.
Patient-Reported Outcome Measures (PROMs)	Questionnaires used to collect feedback from patients about their health outcomes and quality of life, helping to improve care and treatment strategies.
Rare Disease (RD)	Conditions affecting a small percentage of the population, often requiring specialised care and resources.
Work Package (WP)	Distinct components of a project, each focusing on specific objectives and tasks.
Working Group (WG)	Sub-groups within ERNs focusing on specific tasks or areas of interest.
Workstream (WS)	Parallel paths of activity within a project, each addressing different aspects of the overall objectives.

6. FINAL THOUGHTS

Your role as an ePAG representative is crucial to ensuring that the patient's voice is heard at every level of ERN eUROGEN.

By working together, we can improve care, research, and outcomes for those with rare uro-recto-genital diseases.

Thank you for joining us on this journey!

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.