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

ERN eUROGEN European Patient Advocacy Group

2026 Strategy and 2025 Report

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FOREWORD FROM THE EPAG CHAIR

"The ERN eUROGEN ePAG strategy is wide-ranging and ambitious, a true reflection of the experience, skills, and expertise within a mature ePAG that is working effectively as a group and realising its full potential.

In 2025, one of our aims was to expand the group's membership into new disease areas, which we have achieved. We plan to build on our successes through the new projects identified within this strategy not only within our respective disease disciplines but to draw together colleagues from across the wider family of ERNs and ePAGs to work together to improve the awareness, understand and knowledge of rare diseases, both within the general population but also amongst healthcare providers to improve health outcomes and quality of life for patients.

None of this could be achieved without the commitment, skills, and expertise of the supporting project officers within ERN eUROGEN and EURORDIS who work tirelessly to help us identify, plan, and achieve our goals."

John Osborne

Chair, ERN eUROGEN European Patient Advocacy Group (ePAG*)*

1. 2026 STRATEGY

During the ERN eUROGEN ePAG Bi-Monthly Meeting on 3 February 2026, the group reviewed progress against the 2025 ePAG Strategy and discussed priorities for 2026 and beyond. It was noted that several 2025 objectives had been completed or were well advanced, including developing patient empowerment resources, active involvement in guideline development, initiating the Rare PREPARE project, and early work on centralisation of care. These activities provide a strong foundation for the next strategic period. In parallel, ePAG representatives continue to contribute across multiple ERN eUROGEN work packages, including governance, dissemination, evaluation, training, registries, and guideline development, embedding the patient voice across the network's core activities.

Building on this progress, the following key objectives were identified for 2026.

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1.1. Rare PREPARE (pre-appointment questionnaire/checklist)

Goal: To co-create, refine, and reach consensus on the Rare PREPARE pre-appointment questionnaire, through structured collaboration with patients and clinicians from multiple ERNs, with the aim of finalising a pilot-ready tool by the end of 2026.

- Complete consensus-building with the patient and clinician panels
- Agree on the final scope, content, and format of the tool
- Prepare implementation and piloting plans (including setting and evaluation criteria) for use in routine clinical practice

1.2. Clinical Practice Guidelines and Clinical Decision Support Tools

Goal: To continue and strengthen meaningful patient-centred input into the development and refinement of CPGs and CDSTs within ERN eUROGEN, ensuring that patient perspectives systematically inform clinical decision-making.

- Support completion of deliverables already in progress through ongoing ePAG participation in guideline development groups for:
    - Bladder Exstrophy / Epispadias Complex (EA 1.2)
    - Bladder Pain Syndrome / Interstitial Cystitis (EA 1.5)
    - Penile Cancer (EA 3.1)

1.3. Patient Journeys, including Transition

Goal: To further develop and disseminate patient journey resources that reflect common lived experiences across rare uro-recto-genital conditions, with a specific focus on the transition from paediatric to adult care.

- Build on the *"Patient Empowerment: A Journey from Isolation to Advocacy"* and the anorectal malformation journey work delivered in 2025.
- Address gaps identified in transition pathways, including gender-specific issues and disparities between countries.
- Increase emphasis on psychological well-being, medical trauma, and long-term quality of life.
- Support condition-specific journey development where prioritised by ePAG representatives.

1.4. Centralisation of Care

Goal: To advance patient-led advocacy for the centralisation of highly specialised care, particularly complex surgery, while recognising national variation and clinical constraints.

- Progress development of an ERN eUROGEN position paper defining which procedures are appropriate for centralisation versus those requiring local or emergency delivery
- Support data collection and consultation with clinicians to underpin advocacy with evidence (e.g., a survey)
- Use the position paper as a basis for future engagement with policymakers, professional societies, and other ERNs

1.5. Strategic Collaboration with Professional Societies

Goal: To strengthen structured engagement between the ERN eUROGEN ePAG and the professional societies that are Supporting Partners of the network, ensuring patient perspectives are embedded in education, guidelines, and policy discussions.

- Increase interaction with the European Association of Urology (EAU) through the EAU Patient Office
- Strengthen collaboration with ESPU, EUPSA, ICS, and ESSIC
- Identify clear opportunities for patient involvement (e.g., guidelines, workshops, surveys, or joint statements)

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1.6. Preparation for the ERN eUROGEN Grant Application 2028–2034

Goal: To contribute proactively to shaping patient-centred priorities within the next ERN eUROGEN grant application to the European Commission (to be submitted in 2027, relating to funding from 2028-2034).

- Identify strategic themes based on gaps and successes since the current grant started in 2023
- Support early planning and prioritisation of patient-focused activities
- Ensure ePAG perspectives are embedded in future funding proposals

2. REPORT ON 2025 STRATEGY & ACHIEVEMENTS

2.1. Strengthening Patient-Clinician Communication

2.1.1 Pre-Appointment Questionnaire

Goal: Developing a standardised pre-appointment questionnaire/checklist to help patients articulate their needs and expectations during clinical visits.

Status: Rare PREPARE is a patient-centred initiative initiated by John Osborne (ERN eUROGEN ePAG Chair) to develop a standardised pre-appointment questionnaire/checklist that helps people living with rare and complex conditions better articulate their needs, priorities, and expectations during clinical consultations. The project is being supported by EURORDIS and aligns directly with the ePAG strategic goal of strengthening meaningful patient participation in care. A core project team is in place, and recruitment is well advanced, with 10 patient representatives and 10 clinicians confirmed from multiple European Reference Networks, including ERN eUROGEN, ensuring broad clinical and lived-experience perspectives. An application has been submitted to the ERDERA Networking Support Scheme to fund a face-to-face co-creation workshop (with plans to run this online if funding is unsuccessful). Next steps include the next core team meeting to finalise methodology and timelines, followed by the first full panel meeting to begin structured consensus-building on the questionnaire content and scope.

2.1.2 Guidance for Clinicians

Goal: Providing training and resources for healthcare professionals on effective communication with rare disease patients, particularly those transitioning from paediatric to adult care. Potential delivery formats include webinars or written guidelines based on best practices (e.g., Sant Joan de Déu guidance).

Status: This activity was not initiated in 2025 due to limited time and resource capacity. However, in October 2025, VASCERN published a comprehensive *Toolkit on Communication in Rare Diseases*, providing practical, evidence-based guidance and training resources for healthcare professionals on effective communication with patients with rare diseases and their caregivers, including paediatric contexts and shared decision-making. As this toolkit fully addresses the original aim of providing clinician-facing communication guidance and avoids duplication of effort, it was agreed that this objective does not need to be rolled forward to 2026.

2.2. Patient-Centred Clinical Decision-Making (CPGs and CDSTs)

2.2.1 Bladder Pain Syndrome/Interstitial Cystitis

Goal: Providing patient input on Clinical Practice Guidelines & Clinical Decision Support Tools covering conditions such as eosinophilic cystitis, ketamine cystitis, glandular cystitis, radiation cystitis, follicular cystitis, cystitis cystica, and haemorrhagic cystitis (ERN eUROGEN Direct Operational Grant 2023-2027 Work Package 7, Deliverables 7.10-17).

Status: This activity is in progress. A dedicated multidisciplinary working group on Rare Inflammatory Bladder Diseases has been established under ERN eUROGEN, bringing together urologists, pathologists, immunologists, and rheumatologists, with support from the International Society for the Study of Bladder Pain Syndrome (ESSIC). Patient input is embedded in the guideline development process, with Anna De Santis (ERN eUROGEN ePAG representative) included in the working group. Work to date has included scope definition, development of a detailed PICO framework, completion of the systematic literature review, and ongoing evidence appraisal, with completion anticipated by the end of 2027.

2.2.2 Penile Cancer

Goal: Contributing patient input to the Clinical Decision Support Tool for centralisation of penile cancer (ERN eUROGEN Direct Operational Grant 2023-2027 Work Package 7, Deliverable 7.18) and continuing efforts to promote the centralisation of penile cancer and other rare diseases in collaboration with EAU Guidelines Office and its Penile Cancer Guidelines Panel.

Status: This activity is under discussion with relevant stakeholders. The ERN eUROGEN ePAG has previously contributed patient input by participating in international guideline development efforts coordinated by the European Association of Urology (EAU) and the American Society of Clinical Oncology (ASCO), resulting in the publication of international collaborative penile cancer guidelines in 2023. ERN eUROGEN has engaged with the EAU Guidelines Office to clarify timelines for the next guideline update and the potential inclusion of a CDST on centralisation.

2.3. Empowering Patients Through Advocacy & Support

Empowering patients by raising awareness and helping others find their voice through collaboration and advocacy.

2.3.1 Patient Journeys

Goals:

1. Developing a patient journey relating to common needs in uncommon uro-recto-genital conditions, emphasising the importance of empowerment to help patients move from isolation to advocacy.
2. Developing a patient journey on Klinefelter syndrome (KS/XXY).

Status:

1. ERN eUROGEN supported the co-creation and dissemination of the patient empowerment resource *"Patient Empowerment: A Journey from Isolation to Advocacy"*, adapted from lived-experience work by Kate Tyler from the ERN eUROGEN ePAG and patient representatives from TOFS, Max's Trust, and VACTERL Association UK. The resource highlights shared challenges across rare conditions and illustrates pathways from isolation to empowerment and advocacy. This work was further amplified through a patient-led presentation delivered at the VACTERL Association annual meeting in June 2025, supported by ERN eUROGEN, and shared via ERN communication channels.
2. The planned patient journey focused on Klinefelter syndrome (KS/XXY) did not progress in 2025 due to limited time and resource capacity. ERN eUROGEN remains supportive of advancing this work and will initiate collaboration with EURORDIS if requested by Claire Harkin (ERN eUROGEN ePAG representative for KS/XXY).

2.3.2 EURORDIS Mental Health & Wellbeing Partnership Network

Goal: Continuing participation in the EURORDIS Mental Health & Wellbeing Partnership Network to raise awareness and advocate for policy improvements.

Status: ERN eUROGEN continued its engagement with the EURORDIS Mental Health & Wellbeing Partnership Network through active participation by ERN representatives, including Kate Tyler (ERN eUROGEN ePAG Representative), Jen Tidman (ERN eUROGEN Business Support Manager), and Michaela Dellenmark Blom (ERN eUROGEN HCP Representative). Contributions included attending network meetings and participating in knowledge-sharing activities. Due to staff changes and funding constraints at EURORDIS, the network is currently on hiatus. ERN eUROGEN intends to resume its participation as soon as the network's activities restart.

2.3.3 Penile Cancer Patient Survey

Goal: Continuing the Penile Cancer Patient Survey to assess patient experiences, identify best practices, highlight areas for improvement, and share findings with patients and clinicians to drive enhancements in service quality and patient outcomes.

Status: The penile cancer survey is ongoing. It is the largest patient-led survey into the patient experience of penile cancer ever undertaken. With the support of ERN eUROGEN and the EAU Patient Office, the survey is now available in fifteen languages. To date, there have been 107 responses from 12 countries. The results already provide remarkable insights that challenge some previous research findings, particularly regarding psychological support and quality of life. Work is underway to extend the survey to the USA, Canada, South America, and India (through the Global Society for Rare Genitourinary Tumors), and to continue encouraging men in Europe to participate. The survey will also be featured in several presentations at the annual EAU Congress in London in March 2026.

2.4. Advancing Centralisation of Care

2.4.1 Advocacy for Centralisation

Goal: Exploring advocacy opportunities to lobby national health ministries in policy change.

Status: This activity is in progress. Advocacy for the centralisation of highly specialised care, particularly complex surgery, remains a priority in ERN eUROGEN discussions. Through ePAG engagement and ongoing dialogue with clinical experts, the network has been exploring how patient perspectives can inform policy-level conversations at national and European levels, recognising differences in healthcare systems and the practical constraints around emergency versus elective care. This work is being taken forward in parallel with the development of a formal ERN eUROGEN position on centralisation, which will provide a foundation for future advocacy with national health authorities and policymakers.

2.4.2 Collaborative Position Statement

Goal: Potentially developing a cross-ERN/EURORDIS document supporting centralisation efforts.

Status: This activity is in progress. Following discussion at the ERN eUROGEN ePAG bi-monthly meetings, Dalia Aminoff and Miriam Wilms (ERN eUROGEN ePAG Representatives) have agreed to collaborate on drafting a position paper for ERN eUROGEN on the centralisation of care, with a particular focus on surgical procedures. The paper will aim to clearly distinguish which rare uro-recto-genital surgeries are complex and elective, and therefore suitable for centralisation, and which are emergencies and not amenable to centralised delivery. The work will consider variation in national contexts, draw on examples from other specialties (such as cancer care), and seek to establish a gold-standard ERN eUROGEN statement. The Coordination Team will support exploration of data collection from surgeons and relevant ERN workstreams, and the use of a survey is being considered to underpin the position with clinical evidence. Opportunities for collaboration with other ERNs and EURORDIS will also be explored. Progress will continue as capacity allows.

3. ADDITIONAL ACTIVITIES & ACHIEVEMENTS

In addition to the objectives set out in the 2025 ePAG Strategy, several significant activities were initiated or delivered during the year that were not originally foreseen but strongly align with ERN eUROGEN's patient partnership and empowerment objectives.

3.1. Expansion of the ERN eUROGEN ePAG

In 2025, ERN eUROGEN continued to strengthen and diversify the ePAG through the recruitment of three new members, expanding representation across Expertise Areas. This growth enhances the breadth of lived experience within the network and supports more comprehensive patient input across workstreams.

- **Miriam Wilms**, Representative of SoMA e.V. (Germany), a patient organisation for anorectal malformation, Hirschsprung's disease, and cloacal exstrophy. Represents Workstream 1 (EA 1.7 Anorectal malformations)
- **Lieke Janssen**, Representative of De patiëntenvereniging voor blaasextrofie Nederland (Netherlands). Representative for Workstream 1 (EA 1.2 Bladder exstrophy/epispadias).
- **Frans Baan**, Independent ePAG advocate from the Netherlands. Represents Workstream 3 (Upper Tract Urothelial Carcinoma).

3.2. ERN eUROGEN Anorectal Malformations Book – Patient Perspectives Chapter

ERN eUROGEN ePAG members contributed a dedicated chapter on the patient perspective to the forthcoming ERN eUROGEN book on anorectal malformations, providing insight into lived experience, long-term outcomes, and patient priorities across the life course. The chapter is currently under revision, with publication of the book expected in January 2027. This represents an important opportunity to embed patient voices within academic and clinical reference materials.

3.3. JARDIN Rare Disease Day Campaign 2026

In January 2026, ERN eUROGEN ePAG members contributed personal stories to the Joint Action on Integration of ERNs into National Health Systems (JARDIN) Rare Disease Day campaign, highlighting lived experience and patient priorities at the European level. These contributions were published on 13 and 14 February 2026 and support wider awareness-raising and advocacy objectives beyond the network.

3.4. Patient Information Videos on Penile Cancer

In addition, ERN eUROGEN, in collaboration with the European Association of Urology Patient Office and Orchid, previously co-created animated patient information videos on penile cancer in English and Spanish (financed under the previous Bridging Grant and published in 2023). As of January 2026, these resources have demonstrated exceptional reach and impact, with the Spanish-language version ranking among the top 20 most-viewed EAU videos (over 136,000 views) and the English version ranking 36th (over 81,000 views). This highlights the effectiveness of co-created, multilingual patient resources in reaching and engaging diverse audiences.

4. OVERALL STRATEGY

The ERN eUROGEN European Patient Advocacy Group (ePAG) brings together patient representatives for rare uro-recto-genital diseases and complex conditions to actively participate in the European Reference Network (ERN), working in partnership with clinicians and researchers. EURORDIS (Rare Diseases Europe) supports the group in its activities.

The ERN eUROGEN ePAG aims to empower patients to advocate for their needs by amplifying the patient voice within the network and ensuring patient-centricity across all activities. The ePAG representatives' input helps shape healthcare services, training, and research to better address patient needs.

Key responsibilities:

- **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.

5. THE PATIENT PARTNERSHIP FRAMEWORK

Aligned with **EURORDIS Rare Disease Europe's Patient Partnership Framework for ERNs** (2023), the ERN eUROGEN ePAG aims to:

- Foster a shared understanding of patient partnership, ensuring patients and healthcare professionals collaborate as equal partners.
- Emphasize transparency, shared leadership, teamwork, and continuous engagement.
- Define desired outcomes and align activities with stakeholder motivations.
- Tailor engagement strategies to accommodate the diverse needs, preferences, and characteristics of patient communities.
- Address accessibility barriers, such as language, cost, and logistical challenges, to ensure inclusive participation.
- Facilitate effective dissemination of information.
- Implement structured evaluation mechanisms to assess the impact of patient engagement and iteratively improve activities.
- Support patient representatives in capturing and analysing community perspectives.
- Encourage collaborative selection of engagement methods, ensuring alignment with activities such as guideline development, education, or data management.
- Provide training and resources to empower patients for meaningful engagement.
- Establish support structures that enhance the capacity of patient representatives for effective collaboration.

5.1. Defining Patient Partnership in ERNs

Patient partnership within ERNs is a collaborative relationship where patients, caregivers, and healthcare professionals work together as equal stakeholders in all network activities. This partnership ensures that both the experiential knowledge of patients and the clinical expertise of healthcare professionals are equally valued in decision-making, co-design, and implementation.

Key principles of true patient partnership:

- **Shared Decision-Making**: Patients and healthcare professionals contribute equally to discussions, with each voice carrying weight.
- **Mutual Respect and Trust**: Recognizing patients as experts by lived experience and professionals as experts by training.
- **Co-Creation and Collaboration**: Patients actively shape policies, guidelines, and healthcare improvements.
- **Transparency and Accountability**: Clearly defined roles and responsibilities prevent token representation.
- **Continuous Learning and Adaptation**: Ongoing dialogue, training, and feedback refine collaboration over time.

This approach shifts healthcare from being "for" patients to being "with" patients, ensuring rare disease networks are shaped by those who live with these conditions.

5.2. Ensuring Accessibility, Inclusivity, and Diversity

- Patient representatives are encouraged to disclose any accessibility needs for meetings.
- Most meetings allow remote participation, and reimbursement is provided for in-person attendance.
- Flexible scheduling is facilitated through polling patient representatives.
- ERN eUROGEN actively recruits patient representatives from diverse backgrounds and partners with patient organizations to amplify underrepresented voices.

5.3. Fostering Meaningful Engagement

- ERN eUROGEN ePAG establishes outcome-based goals and holds bi-monthly progress meetings to define and communicate objectives.
- Structured processes ensure meaningful patient involvement (e.g., clear roles, responsibilities, and recognition of contributions) to prevent tokenism.
- Patient representatives are regularly invited to provide feedback on their engagement experiences.

5.4. Supporting Collaboration and Training

- A welcome guide has been developed for new patient representatives, outlining collaboration processes, roles, and available training resources.
- EURORDIS provides additional task-specific guides for engagement in activities such as registries and clinical practice guidelines.

5.5. Dissemination and Knowledge-Sharing

- Successes are celebrated by recognising contributions from patient representatives.
- Outcomes of effective patient engagement are disseminated in order to share knowledge.

5.6. Evaluation and Continuous Improvement

- The annual ePAG strategy enables systematic evaluation of patient engagement effectiveness.
- Evaluation includes achievement of deliverables, satisfaction surveys, participation rates, and impact assessments.
- Periodic reviews ensure alignment with strategic goals, incorporating patient feedback into future strategies.

6. ASSESSING PATIENT PARTNERSHIP IMPLEMENTATION

In line with EURORDIS guidance, ERN eUROGEN implemented the *Assessing Patient Partnership Implementation in ERNs* questionnaires in early 2026 to support structured reflection on patient–clinician collaboration. Two surveys were circulated: one to ERN eUROGEN ePAG representatives and one to members of the ERN Leadership Team (including the Coordination Team, Workstream Leads, and ePAG Chair).

Response rates were limited, but overall, responses from both ePAG representatives and ERN leadership reflected high levels of perceived commitment to patient partnership, strong support for patient involvement across ERN activities, and clear examples of patient input influencing initiatives and decision-making. Free-text responses highlighted the value of experienced patient advocates, effective support from the Coordination Team, and meaningful opportunities for co-creation, while also identifying ongoing challenges related to capacity, resources, and sustainability of engagement.

The findings will be discussed further at the ERN eUROGEN Strategic Board Meeting 2026 to identify practical, proportionate follow-up actions and improve response rates in future iterations. Repeating the exercise over time will allow ERN eUROGEN to monitor progress and strengthen patient partnership in a structured and sustainable way.

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