



ERN eUROGEN Strategic Board Meeting Report

26-27 February 2026, Nijmegen (NL) and online



TABLE OF CONTENTS

1. Executive Summary & Consolidated Actions	2
2. Meeting Background, Arrangements & Presentations	3
3. Introduction to the Meeting.....	4
4. Coordination (Work Package 1).....	4
5. Dissemination (Work Package 2).....	6
6. Evaluation (Work Package 3).....	7
7. Healthcare and New CPMS (Work Package 4)	8
8. Registries, Data Management and Analysis (Work Package 5).....	8
9. Training & Education (Work Package 6).....	9
10. Clinical Practice Guidelines and Clinical Decision Support Tools (Work Package 7).....	10
11. Capacity Building and Best Practice Sharing / Other Activities for Ukraine (Work Packages 8/9)	11
12. Attendees	12



1. EXECUTIVE SUMMARY & CONSOLIDATED ACTIONS

The ERN eUROGEN Strategic Board Meeting took place on 26–27 February 2026 at the Radboudumc Experience Center, Nijmegen, in a hybrid format. A total of 76 participants attended, with 34 present in person and 42 joining online.

ERN eUROGEN is performing well across its work packages. The mid-term interim report for the 2023–2027 Direct Operational Grant was submitted in February 2026, ahead of an independent review by HaDEA-appointed experts on 27 March 2026. Most planned grant targets are on track or have been exceeded in areas including dissemination, webinars, and guideline development. The registry and CPMS remain areas requiring focused effort to reach end-of-grant targets, and specific actions have been agreed to address this.

Several cross-cutting strategic themes emerged across the two days. Planning for the next grant cycle (2028–2034) featured prominently, with members invited to contribute input on priorities. HCP engagement, including attendance at workstream meetings, registry data entry, and CPMS usage, was identified as a shared challenge across multiple work packages.

All arising actions are consolidated in the table below:

Work Package	Owner(s)	Action(s)
WP1 – Coordination	Coordinator / Programme Manager (Peter Mulders / Michelle Battye)	Raise concerns about ERDERA funding call complexity and exclusion of surgical/oncological topics at the ERN Coordinators Group meetings and with EC DG SANTE (Radboudumc visit, May 2026)
	All HCPs	Contact Michelle Battye/Jen Tidman for advice, input, and proofreading support on ERDERA and other funding/ethical committee applications.
WP2 – Dissemination	Business Support Manager (Jen Tidman)	Explore feasibility of producing YouTube Shorts and Instagram Reels using existing webinar assets and/or new ePAG patient stories; develop standardised ‘HCP Spotlight’ questionnaire and build pipeline of features for monthly newsletter; contact ESPU and EUPSA to request national paediatric urology/surgery society contact lists for extended National Societies outreach campaign
WP3 - Evaluation	ERN eUROGEN Lead IT & Data Performance Analyst (Darren Shilhan)	Finalise the revised ERN eUROGEN Monitoring & Assessment Protocol, incorporating: (a) updated and new mandatory expectations for full HCP members; (b) the finalised template for the Annual HCP Activity Report; and (c) a balanced solution for differentiated HCP expertise levels per Expertise Area. Issue to the network for approval in late March/early April 2026. Check EC position on publishing patient and procedure numbers transparently on the ERN eUROGEN website; clarify and improve governance information regarding the scope of each HCP’s recognised Expertise Areas to prevent misuse of the ERN eUROGEN logo; organise a meeting with the WS2 Lead and relevant WS2 HCP representatives to agree on appropriate patient and procedure data definitions for WS2 Expertise Areas.
WP4 – CPMS	CPMS Helpdesk (Darren Shilhan / Parmida Anvary)	Develop step-by-step PDF guide and video tutorials for CPMS EU login and onboarding; identify designated moderator and note-taker for CPMS video case discussion sessions; organise introductory "getting started" sessions for new CPMS users; schedule two annual one-hour case discussion sessions per workstream with a “best presenter” prize; disseminate success stories in CPMS/main newsletter; include CPMS reimbursements in next grant.
WP5 – Registry	Registry Team (Loes van der Zanden / Lotte Boormans)	Develop protocol and standard patient letter for contacting patients missed for registry inclusion; communicate Informed Consent Form changes to Principal Investigators; send quarterly reminders on open queries and available Clinical

		Practice Snapshots; organise registry walk-in hours and follow-up meetings with HCPs.
	All HCPs	Begin contacting patients missed for registry inclusion; invite patients prospectively for all EAs; consider research proposals using registry data; complete open queries and Clinical Practice Snapshots.
WP6 – Training	All HCPs	Encourage PhD candidates/young researchers encouraged to present webinars, assisted by supervisor during discussion;
	Webinar Helpdesk (Darren Shilhan / Parmida Anvary)	Include two different HCPs per webinar; include patient representatives alongside clinicians; get EAC/vice-EAC approval for webinar proposals; actively promote pre-recording option to potential presenters; set up native language webinar pilot if requested by a presenter; include webinar information form in first contact email to potential presenters
	Programme Manager (Michelle Battye)	Encourage recording of rare surgeries for training purposes; explore including surgical telemedicine, training simulators, and exchange programme in next grant; compile a structured list of experts able to support specific Expertise Areas in training and cross-border care.
WP7 – Guidelines	All HCPs	Review links to EC Methodological Handbook, Quick Guide, and EU Academy course on CPG/CDST methodology.
	Programme Manager (Michelle Battye)	Explore including development of a guidelines app/chatbot in the next grant.
WP8/9 – Ukraine	Programme Manager (Michelle Battye)	Explore feasibility of ERN eUROGEN clinicians travelling to Ukraine to deliver in-person training and surgical support, subject to safety and post-operative care considerations
Next Grant	All HCPs / ePAG Reps	Submit three bullet points on priorities for the next grant cycle (2028–2034) to the Coordination Team following circulation of SBM report.

2. MEETING BACKGROUND, ARRANGEMENTS & PRESENTATIONS

Purpose

The ERN eUROGEN Strategic Board Meeting (SBM) provides the network's governance body with a comprehensive update on activities and progress across all work packages and serves as a key forum for strategic discussion, decision-making, and network-wide engagement.

Meeting format

The 2024 Strategic Board Meeting was held entirely online. Following that meeting, the Board expressed a preference for returning to an in-person or hybrid format, noting that face-to-face attendance offers significant benefits for networking, discussion, and engagement that are difficult to replicate in a virtual setting.

Given that travel and accommodation costs could not be reimbursed under the current grant (except for ePAG representatives), the Coordination Team polled the Board on willingness to attend in person at their own expense or with institutional support. A substantial proportion indicated they were able and willing to do so. A hybrid format was adopted to ensure that those unable to travel could still participate fully.

Finding a suitable date proved challenging: polling conducted during 2025 revealed that major external congresses and events made it impossible to identify a date that would not exclude a significant proportion of members. A suitable date was ultimately identified in early 2026.

Nijmegen was selected as the host city as the seat of Radboudumc, ERN eUROGEN's coordinating HCP. The city benefits from excellent rail connectivity, with direct train services (approximately 1 hour and 30 minutes) from Amsterdam Schiphol Airport (a major European hub airport) and connections across the broader European rail network. The Experience Center provided state-of-the-art facilities well-suited to hybrid delivery, ensuring a high-quality experience for both in-person and online participants.

The meeting was structured as two half-days rather than a single full day. This format was chosen deliberately to minimise time away from clinical duties and reduce the cost of attendance. With a Thursday afternoon start, attendees could travel to Nijmegen on Thursday morning and return home on Friday afternoon after the meeting closed, meaning just two days out of the clinic and one night's accommodation. A full-day format, by contrast, would have required travel the day before and the day after the meeting, resulting in three days away and two nights' accommodation. A networking dinner was held on the evening of Thursday, 26 February, providing an opportunity for informal exchange between in-person participants.

Attendance

A total of 76 participants attended the meeting. Of these, 34 attended in person (comprising 8 members of the Coordination Team, 3 ePAG representatives, and 23 HCP representatives) and 42 participated online (comprising 5 ePAG representatives and 37 HCP representatives).

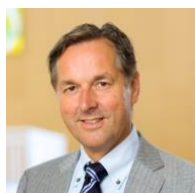
Agenda structure

The agenda was structured work package by work package, covering all seven compulsory work packages under the 2023–2027 Direct Operational Grant, together with the two Ukraine work packages (WP8 and WP9). Each session combined a presentation from the relevant work package lead with structured board discussion and, where applicable, Mentimeter polling to gather real-time input from participants.

Presentations

The presentation slides delivered at the ERN eUROGEN Strategic Board Meeting on 26–27 February 2026 are compiled in the accompanying document: *ERN eUROGEN Strategic Board Meeting 2026: Compiled Presentations*.

3. INTRODUCTION TO THE MEETING

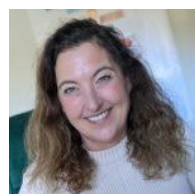


Welcome and Attendee Introductions – Peter Mulders (ERN eUROGEN Coordinator)

Peter welcomed everyone to the meeting. He provided a brief overview of the High-Level Meeting on Rare Diseases (HLM Rare), a European advocacy initiative aimed at galvanising political commitment to rare disease research, innovation, and care. He highlighted the Declaration on a European Innovation and Care Ecosystem for Rare and Complex Diseases, which calls for ringfenced funding for ERNs under the 2028–2034 Multiannual Financial Framework. Key milestones for 2026 included Rare Disease Day (28 February), the ERN Meeting (26 March, Brussels), and HLM Rare 2.0 (8–9 December, Brussels).

The attendees introduced themselves and explained which HCP they represented, their position in their HCP, and their role in ERN eUROGEN. A full list of attendees is at the end of this report.

4. COORDINATION (WORK PACKAGE 1)



Management & Grant Actions of the Network – Michelle Battye (ERN eUROGEN Programme Manager)

Presentation summary: The Strategic Board received an overview of WP1 management and grant activities for Years 1–2 of the 2023–2027 grant period.

Key leadership changes were reported: following the retirement of Wout Feitz in May 2024, Peter Mulders was unanimously elected as the new ERN eUROGEN Coordinator, and the EC was notified accordingly. Workstream leadership changes were also made, with Giovanni Mosiello (Rome, IT) taking over as Workstream 1 Lead and Tahlita Zuiverloon (Rotterdam, NL) as Workstream 3 Lead.

Grant context was provided: ERN eUROGEN receives €3.25 million under the current grant (a 20% reduction on the previous proposal), with 100% eligible cost coverage and 50% pre-financing; both exceptional arrangements across the 24 ERNs. The mid-

term interim report was submitted in February 2026, with an independent review by HaDEA-appointed experts scheduled for 27 March 2026. All planned WP1 deliverables (D1.1–D1.4) were completed. Achievements included maintaining governance and communication structures, active participation in cross-ERN working groups, and strong external engagement.

Areas for improvement include addressing disparities in HCP engagement and attendance and improving inter-HCP communication, as highlighted in the Network Survey.

Looking ahead, priorities include integrating new Affiliated Partners, expanding disease area coverage, and preparing for the next EC Multiannual Financial Framework (2028–2035), including addressing a potential three-month funding gap between the current grant end (September 2027) and the new MFF start (January 2028).



ePAG Activities and Updates 2025 – Jen Tidman (ERN eUROGEN Business Support Manager) on behalf of John Osborne (ePAG Chair)

Presentation summary: The presentation outlined the structural embedding of patient representatives across ERN eUROGEN work packages, including governance, dissemination, evaluation, registry governance, training, and guideline development.

Key 2025 achievements included progress on the Rare PREPARE pre-appointment question prompt list, active patient involvement in multiple Clinical Practice Guidelines and Clinical Decision Support Tools (including anorectal malformations, paediatric neurogenic bladder, rare inflammatory bladder diseases, and penile cancer), development and dissemination of patient journey resources, expansion of the penile cancer patient survey, and advancement of work on centralisation of care.

The ePAG also expanded its membership in 2025, strengthening representation across expertise areas. Results from the Assessing Patient Partnership Implementation questionnaires were presented, indicating strong perceived commitment to patient partnership, alongside ongoing challenges related to capacity and sustainability.

Looking ahead, 2026 has been framed as a year of consolidation and impact, with priorities including finalisation and piloting of Rare PREPARE, continued patient input into guidelines and CDSTs, progression of the centralisation position paper, strengthened collaboration with professional societies, and early embedding of patient priorities into the 2028–2034 grant preparation.



Joining Forces and ERN Participation – Wout Feitz (Past ERN eUROGEN Coordinator)

Presentation summary: An overview of ERN eUROGEN's participation in broader European initiatives and key network achievements during Years 1–2 of the grant was provided.

On the broader ERN landscape, Wout noted ongoing EC alignment across the 24 ERNs, including the ERN Evaluation Report (2024), the new ERN Monitoring Report (2025), and preparations for the BoMS next call for Affiliated Partners (2026). A new EU call for Affiliated Partners has been approved, though pending legal advice. The importance of continued engagement with EU institutions (including the European Parliament, Council, and Commission) was emphasised in the context of securing ERN funding under the next Multiannual Financial Framework (2028–2034).

ERN eUROGEN-specific achievements highlighted included: delivery of European video consultations via CPMS 2.0; European patient representative collaborations; a growing registry; completed guidelines and clinical decision support tools; the webinar series; and the *Rare and Complex Urology* Expertise Area Book Series. Two recent research publications using ERN eUROGEN data (on anorectal malformations and paediatric kidney transplantation care) were also showcased, alongside the AGORA project on Posterior Urethral Valves.

Under improvements, Wout presented ERN eUROGEN's connections to related European research programmes (including JARDIN and ERDERA) and the importance of National Mirror Boards and increased HCP participation. Progress on Clinical Practice Snapshot Studies across multiple Expertise Areas was noted, alongside growing engagement with external partners, including ARM-Net, EAU, EPU, EUPSA, ESSIC, EURORDIS, and ICS.

Wout Feitz later highlighted the World Orphan Drug Congress in Amsterdam (27–28 October 2026) as a valuable opportunity, noting that ERN members can attend free of charge and that it offers useful support and advice on orphan drug development. Those interested can use the following links to access the [main website](#) and the [guest pass application form](#).

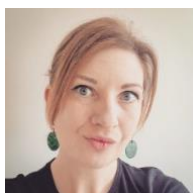
Board discussion and arising actions:

- 1. ERDERA Funding Calls:** The Board raised concerns regarding ERDERA funding calls. Members noted that the calls have been complex and difficult to navigate, making it hard to determine whether a proposed idea would be eligible without seeking clarification. When members approached the ERDERA Secretariat for guidance, the Secretariat was unable to

provide sufficiently clear advice. It was further noted that the European Joint Programme on Rare Diseases (EJPRD) and ERDERA Joint Transnational Calls have, to date, been non-surgical in focus and have excluded rare cancers, limiting their relevance to a significant proportion of ERN eUROGEN members. Peter Mulders and Michelle Battye will raise these concerns at the ERN Coordinators Group meetings and with the EC DG SANTE team during the EC DG SANTE team's visit to Radboudumc in May 2026.

- Funding / Ethical Committee Applications:** The Board noted the value of providing members with support for ethical committee applications related to clinical research and suggested that this be considered. Michelle Battye and Jen Tidman are available to provide advice and input on funding and ethical committee applications, including proofreading and rewriting support as native English speakers. Members wishing to take up this offer should contact them directly.

5. DISSEMINATION (WORK PACKAGE 2)



Dissemination and Communication – Jen Tidman (ERN eUROGEN Business Support Manager)

Presentation summary: The Strategic Board received an overview of dissemination and communication activities delivered under WP2 during Years 1–2 of the 2023–2027 Direct Operational Grant.

WP2 has exceeded most planned targets. Achievements included significant growth in newsletter subscriptions and digital engagement, regular website updates, high-volume social media activity, dissemination of webinar recordings, and increased scientific publication visibility. Patient-focused materials were developed in collaboration with ePAG representatives, and a National Societies outreach campaign was conducted across 29 EU/EEA countries plus Ukraine.

Areas for improvement identified through the Network Survey were presented, including clearer clinical summaries in communications, improved audience segmentation, and further optimisation of the website. The decision to discontinue using X (formerly Twitter) in October 2025, due to limited engagement, platform controversies, and strategic considerations, was also noted.

For the remaining two years of the grant, priorities include delivering remaining contractual commitments, strengthening national-level engagement, enhancing cross-ERN collaboration, and refining measurement of dissemination impact. Initial discussion also took place regarding the future scope and sustainability of WP2 beyond 2027.

Board discussion and arising actions: The Board made several constructive suggestions:

- Exploration of TikTok as a dissemination channel:** It was suggested that ERN eUROGEN consider creating a TikTok channel to broaden reach, particularly among younger audiences, with each HCP member potentially contributing one short (1–2-minute) video annually for central upload.

However, following internal consideration after the meeting, it was concluded that TikTok is not the right platform for ERN eUROGEN at this stage. ERN eUROGEN's current dissemination priorities centre on reaching clinicians (particularly raising awareness of CPMS, webinars, guidelines, and the registry), and TikTok's audience and algorithm are not well-suited to this goal. From an operational perspective, building a meaningful presence on TikTok requires consistent, frequent posting (ideally *multiple* posts per week) and platform-specific content skills; an annual contribution per HCP member would be unlikely to generate sufficient engagement to justify the investment, and with the ERN eUROGEN Business Support Manager's current workload and funding constraints, the dissemination resources required to manage a new and additional platform of this nature are not available.

The potential value of short-form video content for patient-facing awareness (particularly to support younger people living with rare uro-recto-genital conditions) is acknowledged. However, external organisations that do this effectively typically have full-time social media staff.

Therefore, it is felt that educational content is better pursued through the channels that ERN eUROGEN already maintains. As a next step, the Coordination Team will explore the feasibility of producing YouTube Shorts and Instagram Reels, drawing on existing webinar assets and/or new patient stories from the ePAG.

- Monthly "HCP Spotlight" Feature:** The Board suggested featuring one healthcare provider or clinician per month in the main newsletter, including a short interview, centre profile, summary of their role within ERN eUROGEN, and a photo. This approach has already been successfully used in internal WS3 newsletters and will now be extended to the main ERN eUROGEN newsletter. The feature aims to humanise the network, highlight expertise across member centres, and strengthen community engagement among HCPs. To ensure sustainability, a standardised short questionnaire will be developed so that HCPs can contribute by email without the need for a formal interview. A pipeline of features will be built up in advance to avoid last-minute preparation.

3. **Expansion of National Societies Outreach:** The initial outreach campaign, conducted with contact details provided by the European Association of Urology (EAU), focused on adult urology societies. The Board recommended extending this to national paediatric urology/surgery societies, reflecting the significant proportion of ERN eUROGEN conditions that present in childhood. ERN eUROGEN's paediatric Supporting Partners (ESPU and EUPSA) will be contacted to establish whether equivalent contact lists can be provided. Subject to this, the outreach campaign will then be extended accordingly.

6. EVALUATION (WORK PACKAGE 3)



Reporting, Monitoring, & Evaluation – Darren Shilhan (ERN eUROGEN Lead IT & Data Performance Analyst)

Presentation summary: The Strategic Board received an overview of progress in evaluation work to date during the current grant, as well as proposed changes to the ERN eUROGEN Monitoring & Assessment Protocol to improve HCP engagement and ensure expert provision across our Expertise Areas (EAs) going forward.

Within Work Package 3, achievements for the first two years of the Direct Grant have included the successful submission of Annual Monitoring Indicators for 2023 and 2024, with contributions from almost 100% of our HCPs. Furthermore, the ERN eUROGEN Evaluation Plan has been created and agreed upon through the Quality Improvement Group (QIG). Evaluation Reports for Year 1 and Year 2, including thorough evaluation reports of both our website and our webinar programme, have also been submitted. The ERN eUROGEN Monthly Performance Report has been issued continuously during this period, allowing all members to see at a glance how the network is performing across all its work packages.

Despite these successes, many improvements are still clearly required, particularly around how membership and expertise coverage are handled as a result of the level of engagement from HCP members, as well as their continued level of expertise, as evidenced by the annual monitoring indicators, primarily the level of patient and procedures against the stated network-specific criteria for each EA. As a result, the board discussion centred on introducing more stringent expectations for HCPs regarding their engagement across a number of areas, including the issuance of an annual report to each HCP's CEO detailing their contributions and activities over the previous 12-month period.

Board discussion and actions:

1. **Introduction of additional mandatory expectations for HCP full-members:** The proposed changes to the ERN eUROGEN Monitoring & Assessment Protocol, consisting of changes to current mandatory measures and the addition of new mandatory requirements were accepted by the Board and they will be used to assess the level of engagement from full members once the revised protocol is signed off, being included within the monthly performance report and the proposed Annual HCP Activity Report (see below).
2. **Introduction of Annual HCP Activity Report:** The Network Board spoke favourably about the introduction of this report, with some representatives believing it would help leverage more support and resources from their centres to drive greater network engagement. No objections were raised to this proposal, and it was agreed that a finalised draft of the report would be included in the revised ERN eUROGEN Monitoring & Assessment Protocol, to be issued to the network for approval in late March/early April.
3. **Monitoring & Assurance of HCP Expertise:**
 - a. There was an intense discussion on this point, highlighting the balance that the Network needs to continually tread between ensuring that those HCPs covering EAs continue to demonstrate the necessary level of expertise to ensure that patients are assured about receiving the expected quality of advice and treatment from those HCPs, whilst on the other hand fostering a sufficient community of HCPs for each EA to facilitate the continued exchange and transmission of advice and knowledge, especially with regard to smaller HCPs in less populous member states. Several ideas, including the possible differentiation of expert levels for an EA, were proposed. It was agreed that these will be considered, and a balanced solution will be proposed within the revised Monitoring & Assessment Protocol.
 - b. One delegate asked how people would feel about more transparency in this regard, for example, by publishing the patient and procedure numbers on the website. This was supported by another expert who pointed out that it's in the operational criteria that the numbers are published transparently in patient understandable language. The Coordination Team will check this and ensure that the European Commission has no objections.
 - c. On a related note, the issue of HCPs using the ERN eUROGEN logo to suggest that they are an expert centre for EAs other than the ones for which they are officially recognised by the network. Whilst no immediate solution was proposed, it was agreed that the Coordination Team would consider whether any further improvements

could be made to existing governance and organisational information to ensure that the scope of expertise for each HCP is clear.

- d. Provision of Patient and Procedure Numbers for Workstream 2: The issue was raised that it is more difficult to define exactly what patient data should be provided for many of the EAs in WS2. This has been an ongoing problem for several years, and it was agreed to set up a meeting with the WS2 Lead and relevant WS2 HCP representatives to discuss this further.

7. HEALTHCARE AND NEW CPMS (WORK PACKAGE 4)



CPMS – Parmida Anvary (ERN eUROGEN Clinical Data Specialist) and Darren Shilhan (ERN eUROGEN Lead IT & Data Performance Analyst)

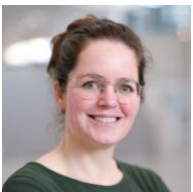
Presentation summary: The Strategic Board received an overview of CPMS implementation and usage progress during Years 1–2 of the 2023–2027 grant period.

Achievements included the successful launch of CPMS 2.0 in January 2025, a significant increase in video meetings, the introduction of the CPMS App (with a live demo showing quick mobile access), and growth in non-member cases. A graph illustrated current progress toward the end-of-grant target of 225 CPMS cases by September 2027 (currently ~50 cases), noting that only 26 of 75 registered HCP representatives have logged into the new system. Barriers to adoption were discussed, with real-time Mentimeter input collected on EU login issues, strategies to boost CPMS usage, and the perceived value of reimbursements.

Board discussion and arising actions: The Board made several constructive suggestions:

1. **Creating a step-by-step PDF guide and video tutorials:** The discussion highlighted EU login challenges as the primary user hurdle—especially first-time setup or after app reinstalls/device changes—with offers for assisted video consultations to resolve issues permanently.
2. **Appointing a designated moderator and note-taker:** The Helpdesk member (Darren Shilhan or Parmida Anvary) will offer to moderate the session, but as they may be occupied with technical aspects, someone else may be identified in advance to moderate live video case discussions. Furthermore, a note-taker needs to be identified upfront as well to create and upload a summary afterwards. The moderator may also play a role in fostering critical discussion of contradictory opinions/advice.
3. **Creating learning opportunities:** Further priorities for the remaining grant years encompass involving young colleagues via introductory "getting started" sessions and scheduling two annual one-hour case discussion sessions per workstream (concentrating on one or two HCPs, covering the same Expertise Areas). These sessions provide space to discuss complex cases—not just for consultation on complications, but also to share knowledge and learn from each other's experiences. It was discussed to introduce a 'best presenter' prize for these multi-case presentation sessions to make them more engaging. Success stories will be disseminated in the CPMS newsletter and, potentially, the main newsletter.
4. **Continue including reimbursement in the next grant:** The board emphasized using reimbursements to demonstrate value to department CEOs/management, thereby supporting ERN sustainability.

8. REGISTRIES, DATA MANAGEMENT AND ANALYSIS (WORK PACKAGE 5)



Registry – Loes van der Zanden (ERN eUROGEN Registry Coordinator) & Lotte Boormans (ERN eUROGEN Registry Manager)

Presentation summary and board discussion: The presentation began with a status update on the number of healthcare providers (HCPs) with partial or full approval for the ERN eUROGEN registry and the patient data entry numbers. The current inclusion rate is not sufficient to reach the target of 4500 registered patients by the end of the grant in

September 2027.

To increase patient numbers, it was suggested to contact new patients who were missed for the registry since the demonstration meeting via regular post or email. Most responders to the Mentimeter indicated that this would be an option for their HCP, but that support from the registry team would be appreciated. Therefore, the registry team will provide HCPs with a protocol, a template patient information letter, and inform them of changes to the Informed Consent Form within the next few weeks, so HCPs can start this effort.

Patient inclusion is best for Expertise Areas (EAs) where a Clinical Practice Snapshot (CPS) is available. For all EAs, prospective inclusion is possible, and it costs less time to include those patients, although they do count towards the grant indicator. The HCPs are asked to do so, while the registry team will put more effort into developing the CPSs.

The [annual reports](#) are created to motivate clinicians and data managers to enter patient data into the registry. Mentimeter answers showed that the reports are approved of in their current form. Regarding motivation to enter patients into the registry, intrinsic motivation to contribute to a rare disease registry scored highest, followed by the annual reports and the availability of a Clinical Practice Snapshot.

Another reason to develop the [annual reports](#) is to promote the use of the registry data. Data can be applied for via a data application (see "[Research Results](#)" via the link). HCPs are asked to consider possibilities and use available data where possible.

Increasing data quality will be a focus for the remainder of the grant to improve data usability. The registry team will regularly email data managers and clinicians with open queries and open Clinical Practice Snapshots, and HCPs are asked to act on them.

Via Mentimeter, responders indicated they would be interested in both an online walk-in hour for on-the-spot questions and a follow-up meeting with each HCP two years after the demonstration meeting. The registry team will organise these.

Arising actions:

1. Registry team: Develop a protocol and a standard letter to contact patients who were missed and may still be invited to the ERN eUROGEN registry.
2. Registry team: Communicate changes to the Informed Consent Form to Principal Investigators.
 - a. Change ICF by adding a checkbox for general consent to inclusion in the ERN eUROGEN registry
 - b. Replace 'Wout Feitz' with 'Peter Mulders' on the Informed Consent Form.
3. Registry team: Send quarterly reminders about open queries, together with the availability of open Clinical Practice Snapshots.
4. Registry team: Organise walk-in hours and follow-up meetings with HCPs.
5. HCPs: Start the process to invite new patients who were missed for the registry.
6. HCPs: Invite patients prospectively for all Expertise Areas.
7. HCPs: Think about possible research proposals using the registry data.
8. HCPs: Fill out open Clinical Practice Snapshots and open queries.

9. TRAINING & EDUCATION (WORK PACKAGE 6)



Webinar Programme – Parmida Anvary (ERN eUROGEN Clinical Data Specialist) and Darren Shilhan (ERN eUROGEN Lead IT & Data Performance Analyst)

Presentation summary: The Strategic Board received an overview of the ERN eUROGEN webinar programme delivered during Years 1–2 of the 2023–2027 grant period.

Achievements included producing 55 webinars with 9,700 registrants and 4,000 attendees.

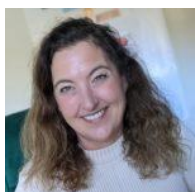
The YouTube channel showed strong growth, reaching 78,000 views and 1,100 subscribers. Webinars received CME accreditation, and switching from GoToWebinar to Zoom proved highly successful—no technical issues encountered, plus multilingual subtitle options.

Areas for improvement discussed with the board, again using Mentimeter, included ensuring at least two presenters per webinar, consulting relevant Expertise Area Coordinators on topics, defining presenter qualifications, streamlining the setup process (e.g., better collaboration on titles and details), and assessing the importance of continuing CME accreditation, which is currently paused.

Board discussion and arising actions: Several suggestions were made during the board discussion to enhance the webinar programme:

1. **Maintaining high-quality webinars:** The board suggested encouraging PhD candidates/young researchers to present (to boost HCP participation), but they should be assisted by their professor/supervisor during the post-presentation discussion. It was also suggested that at least two different HCPs be included per webinar to ensure diverse perspectives and avoid presenting only one opinion. Including patients to share their perspective during webinars is also encouraged, provided clinicians are present to cover the clinical aspects. Webinar proposals should be reviewed and approved by the relevant Expertise Area Coordinator and Vice-Coordinator to ensure quality. They can also suggest suitable HCPs for inclusion and moderate the session to guarantee diverse opinions are represented.

2. **Pre-recorded webinars:** It was also emphasized that there is always the option to pre-record the presentation and then join live for the discussion afterward. This may help and make it more appealing for members to deliver a webinar. The Helpdesk is happy to assist with recordings if needed, and presenters can always record themselves using PowerPoint's built-in recording option.
3. **Language of Webinars:** Most members prefer presenting webinars in English. However, we will offer the option to present in their native language while testing subtitle implementation. This will only be done as a test pilot if a presenter prefers to present in their native language. Afterwards, this will be evaluated and discussed before implementing. This should encourage more people to present.
4. **Webinar Information form:** To improve the webinar setup process, the Helpdesk will include the webinar information form in the very first email sent to potential presenters/proposals. This allows presenters to provide all required details immediately via the form.



Training Courses – Michelle Battye (ERN eUROGEN Programme Manager)

Presentation summary: The Strategic Board received an overview of WP6 training and education activities delivered during Years 1–2 of the 2023–2027 grant period.

Achievements included delivering annual paediatric colorectal surgical training courses in 2024 and 2025, in collaboration with EUPSA, and an expert consensus meeting on vaginal replacement in children with anorectal malformations (Lund, SE, April 2025). Sustained collaboration with other ERNs on cross-cutting priorities was maintained throughout. Beyond grant requirements, WP6 activities also included the launch and dissemination of the *Rare and Complex Urology* book and Expertise Area book series, participation in cross-ERN nursing and surgical training initiatives, and endorsement of external workshops and postgraduate training programmes.

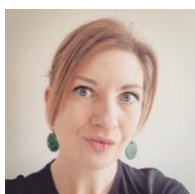
An area for improvement was identified regarding the flagship highly specialised surgical training programme, which has encountered implementation challenges. The Board was invited to suggest alternative approaches and consider how collaboration with scientific societies could be strengthened.

Looking ahead, a quality-of-life workshop for healthcare professionals is planned for late 2026 (Gothenburg, SE), along with an associated expert consensus document. The Board was additionally invited to contribute views on the content of WP6 in the next grant cycle.

Board discussion and arising actions:

1. **Surgical training:** It was proposed that all rare surgeries should routinely be recorded, both to enable surgeons to self-evaluate their practice and to develop surgical training videos as a learning resource for trainees. It was also suggested that using surgical telemedicine and the potential use of a training simulator should be prioritized for the next grant cycle. In addition, it was suggested that the exchange programme should be reinstated and funded under the next grant. The Board recommended compiling a structured list of experts able to support specific Expertise Areas in terms of training and cross-border care.

10. CLINICAL PRACTICE GUIDELINES AND CLINICAL DECISION SUPPORT TOOLS (WORK PACKAGE 7)



Guidelines: Overview, Support, & Timeline – Jen Tidman (ERN eUROGEN Business Support Manager)

Presentation summary: The Strategic Board received an overview of progress under WP7 during Years 1–2 of the 2023–2027 grant period, following the Independent Evaluation Body's recommendation to prioritise guideline development.

Two Clinical Practice Guidelines (Anorectal Malformation and Paediatric Neurogenic Bladder) and one Clinical Decision Support Tool (Posterior Urethral Valves) were completed. Multiple additional CPGs and CDSTs are actively progressing across expertise areas, supported by structured governance through the ERN eUROGEN Guidelines Expert Panel and extensive collaboration with other ERNs and scientific societies.

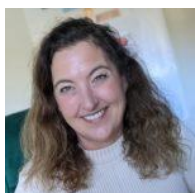
Survey feedback highlighted three areas for further consideration: the need for a sustainable funding model for methodological and coordination support, the potential development of shorter or “pocket” versions of guidelines to enhance usability, and the importance of strengthening national-level implementation mechanisms.

For the final two years of the grant, the focus will be on delivering remaining guideline commitments and enhancing implementation. A strategic discussion was initiated regarding the direction of WP7 beyond 2027, including prioritisation, sustainability, resourcing, and implementation strategy.

Board discussion and arising actions: The Board discussion focused on two key areas:

1. **Clarification of CPG vs CDST Terminology:** It became apparent that some members were unclear about the distinction between Clinical Practice Guidelines (CPGs), Clinical Decision Support Tools (CDSTs), and other forms of guidelines. Reference was made to the European Commission's [Methodological Handbooks & Toolkit for Clinical Practice Guidelines and Clinical Decision Support Tools for Rare or Low-Prevalence and Complex Diseases](#), in particular the [Quick Guide](#), which outlines the different types on pages 15-28. There is also an associated [EU Academy course](#). These resources provide detailed clarification of definitions, scope, and methodological standards.
2. **Potential Development of a Guidelines Chatbot (LLM-based Tool):** It was suggested that ERN eUROGEN explore the future possibility of developing a chatbot-based tool to support access to guidelines, similar to initiatives undertaken by the EAU. This would be considered in the context of the next grant cycle, subject to feasibility, governance, and methodological considerations.

11. CAPACITY BUILDING AND BEST PRACTICE SHARING / OTHER ACTIVITIES FOR UKRAINE (WORK PACKAGES 8 / 9)



Ukraine: Current Status, Challenges & Next Steps – Michelle Battye (ERN eUROGEN Programme Manager)

Presentation summary: The Strategic Board received an update on WP8 and WP9 activities supporting Ukrainian healthcare providers during Years 1–2 of the 2023–2027 grant period.

Key achievements included delivering 18 webinars to Ukrainian clinicians, with the programme on track to exceed the target of 20, covering topics such as spina bifida and complex urology, and with accessible recordings and subtitles now available. A strong collaboration has been established with Khmelnytsky Children's Hospital, supported by 16 coordination meetings; the hospital has since been accredited as a centre of expertise for spina bifida in Ukraine. Contact was also made with the Rare Diseases Hub in Kyiv. On clinical support, CPMS access was granted to a Ukrainian clinician, and the first patient case was successfully discussed via the system, enabling expert virtual advice for a patient with spina bifida. ERN eUROGEN guidelines and patient information materials were also shared. Three awareness campaigns were completed, including participation in Rare Disease Day and outreach to national urological societies.

Areas for improvement focus on maintaining the Kyiv Rare Diseases Hub collaboration, increasing awareness of ERN eUROGEN support among Ukrainian clinicians, and promoting greater uptake of CPMS.

Next steps include implementing a webinar series co-developed with Ukrainian clinicians and further promoting CPMS use. Looking beyond the current grant, the continuation of the webinar series is planned, and the possibility of in-person training at ERN eUROGEN HCPs (contingent on the end of the war) was raised for Board discussion.

Board discussion and arising actions:

1. **Surgical outreach to Ukraine:** As Ukrainian clinicians cannot currently leave Ukraine, the Board raised the possibility of ERN eUROGEN clinicians travelling to Ukraine to deliver in-person training and surgical support. The Coordination Team will explore the feasibility and willingness of ERN eUROGEN clinicians travelling to Ukraine, subject to safety considerations and the availability of appropriate post-operative care at the receiving institution.

12. ATTEENDEES

Coordination Team

- Darren Shilhan,
- Jen Tidman,
- Loes van der Zanden,
- Lotte Boormans,
- Michelle Battye,
- Parmida Anvary,
- Peter Mulders,
- Wout Feitz

ePAG Representatives (In Person)

- Frans Baan,
- Lieke Janssen,
- Miriam Wilms

HCP Representatives (In Person)

- Anna Borjesson (SE 03 – Lund SUS),
- Arnout Alberts (NL 03 – Rotterdam Erasmus),
- Charlotta "Lotta" Levén Andréasson (SE 02 – Gothenburg Sahlgrenska),
- Davide Dalla Rosa (IT 05 – Bergamo Papa Giovanni XXIII),
- Eberhard Schmiedeke (DE 09 – Bremen-Mitte Klinik),
- Giovanni Mosiello (IT 58 – Rome Bambino Gesù),
- Gjetrud Wennevik (DK 02 – Copenhagen Rigshospitalet),
- Hans Langenhuijsen (NL 09 – Nijmegen Radboudumc),
- Herjan van der Steeg (NL 09 – Nijmegen Radboudumc),
- Ivo de Blaauw (NL 09 – Nijmegen Radboudumc),
- Jan-Hendrik Gosemann (DE 10 – Leipzig UK),
- Karin Ruitenbeek (NL 02 – Groningen UMC),
- Katja Wolffenbuttel (NL 03 – Rotterdam Erasmus),
- Lotta Renström Koskela (SE 01 – Stockholm Karolinska),
- Luka Penezic (HR 01 – Zagreb KBC),
- Luisa Weil (DE 13 – Mannheim UK),
- Magnus Anderberg (SE 03 – Lund SUS),
- Marieke Witvliet (NL 09 – Nijmegen Radboudumc),
- Matthieu Peycelon (FR 10 – Paris Robert-Debré),
- Olga Arguedas Flores (NL 01 – Amsterdam AMC),
- Pernilla Stenström (SE 03 – Lund SUS),
- Sofia Sjöström (SE 02 – Gothenburg Sahlgrenska),
- Tahlita Zuiverloon (NL 03 – Rotterdam Erasmus)

ePAG Representatives (Online)

- Anna De Santis,
- Annette Lemli,
- Dalia Aminoff,
- Kate Tyler,
- Robert Cornes

HCP Representatives (Online)

- Alessandro Morlacco (IT 07 – Padua AOU),
- Ádám Széles (HU 03 – Budapest Semmelweis),
- Andrzej Gołębiowski (PL 14 – Gdansk UCC),
- Anne Ebert (DE 36 – Ulm UK),
- Antonio Di Cesare (IT 34 – Milan Policlinico),
- Barbara Dobrowolska-Glazar (PL 23 – Krakow USD),
- Célia Crétolle (FR 09 – Paris Necker),
- Dario Guido Minoli (IT 34 – Milan Policlinico),
- Francesco Fascetti Leon (IT 07 – Padua AOU),
- Gilvydas Verkauskas (LT 01 – Vilnius SK),
- Gisela Reinfeldt Engberg (SE 05 – Uppsala Akademiska),
- Gundela Holmdahl (SE 01 – Stockholm Karolinska),
- Ilaria Marcoccio (IT 34 – Milan Policlinico),
- João Pedro Lobo (PT 08 – Porto IPO),
- John Heesakkers (DE 29 – Aachen UK),
- Jose Medina Polo (ES 10 – Madrid 12 de Octubre),
- Katharina Rall (DE 22 – Tübingen UK),
- Lucia Migliazza (IT 05 – Bergamo Papa Giovanni XXIII),
- Maria Joaquina Mauricio (PT 08 – Porto IPO),
- Mateja Vinksel (SL 02 – Ljubljana UKC),
- Michel Wyndaele (NL 13 – Utrecht UMC),
- Mirela Kekić (External),
- Niklas Pakkasjärvi (FI 01 – Helsinki HUS),
- Nikola Knezevic (HR 01 – Zagreb KBC),
- Olessia Koulikova (FR 10 – Paris Robert-Debré),
- Oliver Muensterer (DE 03 – Munich LMUK),
- Patricia Reis Wolfertstetter (DE 19 – Regensburg UK),
- Piotr Czauderna (PL 14 – Gdansk UCC),
- Radim Kočvara (CZ 02 – Prague VFN),
- Rafał Chrzan (PL 23 – Krakow USD),
- Robert Kordič (SL 02 – Ljubljana UKC),
- Romy Gander (ES 09 – Barcelona Vall d'Hebron),
- Stefan Anzelewicz (PL 14 – Gdansk UCC),
- Tim Ludwig (DE 40 – Hamburg-Eppendorf UK),
- Vincenzo Davide Catania (IT 11 – Bologna AOU),
- Yazan Rawashdeh (DK 01 – Aarhus DNU),
- Yue Che (DE 37 – Düsseldorf UK)



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.



European
Reference
Network

ERN eUROGEN
Rare Uro-Recto-Genital Diseases
& Complex Conditions



Funded by
the European Union