

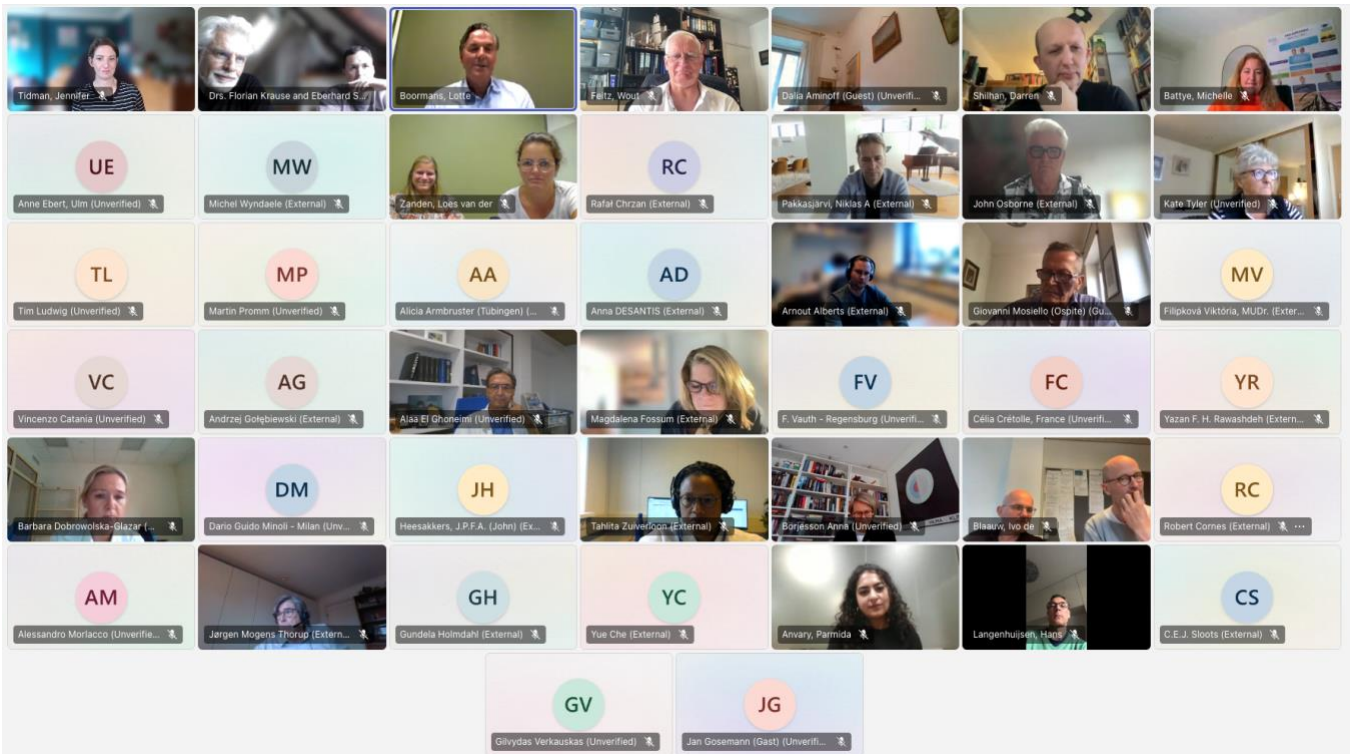


# ERN eUROGEN Strategic Board Meeting Report

## 24.09.2024, virtual

### Background

Due to budget constraints, it was decided to hold the meeting virtually. A poll was sent out to determine the best date, and the meeting was held on 24 September 2024. The [agenda](#) was drafted and sent to all full member and affiliated partner [Healthcare Providers](#) (HCPs), [European Patient Advocacy Group](#) (ePAG) advocates, and [Supporting Partners](#) (organisations and individual experts), according to the ERN eUROGEN [Governance Statutes](#). Attendees were requested to put the event in their diaries and submit any items for Q&A, discussion, and voting by 17 September 2024. The meeting was held via Microsoft Teams. Links to slides and further information can be found below.



## INTRODUCTION



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

Peter welcomed everyone to the meeting.

The attendees introduced themselves and explained which HCP they represented, their position in their HCP, and their role in ERN eUROGEN.



# 1. COORDINATION (WORK PACKAGE 1)



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

[Link](#) to download presentation slides.

[Michelle Battye](#) noted the change in Coordinator in 2024, which included the Coordination Team developing a Coordinator Transition Protocol to ensure a smooth and professional transfer of duties and the business continuity of ERN eUROGEN. She gave an overview of the current grant (2023-2027), including the timing and technical elements, followed by the Specific Objectives, Deliverables, Milestones, and Indicators for each Work Package.



## **ePAG Activities and Updates 2023 (Year 7) – John Osborne (ePAG Chair)**

[Link](#) to download presentation slides.

As Chair of ERN eUROGEN's [European Patient Advocacy Group \(ePAG\)](#), John Osborne gave an overview of the ePAG's activities over the past year and their future activities and ambitions for the next year. He thanked Dalia Aminoff for all her hard work as the previous ePAG Chair and the other ePAG Representatives for their efforts and dedication. He emphasised the need for inclusion and collaboration and ensuring the patient's voice is heard. Specifically, in terms of evaluation, he noted the importance of validating the network's patient numbers and patient involvement in the Quality Improvement Group (QIG). Regarding the ERN eUROGEN Registry, patient-reported outcome measures (PROMs) will be vital. He showed a video relating to the preliminary results of a penile cancer patient survey that he had initiated. In conclusion, he noted that much has been achieved, but there is much to do – patients must continue to have a central role in the workings of ERN eUROGEN.



## **Update on Addressing the Impact of Rare Conditions on Mental Health – Matt Johnson (EURORDIS)**

[Link](#) to download presentation slides.

[Matt Johnson](#), EURORDIS's Mental Wellbeing Lead and Healthcare Advisor, presented the impact of rare diseases on mental health where there is a proven unmet need. He noted the effects of rare diseases on emotional well-being, financial independence, social isolation, and holistic care. EURORDIS is working on a Rare Barometer survey on wellbeing and health, which will be shared in due course, and the network's support in responding/disseminating will be appreciated. ERN eUROGEN is represented in the EURORDIS Mental Health Wellbeing network, which aims to unite and empower, increase visibility, and impact policy. EURORDIS runs a series of [open webinars](#) on mental wellbeing – an upcoming webinar will include Kate Tyler, one of ERN eUROGEN's ePAG Representatives, on the panel. The [EURORDIS Position Paper on Mental Health and Wellbeing](#) aims to improve outcomes through care delivery. Future activities will include developing a Mentally Healthy Toolkit and conducting a literature review.



## **Collaborations: Cross-ERN, Supporting Partners, WHO GNRD, European Rare Diseases Research Alliance – Wout Feitz (Past ERN eUROGEN Coordinator)**

[Link](#) to download presentation slides.

[Wout Feitz](#) gave an overview presentation covering ERN eUROGEN's collaborations. The network has cross-ERN collaborations with the [other 24 ERNs](#) and through the ERN Coordinators Group and other working groups. In addition, there is collaboration with and through the European Commission, such as meetings with the ERN Board of Member States ([BoMS](#)) and the Joint Action on Integrating ERNs into National Health Systems ([JARDIN](#)). Wout outlined ERN eUROGEN's current [Supporting Partners](#), both organisations and individual experts. There are also research collaborations such as the European Rare Disease Research Coordination and Support Action consortium ([ERICA](#)) and the European Rare Diseases Research Alliance ([ERDERA](#)), which has now launched to replace the European Joint Programme on Rare Diseases ([EJP RD](#)). ERDERA will have a launch event on 28 October from 2-3.30 pm CET, during which they will explain future activities and opportunities – joining information will be circulated when available. Wout noted that the ERN eUROGEN Registry will be key to research collaboration.

## 2. DISSEMINATION (WORK PACKAGE 2)



### [Overview and Dissemination and Communication Actions – Jen Tidman \(ERN eUROGEN Business Support Manager\)](#)

[Link](#) to download presentation slides.

[Jen Tidman](#) presented ERN eUROGEN's Dissemination and Communication Plan, aimed at raising awareness of the network's activities, sharing key results, and maximising impact across scientific, commercial, and societal channels. The plan targets both internal (member healthcare providers, ePAG, and Supporting Partners) and external (non-ERN healthcare providers, patients, academics, and policymakers) audiences to promote collaboration and improve patient outcomes. Key messages focus on resource sharing, expert collaboration, EU-wide access to expertise, and capacity building. Dissemination efforts include maintaining a dynamic website, issuing regular newsletters, leveraging social media, and participating in conferences. Initiatives such as JARDIN and LinkedIn campaigns further raise awareness, with ongoing monitoring of KPIs like website traffic and webinar attendance to refine strategies. The plan ultimately seeks to enhance ERN eUROGEN's visibility and encourage participation in future activities.

## 3. EVALUATION (WORK PACKAGE 3)



### [Update on Reporting, Monitoring, & Evaluation – Darren Shilhan \(ERN eUROGEN Lead IT & Data Performance Analyst\)](#)

[Link](#) to download presentation slides.

[Darren Shilhan](#) gave an overview of the monitoring exercise, including timing, requirements, and indicators. He outlined the Healthcare Provider responsibilities, including changes for 2025. He noted the importance of patient numbers and discussed the process for setting thresholds for ERN eUROGEN's Expertise Areas. Work is underway to improve coding, good practice, and improving the quality of the numbers. Darren also outlined ERN eUROGEN's performance dashboard and HCP scoring. He mentioned that the next 5-year evaluation will be in 2027 for all current full members – a working group has been set up to ensure this is run effectively and avoid the problems with the last evaluation. Darren encouraged people to join the Quality Improvement Group (QIG) to help improve the network – his slides gave an overview of the results of a recent quality improvement survey.

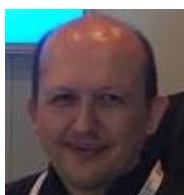
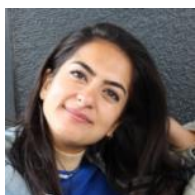


### [How to deal with complete, incomplete, realistic and unrealistic data registration – Eberhard Schmiedeke \(HCP Representative, Klinikum Bremen-Mitte, DE\)](#)

[Link](#) to download presentation slides.

In a presentation co-authored with Dalia Aminoff (ePAG Representative, AIMAR) and Ivo de Blaauw (ERN eUROGEN Sub-Coordinator and Expertise Area Coordinator 1.7 Urorectal/anorectal malformations), Eberhard Schmiedeke highlighted network issues with monitoring and data collection relating to Expertise Area (EA) 1.7 Urorectal/anorectal malformations. The importance of data collection was emphasised to both demonstrate the network's impact to the EC and to allow for internal evaluation of expertise centres across Europe. From next year on, the number of reconstructive surgeries (PSARP etc.) will be reported, according to the different fistula forms, too. The current state of data reporting was discussed, showing improvements from 2022 to 2023, but challenges persist, particularly with clinics providing incomplete or no data. The low number of new and surgically corrected complex cases, such as cloacal malformations, was highlighted as a concern, with the group stressing the need to reach minimal numbers of new patients and surgeries to gain sufficient experience. Moving forward, cooperation at regional, national, and international levels was suggested as a potential solution to address these issues and improve patient care quality.

## 4. HEALTHCARE AND NEW CPMS (WORK PACKAGE 4)



### [CPMS Transfer and CPMS 2.0 – Parmida Anvary \(ERN eUROGEN Clinical Data Specialist\) and Darren Shilhan \(ERN eUROGEN Lead IT & Data Performance Analyst\)](#)

[Link](#) to download presentation slides.

[Parmida Anvary](#) gave an overview of ERN eUROGEN's CPMS performance regarding the number of panels and users. She reminded attendees of the ways the ERN eUROGEN CPMS Helpdesk can provide support. [Darren Shilhan](#) explained about reimbursement for CPMS panels—€500 per panel issued on a first-come-first-served basis up to a limit of €55,000 for the network over four years. CPMS 2.0 is technically live but cannot be used until data is migrated, which should happen for ERN eUROGEN next month – once the switchover happens, the network will be informed, and training will be available.

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

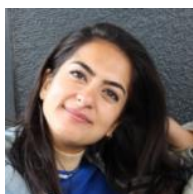


### [Registry Update and Developments –Lotte Boormans \(ERN eUROGEN Registry Manager\)](#)

[Link](#) to download presentation slides.

[Lotte Boormans](#) outlined the registry's current status, including ethical and legal approval and patient numbers, which are also included in the monthly performance report. She covered the requirements for reimbursement for data entry—€32,000 is available until October 2027. Results and retrospective data analysis are available per HCP and Expertise Area. The included data elements, such as clinical practice snapshots and PROMs, will be further developed and piloted. Data quality will be improved using the Castor query system to allow a sustainable and central overview of queries.

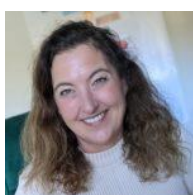
## 6. TRAINING & EDUCATION (WORK PACKAGE 6)



### [Webinar Programme – Parmida Anvary \(ERN eUROGEN Clinical Data Specialist\)](#)

[Link](#) to download presentation slides.

[Parmida Anvary](#) gave an overview of the ERN eUROGEN webinar programme, including when they are held, what they cover, and who delivers them. She noted the special webinar series: the colorectal series, the IC/BPS series, and the Ukraine series. The webinars have a large worldwide and European audience, and EACCME has accredited all webinars since September 2023. Parmida gave results from the post-session and annual surveys, which evaluate the webinar format and are used to improve the programme. The annual survey showed a 97% positive response in terms of overall satisfaction, and feedback on individual questions was also highly positive.



### [Training Courses – Michelle Battye \(ERN eUROGEN Programme Manager\)](#)

[Link](#) to download presentation slides.

[Michelle Battye](#) explained that the primary aim of WP6 is to enhance the training of the next generation of surgeons and urologists, particularly in the field of rare uro-recto-genital diseases and complex conditions. The flagship initiative, a highly specialised surgical training programme, is being co-developed with ERN ERNICA and focuses on collaborative patient care and surgical training. Michelle also highlighted specific training courses, including a paediatric colorectal course and developing highly specialised surgical videos. Plans for future workshops on quality of life and gynaecological concerns, a series of CME-accredited webinars, and the forthcoming publication of a series of books on rare and complex urology were discussed.

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



### [Guidelines: Overview, Support, & Timeline – Michelle Battye \(ERN eUROGEN Programme Manager\)](#)

[Link](#) to download presentation slides.

[Michelle Battye](#) presented an update on Clinical Practice Guidelines (CPGs) and Clinical Decision Support Tools (CDSTs) within the ERN eUROGEN. The focus was on various guideline deliverables, including CPGs for bladder exstrophy, paediatric neurogenic bladder, and anorectal malformations, as well as CDSTs on congenital solitary functioning kidney, vaginal malformation, and posterior urethral valves, among others. Collaboration with scientific societies and patient representatives (ePAGs) was emphasised, particularly in developing transparent and applicable guidelines across Europe. Overall, the progress of the guidelines, the inclusion of expert groups, and the use of ERN methodology were highlighted as key to improving clinical outcomes and supporting healthcare professionals.

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



### [Webinars for Ukraine: Outcome Analysis & New Programme – Giovanni Mosiello \(Workstream 1 Lead and Expertise Area Coordinator 1.4 Non-syndromic urogenital tract malformation\)](#)

[Link](#) to download presentation slides.

[Giovanni Mosiello](#) presented the outcome analysis of the eUROGEN webinar series for Ukraine and outlined the upcoming programme. The webinars were aimed at providing educational support, particularly focusing on managing conditions such as spina bifida, with a multidisciplinary approach involving experts from both Ukraine and Europe. The analysis revealed high registration numbers across multiple countries, including Ukraine, Italy, and Germany, with attendees representing various medical fields such as urology, paediatric surgery, and gynaecology. The feedback from participants was largely positive, with most attendees finding the content useful and the presentations clear. Future webinars are planned, covering topics such as spina bifida, botulinum toxin use in neurogenic bladder management, and paediatric urology procedures. The overarching goal of these webinars is to bridge the gap between expert centres and patient needs, improve knowledge transfer, and support the transition of care from paediatric to adult services.

### [EU-Ukraine Legislation and CPMS 2.0](#)

[Darren Shilhan](#) explained that, under the legislation, Ukrainian panels are not possible in the current version of CPMS but will be under CPMS 2.0. The Ukrainian Rare Diseases Hub will facilitate these, liaising with the CPMS Helpdesks of the relevant ERNs. This is anticipated to start in November 2024.

## GOVERNANCE: STRATEGIC BOARD DISCUSSION

### [Supporting Partners: Organisations & Individual Experts](#)

The meeting attendees had no comments on the current requirements for Supporting Partner organisations or individual experts. It was noted that the agreement with the European Paediatric Surgeon's Association (EUPSA) was being renewed, that Heiko Reutter (a geneticist) had been added as an individual expert and that Miriam Wilms had been proposed as an individual expert.

### [EUPSA Network Office – Permanent ERN eUROGEN Representative](#)

The European Paediatric Surgeon's Association (EUPSA) has invited ERN eUROGEN to nominate a permanent representative to their Network Office. The office focuses on facilitating collaboration and networking among EUPSA members, encouraging participation in various opportunities, and inviting members to propose new projects and surveys. It supports research through the Small Grants Scheme, coordinates multi-centre cohort studies, and promotes collaboration to avoid duplicated efforts and strengthen shared interests. It was suggested that Ivo De Blaauw, ERN eUROGEN Sub-Coordinator, could become the permanent representative unless anyone else wished to take the position.

## Future Strategic Board Meetings

Due to the current grant's budget restrictions, the network cannot fund face-to-face Strategic Board Meetings. The Coordination Team realises that face-to-face meetings are preferred, and so asked attendees to consider whether they or their institutions would be prepared to self-fund their attendance (travel, accommodation, and subsistence). The meeting would be in a hybrid format for those unable to attend in person.

## Publications and Presentations

It was emphasised that ERN eUROGEN and membership of the network should be acknowledged where possible when submitting publications or giving presentations, but care should be taken not to state that single-centre work, particularly on controversial topics, was "on behalf of" the network. In case of any doubts, members should contact [Jen Tidman](#) to ask how to phrase an acknowledgement.

## SUMMARY OF MEETING

In conclusion, Peter Mulders (ERN eUROGEN Coordinator) thanked all the presenters and attendees for their contributions, specifically those engaged in the broader work of the ERN eUROGEN network. Peter emphasised the importance of ongoing collaborative efforts, encouraged everyone to continue supporting the network's initiatives, and reinforced the need for sustained commitment to achieve the shared goals of improving patient care and advancing knowledge in rare urorectogenital diseases and complex conditions.

**If any additional questions or important suggestions arise after reviewing the abovementioned and using the links, please [contact the Coordination Team directly](#), who will then take appropriate action. If no reply is received within the normal two-week consultation period, the Coordination Team will presume the report is final.**

## ATTENDEES

### Coordination Team (NL - Nijmegen):

Anvary, Parmida  
Battye, Michelle  
Boormans, Lotte  
De Blaauw, Ivo  
Mulders, Peter  
Shilhan, Darren  
Tidman, Jen  
van der Zanden, Loes

### HCP Representatives:

Albers, Peter (DE - Düsseldorf)  
Alberts, Arnout (NL - Rotterdam)  
Anderberg, Magnus (SE - Lund)  
Armbruster, Alicia (DE - Tübingen)  
Bagolan, Pietro (IT - Rome Bambino Gesù)  
Börjesson, Anna (SE - Lund)  
Brouwer, Oscar (NL - Amsterdam AvL)  
Catania, Vincenzo (IT - Bologna)

Che, Yue (DE - Düsseldorf)  
Chrzan, Rafał (PL - Krakow)  
Crétolle, Célia (FR - Paris Necker)  
Dobrowolska-Glazar, Barbara (PL - Krakow)  
Ebert, Anne (DE - Ulm)  
El Ghoneimi, Alaa (FR - Paris Robert-Debré)  
Feitz, Wout (NL - Nijmegen)  
Fenech, Carol (MT - Malta Mater Dei)  
Ferenschild, Floris (NL - Nijmegen)  
Filipková, Viktória (CZ - Prague Thomayer)  
Fossum, Magdalena (DK - Copenhagen)  
Gołębiewski, Andrzej (PL - Gdansk)  
Gorter, Ramon (NL - Amsterdam AMC)  
Gosemann, Jan (DE - Leipzig)  
Holmdahl, Gundela (SE - Stockholm)  
Kekić, Mirela (HR - Zagreb Sestre Milosrdnice)  
Klijn, Aart (NL - Utrecht)  
Krause, Florian (DE - Bremen-Mitte)  
Langenhuijsen, Hans (NL - Nijmegen)

Levén Andréasson, Charlotta "Lotta" (SE - Gothenburg)  
Ludwig, Tim (DE - Hamburg)  
Migliazza, Lucia (IT - Bergamo)  
Minoli, Dario Guido (IT - Milan Policlinico)  
Morlacco, Alessandro (IT - Padua AOU)  
Mosiello, Giovanni (IT - Rome Bambino Gesù)  
Nappo, Simona (IT - Turin)  
Nordenström, Josefin (SE - Gothenburg)  
Pakkasjärvi, Niklas (FI - Helsinki)  
Promm, Martin (DE - Regensburg)  
Rawashdeh, Yazan (DK - Aarhus)  
Reference Center for Rare Urinary Tract Malformations (MARVU) (FR - Paris Robert-Debré)  
Schmiedeke, Eberhard (DE - Bremen-Mitte)  
Sloots, C.E.J. (NL - Rotterdam)  
Stenström, Pernilla (SE - Lund)  
Thorup, Jørgen (DK - Copenhagen)  
Vauth, Franziska (DE - Regensburg)  
Verkauskas, Gilvydas (LT - Vilnius)  
Vinkšiel, Mateja (SL - Ljubljana)  
Weil, Luisa (DE - Mannheim)

Willemse, Peter-Paul (NL - Utrecht)  
Wolffenbuttel, Katja (NL - Rotterdam)  
Wyndaele, Michel (NL - Utrecht)  
Younsi, Nina (DE - Mannheim)  
Zuiverloon, Tahlita (NL - Rotterdam)

**ePAG Representatives:**

Aminoff, Dalia (AIMAR/ARM-Net)  
Bartezzati (independent)  
Cornes, Rob (Orchid)  
De Santis, Anna (AICI)  
Harkin, Claire (KSA)  
Osborne, John (independent)  
Tyler, Kate (TOFS/EAT)

**Supporting Partners:**

Bolz-Johnson, Matt (EURORDIS)  
Grano, Caterina (IT - Sapienza)  
Heesakkers, John (NL - Maastricht UMC / ICS)  
Thomas, Kay (UK – Guy's & St Thomas)  
Van Poppel, Hein (EAU)