

# Report of ERN eUROGEN Strategic Board Meeting

11-12.09.2023, Van der Valk Hotel Nijmegen-Lent, NL



## BACKGROUND

It was decided to hold the meeting at the same venue as the previous year, the [Van der Valk Hotel Nijmegen-Lent](#), in Nijmegen, The Netherlands, in the same city as [Radboudumc](#), the ERN eUROGEN HCP Network Coordinator. A poll was sent out to determine the best dates, with the result that an in-person meeting was held from 11-12 September 2023.



The [agenda](#) was drafted and sent out to all full member and affiliated partner [healthcare providers](#) (HCPs), [ERN Patient Advocacy Group](#) (ePAG) advocates, and [Supporting Partners](#) (organisations and individual experts), according to the ERN eUROGEN [Governance Statutes](#), with the request that attendees register for the meeting, book their own travel and accommodation (to be reimbursed according to the ERN eUROGEN Expenses Factsheet and EC Unit Costs) and submit any items for Q&A, discussion, and voting by 1 September 2023.



A live stream component was provided (via [GoToMeeting](#) and the support of the audio-visual and IT team of [Moos + Spike](#)) so that attendees could watch and participate remotely. Recordings were made for stakeholders to watch at their convenience (see [full YouTube playlist](#)). Links to individual recordings, slides, and further information can be found below.

## DAY 1 – 11 SEPTEMBER

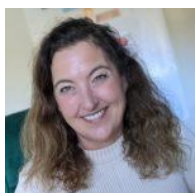
### Coordination (Work Package 1)



#### **ERN eUROGEN Innovations – Wout Feitz (ERN eUROGEN HCP Network Coordinator Representative)**

[Link](#) to watch on YouTube. [Link](#) to download presentation slides. [Link](#) to coordination information.

[Wout Feitz](#) welcomed everyone to the meeting, joining in person and online. He then gave an overview presentation covering ERN eUROGEN's tasks from 2023-2027 under the next grant, covering the EU Action on Rare Diseases, the nine ERN eUROGEN work packages, collaboration and research.

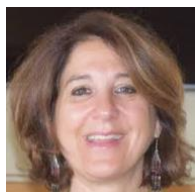


#### **Management & Grant Actions of the Network – Michelle Battye (ERN eUROGEN Programme Manager)**

[Link](#) to watch on YouTube. [Link](#) to download presentation slides.

[Michelle Battye](#) gave an overview of the revised call and new proposal for the next grant (2023-2027), including the two new work packages relating to Ukraine, the reduced budget, the timeline, and the expectations for ERN eUROGEN's healthcare providers (HCPs).

### ERN Patient Advocacy Group (ePAG)



#### **ePAG Activities and Updates 2023 (Year 6) – Dalia Aminoff (ePAG Chair / AIMAR)**

[Link](#) to watch on YouTube. [Link](#) to download presentation slides. [Link](#) to ePAG information.

Dalia Aminoff, as ERN eUROGEN's ERN Patient Advocacy Group (ePAG) Chair, gave an overview of the ePAG's activities over the past year, including their role and relationship with EURORDIS and their involvement in ERN eUROGEN's 5-year evaluation, webinars, book, registry, guidelines, transition working group, and patient journeys. She also outlined the ePAG's planned activities over the next year.



#### **ARM Patient Journey: A Lifelong Journey Taken One Step at a Time – Kate Tyler (TOFS) & Nicole Schwarzer (SoMA eV)**

[Link](#) to watch on YouTube. [Link](#) to download presentation slides.

Kate Tyler is a member of the ERN eUROGEN ePAG and an adult with anorectal malformations (ARM). With Dalia Aminoff and Nicole Schwarzer, she has been working on updating the ARM patient journey, and in her presentation, she outlined the aim, objectives, stages and structure of this important piece of work, which has nearly completed development.



#### **Penile Cancer Initiatives and ePAG Involvement 2023-2024 – Rob Cornes (Orchid Cancer)**

[Link](#) to watch on YouTube. [Link](#) to download presentation slides.

Rob Cornes gave an update on penile cancer initiatives he has undertaken over the past year together with two other ERN eUROGEN ePAG members, Kenneth Manzie and John Osborne. This has included input to the [EAU-ASCO Collaborative Guidelines on Penile Cancer](#), an EAU patient animation, and an EAU patient information website update, and the creation of two new videos to raise awareness of penile cancer, with [the first being launched on penile cancer awareness day](#) (20 September). He also outlined future activities over the next year and beyond.





The process for agreement of [Supporting Partners](#) is outlined in the ERN eUROGEN [Governance Statutes](#). The ERN eUROGEN Coordination Team also welcomes any comments on the process for, and agreements with, Supporting Partners. Our **Supporting Partners (Organisations)** are [ARM-Net](#), the European Association of Urology ([EAU](#)), the European Society for Paediatric Urology ([ESPU](#)), the European Paediatric Surgeon's Association ([EUPSA](#)), and the International Society for the Study of Bladder Pain Syndrome ([ESSIC](#)). Our **Supporting Partners (Individual Experts)** are individual clinicians whose HCPs are not part of the network, including those who are not in the EC/EEA, who can provide specific expertise that is relevant to and of value to the network. No changes were proposed to the current protocols.

## Collaboration – European and Global



### [The Impact of RDs on Mental Health & Europe's Response to Addressing These Needs – Matt Johnson \(EURORDIS\)](#)

[Link](#) to download presentation slides.

[Matt Johnson](#), Mental Wellbeing Lead & Healthcare Advisor, [EURORDIS](#), gave a presentation on the impact of rare diseases on mental health and wellbeing. He highlighted the EU, UN and WHO priority actions on mental health. He gave an overview of the EURORDIS Mental Wellbeing Initiative, a four-year initiative supported by a new EURORDIS Mental Wellbeing Partnership Network, in which ERN eUROGEN will be involved.



### [Global Network for Rare Diseases: Global Collaboration to Support Timely Diagnosis and Care for Persons Living with a Rare Disease – Mary Wang \(Rare Diseases International\)](#)

[Link](#) to download presentation slides.

[Mary Wang](#), Programme Director, [Rare Diseases International](#), provided background relating to RDI, their policy framework, and their memorandum of understanding with the WHO. She then gave an overview of the Global Network for Rare Diseases (which ERN eUROGEN has been active in contributing to the development of), including its vision and objectives, panel of experts, working groups, operational framework, past and future activities, and expected impact.



### [H-Care Developments & Future Proposal – Jessie Dubief \(EURORDIS\)](#)

[Link](#) to download presentation slides.

[Jessie Dubief](#), Rare Barometer Programme Senior Manager, [EURORDIS](#), explained that the Rare Barometer Programme is EURORDIS' survey initiative, which includes the H-Care Project to monitor the healthcare experience of people living with rare diseases through the development and validation of Patient Reported Outcome Measures (PREMs). These could be used by the ERNs for network evaluation purposes. She gave an overview of progress and future plans.

## Research



### [Research Activities relating to 1.4 Non-syndromic urogenital tract malformation – Giovanni Mosiello \(Expertise Area Coordinator\)](#)

[Link](#) to watch on YouTube. [Link](#) to download presentation slides.

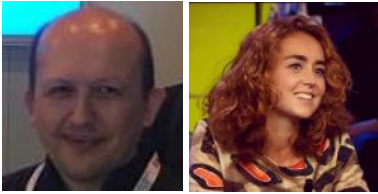
[Giovanni Mosiello](#), Expertise Area Coordinator for ERN eUROGEN Expertise Area (EA) 1.4 Non-syndromic urogenital tract malformation, delivered a case study on how EA activities can be coordinated, including cross-ERN and global collaboration, research workshops, publications, classification and coding updates, and guidelines development amongst other actions.

## [EU Rare Disease Partnerships and ERN Research Programme – Wout Feitz \(ERN eUROGEN HCP Network Coordinator Representative\)](#)

[Link](#) to download presentation slides.

[Wout Feitz](#) gave an overview of future potential network research activities, noting the launch of the European Partnership for research activities for rare diseases in 2024, in which over €2.4 billion has been allocated to support national, local, and European research and innovation programmes.

## [Evaluation \(Work Package 3\)](#)



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

[Link](#) to watch on YouTube. [Link](#) to download presentation slides. [Link](#) to evaluation information.

[Darren Shilhan](#) and [Loes Oomen](#) explained the reasons for reporting and outlined the expectations for network members. They emphasised their understanding of the issues faced and outlined the ERN eUROGEN process for struggling HCPs. They outlined current activities, such as ORPHAcode review and threshold setting, explained the monthly performance report, and summarised ERN eUROGEN's results from the 5-year evaluation of the ERNs. They introduced the new ERN eUROGEN Quality Improvement Group (QIG), asked for volunteers for this, and gave a quick summary of initial survey results.

## **DAY 2 – 12 SEPTEMBER**

### [Healthcare and New CPMS \(Work Package 4\)](#)



### [Update on Forthcoming Changes to CPMS – Darren Shilhan \(ERN eUROGEN Lead IT & Data Performance Analyst\)](#)

[Link](#) to watch on YouTube. [Link](#) to download presentation slides. [Link](#) to CPMS information.

[Darren Shilhan](#) reported on current ERN eUROGEN CPMS performance, explained how the ERN eUROGEN CPMS Helpdesk can support users, outlined the CPMS reimbursement protocol, and delivered a 'forward look' at the new "CPMS" currently under development by the EC and IBM.

### [Registries, Data Management and Analysis \(Work Package 5\)](#)



### [ERN eUROGEN Registry Update and Developments – Loes van der Zanden \(ERN eUROGEN Registry Coordinator\) & Lotte Boormans \(ERN eUROGEN Registry Manager\)](#)

[Link](#) to watch on YouTube. [Link](#) to download presentation slides. [Link](#) to registry patient information video. [Link](#) to registry information.

[Loes van der Zanden](#) and [Lotte Boormans](#) outlined the registry's current status, including ethical and legal approval, retrospective inclusion, and prospective inclusion, as well as explaining reimbursement for data entry and playing a new patient information animation explaining the registry. They urged all HCPs that don't have ethical and/or legal approval yet to put pressure on their ethical and legal committees and to start preparing retrospective inclusion, while HCPs with approval were asked to start including new patients prospectively. They concluded by outlining some initial results and future developments.



## Training & Education (Work Package 6)



### **ERN eUROGEN Webinar Programme & ERN Academy – Loes Oomen (ERN eUROGEN Clinical Data Specialist)**

[Link](#) to watch on YouTube. [Link](#) to download presentation slides. [Link](#) to webinar information.

[Loes Oomen](#) gave an overview of the ERN eUROGEN webinar programme, including information on statistics, survey results, accreditation, and the forthcoming schedule. News is still awaited from the EC regarding the ERN Academy.



### **Exchange Programme: Results and Suggestions for the Future / ERN eUROGEN Book on Rare & Complex Urology – Jen Tidman (ERN eUROGEN Business Support Manager)**

[Link](#) to watch on YouTube. [Link](#) to download exchange presentation slides. [Link](#) to download book presentation slides. [Link](#) to Elsevier product page.

[Jen Tidman](#) reported ERN eUROGEN's positive results in both the EC pilot exchange programme and ERN eUROGEN's own exchange programme, giving examples of exchanges that had been facilitated, including feedback from visitors. Regarding the book, she gave an overview of the background, cover, table of contents, contributors, production, publication and launch, noting that the book can already be pre-ordered.

## Clinical Practice Guidelines and Clinical Decision Support Tools (Work Package 7)



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

[Link](#) to watch on YouTube. [Link](#) to download presentation slides. [Link](#) to guidelines methodological handbooks. [Link](#) to guidelines training. [Link](#) to guidelines information.

[Michelle Battye](#) gave an overview of guidelines development work, including the EC guidelines consortium, the ERN eUROGEN guidelines expert panel, training, current activities, joint working, and future activities under the next grant (2023-2027).

## Summary & Strategic Board Actions:

### Overall Q&A and Discussion

There was extensive discussion about Expertise Area diagnoses, coding, and thresholds, which will be considered and progressed by the ERN eUROGEN Coordination Team and voted upon by the Strategic Board where required according to the network's Governance Statutes.

### Strategic Board Discussion & Voting - HCP Termination of Membership (Liege)

Following the 5-year evaluation of the ERNs, ERN eUROGEN full member Centre Hospitalier Universitaire de Liège voluntarily requested to withdraw from the network. In accordance with the ERN eUROGEN Governance Statutes on member termination, this request was shared with the Strategic Board by email with a two-week response deadline. There had been no objections to the withdrawal and so this was shared with DG SANTE, who will confirm the withdrawal with the Board of Member States for the ERNs. There were no additional objections from the attendees present at the meeting.

### Summary of Meeting – Michelle Battye (ERN eUROGEN Programme Manager)

Michelle Battye thanked everyone for their help and involvement with the meeting and the network. She stressed that ERN eUROGEN is a collaborative effort between all stakeholders. She emphasised three key areas:

- Network Specific Criteria (Thresholds) will be a network priority and members should please engage with updating these at an Expertise Area level.

- Mental health is an EC/EU4Health priority and ERN eUROGEN will be represented in the EURORDIS Mental Wellbeing Network, so the network will be monitoring available projects and actions relating to this.
- The Coordination Team scans for potential funding opportunities and these are included in the monthly newsletter. Please make the team aware of anything that you come across and they will be happy to support any applications alongside members' institution's grants teams.

On behalf of the Coordination Team, Michelle wished everybody a safe journey home.

### Future Meetings

ERN eUROGEN will hold an informal interim face-to-face meeting in Paris during the annual European Association of Urology (EAU) congress (EAU24) for anyone who is already attending the meeting. Due to the funding issues discussed during this meeting, the next ERN eUROGEN annual strategic board meeting will be virtual rather than face-to-face. Details for both these meetings will be circulated in due course.

**If any additional questions or important suggestions arise after reviewing the above-mentioned documents using the links in this report, 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 agreement with the current versions.**

## IN-PERSON ATTENDEES

### Chair:

Feitz, Wout

Di Cesare, Antonio

Nappo, Simona

Dobrowolska-Glazar, Barbara

Nordenström, Josefin

Duci, Miriam

Otavová, Katarína

### Coordination Team:

Ebert, Anne

Renström Koskela, Lotta

Anvary, Parmida

El Ghoneimi, Alaa

Schmiedeke, Eberhard

Battye, Michelle

Ferenschild, Floris

Stein, Raimund

Boormans, Lotte

Filipková, Viktória

Stenström, Pernilla

Oomen, Loes

Gorter, Ramon

Taskinen, Seppo

Shilhan, Darren

Gosemann, Jan

Thorup, Jorgen

Tidman, Jen

Heesakkers, John

Vauth, Franziska

van der Zanden, Loes

Höller, Alice

Willemse, Peter-Paul

Holmdahl, Gundela

Wolffenbuttel, Katja

### HCP Representatives:

James, Cyril

Wyndaele, Michel

Alberts, Arnout

Lacher, Martin

Zuiverloon, Tahlita

Anderberg, Magnus

Langenhuijsen, Hans

Brouwer, Oscar

Ludwig, Tim

### ePAG Advocates:

Che, Yue

Mansouri, Rafik

Aminoff, Dalia

Crétolle, Celia

Midrio, Paola

Cornes, Rob

Dalla Rosa, Davide

Migliazza, Lucia

Haanen, Michel

de Blaauw, Ivo

Morlacco, Alessandro

Schwarzer, Nicole

de Jong, Justin

Mosiello, Giovanni

Tyler, Kate

Dellenmark Blom, Michaela

Muensterer, Oliver

## ONLINE ATTENDEES

### HCP Representatives:

Catania, Vincenzo

Kulis, Tomislav

Mesch, Lena

Minderjahn, Maxi

Spinoit, Anne-Francoise

Willemse, Peter-Paul

Verkauskas, Gilvydas

### ePAG Advocates:

De Santis, Anna

### External Speakers:

Dubief, Jessie ([EURORDIS](#))

Johnson, Matt ([EURORDIS](#))

Wang, Mary ([RDI](#))