



# ERN eUROGEN Strategic Board Meeting 2026

## Compiled Presentations

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# The EU Innovation Lab From Rare Diseases to a European Health Union Ecosystem

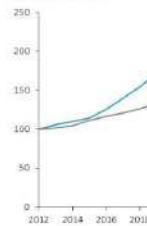


## WHY WE NEED HLM RARE

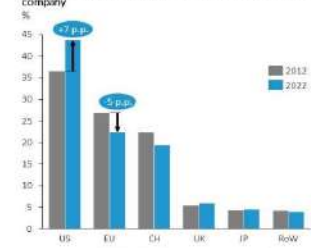
	US	EU
Public investment	EUR 47 billion in 2023	EUR 13.6 billion over 6 years
Private equity investment	USD 62.5 billion in 2021-2022	USD 11.2 billion same period
Focus on hubs	NIH support to hub	National and therefore fragmented hub approach
Tax policy	Harmonized Orphan Drug Tax Credit	National Tax Credits (e.g. BE/IE)

### Market share erosion in the key segment of biologics

Sales evolution in the EEA for pharmaceuticals 2012 indexed to 100



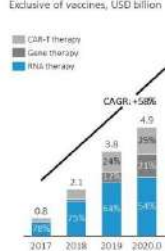
Market share of biologics sold in the EEA by origin of selling company %



Source: European Commission. Based on IQVIA MIDAS\* quarterly volume sales data for period 2012 - 2022 reflecting estimates of real-world activity. Copyright IQVIA. All rights reserved. Data for EEA markets (no data for CY, MT, IS and LI; retail data only for DK, EE, EL, LU, SI) and EC data (ARC RBD scoreboard) for regional allocation of companies.

### Low market presence in nascent market for ATMPs

Global ATMP market development  
Exclusive of vaccines, USD billion



Sales of AIMPs in the EEA in 2022: shares held by origin of selling company %



Source: replicated from IQVIA 2023 (primary source: IQVIA EMEA Thought Leadership, IQVIA) MIDAS MAT Q4 2022 and Company Financial Statements) European Commission. Based on IQVIA MIDAS\* quarterly volume sales data for period 2012 - 2022 reflecting estimates of real-world activity. Copyright IQVIA. All rights reserved.

# Our Goal: CURE



Share. Care. Cure.

## C

Creating a pan-European space for research and innovation, fully harnessing the 5th freedom.

## U

Uniting the rare diseases community under the Draghi, Letta, Heitor and Niinistö reports

## R

Reinforcing the ecosystem for innovation and care of rare and complex diseases.

## E

Enhancing the European Reference Networks Ecosystem to drive scientific, medical and industrial excellence.

# WHAT INSPIRED US



### FOCUS ON:

The importance of research and innovation in driving the Single Market's future success. A core proposal is the introduction of a "fifth freedom" - the freedom of movement of knowledge, complementing the existing four freedoms (movement of goods, services, capital, and people)

### FOCUS ON:

A roadmap for strengthening Europe's R&I ecosystem, ensuring that Europe remains at the forefront of scientific and technological progress to address pressing societal challenges and drive sustainable economic growth. It calls for a mission-oriented approach to research and innovation, focusing on developing solutions to improve the lives of European citizens

### FOCUS ON: XYZ

### FOCUS ON:

A vision for a more dynamic, innovative, and sustainable European economy. It calls for establishing a Research and Innovation Union, fostering public and private collaboration and investing in cutting-edge technologies and world-class innovation hubs in life sciences for advanced therapy medicinal products (ATMPs) and scaling niche know-how in rare diseases.

# HLM RARE 2025



+80 speakers

were part of the programme, including 2 EU Commissioners, 1 MoH and about 40 MEPs, as well as 6 EC and 2 EMA representatives, and WHO

POLITICO

HC Newsletter

Mentions from Politico during the days of our event



10,214

HLM Rare unique page views in December 2025 alone



# HLM RARE 2025



250 people

registered for in-person attendance across the 3 days



250 people

watched the livestreaming each day



36 earned media

mentions on LinkedIn from different key stakeholders, including Emer Cooke and Hans Kluge



# The Declaration on a European Innovation and Care Ecosystem for Rare and Complex Diseases

Prioritise the EU Action Plan on Rare Diseases with a Clear Governance unifying the Rare Disease Community

Strengthen Workforce Development and Capacity Building for Rare Diseases and formalise the ERN Academy

Accelerate Equitable Access to Diagnostics and enable Early Treatment Onset with Innovative Orphan Drugs for Unmet Medical Needs

Foster EU Leadership in Clinical Trials for Rare Diseases through Inclusive Collaboration between Academy, Patient Groups and Industry to accelerate Innovation for people living with rare diseases

Create, in each Member State, at least one comprehensive rare disease infrastructure cluster (CoRDIC) for research, innovation and care



## WHO THE DECLARATION REPRESENTS

The Declaration reflects a broad, multi-stakeholder coalition engaged in advancing rare and complex disease research, innovation and care across Europe. This diversity underpins the Declaration's legitimacy and supports a shared, system-level approach to addressing fragmentation and unmet needs.

It represents:



European Reference Network

European Reference Networks



# WHAT HAPPENS NEXT WITH THE DECLARATION

The Declaration is a vehicle to mobilise political commitment and enable coordinated, measurable EU-level action on rare and complex diseases. Therefore, we are now garnering community support, including through a growing number of official endorsing organisations as well as individuals.

Build coordinated EU action on rare diseases, starting with the adoption of a comprehensive EU Action Plan on Rare Diseases

Ensure systematic impact assessments of EU legislation on rare and complex diseases across health, research, data and innovation policies

Secure long-term sustainability of the ecosystem, including ringfenced funding for ERNs and rare disease actions under the 2028-2034 MFF

Send a strong political signal by broadening endorsement and collective ownership of the Declaration, including through the launch of an EU Citizen Initiative by the end of 2026 to collect 1M signatures

## Key Milestones in 2026

Rare Disease Day  
28 February

ERN Meeting (led by the EU Commission)  
March 26, Brussels

European Conference on Rare Diseases (ECRD) 2026  
3-4 June, Prague

European Health Forum Gastein  
29 September-2 October, Gastein

The EU Innovation Lab From Rare Diseases to a European Health Union Ecosystem (HLM RARE)  
8 - 9 December, Brussels

HIM-RARE 2.0 Application  
January 6<sup>th</sup>

Advancement of Treatments for Rare Diseases  
5-6 March, Nicosia

Policy Briefing  
June, Brussels

World Health Summit  
11-13 October, Berlin

European Health Summit  
Early December, Brussels



Cyprus Presidency  
(January - July 2026)



Ireland Presidency  
(July - December 2026)

# TAKE HOME MESSAGE

- The HLM-RARE is a high level Movement, it functions as a **convergence point** where political will, scientific expertise, patient advocacy, and institutional commitment coalesce into a concrete working force.
- The HLM DECLARATION is an Action Plan to satisfy the unmet need of patients affected by rare diseases
- The HLM-RARE represents the operational translation of vision into action.
- HLM-RARE should be positioned not as one among several contributing elements to the EU Action Plan discussion, but as **the catalytic instrument** capable of transforming accumulated recommendations into implementable policy.
- The complementarity of our efforts—EURORDIS's analytical rigour, advocacy expertise and network mobilisation combined with the amplified political momentum and institutional engagement generated by HLM-RARE—creates a formidable platform for success.

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# ERN eUROGEN

## The European Reference Network for Rare Uro-Recto-Genital Diseases and Complex Conditions

### SBM 2026

#### WP1: Management & Grant Actions of the Network

Michelle Battye, ERN eUROGEN Programme Manager  
26 February 2026 12:40-13:00



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Rare Uro-Recto-Genital Diseases  
& Complex Conditions



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## WP1 Coordination – leadership changes

### Change of Coordinator

- Retirement of previous Coordinator – Wout Feitz - in May 2024
- Development of Coordinator transition protocol
- To ensure a smooth and professional transfer of duties
- To ensure the business continuity of the ERN eUROGEN network

### New Coordinator – Peter Mulders

- Vote of the network Strategic Board
- Unanimously accepted
- EC informed according to their protocols



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23 March,  
2026

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## WP1 Coordination – leadership changes

### Change of Workstream 1 Lead

- Previous Workstream 1 Lead retired – Wout Feitz - in May 2024
- Replaced by Giovanni Mosiello, Rome IT
- Vote of the workstream HCPs

### Change of Workstream 3 Lead

- Previous Workstream 3 Lead, Hans Langenhuijsen, NL, stepped down
- Replaced by Tahlita Zuiverloon, NL
- Vote of workstream HCPs



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## Overview of current grant

### Timing: 1 October 2023 – 30 September 2027

- Radboudumc coordinating HCP – mono beneficiary
- €77million for 24 ERNs
- €3.25million for each ERN 20% reduction in budget from last proposal submitted (€3,870,000) to €3,225,000 (new proposal) – cut €645,000
- 100% of eligible costs paid by EC - exceptional for 24 ERN grants!
- 50% of total grant pre-financed by EC – exceptional for 24 ERN grants!



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## Overview of current grant

**Timing: 1 October 2023 – 30 September 2027**

- 7 compulsory WPs for all ERNs, 2 additional on Ukraine for ERN eUROGEN
- Indicators defined in call for proposals by EC
- Unit costs to be used in all EU4Health projects
- Reporting to EC - 1 mid-term interim report (M27 **end Feb 2026**)
- Review of 24 ERNs interim reporting – by independent Experts appointed by HaDEA – **27 March 2026**
- Final report (M48)



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## Current grant

- EC want more consistency across ERNs and monitoring
- Indicators to monitor activity and outputs (KPIs)
- EC publish monitoring data in annual report
- Internal ERN monitoring systems (our performance dashboard)
- More detail from Darren



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## 1. Achievements – Deliverables and governance

- All planned deliverables (D1.1–D1.4) completed and submitted – some delays due to late grant signing
- ERN Development Plan and Risk Assessment created and approved
- Continuous Performance Indicator System maintained and updated
- Annual Network Survey undertaken and revised version resubmitted to include Years 1 & 2
- Governance statutes reviewed annually – no updates needed.



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## 1. Achievements – coordination and communication

- Maintained updated mailing lists and communication channels
- Regular coordination, workstream, and ePAG meetings held with full documentation
- Active collaboration with DG SANTE, other ERNs, EURORDIS, and international stakeholders



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## 1. Achievements – Working Groups

- Active participation and leadership in Monitoring WG and WG on Management Activities, involved in other WGs
- Regular meetings held
- Collaboration with 24 ERNs to improve grant management, data collection, and monitoring.
- Strategic Board: 2024 meeting held virtually; 2026 meeting now, hybrid at Radboudumc
- External engagement: over 20 meetings/conferences between 2023–2025 with EURORDIS, RDI, EMA, EAU, etc.
- Implemented evaluation recommendations to strengthen clinical guideline production (linked with WP7)
- Contributed to Task Force on ERN 5 year Evaluation to hopefully improve the process next time!



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## 2. Improvements

- Improving disparity in engagement by HCPs
  - e.g. lack of attendance at workstream meetings
  - Ensuring expertise of HCPs
- Better communications between HCPs (from Network Survey)



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## 2. Improvements

- Ongoing refinement of protocols for inactive members and consortium creation (Darren)
- Enhanced cross-ERN cooperation on data consistency and indicator alignment – via Monitoring WG

## 3. Next steps

- Integration of new Affiliated Partners (new call 2026?)
- Addition of new disease areas & expansion of HCPs' coverage
- Revision of Monitoring & Assessment protocol (more details later)
- Prepare for next funding round - Next EC Multiannual Financial Framework (MFF) 1/1/2028 – 31/12/2035
- ERNs funding ends on 30/9/27 and new MFF starts on 1/1/2028  
– **3 month funding gap – bridging grant needed?**

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# ERN eUROGEN

The European Reference Network for Rare Uro-Recto-Genital Diseases and Complex Conditions

## SBM 2026

ePAG Activities and Updates 2025 (Year 7)

John Osborne, ERN eUROGEN ePAG Chair

Jen Tidman, ERN eUROGEN Business Support Manager

26 February 2026 13:00-13:20



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## ■ ERN eUROGEN European Patient Advocacy Group (ePAG)

- Patient representatives across all Workstreams
- Supported by ERN eUROGEN Coordination Team & EURORDIS
- Embedded across governance, guidelines, dissemination, registry, and strategy
- Equal partners in network development



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## ERN eUROGEN European Patient Advocacy Group (ePAG)

- John Osborne (Chair) Penile Cancer
- Dalia Aminoff, Anorectal Malformation
- Kate Tyler, Anorectal Malformation
- Miriam Wilms, Anorectal Malformation
- Lieke Janssen, Bladder Exstrophy
- Claire Harkin, KS/XXY
- Anna De Santis, BPS/IC
- Rob Cornes, Penile & Testicular Cancer
- Kenneth Manzie, Penile Cancer
- Frans Baan, Upper Tract Urothelial Carcinoma



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## The ePAG's Overall Strategic Role

- Amplify the patient voice across ERN eUROGEN
- Shape services, training, guidelines and research
- Ensure patient-centred decision-making
- Advocate for equity and access to specialised care
- Strengthen European collaboration



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## Patient Voice Embedded Across Core ERN Work

### Governance & Coordination (WP1)

- Input into governance, criteria setting, expertise area expansion
- Participation in Strategic Board and management meetings
- Annual ERN survey contributions

### Dissemination & Communication (WP2)

- Website, newsletter, social media
- Conference presentations
- Co-creation of patient materials

### Evaluation & Quality (WP3)

- Indicator validation
- Quality Improvement Group
- ORPHAcodes input

### Registry (WP5)

- Governance involvement
- Data use discussions

### Training & Education (WP6)

- Transition Working Group
- Surgical training programme input
- Webinar programme
- Book authorship

### Guidelines & CDSTs (WP7)

- ARM & Paediatric Neurogenic Bladder CPGs
- Rare bladder inflammatory conditions CPG
- Penile cancer centralisation CDST
- Guidelines Expert Panel



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## 2025 in Focus – What the ePAG Set Out to Do

- Strengthen patient–clinician communication
- Embed patient input in CPGs & CDSTs
- Empower patients through journeys & advocacy
- Advance centralisation of care
- Expand and strengthen the ePAG



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## Major Achievement 1 – Rare PREPARE

### Rare PREPARE Pre-Appointment Question Prompt List (QPL)

- Patient-led initiative initiated by John Osborne
- Core Team: 3 patient representatives + 3 clinicians (multi-ERN)
- Panel: 10 patient representatives + 10 clinicians (multi-ERN)
- Supported by EURORDIS (methodology)
- Funding application submitted (ERDERA Networking Support Scheme)
- Structured consensus methodology underway

### Strategic impact:

- Practical tool for improving consultations
- Scalable across ERNs
- Moves patient partnership from principle → implementation

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## Major Achievement 2 – Guidelines

### Anorectal Malformations

- ePAG involvement in guideline development group
- Input on long-term outcomes and quality of life
- Emphasis on transition and psychosocial impact

### Paediatric Neurogenic Bladder, including Spinal Dysraphisms

- Patient representation in working group
- Contribution to lifelong management perspective
- Highlighting lived-experience challenges in daily care

### Bladder Pain Syndrome / Rare Inflammatory Bladder Diseases

- ePAG embedded in multidisciplinary working group
- Patient representatives involved in PICO and scope development
- Evidence appraisal underway

### Penile Cancer

- Continued engagement with EAU Guidelines Office
- CDST for centralisation under discussion
- Ongoing collaboration with EAU & ASCO

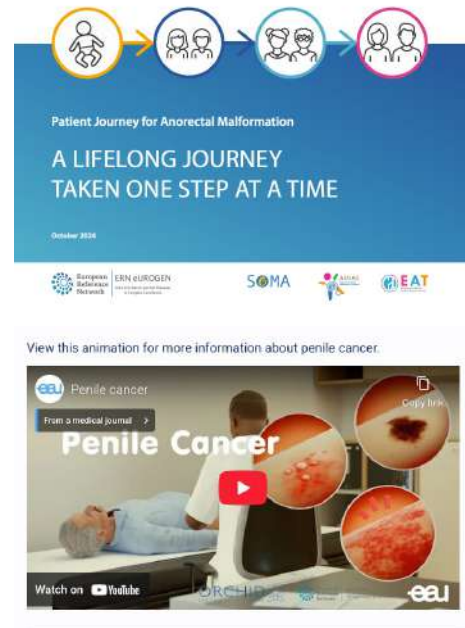
## Major Achievement 3 – Patient Information

### Anorectal Malformations

- Full version, short brochure version, and audio version
- Patient perspective chapter in new ARM book

### Penile Cancer

- Animated videos developed with the EAU Patient Office and Orchid (under previous Bridging Grant) (2023)
- Co-created multilingual resources reaching global audiences
- Spanish version – now in Top 20 most viewed EAU videos
- English version – now in Top 40 most viewed EAU videos



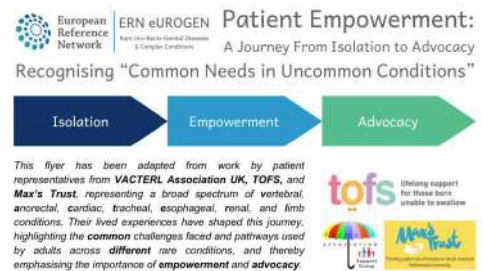
## Major Achievement 4 – Patient Empowerment/Mental Health

### Patient Empowerment Resource

- “From Isolation to Advocacy” co-created
- Presented at VACTERL meeting
- Disseminated via ERN channels

### EURORDIS Mental Health & Wellbeing Network

- Active participation (ePAG + ERN team)
- Currently paused due to external constraints



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## Major Achievement 5 – Penile Cancer Survey

### Penile Cancer Survey

- Largest patient-led survey in this field
- 107 responses | 12 countries
- Available in 15 languages
- Challenging existing assumptions
- To be presented at EAU 2026

### Strategic impact:

- Data-driven advocacy
- Evidence base for centralisation discussions
- International expansion planned



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## Major Achievement 6 – Centralisation of Care

### Centralisation of Care – work in progress:

- Drafting ERN eUROGEN position paper
- Distinguishing elective complex surgery vs emergency care
- Exploring survey of surgeons
- Considering cross-ERN collaboration

### Strategic Aim:

- Establish a clear, evidence-informed patient position to support policy discussions.



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## Major Achievement 7 – Expanded ePAG

### Strengthening the ePAG – 2025 Growth

- 3 new representatives recruited
  - Miriam Wilms, Anorectal Malformation
  - Lieke Janssen, Bladder Exstrophy
  - Frans Baan, UTUC
- Expanded Expertise Area coverage
- Broader lived-experience representation
- Increased sustainability of engagement

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## Assessing Patient Partnership Implementation

- EURORDIS-aligned questionnaires implemented
- Surveyed both ePAG and Leadership Team
- High perceived commitment to partnership
- Identified challenges:
  - Capacity
  - Resources
  - Sustainability
- Plan to repeat periodically

### Questionnaires for Assessing Patient Partnership in the ERNs



Questionnaire for ERN patient representatives (ePAG)



Questionnaire for ERN leadership team

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## 2026 Strategic Priorities: Consolidation & Impact

- 1 Rare PREPARE – finalise & pilot
- 2 Continue patient input into CPGs & CDSTs
- 3 Advance centralisation position paper
- 4 Strengthen collaboration with professional societies
- 5 Embed patient priorities in next grant application



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## Preparing for the 2028–2034 Grant

- Identify strategic patient-centred priorities
- Embed ePAG input early in proposal development
- Align funding priorities with real-world lived-experience patient gaps



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## Statement from John Osborne, 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, understanding 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)



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## Conclusion: A Mature, Embedded, Strategic Patient Partnership

- From participation → co-creation
- From voice → influence
- From advocacy → measurable impact
- From 2025 foundations → 2026 consolidation

**On behalf of John and the ePAG,  
thank you for your continued collaboration and support.**



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# ERN eUROGEN

The European Reference Network for Rare Uro-Recto-Genital Diseases and Complex Conditions

## SBM 2026

WP1: Joining Forces and ERN Participation

Wout Feitz, Former ERN eUROGEN Coordinator

26 February 2026 13:20-13:40



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## 1. Achievements

### European Commission, Patients and Experts

EC / ERN

DEVELOPMENT  
ALIGNMENT 24X  
CONTINUATION

Policy Developments (2002)  
Legal Embedding (2011)  
Implementation (2017)  
Evaluation Report (2024 -)  
Monitoring Report (2025 -)  
BoMS EC Next Call AP (2026)



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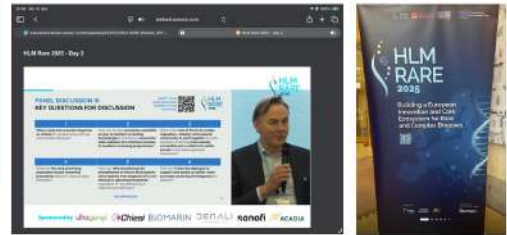
# 1. Achievements

## ■ ERN Coordinators and Stakeholders 2025

EC / ERN  
HIGH  
LEVEL  
MEETINGS

European Parliament  
European Council  
European Commission  
>>> Multi Annual Financial Framework (7yrs)

**Evidence Based Hope !**  
**Goal: C U R E !**  
**HLMRare: Declaration on Innovation and Care for the Rare / Complex ECO System**



# 1. Achievements

## ■ EU ERNs 2026: 1606 Expert Teams – 375 HCPs – 24 ERNs

EC / ERN  
BoMS  
MEETINGS

**Joining Forces !**  
**EU call for National Affiliated Partners 2026**

New EU call for Hospitals waiting on legal advice !

ERN eUROGEN  
EXAMPLES

ERN eUROGEN Registry Data Entry (2026)  
ERN eUROGEN Registry Data Research  
ERN Guidelines, Book Chapters, Collaborations



# 1. Achievements

National recognized Radboudumc Expertise Centers for Rare Diseases or Complex Conditions

**Radboudumc ERN eUROGEN Member NL09:**  
Clinical Expertise, Research and **Multidisciplinair** Team

- **Pediatric Urology:** Congenital Urological Anomalies
- **Pediatric Surgery:** Colorectal Malformations
- **Pediatric Nephrology:** Rare Kidney Diseases
- **Pediatric Endocrinology:** DSD and pediatric urology surgery
- **Adult Urology:** Rare and Complex Adult Urology



ERN / ECZA

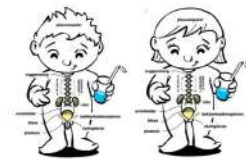
SUSTAINABLE  
TRANSITION  
CONTINUATION

➔ **COVERAGE EXPANSION OF RARE DISEASES OR COMPLEX CONDITIONS !**

**Pediatric Urology: Congenital Urological Anomalies**

**Orphanet Codes and ICD10:**

- DSD and Surgery
- Bladder Exstrophy Complex
- Rare Kidney Anomalies
- Spina Bifida
- Posterior Urethral Valves
- Posterior Hypospadias
- Uro-Ano-Rectal malformations



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

# 1. Achievements

## ERN eUROGEN Realisations 2026

European **video consultations** with European Experts (**CPMS 2.0**)

European **patient representative** collaborations for inclusive care

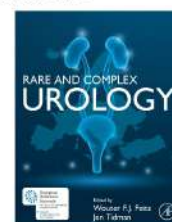
European **registry** for patients with a rare diseases/complex conditions

European **guidelines** and **support tools** for rare diseases/complex conditions

European **webinar series** and other educational/training activities

**European collaborations** with patients, politicians, policymakers, Ministries of Health, Health Care Providers and **EXPERTS !**

Visual style of the CPMS Mobile App



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19 January,  
2026

13

# 1. Achievements

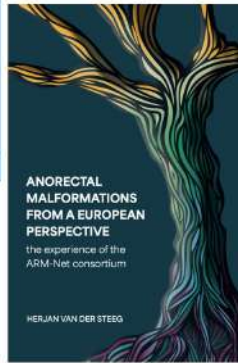
ERN eUROGEN  
EXAMPLES



**A journey from clinical data to clinical care for anorectal malformation patients across Europe and Australia:**

**Methodological implications of registries and epidemiological comparisons**

Isabel C. Hageman



**Anorectal malformations from a European perspective: the experience of the ARM-Net consortium**

H.J.J. van der Steeg

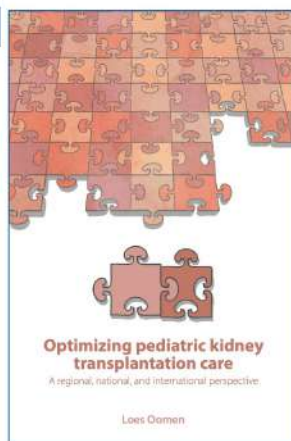
Source: Radboud Repository



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# 1. Achievements

ERN eUROGEN  
EXAMPLES



**Optimizing pediatric kidney transplantation care**

**A regional, national, and international perspective**

L. Oomen

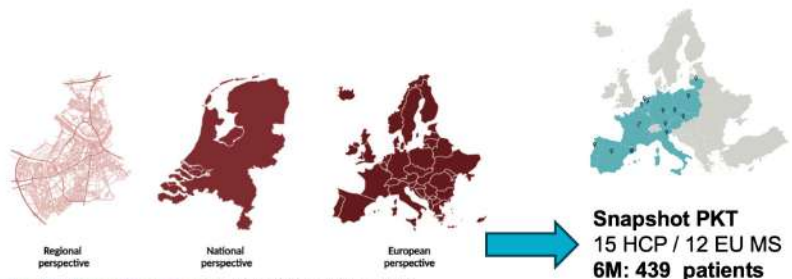


Figure 1. Multi-perspective research approach. A visual display of the structure of this thesis

Source: Radboud Repository



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# 1. Achievements

## ERN eUROGEN Guidelines

ERN eUROGEN  
EXAMPLES



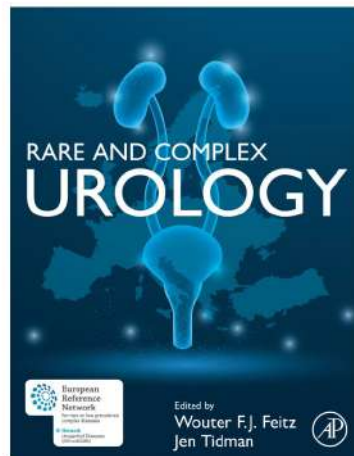
### New Publication: Revised Orphanet Classification for Spina Bifida & Other Spinal Dysraphisms

A major update to the Orphanet classification for spina bifida and other spinal dysraphisms (SBoD) has been published, following a cross-ERN collaboration led by experts from ERN eUROGEN and ERN ITHACA.



# 1. Achievements

ERN eUROGEN  
EXAMPLES



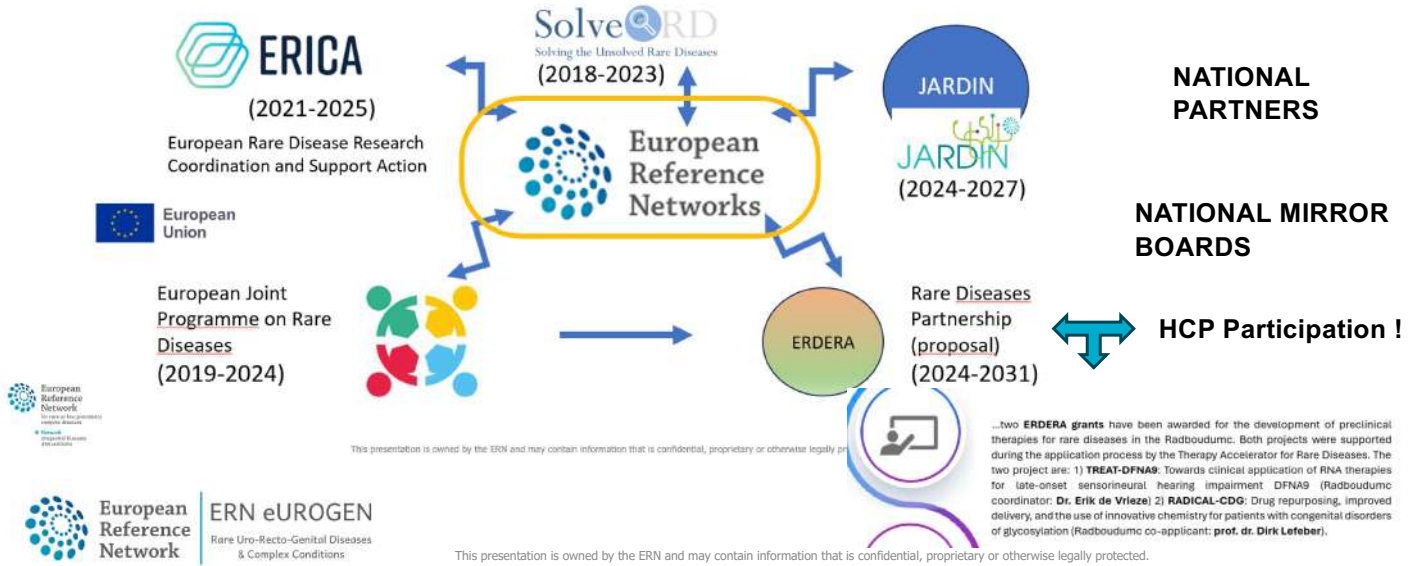
## ERN eUROGEN Expertise Area Book Series



## 2. Improvements

### EU JARDIN, Rare Disease Partnership, and ERNs 2026

Relation with some other European projects



## 2. Improvements

### Clinical Practice Snapshot Studies 2026

#### Already Participating ! Registry Entries 2026



#### DATA ENTRY AND ANALYSIS

- 1.2: Bladder Exstrophy
- 1.5: Posterior Urethral Valves
- 1.7: Anorectal Malformations
- 1.8: Paediatric Kidney Transplantation



#### 2.1: AMS800 Urethral Sphincter Prosthesis

- 3.2: Testicular Cancer
- 3.3: Adrenal Tumours

Further to be developed: Spider, CPS's, Follow up and Patient Experiences

### AGORA: CDH12 candidate gene for kidney injury in PUV

Joining Forces: Specific Expertise, Patient Clinical Data, Questionnaires, DNA Samples

AGORA: Maternal risk factors for Posterior Urethral Valves

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407 PUV versus 814 controls

- Family + aOR 3.3 (95CI 1.4-7.7)
- Age < 25 aOR 1.7 (95CI 1.0-2.8)
- RR ↑ aOR 2.1 (95CI 0.0-5.1)
- Age > 35 aOR 0.7 (95CI 0.4-1.0)

Manuscript accepted for publication in Pediatric Nephrology, 1 July 2024 at 10:00:00 AM PT

## 2. Improvements

→ COVERAGE EXPANSION OF RARE DISEASES OR COMPLEX CONDITIONS !

**CPMS 2.0**



↔



**IRDIRC Newsletter**  
IRDIRC - News & Events - Newsletter

**RARE DISEASES INTERNATIONAL**  
Announcing the Adoption of the WMA Resolution on Rare Diseases

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**Meeting of the MDCG taskforce on orphan devices Minutes**  
Program on orphan medical devices, in particular targeting paediatric patients: presentation of the three projects selected under the EU4Health programme (EU4H-2023-PJ-11)  
- i4KIDS 4RARE  
- OrphaDev4kids  
- DeCODe

**EU4H-2026-SANTE-PJ-07 - Call for proposals for a programme on orphan medical devices, in particular targeting paediatric patients (HS-g-25-24)**  
EU4H-2026-SANTE-PJ-07 € 1,200,000 for 3 expected grant agreements

## 3. Next steps

### Joining Forces !

EU call for National Affiliated Partners approved

New EU call for Hospitals waiting on legal advice !



ERN eUROGEN Expertise Area Book Series



**EU4Health Programme**  
for a healthier and safer Union

November 2025  
#EU4Health #HealthUnion

€4.6 billion to invest from 2021-2027

- 40% increase in participation in European Reference Networks – 1619 healthcare providers have allowed 2.24 million patients to receive expert advice on diagnoses and treatments.

**MFF ! 28 - 34**

### 3. Next steps

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Rare Uro-Recto-Genital Diseases & Complex Conditions

Home About Our Work Who We Are Expertise Consultations Webinars Dissemination Contact

ERN eUROGEN: Equitable Access to Diagnosis, Treatment and Care for Patients with Rare Uro-Recto-Genital Diseases and Complex Conditions

ERN Ecosystem

Share. Care. Cure.

**THANK YOU FOR YOUR ATTENTION !**  
**Prof. Wout F. J. Feitz, Radboudumc, Nijmegen, NL09**  
**[Wout.Feitz@radboudumc.nl](mailto:Wout.Feitz@radboudumc.nl)**

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# ERN eUROGEN

The European Reference Network for Rare Uro-Recto-Genital Diseases and Complex Conditions

## SBM 2026

WP2: Dissemination and Communication

Jen Tidman, ERN eUROGEN Business Support Manager  
26 February 2026 14:30-15:00



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## 1. Achievements: Years 1-2 of Grant

- **Exceeded most WP2 targets:**
  - 24 newsletters (+57% subscriber growth)
  - 90+ website news updates
  - 65 webinar recordings on YouTube
  - LinkedIn campaign (+365% YouTube growth)
  - 16 eligible scientific publications
  - 32 conferences / 51 presentations
  - Major patient materials co-developed
  - National Societies Outreach (31 countries contacted)



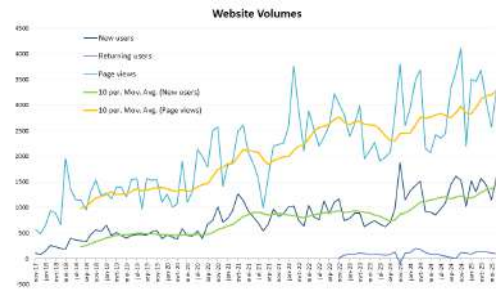
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## 1. Achievements: Digital Reach & Visibility

- Website redesign (2023) → sustained growth
- Social media: avg 15 posts/week (target was 2)
  - LinkedIn +102%
  - YouTube +151%
  - Facebook +127%
  - Instagram +64%
  - X +8% (modest compared to other platforms)
    - Declining clinical engagement + platform instability & reputational considerations
    - Stopped using in October 2025. **Board agreement on continued non-use?** 😞
- Newsletter: 4,496 subscribers (+57%)



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## 1. Achievements: Scientific & Educational Outputs

- 16 reportable publications (target exceeded)
- ARM CPG & Paediatric Neurogenic Bladder CPG
- ERN eUROGEN Book – Rare & Complex Urology
- Special Issue in EJPS replacing MDPI Children plan
- 65 webinars supporting WP6



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## 1. Achievements: Patient-Focused Dissemination

- ARM Patient Journey (full, short, audio)
- Patient Empowerment Flyer
- Co-creation with ePAGs
- Animated patient information videos on Duplex Congenital Malformations (with EAU Patient Office; ~5,000 views)



## 1. Achievements: Strategic & Cross-Network Outreach

- National Societies Campaign (29 EU/EEA + Ukraine)
  - Overview video
- JARDIN
  - Newsletter feature
  - Advent calendar
  - Rare Disease Day 2026
- Active role in Cross-ERN Comms WG
  - Best practice sharing and harmonised campaigns

## 2. Improvements: Areas Highlighted In Network Survey

### 1. Clinical Clarity

- More concise clinical summaries & highlights of practical outcomes 🤔
- Reduce administrative terminology / use clearer clinical language / stronger naming of disease groups (e.g., bladder exstrophy rather than just EA 1.2) ✅

### 2. Newsletter Optimisation

- Add short contents summary at top - make it easier for busy clinicians ✅

### 3. Email Targeting

- Clarify audience (Clinical? Administrator? Legal?) 🤔
- Better segmentation 🤔



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## 2. Improvements: Areas Highlighted In Network Survey

### 4. Website Structure

- Greater sectorisation by pathology 🤔

Workstream 1: Rare Congenital Uro-Recto-Genital Anomalies (Paediatrics)	
EA 1.1 Complex genital reconstructions (DSDs)	+
EA 1.2 Bladder exstrophy/epispadias	+
EA 1.3 Rare urological stone and kidney diseases	+
EA 1.4 Non-syndromic urogenital tract malformation	+
EA 1.7 Urorectal/anorectal malformations	+

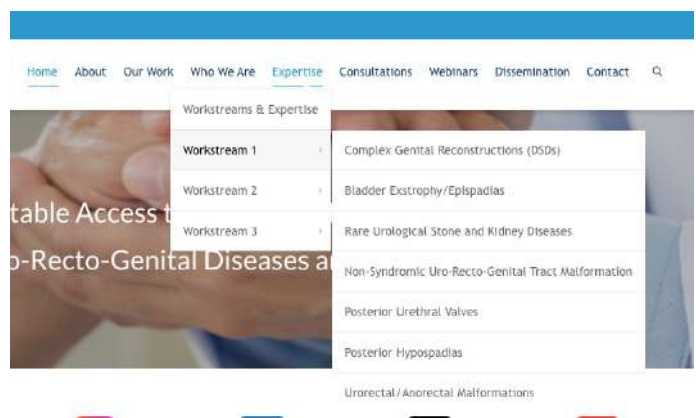
Workstream 2: Functional Urogenital Conditions Requiring Highly Specialised Surgery	
EA 2.5 Invernal Cysts	+

Workstream 3: Rare Urogenital Tumours	
EA 3.1 Penile Cancer	+
EA 3.2 Testicular Cancer	+

Guidelines Produced by ERN eUROGEN

Anorectal Malformations (CPG by ERN eUROGEN)	+
Spinal Dysraphism in Children and Adolescents (CPG by EAU, ESPU, ERN eUROGEN, ERN ITHACA, ERN ERNet, IFSBH)	+



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### 3. Next steps: Final 2 Years of Grant – Priorities

- Deliver Remaining Grant Commitments:
  - D2.3 – Dissemination Report (Years 3–4)
  - D2.4 / T2.12 – ERN eUROGEN Special Issue of European Journal of Pediatric Surgery
  - T2.4–T2.11 Activities – website optimisation, newsletter improvements, email targeting refinement, social media platform strategy, more publications/presentations and patient/clinician materials, follow-up of National Societies outreach



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### 3. Next steps: Final 2 Years of Grant – Priorities

- Deepen National & European Level Engagement
  - Follow-up National Societies campaign
  - Engage underrepresented Member States
  - Encourage increased dissemination by Supporting Partners
- Strengthen Cross-ERN Collaboration
  - Cross-ERN Comms WG
  - JARDIN: WP2 Dissemination & Communication
  - Joint awareness campaigns and shared messaging toolkits



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## 3. Next steps: Preparing for the Next Grant

### Current WP2 Deliverables & Tasks (2023–2027)

- Deliverables = dissemination plan, 2 x dissemination reports, journal special issue
- Tasks = website, monthly newsletters, social media & YouTube, scientific publications, conference dissemination, patient & clinician materials, JARDIN alignment

### What should WP2 look like from 2027 onwards?

- 🤔 Should WP2 maintain current breadth, or prioritise high-impact channels?
- 🤔 Is dedicated communications resourcing required?
- 🤔 What digital strategy should be formalised (platform selection, paid campaigns)?
- 🤔 How could engagement/collaboration be strengthened?
- 🤔 How should impact be measured beyond activity metrics?



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# ERN eUROGEN

## The European Reference Network for Rare Uro-Recto-Genital Diseases and Complex Conditions

### SBM 2026

### WP3: Reporting, Monitoring, & Evaluation

Darren Shilhan, ERN eUROGEN IT and Data Performance Analyst  
26 February 2026 15:00-15:45



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## 1. Achievements

- Annual Monitoring Indicators submission for 2023
  - 54/56 HCPs submitted patient data
  - 35 Educational events
- Annual Monitoring Indicators submission for 2024
  - 53/56 HCPs submitted patient data
  - 33 Educational events
- Evaluation Plan via Quality Improvement Group (QIG)
- Evaluation Reports for Year 1 and Year 2
  - Website and webinar evaluation
- Monthly Performance Report



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## 2. Improvements

- Improve level of engagement from some HCPs
  - Quite a disparity between HCPs – need to share responsibilities more equally



- Proposed changes to Monitoring & Assessment protocol
  - HCP annual report to be sent to CEO of each HCP member
- Monitoring of Expertise Area coverage
  - Patient and procedure numbers must be provided to continue expertise
  - Those numbers must also meet thresholds (exact criteria to be defined)
  - How can we retain members where surgery has been centralized?
  - How else should we assess expertise?



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## 2. Improvements – Proposed changes to assessment

Activity	Level	Standard
Monitoring (patient) data provided	Network/Expertise Area	For all EAs covered
Registered & active CPMS account	Expertise Area	For all EAs covered
Webinar delivered/planned	Workstream	1 per WS covered every 24 months
Named experts provided to Network	Expertise Area	For all EAs covered
Use of ERN eUROGEN registry approved	Network	Registry approved
WS meeting attendance rate	Workstream	33% in last 12 months
Registry input taking place	Expertise Area	10% of declared patients per year
Patients uploaded to CPMS for discussion	Workstream	At least 1 patient in last 12 months
Contribution to CPMS discussion or meeting	Workstream	HCP contributed to 33% of cases in last 12 months to which they were invited
SBM attendance	Network	HCP rep attended in person or online
Workstream Lead or EAC post held	Network	HCP expert holds such a post
Member of guidelines/consensus document group	Network	HCP expert holds such a post

- Three current mandatory measures – now applied at lower level
- Three additional mandatory measures



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## 2. Improvements – Current mandatory measures

- **Monitoring (patient) data provided**
  - Expert coverage of an EA would be removed where no data is provided for it
  - **Rationale:** To demonstrate continued expertise in a particular EA, we need to be provided with the patient and procedure numbers to assess against the thresholds
- **Registered & active CPMS account**
  - Each EA covered requires an active CPMS account for one of the named experts (see next slide)
  - **Rationale:** For each EA covered by an HCP, we need to be able to invite an expert from that HCP to CPMS cases related to that EA. We do not expect these experts to provide advice for every case to which they are invited, but rather that each HCP covering the EA contributes to a share of these cases
- **Webinar delivered/planned**
  - Requirement moves from an 18-month period to a 24-month period. However, it becomes a workstream-level measure
  - **Rationale:** Some HCPs cover 2 or 3 workstreams, and therefore it seems fair that they contribute a webinar for each workstream covered as these are different experts

---

## 2. Improvements – Additional mandatory measures

- **Named experts provided to Network**
  - The name and email address of a relevant expert provided for each EA covered
  - **Rationale:** Where we have disease-specific issues, we need to have a list of experts to contact, e.g., CPMS cases, identifying authors for ERN eUROGEN publications, identifying members for guideline development groups, identifying experts that can help develop Clinical Practice Snapshots for the Registry etc. Also enables us to target communications more effectively
- **Use of ERN eUROGEN registry approved**
  - HCPs without approval must engage with the registry team to work toward approval. If there is a genuinely valid reason why approval is impossible for a particular HCP, an exemption would be granted.
  - **Rationale:** The registry team has extensive experience dealing with local obstacles in the approval process. HCPs should have engaged with the Registry Team rather than simply disregarding the possibility
- **Workstream meeting attendance rate (at least 33%)**
  - This measure will remain as it is currently, but it will become mandatory to achieve at least 33% attendance in the given period.
  - **Rationale:** The regular workstream meetings are an important way for HCPs to stay up to date on what is happening within the network, as well as aiding and improving communication between HCPs

## 2. Improvements – Annual HCP Performance Summary

### ERN eUROGEN: Annual HCP Engagement Summary

#### HCP: EG 01 - HCP Example

Please ensure the contacts stated below for your HCP are correct:

HCP Info	Name	Email
CEO		
Main Rep		
Sub Rep		

The table below shows the level of engagement of your HCP across the main areas of focus for ERN eUROGEN during the previous 12-month period.

A number of these areas are mandatory and thus lack of engagement may result in the removal of HCP expertise from certain Expertise Areas (EAs) or Workstreams, or membership of the network.

Work Package	Activity (* = mandatory)	Level	Rating	Notes/Issues
1	SBM attendance*	Virtual	Green	No Issues
1	WS1 attendance rate*	70%	Green	No Issues
1	WS3 attendance rate*	0%	Red	Below standard - recommend removal of Workstream
1	Named experts for each EA covered*	6/8 EAs	Red	Expert names to be provided for missing EAs or EAs to be removed
1	WS Leads & EAs	None	Green	No Issues
3	Patient data provided*	Fully	Green	No Issues
4	Registered CPMS account*	3/8 EAs	Red	CPMS accounts to be created for missing EAs or EAs to be removed
4	Patients uploaded to CPMS for discussion	Yes	Green	No Issues
4	Contribution to CPMS discussions & meetings	45%	Green	No Issues
5	Registry approval*	Yes	Green	No Issues
5	Registry input (10% of declared new patients)	1/4 EAs	Red	% of patients input below expected level for some EAs
6	Webinar delivered/planned for each WS covered*	2/3 WS	Red	No webinar delivered/scheduled for a WS - to be removed
7	Member of guidelines/consensus document group	Yes	Green	No Issues



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- Sent directly to your CEO (with you cc'd)
- Each measure in the HCP Performance Overview rated
- Where action will/might be taken, this is flagged in red
- There will be a grace period for taking necessary actions

## 2. Improvements – Annual HCP Performance Summary

The table below shows which ERN eUROGEN Expertise Areas your HCP currently covers and whether your provided patient and procedure numbers are meeting the required thresholds for those EAs. Where they are not, that EA will be removed from your HCP.

Likewise, this will also be the case for those EAs where we have not been provided with the name of at least one relevant expert for each EA covered who is qualified to contribute to relevant CPMS cases etc. for that area.

EAs covered				
EA	Name	Meeting Thresholds?	Expert Name	Email
1.2	Bladder exstrophy/epispadias	Y		
1.5	Posterior urethral valves	Y	Dr. Alpha	alpha@cmail.com
1.6	Posterior hypospadias	Y		
1.7	Urorectal/anorectal malformations	N	Dr. Beta	beta@cmail.com
2.5	Interstitial cystitis	Y	Dr. Zeta	zeta@cmail.com
3.1	Penile cancer	Y	Dr. Kappa	kappa@cmail.com
3.2	Testicular cancer	Y	Dr. Upsilon	upsilon@cmail.com

- A table of Expertise Areas covered will be included
- This will show whether the patient numbers have been provided, whether they meet the thresholds, and whether the names of experts have been provided



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## 3. Next steps

- Additional Expertise Areas added to ERN eUROGEN
  - 1.8 Paediatric transplant urology
  - 2.8 Male infertility
  - 3.6 Rare bladder tumour surgery
  - 3.7 Paediatric oncological urology
  - ? Gynaecology
- Expertise Area expansion for HCPs
  - Apply for additional existing and new areas above
- Setting up of internal consortia
  - Current members can form a consortium with non-member HCPs to continue membership



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# ERN eUROGEN

The European Reference Network for Rare Uro-Recto-Genital Diseases and Complex Conditions

## SBM 2026

### WP4: Clinical Patient Management System (CPMS)

Darren Shilhan, ERN eUROGEN IT and Data Performance Analyst  
& Parmida Anvary, ERN eUROGEN Clinical Helpdesk Specialist  
26 February 2026 15:45-16:30



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## 1. Achievements

- Introduction of CPMS 2.0 in January 2025
- Increase in number of video meetings
- Introduction of the CPMS App
- Increase in non-member cases



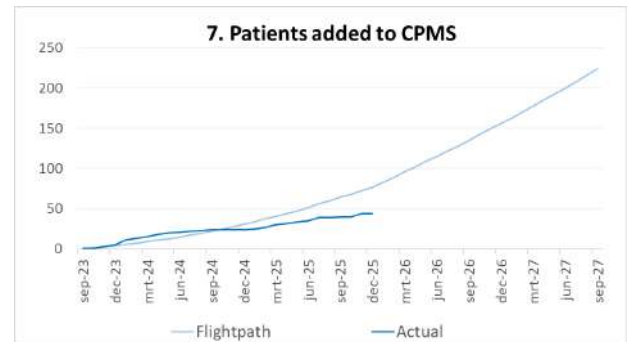
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## 2. Improvements/discussion points

- Helping users with EU Login issues
  - We can't change the use of EU Login, but how can we help with this?
  - Change of mobile phone – do you want written instructions? A video guide?
- How can we increase CPMS use?
  - Only 26 of 75 registered HCP reps have logged into the new system
  - What barriers are you facing?
- Is the reimbursement useful?
  - Should it be continued in the next grant?
- Any other ideas?



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## 3. Next steps

- Year 3 & Year 4 reports
- Production of updated ERN eUROGEN user guides
  - Should this include video guides?
- Please use the system
  - Do you have suggestions for improvements?
  - Then email us ([cpmshelpdesk@eurogen.ern-net.eu](mailto:cpmshelpdesk@eurogen.ern-net.eu))
  - or DG Sante ([sante-ern-cpms-itsupport@ec.europa.eu](mailto:sante-ern-cpms-itsupport@ec.europa.eu))



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# ERN eUROGEN

The European Reference Network for Rare Uro-Recto-Genital Diseases and Complex Conditions

## SBM 2026

### WP5: Registries, Data Management & Analysis

Lotte Boormans, ERN eUROGEN Registry Manager

26 February 2026 16:30-17:15



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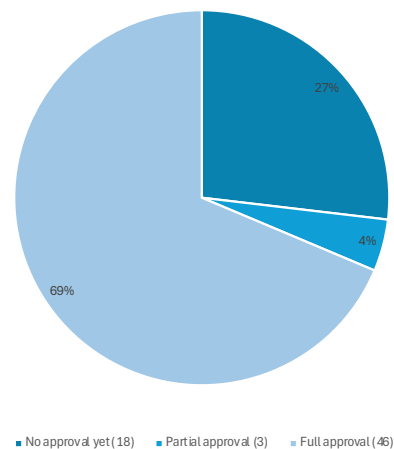
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## 1. ERN eUROGEN registry progress

- HCP approval status

HCP approval status for ERN eUROGEN registry



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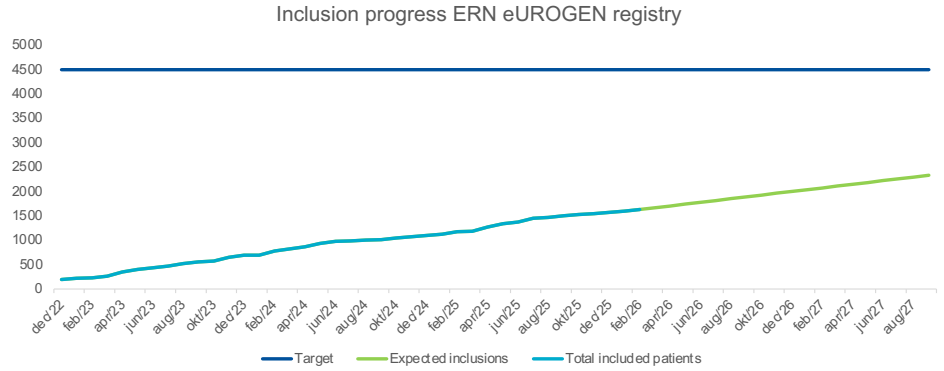
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# 1. ERN eUROGEN registry progress

- HCP approval status

- Patient inclusion

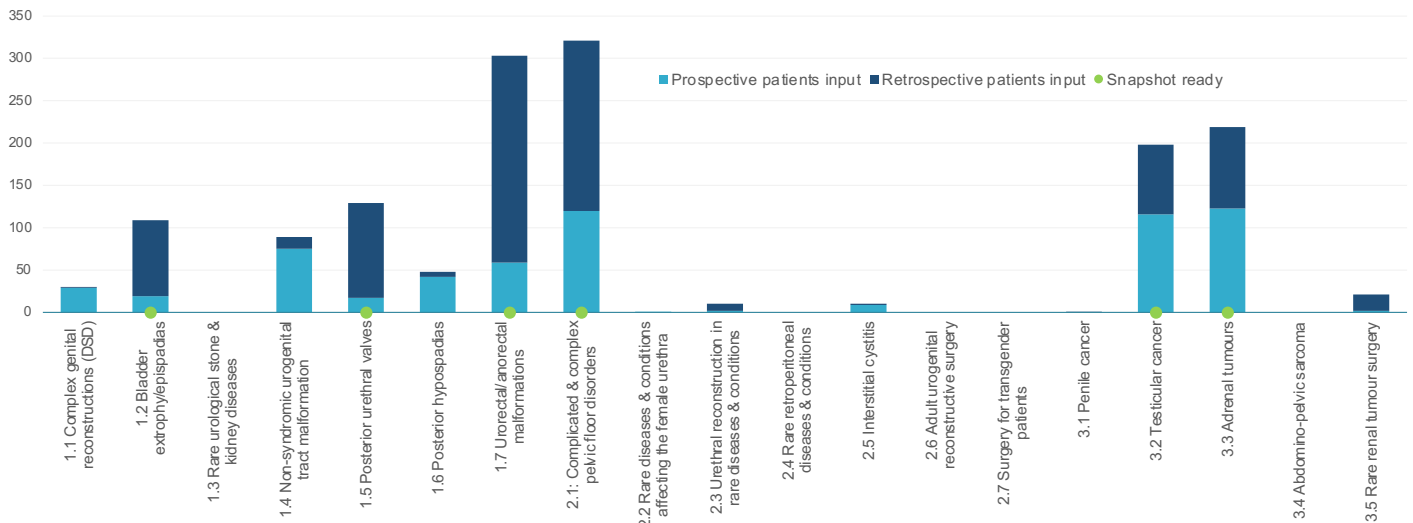
- Target of 4500
- Contact missed patients
- MM 1&2



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# 1. ERN eUROGEN registry progress

ERN Registry cases input by Expertise Area



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## 2. Improvements and next steps

- Reports
  - Do they help in motivating you for patient data entry?
  - What clinical information from the registry would interest you?
  - How can they be improved?
    - Also for Expertise Areas without Clinical Practice Snapshot?
  - MM 5



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## 2. Improvements and next steps

- Data quality



eUROGEN  
Urogenital Diseases

ERN eUROGEN registry • Live (Form Sync Version 113.0)

### Participants

Participant   Exact match

List Visit Form

<input type="checkbox"/>	Participant ID ↓	Site ↑↓	Survey co... ↑↓	Progress ↑↓	Created by ↑↓	Updated on ↑↓	Status ↑↓			
<input type="checkbox"/>	TEST000001	Test Institute	-	<div style="width: 100%;"></div>	<a href="#">Lotte Boormans</a>	26 Feb 2026	<span style="color: orange;">●</span> CPS available			



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## 2. Improvements and next steps

- Data quality
  - More investment in data quality to improve data usability
  - MM 6&7
  - Fill out available CPS → reimbursed

HCP	Number of open queries
DE19	1
IT34	4
IT58	5
NL01	12
NL03	4
NL09	6



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## 2. Improvements and next steps

- MM8: Would you be interested in
  1. A regular online walk-in session to ask registry-related questions?
  2. An online follow-up meeting for your HCP two years after the demonstration meeting?



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## 3. Improvement suggestions & Questions

- ...



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# ERN eUROGEN

The European Reference Network for Rare Uro-Recto-Genital Diseases and Complex Conditions

## SBM 2026

### WP6: Webinar Programme

**Darren Shilhan, ERN eUROGEN IT and Data Performance Analyst  
& Parmida Anvary, ERN eUROGEN Clinical Helpdesk Specialist**  
**27 February 2026 09:00-09:30**



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## 1. Achievements

- 55 webinars produced
- 9,700 registrants
- 4,000 attendees
- YouTube channel
  - 78,000 views
  - + 1,100 subscribers
- Accreditation
- Zoom platform



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## 2. Improvements

- Ensuring at least two presenters for each webinar
- Checking topics with relevant Expertise Area Coordinator
- What level should presenters be? (Do we need to ask for publications on Webinar information form?)
- How can we improve the set-up process, given we need title, etc. – how do we work together better on this?
- Accreditation is stopping for now – is this important?



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## 3. Next steps

- Another webinar survey and analysis
- Cover EAs that are under-represented, plus also new areas being added to network



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# ERN eUROGEN

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## SBM 2026

### WP6: Training Courses

Michelle Battye, ERN eUROGEN Programme Manager

27 February 2026 09:30-10:15



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## 1. Achievements - overview

- Range of training and education activities delivered
- Strengthened specialist knowledge and surgical skills
- Enhanced cross-ERN collaboration and knowledge exchange
- Strong foundation built for sustainable expertise development



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## 1. Achievements

- Surgical training courses (colorectal) in 2024 and 2025 with EUPSA
- Expert consensus meeting on Vaginal Replacement in Children with Anorectal Malformations (ARM) 24–25 April 2025 Lund, SE
- Planning for workshop on quality of life and gynaecological concerns in rare malformations in November 2026
- Transition and lifelong-care working groups
- Sustained collaboration with other ERNs



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## 1. Achievements - in addition to grant requirements

- Launch and dissemination of the Rare and Complex Urology book
- ERN eUROGEN Expertise Area book series
- Participation in cross-ERN nursing and surgical training initiatives
- Endorsement of external workshops and postgraduate training programmes



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## 2. Improvements

- Flagship highly specialised surgical training programme - difficulty with implementation
- Alternative suggestions?
- More collaboration with scientific societies? How?



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## 3. Next steps

- Quality-of-life workshop and a related expert consensus document to take place in Gothenburg, SE in 2026
- Continuation of webinar programme and special series for Ukraine



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### 3. Next steps – preparing for next grant

- What should WP6 contain?
- Webinars? Accreditation needed?
- Other suggestions?



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# ERN eUROGEN

## The European Reference Network for Rare Uro-Recto-Genital Diseases and Complex Conditions

### SBM 2026

### WP7: Guidelines – Overview, Support, & Timeline

Jen Tidman, ERN eUROGEN Business Support Manager

27 February 2026 10:15-11:00



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## 1. Achievements: Years 1-2 of Grant

- 5-Year Evaluation: Independent Evaluation Body recommended that ERN eUROGEN prioritise guideline development
- WP7 designed as a comprehensive and ambitious work package, with 15 tasks and 20 deliverables
  - 2 CPGs completed
  - 1 CDST completed
  - 7 additional CPGs/CDSTs actively progressing toward completion
  - Structured governance through Guidelines Expert Panel



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# 1. Achievements: Completed Guidelines

## Completed CPGs:

- Anorectal Malformation
  - Full pathway coverage (diagnosis → transition)
  - 4-part CPG published in EJPS
  - Accompanying patient journey
- Paediatric Neurogenic Bladder
  - Multi-ERN & multi-society collaboration
  - Integrated into ERKNet/Leila App
  - Triggered revised Orphanet nomenclature (25 new ORPHAcodes, OJRD publication)

## Completed CDST:

- Posterior Urethral Valves
  - European consensus process
  - Manuscript submitted for peer review



# 1. Achievements: In Progress

- Bladder Exstrophy (translation & adaptation with DGU)
- Vaginal Malformation (multi-ERN, gynaecology involvement)
- Vesicovaginal Fistula (DGU collaboration, potentially EAU)
- Rare Inflammatory Bladder Conditions (8 subtopics)
- Adrenal Tumours (translation + Endo-ERN)
- Megaureters (cross-ERN, multi-society)
- Penile Cancer Centralisation (EAU)

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## 2. Improvements: Areas Highlighted In Network Survey

### 1. Sustainable Financial Support

- “A sustainable funding model for methodological and coordination support is needed” 🤔

### 2. ARM Guideline – Pocket Version

- “Had to use the ARM guideline, very good, but there needs to be a pocket version.” 🤔

### 3. National-Level Implementation

- “National structures (e.g., Centres for Rare Diseases) could play an important role in supporting dissemination and implementation at national level.” 🤔



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## 3. Next steps: Final 2 Years of Grant – Priorities

- Deliver Remaining Grant Commitments:
  - Bladder Exstrophy
  - Vaginal Malformation
  - Vesicovaginal Fistula
  - Rare Inflammatory Bladder Diseases
  - Adrenal Tumours
  - Megaureters
  - Penile Cancer Centralisation (Clarify with EAU)
  - D7.2 – Years 3–4 Report



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## 3. Next steps: Preparing for the Next Grant

What should WP7 look like from 2027 onwards?  
Focus on new topics? And/or strengthening implementation?

### 🤔 New Topics?

- Is current volume sustainable?
- Prioritise fewer, higher-impact guidelines?
- What level of methodological funding is required?

### 🤔 Strengthening Implementation?

- Deeper collaboration with European scientific societies – how?
- Short / pocket versions of existing CPGs?
- Digital integration (apps)?
- National society endorsement pathways?
- Engage other national structures?
- How should implementation be measured?



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# ERN eUROGEN

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## SBM 2026

WP8 & WP9: Ukraine – Current Status, Challenges, & Next Steps

Michelle Battye, ERN eUROGEN Programme Manager

27 February 2026 11:15-11:45



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## 1. Achievements - overview

- Strong cooperation established with Ukrainian healthcare providers
- Capacity building delivered online despite war conditions
- Improved access to ERN expertise and resources



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## 1. Achievements – training and education

- 18 webinars delivered to Ukrainian clinicians
- Programme on track to exceed 20 webinar target
- Training included spina bifida and complex urology
- Technical improvements - accessible recordings with subtitles now provided



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## 1. Achievements - collaboration

- Partnership with Khmelnytsky Children's Hospital
- 16 coordination meetings held
- Rare Diseases Hub in Kyiv contacted
- Khmelnytsky Children's Hospital now accredited as centre of expertise for spina bifida in the Ukraine



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## 1. Achievements - Tools and Clinical Support

- CPMS access granted to Ukrainian clinician
- First patient case successfully discussed using CPMS
- Enabled expert virtual advice to help a Ukrainian patient with spina bifida
- ERN eUROGEN guidelines and patient information shared



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## 1. Achievements – awareness raising

- 3 awareness campaigns completed
- Rare Disease Day participation
- Outreach to national societies
- Promotion of ERN tools and resources



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## 2. Improvements

- Maintain collaborations with the Rare Diseases Hub in the Kyiv
- Increase awareness of ERN support amongst Ukrainian clinicians
- Promote/increase use of CPMS
- Monitor results of engagement with Ukrainian urological societies



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## 3. Next steps

- Implement webinar series co-developed with Ukrainian clinicians
- Promote/increase the use of CPMS



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### 3. Next steps – next grant

- Continuation of webinar series for Ukrainian clinicians
- Increase use of CPMS
- If war ends, training in our HCPs?
- Other suggestions? All welcome!



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