



Endo-ERN Steering Committee/Advisory Board Meeting

Date: February 4, 2025

Time: 9:30 –11:30 CET



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Agenda

09:30 – 09:35 Welcome

09:35 – 11:15 Presentation WP activities incl. discussion

11:15 – 11:30 AOB

10 minutes per Work package / Working Group

WP1 Management & Coordination

Alberto Pereira, Adult Chair Endo-ERN

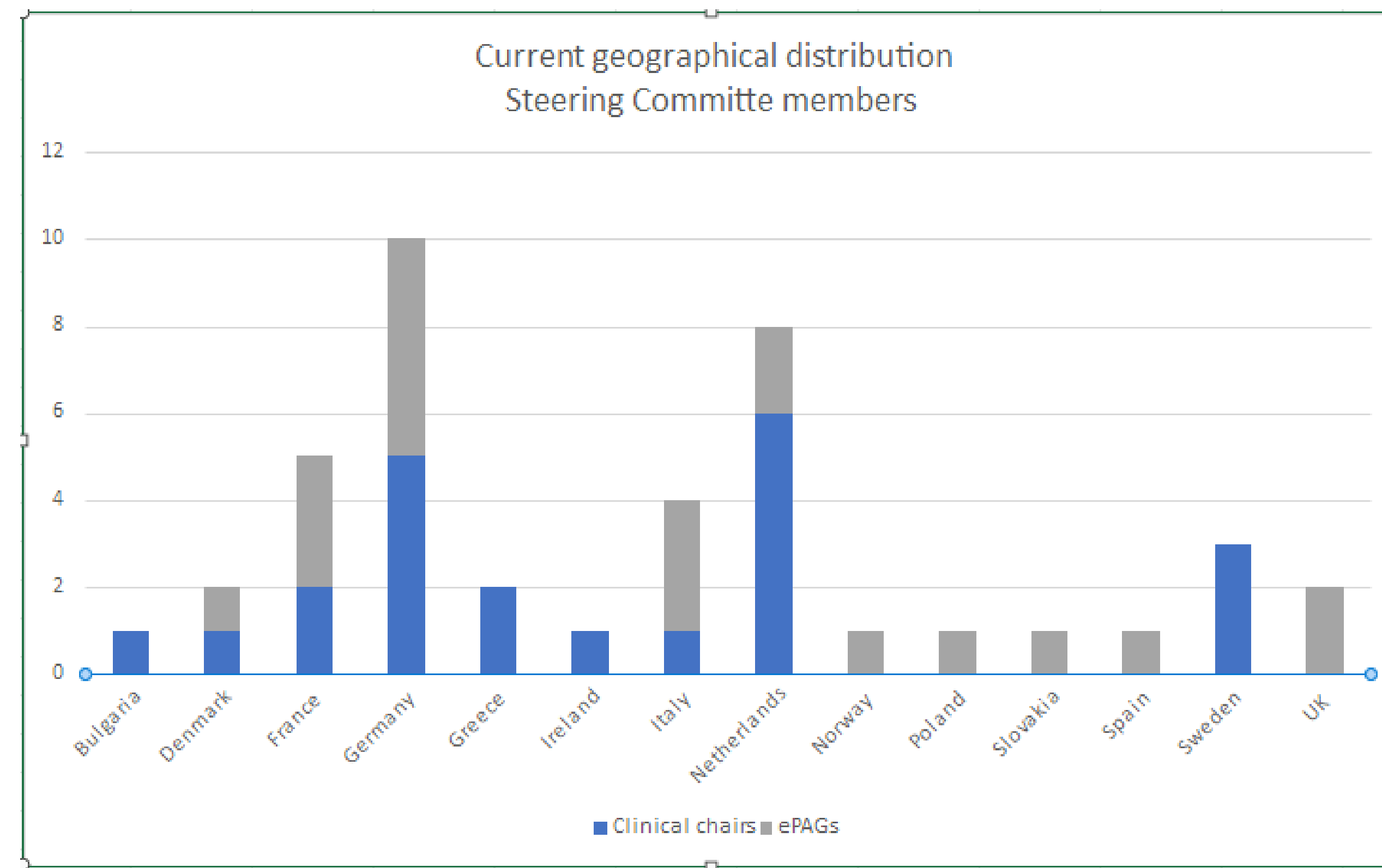
Olaf Hiort, Paediatric Chair Endo-ERN

Charlotte van Beuzekom, Project Manager Endo-ERN

Replacement/new (chair) positions



- New ePAG MTG6: Marta Baranska, Pituitary Gland Association, Poland
- New Paediatric National Coordinator Germany: Corinna Grasemann





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Endo-ERN

Endocrine Connections – special issue 2025

- Theme: Rare Diseases and Transition in Care
- 11 paper topic suggestions submitted and approved
- Author instructions sent out, submission date 31 March 2025
- First papers published during Joint congress in May 2025
- Linked (dissemination) network activities
- Separate section Endo-ERN website: *For professionals --> publications*



Endocrine Oncology – special issue 2026



MTG HCP meetings

- MTG chairs organize 3 meetings/year: 2 online, 1 in-person during GA
- Attendees: The designated representatives from our member HCPs
- Standing agenda covering all Work Package specific activities
- Meeting minutes at our website: ***For members --> MTG representatives***
 - ✓ **All MTGs organized their Autumn 2024 meeting**

Attendance



MTG	Date	Invited	Participated
MTG1	27-Nov-24	147	12
MTG2	4-Dec-24	102	10
MTG3	23-Oct-24	113	15
MTG4	25-Nov-24	90	9
MTG5	7-Oct-24	129	16
MTG6	8-Nov-24	181	27
MTG7	30-Oct-24	112	16
MTG8	12-Nov-24	122	19

- 10% of invited persons
- 25% of endorsed HCPs

GA 2025

Day	Time	What	Remark
Friday 9 May	12-13 hrs	SCAB meeting	
	13:30-19 hrs	Plenary presentations incl voting	
	19-22 hrs	Informal dinner	Not yet confirmed
Saturday 10 May	9-12 hrs	MTG parallel sessions	

Programme: Available at Endo-ERN website

Location: Bella Center, Copenhagen, Denmark

→ Please register if not done yet



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Joint Congress of ESPE/ESE

Day	Time	What
Saturday 10 May	16:45 hrs	Welcome ceremony
Sunday 11 – Tuesday 13 May	Full day	Congress Endo-ERN booth
Tuesday 13 May	10:30 hrs	Endo-ERN symposium

Endo-ERN symposium @ joint congress, Tuesday 13 May 2025

Session chairs: Alberto Pereira & Olaf Hiort

- | | |
|-------------|---|
| 10:30-10:50 | Endo-ERN > a key player in the trias with the European Endocrine Societies (Alberto Pereira & Olaf Hiort) |
| 10:50-11:10 | Transversal Working Group on Transition of Care (Andrea Isidori & Ulla Doehnert) |
| 11:10-11:35 | (inter) national care pathway development DSD/AGS OR Genital Surgery in Disorders of Sex Development (Hedi Claahsen) |
| 11:35-12:00 | The patient's perspective on key perspectives (Lexi Breen) |

Linkage to other European RD projects

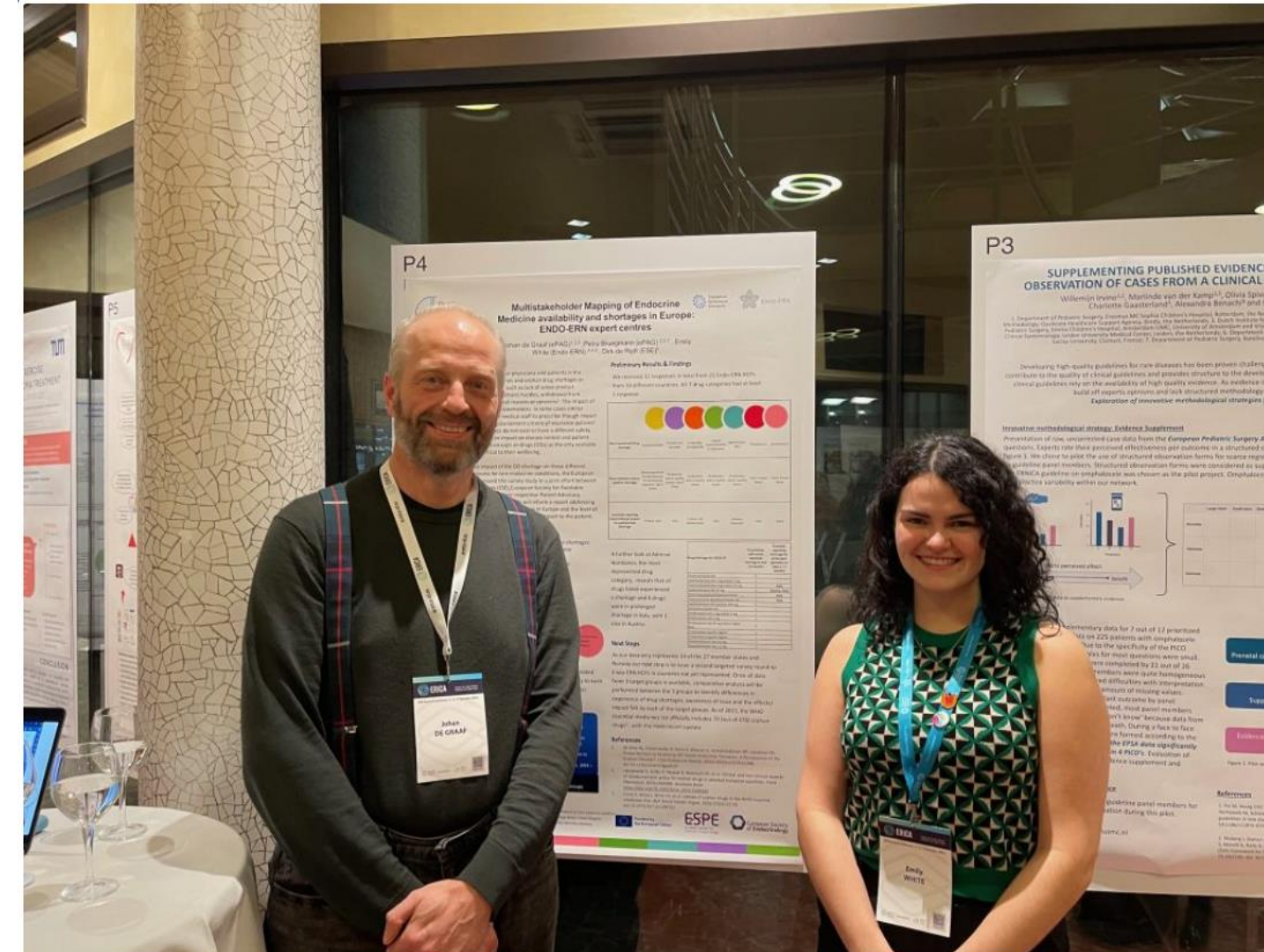


European Rare Disease Research Coordination and Support Action

2020-2025
Horizon2020



Best oral presentation



Best poster

www.ERICA-rd.eu



Linkage to other European RD projects



2024-2034
Horizon Europe

THE 2025 JOINT TRANSNATIONAL CALL IS OPEN!

<https://erdera.org>

CALL OPENS	December 10, 2024	PRE- PROPOSAL DEADLINE	February 13, 2025
LEARN MORE: JOIN THE WEBINAR	December 17, 2024	FULL PROPOSAL DEADLINE	July 9, 2025

Linkage to other European RD projects



- Joint **A**ction on **R**are **D**iseases and ERN **IN**tegration into National Healthcare Systems

2024-2027
EU4Health

ERDERA & JARDIN: proposed 3 levels of collaboration





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Quality of Care Improvement through Research Council

Emily White, Project Manager & Endo-ERN Operational Helpdesk Manager



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Quality of Care Improvement through Research Council



Summary since last SCAB :

- 1st formal council meeting
- remit of council created

First call for research grants to be launched in coming 6 months:

- Competitive application process
- Research PI must be affiliated with at least Endo-ERN member HCP and/or Patient Organization/ advocacy group.
- Research criteria will be provided via Endo-ERN website including proposal submission guide / deadlines



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Transversal Working Group on Genomic Testing

Thomas Eggermann (University Hospital Aachen, Germany)

Dirk Prawitt (Center for Paediatrics and Adolescent Medicine, University Medical Center, Mainz, Germany)



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Joint paper (in preparation): „What the endocrinologist expects from genetic testing and reporting“



The idea is "just" to get an overview of the aspects which have to be considered in context with genetic testing.

How to prepare the paper: As an initial step we would like to ask you for your help and input for the following points:

Step 1:

Which aims do we want to address? please add:

- When is a genetic test appropriate?
- Standardised genetic testing procedures (single gene analysis vs targeted panel vs WES vs WGS) What is optimal?
- How to achieve a standardized genetic testing quality?
- Standardized reports addressing the needs of the clinicians
- Germline and somatic genetic testing have to be considered
- How to deal with VUSs, incidental findings....
- Recall of VUSs
- Common research activities
- How genetic testing is reimbursed across Europe?

Step 2:

Identification of guidelines, major papers, stakeholders/organisations which should be included to avoid double work and contradictory suggestions.

Feel free to contact us at any time!

Ideas/Suggestions/Contacts are welcome,
preferably from every MTG

Contact:

Thomas Eggermann
(teggermann@ukaachen.de)

Dirk Prawitt
(dprawitt@uni-mainz.de)



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Transversal Working Group on Transition in Care

Andrea Isidori (Azienda Ospedaliero-Universitaria Policlinico Umberto I, Rome, Italy)

Ulla Doehnert (Universitätsklinikum Schleswig-Holstein, Luebeck, Germany)



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Transition of Care Working Group activities

1. Completed

- Members: all MTGs involved, wide paediatric / adult representation
- Formal approval, kick-off meeting, development of visual identity
- Collection of papers, consensus documents, etc. related to ToC (shared Drive folder)
- Development of ToC e-Survey across different EU countries, MTGs, and HCPs
- Bilateral coordination meetings with sister ERNs: EuroBloodNet, eUROGEN, EURO-NMD, etc.
- Active involvement in the ESE-ESPE group of Transition
- Survey dissemination through Endo-ERN, ESE, HCPs...

2. In progress

- Survey is **ongoing!** ESE-ESPE joint Symposia meeting (in preparation)
- Further ePAG involvement

3. Approved tasks underway

- Drafting of the “First international consultation on ToC for rare endocrine disorders”

4. 7th TALENT meeting (12-13th February 2025 in Rome, Italy)

- Endorsement by Endo-ERN, ESE, EAA, among others
- Definitive programme available at: tinyurl.com/tyc55cnr

Endo-ERN 'Transition of Care' Working Group composition

N	MTG / Role	Representative	Ped/Adu	E-mail (transitionwg@endo-ern.eu)
1	Chair	Andrea Isidori	Adu	andrea.isidori@uniroma1.it
2	Co-chair	Ulla Döhnert	Ped	u.doehnert@uni-luebeck.de
3	1/Adrenal	Svetlana Lajic	Ped	svetlana.lajic@ki.se
4	1/Adrenal	Nicole Reisch	Adu	Nicole.Reisch@med.uni-muenchen.de
5	1/Adrenal	Uta Neumann	Ped	uta.neumann@charite.de
6	2/Calcium&Phosphate	Corinna Grasemann	Ped	corinna.grasemann@rub.de
7	2/Calcium&Phosphate	Eva Kassi	Adu	ekassi@med.uoa.gr
8	2/Calcium&Phosphate	Graziamaria Ubertini	Ped	graziamaria.ubertini@opbg.net
9	3/Glucose&Insulin	Felix Reschke	Ped	felix.reschke@hka.de
10	3/Glucose&Insulin	Pietro Maffei	Adu	pietro.maffei@aopd.veneto.it
11	4/Genetic tumours	Annemarie Verrijn-Stuart	-	a.a.verrijnstuart@umcutrecht.nl
12	5/Growth&Obesity	Susan O' Connell	Ped	susan.oconnell@childrenshealthireland.ie
13	5/Growth&Obesity	Claudia Giavoli	Mix	claudia.giavoli@unimi.it
14	5/Growth&Obesity	Danilo Fintini	Ped	danilo.fintini@opbg.net
15	6/Hypothal&Pit	Evangelia Charmandari	Ped	evangelia.charmandari@googlemail.com
16	6/Hypothal&Pit	Nienke Biermasz	Adu	n.r.biermasz@lumc.nl
17	6/Hypothal&Pit	Violeta Iotova	Mix	violeta.iotova@mu-varna.bg , iotova_v@yahoo.com
18	7/DSD	Hedi Claahsen	Ped	Hedi.Claahsen@radboudumc.nl
19	7/DSD	Kirstine Stochholm	Mix	Kirstine.stochholm@aarhus.rm.dk
20	8/Thyroid	Dana Craiu	-	dcraiu@yahoo.com
21	8/Thyroid	Andreea Badea	-	dr.andreea.badea@gmail.com
22	Manager	Francesco Carlomagno	Mix	francesco.carlomagno@uniroma1.it
23	Manager	Matteo Spaziani	Mix	matteo.spaziani@uniroma1.it
24	ePAG	Diana Vitali	-	d_vitali@yahoo.com



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HEAL ITALIA FOUNDATION

SAPIENZA
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Endo-ERN
TALENT
TRANSITION OF CARE
WORKING GROUP

7th Conference Meeting
An Endo-European Reference Network and Heal Italia
Foundation PNRR Spoke 4 EU grant event

ENDORSED BY
European Reference Network Endo-ERN

Roma Eventi Fontana di Trevi
Piazza della Pilotta, 4

ROMA
12.13
february
2025

Under the patronage of SIE, SIAMS and OMCeO Roma

7th TALENT Conference Meeting



12.02
2025

PRE-TALENT – Working Groups Meeting

- 09.00-10.30 **Old-TALENT** Meeting and report of the Working Groups of the 6th Talent Conference
- 10.30-11.00 Coffee break
- 11.00-12.30 **New-TALENT** Meeting and presentation of the proposals of the Working Groups of the 7th Talent Conference
- 12.30-13.00 Lunch

TALENT CONFERENCE OPENING

- 13.00 Registration of participants
- 13.15-13.30 Opening of the conference and greetings from the Authorities
 - **Andrea Lenzi & Marco Cappa**, *Talent Presidents*
 - Presidential Addresses from Partner Societies
- 13.30-13.50 A history of Talents
 - **Ashley Grossmann & Martin Savage**
- 13.50-14.00 Welcome ToC! The new kid on the *Endo-ERN*
 - **Andrea M. Isidori & Ulla Döhnert**

TALENT for ADRENAL DISEASES

Endo-ERN MTG1 Symposium

Moderators: R. Pivonello, K. Alexandraki

- 14.00-14.20 **LECTURE 1** Adrenal insufficiency and congenital adrenal hyperplasia: the new therapeutic approaches
 - **Svetlana Lajic**, *Karolinska University Hospital, Stockholm, Sweden*
- 14.20-14.40 **LECTURE 2** Fertility issues in adrenal adenomas and carcinomas
 - **Nicole Reisch**, *Ludwig-Maximilian-University Munich, Munchen, Germany*
- 14.40-15.00 **LECTURE 3** Clinical management and therapeutic approaches in adrenoleukodystrophy
 - **Marco Cappa**, *IRCCS Ospedale Pediatrico Bambino Gesù, Roma, Italy*
- 15.00-15.20 Discussion



13.02
2025

- 15.10-15.30 **LECTURE 19** Neurological outcomes of levothyroxine therapy in hypothyroid patients (pre-recorded lecture in Marinetti room)
 - **Andreea Badea**, *Universitatea din Bucuresti, Bucharest, Romania*
- PARALLEL LECTURE 20** Why Transition is pivotal to Endo-ERN: a paediatric perspective on integrating lifetime care
 - **Olaf Hiort**, *Universitätsklinikum Schleswig-Holstein, Lubeck, Germany*

- 15.30-15.45 Discussion
- 15.45-16.15 Coffee break

The ENDO-ERN International Consultation and HEAL Italia Welcome

- 16.30-17.00 Introductory speech and Authorities welcome
- 17.00-18.30 Parallel Sessions

SYMPOSIUM ON PRECISION MEDICINE “Heal Italia Foundation”

Under the patronage of SIE LAZIO and OMCeO Roma

Moderators: G. D’Amati, G. Moroncini

- 17.00-17.20 Precision Imaging in Endocrine Tumors
 - **Valeria Panebianco**, *Sapienza Università, Roma, Italy*
- 17.20-17.40 Decoding Thyroid Cancer: Genomic Signatures of Indeterminate Thyroid Nodules
 - **Fabio Medas**, *Università degli Studi di Cagliari, Cagliari, Italy*
- 17.40-18.00 The AI innovation in Precision Medicine: results from HEAL Italia Spoke 2
 - **Stefano Diciotti**, *Alma Mater Studiorum Università degli Studi di Bologna, Bologna, Italy*
- 18.00-18.30 An external view on Heal Italia (remote live presentation)
 - **Marta Korbonits**, *Queen Mary University of London, London, United Kingdom*

Parallel session

Round Table with all Members of TOC Working Group

Moderators: S. Negggers, E. Le Roux, C. Gaasterland

Drafting the Consensus Document of “The First International Consultation on the Transition of Care in Rare Endocrine Disorders”

- 18.30 Conclusions of the day’s work

The program may undergo slight changes due to unforeseen circumstances

Endo-ERN 'Transition of care' survey for rare endocrine disorders

Dear Participant,

Thank you for taking the time to participate in this survey, developed by the **Endo-ERN 'Transition of Care' Working Group**.

This survey aims to explore current practices, challenges, and strategies in managing the **transition of care** for patients with **rare endocrine diseases** across different healthcare providers and institutions. The questions address key aspects of evaluation, treatment, follow-up, and multidisciplinary collaboration during the **transition from pediatric to adult care**.

Survey Details:

- Estimated completion time: **15-20 minutes**.
- All responses will be treated as **confidential** and will be used exclusively for research purposes within the framework of Endo-ERN.

At the end of the survey, you will also have the opportunity to share **comments** or **suggestions** to further enhance this research.

If you have any questions or need further clarification, please feel free to contact us at:

andrea.isidori@uniroma1.it & u.doehnert@uni-luebeck.de (Chairs)

francesco.carlomagno@uniroma1.it & matteo.spaziani@uniroma1.it (Managers)

Thank you for your valuable contribution!

Endo-ERN Transition of Care Working Group

[START SURVEY NOW](#)



ToC Survey is ongoing!

- Directed at paediatric / adult centres dealing with ToC in rare endocrine diseases
- 1-2 response(s) per centre (paed / adu)

Preliminary data to be presented at the TALENT meeting

- More than 90 respondents (centres)
- Across 20+ EU countries



tinyurl.com/8bpajmuw

Setting

Evaluate current clinical setups (e.g., shared outpatient clinics, visit frequency) and standardized transition protocols from paediatrics to adult care.

5. Does your centre provide shared outpatient clinics for transitioning patients?*

Select one answer

a) Yes, a dedicated clinic for chronic endocrine conditions in adolescent and transition age patients (e.g., between the ages of 16 and 24)

b) Yes, either a joint clinic or visits between paediatric and adult units before transfer. The adult physician (or specialised nurse) comes to the paediatric unit, or vice versa

c) No, patients are directly referred to the adult unit at a specific age (e.g., ages 16-18) ✓

d) Other (please specify)

6. In case, how many joint visits are conducted before the actual transfer?*

Select one answer

a) None

b) 1-2 visits ✓

c) 3 or more visits

d) A variable number, depending on the individual patient/condition



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WP2 Communication & Dissemination

Aimee Casey, Communication Manager, Endo-ERN



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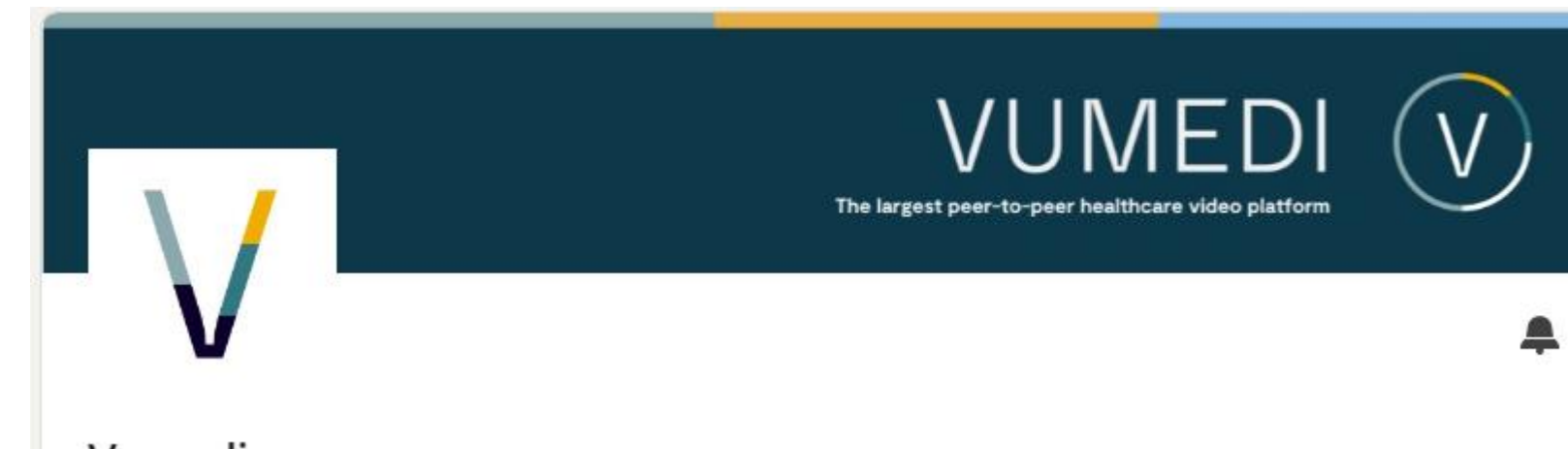


Endo-ERN

Social media update 2024

	Current total	Increase from February
LinkedIn	665	+189
Facebook	418	+39
YouTube	522	+261
Newsletter subs	2386	+1098

VuMedi



- Medical “YouTube”
- Privacy policy is clear on the website and using opt-in
- Our videos are on YouTube and that link will remain on our website
- How long will the video be stored?
- Copyright concerns



Feb-Jun

- Updating patient and member section of the website
- Launch and promotion of publication database
- Increasing Endo-ERN content showcasing members – profile type articles.



February

Rare Disease Day 28 February

- All ERN promotion
- EU publication showcasing ERN success stories
- RDD newsletter showcasing relevant ERNs






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April



**World
Hormone Day**
Because Hormones Matter
24 April 2025





European
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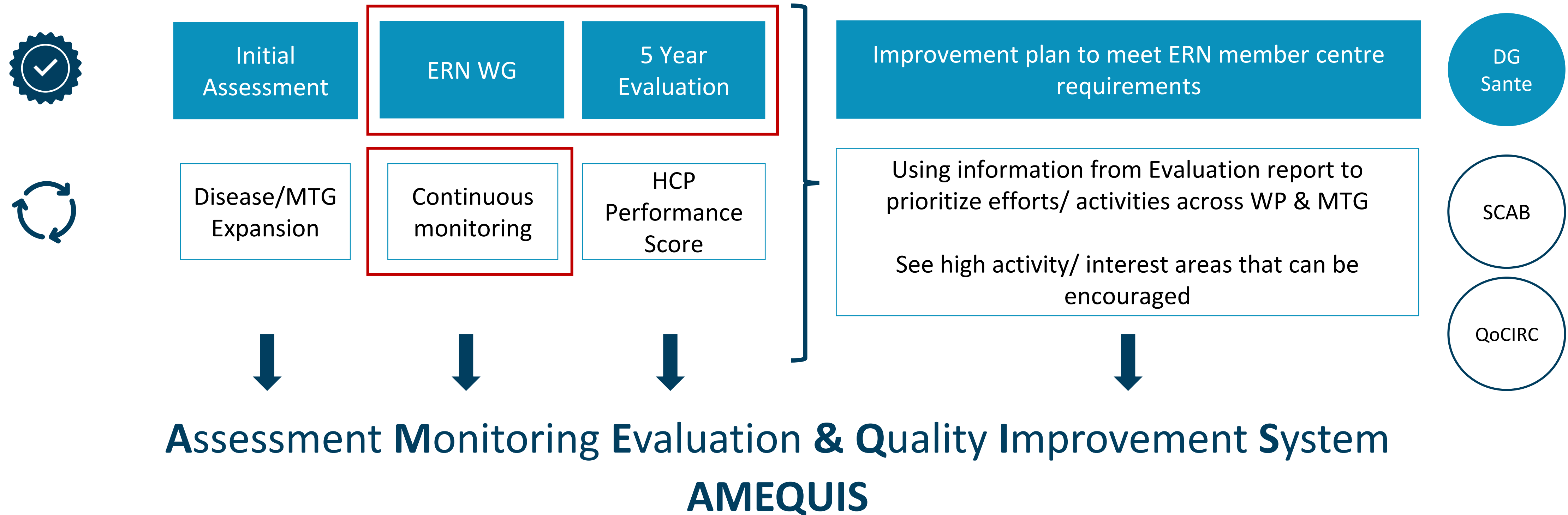
WP3 Evaluation

Emily White, Project Manager & Endo-ERN Operational Helpdesk Manager



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Evaluation in Endo-ERN – QI



Continuous monitoring



January 1 – February 28, 2025

1. **Download** your centre's new Patient Numbers for rare endocrine diseases in 2024 via [e-REC](#)

Deadline has passed to update e-REC for 2024

2. **Report** in the DG Sante/European Commission portal directly on 2 indicators:

- [Download](#) the guide for requesting access to the new ERN monitoring platform
- [Link to platform](#)

3. **Complete** the [survey](#) on the remaining indicators that has been sent to the HCP representatives from Endo-ERN

Continuous monitoring



As of 31st January 7 HCPs submitted Endo-ERN survey

Common Queries:

- If our HCP does not use Orphacodes what do we do?

We can provide you with an overview of ICD 10, ICD 11 and Snowmed codes that are applicable to our network conditions

- How long does the survey take?

The survey requires input from multiple team members at your HCP. It is advised to meet together, discuss who will gather what data and supply it to the representative reporting.

If you have all information gathered then the survey take 10-15 minutes.

- If you have not reported to e-REC in time for 2024 what happens?

If you have a new case(s) not yet reported in e-REC, you should report the total number of new Endo-ERN cases you have seen in you HCP in 2024 based on the total in your local records/system

Next Q&A: **14th of February at 13:00 CET**

Evaluation WG update

Evaluation WG have reviewed and redrafted the Measurable Elements (MEs) for the 5 year evaluation

- All ERNs coordinators and ePAGs had chance to review proposed redraft
- Next meeting 11th February with our ePAG representatives & EURORDIS

Next 5 year evaluation for all HCPs based on years **2022-2027**

WP4 Healthcare & CPMS

Olaf Hiort, Paediatric Chair Endo-ERN

Greta Ginski, CPMS Operational Helpdesk Manager

Emily White, Project Manager & CPMS Operational Helpdesk Manager






CPMS 2.0 – current status

 CPMS 2.0 is Live!

The previous CPMS is now in read-only mode since January 29, 2025

Migration Progress:

-  User migration: completed
-  Patient data migration: ongoing
-  Patient files migration: ongoing

CPMS 2.0 – current status

To Do for every CPMS User

- Log in to CPMS 2.0 and make sure settings are accurate
- Update your expertise (Profession; Clinical Focus (Pediatric/Adult); Thematic Group (MTG))

CPMS 2.0 – current status

Important Note

You are required to use **two-factor authentication with the EU Login Mobile App** to access CPMS 2.0 ([Guide to set up your two-factor authentication](#))

Regular Meeting Schedule

Meetings will continue in February based on feedback from chairs.

Updated manuals for CPMS 2.0 on our [website](#)

Reminder – Get permission to use CPMS 2.0

 DG Santé has reached out to Data Protection Officers (DPOs), a public session was held on November 5, 2024

- Before entering a case into CPMS 2.0 → Confirm with your DPO that your HCP has permission to use the new system and follow the consent procedure at your HCP
- **To MTG Chairs:** Who has permission? Who needs help?

 → Give feedback in the chat

Recurring meeting schedule

Updated schedule for MTG2

MTG1:

Every 2 months, 1st Tuesday @1500

MTG2:

Every month, 2nd Monday @13:00 or 2nd Wednesday @13:00

MTG3:

Every month, last Wednesday @13:30

MTG4:

Every month, 2nd Thursday @14:00

Recurring meeting schedule

Updated schedule for MTG7

MTG5:

Every 2 months, 3rd Tuesday @17:00

MTG6:

Every month, 3rd Friday @13:00

MTG7:

Every month, 1st Wednesday @16:00

MTG8:

Every 3 months, 1st Wednesday @09:00

Trainings for CPMS 2.0



Training sessions by DG Santé

- Thursday 23 January 2025 at 16:00 CET
- Thursday 6 February 2025, 9:00 CET
- Tuesday, 11 February 2025, 4:00 pm CET
- Thursday, 20 February 2025, 4:00 p.m. CET
- Thursday 27 February 2025, 9:00 a.m. CET

Other training opportunities

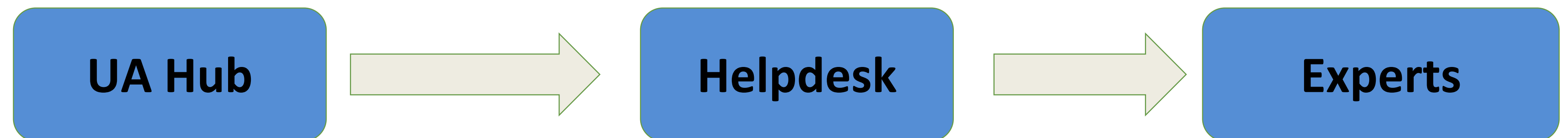
- Option: use the first regular meeting in CPMS 2.0 for a training session?
- CPMS 2.0 system tour planned for MTG Chairs: Friday, 7th Feb
- Endo-ERN Webinar for CPMS 2.0 mid February
- Dedicated trainings for new roles in the system (e.g. assistant) starting in March

Contact the CPMS
helpdesk if you need
additional training!

CPMS 2.0 and Ukraine

The process is coordinated via the Ukrainian hub in Kyiv (Ohmatdyt children's hospital)
(hub_ukraine@ohmatdyt.com.ua)

If a case comes through the helpdesk will contact relevant experts

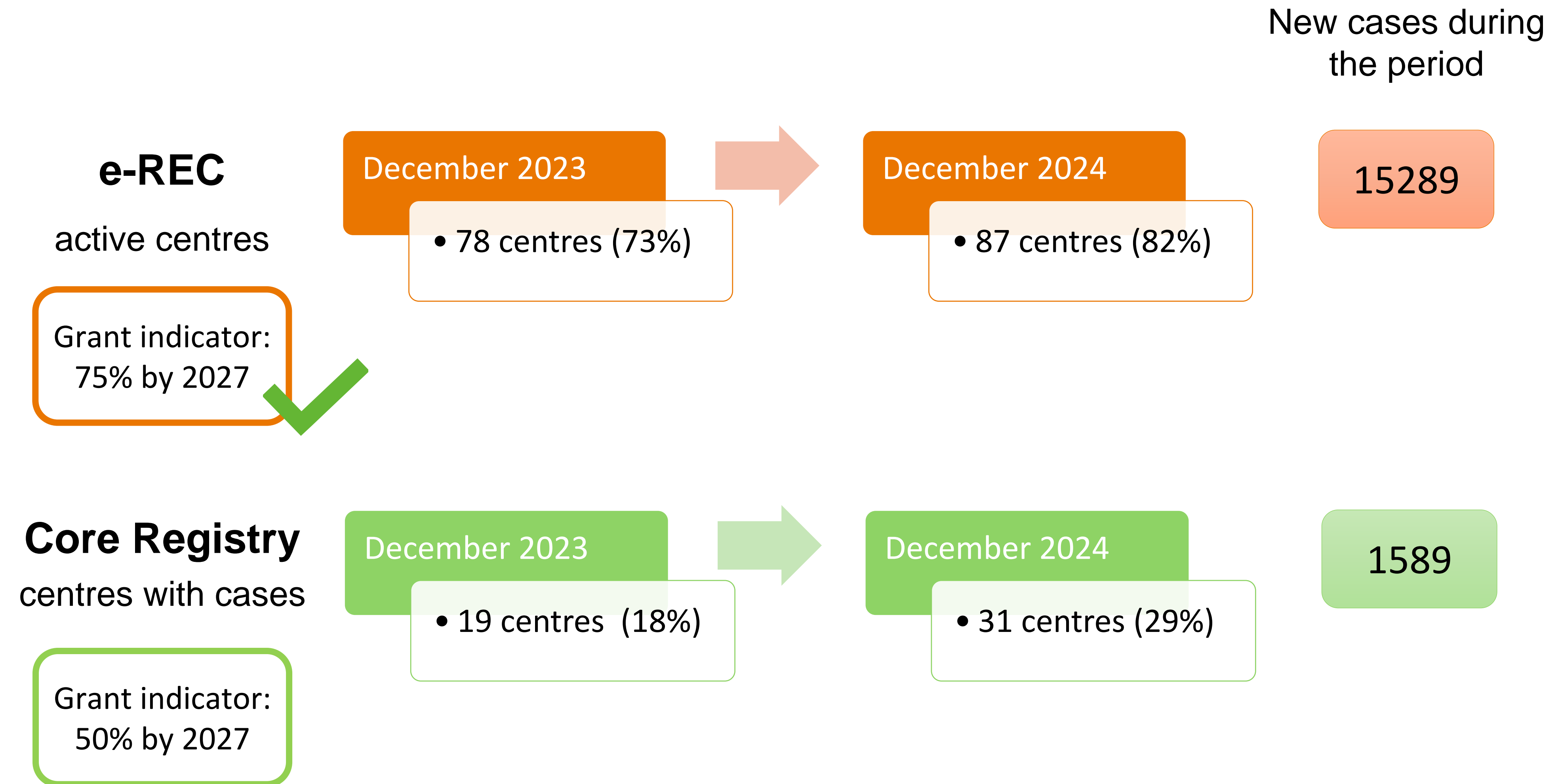


Work Package 5

EuRREB Registries, Data Management and Analysis

Natasha Appelman-Dijkstra, Faisal Ahmed

Endo-ERN members activity



Study Groups and Working Groups



New Study Groups

- Pituitary module: PANOMEN
 - Lead by Alberto Pereira Arias
- Pituitary module: Transcription factors
 - Lead by Alberto Pereira Arias

Current Working Groups

- Langerhans Cell Histiocytosis
 - A collaboration between ERN BOND, ERN-EuroBloodNet and Endo-ERN
- Chronic Non-bacterial Osteitis

Would you like to develop a condition-specific module?

Send us an email at registries@lumc.nl before **April 15th 2025**. We will then discuss next steps during the Endo-ERN GA in May.

Rebranding

- March 2025
- Removing EuRRECa and EuRR-Bone -> **EuRREB**
- New logo



- Updated website look & feel
- New conference materials





WP6 Education and Training

Violeta Iotova, Kami Markovska, Sevim Zekerries,
Manuela Brösamle, Petra Bruegmann

WP6 Topics

1st slide

- Endorsements
- Accreditation
- Clinical Exchange Program

2nd slide

- Webinars

3rd slide

- Future tasks

Endorsements, Accreditation & Clinical Exchange



Endorsement

- 6 endorsed events for the whole 2024
- 8 endorsed events for 2025 so far
- **NOTE** for those interested in receiving an Endorsement:
 - General requirements of the Network
 - Follow-up info required

Accreditation

- 32 Certificate requests for 5 accredited Webinars
- Accreditation means more registrants and attendees
- Minimum 5 webinars per accreditation pack

Clinical Exchange

- 1st call for 2025
 - 8 applicants
 - 6 approved
- 2nd call for 2025
 - 2 open slots
 - Suggested date for second call- **June 1** (update info will be on the website)

Webinars





Webinars per MTG for 2024

- **16** webinars were organized in 2024 (some between 2 MTGs)
- **10** webinars planned for 2025 so far
- **REMINDER:** MTGs need to provide a minimum of 2 webinars per year

MTG1	3 Webinars
MTG 2	2 Webinars
MTG3	2 Webinars
MTG4	1 Webinar
MTG5	1 Webinar
MTG6	1 Webinar
MTG7	8 Webinars
MTG8	1 Webinar

- Organizing a webinar needs to be reported to WP6 at least 4 weeks in advance
- **NOTE:** The earlier a webinar is organized:
 - the more registrants it has
 - the higher the chance to apply for accreditation

← ↻ 🏠 🔒 https://endo-ern.eu/webinars/ 🔊 ☆ ⚙️ 🖨️ ⌕ 📌 📄 ⋮ 📺

  Endo-ERN Find an expert

Rare Endocrine Conditions ▾ About Us ▾ For Professionals ▾ For Members ▾ For Patients ▾ 🔍

🏠 / Webinars

Index

Upcoming events

Webinars

Registration

Previous events

Overview of Webinars

Showing 95 entries

🔍

MTG	Theme / Title	Date	Time CET	Speaker(s)	Register	View	CPMS
MTG7	Long-term outcomes in CAIS	2025-03-17	17:30 - 18:30 hr	Giovanna Mantovani and Alessandra Mangone			
MTG7	Care of adult patients with Klinefelter syndrome	2025-03-05	16:00 - 17:00 hr	Claus H. Gravholt			
MTG1	Adrenoleukodystrophy: Presentation of two siblings	2025-02-19	15:00 - 16:00 hr	Maria Dolianiti			
MTG6	The changing landscape of adult GH deficiency	2025-02-17	16:00 - 17:00 hr				
MTG5	Update SGA, GH treatment beyond childhood webinar	2025-02-10	15:00 - 16:00 hr				
MTG6	ESE Talks...Rare Diseases Hypothalamic Obesity: Treatment modalities and prerequisites for treatment efficacy	2025-02-04	17:00 - 18:00 hr	Hanneke van Santen and Ulrich Dischinger			
	ESPE Connect webinar on Monogenic, neonatal and rare diabetes	2025-01-29	16:00 - 17:30 hr				
	Together4RD & ERICA industry collaboration webinar	2025-01-16	17:00 - 17:45 hr				
MTG5	Management of genetic obesity and food seeking behaviour e.d. in BBS/ALSTRÖM/PRADER WILLI syndromes / use of GLP-1 agonists in these conditions	2024-12-06	14:00 - 15:00 hr	Julia von Schnurbein, Dr Tony Goldstone and Bernd Rosenbichler			
MTG7	The new genetics of Turner	2024-12-02	17:30 - 18:30 hr	Claus H. Gravholt			



Further initiatives

Summer school of rare diseases (Erasmus+? Other resources/volunteers?)

Rare diseases academy

Patients involvement in educational activities

WP7 Clinical Practice Guidelines & Clinical Decision Support Tools

Olaf Dekkers, Anna Nordenström, Charlotte Gaasterland,
Jette Kristensen, Alessandro Lazzerini, Diana Vitali

Work package members

Olaf Dekkers **Adult chair**

Leiden University Medical Center (Leiden , Netherlands)



Anna Nordenström **Paediatric chair**

Karolinska University Hospital (Stockholm, Sweden)

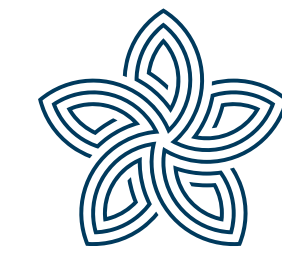


Jette Kristensen **ePAG representative**

Addison Foreningen Danmark (Denmark)



European
Reference
Network



Endo-ERN



Alessandro Lazzerini **ePAG representative**

Spanish Association of Congenital Adrenal Hyperplasia (CAH) (Spain)



Diana Vitali **ePAG representative**

SOD ITALIA – Italian organization for septo optic dysplasia and other neuroendocrine disorders (Roma, Italy)

New member!



Dr. Charlotte Gaasterland
Guideline methodologist
LUMC, department of Epidemiology

3rd Endo-ERN CPG: Transition (MTG6)

- Chairs: Nienke Biermasz (adults), Evangelia Charmandari (pediatric)
- Talent conference in February to align with all initiatives around transition
- Working group almost complete

Next CPG topic

- WP7 will ask all MTGs for theme suggestions
- WP7 will comment on the feasibility of the topics from a methodological point of view
- These topics plus comments will be discussed with the Steering Committee, who will then make a decision
- Is this a procedure that you agree with?

Standard Operating Procedures for the development process, methodology, and endorsement of CPGs

- SOP on guideline process & methodology is drafted
- SOP on endorsement is still in development
- No clear strategy in other ERNs – we are currently building a network with other ERN methodologists to discuss this issue



MTG specific CDSTs (Clinical Decision Support Tools)

Information for Individuals on Glucocorticoid (Steroid) Therapy



This patient leaflet is based on the European Society of Endocrinology (ESE) and Endocrine Society (ES) Joint Clinical Guideline on the diagnosis and management of glucocorticoid-induced adrenal insufficiency. It has been written by an international panel of experts who were involved in the development of the Guideline. The Joint Guideline is designed to help clinicians manage patients who have, or are at risk of developing, glucocorticoid-induced adrenal insufficiency. You can read the guideline in the *European Journal of Endocrinology* (2024) and the *Journal of Clinical Endocrinology and Metabolism* (2024).

For discussion:
Lay versions, how
and what format?



WP8 & WP9 Activities for Ukraine

Alberto Pereira, Adult Chair, Endo-ERN

Capacity building and best practice sharing for Ukraine (WP8)

Objectives: **Capacity building and best practice sharing with Ukraine** is the active engagement of physicians in Ukraine in the same manner as their European counterparts.

To this end we invite Ukrainian physicians to express their interest by completing this [survey](#). We also invite Endo-ERN network representatives that have existing relationships with Ukrainian physicians to share this page with their contacts.

WP9 – the use of CPMS 2.0 for Ukrainian health care providers: *Presented in WP4*



Any Other Business



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