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MTG7 / HCPs meeting

Date: January 16th, 2024

Time: 2.00 – 3.00 pm CET

Olaf Hiort, Luca Persani, Hedi Claahsen , Arlene Smythe, Manuela Brosamle, Chris Breen

MTG7 Chairs





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Introduction



Olaf Hiort





Hedi Claahsen

A warm welcome to new MTG7 Pediatric Chair Hedi Claahsen!

Plan/provide notice of meetings for next 12 months

- At least one more meeting online with MTG7 HCPs in Q3 or Q4. Give preference in the chat for:
- 1 meeting or more than ^{W0}
- o Q3 or Q4

WP specific contact persons

- Luca Persani announced he would also be stepping down as adult chair before the end of the year
- Option taken to have meeting in Q4

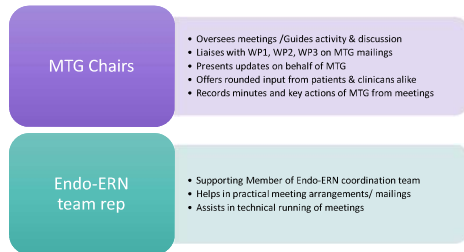
Slide 2

W(0 can assign chairs to each WP or recruit from this meeting
White, E.K. (Emily); 2024-01-12T15:43:56.565

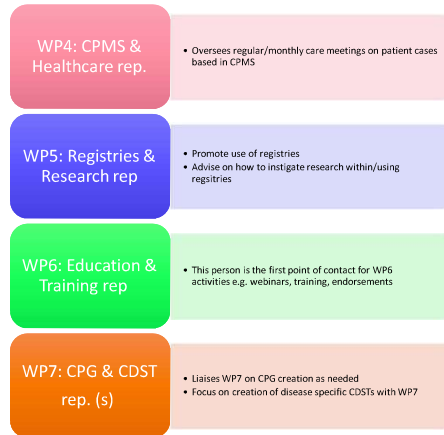
MTG Organisation/ Role Template



MTG Chairs



WP Representatives





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WP1: Management & Coordination

Information:

- Klinefelter as a new condition within ENDO ERN MTG7

Discussion

- Proposed topics for educational session GA meeting April 2024
 - Genital surgery in dsd infants and children: European restrictions
 - Evaluation of children with DSD
 - Gonadal tumours
- Suggestion to use mentimeter as a tool for interactive session [Interactive presentation software - Mentimeter](#)

- Suggestion was made to circulate Q&A to gather topic suggestions



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WP2: Communication & Dissemination

- Using correct logos, templates for Endo-ERN
- New publications/ patient information to be endorsed/updated/disseminated

Information

- Handbook of Endocrinology and Metabolism** (Editors: Luca PERSANI, Olaf HIORT, Mario MAGGI, Alberto M. PEREIRA) has just been published
- Update from Manuela about pat informatiob
- Update about survey nomenclature (Manuela)

- In addition to listed, the survey submitted by Andrea Isidori & Giovanna Mantovani has been disseminated to members for response
 - Survey link: <https://www.surveymonkey.com/survey/d/K2E1A9H2A9E4J6D6X>
 - Title: “High-grade aneuploidies (HGAs) of sex chromosomes with male phenotype (e.g., 48, XXYY; 48, XXXY; 49, XXXXY syndromes)”.
- Request to add Pubertal Induction CPG to our MTG7 website section
 - <https://endo-ern.eu/publication/pubertal-induction-and-transition-to-adult-sex-hormone-replacement-in-patients-with-congenital-pituitary-or-gonadal-reproductive-hormone-deficiency-an-endo-ern-clinical-practice-guideline/>

EndoCompass Research Roadmap Project



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The project is planned to provide as **final deliverables**:

1. A detailed research roadmap for different areas of endocrine research, that will be published as the Roadmap academic journal paper
2. A research and health policy summary derived from the Roadmap paper, outlining to policy and funding stakeholders the most important areas of endocrinology where research investments will provide the highest societal returns
3. An online communication and dissemination platform for respective target audiences



Roadmap deliverables information flow

*Discussion -
Involvement of
the ENDO ERN in this
process*

This is an ESE & ESPE initiative to roadmap Endocrine Research Priorities

- Several of our members are involved in this project and it will soon become an active resource Endo-ERN will promote and apply to our Network research endeavours



WP3: Continuous Monitoring / Evaluation

Ensure that HCP members are entering data into e-REC for the continuous monitoring process.

Information

- Update EuRRECA registry by MTG7 involved centres (update from Emily)
- Annual **Continuous Monitoring** exercise to be completed by Endo-ERN HCPs (Full Member and Affiliated Partners) for 2023 data will run from **1st January until 29th February 2024**

Discussion:

- How to improve participation?

The link to the website [Continuous Monitoring Programme 2024 - Endo-ERN](#)

- Queries to e.k.white@amsterdamumc.nl

- Next Q&A = **February 9th , 13:00-14:00 CET**





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WP4: CPMS updates

Regular meeting dates review for next meetings

- Any cases for upcoming meetings?
- Need help – contact helpdesk

Information

- Monthly CPMS MTG7 meeting first Friday of every months at 2.00 pm. Does this time work?
 - Emily, please give an update in numbers of cases for every session.

Discussion:

- Is it useful to appoint a chair for every month to share responsibilities?
- Should we plan join meetings with other ERNS? For example Urogen for the discussion of surgery/pathology etc

Suggestion to use CPMS monthly slots for clinical care/medical discussion , not just single case basis or immediate treatment/diagnosis need

- Martine Cools will lead a discussion on a previous case in CPMS **Friday 2nd Feb. at 14:00 – 15:00**, concerning Controversy around genital surgery based on her paper
- [Working towards convergence of the clinical management of differences of sex development/intersex conditions and the human rights framework: A case study - Cools - Clinical Endocrinology - Wiley Online Library](#)



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WP5: Registries

Any issues or barriers to using the affiliated registries aka. [EuREB](#) (EuRECa & EuRR-Bone)?

Information:

- Gender incongruence condition specific module in EuRECa announced in December 2023

Discussion

- Should we think about other condition specific modules?
 - This will committed time and people to oversee it



A new Condition Specific Module will soon become available on Gender Incongruence will soon be available to report in. Please report in the meantime in the [Core Registry](#)/ get permission to do so in your institution



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WP6: Education & Training

- Plan and schedule webinars for the next 12 months
- Each MTG is to host at least 3 webinars per year and include ePAGs.
- Endorsed events & training updates of interest

Information:

- [Planned Webinars](#)
 - Gonadal function CAH (Claahsen, Brosamle)
 - Adult care CAH (Reisch)

Discussion:

- other suggestions for topics to be covered?
- Should we try to organize 1 webinar for MTG7 per month = 1 webinar per HCP representative?

Webinar's schedule – suggestion to try and organize a webinar per month along the same lines as the monthly CPMS meeting

- To suggest topics please contact our [MTG7 chairs](#) or communications manager Aimee
- To have events, k webinars, education, training endorsed by the network see here [Endorsement - Endo-ERN](#)



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**WP7: Updates
local guidelines,
update treatment
options**

Information

- Gender incongruence in TG adolescence ESPE guideline

Discussion:

- Other guidelines to develop?



In addition:

- In terms of promotion, it qualifies for endorsement, a webinar that should include patient perspective and addition to the guides at our website
- There is a Turner's Syndrome guideline coming out soon

A request was made to have a webinar on the different guideline types, what is possible and most appropriate for rare disease – can be brought to WP7 chairs during Steering committee discussions



**Any other business/ideas from your
HCP/Organization ?**



