

MTG Genetic Disorders of Glucose and Insulin Homeostasis

Virtual Meeting - Notes

Meeting Date: 17 November 2023, 11:00 h – 12:00 h (CET)

MTG3 Chairs: Thomas Danne, Pietro Maffei,

ePAG representatives: Valeria Corradin, Nolwen LeFloch

Attendees: Charlotte van Beuzekom, Ingrida Stankutė, Corinne Vigouroux, Christina Kanaka-Gantenbein, Sebastian Kummer, Schroijsen, Marielle, Pietro Maffei, Julia v. Schnurbein, Miettinen Päivi, Thomas Danne, Thomas Bobbert, Kristina Casteel, Felix Reschke, Zdeněk Šumník, Angela Galler, Peter Kühnen, Ann Mertens, Guido Di Dalmazi, Luisa De Sanctis, Anne Rochtus, Agnieszka Szypowska, Barbara Piccini, Roque Cardona-Hernandez, Gun Forsander, Maude Beckers, Katharina Klee

Meeting objectives

Follow-up on the work that is in progress within the MTG and WPs.

Action items:

- **CPMS:** register here: <http://cpms.ern-net.eu>
- **CPMS:** enroll a patient and schedule a case discussion!
- **Endo-ERN General Assembly:** 23-24. April 2024 in Milan, Italy
- **WPs:** Webinars, Journal digests, and Educational material is requested, see below.

Discussion / Conclusions:

1. WP1 Management & Coordination

- Registries Symposium on 22. April 2024 in Milan, Italy
- Endo-ERN General Assembly on 23-24. April 2024 in Milan, Italy

2. WP2 Communication & Dissemination

- Using correct logos, templates for Endo-ERN
- New publications/patient information to be endorsed/updated/disseminated
- It would be great if you come up with suggestions for review papers on your particularly area of interest that we can show that the MTG three is alive and well also in terms of publications. And if you're interested, just contact us and suggest something and we'll try to figure out how this can be then done.
- Corinne Vigouroux suggested a joint initiative for an European recommendation on diagnosis and management of lipodystrophy -> Pietro Maffei explained that there is a policy to manage this in order to have a guideline or a consensus under the endorsement of the Endo ERN, see Endo-ERN website, contact Perreia!
- Thomas Danne: we should put it on the agenda for our next year's program and make sure that everybody of MTG3 is included who wants to participate
- Julia v. Schnurbein suggested to check with the ECLIP registry to make sure that the work is not done twice. There currently 590 patients in the registry and 17th centuries, so it is quite large, but they would love to include all centers from Europe especially ERN centers. So if anyone is interested in joining ECLIP registry, reach out to Julia, to Corinne or just have a look at the ECLIP webpage.

3. WP3 Continuous Monitoring/Evaluation

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

4. WP4 Healthcare and CPMS

- Use the CPMS!
- based on a lot of comments on the difficulty to use the system, the European Commission has built on the second version, CPMS 2.0, and it will be launched soon.
- also if you don't have cases yourself to upload, it's also important to register yourself as an expert.
- MTG three has scheduled a recurring meeting, which is every month, the last Wednesday at 1:30 pm, so the next one is November 29th. Kristina Casteels points out, that Wednesday afternoon is difficult for some centers because of consultations in the afternoon.

5. WP5 Registries

- Any issues or barriers to using the affiliated registries?
- avoid overlap of the data and keep when possible the main data in just one single registry
- [Registries \(WP5\) - Endo-ERN](#)
- [Startseite - EuRRECa und EuRR-Bone \(eureb.eu\)](#)
- enter the patients to eREC (EuRRECa) for new cases, and in other specific registries, for example the pediatric thyroid cancer registry after the consent of the family.

6. WP6 Training & Education

- 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 and training updates of interest
- Next webinars (date in progress):
 - Prof Vincent Marion: Strasbourg University (adipose tissue mechanisms of insulin resistance and diabetes)
 - Prof Robert Semple: Edinburgh University (new Alstrom syndrome mouse model)
- Please think about giving a webinar in 2024 in your field of expertise! Contact Thomas Danne / Pietro Maffei / Charlotte van Beuzekom to start the organization.

7. WP 7 CPG&CDST

- Updates local guidelines, update treatment options
- If you have the useful information for patients and families, so I invite you to share this information in your language! Can be put on the Endo ERN Website under the resources of MTG3 as a download link
- Transition is an important topic
- Get more patient groups involved in MTG3

8. Miscellaneous

- If you feel like, I would like to be more involved in the CPMS, the cases or in the registry or webinars or the clinical practice guidelines and you can function as a kind of contact person within the main thematic group, then in it will increase the well, the chance of keep the ball rolling. Let us know!