

MTG5 HCP meeting

Tuesday 21st April 2026
Athens, Greece

MTG chairs

- Susan O'Connell (Dublin, Ireland) - Paediatric Endocrinologist
- Charlotte Höybye (Stockholm, Sweden) - Adult Endocrinologist

E-PAGs

- Patricia Carl (Germany)
- Nathalie Ferard (France)



WP1 Management & Coordination

The members of MTG5

Other members are practicing endocrinologists with access to multi-disciplinary care.

We aim to

- Promote personalised medicine for ultra-rare obesity syndromes.
- Facilitate a forum for discussion of syndromes/complex conditions with growth issues.

WP2

Communication & Dissemination



- The members of MTG5 have published guidelines both nationally and internationally which are communicated to colleagues, national organizations, authorities, and other ERNs.
- No newly published guidelines since last General Assembly.
- First meeting held 31st March 2026 regarding Hypothalamic Obesity Guideline with MTG6.
- Paediatric Chair participated in the First Rare Endocrine Diseases Winter Fellow's School in Varna Bulgaria 28th Feb-3rd March.

Thanks to the fabulous Bulgaria team including Violeta and Kamelia!



WP3 Evaluation



- MTG5 promotes registration in e-Rec.
- Ethics Approval and Data Protection approval for the Core Registry has been granted at Dublin centre (January 2026).
- Recruitment of ENDO-ERN Care co-ordinator and data manager at Dublin centre.
- ERN-Leads at both institutions.

Progress!

WP4 Healthcare & CPMS



- MTG5 CPMS case (April 2025).
- MTG CPMS case discussion pending (subject to DPO approval).
- We request members of MTG5 to submit 2 cases per year. Please contact chairs or Amsterdam office.
- Huge challenges of clinical work and administrative work associated with this activity.

WP5

Registries, data management & analysis



- Members of MTG5 register patients in the EuRREB.
 - In addition, we are part of the application for the Globe Registry for PWS and growth hormone deficiency.
 - Challenges for those using paper records versus Electronic Healthcare records.
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- ✓ In 2025 **48 Endo-ERN centres** reported in MTG5 – 428 new suspected and 854 new confirmed cases in e-REC (1282 in total).
 - ✓ **8 Endo-ERN centres** are contributing to the Core registry for MTG5: 119 cases in total (since 2019).
 - ✓ Condition-specific module (registry) for rare syndromic and non-syndromic obesity available since 2023.
 - ✓ Active working group for creating registry for Rohhad syndrome (since 2025).

WP6 Education & Training



Webinars	Dec 6, 2024 Monogenic obesity (including Bardet Biedl Syndrome, Prader Willi, Alstrom Syndrome), and GLP-1 agonists in PWS/Monogenic obesity. Julia von Schnurbein, Ulm, Germany Tony Goldston, London, UK E-Pag- Bernd Rosenbichler, Germany	Webinars	Feb 2026 An update on genetics and clinical management of tall stature. Lars Sävendahl
	Feb 10, 2025 Update SGA, GH treatment beyond childhood. Anita van Hoggen, The Netherlands		TBA 2026 Silver Russell and Temple Syndrome updates Irene Netchine
	October 20, 2025 An update on Primordial Dwarfism conditions. Andre Jackson, Edinburgh, UK	Training	No clinical exchanges since September 2024 (Ireland-Malta)

WP7

Clinical Practice Guidelines & Clinical Decision Support Tools



- Paediatric lead member attended TALENT Congress in Rome Italy, Feb 2025 and 2026 and is a member of the ESE-ESPE Transition project in rare diseases and participated in Endo-ERN Survey on Transition of Care.

“Mapping Transition of Care for Rare Endocrine Conditions: Findings from a Cross-Sectional Survey by the Endo-ERN ToC Working Group” under review.

- We are involved in the hypothalamic obesity guideline with MTG6.
- We are all working on local institutional guideline development and updates in relation to adrenal insufficiency and dynamic function testing.
- Call for research projects: FIRENDO x ENDO-ERN collaboration funding available.

<https://www.firendo.fr/en/call-for-research-projects-europe-2025>



WP8/9

Capacity building and best practice sharing for Ukraine



- Capacity building and best practice sharing with Ukraine is the active engagement of physicians in Ukraine in the same manner as their European counterparts.
- Ukrainian physicians are invited to express their interest by completing this [survey](#) (at Endo-ERN website)
- Any contacts with Ukrainian endocrinologists?
MTG5 has no contact with Ukrainian specialists.
- Endo-ERN network representatives that have existing relationships with Ukrainian physicians are invited to share this page with their contacts.

MTG5 – 2025 Stats

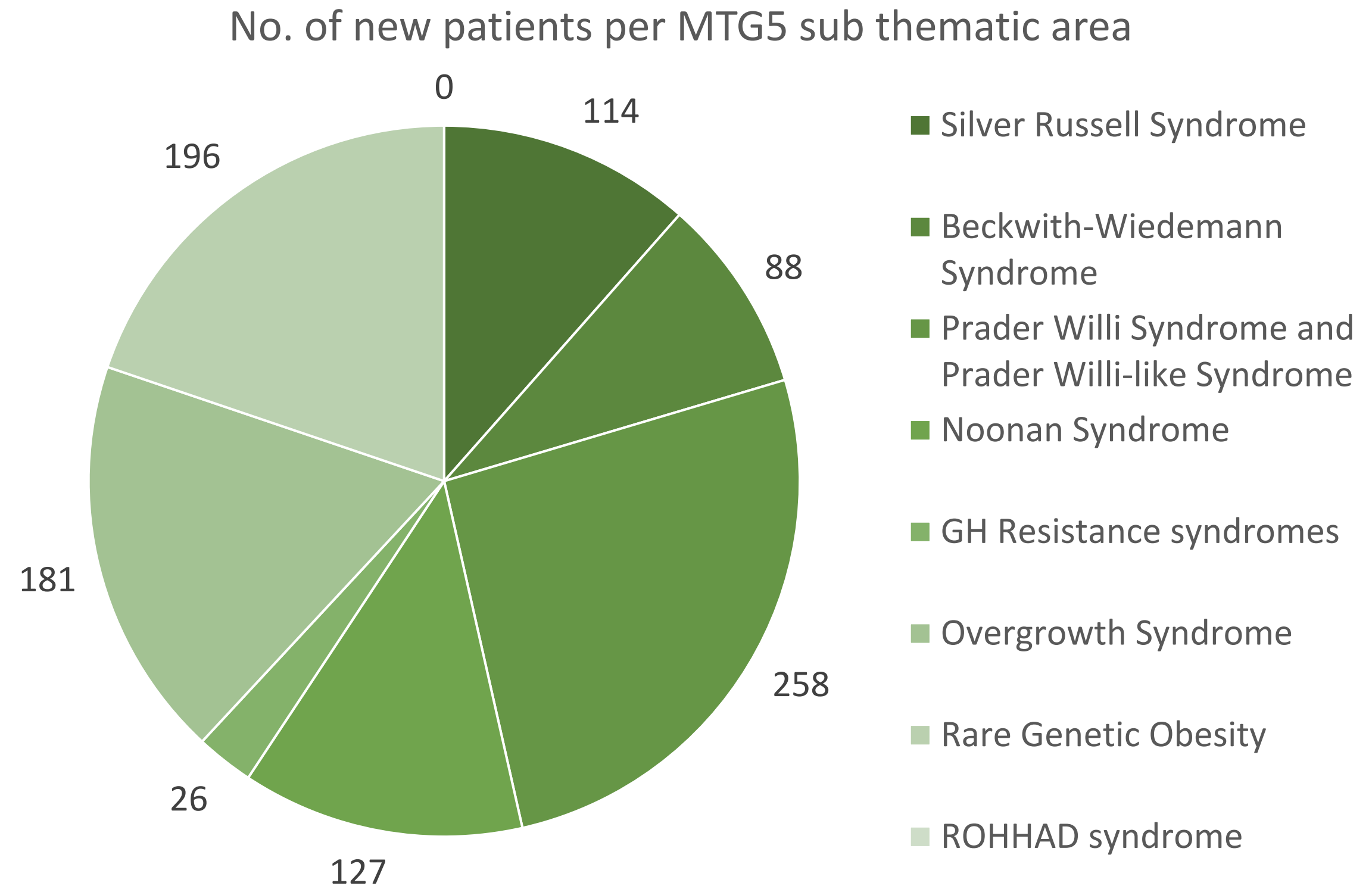
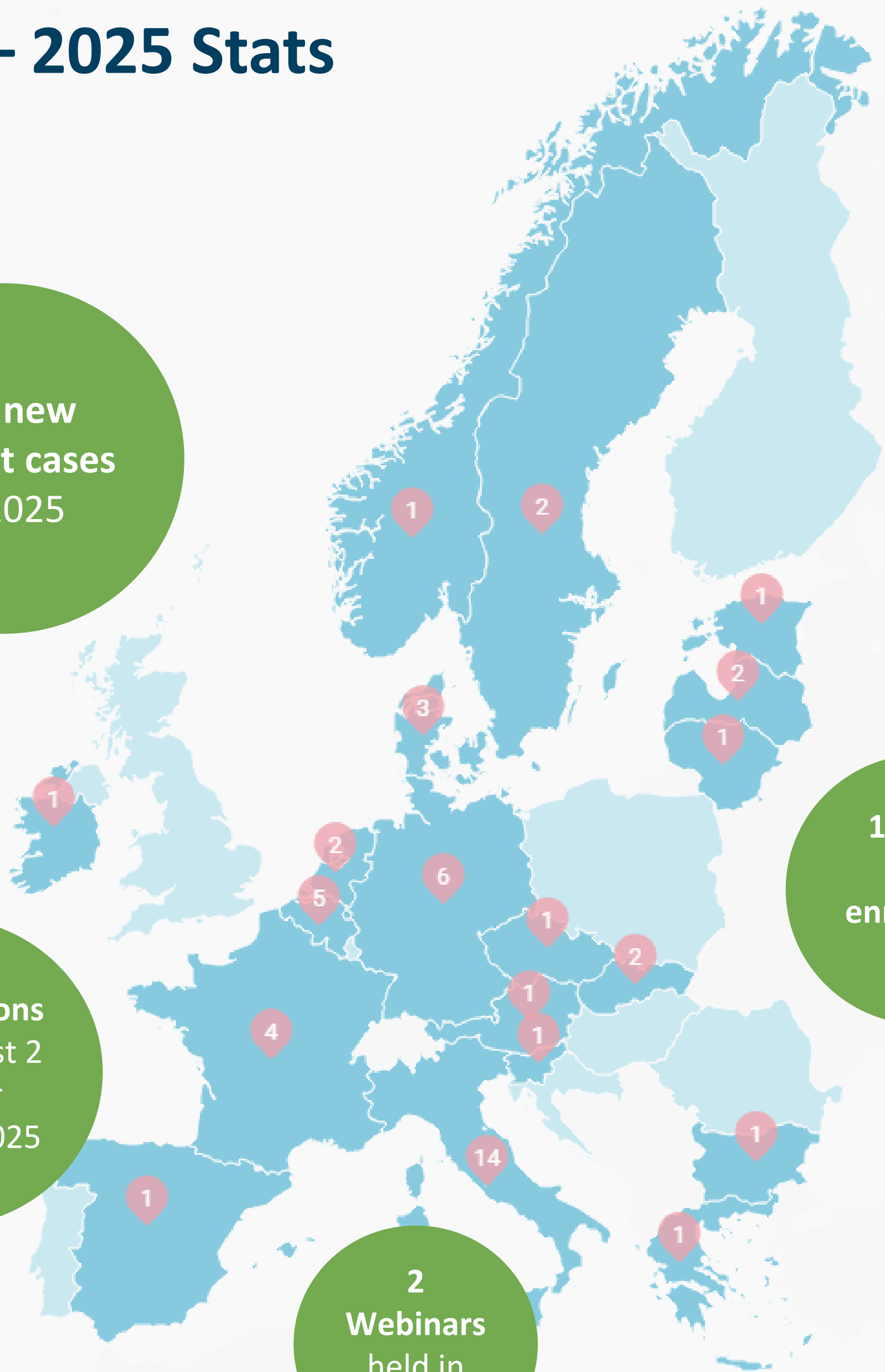


990 new patient cases in 2025

4 publications with at least 2 member states in 2025

2 Webinars held in 2025

1 CPMS case enrolled in 2025



Ideas for new MTG5 activities?

