

Adrenal MTG1

MTG1 chairs: Svetlana Lajic, Nicole Reisch, Manuela Brösamle, Giorgio Dal Maso, Alessandro Lazzerini, Zuzana Smith, Marc Büdenbender

Athens April 20.4.2025

Introduction

- Svetlana Lajic, Pediatric chair MTG1, Karolinska university hospital, Stockholm and Sahlgrenska university hospital, Gothenburg
- Nicole Reisch, Adult chair MTG1, LMU University Hospital, Munich
- ePAGS:
Manuela Brösamle, Germany
Giorgio del Maso, Italy
Alessandro Lazzerini, Spain
Zuzana Smith, Slovakia
Marc Büdenbender, Germany

Work package 1 Management & Coordination

- HCP MTG1 meetings:
- Approx. every 2 months, 1st Tuesday @15.00
- To be scheduled.

Work package 2

Communication & Dissemination

Use the EndoERN logos, templates when you organise events endorsed by Endo-ERN.

New publications/patient information to be endorsed/updated/disseminated:

- **Carlomagno F**, Spaziani M, Gaasterland CM, Lajic S, Reisch N, Neumann U, Grasemann C, Kassi E, Ubertini G, Reschke F, Maffei P, Verrijn Stuart A, O'Connell SM, Giavoli C, Fintini D, Charmandari E, Biermasz NR, Iotova V, Claahsen-van der Grinten HL, Stochholm K, Craiu D, Badea AI, Kyrilli A, Le Roux E, Neggers S, Döhnert U, Isidori AM. Mapping transition of care for rare endocrine conditions: findings from a cross-sectional survey by the Endo-ERN ToC Working Group. *Endocr Connect*. 2026 Apr 15;15(4):e250798. doi: 10.1530/EC-25-0798. PMID: 41961009.
- **Tabarin A**, Espiard S, Deutschbein T, Amar L, Vezzossi D, Di Dalmazi G, Reznik Y, Young J, Desailoud R, Goichot B, Drui D, Assié G, Lefebvre H, Mai K, Castinetti F, Laboureau S, Terzolo M, Ferriere A, Georget A, Frison E, Vantyghem MC, Fassnacht M, Gosse P; CHIRACIC Collaborators. Surgery for the treatment of arterial hypertension in patients with unilateral adrenal incidentalomas and mild autonomous cortisol secretion (CHIRACIC): a multicentre, open-label, superiority randomised controlled trial. *Lancet Diabetes Endocrinol*. 2025 Jul;13(7):580-590. doi: 10.1016/S2213-8587(25)00062-2. Epub 2025 May 12. Erratum in: *Lancet Diabetes Endocrinol*. 2025 Aug;13(8):e11. doi: 10.1016/S2213-8587(25)00195-0. PMID: 40373786.
- **Mondin A**, Barbot M, Ceccato F, Pereira AM, Angelousi A, Elenkova A, Zilaitiene B, Schalin-Jäntti C, De Herdt C, Kanaka-Gantenbein C, Maiter D, Gatto F, Johannsson G, Stochholm K, Bugalho MJ, Detomas M, Reincke M, Toumba M, Giordano R, Tsagarakis S, Webb SM, Biermasz NR, Scaroni C. European survey on metabolic and cardiovascular risk in Cushing syndrome. *J Endocrinol Invest*. 2025 Nov;48(11):2657-2670. doi: 10.1007/s40618-025-02663-9. Epub 2025 Sep 6. PMID: 40913679; PMCID: PMC12602549.
- **Krysiak R**, Claahsen-van der Grinten HL, Reisch N, Touraine P, Falhammar H. Cardiometabolic Aspects of Congenital Adrenal Hyperplasia. *Endocr Rev*. 2025 Jan 10;46(1):80-148.
- **Van't Westeinde A**, Karlsson L, Messina V, Wallensteen L, Brösamle M, Dal Maso G, Lazzerini A, Kristensen J, Kwast D, Tschaidse L, Auer MK, Nowotny HF, Persani L, Reisch N, Lajic S. An update on the long-term outcomes of prenatal dexamethasone treatment in congenital adrenal hyperplasia. *Endocr Connect*. 2023 Mar 15;12(4):e220400
- **Falhammar H**, Lajic S, Nordenström A. Recent advances in treatments for congenital adrenal hyperplasia. *Nat Rev Endocrinol*. 2025 Apr;21(4):197-198
- **Cherenko M**, Appelman-Dijkstra NM, Priego Zurita AL, Biermasz NR, Dekkers OM, Klok FA, Reisch N, Aulinas A, Biagetti B, Cannavo S, Canu L, Detomas M, Devuyst F, Falhammar H, Feelders RA, Ferrau F, Gatto F, Grasselli C, van Houten P, Hoybye C, Isidori AM, Kyrilli A, Loli P, Maiter D, Nowak E, Pivonello R, Ragnarsson O, Steenaard RV, Unger N, van de Ven A, Webb SM, Yeste D, Ahmed SF, Pereira AM. Venous thromboembolism in Cushing syndrome: results from an EuRRECa and Endo-ERN survey. *Endocr Connect*. 2024 May 7;13(6):e240046..

Work package 3

Continuous Monitoring/Evaluation

- Ensure that HCP members are entering data into e-REC for the continuous monitoring process.
- Data entered each month, newly diagnosed cases.
- Contact coordination office if you have questions.
- E-REC:

TOTAL: Adrenal Pediatric 970, Adult 5459 cases

2024 entered new cases 1534 (AI 424, CAH 288, ACC 153, adrenal Cushing 287)

Work package 4

Continuous Monitoring/Evaluation



- Scheduled **CPMS sessions**, responsible center:
MTG1 sessions **first Tuesday of every other month at 3 pm**
Schedule HCPs
- **Contact the coordinating office** for assistance with setting up the session.
- **Patient informed consent** form in local language to be downloaded from the CPMS web page.
- Virtual CPMS consultation or written statements available.

Work package 5 Registries

- Any issues or barriers to using the affiliated registries?
 - I-CAH
 - ENSAT
 - eREC

Work package 6 Training & Education



Webinars:

- *Please come up with suggestions, speakers and topics!*
- *Coordinate webinars with others MTGs such as MTG4/**Genetic Endocrine Tumour Syndromes**.*
- Coordinating office will assist in setting up the webinars.

Endorsed events and training updates:

- Rome Feb 2026 – Transition in endocrine diseases, disease management – 8th TALENT conference.

Work package 7

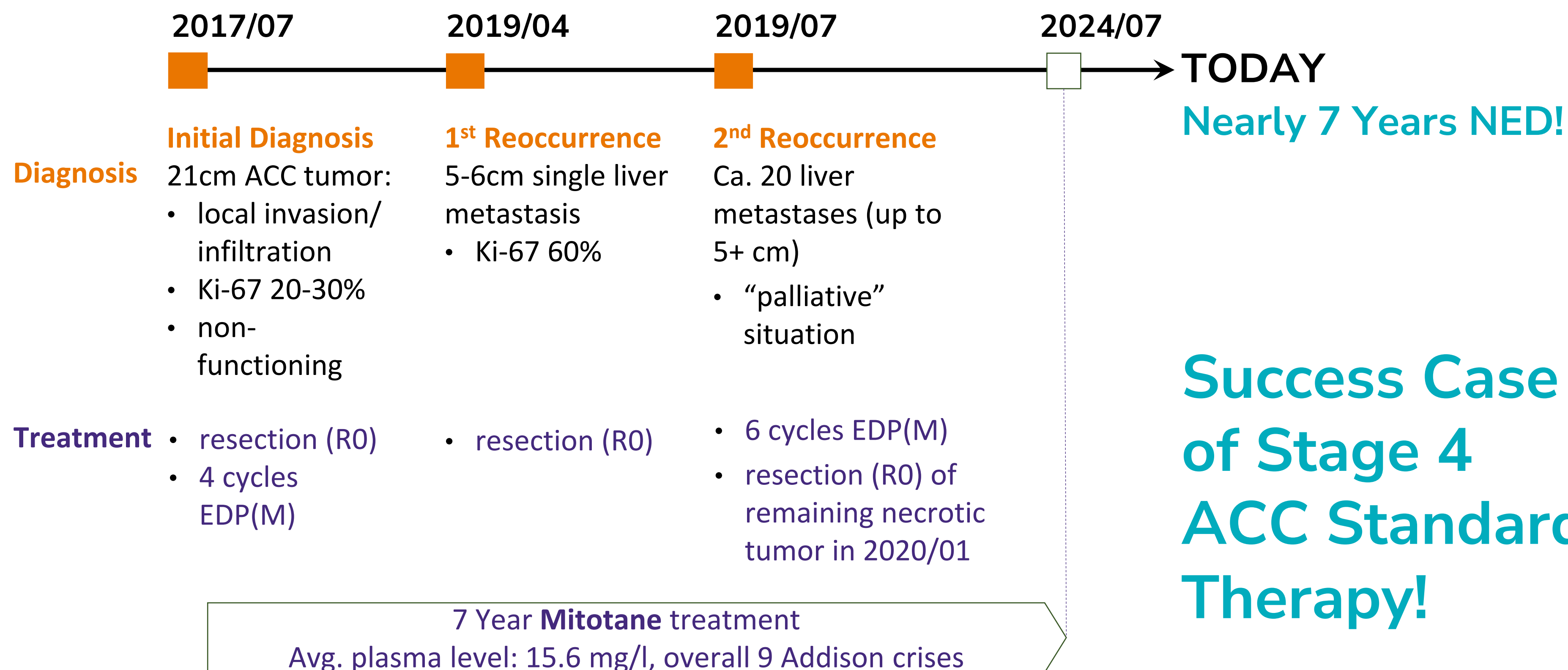
- Updates local guidelines, updates treatment options:

Local guidelines that could be put on the home page?

In local language.

Can be translated via the automatic translation system and cross-checked.

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of Stage 4
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Any other business (AOB)



Work in progress:

2026:

- 8 th TALENT meeting 2026 in Rome, Feb 11-13: Transition Adolescence and Young Adults – Endocrine disease management (represented by N Reisch).
- RED Winter school in Varna, Bulgaria on rare endocrine diseases 28 Feb – 3 March, 2026 (represented by S Lajic).

- JARDIN project – Care pathway for CAH with MTG7.
- Participation in the transversal working group on Transition.

New projects and ideas?

The I-CAH registry could be used for some of these initiatives.

New projects:

Prenatal treatment of CAH – evaluation of cases in Europe via web-based protocols. Contact Svetlana Lajic Svetlana.Lajic@ki.se

PREDICT international trial on prenatal Dex in CAH
uta.neumann@charite.de; Nicole. reisch@med.uni-muenchen.de



European
Reference
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