

ESPE & ESE Rare Disease Committees - Collaboration

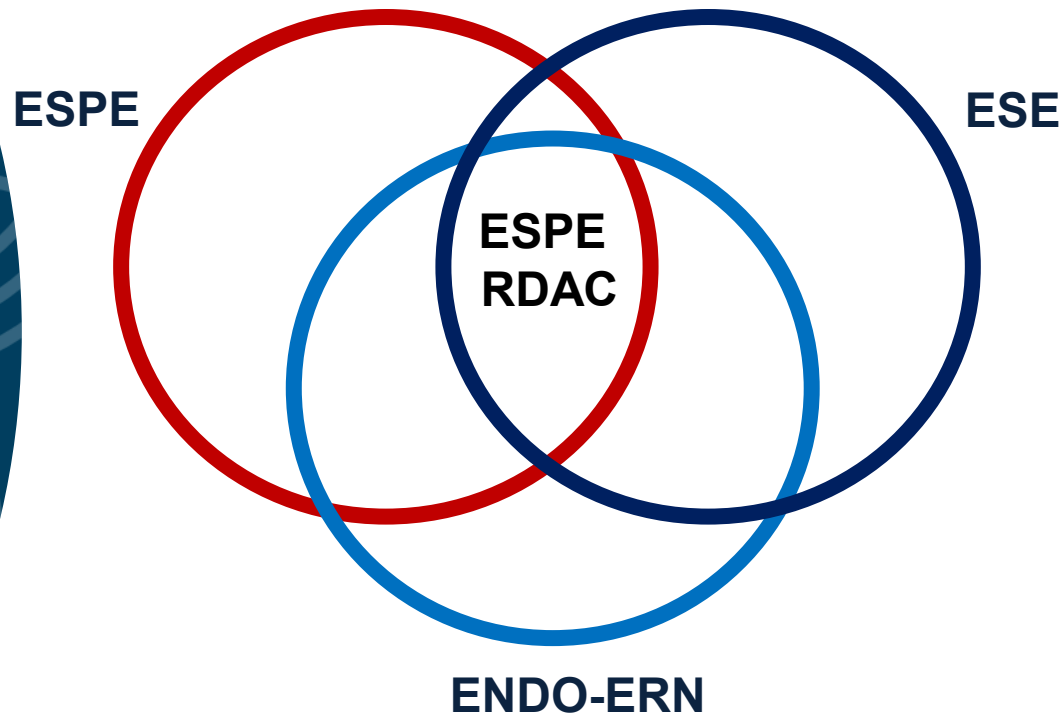
Evangelia Charmandari, ESPE RD Advisory Committee

Elena Valassi, ESE RD Committee



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ESPE Rare Disease Advisory Committee (RDAC)



- The main role of RDAC is to advise the ESPE Council about important aspects pertaining to rare endocrine diseases in children and adolescents
- ESPE RDAC represents a Committee with a vision and role similar to the ESE Rare Disease Committee (RDC)
- Lies at the core of the interface of ESPE, ENDO-ERN and ESE

ESPE RDAC and ETC

Rare Ped Endo Disease Schools



10th ASPED ESPE Endocrine Academy



**RARE ENDOCRINE DISEASE
WINTER SCHOOL VARNA**

RED Winter School

28.02 - 3.03.2026

- RDAC integrated rare disorders into ESPE educational activities
- The first Rare Ped Endo Disease Summit was organized by ESPE and ASPED (July, 2025)
- It was followed by RED Winter School (March 2026)
- ESPE Summer School will dedicate one day to rare disorders
- YES group organizes activities in promoting rare disease awareness, including webinars

ESPE RDAC and CPC



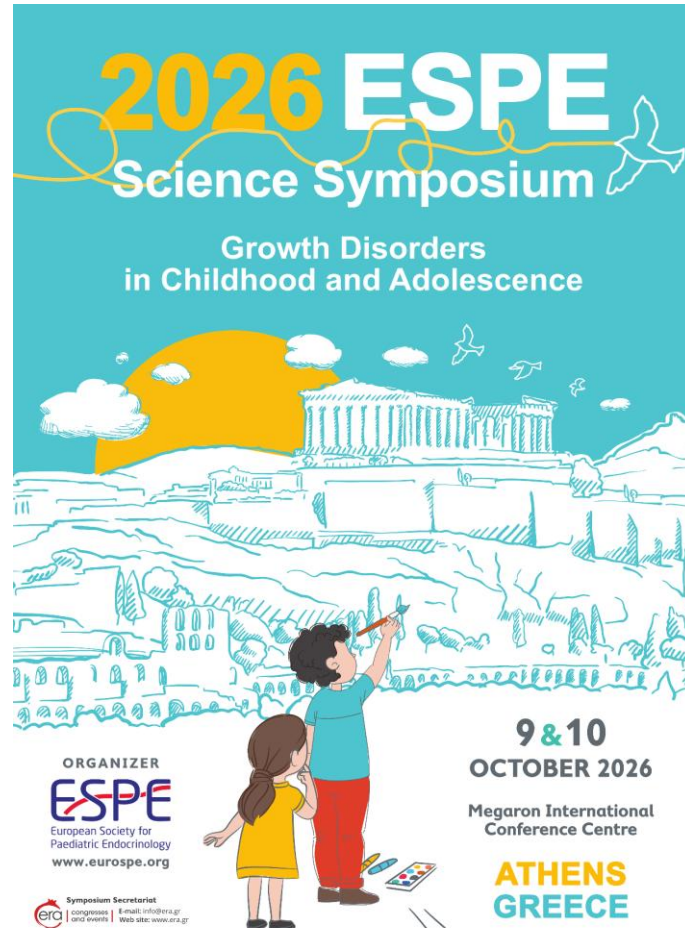
- **International guideline on genetic testing of children with short stature.** Dauber A et al. Eur J Endocrinol. 2026; 194(2):R17-R36.
- **Diagnostic yield of genetic testing in children with short stature: A systematic review.** Scalco RC et al. Eur J Endocrinol. 2026; 194(2):S15-S24.
- **European Society for Paediatric Endocrinology (ESPE) and European Society of Endocrinology (ESE) joint clinical practice guidance for healthcare transition from paediatric to adult endocrine care.** Le Roux E et al. Eur J Endocrinol. 2026; 194(2):G1-G10.
- **EndoCompass project.** Eur J Endocrinol. 2025; 193 Suppl. 2.

ESPE RDAC and CPC



- **Central Precocious Puberty: An Endocrine Society Clinical Practice Guideline.** Latronico AC et al. J Clin Endocrinol Metab (in press)
- **Endocrine testing in children with obesity** – To be submitted, under the coordination of Erica van den Akker
- **International Guidelines for Congenital Adrenal Hyperplasia** – In progress, under the coordination of Nils Krone
- **International consensus on the diagnosis and management of endocrine complications of sickle cell disease** – In progress, under the coordination of Abdelhadi Habeb
- **Survey on Secondary Adrenal Insufficiency** – In progress

ESPE RDAC and POC / SC



- RDAC proposed to include one session dedicated to rare diseases in the scientific program of the ESPE Annual Meeting, which would be separate from ENDO-ERN session
- RDAC proposed to the ESPE SC that rare disease related topics will be selected for the ESPE Science Symposia held every 2 years
- The 6th ESPE Science Symposium is on 'Growth Disorders in Childhood and Adolescence' and will be held on October 9-10, 2026 at the Megaron International Conference Center in Athens, Greece

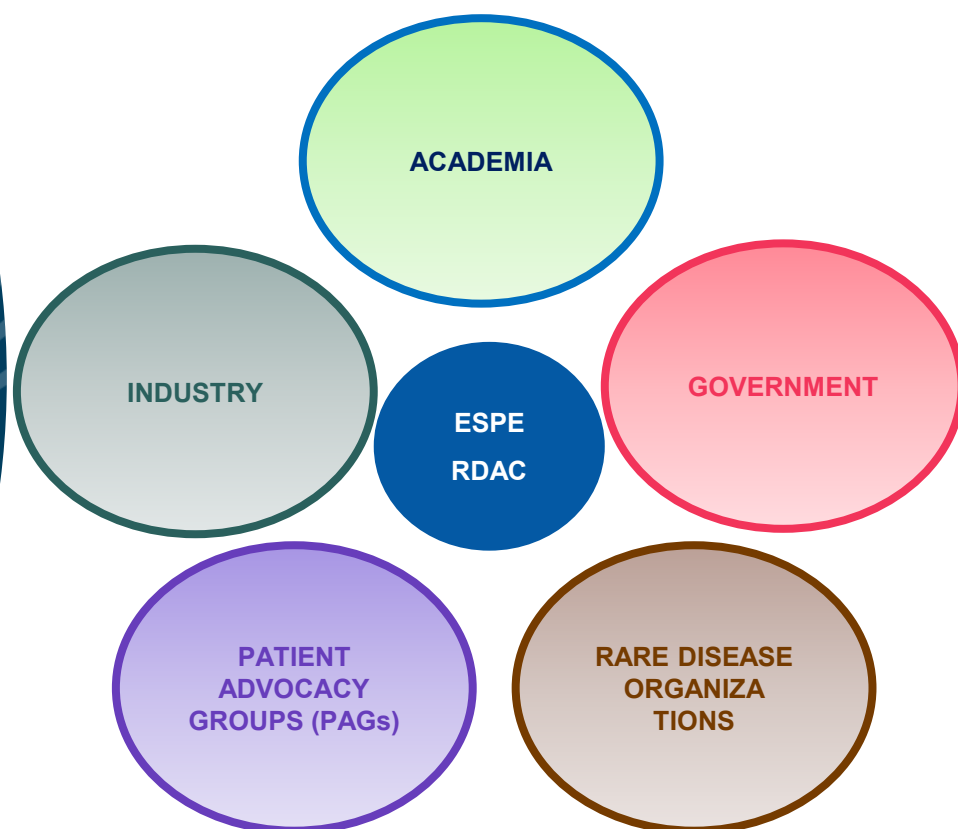
ESPE RDAC and Endo-ERN



Webinars

- **Novel monitoring tools to detect chronic over- or undertreatment in children with CAH** (June 3, 2025)
- **Cushing's disease and Cushing's syndrome** (June 10, 2025)
- **Congenital combined pituitary hormone deficiency in Europe** (June 25, 2025)
- **Corticotroph tumors and Postoperative Quality of Life – Perspectives from a Neurosurgeon, an Endocrinologist and a Patient** (March 2026)

ESPE Rare Disease Advisory Committee (RDAC)



- Continued investment in rare disease research and development may provide better treatment options for patients with these diseases and ultimately offer cure
- Patient engagement in research ensures that the needs and perspectives of patients are considered in the development of new therapies
- Collaboration between academia, industry, government, and patient advocacy groups may help accelerate the development of new therapies, increase awareness and understanding of rare diseases, and improve patient outcomes

ESPE Rare Disease Advisory Committee (RDAC)



Thank you!!!

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Thank you!!!

