

TO

Professor Alberto Pereira, Coordinator of Endo-ERN, Adult Chair

Professor Olaf Hiort, Deputy Coordinator of Endo-ERN, Pediatric Chair

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September 17, 2024

Dear Professor Pereira,

Dear Professor Hiort,

RE: **ESPE Rare Disease Advisory Committee (RDAC)**

We are writing to you on behalf of the members of the Rare Disease Advisory Committee (RDAC) of the European Society for Paediatric Endocrinology (ESPE) to inform you and all Endo-ERN members about the remit and the role of RDAC, which is a sister-Committee to the Rare Disease Committee (RDC) of the European Society of Endocrinology (ESE).

The main role of RDAC is to advise the ESPE Council about important aspects pertaining to rare endocrine diseases in children and adolescents.

More specifically, the role of the RDAC is to:

- Review the current activities of ESPE (committee by committee) in the field of rare diseases and identify opportunities for development among ESPE committees, as well as other organizations involved in the field of rare diseases
- Provide recommendations to ESPE Council on the following:
 - Fostering collaborations with all ERNs, including Endo-ERN and ERN-BOND
 - Focusing on opportunities for knowledge exchange in Europe, as well as beyond Europe, which would include activities, such as webinars, guideline development, research projects
 - Collaboration with international rare disease patient organizations
 - The role and remit of ESPE representatives in ERNs and other rare disease organizations
 - Improving awareness and engaging researchers and clinicians with rare-disease registries. Specifically, the RDAC should advise how ESPE should act as a stakeholder in the EuRRECa project
 - Promoting rare disease research through its existing activities
 - Acting as an advocate for rare diseases by raising public awareness of rare diseases through collaboration with European institutions and other relevant national and international organizations
 - Engaging with industry that have a focus on rare diseases
 - Engaging with other professional scientific societies, especially ESE
- Advise ESPE Council on its long-term strategy for maintaining a focus on rare diseases

COUNCIL MEMBERS:

President
Anita Hokken-Koelega
Rotterdam, Netherlands

Chair of Strategic and Finance Committee
Rasa Verkauskiene
Paris, Lithuania

Annual Meeting Host
Mehul Dattani
London, UK

Annual Meeting Host-elect
Anders Juul
Copenhagen, Denmark

Chair of Programme Organising Committee
Peter Kühnen
Berlin, Germany

Chair of Clinical Practice Committee
Stefano Cianfarani
Rome, Italy

Chair of Corporate Liaison Board
Mohamad Maghnie
Genova, Italy

Chair of Education and Training Committee
Rasha Hamza
Cairo, Egypt

Chair of Science Committee
Martine Cools
Ghent, Belgium

Chair of Communications Committee
Indi Banerjee
Manchester, UK

The full list of the Committee members are as follows:

Evangelia Charmandari | Chair

Marek Niedziela | Co-Chair

Anita Hokken-Koelega | ESPE President (Ex Officio)

Olaf Hiort | Endo-ERN Representative

Nicole Reisch | ESE Representative

Ola Nilsson | Programme Organising Committee (POC) Representative

Anne-Simone Parent | Science Committee (SC) Representative

Abdelhadi Habeb | Education and Training (ETC) Representative

Stefano Cianfarani | Clinical Practice Committee (CPC) Representative

Amit Pandey | Non-Clinical Scientist

Asmahane Ladjouze | Representative outside of Europe

Amanda Helm | ESPE Corporate Relations Manager (Ex Officio)

Emma Jenkins | ESPE Senior Operating Officer (Ex Officio)

We would be most grateful if you could kindly forward this letter to the Chairs and Patient Representatives of all Endo-ERN Main Thematic Groups (MTGs), as well as to all members of the Endo-ERN General Assembly in order to inform them about the ESPE Rare Disease Advisory Committee and to explore and encourage opportunities for further collaborations.

We truly hope that our clinical and scientific collaboration, with ESPE and ESE as sisters societies, as well as with the Endo-ERN, will be extremely successful and will benefit both patients and health care professionals significantly.

Please, let us know if you need any further information.

We look forward to hearing from you!

Thank you very much in advance!

With best wishes,

Yours sincerely,

On behalf of the ESPE Rare Disease Advisory Committee (RDAC)

Evangelia Charmandari | Chair

Marek Niedziela | Co-Chair