

## **A European Reference Network for Rare Endocrine Conditions – An Update from the European Society for Paediatric Endocrinology (ESPE) and the European Society of Endocrinology (ESE)**

The call for the first [European Reference Networks](#) (ERNs) is anticipated in March. The objectives of an ERN are to share expertise, improve diagnosis, educate and train patients, care providers and doctors, produce guidelines, build databases, develop connections to facilitate research, perform clinical trials on rare endocrine conditions, disseminate results to patients, health care providers (HCPs) and public health organisations, and link up with other ERNs.

ESPE Council and the ESE Executive committee view a European Reference Network for Rare Endocrine Conditions as vital for improving the care of people with the diverse range of rare conditions that present in childhood and are managed by the members of the two societies. There is currently a great deal of discussion about how an Endocrine ERN might be formed and the processes required to achieve this. ESPE and ESE are willing to support and facilitate these processes, and we would therefore like to outline our participation to date and going forward.

An ERN is formed from Endocrine centres approved in their own countries as European Reference Centres (ERCs) according to standard criteria. Approved ERCs are then eligible to join an ERN. A bid to form an ERN must come from a single HCP with a named co-ordinator along with all the HCPs of Centres that will make up the ERN.

ESPE and ESE firmly hold the view that an ENDO ERN should cater for the full range of rare endocrine conditions from birth through adulthood, and they will commit to providing support for this. From a pragmatic aspect, it is likely that the initial ERN bid will be shaped around networks that are already in place and have a strong track-record of collaboration at a European level. In time, this platform will allow the development of multiple domains under a single over-arching umbrella.

Professor Olaf Hiort [ESPE] (Universitätsklinikum Schleswig-Holstein, Luebeck, Germany) has offered to take a lead role in the development of an ENDO ERN, subject to the approval of his local health care provider (HCP). Olaf Hiort is a very experienced paediatric endocrinologist with particular expertise in endocrine conditions that affect sex development and metabolic bone health. He is currently leading on the EU COST action DSDnet and is on the management committee of another EU Cost action on imprinting disorders. In addition, he has been a long-standing representative of Germany and paediatric endocrinology on the EU Committee of Experts on Rare Diseases (EUCERD).

Professor Alberto Pereira [ESE] (Leiden University Medical Center, the Netherlands) has also offered to take a lead role in the development of an ENDO-ERN, subject to the approval of his local HCP, and he has obtained full institutional support to hire the necessary means to develop an ERN application. Alberto Pereira holds the Chair of Endocrinology in Leiden, and has founded and chairs a Reference center which is based on multi-disciplinary, patient-centered care and research. He is the Dutch representative of the Reference centers with national endorsement for rare endocrine

diseases. At the European level, he has enabled and established innovative multidisciplinary collaborative networks and he is president-elect of the European Neuro Endocrine Association (ENEA).

Both Prof. Hiort and Prof. Pereira are arranging meetings to discuss a proposed ENDO ERN with ESPE and ESE members. Both are looking at how an ENDO ERN can include a broad range of Rare Diseases through the life course, that are managed by Health Care Providers eligible to join the network. ESPE and ESE will be working to ensure that a 'joined-up' ENDO ERN is created.

As such, the exact format of the proposed ERN is under discussion but it is likely to have a Co-ordinator and possibly a deputy (to ensure paediatric and adult aspects are covered), a Management board, a Steering committee and a number of Working Groups to address the Objectives outlined above. It is anticipated that the Steering committee will consist of stakeholders including patient associations and professional societies such as ESPE, ESE and other Societies with interests in this field. The management board will consist of representatives from the HCPs and they will oversee the work of the ERN.

ESPE and ESE members who practice within an EU member state and are interested in being involved in a collaborative European paediatric/adult endocrinology network should enquire of their local HCP and national authorities to make sure their centre meets the requirements to be endorsed as a European Reference Centre (ERC). As indicated above, these HCP-approved ERCs will form the backbone of the ERN. A list of the eligible countries and national endorsement contacts are listed below. For those who are not eligible, collaborative partnership is possible through the scientific advisory boards or involvement in the working groups.

ESPE and ESE members who are interested in an ENDO ERN are advised to contact Faisal Ahmed ([Faisal.Ahmed@glasgow.ac.uk](mailto:Faisal.Ahmed@glasgow.ac.uk)), ESPE Council member and Science Committee Chair, or Jerome Bertherat ([jerome.bertherat@aphp.fr](mailto:jerome.bertherat@aphp.fr)), ESE Executive Committee member and Clinical Committee Chair.

18<sup>th</sup> February 2016

**List of eligible countries:**

<b>Board of Member States</b>	
Austria	Italy
Belgium	Latvia
Bulgaria	Lithuania
Croatia	Luxembourg
Cyprus	Malta
Czech Republic	Netherlands
Denmark	Poland
Estonia	Portugal
Finland	Romania
France	Slovakia
Germany	Slovenia
Greece	Spain
Hungary	Sweden
Ireland	United Kingdom

<b>EEA Countries</b>
Iceland
Liechtenstein
Norway

<b>Members of the ERN Board of Member States</b>				
The list of Members of the Board is currently being updated				
Country	Last name	First name	Organisation	E-mail
Austria	VOIGTLÄNDER	Till	Austrian Health Institute	<a href="mailto:till.voigtlaender@goeg.at">till.voigtlaender@goeg.at</a>
Belgium	VAN DEN BOGAERT	Saskia	FPS Health, Food Chain Safety and Environment	<a href="mailto:saskia.vandenbogaert@health.belgium.be">saskia.vandenbogaert@health.belgium.be</a>
Bulgaria	KOVACHEVA	Irina	Ministry of Health	<a href="mailto:ikovacheva@mh.government.bg">ikovacheva@mh.government.bg</a>
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Denmark	CHRISTIANSEN	Niels Moth	Danish Health Authority	<a href="mailto:NMC@SST.DK">NMC@SST.DK</a>
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