

An Update on the Application for 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)

Following the launch of the call for the European Reference Network (ERN) on 16th March 2016, members of the short-life ERN task force of ESPE and ESE (Figure 1) met in Boston on the 1st April 2016 to prepare the groundwork for developing a joint application for an ERN for rare endocrine conditions (EndoERN).

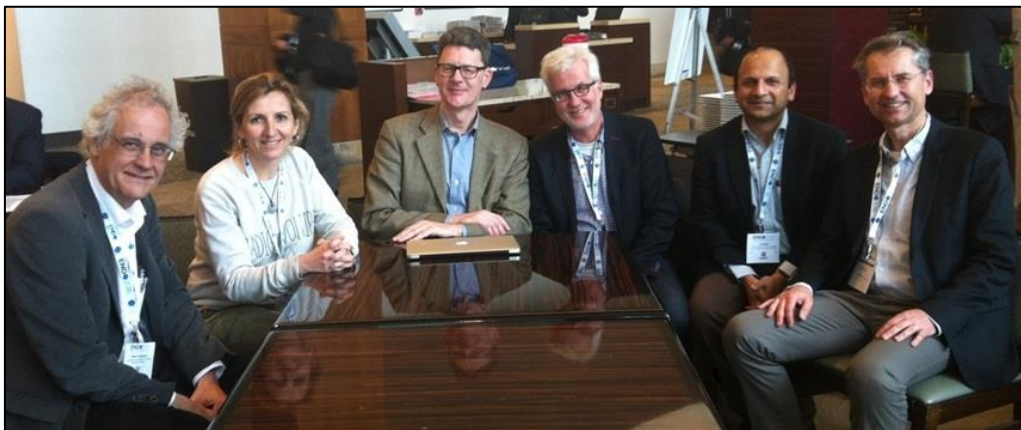


Figure 1. Meeting of the ERN task force of ESPE and ESE. From left to right: Georg Brabant (ESE), Agnès Linglart (ESPE), Alberto Pereira (ESE), Olaf Hiort (ESPE), Faisal Ahmed (ESPE), Jérôme Bertherat (ESE).

The preparation of this application will be led jointly by Professors Alberto Pereira and Olaf Hiort as Coordinator and Deputy Coordinator, respectively. The detailed governance structure of the proposed ERN will develop over the next few weeks and will include representation from paediatric and adult endocrinology in its steering committee and management board.

The application will be primarily shaped around endocrine networks that are already in place and have a strong track record of collaboration at a European level. Currently, the main themes of these domains have been identified as rare conditions affecting (i) adrenals, (ii) calcium and phosphate homeostasis, (iii) glucose & insulin homeostasis, (iv) growth, (v) pituitary, (vi) sex development and maturation, (vii) thyroid, and (viii) genetic endocrine tumour syndromes that are not covered in the above categories. A separate application is also being prepared for an ERN which will focus primarily on rare conditions affecting bone including skeletal dysplasia, metabolic bone diseases and skeletal fragility and those interested in this bone ERN should contact Agnes Linglart (agnes.linglart@aphp.fr).

The thematic groups have been chosen on existing networks and will be led by a chair and a co-chair; besides being experts in their area, these leads have to bring added value to the ERN and will contribute to the writing of the application. Their thematic groups will consist of nationally approved health care partners (HCP) with a track record in the care of people with the rare conditions within that theme; each thematic group will consist of a minimum of 5 member states (MS) and preferably more. ESE and ESPE are working with EndoERN to identify suitable leads.



The full ERN application has to be submitted by 21st June 2016. However the schedule is very tight and the application forms as well as the national endorsement will have to be provided by each HCP much in advance. Those members who are interested in any aspect of the EndoERN are advised to contact Olaf Hiort (olaf.hiort@uksh.de) or Alberto Pereira (RareEndoERN@lumc.nl).

Communication will take place via a SharePoint website. Those who have already expressed an interest will receive an invite this week to join this website as well as a user-manual, detailing how to log-on and how to use the system. Please check your spam folder to ensure you do not miss this invitation. If you have not yet expressed your interest but want to join EndoERN, just let us know at RareEndoERN@lumc.nl.