



Endo-ERN

European Reference Network
on Rare Endocrine Conditions

Newsletter April 2017
about the first General Assembly



114 participants of 70 Health Care Providers

The European Reference Networks for rare and complex diseases (ERNs) were officially installed on 9 March 2017 at the 3rd conference on Rare diseases in Vilnius, Lithuania. The first General Assembly (GA) of the European Reference Network on Rare Endocrine Conditions (Endo-ERN) was held on Monday 27 March 2017, in Leiden, The Netherlands. The purpose of this first annual meeting was first to inform and update all members and other stakeholders on the mission, structure, and governance of Endo-ERN, and subsequently to approve the current application by the members via voting in order to be officially operational, and finally to attain contribution of each Health Care Provider (HCP) to the pre-defined deliverables, as specified in the grant application.

A total of 114 participants attended the GA. Of all 71 Health Care Providers part of the network, 70 were represented; other attendees included Endo-ERN steering committee and advisory board members (ESPE and ESE representatives and national coordinators), ePAG patient representatives, and others that had specifically expressed interest to attend the meeting (observers).

After official opening by the dean of Leiden University Medical Center, the first session of the day informed the members on the mission, structure and Governance of Endo-ERN (*Alberto Pereira*, coordinator and adult chair), on opportunities, pitfalls, priorities, and dissemination of expertise (*Olaf Hiort*, deputy-coordinator and paediatric chair), and on patient's involvement, concerns, and ambitions (*Jette Kristensen*, Endo-ERN ePAG patient representative, Denmark).



Olaf Hiort



Alberto Pereira



Endo-ERN

After the coffee break, the second session focused on different aspects of ICT and E-Health. Faisal Ahmed (WP Chair E-Health & ICT) discussed strategic considerations and presented data on a recently performed survey on current participation to registries and on the recently submitted EU application for registries for rare endocrine conditions.

The new logo and Endo-ERN website (public domains) were presented by Alberto Pereira, and Herman Brand (Head of unit Information Systems, DG Health&Food) subsequently focused on the EU IT-platform ERN (secured Patient Management system) that will enable to share patient data and virtual consultations. Mark Thompson (LUMC, the Netherlands) informed us on FAIR (Findable, Accessible, Interoperable, Reusable) data management.

In order to optimise dissemination of expertise Jérôme Bertherat (national coordinator France, and Endo-ERN ESE representative) presented the French experience with national networks for rare diseases, and how these enable to connect European reference centers with national- and regional centers. This dissemination of expertise is of key importance for all ERNs.

The plenary voting concluded the morning session. The members were asked to accept or reject the Endo-ERN application and its board terms of reference as it was presented and had been approved by the EU Commission. All HCPs were allowed to vote and voting was done via mobile devices; the results were depicted directly on the big screen. With overwhelming support (All HCP members agreed) Endo-ERN became officially operational.

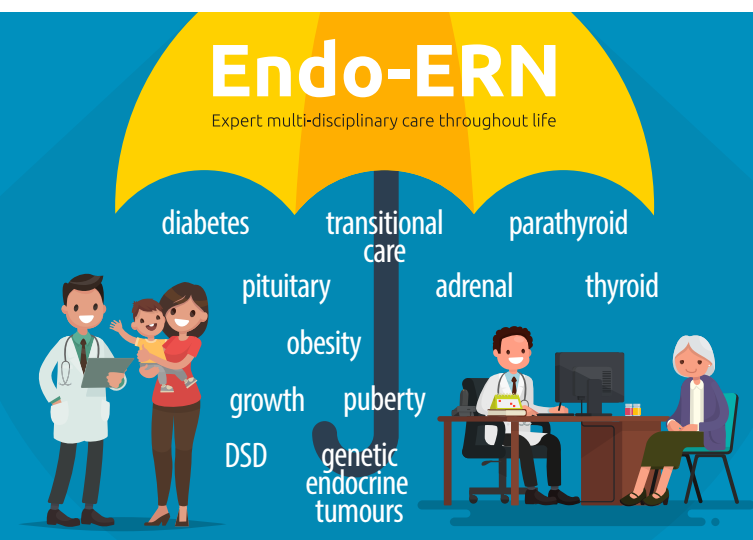




Endo-ERN

After lunch, all Work Packages and Main Thematic Group Chairs presented their respective WPs and MTGs with a 4 minute pitch. These plenary pitches explained the goals through the pre-defined deliverables, specifically for the first year. This was followed by speed dating sessions around the respective posters to inform the members, increase awareness, exchange ideas, and finally to make concrete plans how to meet the deliverables for the first Endo-ERN year.

The day was concluded by a plenary round up and take home plans by all chairs, and symbolically closed by the host with a Dutch gift of Endo-ERN: an Endo-ERN Umbrella for all participants!



European
Commission



European
Reference
Networks

Endo-ERN Coordinating Center:
Leiden University Medical Center
The Netherlands
info@endo-ern.eu
www.endo-ern.eu

Endo-ERN Newsletter April 2017

