



After only 5 months of being operational the European Reference Network on rare Endocrine conditions (Endo-ERN) has made a lot of progress. These months have been directed at deciding a specific strategy for active recruitment of engaged members. This was initiated at the first General Assembly in March 2017 by the sign up lists of interested members in work packages and this has continued since then. The Main Thematic Group (MTG) chairs and the Work Package (WP) chairs have steered the identification of leads to complete the first year deliverables.

Active recruitment of engaged members and more

At the ECE meeting in Lisbon, Portugal, on the 21st of May, the Steering committee had its second meeting to discuss and align the progress of activities. Currently, structured working groups consisting of two experts from each MTG, the WP chairs, and ePAGS are being formed. These working groups will lead the way to complete the first year deliverables.

Gap analysis

Included in the first year deliverables is the gap analysis of available expertise within all Endo-ERN countries, including consulting the Endo-ERN members and national coordinators, in order to facilitate optimal dissemination. This also includes the evaluation of the number of Health Care Providers (HCPs) per country and their participation to specific MTGs. This will also advise us on the present gaps of expertise and how we will be able to address potential new applications in consultation with a national coordinator or HCP members.



New call for new members

The call for new full members to join existing ERNs will be announced in December, open in March 2018 and close in June 2018. More HCPs joining existing ERNs ensures the opportunity for a more geographically balanced coverage of expertise.



EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES

Share. Care. Cure.



It is possible to join an ERN as an affiliated member. The Board of Member States gave this statement about affiliated members: ERN applicants will be encouraged to liaise with National authorities, where appropriate, to identify a list of potential affiliated partners, for collaboration with the network from the outset. However, for all potential affiliated partners (those identified before the ERN approval or those that will come up after the ERN approval) the affiliation process will take place only after the approval of the ERN by the Board and following the formal designation of each of the affiliated partners by its national authorities. [Read the full paper here.](#)

Any updates regarding the upcoming call will be posted on the Endo-ERN website.

Website and Social Media

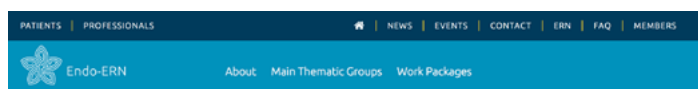
The development of a specific dissemination strategy is the first of deliverables in the first year. This includes an active Endo-ERN public website (www.endo-ern.eu). This website features information on ERNs, the structure of Endo-ERN, cross-border healthcare, and other information relevant for patients, members and other healthcare experts.



Endo-ERN

European Reference Network on Rare Endocrine Conditions

Endo-ERN's mission is to reduce and ultimately abolish inequalities in care for patients with rare endocrine disorders in Europe, through facilitating knowledge sharing and facilitating related healthcare and research.



EU public consultation survey on digital single market

Posted on July 24th, 2017

The EU public consultation survey on transformation health and care in the digital single market is open until the 12th of October 2017. The purpose of this consultation is to define the need and scope of policy measures that will promote digital innovation in improving people's health, and address systemic challenges to health and care systems.



The consultation collects views on:

- Cross-border access to and management of personal health data;
- A joint European exploitation of resources (digital infrastructure, data capacity), to accelerate research and to advance prevention, treatment and personalised medicine;
- Measures for widespread uptake of digital innovation, supporting

Recent News

General Assembly 2018

The second Endo-ERN general assembly will be held in Lübeck, Germany on Thursday the 22nd of February, 2018! Last year the LUMC in Leiden hosted [...]

Future call

The first ERNs were launched in March 2017, involving more than 900 highly-specialised healthcare units from over 300 hospitals in 26 Member States. The 24 [...]

Endo-ERN is on Twitter

Endo-ERN is now on Twitter! The Twitter page for Endo-ERN is online. Follow the page to stay updated on news regarding ERNs, Endo-ERN, Paediatric [...]

[Video reportages European Reference Networks](#)

The website also contains a continuously updated news and event section. All contact information regarding the Endo-ERN coordination center can also be found on the website, and all are encouraged to contact us with any and all questions.

We can also be contacted via twitter! www.twitter.com/rareendoern An Endo-ERN twitter was established in June and is actively engaged in the online endocrine community. Follow us for more information on the progress Endo-ERN is making and to stay updated on all related news.



New ePAGs

Awaiting definite approval from Eurordis, Endo-ERN will very soon welcome five new ePAGS to the team. Specific criteria to become an Endo-ERN ePAG member have been established in close collaboration with current ePAGS. After a formal application and instalment via EURORDIS Carole Delorme from France, Patricia Carl from Germany, Elisabetta Freo from Italy, Manuela Brösamle from Germany, and Marika Porrey from The Netherlands will be joining the current ePAGs. Each ePAG is specialised in one of the 8 Main Thematic Groups and will contribute to different Work Packages.

EUSurvey digital single market

An EU survey on public consultation on transformation health and care in the digital single market will be open until the 12th of October 2017. The purpose of this consultation is to define the need and scope of policy measures that will promote digital innovation in improving people's health, and address systemic challenges to health and care systems.

The consultation collects views on: Cross-border access to and management of personal health data; A joint European exploitation of resources (digital infrastructure, data capacity), to accelerate research and to advance prevention, treatment and personalised medicine; Measures for widespread uptake of digital innovation, supporting citizen feedback and interaction between patients and health care providers. Digital data sharing is of vital importance to all cross-border healthcare initiatives, such as Endo-ERN.

[The link to the survey can be found on the Endo-ERN website.](#)

Clinical Patient Management System

The European Commission has created a Clinical Patient Management System (CPMS) which will enable to diagnose and treat patients in all ERNs based on: a single business process (with flexibility, e.g. distribution of roles); a single set of common data elements (with flexibility e.g. free-text, upload attachments). CPMS will grant easy access to patient file transfer between HCPs and ERNs and it will make it possible for multiple ERN specialists to contribute to the assessment of the patient file through comments, formal contribution, and reviews of outcome document. Once this system is operational we will inform you in due course.

Board of Coordinators meeting

Following the first meeting of the ERN-BC on April 26, 2017, where the Board of Coordinators was formalized, the discussion on the creation of Working Groups, and a discussion on the governance of the ERN-BC was initiated, a second meeting was held on June 21st in Brussels to discuss the following agenda:

1. Governance of the ERN-BC and nomination of the leading structure;
2. Organisation of ERN Working groups
3. Discussion on the CEF call INEA;
4. Discussion on the EJP;
5. Next call for Members.

Governance of the ERN-BC

The ERN-BC agreed to identify a Chair and Vice-Chair of the ERN Coordinators Group. Both Chair and Vice-Chairs are elected among the 24 ERNs coordinators for a mandate of one year. The role is merely of coordination. No deci-



Maurizio Scarpa

sions can be taken without prior consultation and agreement with all ERN Coordinators. Decisions are taken by consensus. Maurizio Scarpa, chair of MetabERN, was nominated unanimously to be the first Elected Chairman of the ERN-BC. Maurizio Scarpa accepted the mandate and did act as Chair for the meeting. The mandate will last one year, starting June 21st, 2017.

Organisation of ERN Working groups

On the occasion of the last ERN-BC meeting (April 26, 2017), the setup of the 7 working groups was agreed upon unanimously on the following topics:

1. IT and data sharing;
2. Research;
3. Knowledge generation: Training, education, capacity building; guidelines development;
4. Data protection, ethics, informed consent;
5. Cross-border healthcare;
6. Brexit;
7. Monitoring, assessment and quality improvement.

Endo-ERN (with its chairs Alberto Pereira and Olaf Hiort) co-chairs the Working Group Research and as such represents ERNs in the research pillar 3.

CEF call

The regulation by the European parliament and of the council establishing the Connecting Europe Facility of 2013 determines the conditions,





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methods and procedures for providing Union financial assistance to trans-European networks in order to support projects of common interest in the sectors of transport, telecommunications and energy infrastructures and to exploit potential synergies between those sectors. It also establishes the breakdown of the resources to be made available under the multiannual financial framework for the years 2014-2020.

The INEA proposal will be a great opportunity to tune up the activity of ERNs on Patient virtual Counselling and others activities involving the IT platform which will be shortly made available by the EC. It was unanimously decided by the Coordinators to apply with similar proposals aimed at the hiring personnel able to introduce and manage the

new IT systems to support in the one hand implementation but also to support improvements and adaptations specific for each ERN. Thus a network of ERN-IT tool administrators will be created amongst ERNs able to optimize the application of the system for the daily activity of the ERN.

Coming up

The next steering committee meeting will be held on **October 9th, Leiden**, The Netherlands. Here the progress that has been made and the upcoming plans will be discussed.

The second General Assembly will be held on Thursday **February 22nd, in Lübeck**, Germany. More information regarding the programme will follow soon.

Erratum:

To avoid misinterpretations the following text on page 4 has been changed from "Endo-ERN will play a vital role in Working Group 2: Research, with chairs Alberto Pereira and Olaf Hiort leading pillar 3", to "Endo-ERN (with its chairs Alberto Pereira and Olaf Hiort) co-chairs the Working Group Research and as such represents ERNs in the research pillar 3."

