



***What have we done?** September has been a busy month for Endo-ERN and its members. The Endo-ERN coordinating center, together with Lübeck, Glasgow and Copenhagen, wrote a proposal for the CEF Telecom Call in order to receive funding for ICT support, new ePAGs joined Endo-ERN officially, and several meetings were held by Main Thematic Groups (MTGs) and Work Packages (WPs) in order to discuss the division of work and the completing of the first year objectives.*

### Connecting European Facility

On the 21<sup>st</sup> of September Endo-ERN applied for the 2017 CEF Telecom Call – eHealth (CEF-TC-2017-2). The Connecting European Facility launched in January 2014 and is a flagship funding programme of the Europe 2020 Strategy in the sectors of transport, energy and telecommunications. It contains a separate call for the transport sector, the energy sector, and the telecom sector.

Endo-ERN applied for the specific eHealth Digital Service infrastructure within the telecom call, which will facilitate the connection between members of ERNs by ensuring the adequate and efficient use of the ERN Core Services (Clinical Patient Management System and ERN Collaborative Platform).

This includes activities such as:

- Provision of IT technical support to ensure the appropriate use of the ERN Core Services
- Training necessary for the use of ERN Core Services
- Purchase of hardware and software necessary for the use of ERN Core Services



The first outcome of the proposal evaluation is expected to be announced by December 2017.

### New ePAGS

5 new ePAGs have joined the team. In September EURORDIS approved Carole Delorme from France, Patricia Carl from Germany, Elisabetta Freo from Italy, Manuela Brösamle from Germany, and Marika Porrey from The Netherlands as official Endo-ERN ePAGs. Endo-ERN now has 10 ePAGs in total, covering expertise throughout 6 Main Thematic Groups. If you are interested, or know someone interested in becoming an ePAG, [check out our website for the qualifications](#).



# Endo-ERN



Carole Delorme



Patricia Carl



Elisabetta Freo



Manuela Brösamle



Marika Porrey

## European Registries for Rare Endocrine Conditions

The call for proposals for Projects on Rare Disease Registries for approved ERNs was published by the EU Commission on December 21<sup>st</sup>, 2016 and Endo-ERN has just received approval. Endo-ERN covers an exceptionally large number of rare conditions across the age span. Whilst some conditions are covered in established international disease registries, there are several that are not. EuRRECa aims to ensure that Endo-ERN achieves its mission of driving up standards of clinical care and patient-centred research through maximizing participation in disease registries. The Grant approved by the EU will help Endo-ERN accomplish this aim.

This project will be led by *Prof. Faisal Ahmed* (Work Package e-Health & ICT chair) from the University of Glasgow, joined by 12 Endo-ERN members

### Partners:

- University of Glasgow, United Kingdom
- University of Lübeck, Germany
- Leiden University Medical Center, The Netherlands
- University of Ghent, Belgium
- Istituto Auxologico, Italy
- Assistance Publique, France
- Semmelweis University, Hungary
- Great Ormond Street Hospital for Children NHS Trust, United Kingdom
- Erasmus University, The Netherlands
- Ludwig-Maximilians-University, Germany
- Karolinska University Hospital, Sweden
- University Hospital Motol, Czech Republic
- Hannoversche Kinderanheilstalt, Germany



## Events

On **September 7<sup>th</sup>-9<sup>th</sup>** our chair, *Alberto Pereira*, attended the 5<sup>th</sup> ENEA workshop dedicated to “Hyperprolactinemia and other endocrine causes of infertility” in Saint-Petersburg, Russia. Here the 2017 Rolf Gaillard Prize in neuroendocrinology is awarded to *Prof. Albert Beckers* (middle). (*Prof. Pereira* on the left and the representative of the Gaillard family, *Olivier Gaillard* on the right).



On **September 14-17<sup>th</sup>** the *International meeting of Paediatric Endocrinology* took place in Washington DC, United States of America. This congress brought together the world's Paediatric Endocrinology Societies. Many of our Endo-ERN members were present here, including deputy-coordinator and paediatric chair *Olaf Hiort*.



## Upcoming events

- On the **9<sup>th</sup> of October** the Endo-ERN Steering Committee and Advisory Board will meet in Leiden, the Netherlands to discuss the current progress and upcoming tasks.
- On the **11<sup>th</sup> of October** *Alberto Pereira* will attend the ERN coordinators meeting in Brussels, Belgium to discuss the tasks of the work packages.
- On the **22<sup>nd</sup> of February** the 2<sup>nd</sup> Endo-ERN General Assembly will be held in Lübeck, Germany, to be attended by all Endo-ERN members. Here the progress of the first year will be reported to all attending HCPs and the objectives for the upcoming year will be discussed.