

EndoERN – a European Reference Network for Rare Endocrine Conditions

It is with great pleasure that we are able to announce today that an application to the European Commission to establish a European Reference Network for Rare Endocrine Disorders (EndoERN) has been successful.

The application, co-coordinated by Alberto Pereira and Olaf Hiort, was supported by the European Society of Endocrinology (ESE) and the European Society for Paediatric Endocrinology (ESPE). The network will be formed from more than 70 nationally recognised healthcare centres across Europe.



Figure 1. EndoERN Registries & ICT Workshop: Alberto Pereira presents the ERN structure during the EndoERN Registries and ICT Workshop held on 15 December 2016 in the Wolfson School of Medicine Building, University of Glasgow, UK.

With a focus on ensuring that high quality expertise in the treatment of rare diseases is provided as close to the patient as possible, these networks will work to share expertise, improve diagnosis, educate care providers, facilitate research and link up with other ERNs with the ultimate goal of improving patient care.

Upon hearing of the application’s successful outcome, Professor Alberto Pereira stated that, “The creation of these ERNs fulfils a long-felt desire. Patients’ associations kept on lobbying for it: care in case of rare diseases must become more accessible and information more transparent. In 2011 the EU passed a law stating that every patient suffering from a rare disease is entitled to the best treatment, even if the expertise is in a different country.”

EndoERN serves as an opportunity to advance the treatment of people with rare endocrine conditions while significantly improving the patient experience. With a strong base of collaboration and partnership, the network will span paediatric and adult care ensuring all patients are able to benefit and the lessons learnt will benefit the endocrine community in Europe and beyond.

Both ESE and ESPE remain committed to supporting the EndoERN in the future and look forward to the success it brings to the field of endocrinology.