

# EuRRECa Newsletter

## July 2018



**EuRRECa**  
European Registries For  
Rare Endocrine Conditions

EuRRECa (European Registries for Rare Endocrine Conditions) is supported by the EU Health Programme, the European Society for Paediatric Endocrinology (ESPE) and the European Society of Endocrinology (ESE). The project which is closely linked to the European Reference Network for Rare Endocrine Conditions (Endo-ERN) was launched in February 2018 and aims to support the needs of the wider endocrine community.

### Aim Of The Newsletter

The aim of the newsletter is to provide an update on recent activities. The newsletter will be issued twice a year at the end of January and July. You can subscribe to the newsletter at [eurreca.net/newsletter](http://eurreca.net/newsletter).

### EuRRECa In Brief

Specific aims of the EuRRECa project include:-

- e-REC: e-reporting programme of Rare Endocrine Conditions
- Develop a new Core Endocrine Registry that collects a core dataset for all rare endocrine conditions in Endo-ERN
- Incorporate core clinical outcomes in the Core Endocrine Registry
- Signpost participants to detailed, disease-specific registries that have been endorsed by EuRRECa
- Inform the development of new high-quality detailed disease registries

### The EuRRECa Website

Detailed information is available at the project's new website [eurreca.net](http://eurreca.net). You will find information on milestones, deliverables, the Work Packages and the Expert Working Groups that form the EuRRECa Project Group, the Independent Advisory Board, past and future events and also resources that are relevant for developing registries. So please visit the website and do let us know if you have any ideas of how it can be improved.

### EuRRECa At ESE & ESPE 2018

The EuRRECa team was present at ESE 2018 in Barcelona at a joint stand with Endo-ERN and it will be present at ESPE 2018 in Athens. EuRRECa will also be prominent in the main programme (FC14 and ERN1.5).

### Registries Kick off Meeting In Luxembourg

EuRRECa was present at the Rare Disease Registries Projects kick-off meeting in Luxembourg in April. The meeting, hosted by CHAFAE was attended by representatives from all 5 of the registries projects awarded funding from the EU's Health Programme to develop registries for rare conditions covered within the ERNs.



### e-REC

e-REC (e-Reporting Of Rare Endocrine Conditions) is an electronic reporting system which captures activity and allows for a better understanding of the occurrence of rare endocrine conditions. This system will allow Endo-ERN to objectively map the conditions, the expert centres and other related activity. The reporting platform has been undergoing a limited pilot which will be followed by a more extensive pilot from August 2018. Although e-REC is currently aimed at serving the needs of Endo-ERN, it is open to all endocrine health care professionals. To find out more or to participate, please visit [eurreca.net/e-rec](http://eurreca.net/e-rec).

### Core Data Elements For The Core Endocrine Registry

WP3 on Quality Assurance & Evaluation and WP6 on Registry Development met in July at a meeting hosted by Luca Persani to discuss the core data elements (CDE). A draft copy is now available on the EuRRECa website.



### Core Clinical Outcomes

Olaf Dekkers in WP4 has received valuable input from the EuRRECa Expert Working Groups. A preliminary list of condition specific clinical outcomes can now be explored for future inclusion into the Core Endocrine Registry.

### News From The Patient, Parents & Ethics WP

WP5 on Patient Parent & Ethics led by Martine Cools met in Ghent to develop a set of recommendations that can guide the development of registries for rare endocrine conditions. The draft recommendations will soon be available for open consultation.

### Recommendations On Rare Disease Registries

A group of experts, including members of EuRRECa, have recently published recommendations in the International Journal of Environmental Research & Public Health that can be used as a framework to guide the organizational and data quality of rare disease registries. These recommendations will guide the development of the toolkit that EuRRECa will use to support the quality of registries.

### Rare Disease Registries Workshop

The 6th International Summer School Rare Disease & Orphan Drug Registries, including a "Bring Your Own Data (BYOD)" to Link Rare Disease Registries session, will take place from September 10-14, 2018, at the Istituto Superiore di Sanità in Rome, Italy. The course has free registration but places are going fast. To find out more visit <http://old.iss.it/cnmr/?lang=1&id=2795&tipo=3>.

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