

# EuRRECa Newsletter

## July 2020

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.

### EuRRECa In Brief

Specific aims of EuRRECa include:-

- e-REC: e-reporting of Rare Endocrine Conditions
- Core Registry that collects core dataset for conditions covered by Endo-ERN and ERN-BOND
- Identify core outcomes for the Core Registry
- Promote high-quality detailed disease registries

### EuRRECa Annual Meetings

The second EuRRECa Annual Project Group Meeting took place as a webinar on Monday the 9<sup>th</sup> March 2020. The slides are available to project group members on the EuRRECa website. The 3<sup>rd</sup> annual meeting will take place in Verbania near Milan in March 2021 alongside the Endo-ERN General Assembly

### EuRRECa At ECRD & ESE

EuRRECa figured prominently at ECRD 2020 online meeting in May and will be present at eECE 2020 (5-9<sup>th</sup> Sep). The joint virtual stand with Endo-ERN is a platform for disseminating activities of both projects and affords a great opportunity for networking. There will also be a joint Endo-ERN, EuRRECa and EuRR-Bone symposium session.



### New Rare Endocrine Registries

Following the Rare Registries workshop in Glasgow in December 2019, a call was launched for applications to fund the development of rare condition registries. Grants have been awarded to consortiums led by Janiëlle van der Velden, Nijmegen for Turner Syndrome and Agnes Linglart, Paris for inactivating PTH/PTHrP signalling disorder (iPPSD).

### EuRR-Bone

The EuRRECa platforms are also being used by EuRR-Bone which supports ERN-BOND. The project is led by Natasha Appelman-Dijkstra, Leiden. For further info visit [www.eur-bone.com](http://www.eur-bone.com)

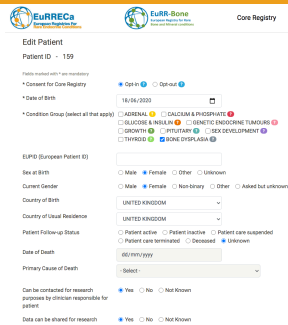


**EuRRECa**  
European Registries For  
Rare Endocrine Conditions

### e-REC

The platform for e-Reporting Of Rare Conditions (e-REC) has been extended to include rare Bone conditions included in the EuRR-Bone project. There is also a section to report COVID-19 cases in any rare endocrine or bone patients. To date there have been almost 5000 cases reported across all of the condition groups. Data are now available for interested parties to use for secondary studies and further surveys. For further information and to register for reporting, visit [eurreca.net/e-rec/](http://eurreca.net/e-rec/)

### Core Registry



The Core Registry is now hosting the EuRR-Bone registry with 80 specific Bone Dysplasia conditions to select from. There are currently over 100 patients registered across all condition groups. A report describing the Core Registry is available at [eurreca.net/reports](http://eurreca.net/reports).

### PhD Candidate Opportunity

EuRRECa is seeking a research fellow to be based in Leiden to study rare endocrine conditions through real world data collected in registry based European projects. To find out more visit the [EuRRECa homepage](http://EuRRECa homepage)

### Core Outcome Modules

A core clinical outcome module has been developed for Thyroid and is currently being piloted. New core outcome modules can be developed for any group of conditions. Contact [Jillian.Bryce@Glasgow.ac.uk](mailto:Jillian.Bryce@Glasgow.ac.uk) for details.

### Ethics & Governance

Revised Patient Information Sheets and Consent Forms for the Core Registry have recently received ethics approval. The new consent will also facilitate the exchange of data in other EuRRECa-approved registries. These can be downloaded now in English and Dutch. We invite offers of help to translate these documents, including the e-REC public information sheet, into other languages. [eurreca.net/information-sheets/](http://eurreca.net/information-sheets/).

### ESE Rare Disease Committee

The Rare Disease Committee of the European Society of Endocrinology had its inaugural meeting in April and one of its first tasks was to explore the use of EuRRECa's e-REC platform to understand the burden of COVID-19 on people with endocrine conditions. For further information, visit [www.e-se-hormones.org/about-us/committees/rare-disease-committee/](http://www.e-se-hormones.org/about-us/committees/rare-disease-committee/)

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