EuRRECa Newsletter
January 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
- Identify core outcomes for the Core Registry
- Promote high-quality detailed disease registries

EuRRECa Annual Meetings

The second EuRRECa Annual Project Group Meeting will take place on Monday the 9th March 2020 in Verbania near Milan. The meeting is open to project group members, as well as other members nominated by ESPE, ESE and Endo-ERN. Please contact info@eurreca.net for further details.

EuRRECa At ESE & ESPE

EuRRECa will be present at ECE 2020 in Prague and ESPE 2020 in Liverpool. The joint stand with Endo-ERN is a platform for disseminating activities of both projects and affords a great opportunity for networking.

Endocrine Registries Workshop, Glasgow

The Office for Rare Conditions in Glasgow organised a workshop on 'Registries for Rare Endocrine Conditions' in Dec 2019. Topics covered included an update EuRRECa project as well as the value of rare disease registries for informing patient care, research and health technology assessment and regulation. Participants shared their own experience of existing and emerging registries in the field of endocrinology. The workshop was also supported by the University of Glasgow and Novo Nordisk. Presentations are available to download from eurreca.net/rare-endocrine-registries-workshop/

e-REC

A brand new platform has been launched for e-Reporting Of Rare Conditions. The new and improved platform supports reporting of bespoke selection of Endocrine and Bone Conditions. Unique IDs are generated instantly upon submission of monthly returns. For further information and to register for reporting visit eurreca.net/e-rec/

Core Registry

The Core Registry has been improved to provide patients with access to their own record, set preferences and to complete patient reported outcomes

A walkthrough guide is available on the website eurreca.net/core-registry

Patient Reported Outcomes (EQ5D)

Patient reported outcomes can now be completed in the Core Registry using EQ5D (euroqol.org). Clinicians and patients can use the tool to report generic outcomes. EQ-5DL is available in 7 languages and the version for children (Y) in 2 (English and Italian).

Ethics

Revised Patient Information Sheets and Consent Forms for the Core Registry have recently received ethical approval. The new consent will facilitate the exchange of data in other EuRRECa-approved registries. These can be downloaded now in English and soon in 11 other languages from eurreca.net/information-sheets/.

EuRR-Bone

Following a successful small group inter-ERN meeting hosted by Agnes Linglart in Paris in June 2019, under the leadership of Natasha Appelman-Dijkstra in Leiden, ERN-BOND has successfully applied to extend the use of the EuRRECa platform (e-REC and Core Registry) for rare bone conditions (EuRR-Bone).

Rare Endocrine Registries Development Grant

At the Rare Registries workshop a call was launched inviting applications for developing Rare Disease-Specific Endocrine Registries or modules where a gap has been identified. Further information and the application forms are available at eurreca.net/call-for-applications-to-develop-disease-registries/. Deadline 28th February 2020