

EuRRECa Newsletter

July 2019



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.

Career Opportunity

Opportunity for a Data Scientist to join EuRRECa and other exciting projects in Office for Rare Conditions, Glasgow. For details see www.gla.ac.uk/it/iframe/jobs/ref_027615

EuRRECa In Brief

Specific aims of EuRRECa include:-

- e-REC: e-reporting of Rare Endocrine Conditions
- Core Endocrine Registry that collects core dataset for conditions covered by Endo-ERN
- Identify core outcomes for the Core Endocrine 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 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 was present at ESE 2019 in Lyon and will be at ESPE 2019 in Vienna. The joint stand with Endo-ERN is a platform for disseminating activities of both projects and affords a great opportunity for networking.



European Rare Disease Registry Infrastructure

DG Sante has supported the development of tools that will allow registries and the fields within these registries more searchable and findable. The European Rare Disease Registry Infrastructure (ERDRI) will provide a European Directory of Registries (ERDRI.dor), Central Metadata Repository (ERDRI.mdr), Pseudonymisation Tool (EUPID). For further information visit <https://eu-rd-platform.jrc.ec.europa.eu/erdri-description>

EU Call For Proposals For Registries for ERNS

In the first round Five ERNs (ERKNet, EndoERN, MetabERN, ERN-LUNG and ERN PaedCan) were successful in securing funds to develop registries. Funding has now been made available for all other ERNs. https://ec.europa.eu/research/participants/data/ref/other_eu_prog/hp/hp_call_proposals_pj-2019_en.pdf

e-REC

e-REC (e-Reporting Of Rare Endocrine Conditions) is a simple electronic reporting system which will allow Endo-ERN and other stakeholders to objectively map rare conditions, expert centres and related activity. The reporting platform is now available to any centre that wants to participate. The first year results of e-REC will be presented at the ESPE meeting in Vienna. Further details are available at eurreca.net/e-rec.

Core Endocrine Registry



The Core Endocrine Registry is now ready to use and has all the necessary ethical and legal approvals. A draft Data Access Policy has been developed by WP2 and WP6 on Dissemination and Access. Please use and give us your feedback!

To find out more visit <https://eurreca.net/core-registry/>

A Toolkit To Assess Quality Of Patient Registries

Under the guidance of WP3 on Quality Assurance & Evaluation and WP5, a detailed questionnaire has been developed for evaluating the quality of patient registries. The draft tool is available on the EuRRECa website and was implemented in the first half of 2019.

News From The Patient, Parents & Ethics WP

WP5 on Patient Parent & Ethics has developed a set of recommendations for the development of registries and these are available on the EuRRECa website. WP5 has also advised WP6 in its application for ethical approval of the Core Endocrine Registry. All information sheets and consent forms have been translated into 12 languages.

Summer School For Rare Disease Registries, Rome

The 7th International Summer School for Rare Disease & Orphan Drug Registries will take place from September 23-27, 2019 in Rome, Italy.

Endocrine Registries Workshop, Glasgow

The Office for Rare Conditions, Glasgow is holding a two day workshop on the 12th and 13th of December 2019 in Glasgow on the subject of Registries for Rare Endocrine Conditions. The workshop will provide an update on the EuRRECa project, allow sharing the experience of international endocrine registries and cover the views of stakeholders including the EMA, EURORDIS and professional societies.

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