

# ERCUSYN Newsletter

August 2020

The **ERCUSYN** (European Register on Cushing's Syndrome) project, is aimed at registering clinical data on patients with Cushing's syndrome throughout Europe, with the following **objectives**:

- 1) to set up a European Register on the diagnosis, management, quality of life and outcomes of patients affected by Cushing's syndrome across European countries;
- 2) to define relevant health indicators and information to develop epidemiological data at EU level;
- 3) to collect data on the impact of Cushing's syndrome on Health-related Quality of Life;
- 4) to define the optimal diagnosis strategy and the short and long term therapeutic goals;
- 5) to increase awareness about the disease by disseminating what has been learnt from the project;
- 6) to evaluate the persistent consequences of having suffered Cushing's syndrome

## ERCUSYN DATA

**-1st ERCUSYN article: follow-up:** The article "The European Registry on Cushing's syndrome: 2-year experience. Baseline demographic and clinical characteristics" was published in the *European Journal of Endocrinology in 2011*. It was one of the **Top 10 cited articles** in the *European Journal of Endocrinology* between 2011-2012 and nine years after its publication it is still receiving a considerable volume of yearly citations.

2016	2017	2018	2019	2020	Total
citations	citations	citations	citations	July citations	citations
20	18	19	27	17	169

## Call for Scientific Ideas

All ERCUSYN partners are encouraged to send their **scientific ideas** on possible data analysis. Proposals will be evaluated by the scientific steering committee. The new deadline for receiving proposals is December 2020 (contact [asantos@ercusyn.eu](mailto:asantos@ercusyn.eu) for proposals and more information).



By August 2020, **1971 patients** have been included, with partners from **60 centers** in **26 countries** (database developed by Lohmann & Birkner Health Care Consulting GmbH –L&B).

See link to map with details of all centers:

<https://www.ercusyn.eu/find-your-center/>

### Invitation to join the project:

The ERCUSYN project welcomes European centers of excellence who work with CS to join and contribute to the project, if they are prepared to include patients and update their outcome periodically. If interested please contact [asantos@ercusyn.eu](mailto:asantos@ercusyn.eu)

**Scientific Steering Committee:** Susan M Webb, Christian Strasburger, Peter Trainer, Antoine Tabarin and John Newell-Price

**Supervising board:** Jens Bollerslev, Michael Buchfelder, Ezio Ghigo and John Wass

**Project Manager:** Alicia Santos; **Quality Data Manager:** Elena Valassi; **Database support:** Holger Franz, Daniel Thyroke, L&B

For any further information please contact: [asantos@ercusyn.eu](mailto:asantos@ercusyn.eu)



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