

# ERCUSYN Newsletter

December 2021

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

- **New article:** An article on Nelson's syndrome in Cushing's syndrome has been prepared and is currently under review in the *European Journal of Endocrinology*.



## 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 June 2022 (contact [asantos@ercusyn.eu](mailto:asantos@ercusyn.eu) for proposals and more information). This year three new proposals have been sent forward to investigate neoplasias and quality of life, as well as coagulation problems in Cushing's syndrome within ERCUSYN.



By December 2021, **2200 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, 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:** Daniel Thyroke, L&B

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

**ERCUSYN**  
The European Register  
on Cushing's Syndrome

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