

ERCUSYN Newsletter

June 2024

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

- **Recent article:** The article *"High prevalence of venous thrombotic events in Cushing's syndrome: data from ERCUSYN and details in relation to surgery"* was published in the European Journal of Endocrinology in January 2024.



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 2024 (contact asantos@ercusyn.eu for proposals and more information).



By June 2024, **2538 patients** have been included, with partners from **62 centers** in **27 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

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:** Gisela Skrobek-Enge, L&B

For any further information please contact: asantos@ercusyn.eu

ERCUSYN
The European Register
on Cushing's Syndrome

The ERCUSYN project has received funding from the European Commission (PHP 800200) and is supported by the ESE and by unrestricted support from Novartis, Ipsen and HRA.