

ERCUSYN Newsletter

June 2026



ERCUSYN DATA



ERCUSYN articles: The article *"Prevalence, risk factors and management of bone complications in Cushing's syndrome across Europe. Data from the European Registry on Cushing's syndrome (ERCUSYN)"* was published in the *Annales d'Endocrinologie Journal* in February 2026.

REGISTRY GROWTH & EVOLUTION

By June 2026, **3030 patients** have been included, with partners from **65 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/>

COLLABORATIONS

An international, prospective observational Post-Authorization Safety Study (PASS) is currently ongoing to evaluate the safety, effectiveness, and real-world use of oral ketoconazole in patients with Cushing's syndrome. This study is being conducted across nine European countries.

All ERCUSYN partners participating in this study are warmly encouraged to include every eligible patient. This initiative highlights the critical importance of rare disease registries, where comprehensive and high-quality data collection is essential for real-world evidence generation.

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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

Coordinator: Elena Valassi

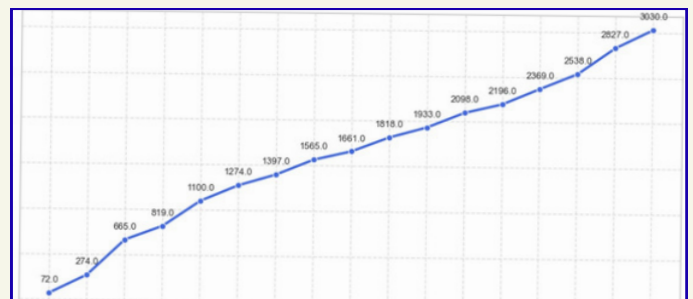
Project & Quality Data Manager: Marc Casas

Database support: Gisela Skrobek-Enge, L&B

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 ESTEVE.

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.



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 2026 (contact mcasas.ercusyn@gmail.com for proposals and more information).

JOIN THE PROJECT



The ERCUSYN project welcomes European centers of excellence that take care of patients with CS to join and contribute to the project, if they can include patients and update their outcome periodically. If interested please contact mcasas.ercusyn@gmail.com