

ERCUSYN Newsletter

December 2016

The **ERCUSYN** (European Register on Cushing's Syndrome) project, is aimed at registering clinical data on patients with Cushing's syndrome throughout Europe. In summary its **objectives** are:

- 1) to set up a network for improving information, monitoring and surveillance of Cushing's syndrome (CS);
- 2) to define relevant health indicators and information to be collected from the patients in order to develop comparable epidemiological data at EU level;
- 3) to develop and validate a Cushing's syndrome generated Health-related Quality of Life tool (CushingQoL);
- 4) to establish a European Register to gather data on the diagnosis, management, QoL and outcomes of patients affected by CS across European countries involved in the project;
- 5) to define the optimal diagnosis strategy and the short and long term therapeutic goals;
- 6) to increase awareness about the disease by disseminating what has been learnt from the project.

ERCUSYN DATA

- **New articles coming soon:** Several articles based on the ERCUSYN data are being prepared. One of them is currently under review in the *European Journal of Endocrinology* on diagnostic tests for Cushing's syndrome.



Call for Scientific Ideas

The ERCUSYN partners are encouraged to send their **scientific ideas**. Proposals will be evaluated by the scientific steering committee. The new deadline for receiving proposals is December 2016 (contact asantos@ercusyn.eu for proposals and more information).



By December 2016, **1450 patients** have been included, with partners from **59 centers** in **29 countries** (database developed by Lohmann & Birkner Health Care Consulting GmbH –L&B).

See link to map with details of all centers:

<http://www.lohmann-birkner.de/ercusyn/wEnglish/gmap/index.php>

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, 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, L&B

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



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