

ERCUSYN Newsletter

August 2018

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 articles published in 2018:** An article on preoperative medical treatment in Cushing's syndrome (*European Journal of Endocrinology*, April 2018) and another one on long-term quality of life in Cushing's disease (*Clinical Endocrinology*, June 2018) have been recently published. A further manuscript is in preparation.

Preoperative medical treatment in Cushing's syndrome: frequency of use and its impact on postoperative assessment: data from ERCUSYN

Elena Valassi¹, Holger Franz², Thierry Bruer^{3,4}, Richard A Feelders⁵, Romana Netea-Maier⁶, Stylianos Tsagarakis⁷, Susan M Webb^{1,2}, Maria Yaneva⁸, Martin Reinecke⁹, Michael Droste¹⁰, Irina Komerudus¹¹, Dominique Malter¹², Darko Kastelan¹³, Philippe Chanson^{14,15,16}, Marija Pfeifer¹⁷, Christian J Strasburger¹⁸, Miklós Tóth¹⁹, Olivier Chabre²⁰, Michal Krsek²¹, Carmen Fajardo²², Marek Bolanowski²³, Alicia Santos¹, Peter J Trainer²⁴, John A H Wass²⁵, Antoine Tabarin²⁶, for the ERCUSYN Study Group[†]

This Article

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ORIGINAL ARTICLE

Worse Health-Related Quality of Life at long-term follow-up in patients with Cushing's disease than patients with cortisol producing adenoma. Data from the ERCUSYN

Elena Valassi¹, Richard Feelders², Dominique Malter³, Philippe Chanson⁴, Maria Yaneva⁵, Martin Reinecke⁶, Michal Krsek⁷, Miklós Tóth⁸, Susan M Webb⁹, Alicia Santos¹⁰, Isabel Palva¹¹, Irina Komerudus¹², Michael Droste¹³, Antoine Tabarin¹⁴, Christian J Strasburger¹⁵, Holger Franz¹⁶, Peter J Trainer¹⁷, John Newell-Price¹⁸, John A H Wass¹⁹, Eleni Papakostantinou²⁰, Oskar Ragnarsson²¹, for the ERCUSYN Study Group. ... See fewer authors ^

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 2018 (contact asantos@ercusyn.eu for proposals and more information).



By August 2018, **1661 patients** have been included, with partners from **60 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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