

ERCUSYN Newsletter

December 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 ERCUSYN articles:** At the beginning of the year two articles were published on preoperative medical treatment in Cushing's syndrome (*European Journal of Endocrinology, April 2018*) and on long-term quality of life in Cushing's disease (*Clinical Endocrinology, June 2018*). A further manuscript on mortality is in preparation.

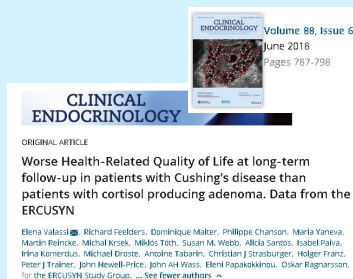
Preoperative medical treatment in Cushing's syndrome: frequency of use and its impact on postoperative assessment: data from ERCUSYN

Elena Valassi¹, Holger Franz², Thierry Bruze^{3,4}, Richard A Feelders⁵, Romana Netea-Maier⁶, Stylianos Tsagarakis⁷, Susan M Webb^{1,2}, Maria Yaneva⁸, Martin Reinecke⁹, Michael Droste¹⁰, Irina Komerdus¹¹, 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 Group¹

This Article

Published online before print
February 12, 2018, doi: 10.1530/EJE-17-0097

Eur J Endocrinol April 1, 2018 178
399-409



CLINICAL ENDOCRINOLOGY

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 Feelders⁵, Dominique Malter¹², Philippe Chanson¹⁴, Maria Yaneva⁸, Martin Reinecke⁹, Michal Krsek²¹, Miklós Tóth¹⁹, Susan M Webb¹, Alicia Santos¹, Isabel Palva¹¹, Irina Komerdus¹¹, Michael Droste¹⁰, Antoine Tabarin²⁶, Christian J Strasburger¹⁸, Holger Franz², Peter J Trainer²⁴, John Newell-Price²⁵, John A H Wass²⁵, Eleni Pasakopoulou²⁷, Oskar Ragnarsson²⁸, for the ERCUSYN Study Group. ... See fewer authors >

New ERCUSYN website and database

This year we have improved our ERCUSYN website and database. You can access the website at www.ercusyn.eu. Information for patients is available in several languages.



By December 2018, **1674 patients** have been included, with partners from **63 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



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.