

# Ercusyn Newsletter

October 2014

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.

The **ERCUSYN** article "The European Registry on Cushing's syndrome: 2-year experience. Baseline demographic and clinical characteristics" was one of the **Top 10 cited articles** in the European Journal of Endocrinology between 2011-2012.

The ERCUSYN data led to **two oral presentations in international congresses** during 2014 (ICE/ENDO 2014 and ECE2014). The presurgical medical treatment and the diagnostic and therapeutic outcome of CS patients were analysed.

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## CLINICAL STUDY

### The European Registry on Cushing's syndrome: 2-year experience. Baseline demographic and clinical characteristics

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## Abstract

**Objective:** The European Registry on Cushing's syndrome (ERCUSYN) is designed to collect prospective and follow-up data at EU level on Cushing's syndrome (CS).

**Design and methods:** Baseline data on 481 CS patients (390 females, 91 males; mean age  $(\pm s.d.)$  44  $\pm$  14 years) collected from 36 centres in 23 countries, including new patients from 2008 and retrospective cases since 2000. Patients were divided into four major aetiological groups: pituitary-dependent CS (PIT-CS) (66%), adrenal-dependent CS (ADR-CS) (27%), CS from an ectopic source (ECT-CS) (5%) and CS from other aetiologies (2%).

**Results:** Proportion of men in the ECT-CS group was higher than in the other groups ( $P < 0.05$ ). The ADR-CS group was older than the PIT-CS ( $P < 0.05$ ) and diabetes (74%) in ECT-CS was higher than in the other groups ( $P < 0.05$  and  $P < 0.01$  respectively). PIT-CS had more skin alterations, menstrual irregularities and hirsutism than ADR-CS ( $P < 0.01$ ). Reduced libido was more prevalent in men than women ( $P < 0.01$ ). Prevalence of spine osteoporosis was higher in men than women ( $P < 0.05$ ), and males had more vertebral and rib fractures than females (52 vs 18% for vertebrae;  $P < 0.001$ ) and 34 vs 23% for ribs;  $P < 0.05$ ). ECT-CS consisted a diabetologist more frequently than ADR-CS ( $P < 0.05$ ), while a gynaecologist was consulted more often by women with PIT-CS or ADR-CS than with ECT-CS ( $P < 0.05$ ). Overall, weight gain was more common in women than men ( $P < 0.01$ ). CushingQoL and EuroQoL visual analogue scale scores did not differ between the groups.

**Conclusion:** The ERCUSYN project demonstrates a heterogeneous clinical presentation of CS at a European level, depending on gender and aetiology.

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By October 2014, over 1166 patients have been included in the database from **57 centers in 28 countries** (database developed by Lohmann & Birkner Health Care Consulting GmbH).

From this link a map with the details of the centers can be found:  
<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](mailto:asantos@ercusyn.eu)

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