

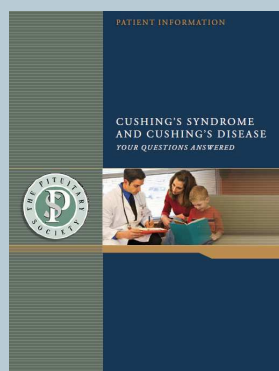
Ercusyn Newsletter

February 2010

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;
- 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.

In order to help patients understand more about Cushing's Syndrome the following leaflet has been prepared by the Pituitary Society, and translations have been provided by ERCUSYN partners. It is currently available in 4 languages (English, Spanish, German and French) and can be downloaded from <http://www.pituitarysociety.org/public/specific/cushing>



Since there is usually a long delay between the appearance of initial symptoms and final diagnosis another leaflet has been prepared to increase the awareness of general practitioners and health professionals in primary care. It can be downloaded from <http://lohmman-birkner.de/ercusyn/wMedia/pdf/brochure/cushinggsEN.pdf>

Brochure for Primary Care Physicians, to increase awareness of Cushing's syndrome (CS)

AIM

Produce a brochure to increase awareness of CS for Primary care physicians.

Increase the suspicion on possible CS, to reach an earlier diagnosis and reduce the long-term morbidity and mortality associated with this condition.

Could this patient have Cushing's syndrome?

Consider CS especially if clinical symptoms progress over time.

Photos illustrating these changes in appearance can be useful to the physician.

- Female
- Purple striae (stretch marks) and/or easy bruising
- Central obesity or rapid weight gain
- High blood pressure
- Diabetes mellitus (DM)
- Muscle atrophy
- Excessive body hair and menstrual irregularity



Is Cushing's syndrome so rare?



Yes, it has a low incidence of 2-3 patients/million inhabitants/year.

- But it is often associated with common abnormalities:
- Poorly controlled diabetes mellitus (1-3% of DM are CS)
- Obesity
- Poorly controlled hypertension (0.5-1% of HT have CS)
- Osteoporosis (11% of older patients with osteoporosis and vertebral fractures had CS)
- Depression

Since screening tests are not completely specific, false positive results (i.e., abnormal test results in healthy subjects) may appear.

By February 2010, over 200 patients have been included in the database by 23 centers in 19 countries (database developed by Lohmann & Birkner Health Care Consulting GmbH).

In this link a map with the details of the centers can be found:

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

Evaluation of Health Related quality of Life (HRQoL) in patients with Cushing's Syndrome.

A specific questionnaire to evaluate HRQoL in patients with Cushing's Syndrome (CushingQoL) is available in 13 European languages (Webb et al, EJE 158: 623-30, 2008). With this tool it is possible to assess quality of life in these patients and learn more on how the disease affects different aspects, important for HRQoL.

Invitation to the next Ercusyn meeting:

During the next European Congress of Endocrinology, to be held in Prague, April 24-28, 2010 an ERCUSYN meeting will take place. Anybody interested to attend please contact asantos@ercusyn.eu

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European Register on Cushing's Syndrome

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