

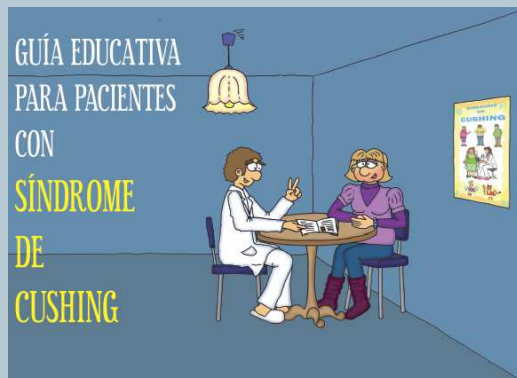
Ercusyn Newsletter

August 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 (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.

In order to help patients understand more about Cushing's Syndrome an educational guideline has been created. Currently available only in Spanish, it is planned to translate it into further languages. It can be downloaded from http://lohmann-birkner.de/ercusyn/wMedia/pdf/brochure/GuiaEducativaParaPacientes_1.pdf



The brochure devoted to Primary Care General Practitioners and Health Professionals aimed at increasing the awareness of Cushing's Syndrome is now available in English, Spanish, Catalan, Italian, Portuguese, Polish, Greek, Bulgarian, Hungarian and German; Dutch is underway. It can be downloaded from <http://www.lohmann-birkner.de/ercusyn/wEnglish/cushings/index.php?navanchor=1110012>

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 are 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 August 2010, over 400 patients have been included in the database from 31 centers in 19 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>

The future of the project.

Even if the initial project to create a Cushing's Syndrome register was established for 3 years, the ERCUSYN database will continue, with the aim of learning more about the disease and improve long-term prognosis and the impaired quality of life of the patients.

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

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European Register on Cushing's Syndrome

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