

# ERCUSYN Newsletter

December 2017

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

- An article on diagnostic tests for Cushing's syndrome was published in May, in the *European Journal of Endocrinology*. A new article on preoperative medical treatment has been sent for publication, and another manuscript is in preparation.

Diagnostic tests for Cushing's syndrome differ from published guidelines: data from ERCUSYN

Elena Valassi<sup>1</sup>, Holger Franz<sup>2</sup>, Thierry Bruza<sup>3</sup>, Richard A Fardella<sup>4</sup>,  
Dimitris Ntzani Maleski<sup>5</sup>, Soghiana Tsagaraki<sup>6</sup>, Susan H Wessell<sup>7</sup>,  
Maria Yaneva<sup>8</sup>, Maria Retiche<sup>9</sup>, Michael Drouot<sup>10</sup>, Hana Konecna<sup>11</sup>,  
Dominique Hainel<sup>12</sup>, Darko Kostelan<sup>13</sup>, Philippe Chanson<sup>14,15,16</sup>,  
Marjka Pihlström<sup>17</sup>, Christian J Strassburger<sup>18</sup>, Antoine Tabarin<sup>19</sup>, Olivier Chabre<sup>20</sup>,  
Antoine Tabarin<sup>21</sup>, Michael Kowalek<sup>22</sup>, Carmen Caparros<sup>23</sup>, Frank Holtenowski<sup>24</sup>,  
Alicia Santos<sup>25</sup>, John A H Wass<sup>26</sup>, Peter J Trainer<sup>27</sup>, for the ERCUSYN Study Group<sup>†</sup>



## 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 current deadline for receiving proposals is December 2017 (contact [asantos@ercusyn.eu](mailto:asantos@ercusyn.eu) for proposals and more information).



By December 2017, **1629 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](mailto: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](mailto:asantos@ercusyn.eu)



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