

ECFS Patient Registry Newsletter



Welcome to the 3rd issue of the ECFS Patient Registry newsletter. In the beginning of the new year, we have a lot of interesting news we would like to share with you on the developments and recent projects of the ECFS Patient Registry.

ECFS conference 2012

We had a valuable Steering Group meeting at the ECFS conference in Dublin last summer. Many subjects were presented and discussed: the director's report, the requests for data and an update by our Eastern Europe coordinator Jitka Brazova about the inclusion of the Eastern European countries in the ECFS Patient Registry. Highlight of the meeting was the presentation of the ECFSPR Annual Report 2008-2009 with the biggest collection of European clinical data in cystic fibrosis so far, including demographic and clinical data from 20 European countries and representing more than 18,000 CF patients. The annual report is available online www.ecfs.eu/files/webfm/webfiles/File/ecfs_registry/ECFSPR_Report0809_v32012.pdf



ECFSPR Steering Group 2012

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Did you know

that the ECFSPR database contains:

26.000 patients

from

21 countries



Presentation of the ECFSPR Team

The ECFSPR Team consists of:

Executive Director: Hanne Vebert Olesen (back right). Hanne is also Director of the Pediatric CF Clinic, Aarhus University Hospital in Denmark.

Executive Coordinator: Jacqui van Rens (back left). Jacqui is responsible for the coordination of the day-to-day operation of the ECFSPR. She is located at the University Hospital Leuven in Belgium.

The statisticians: Laura Viviani (back middle) and Anna Zolin (front middle) of the University of Milan, Italy. Their main responsibilities are data management and data analysis.

The Helpdesk team: Alice Fox (front left) and Patrizia Iansa (front right). The Helpdesk provides technical assistance to the centres and countries that send or plan to send their data to the ECFSPR. Patrizia Iansa and Alice Fox are located in Verona, Italy.

Each contributing centre will get an individual centre report with data of 2009 in January 2013.

ECFRecord

A new upgrade of the data-entry programme ECFRecord has been released. In the upgrade additional automatic data controls are incorporated and the procedure for uploading the XML files for national registries has been simplified.

Since the new release of ECFRecord has been made available on the website, the Helpdesk is offering assistance to all individual centres and national registries to upgrade/upload the software on different computer systems to try to minimize any problem or inconvenience as much as possible. For information contact:

helpdesk@ecfregistry.eu

New Software

The ECFS Patient Registry is aiming to develop new software that will suit the needs of a multipurpose pan-European patient registry, customised to the needs and wishes of the ECFSPR. The new software will maintain the already created pan-European database, but will improve the existing data collection and make data acquisition easier for both the individual centres and national registries.

We plan to include in the new software the possibility for centres and countries to add some extra features, e.g. collecting additional data specifically for their centres/countries. We are also planning to better meet the complex needs of the growing registry, e.g. by accommodating technical solutions for pharmacovigilance and post marketing studies, feasibility studies and site-selection for clinical trials. With the new software, the platform for collecting data will be changed, but the variables and their coding/definitions will remain the same.

We sent out a Request for Proposal for the development of database software to the software companies mid September and interviewed several Bidders in the beginning of December. The final decision will be taken by the ECFS Board in January. We plan to start working on the development of the new software at the beginning of 2013 and aim to have the software ready for uploading the 2011 data in the autumn of 2013.

Winter meeting 2013 in Paris

Representatives from most of the participating countries will meet at the “Vaincre La Mucoviscidose” venue in Paris on January 25, 2013 for the winter meeting of the ECFSPR Steering Group. The Clinical Trials Network and representatives of European CF patient organisations will arrange meetings in parallel at the same location. This will be an excellent opportunity for all groups to meet and to discuss common subjects and ways of cooperation.

Project Data Quality Control

At the ECFS conference in Dublin the idea was launched to set-up a project group to improve the quality of the ECFSPR data. The idea was largely supported by the national coordinators of the Steering Group. The project group has now come to live and consists of national registries coordinators, data managers, the Helpdesk team and a statistician from the ECFSPR. Vincent Gulmans, national coordinator of the Dutch CF Registry and member of the Executive Committee and Steering Group of the ECFSPR, will lead the project. The first meeting will be held on January 24, 2013 in Paris. The main objective of this meeting is to share and discuss the expertise, experiences and hurdles on the data quality control procedures on an European level and come to a plan of approach. It is planned to have a second meeting during the ECFS conference 2013 in Lisbon.

The European Platform of Rare Diseases

The European Platform for Rare Disease registries (EPIRARE) is a three-year project, co-founded by the European Commission within the EU Commission, DG SANCO (2008-2013). The EPIRARE project organized the International Workshop “Rare Disease and Orphan Drug Registries”, October 8-9 in Rome. For the scientific community, patients associations, industry and institutions, from the EU and beyond, it was an excellent opportunity to debate on the use of rare disease registries, on their needs and on the possibility to create common grounds and to share data.

The ECFS Patient Registry was well represented with 4 abstracts and posters. Jacqui van Rens, Executive Coordinator of the ECFSPR, was one of the invited speakers at the conference to present the ECFSPR and the way the ECFSPR provides information to patients.

www.epirare.eu

A new Director

Hanne Vebert Olesen has announced in the Steering Group meeting at the ECFS conference in Dublin that she will step back as Executive Director of the ECFS Patient Registry in the summer of 2013.

The job description for this vacancy has been published on the ECFS website. A suitable candidate will be nominated by the Steering Group to the ECFS Board during the winter meeting in January 2013 in Paris.

Article

Reference percentiles for FEV1 and BMI in European children and adults with cystic fibrosis

Pierre-Yves Boëlle, Laura Viviani, Pierre-Francois Busson, Hanne V Olesen, Sophie Ravilly, Martin Stern, Baroukh M Assael, Celeste Barreto, Pavel Drevinek, Muriel Thomas, Uros Krivec, Meir Meir-Zahav, Jean-François Vibert, Annick Clement, Anil Mehta and Harriet Corvol on behalf of the French CF Modifier Gene Study Investigators and the European CF Registry Working Group;

Orphanet Journal of Rare Diseases 2012, **7**:64.

www.ojrd.com/content/pdf/1750-1172-7-64.pdf

Requests for data

The ECFS Patient Registry has a large database with anonymised data containing more than 26.000 patients of 21 countries, reflecting the natural heterogeneity in cystic fibrosis manifestation across Europe. We like to encourage the use of these important data for scientific research and welcome requests for data. If you wish to make an application for data you will find all information about the procedure including the necessary documents on our website

www.ecfs.eu/projects/ecfs-patient-registry/data-request-application.

New sponsor

Since June 2012 Quintiles is supporting the ECFS Patient Registry project. Quintiles is a provider of biopharmaceutical services.

www.quintiles.com/



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www.ecfs.eu/projects/ecfs-patient-registry/intro

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