

European Cystic Fibrosis Registry

c/o European Cystic Fibrosis Society
Kastanienparken 7,
7470 Karup

October 1, 2009

Dear all,

We thank you very much for your continuing interest in the European CF Registry (ECFR) and the EuroCareCF project. The EuroCareCF project has now ended, and the work will be continued under the management of ECFS and the ECFR Steering committee.

For those of you who have no national registry so far, we now offer an online software system for entering data to the ECFR on a yearly basis. This software replaces the less-than-handly excel spreadsheet, but entails approximately the same variables. Centers using this software will receive an Excel spreadsheet with all the data of your center, and where applicable a representative of your country will receive the national data (see below). In the near future this software will be supplemented by a more elaborate database, that will make it possible to enter data on a clinic-visit basis and furthermore offer graphics, queries etc, that can help your patient management in your daily clinical setting. We will return to you with more information when this software is ready.

For now we welcome you to use the core database to enter data from the year 2008 (from Jan 1, 2008 till Dec 31, 2008). In order to access the database, you will need to acquire a username and password from us (including a random European center code for your center). Due to data protection issues we will need confirmation from you that the data you report to the ECFR has been collected according to your national data protection laws, and that you are allowed to forward these data anonymously to the ECFR. This confirmation should be in form of

1. Permission from the data protection agency, preferably in English, but if not, then in original with a translation by the person requesting the access
2. Ethical approval if required for your country, preferably in English, but if not, then in original with a translation by the person requesting the access
3. Statement from the person requesting the access (see page 3 of this document)

These statements can be submitted for a whole country at a time, or for a single center where applicable. If the country has appointed a country administrator we need confirmation from each participating center that this person should be granted access to their data.

For information on the data security specifications and guidelines of the registry please see attached papers (datasecurityECFR.doc and guidelinesECFR2009.doc), which you may use when applying to your local authorities.

An electronic copy of your permission and the statement (numbers 1 to 3 above) should be emailed to Hanne Vebert Olesen, hvo@dadlnet.dk (scanned picture or pdf file), and also sent by ordinary mail to the ECFS office (ECFS, Kastanieparken 7, 7470 Karup, Denmark, att. Christine Dubois). After you receive confirmation that this paperwork is accepted, you will be directed to Patrizia Iansa (helpdesk@ecfregistry.eu) to receive your center code, username and details on how to log onto the registry and start entering your data.

In case of questions, please feel free to contact us. Questions referring to data protection matters should be sent to Hanne Olesen (hvo@dadlnet.dk), questions referring to technical issues, such as username/password/login problems, should be sent to Patrizia Iansa (helpdesk@ecfregistry.eu) at the registry help desk.

We look forward you to join us to build a sustainable and effective European CF Registry, adding to the knowledge of this disease.

Hanne Vebert Olesen, MD

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Patrizia Iansa

ECFR help desk manager and trusted third party
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Confirmation of Legal & Ethical Compliance to use the European Registry Software

(The information below should be given for all centers willing to join the European CF Registry)

I confirm that the legal and ethical requirements of my country have been satisfied for using the ECFS European Registry software.

Centre name, hospital, city and country	
Name of center director	
Name of Registry administrator for centre (if not the center director):	
Email address of Administrator	
Postal address	
FAX number	
Country	

Signature of center registry administrator: _____

Date of signature:.....

In case your country wants a country administrator, please confirm below that you accept this person as your country administrator with access to anonymous data.

Name of appointed country administrator:

Email of appointed country administrator:

I hereby confirm, that I accept the above person as country administrator

Signature of centre registry administrator: