



ANNUAL REPORT CYSTIC FIBROSIS EUROPE JUNE 2005-JUNE 2006

Projects and activities

In January 2006, Karleen visited the Polish Society for CF and met the Board, visited the CF clinic in Rabka and talked to the media and politicians about better access to care for CF patients in Poland. A full report of this visit can be downloaded from the website or sent on demand.

From 21 to 23 April 2006 Cystic Fibrosis Europe organized its first Central & Eastern European CF Network Building Conference in Warsaw, Poland. The primary aim of this conference was to support patient network building and exchange, reinforce patient associations, define the needs in the region and develop strategies to improve the care and quality of life. Representatives, mostly CF parents and young CF adults, from Armenia, Czech Republic, Georgia, Latvia, Macedonia, Poland, Romania, Russia, Serbia; Slovak Republic and Ukraine came together to learn from each others experiences and from the expertise present in countries where the CF care is more developed. Conference languages were English and Russian. To ensure that everyone who could profit from this conference would be able to attend, CF Europe paid all costs for all participants (transport, lodging and conference). A very heavy, but valuable investment! A full report of this conference can be downloaded from the website or sent on demand

In 2005, a form on 'Data on CF in Europe' was sent around to all CF associations. The goal of this study is to get a better view on the situation of CF patients and CF care in Europe. To lobby for better and cheaper treatments in each country, it's important to get a clear view on which medication and treatments are available in all European countries. We received data from about 10 countries. All other countries are invited to send their data as soon as possible, so we can use them for the CF Awareness day and the meeting with the EU on 21 November 2006.

The Solidarity database was set up, in order to know which countries are receiving and offering help and where help is needed most. In some countries access to appropriate CF care and support is very limited. CF associations from other countries where CF care is more developed are offering help to those regions. We hope you will help us in collecting the information by filling in this form. We're still waiting for the forms of most countries. As soon as we have more data an overview will be available on the website. This way we can prevent that some regions receive 'double' and other regions no support and offer help where it is most needed.

Regular updates were made available on the CFE website (part of the CFW website). In the future we hope to get more input from the national associations.

CFE played a very active part in the preparation of the CFW/CFE Conference day in Copenhagen.

A lot of time and energy was put in the preparation of the CF European Awareness day of November 21, 2006.

Contacts

The CFE Board received and made a lot of e-mails and phone calls and had several meetings to fulfil its mission in Europe. You find here a short overview of the most important contacts we established.

European Union and Commission:

- Meeting with JF Ryan, head of Sanco (EC Task force on Health) in Luxemburg in December; no concrete results but we received info on how to obtain funds for future projects (we'll probably need a full time collaborator to read all the application criteria and write the grant applications...)
- Mails with EC Commissioner of health, who promised his moral support and probably presence for our CF Day
- The CFE Awareness day will be announced on the EU Health Portal
- MEP (Bart Staes, Belgium & Dr. Liese, Germany) agreed to host a meeting at the EU for our CF Awareness day

ECFS (European CF Society of researchers and health care professionals)

- meetings with President (elect) Marie Johannessen in Baltimore (10. 2005) and Copenhagen (06.2006);
- regular mails
- plans for annual meeting with the Board

Since CFE was mentioned several times at the scientific conference in Copenhagen (June 2006) it's clear that we succeeded in getting through in the scientific and medical world. ECFS will start its next conference in Turkey with a video report of patients' expectations! But we have to stay alert and assure that patients remain involved and are heard and are not only involved because this is a condition to get funding!

CFW

- Collaboration for conference day in Copenhagen (2006) and Antalya (2007)
- Annual joint board meeting in Crete (June 2005) and Copenhagen (June 2006)
- Website: the CFW webmaster has been very helpful in getting all CFE info on the site within 1 day
- Ulrika Sterky acted as liaison person between the CFE and CFW boards and this was perceived by both as very positive
- We applied for project money for our CF regional Network Building Conference and the CF Day, but received no official reply (at a meeting in Copenhagen the CFW apologised for this miscommunication)

Unesco and WHO promised us their (moral) support for our CF Day

Associations & individuals from all over Europe

We sent around a contact list to all members and countries in Europe and will update the list on the website with the data we received so far. We hope all member associations will send us their contact details.

European collaboration and patient representation

Karleen de Rijcke and Gerardo Tricarico attended the European Stem cell conference, organised by the European Commission in Brussels, December 2005. We were present as observer and to make CF known, but didn't defend a particular point of view, since there's no common standpoint of the European CF associations on this issue.

EuroCareCF, a European project of co-ordination of CF Research, was approved by the EU and started in April 2006. Karleen participates in the advisory committee and in Work Package 1 (on patient care)

as patient representative. A first positive result of this EU project is that it funds the European B. cepacia reference lab (Ghent, Belgium) for which CFE tried to find the necessary funding last year.

Godfrey Fletcher reported on the 1st meeting of EPAT, European Patients Alliance for Transplantation. He attended this meeting for CFE on 11.03.2006 in Dublin (Ireland). The AG in Copenhagen decided to become member of EPAT.

Gerardo Tricorico reported on the European CF Research Institute Verona (Italy) founded this year by the Italian CF Association and CFE.

We supported a new EU grant application, named ECORN-CF: 'European Centres of Reference Network for CF' from Thomas Wagner, Frankfurt. The goal of this project to make scientific info available to everyone involved in CF in Europe via a multilingual website. The following activities will be included:

1. access to info and expert advice for patients & families
2. expert advice for health care professionals
3. quality control system: ensuring similar level of quality and consensus for all answers independent of language and country/decide on priorities - where do we need a new consensus most urgently

Fundraising efforts

Some sponsor money and donations from 4 national CF associations were obtained for the eastern European Conference in Warsaw. Extra support from the Belgian, German and Italian association will help us to cover most of the costs for this conference, but the overall CFE costs for this year will be more than the expected income. The Belgian, German, Italian, Norwegian and Swedish national associations paid all travel and other meeting costs from their Board members.

The limited income is a major problem. Most countries now pay a considerable fee to CFW, but CFW informed us that due to their limited income they have no money available for CFE projects (although they offer logistic support). CF Europe will have to look for additional income.

Possibilities of EU grants will have to be explored. We hope to be able to give some support to the national associations and to CF patients all over Europe via EuroCareCF, which has money available for consensus documents and training.

All countries are invited to transfer any European sponsor contacts they have to the CFE Board (most companies have a European budget so this will not compete with your national fundraising).

Karleen De Rijcke, 14 June 2006