21 NOVEMBER 2006

1ST EUROPEAN CYSTIC FIBROSIS AWARENESS DAY MAJOR SUCCESS ALL OVER EUROPE

Better awareness and more support for Cystic Fibrosis patients in Europe

"On the basis of your initiative, this is the first time that patients and parents appear in public in our country in an attempt to acquaint the broader community with this disease." CF Serbia

On 21 November 2006 Cystic Fibrosis Europe, a federation representing 30.000 patients in 30 European countries, organized its 1st "European CF Awareness Day". Cystic Fibrosis (CF or mucoviscidosis) is the most frequent life threatening genetic disease in Europe. Sticky mucus blocks the respiration and digestion. Without an expensive and time consuming treatment children with CF suffocate! Although patients who have access to appropriate care can become 40 years and older, children who live in countries where the CF care is less developed or available still die at a very young age! With the 1st European CF Awareness day we wanted to fight for equal access to appropriate care for all children and people living with this disease in Europe! The CF care in Europe should and could be improved, without necessarily having to invest a lot of money. Early diagnosis, regular follow-up by specialists, correct treatment of early symptoms and proper hygiene can prolong and save lives, but also save extra health costs. In several countries basic treatments are not available while other, more expensive but less essential, medication is reimbursed.
Ongoing efforts of CF patients, families, associations and health care workers will lead to better and more accessible CF care, and better and longer lives for all CF patients in Europe. But the patients don't have the time to wait too long... We also wanted to make the public aware of Cystic Fibrosis and the problems patients have to cope with. Although 1 of 30 Europeans carries the gene that can cause Cystic fibrosis few people know the disease and the patients and their families have to fight for understanding and support every day.

At this first European CF Awareness Day we urged European and national authorities to do everything in their power to support these efforts and to take away all barriers to equal access to the basic treatment standards for all European CF patients. All over Europe patients and families organized awareness, information and lobbying campaigns. In Brussels CF patients, parents and representatives from the European CF community met with members of the European Parliaments to explain and discuss the problems people with CF face in Europe and suggest strategies to improve their lives. People from 12 different countries attended the meeting in the European Parliament: patients, families and representatives from national associations. Prof. Marie Johannesson, president of ECFS and Prof. Jean-Jacques Cassiman represented the health care professionals and researchers. We met 7 Members of the European Parliament (MEP) who were really interested to know how they could help to improve the situation of the CF patients in Europe. 7 MEP (and/or assistants) may not seem very successful, but for EP standards this is a huge success. Last year for instance we were invited at a patient conference on stem cells organized by the EU, with more then 300 participants from 32 countries and only 1 MEP attended! We discussed the possibilities to get more funds for CF research and they promised us to stimulate their national governments to make appropriate care more accessible for CF patients (since this is still a national competence). We were also invited to organize a next meeting in the EP on a much larger scale next year, because the MEP noticed there was a lot of work to be done and a lot of interest amongst the MEP.

EU première Opera-Musical 'Some Sunny Night'

The highlight of our awareness campaign was the EU première of Thomas Stanghelle's opera-musical "Some Sunny Night" in Residence Palace in the European quarter in. This opera-musical is based on the true story of CF patient Ketil Moe and his handicapped Chinese friend, Mark Wang, who set up the "Run for Life" for both handicapped and healthy people. Ketil passed away after his 14th New York Marathon in 1999, almost 33 years old. His work and visions still live stronger than ever. The soloists from all over Europe, USA, China and other countries and the orchestra Camerata Con Cor(d)e conducted by Jaak Gregoor offered us unforgettable music of the highest level. The performance was beautiful; the concert hall was filled till the very last seat and the public was very enthusiastic... they're probably still singing the songs by now … Everything was recorded by the Norwegian television, there were reports on the 2 main national radio channels and it will be brought on Chinese television too.
Unesco and en Olympic IOC-president Jacques Rogge support the event.
On Wednesday morning we were welcomed in the City Hall in Brussels by Deputy Mayor Bruno De Lille, who gave us a private tour in the beautiful, 15th century building.

But the European CF day was not only organized in Brussels, awareness campaigns were set up all over Europe. On our website you can find a short overview of activities in 15 countries, but each day we hear of new events that took place somewhere…

I hope all our activities were successful and will make lives of people with CF easier and better all over Europe!

Enthusiastic reactions from all over Europe

"I`m impressed by a huge job you made for CF. Thank you very much for inviting me and my daughter (with CF). She is fascinated by all what happened during those 2 days. Everybody was so nice to her!"
Alicja Rostocka, Poland

"I attended the Musical last night and wanted to thank you for this marvelous evening!"
Staff European Parliament

"In the Slovak Republic the media campaign has been very successful and interesting too, with live appearances on national TV in prime time and info in major newspapers, radio, internet...!"
Jaro Lexa, Klub cystickej fibrozy Slovak Republic

"I didn't know anything about this disease but now I know what CF is. I think you're doing very important work and wish you good luck"
Assistant to MEP

"Thank you to everybody in the CF organization for making the "impossible possible" at the EU premiere of Some Sunny Night! We are so happy that the whole event was a big success, and on behalf of all artists, TV-crew and involved people, we send our warmest regards and thank you for a great arrangement in Brussels."
Thomas Stanghelle, composer

"You have done such a good job that I miss words! Thank you!!!!"
Ulrica Sterky, CF Sweden and CF Worldwide

“Once more congratulations for all the work you did to make this day a success. It was a pleasure to join the activities in Brussels.”
Paul Gevaerts, NCFS, CF Netherlands

“I am very happy that the first CF day was so successful. I am sorry I couldn't be there with you. I also believe that it will bring some good results in future. We had our beneficial theatre performance which was very nice and brought us some money and awareness of CF in public which we need a lot in our work.”
Helena Holubova; CF Czech Republic

“… a fantastic job planning and carrying through a great CF day in Brussels! To manage to do this after three and a half year with CFE I think is very impressive. Prof. Marie Johannesson (ECFS) and Mr. Einar Steensnæs (UNESCO) were very satisfied with the day, Mr. Steensnæs said he and UNESCO learned a lot about CF that day. He even wrote a report about our day on the Norwegian UNESCO website: www.unesco.no”
Ingvar Froyland, CF Norway

“Well done on what must have been an enormous logistical nightmare. Next year we will do more now that there is a confirmed annual date. This year we just had too much on. Some good news on our side that same week we were allocated an additional €2m in the government’s budget estimates for 2007… Now with this process underway our focus will shift to facilities… It has been a very hard uphill fight but for the first time I feel that there could be some light at the end of the tunnel!”
Godfrey J. Fletcher,The Cystic Fibrosis Association of Ireland

“Your efforts were well placed! I am sure this will be a resounding impact for CF patients in Europe.”
Christine Noke, USA, CF Worldwide

“We tried to celebrate the European CF Awareness Day as well with the distribution of medical information. We find the decision to have a specific day devoted to CF very special.
Prof. Ioan Popa, President of the Romanian CF Association”

“The Cystic Fibrosis Awareness week has come to the end in Yaroslavl. Info on CF was seen on TV, radio, newspapers, on websites and big screens in the street... Certainly it is necessary to organize such days...”
Natalya Matveeva, the chairmanCF Yaroslavl

More information

Go to www.cfww.org/cfe for:

- A list of activities throughout Europe for the 1st European CF Awareness Day
- Paper on equal access to care presented in the European parliament
- more info and pictures about the European CF Awareness Day

or contact Karleen De Rijcke, president of CF Europe: karleen@muco.be, +32/266 33 904.

Information on the opera-musical on www.somesunnynight.com.

Kind regards,

Karleen De Rijcke

President CF Europe

Cystic Fibrosis (CF) or mucoviscidosis is the most frequent life threatening genetic disease in Europe. Sticky mucus blocks the lungs and digestive system. Although 1/30 Europeans carries the gene causing the disease and 30.000 children and young adults live with it, few people know of CF. Some patients get 40 years old…others 4, depending on where you live in Europe Help to make good care available to every CF patient !

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