



EUROPEAN CYSTIC FIBROSIS AWARENESS DAY 21.11.2006

CF Europe organizes the first European Cystic Fibrosis Awareness Day (ECFAD) on November 21, 2006.

The goal of this CF Day will be to raise public awareness and political interest for the problems of persons confronted with CF on a European level. We want to promote optimal standards of care in all countries of the European Union. The average life expectancy for people with CF who have access to appropriate CF care is now 40 years. But in some regions a lot of patients die before they reach adolescence or adulthood. Especially the newer EU countries stress the importance of a European CF Day and stimulate us to move forward.

All over Europe awareness campaigns can take place from 17 till 26 November. National CF associations can join the ECFD or just mention it in within the frame of their own activities

The ECFAD is organized in collaboration with ECFS (European CF Society, represents CF clinicians and researchers), WHO and CF Worldwide.

Aim European CF Awareness Day 2006: Promote optimal CF treatment in Europe

1. Priority: Awareness and info on "Standards of care"

- Raise awareness of CF as serious and most frequent life threatening disease
- Raise awareness of the deficiencies in CF care throughout Europe and lobby for equal access to optimal care

2. Concrete requests for European authorities

- Initiate report on the situation of CF patients in Europe
- Attention for CF in European programmes
- Need for small budget to realise projects with a major impact

Activities European CF Awareness Day 2006

1. Communication materials

- Publications and info material to be downloaded by local associations; available on this website from September 2006
 - Folder about CF and CF Day with pictures and data about living with CF all over Europe
 - Poster about ECFD
- Website: inform public + exchange of ideas between associations
 - agenda & information on European activities
 - agenda & information on national activities: please send us all your data!

2. Media campaign

- CFE writes press release & contacts international media
- National associations can use the ECFAD for their own national media campaign
- Involve national associations: E.g. data & pictures showing living with CF in several countries



3. Political campaign

- 21/11/2006: Lunch Meeting with interested members of the European parliament in Brussels: Meeting of CF patients, families and caretakers with EU (CFE+ECFS) - A parent from a less developed CF country speaks about life with CF with poor treatment and a CF expert presents the European consensus paper of CF care as valid guidelines for the whole of Europe.
- Letter to all members of European parliament
- Detailed info to ENVI (Health committee of the European Commission)
- National associations can use the CF Day as an instrument to do their own lobbying, with the support of the CF day and CF Europe

4. Event: "Some sunny night" by Thomas Stanghelle, November, Brussels

Besides the political contacts, the highlight of the CF Awareness Campaign will be the performance of "Some Sunny Night"© in Brussels. This opera-musical, composed by Thomas Stanghelle, is based on the true story of CF patient Ketil Moe, known as "the Marathon-hero from Lillesand", and his Chinese friend, handicapped Mark Wang. Together they managed to start the first Beijing Marathon for handicapped people. Ketil Moe completed 14 New York marathons, the last two with transplanted lungs. He also started his own race "Run for Life" for both handicapped and healthy, together with four times Olympic Champion Johann Olav Koss. Ketil Moe passed away after his 14th New York Marathon in 1999, almost 33 years old. His work and visions still live stronger than ever. In China there has even been made a TV-series about Mark and Ketil, "Angel of life", viewed by 800 million people.

The opera-musical "Some Sunny Night" was a major success in China and Norway last year, each time staged in collaboration with the national orchestra, in an important location such as the Great Hall of the People in Beijing. The whole cast will come for free to Brussels in November. But to make this a success we're looking for European personalities who want to collaborate as guest stars (as was the case whenever they performed the opera before in China and Norway). It would be great if we could find a singer who wants to sing a song, but any celebrity who would be willing to say a few words of support on stage would be great!

More info on <http://www.somesunnynight.com/>.

5. Fundraising:

- The CF Day will not interfere or compete with local fundraising activities
- National associations can use this Day to support their own initiatives and campaigns
- CFE can apply for international funds but only from international sources (eg. EU, international charities)

Working group European CF Awareness Day 2006

- CFE Board: Karleen De Rijcke (Belgium); Birgit Dembski (Germany); Inge-Britt Lundin (Sweden); Vladimir Patras (Slovakia)
- Mary Lane Henegha,; CF Association of Ireland; Aisha Ramos, Spanish CF Association; Angelika Prefitsi, Northern Greece CF Association
- ECFS: Professor Marie Johannesson, Sweden, President Elect ECFS

For more info:



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