



## JOIN THE 1<sup>ST</sup> EUROPEAN CYSTIC FIBROSIS AWARENESS WEEK 9-15 NOVEMBER 2009

From 9 to 15 November 2009, CF Europe and patient associations in 33 European countries organize the 1st European CF Awareness Week - to fight for better and longer lives for all people living with CF.



Cystic Fibrosis (CF) or mucoviscidose is the most common life threatening inherited disease in Europe. Although 1/30 Europeans carry the gene causing the disease, few people know of CF. With the CF week we want to make the public aware of CF and make good care available to every CF patient ! Join our actions for a longer and better life for all CF patients in Europe now!

### Towards equal access to appropriate care for Cystic Fibrosis patients in Europe

Although patients who have access to proper 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! Without an appropriate treatment children with CF suffocate. The CF care in Europe should and could be improved. Early diagnosis, regular follow-up by specialists, proper hygiene and correct treatment of early symptoms 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. But even in countries where CF care is better developed, people with CF still have to face a lower life expectancy and the access to optimal care and quality of life can and has to be further improved.

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 time to wait too long...

At this first European CF Awareness Week we urge 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 (as described in the European Consensus on Standards of care for CF). A meeting with members of the European parliament and Commission is planned in Brussels on November 11 and all over Europe patients and families will organize awareness and lobby campaigns.

### Join the solidarity campaign for better and longer lives for people with CF in Europe

We want 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 CF, few people know of the disease and the patients and their families have to fight for understanding and support every day. We call on the public to wear the CF solidarity bracelet and whistle the "Stop CF Hit" with friends and colleagues, to support our fight for a better and longer life for all people with Cystic Fibrosis.



### More information

For more information about Cystic fibrosis and the possibilities to join the European CF Awareness Week in your country, visit [www.cfweek.eu](http://www.cfweek.eu) or contact your local CF Association.

For CF Europe: contact Karleen De Rijcke: [karleen@muco.be](mailto:karleen@muco.be), +32/266 33 904, [www.cfeurope.org](http://www.cfeurope.org).

***Cystic Fibrosis (CF) is the most common life threatening inherited disease in Europe. Sticky mucus blocks the lungs and digestive system. 1/30 Europeans carry the gene causing Cystic Fibrosis. More than 40.000 children and young adults live with the disease. Some live up to 50 years old... others die at 5, depending on where they live in Europe. Access to good care leads to a longer and better life for all CF patients. Help to make good care available to every CF patient in Europe!***