



## 2<sup>ND</sup> EUROPEAN CYSTIC FIBROSIS AWARENESS DAY 21 NOVEMBER 2007

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

On 21 November 2007 Cystic Fibrosis Europe, a federation representing 30.000 patients in 30 European countries, organizes its 2<sup>d</sup> “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 2<sup>d</sup> European CF Awareness day we want 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... At the first European CF Awareness Day in 2006 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.

The first CF Day was very successful. 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 all over Europe heard about the problems people with CF face every day... But the awareness has to be further increased, which we hope to obtain through this second edition. All over Europe patients and families will organize awareness, information and lobbying campaigns.

*“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*

### **More information**

Information on Cystic fibrosis, CF Europe and the Awareness day on [www.cfww.org/cfe](http://www.cfww.org/cfe) or contact Karleen De Rijcke, president of CF Europe: [karleen@muco.be](mailto:karleen@muco.be), +32/266 33 904.

Or contact your local CF association.

### **CFE represents patients in more then 30 member countries:**

Albania, Armenia, Austria, Belgium, Bulgaria, Croatia, Czech Republic, Estonia, France, Germany, Georgia, Greece, Hungary, Ireland, Israel, Italy, Latvia, Lithuania, FYR Macedonia, Netherlands, Norway, Poland, Romania, Russia, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland and Ukraine.



*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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