

TOWARDS EQUAL ACCESS TO APPROPRIATE CARE FOR ALL CF PATIENTS IN EUROPE



3° EUROPEAN CYSTIC FIBROSIS AWARENESS DAY
21 NOVEMBER 2008

Cystic Fibrosis (CF or Mucoviscidose) is the most frequent life threatening genetic disease in Europe. In some countries the median age at death of people with Cystic Fibrosis is more than 35 years, in other countries the majority of children die before their 5th birthday! Guidelines for best standards of care were developed to ensure appropriate treatment in Europe. In countries where these guidelines are followed and appropriate care is provided and patients have full access to medication and treatments life expectancy is now more than 40 years old. Most children have few symptoms and serious problems can be delayed until adulthood. In regions where the disease is not yet well known and access to appropriate care is poor, the life expectancy and quality of life are still very low.

With this 3rd European CF Awareness day we want to continue our fight for equal access to appropriate care for all children and people living with this disease in Europe!

Some CF patients get to 40 years old... others 4, depending on where they live in Europe

All over Europe a lot of patients are never diagnosed and too many patients die too young. But there are major differences between regions.

A CFE survey on data on CF in Europe from 2006 shows that about 50 % of the persons with CF are 18 years or older in countries where CF care is well developed, in other regions this is less than 20%. In some countries people with CF can expect to get 40 years old or older, in others the average age at death is less than 4 years! In countries where CF knowledge is low, the majority of patients are not diagnosed and if diagnosed, patients have poor access to specialized health professionals, essential medication and medical materials needed to survive.

Access to appropriate CF care is inefficient throughout Europe

Although the living conditions of CF patients are especially hard in most of the new EU countries and the countries not (yet) belonging to the EU, the deficiencies in CF care and access to appropriate care or not limited to this region. Problems to get access to care occur in countries with weaker and stronger economies and poor access to optimal care is limited by other than financial barriers.

Some examples from the EU:

- In Belgium 1 of 7 patients ask the national patient association for financial help to cover the treatment costs.
- In Germany only 50% of the treatment costs are paid by the German health care insurances. The other 50 % have to be covered from other sources like donations, research projects etc. Therefore the German CF association with a budget of €500 000 in 2006 as well as the Christiane Herzog Foundation set up financial programs to support CF clinics.
- In Greece the number of hospitals, single-bed rooms as well as medical staff who have received special training for CF is small or non-existent.
- In the R. of Ireland the median age at death in 2000 was only 17 compared to 30 years in neighboring regions (after the independent Pollack Study and a national campaign for an adequate number of multidisciplinary CF clinics and segregation measures major progress was made).
- In Latvia only 6 % of patients are diagnosed; there is no specialized CF center, only one doctor interested in CF
- In the UK nearly 1/3 of patients face problems obtaining adequate life-saving treatment according to a survey of the Cystic Fibrosis Trust in 2004

Deficiencies in CF care in Europe due to more than financial barriers!

The above examples and the Survey on Data on CF clearly show that access to appropriate care is not only limited due to financial means. CF care in Europe should and could be improved, without necessarily having to invest a lot of money.

European Standards of care offer best guarantee to optimal care

For more than 40 years now the CF community, patients, their families, doctors, other caregivers and scientists have been struggling against Cystic Fibrosis. Today scientific and medical knowledge about the biological causes of CF and the way to treat this disastrous disease is far advanced. In 2005 a European Consensus of Standards of CF Care was published in which 36 experts from 15 European countries, the USA, Israel and Russia were involved. In countries offering well developed CF care in hospitals which follow these guidelines about 50 % of the CF patients are 18 and older, and the average life expectancy is 40 years and more. The lives of CF patients depend on correct treatment according to these standards.

Strategies to improve care with relatively little investment

- In the treatment of CF, *preventing complications* is a priority. This can prolong and save lives, but also save extra health costs. It's more expensive to treat severely ill patients in the hospital than to pay for the essential medication that can be taken at home to prevent symptoms. If a patient is regularly checked by specialists trained in the treatment of CF and receives the correct antibiotics, as soon as an infection occurs, expensive and uncomfortable hospitalizations can be avoided.
- An adequate number of CF clinics observing the above mentioned European standard of CF should be established in each European country. In some countries no specialized clinics are available (or not within reach of a majority of the patients), in other countries CF care is spread over too many clinics where the staff is insufficiently specialized and experienced. This costs a lot to society, but also endangers the CF patient's lives.
- *Prevention of infection* in the clinics by proper hygienic and segregation measures is essential to improve the quality of life and the survival chances.
- *Offer the essential treatments for free.* We realize that some countries don't have the means to reimburse all necessary medication and care. Therefore it is important that authorities discuss with patient representatives and specialists which are the most needed treatments. In several countries basic treatments are not available while other, more expensive but less essential, medication is reimbursed.
- *Offer training and education for CF patients and their families and health care professionals* on CF and home care (e.g. use of medication, physiotherapy to clear their lungs from the sticky mucus and high calorie diet to prevent malnutrition).

All over Europe patients and caregivers fight together for better access to care

On this 3rd European CF Awareness day associations all over Europe organized events to improve the knowledge about CF in their region and to raise awareness for the general public, the authorities, health professionals, patients and families..

Main event was the Conference V4-CF "Better? Why not? Together we could do more", organized by the Polish CF Foundation MATIO, Slovak CF Association, Klub nemocných cystickou fibrózou and the Hungarian Cystic Fibrosis Association from 20 to 22 November 2008 in Krakow, Poland. (www.v4-cf.eu)

This conference created an ideal platform to exchange experiences about CF care in the region and made it possible to work on a common strategy to move towards equal access to appropriate care in all countries.

Enclosed you find the declaration for better access to care by the participants and organizers.



EU and national governments have a responsibility in improving access to care in Europe!

According to the World Health Organisation the right to the highest attainable standards of health is an inclusive right which includes timely and appropriate health care as well as a right to the underlying determinants of health like availability, accessibility, acceptability and quality of health care.

The 30.000 European citizens with CF need the support of the EU to obtain this right. CF patients and their organizations who are often struggling hard to obtain at least some basic treatment need support from the European level.

- We count on the members of the European Parliament to urge their national governments to improve adequate access to CF care according to the European standards.
- We ask the EU to initiate a European report on CF treatment to analyze the differences in CF care and the influence on the health outcome.
- Attention for CF, considering the strategies and priorities of CF patients described above, when funding projects. The current set up of application procedures makes it virtually impossible for patient associations such as CFE to apply. But with relatively small budget we can realize projects with a major impact.

We have to continue fighting for a better awareness and access to care for all patients.

It was very encouraging to notice during the many activities for the 3rd Awareness day that a lot of progress has been made the last couple of years. Since the first CF Day in 2006, CF is better known, CF care has become better organized, access to care has improved and CF associations became better organized and more effective all over Europe.

But the access to care is still very insufficient and unequal and too many children still die too young, too early... We have to continue fighting for a better awareness and access to care for all patients.

To make the 4th Awareness Day a success we need your help!

On 11 November 2009 we plan a new major EU awareness campaign. All associations are invited to a meeting with members of the EU Parliament in Brussels. We want to represent and tell the story of CF patients all over Europe. This is not possible without your help! Send us data on CF and pictures about life with CF in your country (for our letters to politicians, publicity materials and an exhibition in the European parliament). Let us know if you have any contact with members of the European parliament who might wish to attend the meeting in Brussels -or even better- give their support by hosting the meeting. We're also still looking for European celebrities to support the Awareness day as celebrity patron.

TOGETHER WE CAN DO MORE AND BETTER.

**Please join the European CF community in their common fight
for longer and better lives of all CF patients in Europe!**

Ongoing efforts of CF patients, families, associations, health care workers and researchers will lead to better and more accessible CF care, and better and longer lives for all CF patients in Europe. At this third European CF Awareness Day on 21 November 2008, CF Europe, together with its member associations from 30 different countries, urges 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.

And remember... CF patients don't have time to wait too long.

