

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



2° EUROPEAN CYSTIC FIBROSIS AWARENESS DAY
21 NOVEMBER 2007

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 clinics where these guidelines are followed and appropriate care is provided 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 the 1st 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!

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 survey on CF in Europe indicates 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 get to 40 years or older, in other countries the average age at death was less than 4! 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, 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 have to 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 Ireland the median age at death in 2000 was only 17 compared to 30 years in neighboring regions.
- 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 CFE 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.

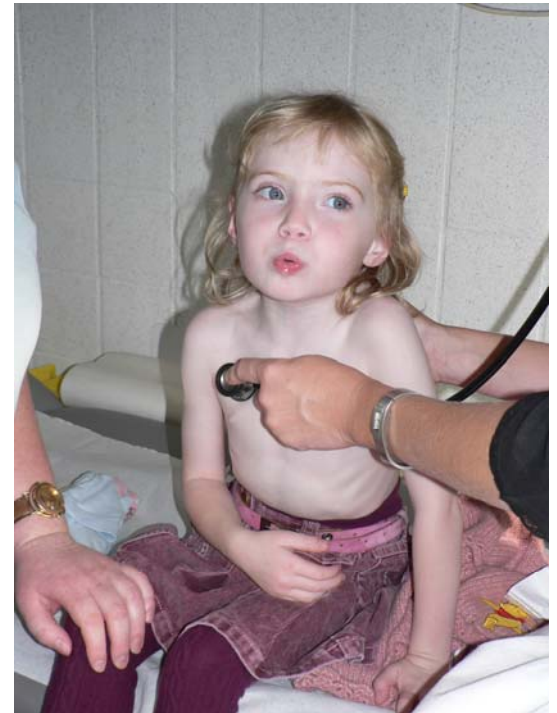


European Standards of care offer best guarantee to optimal care

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 do not 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* 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).



The EU can help to improve 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.

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. But the patients don't have time to wait too long...

At this first European CF Awareness Day on 21 November 2006, 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.



2d European CF Awareness Day 2007- CF Europe- www.cfww.org/cfe

