



## CYSTIC FIBROSIS DECLARATION OF V4 COUNTRIES

*"Towards appropriate CF care for all patients with CF in Europe"*

The participants of the V4 CF Conference urge all member countries to establish the "Standards of care for patients with CF: a European consensus" as guideline for their national CF care.

Cystic Fibrosis (CF) is the most frequent life threatening genetic disease in Europe. There is no cure yet, but the current treatment can prevent, delay or relieve the symptoms. People with CF who have access to care according to the European standards can live longer and better lives. In some regions where access to care is limited, too many children with CF die too young and the limited number of patients who reach adulthood often live in unnecessary difficult conditions.

In the near future fundamental treatments which can cure or at least stop the progress of the disease will be available. Therefore it is our duty to provide all patients access to optimal care. This not only guarantees the best possible quality of life to people living with CF today, but also ensures that – if and when a fundamental treatment will be found - all patients will be able to take full profit of this treatment.

Cystic Fibrosis requires a holistic approach to care. Treatment must start immediately after the diagnosis which should occur as early as possible, ideally just after the child's birth, to slow down progression and avoid or postpone severe symptoms. The evaluation of decades of national and European epidemiologic registries shows that care provided by a multidisciplinary team of trained and experienced health professionals in highly specialized CF centers is essential for optimal patient management and improved outcome. Care in these CF centers is associated with a markedly improved survival and quality of life. This is achieved by frequent clinical checkups, close monitoring for complications and intensive and immediate interventions by physicians and other healthcare workers specifically trained in the management of CF.

In 2005 a document "Standards of care for patients with CF: a European consensus" was published by the European Cystic Fibrosis Society (ECFS), involving experts from Europe and North America. This consensus paper is crucial because it clearly defines what is appropriate CF care needed to improve the health and quality of life CF patients.

Cystic Fibrosis Europe, the federation of national CF associations, representing more than 30.000 patients in 33 European countries, urges all member countries of the European Union to ensure that CF care according to the European consensus on standards of care is provided and that all children and adults with CF, no matter where they live, have full access to specialized CF care and treatment as defined in these guidelines.

In the European Union the WHO postulation of health being a human right should be accepted. The consequence of this, however, is that CF patients are entitled to appropriate care and treatment.

After the V4 CF conference and analysis of the situation in the V4 countries it became clear that the access to care in our countries is very unequal and often largely insufficient. Representatives of national patient associations and CF care experts of the V4 countries, together with Cystic Fibrosis Europe, reunited here today in Krakow, stress the importance of rightful access to appropriate CF care for each patient in our countries. Appropriate care is the fundamental condition to ensure adequate health and good quality of life for all persons with Cystic Fibrosis.

**As V4 CF representatives we recognize the following issues as crucial in establishing appropriate care and improving quality of life of CF patients:**

- “Standards of care for patients with CF: a European consensus” should be accepted as the official guideline for CF care in all countries
- CF Centers should be established in accordance with this European consensus on CF care and with the EU Commission recommendations on Centers for rare diseases (2008) 726 issued on 11.11.2008
- All CF children and CF adults should have full access to all medication and treatments recommended in “Standards of care for patients with CF: a European consensus” and these should therefore be covered by health insurance
- Neonatal screening should be available to all newborns
- Each country should build a uniform national registry and participate in the ECFS European registry
- All efforts to raise the awareness and knowledge about CF of healthcare professionals and the general public about CF should receive full support
- Parents of children with CF and CF adults should receive sufficient support to enable independent worthy living and all discriminating social barriers should be removed.

We believe that the implementation of these measures will lead to longer and better lives of all people with Cystic Fibrosis now and in the future.

It is the responsibility of everyone involved, here and in our countries, to make this come true.

This conference should be an important step forward in the fight against CF. We hope we will all be able to report on achievements and progress in establishing appropriate CF care and improving quality of life at the next V4 CF conference.

Krakow, 21. November 2008

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