COUNTRY CLOSE UP

CF CARE IN DENMARK

By Erik Wendel and Hanne Wendel Tybkjaer

Denmark is one of the three Scandinavian countries, situated in Northern Europe sharing a border to the south with Germany of just under 68 km. The total area is 43,069 square km, excluding the self-governing Faroe Islands and Greenland in the North Atlantic. Denmark has a coastline of 7,314 kms, corresponding to a sixth of the globe‘s circumference and consists of one peninsular and 406 islands, 90 of which are inhabited – the biggest being Zealand (Sjaelland) with the capital Copenhagen (Köbenhavn). The terrain is low and flat with some gentle rolling hills. The highest point, Yding Skovhhöj, is 173 m above sea level.

The fairy-tale writer Hans Christian Andersen (1805-1875) probably remains the best-known Dane in the world. It is well-deserved that one of the figures which emanated from his imagination, the Little Mermaid, has also become the symbol of the Danish capital, Copenhagen. Cast in bronze, she gracefully receives visitors to the city from her wet stone in Copenhagen harbour.

The Mermaid & Denmark Map

Denmark has a population of around 5.4 million. Lutheran Evangelical Christian is the state religion, practiced by 88.9% of the population. Common to all Danes is their tendency to take the ups and downs of life with a touch of irony, often self-irony. The tone between Danes is relaxed. In the schools, the pupils are on first-name terms with the teachers.

Danish Vikings once took to the seas and ravaged half of Europe, but these days they've filed down their horns and forged a society that stands as a benchmark of civilization, with progressive policies, widespread tolerance and a liberal social-welfare system. The Danish Monarchy – one of the oldest in the world - is a constitutional monarchy, reigned by her majesty Queen Margrethe II. The role of the Queen is mostly ceremonial, and the focal point of the democratic system is the Folketing (Parliament) and the government.

The Danish economy is based on up-to-date small-scale and corporate industry as well as modern high technology agriculture. Denmark is characterized by extensive government welfare measures, comfortable living standards and a high level of foreign trade. In 2004, the total gross domestic product (GDP) was US$ 241.4 billion, equivalent to US$ 44,730 per capita; making Denmark one of the richest countries in the world. The proceeds from this are heavily taxed. The income tax to the state is progressive. In Denmark, there is also a high general value added tax (moms) of 25% on all goods and services. Altogether, this produces one of the heaviest tax loads in the world, in 2002 amounting to 49.2% of GDP.

With the revenue from taxes and duties, the state creates great security for its citizens with free education, medical treatment, hospitalisation, early retirement pension for those with reduced capacity for work and – from the age of 65 – a national pension large enough to live on. In

addition, the state subsidises an unemployment benefit, dental costs, and nursing home accommodation for those no longer able to manage on their own.

Sources: visitdenmark.com, visitcopenhagen.com

CF IN DENMARK

January 1, 2006 there were 434 CF-patients in Denmark. The incidence is 12-15 CF children per year. All are in centralized care at two CF-centres; 287 at the Copenhagen CF Centre at Rigshospitalet (Copenhagen University Hospital) and 147 at the Aarhus CF centre at the Aarhus University Hospital.

The Copenhagen Centre was established as early as 1968 by Dr. E.W. Flensborg. When he retired in 1982, his position at the Copenhagen Centre was taken over by Dr. Christian Koch, who passed away in 2004 and was followed by Dr Tania Pressler. Professor Niels Hoiby is chairman of the Department of Clinical Microbiology at the Copenhagen Centre. The Aarhus Centre was established in 1990, professor P. O. Schiötz being the chairman of the centre.

For over 30 years, the Copenhagen Centre has had a leading international role in CF care. The overall perspective in the care has been that bacterial lung infections are the most important factors responsible for the progression of the lung infections among CF-patients. Consequently, microbiology and infection control have been cornerstones in the “Copenhagen CF treatment” approach.

All patients at the Copenhagen CF Centre are seen for monthly controls which include clinical observation, lung function test, height, weight, microbiological examinations of sputum etc. Bacterial infections of the lower respiratory tract are diagnosed by microscopy and culture of secretions from the respiratory tract.

The Copenhagen principles for treatment of bacteria in CF are:

- Positive bacteria cultures are treated with antibiotics whether there are clinical symptoms or not.
- Bacteria such as *Staphylococcus aureus, Haemophilus influenzae* and intermittently colonized *Pseudomonas aeruginosa* (PA) infection should be eradicated when present in the lower respiratory tract whether there are clinical symptoms or not. (*S. aureus* infection is still the most frequently isolated pathogen in CF children but due to efficient antibiotic treatment it is not considered to be a problem among Danish CF patients).
- Chronic PA infection, defined as persistent presence of PA for at least 6 consecutive months, or less when combined with the presence of 2 or more precipitating antibodies against PA, is treated with antibiotics (IV courses) regularly 4 times/year whether there are clinical symptoms or not, plus daily antibiotic inhalations.
- All patients are offered daily Pulmozyme inhalation.

Milestones in Danish CF Treatment

In 1976, a Danish survey showed that a CF patient had 50% chance of surviving 5 years with chronic PA infection. In consequence, the treatment regime against chronic PA infection was changed radically by Dr. Flensborg and elective IV antibiotic courses were introduced, regardless of clinical symptoms when the level of precipitating antibodies against PA reached 2

or higher or the presence of PA for at least 6 consecutive months. As a result of the new treatment regime, the survival among PA chronically infected CF patients increased tremendously over the years. In 1987 daily antibiotic inhalations were added to the treatment.

In the first years with intensive anti-PA IV treatment the risk of cross-infection was high because the wards with inpatients receiving IV treatment were near the outpatient clinic visited by all CF patients who were also not segregated according to presence or absence of PA in their sputum.
In 1981, the Copenhagen CF Centre was reconstructed, separating the wards and the outpatient clinic. Segregation (cohort isolation) was introduced, segregating PA patients from non-PA patients in the wards, in the outpatient clinic, and during social events.
However, an epidemic spread of a multiresistant PA strain in 1983 led to further segregation of patients infected with PA sensitive strain from patients with multiresistant strain.

After the introduction of cohort isolation in 1981 the incidence and the prevalence of both intermittent PA colonization and of chronic PA infection decreased significantly.

Cross-infection
Today, the Copenhagen CF Centre segregates patients based on identification of the following bacteria from the lower airways:
1) No *PA*
2) Intermittent PA infection
3) Chronic infection with antibiotic sensitive PA strain
4) Chronic infection with multiply resistant PA strains
5) Intermittent or chronic infection with organisms belonging to the *Burkholderia cepacia complex* (each patients with B. cepacia complex forms a unique cohort)
6) *Achromobacter xylosoxidans* infection

The principles of cross infection and segregation are also strictly practised at social events arranged by the Danish CF Association. The overall aim of cohort isolation is not to expose any patient to bacteria which can turn into a chronic infection among CF patients and thereby increase the patients' need for treatment and a possible reduction of the life expectancy. This policy is well accepted and understood by both CF patients and families, even though the segregation policy may restrict patients in their social activity with other CF patients. *(Please see article "Prevention of Cross-Infections in CF" by Claus Moser and Niels Høiby in Issue 7, Volume 1-2006).*

Major important changes in Danish CF care:
1976: Elective IV antibiotic courses every 3 months against chronic PA.
1981: Cohort Isolation.
1982: The PEP mask (Positive Expiratory Pressure) – a self-administered lung physiotherapy which gave independence to the patients/families
1984: Diet change from low fat diet to high calorie diet
1989: Early intensive treatment against intermittent PA infection and daily antibiotic inhalation against chronic PA infection.
1994: Pulmozyme inhalation against chronic PA infection

PEP photo

Health care policy in Denmark
Centralized CF care and medical home care is free. However, patients over age 18 make a co-payment of 40 Euro per month. Patients on Early Retirement Pension must pay about 7 Euro per month. Patients and families with CF children under the age of 18 are reimbursed for additional expenditures in their living costs incurred by CF. There are no budget restrictions on prescribed CF drugs.

Flexible working arrangements: If a person's capacity to work is so reduced that the person cannot get a job or retain a job under normal conditions, it is possible to get a so-called Flexjob with part time employment/reduction in duty due to limitations in working capacity - for full time payment (introduced in 1998). The employer pays the full salary to the employee, and the State reimburses the difference to the employer. The Flexjob regulation seems to be a useful method enabling CF patients to stay on the labour market for a longer period and at the same time allowing them to combine a working life with optimal management of CF.

Early Retirement Pension: Persons who cannot support themselves due to long-term impairment of their capacity for work are entitled to a maintenance benefit from the Danish State in the form of early retirement pension. The average pension level for CF patients is around 1,700 Euro after tax per month.

Danish CF Adults, Education, Job, Pension: A Survey: As result of the improved centralized treatment since the late 1960's, most Danish CF patients now reach adulthood. From our perspective CF patients' connection to labour market is important because of the implication it has on CF patients' social and personal life. A survey was performed in 2002 by Liat Damsbo Lund, social worker at the Copenhagen CF Centre and Erik Wendel of the Danish CF Association to analyse social status among CF adults. The conclusion of the survey is - a large number of Danish CF adults are doing very well during education and working on normal working conditions. However, a considerable portion of the patients have been forced to prolong or drop education and stop or change working conditions due to CF. This indicates that CF has a major impact on education and employment.

Vocational and job guidance has therefore become a dominant issue for the Danish CF Association to identify and avoid potential barriers to education and employment, allowing the CF patients to combine their job with optimal management of CF for as long as possible. For more information, please visit: www.cff.dk and click "English" under "CF-Foreningen m.v."

CF Schools for Children and Teens
In 1997, CF specialist nurse Vibsen Bregnballe launched a 'CF school' at the Aarhus CF Centre. Today, the school offers lessons in CF in combination with some of the monthly outpatient clinic visits for CF children at the ages of 5, 10, 14 and 16-18. The aim of the school is to improve the children's knowledge about CF, to teach the children how to cope with the disease, and to teach children how to take responsibility for their care. The Copenhagen CF Centre has also established school for their CF children and teenagers.

The Danish CF Association (CFDK)
CFDK was founded in 1967 by a group of parents, grandparents and medical doctors. The first chairman of the association was the founder of the Copenhagen CF Centre Dr. EW Flensborg. Since 2004, Bjarne Hansen, a top executive from the business community is the chairman of the association. The Board of Directors consists of patients, parents and medical doctors.

Administration and patient advocacy is carried out by 3 staff members. CFDK's mission and objectives are the well-known issues: to support the patients, to support the research and to disseminate knowledge of CF.

Racing cyclists in CF shirts exhibiting the words "cystic fibrosis" is a helpful tool to disseminate information on CF and to attract media, in particular when one of the cyclists is a PWCF - here the Dane *Henrik Gade* (CF, 15 yrs), who raced against Richard Virengue in 116 km RITTER Classic Cycle Race 2005.

In 1998, "Code of Conduct" regarding donations was introduced by the Danish CF Association (www.cff.dk – Code of Conduct). Besides fundraising, patient camps, continued patient advocacy, guidance, and family courses and information. The agenda includes:

- Lobbying for continued optimal CF care and social welfare
- Quality control of CF care
- Maintaining positive media coverage
- Fund-raising, participation with local chapters, and recruiting new members to take action
- Identifying and making a continuous assessment of the patient group's problems, needs, wishes
- Supporting the need for biotech research and development
- Addressing ethical issues such as carrier screening

Erik Wendel has 39 years of "Copenhagen patient experience" behind him. The yearly costs of his treatment are about $275 USD thanks to Danish healthcare policy.

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