

Living with Cystic Fibrosis in Poland

Alicija Rostocka
President, Polish CF Association

Poland is a country in Central Europe with an area of 322, 575 square kilometers and a population of 38 million people. About 1,050 people are known to have Cystic Fibrosis. For the past 10 years we have had a newborn CF screening program in 8 provinces (about half of Poland).



What does it mean to be a Polish person diagnosed with CF? Poor survival, expensive medical care, and a lot of suffering, trouble and misunderstanding. In Poland the mean age of survival for CF patients is only about 17 years. This is less than in USA and less than in many European Union countries. Below are some areas we feel may have affected this:

1) **Diagnosis**

Babies are diagnosed much earlier now in centers where screening is available, so diagnosis occurs early in most cases.

2) **The huge costs of medicines**

The average cost of medicines that every patient needs is about 150 Euro per month. This does *not* include Tobi, nebulisers, special dietary substances or vitamins. The 150 Euro only covers basic medicines. Given that the average salary is 900 Euro per month in Poland and 80% of people earn less than that, means that Polish parents can't afford to pay for everything that their CF children need, including good nutrition and pancreatic enzymes.

3) **Physiotherapy**

Because physiotherapists do not do house calls, parents have to do physiotherapy for their children themselves. This means many parents choose to stay at home and do not earn a second income.

4) **Cross-infection in Hospitals – the most serious issue**

Polish patients have access to very good medicines in hospitals and doctors and nurses are well educated but they do not follow accepted standards for treating CF. The policy of segregating CF patients while they are in hospital is not followed. CF patients are not separated in hospital and patients with *Pseudomonas aeruginosa*, patients with MRSA and CF patients with no lung infection are placed in the same room. They infect each other and as a result they get medicine resistant strains of bacteria. It results in multiple hospital visits where they are infected again resulting in a vicious cycle.

CF families in Poland founded the Polish Society Against Cystic Fibrosis 21 years ago to help improve the lives of CF patients and their families. For the most part, members include CF patients



and their families. However, any person eager to organize and provide help to people with CF can also become a member. Almost 90 % of Polish CF patients are members of the Society.

The aims of Society are to:

- Improve the quality of life for CF patients
- Assist patients with cost of medications, oxygen and funding for lung transplants
- Improve the standards of medical care, especially the control of cross-infection
- Support the patients and their families
- Establish a Cystic Fibrosis Treatment and Rehabilitation Center

The Society had very humble beginnings and was very poor for the first 17 years. They employed one secretary, organized one small conference a year and tried to send a bulletin regularly. Their funds were limited and they were not able to provide direct support to patients. About 4 years ago everything started to change; and the Society now employs 5 people and continues to be involved in many projects:

- Large annual conference with workshops for 200 parents once a year.
- Spreading information through a regular CF bulletin with ~ 100 pages of information for CF patients, parents and doctors and other health professionals
- Purchased 120,000 Euro of physiotherapy equipment and gave it to patients free of charge. They plan to continue this project because except for nebulizers, physiotherapy equipment is not refunded for CF patients in Poland. Even oxygen equipment has to be purchased for the full price.
- During past 12 months the Society gave financial help to buy medicines for 350 patients. The poorest patients got money for one year of treatment.
- A sponsor paid for 7 lung transplants at a total cost of 700,000 Euro. These were the first lung transplants for Polish CF patients. The operations were performed in Vienna and 7 young people got their lives back. This project is continuing and more patients are waiting for transplants.
- Provide funding for a physiotherapist who provides help and advice for CF patients.
- Purchase large quantity of Nutridrinks at a low price and sell it to CF patients, saving them almost 50% of the retail price.

The income of the Society has increased from 40,250 Euro in 2004 to 400,000 Euro in 2007 and is still growing. What happened in 2004 that the Polish CF Society stopped being a poor and helpless organization?

First of all, we stopped hiding CF. We contacted the main Polish television stations and parents and patients started to talk about their lives with the media. During just one half-hour TV program, the Society received 60,000 Euro via SMS pledges. Newspapers, posters, leaflets and calendars helped to inform people about the problem. Once they knew about the problem they could and did help.

In addition the Board of the Society stopped working in isolation; 761 families can do much more than 7 board members. We stimulate parents to take action in their regions. We now have very active families in every part of Poland. We ask for help from volunteers and we cooperate with other organizations. Most importantly we now have Government funds for a disability pension for people with CF.

Three years ago Polish CF Association got special status from the Polish government as a Public Interest Organization. Every taxpayer can allocate that 1 % of their income tax to such an organization, which provides us with a continuous stream of income. Taxpayers can choose which special status organization they want so we convince people to pay to the CF Association.

In summary, we do a lot, but there is still a lot of work in front of us. We don't want our children to die before their parents do. We believe we will succeed. We must.