

# **8<sup>th</sup> National Polish Cystic Fibrosis Week**

## **23.02.2009 – 1.03.2009**

### **Polish activities RARE DISEASE DAY**

[www.rarediseaseday.org](http://www.rarediseaseday.org)

This is already new edition of polish social campaign, which aim is to build awareness of Cystic Fibrosis – **8<sup>th</sup> Polish Nationwide Week of Cystic Fibrosis**. The theme of the action in this year is **“Cystic Fibrosis. Know more, treat better”**. The campaign is patronaged by Ministry of Health. It is organized by Foundation for Help Families and Suffers for Cystic Fibrosis MATIO ( Polish CF Association MATIO) as regular, annual educational program concerning cystic fibrosis and genetic diseases.

Early diagnosis allows introducing appropriate treatment and physiotherapy and ensures better and longer life. Medical standards of treatment Cystic Fibrosis are in Poland still under expectations. Proper medical care is the key condition for keeping good health and quality of life for CF patients. That's why it is so important to inform people, including doctors about this complicated disease and its consequences. Additional problem is to accept in near future by Ministry of Health CF as a rare disease, not only chronic one, what can change the situation of polish patients for better.

The medical experts and celebrities (polish young actress), parents and Foundation start campaign with press briefing (23 February). Thousands of posters and leaflets are exposed in many cites and villages, at hospitals, at praxis, medical universities, university campus, schools, kindergartens, schools for young parents as well as in the shops visited by young parents. There is also the possibility of medical consultation in 20 cities (by telephone).

People who are interested in getting information about CF and life of CF suffers can call a special number or ask their questions via e-mail and they will be provided with relevant information. The website of Foundation ([www.mukowiscydoza.pl](http://www.mukowiscydoza.pl)) is widely promoted in Internet. Numerous articles describing cystic fibrosis disorder and individual cases of CF suffer are published during campaign.

Other campaign actions include:

- Small workshops with medical experts
- press materials and numerous article etc. about CF and patients
- Edition of occasional postcards
- Occasional stamp
- Awareness public opinion poll ( made by Millward Brown SMG/KRC)
- Many other actions organized by volunteers in numerous cities.

#### **Who is Matio Foundation?**

Foundation for help Cystic Fibrosis Sufferers and their Families MATIO (Polish Cystic Fibrosis Foundation MATIO) is an independent organization which points towards helping children and their families who are suffering from this incurable sickness. The Foundation intends to cooperate with all research and development centers in Poland and abroad which focus their attention on cystic fibrosis issues. Our main objectives are:

- educating the public, the sick and their families to increase awareness about mucoviscidosis,

- helping the sick with buying required medicine and rehabilitation equipment,
- organizing and financing home care trainings for sick children's relatives,
- financing mucoviscidosis-related publications,
- advocating increased support for comprehensive scientific research and clinical trials
- taking care of the sick and their families
- co- operation with medical centres worldwide