



# Polish Society of Mucopolysaccharidosis (MPS) and Rare Diseases

Gloskow, 15 March 2011

## Invitation

**Ultra-rare patient – doesn't mean worse - but extraordinary**

The Board of Polish Society of Mucopolysaccharidosis and Rare Diseases located in Gloskow invite to the 9th East European Scientific-Training Conference

**„Rare Diseases - diagnosis, treatment and patient care“**



The conference will be held from 15 to 17 July 2011 in Cedzyna near Kielce. Outstanding scientists in the field of mucopolysaccharidosis and rare diseases, the doctors treating the enzyme replacement therapies, leaders of patient organizations in the country and abroad and representatives of the government will participate in it.

The Conference Venue:

"ECHO" Hotel in Cedzyna

Training – Holiday Resort, 25-900 Kielce

**The aims of the conference**

Collaboration among medical centers, government officials, representatives of patient organizations, and taking steps towards the use of proper diagnostic services, including training of doctors, physiotherapists, nurses, access to specialized medical care and ensuring continuity of reimbursement of orphan drugs.

We do our best to develop permanent cooperation between medical institutions and organizations of patients with rare diseases, through constant cooperation, we want to improve the plight of patients with MPS and rare diseases. We believe that the key issue is equal access to treatment for all patients in Europe and worldwide.

Through the organization of scientific conferences and training we want to improve knowledge of treatment, specialist medical care and social awareness and through a coordinated nationwide action we can improve the quality of life of patients with rare diseases in Poland and abroad.



The conference, which is organized by the MPS Society in Poland, will bring the issues and opportunities for the treatment of rare diseases. Diseases, which will be discussed during the conference, are extremely rare and knowledge about them is still insufficient. **Our goal is to improve the quality of medical services and care for children with rare genetic diseases.**

On behalf of all members of the Polish Society of MPS and Rare Diseases, thank you for the trust and we invite all interested in the plight of patients with MPS and rare diseases to participate in the conference.

**The Conference organizer** – Polish Society of MPS and Rare Diseases will book your conference accommodation and meals. Admission to the conference is free of charge. The hotel is accessible for disabled people. If you have any questions, please do not hesitate to contact me.

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Sincerely yours,

The President of the Society

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