



CEE GN

Central & Eastern European Genetic Network

CEE GN is a coalition of patients, family support groups and individuals, working together with scientists and industry to support people with common and rare genetic and congenital conditions and their families in countries of Central and Eastern Europe.

CEE GN was founded in October 2003 in Cavtat, Croatia, at a meeting where representatives from 8 central and eastern European countries were present.



CEE GN is focused on understanding the common needs of patients with genetic diseases and their families in order to improve the medical care these patients receive consistent with the level received in other European Union countries.

CEE GN network currently counts
alliances of national patient organisations
and individuals in 8 countries:

- **Poland**
- **Hungary**
- **Czech Republic**
- **Slovenia**
- **Bulgaria**
- **Ukraine**
- **Croatia**
- **Serbia & Montenegro**

CEE GN looks for new members
within patient/parent
organizations, individuals who
wish to set up a patient
organisation as well as scientists
and scientific groups and
institutions from Central and
Eastern European Countries.

More information at:

<http://www.ceegn.org/>



Polish Society of Mucopolysaccharidosis and Related Diseases

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Polish Society of
Mucopolysaccharidosis and
Related Diseases was formed in
1990. It was initiated by Prof.
Anna Tylki Szymańska and
parents of children with MPS.

The Polish MPS Society associates approximately 100 families with about 150 affected by MPS children and other related diseases:

- Mucopolidoses
- Mannosidosis
- Fucosidosis
- Sialidosis
- Other very rare genetic diseases

MPS I type Hurler - 11 cases



MPS II type Hunter - 35 cases



MPS III type Sanfilippo - 45 cases



MPS IV type Morquio - 25 cases



MPS VI type Maroteaux-Lamy 3 children



Mucopolipidosis - 8 cases



Mannosidosis - 6 cases



The Polish Society of MPS and Related Diseases has about 160 members:

- 120 – people with MPS
- 6 – Mannosidosis
- 8 – Mucopolipidosis
- 28 cases with other rare genetic diseases

Main aims of the Society of Mucopolysaccharidosis and Related Diseases:

- unite all families of MPS children in Poland,
- increasing public awareness of MPS,
- creation of a fund to help all affected children
- prompting scientific researches and analysis mutually cooperating with MPS specialists, both national and international,
- organizing an international network of MPS societies, co-operating throughout the world.

Between 1990-1999 Polish Society organized the rehabilitation camps (2 weeks) twice a year for children affected by MPS and their families. Since 2000 we organize it only once a year. Those kind of meetings bring a great support to our families.



The aim of this rehabilitation camp is to change the experience and mutual help between parents, to learn how to rehabilitate and take care of MPS children and of course psychological support and social integration in the society.

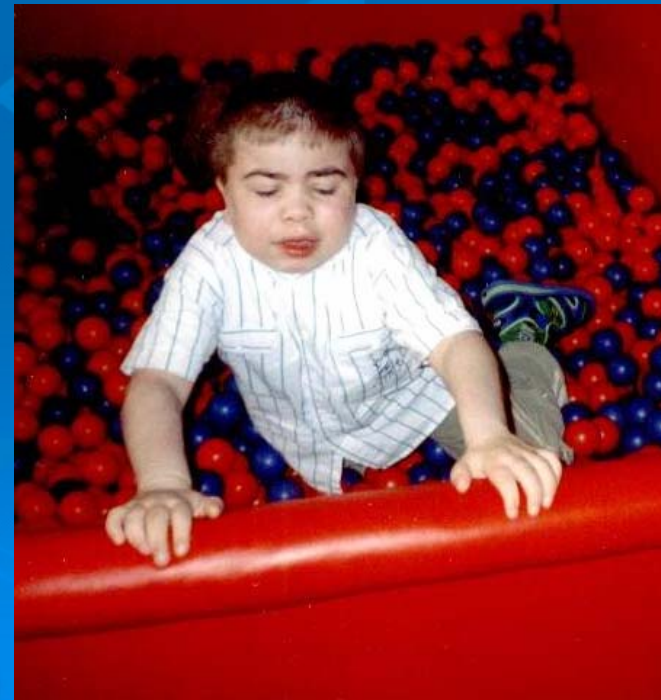


During the camp we organize the annual family conference, where our families are informed about news in researches and progress in the therapy. We also arrange individual meetings with various professionals of medicine.



Our society is giving a newsletter every 4 months, we also public and propagate brochures, leaflets and informers about MPS and related diseases and quarterly The General Polish Information Bulletin, where we print all information about treatment of MPS effects and possibilities of treatment and progress in researches provided by scientists all around the world; information about families living with MPS and their troubles and needs, low advices etc.

We buy and lend rehabilitation equipment for our patients, for example: aspirators, anti-bed-sores mattresses, inhalers etc. We help families to buy diapers, tidiness means, and as much as we can we give the financial support for families in really bad financial conditions.



In January 2001 we applied to the Ministry of Health in the following matters:

- To register MPS as a chronic disease,
- To fund the treatment for MPS I,
- To get a special medical care for children affected by rare and incurable diseases,
- To take over disabled children and their families as a governmental programme of early intervention.


Until 2003 every few weeks we have sent remainders in these matters without an effect. Since April 2003 we started hard negotiations with Ministry of Health, they lasted until September. And thanks to it we finally have got the permission for funding treatment MPS I Hurler.

We wouldn't get it without the great support from wonderful people like: Prof. Tylki Szymańska, Prof. Grzegorz Węgrzyn, Prof. Anna Dobrzańska - The National Consultant in Paediatrics, The spokesman of children and patients rights, The Commissioner of Matters of Disabled People.

But the most effective help we have got from television, press, radio. Every day they have emitted materials about problems of MPS children.

Currently in Poland there are 11 diagnosed and treated children with MPS I. Surely it is the reason to be happy, but it is only one point from our list of expectations, we still have three more points to do, as well as rearrange the social care for children and families, who live with rare genetic diseases.






Unfortunately until today we have not received any answer for our application forms from the government.

Our Society is doing everything to improve the way of life of people affected by rare diseases. We will do as much as we can to help them to get treatment, high-professional medical care and social care..





I would like to pay attention how much important is organizing meetings and conferences, connected with treatment of rare diseases. We really care about spreading the knowledge about treating, helping and taking care of people affected by rare genetic diseases.

The knowledge about that topic is not good enough to effectively treat the results of these diseases.

I am very glad I had an opportunity to introduce the situation of Polish National MPS Society and problems of children living with MPS in Poland.

