

Federation of Rare Diseases Patients' in Central and Eastern Europe



MPS II Russia



MPS III Poland



MPS VI Belarus

The tragedy of rare disease patients lies in their regress, that is a reverse development in both physical and psychic terms. Such persons are born as normal, healthy children, however, some time later the disease manifests itself causing extremely dramatic changes which make beloved children hard to be accepted by others as they grow. In most cases, they die before coming of age.

**Only together are we able to save their lives!
We can help those without treatment to live in dignity, with no pain and suffering!**

Objectives of the Federation of Rare Diseases Patients in Central and Eastern Europe

- to integrate families of the MPS and rare diseases patients in Central and Eastern Europe,
- to draw attention of the public to problems of the MPS and rare diseases patients,
- to establish funds in order to provide assistance to all persons affected by a rare disease.

HOW?

- through establishment of contacts by families with children suffering from MPS and rare diseases,
- through annual conferences during which parents and doctors can meet and obtain necessary information,
- through publishing, in the press, radio, television and websites, information addressed to all interested in problems of the MPS and rare diseases patients,
- through facilitating dissemination of medical knowledge and techniques in the area of MPS and other rare diseases all over the world,
- through attracting sponsors and donors whose donations make it possible to help children suffering from MPS and rare diseases and their families,
- through improving quality of life of the MPS and other rare disease patients in all countries of Central and Eastern Europe,
- through common organisation of meetings and events aimed at development and promotion of new methods of rare diseases treatment,
- through putting pressure on a given state to ensure treatment and specialist medical care to rare diseases patients,
- through stimulating scientific researches and cooperation of experts in the area of rare disease in individual countries and all over the world,
- through development of an international network of cooperation with MPS associations all over the world.

The Federation of Rare Diseases Patients in Central and Eastern Europe was established on 25 July 2010 in Poland.

Don't wait - You can help us, too - support those who need it.

the Federation cares about patients with rare diseases such as:

Mucopolysaccharidosis: MPS type I, Hurler's syndrome; MPS type II mucopolysaccharidosis, Hunter's syndrome, MPS type III – Sanfilippo syndrome, MPS type IV – Morquio syndrome, MPS type VI – Maroteaux Lamy syndrome, MPS type VII – Sly, Mannosidosis, Mucopolipidosis, Sialidosis, Fucosidosis, Pompe disease, Niemann-Pick disease, type B and C, Gaucher disease, Fabry disease, Epidermolysis bullosa (EB), Aspartylglucosaminuria, Ceroidlipofuscinosis, Krabbe Disease, Jadaassohn syndrome, Metachromatic leukodystrophy G-34, GM 1-Gangliosidosis, GM 2-Gangliosidosis; Hallervorden – Spatz Disease (HSD) HSS Syndrome NBIA, Pallister - Killian syndrome, Homocystinuria, Hiperammonaemia type II, PNH - paroxysmal nocturnal hemoglobinuria, LEMS - Lambert Eaton Myasthenic Syndrome, and other ultra-rare diseases.

Please contact us – seriously ill children wait for You and your help!

Where can you obtain medical advice concerning mucopolysaccharidosis and other rare diseases?

You can get information on diagnostics, treatment and medical care from the members of the Board of the Federation of Rare Diseases Patients' in Central and Eastern Europe.

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Founding Committee for the organisation of patients from Central and Eastern Europe (Belarus, Lithuania, Russia, Poland and Ukraine)

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