















Invitation

11th European Conference On Rare Diseases

"Rare Diseases and Upcoming Challenges"

The Society of Mucopolysaccharidosis and Rare Diseases hereby invites you to attend the international conference held on 28-30 June 2013 in Spała, a picturesque holiday resort located in central Poland.

Amongst the chief assets of Spała is its strategic location: 110 km from Warsaw, 60 km from Łódź, and 9 km from Tomaszów Mazowiecki.

Conference Venue:

Ośrodek Wypoczynkowo - Szkoleniowy "Zacisze" Spała, ul. Piłsudskiego 20, 97-215 Inowłódź.



Attendees:

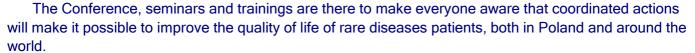
- ☑ Top scientists specialising in rare diseases both from Poland and abroad,
- Physicians administering enzyme replacement therapies,
- Leaders of patient organisations both from Poland and abroad,
- ☑ Representatives of civil servants.

Conference will include:

- ☑ Lectures and seminars for physicians and therapists,
- ☑ Medical consultations.

Conference objectives:

The objective of the Conference is to introduce you to the multifaceted nature of rare diseases.



Through the participation of some outstanding domestic and foreign scientists and speakers, we would like to present the latest scientific advances and knowledge in the field of rare diseases. Also, we would like to make one aware that the rarity of orphan diseases is no 'tormenting question' that ought to be avoided, but rather a spur to development and a virtual humanity test for all of us, including civil servants.

Thus, we would warmly welcome scientists of renowned medical facilities and civil servants. On behalf of the Organising Committee and the members of the MPS Society, we would like to thank you for your trust and cordially invite all those interested in the difficult circumstances of rare diseases patients to the Conference.

The Conference is organised by:

Stowarzyszenie Chorych na Mukopolisacharydozę i Choroby Rzadkie (The Society of Mucopolysaccharidosis and Rare Diseases) with its seat in Głosków in collaboration with rare genetic diseases societies.



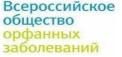




















Medical Sessions:

June 28, 2013 (F	riday)	
8:00- 9:00	Registration	
9:00-11:00	The role of fundamental science in rare diseases	
11:20-13:00	II. Diagnostics in metabolic and genetic disorders	
14:00-16:00	III. Metabolic and other rare diseases - the clinical picture	
16:20-18:00	IV. Metabolic diseases and new therapeutic options	
19:00	Barbecue (Dinner)	
June 29, 2013 (S	aturday)	
8:00- 9:00	V. Different countries experience in rare diseases	
9:00-11:00	VI. Rare diseases - European Union guidelines	
11:20-13:00	VII. Rare diseases in the Polish health care system - Round-table talks - suggestions of patients organisations	
14:00-16:00	VIII. Dysmorphology session	
16:20-18:00	IX. Dysmorphology session	
20:00	Formal Dinner	
June 30, 2013 (S	Gunday)	
8:00-11:00	X. Rare diseases, diagnostics, clinical picture, treatment, patient care	
11:20-13:00	XI. Rare diseases, treatment, diagnostics, clinical picture, patient care	
14:00-18:00	Medical consultations	
14:30-17:00	Trip for conference participants	
17:00-18:00	Mass for patients and their families celebrated in the historic Church dating back to the 1923, dedicated to the Blessed Virgin Mary, the Queen of Poland	
18:00-19:00	Dinner	
Monday, July 1,	2013	
7:00-8:00	Breakfast	
Airport transfer		

Parallel sessions

June 28, 2013 (Friday)		
10:30-11:30	Rare diseases in the Polish health care system	
11:30-13:00	Legislation translated into professional medical care of rare diseases patients	
14:00-18:00	The Federation of Rare Diseases Patients in Central and Eastern Europe: the present and the future	
19:00	Barbecue (Dinner)	
Parallel session	- lectures for patients and carers	
June 29, 2013 (Saturday)	
10:00-11:00	Treatment, specialist medical care and rehabilitation	
11:20-13:00	Specialist medical care in rare diseases	
14:00-16:00	Physiotherapy and rare diseases patients management	
16:20-18:00	Diagnostics and treatment of lysosomal diseases	
20:00	Formal Dinner	



















Co-organised by:

Federation of Rare Diseases Patients' in Central and Eastern Europe,



Association of Patients with Mucopolysaccharidosis and Rare Diseases, PL,



Ukrainian public organization "Association of Persons with Disabilities - patients with MPS"

Belarusian Organization of patients with MPS and other rare genetic disorders

Russian Association of Rare Diseases (RARD)

Union of patients and patient organizations with rare diseases



EURORDIS, Rare Diseases Europe



foundation Watch Health Care im. Prof. Jacka Ruszkowskiego

Scientific Committee

1. prof. n. med. Anna Tylki-Szymańska

Russian Union of Patients

- 2. prof. n. med. Małgorzata Krajewska-Walasek
- 3. prof. n. med. Anna Latos-Bieleńska
- 4. prof. n. przyr. Grzegorz Węgrzyn
- 5. prof. n. med. Aldona Dembińska-Kieć
- 6. dr hab. n. med. Agnieszka Ługowska
- 7. dr n. przyr. Barbara Czartoryska
- 8. dr n. med. Jolanta Kubalska
- 9. dr n. med. Jolanta Wierzba
- 10. dr n. med. Tomasz Kmieć
- 11. dr n. med. Dariusz Rokicki
- 12. dr n. med. Jolanta Marucha
- 13. dr n. med. Ekaterina Zakharova



A "ship" on the Spała pond

Organizing Committee

- 1. Teresa Matulka President of the Board of the Society of Mucopolysaccharidosis and Rare Diseases,
- 2. Małgorzata Doroba Foreign Administrator, MPS and Rare Diseases,
- 3. Aneta Trochimiuk Member of the Board of the Society of MPS and Rare Diseases,
- 4. Justyna Matulka Collector of the Society of Mucopolysaccharidosis and Rare Diseases,

Pursuant to the Minister of Health Regulation of 6th October 2004 on the means of fulfilling obligation of continuous medical education, participants to the Conference will be awarded educational points.

On behalf of the organisers of the Conference, you are now warmly invited to attend. You will be offered a friendly, family atmosphere, high quality lectures and relaxation amidst the natural wonders of the Spała Landscape Park.

We cordially invite you to participate in the conference

We will reserve rooms and board for you for the time of the conference. There is no conference fee. Information available on the website www.chorobyrzadkie.pl

The conference center is accessible for people with disabilities. Please do not hesitate to contact us if you have any questions: sekretariat@chorobyrzadkie.pl

Kindest regards,

President of the Society

Teresa Matulka



European bison reserve in Spała











