



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.

The Conference, seminars and trainings are there to make everyone aware that coordinated actions will make it possible to improve the quality of life of rare diseases patients, both in Poland and around the world.

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 Głusków in collaboration with rare genetic diseases societies.



Medical Sessions:

June 28, 2013 (Friday)		
8:00- 9:00	Registration	
9:00-11:00	I. The role of fundamental science in rare diseases	<input type="checkbox"/>
11:20-13:00	II. Diagnostics in metabolic and genetic disorders	<input type="checkbox"/>
14:00-16:00	III. Metabolic and other rare diseases - the clinical picture	<input type="checkbox"/>
16:20-18:00	IV. Metabolic diseases and new therapeutic options	<input type="checkbox"/>
19:00	Barbecue (Dinner)	
June 29, 2013 (Saturday)		
8:00- 9:00	V. Different countries experience in rare diseases	<input type="checkbox"/>
9:00-11:00	VI. Rare diseases - European Union guidelines	<input type="checkbox"/>
11:20-13:00	VII. Rare diseases in the Polish health care system - Round-table talks - suggestions of patients organisations	<input type="checkbox"/>
14:00-16:00	VIII. Dismorphology session	<input type="checkbox"/>
16:20-18:00	IX. Dismorphology session	<input type="checkbox"/>
20:00	Formal Dinner	
June 30, 2013 (Sunday)		
8:00-11:00	X. Rare diseases, diagnostics, clinical picture, treatment, patient care	<input type="checkbox"/>
11:20-13:00	XI. Rare diseases, treatment, diagnostics, clinical picture, patient care	<input type="checkbox"/>
14:00-18:00	Medical consultations	<input type="checkbox"/>
14:30-17:00	Trip for conference participants	<input type="checkbox"/>
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	<input type="checkbox"/>
18:00-19:00	Dinner	
Monday, July 1, 2013		
7:00-8:00	Breakfast	<input type="checkbox"/>
	Airport transfer	<input type="checkbox"/>

Parallel sessions

Parallel session - for patient organisations and members of the Federation of Rare Diseases Patients in Central and Eastern Europe		
June 28, 2013 (Friday)		
10:30-11:30	Rare diseases in the Polish health care system	<input type="checkbox"/>
11:30-13:00	Legislation translated into professional medical care of rare diseases patients	<input type="checkbox"/>
14:00-18:00	The Federation of Rare Diseases Patients in Central and Eastern Europe: the present and the future	<input type="checkbox"/>
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	<input type="checkbox"/>
11:20-13:00	Specialist medical care in rare diseases	<input type="checkbox"/>
14:00-16:00	Physiotherapy and rare diseases patients management	<input type="checkbox"/>
16:20-18:00	Diagnostics and treatment of lysosomal diseases	<input type="checkbox"/>
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)



Russian Union of Patients



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 Tyłki-Szymańska
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 Kmiec
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.chorobyzadkie.pl

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

Kindest regards,

President of the Society

Teresa Matulka



European bison reserve in Spała



Всероссийское общество орфанных заболеваний

