



# XIII International Conference

## “Rare Diseases Crossing Borders Together”

### Invitation

Association of Patients with Mucopolysaccharidosis and Rare Diseases, on the occasion of 25th anniversary of its activity, invites you to XIII International Conference on Rare Diseases, entitled *Rare Diseases - Crossing Borders Together* which will be held on 02 -06 July 2015 in Białobrzegi, at Conference and Recreational Centre “Promenada”. The centre is situated at Zegrze Lake, surrounded by forests and a beautiful park.

#### Participants of the Conference will be:

- ✎ outstanding researchers of rare diseases from the country and abroad,
- ✎ specialists in genetic, metabolic, neurological etc. diseases,
- ✎ doctors providing direct medical care,
- ✎ leaders of domestic and foreign patient organisations,
- ✎ public administration representatives.

#### The Conference will include:

- ✎ lectures for physicians and researchers,
- ✎ seminars for physicians and therapists
- ✎ medical consultations and medical case conferences.

#### Goals of the Conference:

This jubilee Conference, organised for the thirteenth time, is to highlight the needs of rare diseases patients. By organising conferences, seminars and training sessions on rare diseases we want to draw attention to common undertakings that allow to improve the lives of rare diseases patients in Poland and globally.

By inviting outstanding domestic and foreign specialists and lecturers we want to enrich the knowledge and share the latest scientific developments concerning rare diseases, and thus, improve the diagnostics and medical care of patients.

#### Conference Organisers:

Association of Patients with Mucopolysaccharidosis and Rare Diseases based in Głusków, in co-operation with Federation of Rare Diseases Patients in Central and Eastern Europe, and other associations grouping patients with rare diseases. This XIII Jubilee Conference on rare diseases is served by members of, and financed from funds of Association - MPS and Rare Diseases.

On behalf of Organising Committee and the Polish MPS Association Members, we invite cordially everybody interested in difficult situation of rare diseases patients to actively participate in the Conference. We'll do our best so that this year's conference is an event fit for the twenty-five years' activity of our Association.

Notices on participation in the Conference can be sent on-line, at the website [www.choroby rzadkie.pl](http://www.choroby rzadkie.pl), or by e-mail at: [sekretariat@choroby rzadkie.pl](mailto:sekretariat@choroby rzadkie.pl)

With compliments,

*Teresa Matulka*

Board President, Association of Patients with MPS and Rare Diseases  
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### Program of the Conference

#### Titles of sessions:

#### 2 July 2015 (Thursday)

- 14:00 - 16:00 Registration of participants
- 16:00 - 16:30 Welcome
- 16:30 - 17:00 Summary of 25 years of the Association's activity
- 17:00 - 18:00 Inaugural lecture
- 19:00 - 22:00 Welcome dinner

#### 3 July 2015 (Friday)

- 09:00 - 11:00 Fundamental science in the service of development of rare diseases knowledge
- 11:20 - 13:00 Diagnostic methods in metabolic disorders
- 14:00 - 18:00 Pathophysiology and clinic of chosen metabolic disorders
- 19:00 Barbecue dinner

#### 4 July 2015 (Saturday)

- 08:00 - 10:00 Methods of therapeutic management of rare diseases
- 11:20 - 13:00 **Social Debate** with patient organisation representatives and public administration officials
- 14:00 - 16:00 **I Dysmorphology Session:** Use of new-generation sequencing in clinical practice. Geneticists' opinions and experiences.
- 16:20 - 18:00 **II Dysmorphology Session:** Discussion on unexplained cases.
- 19:00 Dinner party

#### 5 July 2015 (Sunday)

- 08:00 - 13:00 Diagnostic problems, non-diagnosed cases of metabolic disorders.
- 14:00 - 17:00 Diagnostics and treatment of rare diseases in different countries.
- 17:00 - 18:00 Medical consultations of unknown cases.
- 18:00 - 19:00 Dinner

#### 6 July 2015 (Monday)

- 07:00 - 08:00 Breakfast
- 14:00 - 18:00 Transfer to the airport

#### Parallel sessions

Lectures for patients, guardians, rehabilitation specialists, physio- and psychotherapists

#### 4 July 2015 (Saturday)

- 10:00 - 11:30 Novelties in the treatment of rare diseases
- 12:00 - 13:30 Diagnostic options, specialist medical care
- 16:30 - 18:00 Rehabilitation methods in rare diseases
- 14:30 - 16:00 Long-term palliative care of patients
- 19:00 Dinner party

Medical case conferences and specialist consultations

#### 5 July 2015 (Sunday)

- 08:00 - 13:00 Medical consultations
- 14:00 - 17:00 Difficult case conferences
- 18:00 Dinner

Session for patient organisations and members of Federation of Rare Diseases Patients in Central and Eastern Europe

#### 6 July 2015 (Monday)

- 10:00 - 11:30 Examples of European health care systems
- 12:00 - 13:30 Role of psychological support for the patient and his/her family
- 14:30 - 16:00 Benefits from co-operation between patient organisations - exchange of experiences
- 18:00 Dinner





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### Co-Organisers

1. Federation of Rare Diseases Patients in Central and Eastern Europe,
2. Polish Association of Patients with Mucopolysaccharidosis and Rare Diseases
3. Polish Association for AHC Patients ahc-pl, Warsaw
4. Belarusian Organisation of Patients with MPS and Other Rare Genetic Disorders
5. Lithuanian Association of MPS and Other Genetic Metabolic Disorders
6. Ukrainian Association of Disabled Persons - MPS patients
7. Russian Association of Rare Diseases (RARD)
8. Union of patients and patient organizations with rare diseases
9. Eurordis, Rare Diseases Europe

### Scientific Committee

1. Prof. Anna Tylki Szymańska (Warsaw)
2. Prof. Małgorzata Krajewska-Walasek (Warsaw)
3. Prof. Janusz Książyk (Warsaw)
4. Prof. Rafał Płoski (Warsaw)
5. Prof. Anna Latos-Bieleńska (Poznań)
6. Prof. Grzegorz Węgrzyn (Gdańsk)
7. Prof. Irina Naumchik (Minsk, Belarus)
8. Prof. Nataliia Pichkur (Kiev, Ukraine)
9. Dr hab. n. med. Agnieszka Ługowska (Warsaw)
10. Dr n przyr. Barbara Czartoryska (Warsaw)
11. Dr n. med. Jolanta Wierzba (Gdańsk)
12. Dr n. med. Jolanta Marucha (Warsaw)
13. Dr n. med. Zita Krumina (Riga, Latvia)
14. Dr n. med. Ekaterina Zakharova (Moscow, Russia)
15. Dr n. med. Grażyna Kleintiene (Vilnius, Lithuania)

### Organising Committee

1. Teresa Matulka - Board President, Association of MPS and Rare Diseases
2. Małgorzata Doroba - Coordinator for International Relations, MPS and Rare Diseases
3. Justyna Matulka - Treasurer, Association of MPS and Rare Diseases
4. Anna Pruszyńska - Board Deputy President, Association of MPS and Rare Diseases
5. Aneta Trochimiuk - Commission Chairwoman, Association of MPS and Rare Diseases

Accommodation and catering have been booked for Conference Guests at Training Centre "Allianz" and Rewita WDW Rynia. Short distance from Warsaw, closeness with the nature, and comfortable accommodation conditions will let you relax and recreate.

High-quality hotel services and an excellent location promote physical activity and recreation. The above-mentioned hotels are conveniently situated at the eastern shore of Zegrze Lake - 30 kilometres from the centre of Warsaw, and surrounded by an expansive enclosed forest complex will provide our Guests with silence and relaxing comfort.



Training Centre "Allianz"



rooms



Centre Rewita WDW Rynia

On behalf of Organisers, we invite you to take part in the Conference. We guarantee pleasant atmosphere, high scientific standards, relax, and recreation among forests at Zegrze Lake.

With compliments,

**Teresa Matulka**

Board President, Association of MPS and Rare Diseases

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