



Invitation

Białobrzegi, July 1-3, 2016

„Choroby Rzadkie - nasze zadanie”

„Редкие болезни-наша задача”

„Rare Diseases - our task”



Dear Sir/Madam,

The Association of Patients with Mucopolysaccharidosis and Rare Diseases would like to invite you to the 14th International Rare Diseases Conference, titled “**Rare Diseases - our task**”, to be held between 1-3 July 2016 in Białobrzegi at the “Promenada” Conference and Recreational Centre. The Centre is located at the Zegrzynski Reservoir. It is surrounded by forests and a beautiful park.

The conference will be attended by:

- ✂ renowned Polish and foreign scientists specialising in rare diseases,
- ✂ metabolic disease specialists, geneticists, neurologists and cardiologists,
- ✂ physicians providing direct medical care to patients,
- ✂ health care system experts, representatives of the public administration,
- ✂ leaders of Polish and foreign patient organisations.

Conference will include:

- ✂ lectures for physicians and scientists,
- ✂ seminars for physicians and therapists,
- ✂ medical consultations and case conferences,
- ✂ a debate with experts.

Goals of the conference: The 14th edition of the Conference organised by our Association is aimed to bring attention to the needs of patients with rare diseases. By organising conferences, seminars and training with rare diseases as the subject matter, we wish to emphasise that our joint, coordinated efforts allow to improve the situation of patients with rare diseases in Poland and all around the world.

By inviting specialists and lecturers from Poland and abroad, we want to expand knowledge and convey the latest scientific achievements in the field of rare diseases, thus improving diagnostics and specialist health care provided to patients with rare diseases.

The Conference will also be attended by politicians, patient representatives and health care system experts who will share their experience and knowledge, which is the key to success.

The Conference is organized by:

The Association of Patients with Mucopolysaccharidosis and Rare Diseases with its registered office in Głusków in cooperation with the Federation of Patients from Central and Eastern Europe and Associations of patients with rare diseases. Conference services for the 14th International Rare Diseases Conference shall be provided by members of the Association of MPS and Rare Diseases.

On behalf of the Science Committee, Organisational Committee and members of the Association of MPS in Poland, we would like to cordially invite all parties interested in the difficult circumstances of patients with rare diseases to attend the Conference.

Yours faithfully,

Teresa Matulka

Board President, Association of MPS and Rare Diseases
Office phone: +48 22 / 757 81 97



Preliminary conference Programme

Titles of medical session

30 June 2016 (Thursday)

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

- 13.30 - 14.30 Registration
- 14.30 - 14.40 Opening the debate
- 14.40 - 15.30 Presentations of experts who will share their knowledge and experience
- 15.30 - 17.00 A Debate - with experts from the health care system, government officials and representatives of patient organizations
- 17.00 - 18.00 Questions and answers
- 19.00 - 22:00 Welcome dinner for invited conference guests

1 July 2016 (Friday)

- 7.30 - 8.30 Registration of participants
- 8.30 - 9.00 Opening of the conference
- 9.00 - 10.40 Recognition of rare diseases, access to comprehensive health care and social care.

Medical sessions for doctors, scientists, laboratory diagnosticians and physiotherapists

- 9.00 - 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 selected metabolic disorders
- 19:00 Barbecue Dinner

2 July 2016 (Saturday)

- 8.00 - 13.00 Methods of therapeutic management of rare diseases

Genetic sessions for scientists, laboratory diagnosticians etc.

- 14.00 - 16.00 Dysmorphology Session
- 16.20 - 18.00 Dysmorphology Session: Discussion on unexplained cases
- 19.00 Gala Dinner

03 July 2016 (Sunday)

- 9.00 - 11.00 Diagnostic problems, non-diagnosed cases of metabolic disorders.
- 11.20 - 13.00 Between the clinic and the laboratory – case reports.
- 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

4 July 2016 (Monday)

- 8.00 - 9.00 **Breakfast**
- 14.00 - 18.00 **Transfers to the airport**

Parallel session

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

2 July 2016 (Saturday)

- 10:00 - 11:30 Novelties in the treatment of rare diseases.
- 12:00 - 13:30 Diagnostic options, specialist medical care.
- 15.00 - 16.30 Rehabilitation methods in rare diseases.
- 16.30 - 17.30 Long-term palliative care of patients.
- 19.00 Gala Dinner

3 July 2016 (Sunday)

- 8.00 - 13.00 Medical care conference and consultation with specialists. Medical consultations.
- 14.00 - 17.00 Difficult case conferences



Scientific and Organizing Committee

Co-Organizers

Federation of Rare Diseases Patients in Central and Eastern Europe which includes

1. Polish Association of Patients with Mucopolysaccharidosis and Rare Diseases
2. Belarusian Organisation of Patients with MPS and Other Rare Genetic Disorders
3. Lithuanian Association of MPS and Other Genetic Metabolic Disorders
4. Ukrainian Association of Disabled Persons - MPS patients
5. Russian Association of Rare Diseases (RARD)
6. Union of patients and patient organizations with rare diseases

Scientific Committee

1. prof. Anna Tyłki Szymańska (Warsaw, PL)
2. prof. Małgorzata Krajewska-Walasek (Warsaw, PL)
3. prof. Segolene Ayme (Paris, France)
4. prof. Rafał Płoski (Warsaw, PL)
5. prof. Anna Latos-Bieleńska (Poznań, PL)
6. prof. Grzegorz Węgrzyn (Gdańsk, PL)
7. prof. Irina Naumchik Vsevolodovna (Minsk, Belarus)
8. prof. Nataliia Pichkur (Kiev, Ukraine)
9. prof. Shunji Tomatsu (Wilmington, USA)
10. prof. Jörn Oliver Sass (Bonn, Germany)
11. dr hab. n. med. Agnieszka Ługowska (Warsaw, PL)
12. dr n przyr. Barbara Czarłowska (Warsaw, PL)
13. dr n. med. Zbigniew Żuber (Crakow, PL)
14. dr n. med. Zita Krumina (Riga, Latvia)
15. dr n. med. Ekaterina Zakharova (Moscow, Russia)
16. dr n. med. Grażyna Kleinotiene (Vilnius, Lithuania)

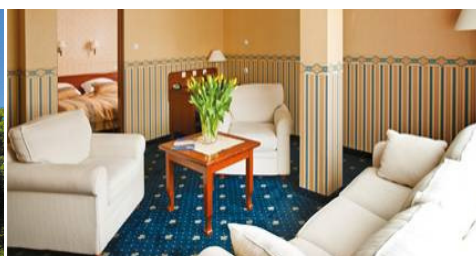
Organising Committee

1. Teresa Matulka - Board President, Polish Association of MPS and Rare Diseases
2. Małgorzata Doroba - Coordinator for International Relations, Polish Association of MPS and Rare Diseases
3. Justyna Matulka – Treasurer, Polish Association of MPS and Rare Diseases
4. Marzena Bartków - Board Member, Polish Association of MPS and Rare Diseases
5. Aneta Trochimiuk – vice -president, Association of MPS and Rare Disea
6. Tamara Matievich - Belarusian Organisation of Patients with MPS and Other Rare Genetic Disorders

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.



Training Centre „Allianz”



Rooms



Rewita Centre WDW Rynia

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.

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.



Information for Conference participants

The conference organizer:

Polish Association of Patients with
Mucopolysaccharidosis and Rare Diseases and
Federation of Rare Diseases Patients in
Central and Eastern Europe

XIV International Rare Diseases Conference



We invite you cordially to participate in the Conference,

The Board of the Association of Patients with MPS and Rare Diseases decided to organize the XIV International Conference on Rare Diseases titled „Rare Diseases - our task”. The conference aims are to raise awareness of rare diseases.

We invite prominent experts and scientists from around the world to bring knowledge and inform about the latest developments on this issue. Patients suffering from these diseases face huge problems due to the lack of dedicated professionals



Polish Association of Patients with MPS and Rare Diseases will provide the conference participants:

- ✦ participation in sessions,
- ✦ publications and conference materials,
- ✦ brochures and information on rare diseases
- ✦ educational points for physicians and laboratory diagnosticians,
- ✦ professional simultaneous translation in three languages,
- ✦ possibility to take part in medical case conferences and consultations with patients
- ✦ participation in celebrations organized by the members of the association
- ✦ coffee breaks, lunches, dinners, and accommodation

Participants who will give lectures during the conference are asked to send a registration form, short biographical note, photo, and summary of the lecture (abstract) as soon as possible, not later than by 20 May 2016

by fax +48: 22/757 81 97, @ e-mail: biuro@chorobyrzadkie.pl. For further information, please call at +48 601 300 452 or +48/22/ 757 81 97

Questions concerning the conference can be also sent to: @ biuro@chorobyrzadkie.pl

Yours faithfully,

Teresa Matulka

Board President, Association of MPS and Rare Diseases
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Białobrzegi near Warsaw, July 1-3, 2016
www.chorobyrzadkie.pl

