



# 15<sup>th</sup> International Conference on Rare Diseases „Rare Diseases - Open Your Heart And Mind“

## Invitation

The Polish Association of Patients with Muchopolysaccharidosis and Rare Diseases has the honor of inviting you to the 15<sup>th</sup> International Conference on Rare Diseases “Rare Diseases - Open Your Heart and Mind.”

The conference will be preceded by a debate attended by representatives of patient organizations active throughout the country, healthcare system experts, scientific organizations, decision-makers and the media.

The Conference will be held on 29 June - 2 July 2017 in Białobrzegi, at the “Promenada” Conference and Recreational Center. The resort is situated on the Zegrzyński Lake and is surrounded by forests and a beautiful park.

### The conference will be attended by:

- ✂ renowned Polish and foreign scientists specializing in rare diseases,
- ✂ metabolic disease experts, geneticists, neurologists and cardiologists,
- ✂ physicians providing direct medical care to patients,
- ✂ healthcare system experts, representatives of public authorities,
- ✂ leaders of Polish and foreign patient organizations,

### The following will be offered during the conference:

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

**Goals of the conference:** The 15<sup>th</sup> edition of the conference that our Association is organizing aims to draw the attention of the public to the needs of patients suffering from diseases. By organizing conferences, seminars and training sessions focusing on this particular topic, we strive to emphasize that our joint, coordinated effort contributes to improving the situation of patients with rare diseases, both in Poland and around the world.

By inviting domestic and international experts and lecturers, we intend to promote the knowledge about rare diseases and to inform about the latest scientific achievements in this particular field, thus making sure that patients are provided with access to improved diagnostic procedures and more comprehensive healthcare.

The Conference will be also attended by politicians, patient representatives and healthcare system experts who will share their experience and knowledge.

### The conference is organized by:

Polish 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, as well as numerous associations of patients with rare diseases. The 15<sup>th</sup> International Conference on Rare Diseases is organized and financed by the Polish Association of Patients with MPS and Rare Diseases.

Acting on behalf of the Scientific and Organizing Committees, as well as on behalf of the members of the Polish MPS Associations, we wish to warmly invite all those expressing interest in the situation of patients suffering from rare diseases, to participate in the Conference.

**Yours sincerely,**

***Teresa Matulka***

President of the Board, Polish Association of Patients with MPS and Rare Diseases

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Białobrzegi  
29.06-2.07.2017  
near Warsaw



29 June – 2 July 2017, Białobrzegi



**Federation of Patients with Rare Diseases from Central and Eastern Europe**  
**Polish Association of Patients with Mucopolysaccharidosis and Rare Diseases**  
**ul. Radnych 9A, 05-503 Głusków, woj. mazowieckie**



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## Medical session

### 29 June 2017 (Thursday)

#### Session for patient organizations and members of the Federation of Patients with Rare Diseases in Central and Eastern Europe

- 1.30 pm - 2.30 pm Registration of participants
- 2.30 pm - 2.40 pm Welcoming address and opening ceremony
- 2.40 pm - 3.30 pm Healthcare system vs. rare diseases - expert lectures
- 3.30 pm - 5.00 pm **Debate** - with the participation of experts, public administration officials and representatives of patient organizations
- 5.00 pm - 6.00 pm Questions and answers
- 7.00 pm - 10:00 pm Welcoming dinner for guests invited to the conference

### 30 June 2017 (Friday)

- 7.30 am - 8.30 am Registration of participants
- 8.30 am - 9.00 am Opening address
- 9.00 am - 10.40 pm Rare diseases, diagnostics, comprehensive healthcare and welfare services

#### Medical sessions for physicians, scientists, laboratory diagnosticians, physiotherapists

- 9.00 am - 11.00 am Expanding knowledge on rare diseases - contribution of fundamental sciences
- 11.20 am - 1.00 pm Diagnostic methods in metabolic and genetic diseases
- 2.00 pm - 6.00 pm From pathophysiology to the clinic in elected metabolic diseases
- 7:00 pm Dinner (barbecue)

### 1 July 2017 (Saturday)

- 8.00 am - 1.00 pm Therapeutic methods and proposals in rare diseases

#### Genetics-related sessions for scientists, laboratory diagnosticians, etc.

- 2.00 pm - 4.00 pm Dysmorphology session
- 4.20 pm - 6.00 pm Dysmorphology session - presentation of unexplained cases
- 7.00 pm Gala dinner

### 2 July 2017 (Sunday)

- 9.00 am - 11.00 am Diagnostic difficulties, unrecognized cases of metabolic diseases.
- 11.20 am - 1.00 pm Between the clinic and a laboratory - case studies
- 2.00 pm - 5.00 pm Diagnosis and treatment of rare diseases in different countries
- 5.00 pm - 6.00 pm Exchange of experience and consultations concerning difficult metabolic disease cases
- 6.00 pm - 7.00 pm Dinner

### 3 July 2017 (Monday)

- 8.00 am - 9.00 am Breakfast
- 9.00 am - a.00 pm Exchange of experience and consultations.
- 2.00 pm - 6.00 pm Transfer to the airport

## Parallel session

#### Lectures for patients, care givers, physiotherapists, therapists and psychotherapists

### 2 July 2017 (Saturday)

- 9:30 am - 11:30 am Advances in rare disease treatment
- 12:00 pm - 1:30 pm Diagnostic abilities, specialized medical care
- 3.00 pm - 4.30 pm Rehabilitation in rare diseases
- 4.30 pm - 5.30 pm Long-term patient care
- 7.00 pm Gala dinner

### 3 July 2017 (Sunday)

- 8.00 am - 1.00 pm Case studies and specialist consultations
- 2.00 pm - 5.00 am Difficult case studies
- 6.00 pm Dinner

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## Co-Organizers

**Federation of Patients with Rare Diseases from Central and Eastern EU, made up of the following:**

1. Polish Association of Patients with Mucopolysaccharidosis and Rare Diseases
2. Belorussian Organization 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 Organizations of Patients with Rare Diseases

## Scientific Committee

1. prof. Segolene Ayme (Paris, France)
2. prof. David J. Begley (London, UK)
3. prof. Johannes Berger (Vienna, Austria)
4. Barbara Czarotryska, PhD (Warsaw, Poland)
5. Grażyna Kleintiene, MD, PhD (Vilnius, Lithuania)
6. prof. Małgorzata Krajewska-Walasek (Warsaw, Poland)
7. Zita Krumina, MD, PhD (Riga, Latvia)
8. prof. Anna Latos-Bieleńska (Poznan, Poland)
9. Agnieszka Ługowska, MD, PhD (Warsaw, Poland)
10. prof. Rafał Płoski (Warsaw, Poland)
11. Nataliia Pichkur, MD, PhD (Kiev, Ukraine)
12. Prof. Natallia Rumiantseva (Minsk)
13. prof. Jörn Oliver Sass (Bonn, Germany)
14. prof. Shunji Tomatsu (Wilmington, USA)
15. prof. Anna Tyłki-Szymańska (Warsaw, Poland)
16. prof. Grzegorz Węgrzyn (Gdańsk, Poland)
17. prof. Marie T. Vanier (Lyon, France)
18. prof. Ekaterina Zakharova (Moscow, Russia)
19. Zbigniew Żuber, PhD (Kraków, Poland)

## Organizing Committee

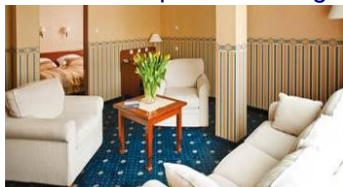
1. Teresa Matulka - President of the Board, Association of Patients with MPS and Rare Diseases PL
2. Małgorzata Doroba - Coordinator for International Relations, Association of Patients with MPS and Rare Diseases PL
3. Justyna Matulka - Treasurer, Polish Association of Patients with MPS and Rare Diseases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

## Accommodation and board

Accommodation and board have been booked for the Conference Guests at the "IRSS" Training Center and the Revita WDW Rynia resort. A short distance to Warsaw, closeness of nature and comfortable accommodation offer a perfect setting to relax and recover.



"IRSS" Training Center



Rooms



Revita WDW Rynia resort

The hotels are conveniently located on the east shore of the Zegrzyński Lake, 30 kilometers from downtown Warsaw.

On behalf of the organizers, we wish to warmly invite you to participate in the conference offering a high scientific level of lectures, a nice atmosphere and the ability to establish new professional relations and to meet the patients.

**Your sincerely,**

**Teresa Matulka**

President of the Board, Polish Association of Patients with MPS and Rare Diseases

**29 June – 2 July 2017, Białobrzegi**



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## Information for conference participants

The Management Board of the Polish Association of Patients with MPS and Rare Diseases has already begun preparations for the 15th International Conference on Rare Diseases **“Rare Diseases - Open Your Heart and Mind”**. The conference aims to deepen and promote knowledge about rare diseases.

Renowned experts from all over the world are invited to present their latest achievements in the field. Patients suffering from rare disorders are facing great difficulties due to the lack of deeply involved specialists. By holding the conference, we strive to stimulate the passion and integrate this unique group of doctors and patients, so that they may cooperate in improving the quality of the patients' lives.

### The conference participants will be provided with the following:

- ✧ participation in conference sessions,
- ✧ conference publications and proceedings,
- ✧ brochures and information on rare diseases,
- ✧ educational credits for physicians and laboratory diagnosticians,
- ✧ professional simultaneous interpretation in three languages,
- ✧ participation in cases studies and patient consultations (facultative),
- ✧ participation in events organized by Association members,
- ✧ accommodation, coffee breaks, breakfasts, lunches, dinners.

A debate will be held during the conference for patient organizations and members of the Federation of Patients with Rare Diseases from Central and Eastern Europe, attended by healthcare system experts, public authority officials and representatives of patient organizations.

Lectures for scientists, physicians, laboratory diagnosticians, therapists, as well as parallel sessions for patients and their care givers will be offered as well.



debate



medical lectures



lectures for patients

**The speakers of this year's conference** are kindly requested to submit the registration form, a biographical note, a photograph and an abstract of their lecture as soon as possible, but in no case later than by 20 May 2017. Timely submission of biographical notes and abstracts is essential for preparation of the conference materials.

**Conference participants** are requested to submit, as soon as possible, their registration forms, which will enable us to book accommodation in the neighboring hotels.

☎ fax: 22/757 81 97, ✉ e-mail: [biuro@chorobyrzadkie.pl](mailto:biuro@chorobyrzadkie.pl). For additional information, please call ☎ +48 601 300 543 ☎ +48/22/ 757 81 97

**The invitation and the online registration form are available on the website of the Polish Association of Patients with MPS and Rare Diseases -** <http://chorobyrzadkie.pl/?s=2&p=ak2#konf2017pl> and on the website of the **Federation of Patients with Rare Diseases -** <http://frd-cee.org/pl/?s=aktualnosci>, **registration form** [http://chorobyrzadkie.pl/txt/konf\\_karta.php](http://chorobyrzadkie.pl/txt/konf_karta.php)

Additional information about the conference may be also obtained by e-mail: ✉ [biuro@chorobyrzadkie.pl](mailto:biuro@chorobyrzadkie.pl)

**Yours sincerely,**

**Teresa Matulka**

President of the Board

Polish Association of Patients with MPS and Rare Diseases

☎ 601 300 543

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