



# 17<sup>th</sup> International Conference on Rare Diseases

«Don't miss ♥ a rare disease»

27-30 June 2019

**Federation of Rare Diseases Patients from Central and Eastern Europe, consisting of:**

1. Polish Association of Patients with Mucopolysaccharidosis (MPS) and Rare Diseases
2. Belarusian Organization of Patients with MPS and Other Rare Genetic Disorders
3. Lithuanian Association of MPS, Other Genetic and Metabolic Diseases
4. Russian Association of Rare Diseases (RARD)
5. Union of Patients and Organizations of Patients with Rare Diseases

## Scientific Committee

1. Professor Segolene Ayme (Paris, France)
2. Professor David J. Begley (London, United Kingdom)
3. Professor Johannes Berger (Vienna, Austria)
4. Professor prof. Timothy M. Cox (United Kingdom)
5. Barbara Czartoryska, Natural Sciences PhD (Warsaw)
6. Professor Marc Doms (Leuven, Belgium)
7. Grażyna Kleintiene, MD, PhD (Vilnius, Lithuania)
8. Professor Małgorzata Krajewska-Walasek (Warsaw)
9. Zita Krumina, MD, PhD (Riga, Latvia)
10. Professor Agnieszka Ługowska (Warsaw)
11. Professor Rafał Płoski (Warsaw)
12. Professor Natalia Pichkur (Kiev, Ukraine)
13. Professor Natalia Rumiantseva (Minsk, Belarus)
14. Professor Jörn Oliver Sass (Bonn, Germany)
15. Professor Jakub Sikora (Prague, Czech Republic)
16. Professor Shunji Tomatsu (Wilmington, USA)
17. Professor Anna Tyłki Szymańska (Warsaw)
18. Professor Grzegorz Węgrzyn (Gdańsk)
19. Professor Marie T. Vanier (Lyon, France)
20. Ekaterina Zakharova, MD, PhD (Moscow, Russia)
21. Professor Zbigniew Zuber (Cracow)

## Organizational Committee

1. Teresa Matulka - President of the MPS and Rare Diseases Association Management Board
2. Małgorzata Doroba - Coordinator for Foreign Affairs of the MPS and Rare Diseases Association
3. Justyna Matulka - Treasurer of the MPS and Rare Diseases Association
4. Aneta Trochimiuk - Vice-President of the MPS and Rare Diseases Association Management Board
5. Grzegorz Cąbrzyński - Vice-President of the Audit Committee
6. Tamara Matievich - President of the Belarusian Association of Patients with MPS and Rare Diseases

## Accommodation and board

**The accommodation and board for the guests of the 17<sup>th</sup> International Conference on Rare Diseases are booked at:**

- Exploris Training and Recreation Centre, ul. Wyzwolenia 57, 86-120 Serock
- Green Park Conference Centre – Training Centre, ul. Wyzwolenia 63, 86-120 Serock

The Centres are located in the direct vicinity of the Zegrzyński Reservoir and surrounded by forests and a beautiful park, which is conducive to active rest following the hours spent in the lecture halls.

Exploris Training and Recreational Centre  
Serock, ul. Wyzwolenia 57

Rooms

Green Park Conference Centre  
Serock, ul. Wyzwolenia 63



On behalf of the organizers, we kindly invite you to participate in the conference offering interesting lectures and a pleasant atmosphere, presence of experienced speakers from the world top centres dealing with rare diseases, a possibility to establish new scientific links and get to know extremely rare patients.

## Information for conference participants



Federation of Rare Diseases Patients from Central and Eastern Europe  
Polish Association of Patients with Mucopolysaccharidosis (MPS) and Rare Diseases  
ul. Radnych 9 A, 05-503 Głusków, Mazovian Province



# 17<sup>th</sup> International Conference on Rare Diseases

«Don't miss ♥ a rare disease»

27-30 June 2019

The Management Board of the Polish Association of Patients with MPS and Rare Diseases is organizing for the seventeenth time the International Conference on Rare Diseases, the message of which is «Don't miss a rare disease».

Rare diseases are often underestimated, and patients are sent from a doctor to a doctor; in the result, patients remain undiagnosed and untreated for many years. This causes enormous suffering and frustration of the patients who frequently, in despair, seek inappropriate and harmful treatment methods.

The objective of the conference is the better knowledge and understanding of rare diseases aiming at their fast and proper diagnosis and at shortening the patients' path to appropriate medical care. It is also an opportunity to share experiences and to conduct joint projects and research.

We invite outstanding specialists and scientists from all over the world in order to provide information on the latest achievements in the field of rare diseases, arouse passion and integrate this extremely rare and unique group of physicians and patients so as to – using our own experiences – act jointly to improve the fate of the patients.

The **registration fee** is a small contribution to the conference organisation; it is not obligatory and does not apply to speakers and special guests.

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

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

**The conference guests** are kindly requested to submit, as soon as possible, their registration forms, which will enable us to book accommodation in neighbouring hotels (hotel rooms are booked by the organiser)

**The conference speakers** are kindly requested to submit the registration form, a biographical note, a photograph and an abstract of their lecture by 1 May 2019 at the latest. 📧 e-mail: [biuro@chorobyrzadkie.pl](mailto:biuro@chorobyrzadkie.pl) for additional information, please call: 📞 +48 601 300 452 📠 +48/22/ 757 81 97 invitations and the online registration form are available on the website of the MPS and Rare Diseases Association

- <http://chorobyrzadkie.pl/?s=2&p=ak2#konf2019en> and on the website of the Federation of Patients with Rare Diseases
- <http://frd-cee.org/en/?s=aktualnosci>, application form
- [http://chorobyrzadkie.pl/txt/konf\\_karta\\_2019.php](http://chorobyrzadkie.pl/txt/konf_karta_2019.php). Questions concerning the conference may also be addressed to the following 📧 e-mail address: [biuro@chorobyrzadkie.pl](mailto:biuro@chorobyrzadkie.pl)

Every year the conference is organised and serviced free of charge by patients, their caretakers and volunteers.



**Yours faithfully,**

**Teresa Matulka**

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