



### Conference organizers

#### 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

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| 1. Prof. Segolene Ayme (Paris, France)                                    | 10. Prof. Rafał Płoski (Warsaw, PL)            |
| 2. Prof. David J. Begley (London, United Kingdom)                         | 11. Prof. Natalia Pichkur (Kiev, Ukraine)      |
| 3. Prof. Johannes Berger (Vienna, Austria)                                | 12. Prof. Natalia Rumiantseva (Minsk, Belarus) |
| 4. Doctor of Natural Sciences Barbara Czartoryska (Warsaw, PL)            | 13. Prof. Jörn Oliver Sass (Bonn, Germany)     |
| 5. Prof. Marc Doms (Leuven, Belgium)                                      | 14. Prof. Shunji Tomatsu (Wilmington, USA)     |
| 6. Doctor of Medical Sciences Grażyna Kleintiene (Vilnius, Lithuania)     | 15. Prof. Anna Tylki Szymańska (Warsaw, PL)    |
| 7. Prof. Małgorzata Krajewska-Walasek (Warsaw, PL)                        | 16. Prof. Grzegorz Węgrzyn (Gdańsk, Poland)    |
| 8. Doctor of Medical Sciences Zita Krumina (Riga, Latvia)                 | 17. Prof. Marie T. Vanier (Lyon, France)       |
| 9. Doctor habilitatus of Medical Sciences Agnieszka Ługowska (Warsaw, PL) | 18. Prof. Ekaterina Zakharova (Moscow, Russia) |

### 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 16<sup>th</sup> International Conference on Rare Diseases have been 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 wish to warmly invite you to participate in the conference offering a cordial atmosphere, a high level of medical and scientific knowledge and a possibility to establish new professional relations and get to know extremely rare patients.





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

## «Understanding rare diseases»

28 June – 1 July 2018

### Information for conference participants

**The Management Board of the Polish Association of Patients with MPS and Rare Diseases is organizing the International Conference on Rare Diseases entitled «Understanding rare diseases» for the sixteenth time.**

The conference aims to broaden the knowledge on rare diseases and help in understanding them better. It is also an opportunity to share experiences from your daily medical practice and to conduct joint projects and research.

Quite often, a medical diagnosis requires many consultations and seeking advice from colleagues. Assistance in carrying complicated biochemical and genetic tests is highly important during this process.

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 special group of physicians and patients so as to – using our own experiences – act jointly to improve the fate of the patients.

Annually, the conference has been organized and serviced free of charge by ill persons, their guardians, and volunteers.

**Conference fees:** Due to the fact that the conference is organized with funds collected by the members of the Association, we would like to ask people registering for the 16<sup>th</sup> International Conference on Rare Diseases to pay a symbolic registration fee in the amount of PLN 150.00 per participant, PLN 100 per medical student. Please transfer the above-mentioned fee to the MPS Association bank account: Bank PeKaO S.A. oddział w Piasecznie, account number: 62 1240 6175 1111 0000 4568 0739, with the note: registration fee.

The above fee is the confirmation of your booking. Should you have any difficulties in paying the above fee, please contact us via the following e-mail address: [biuro@chorobyrzadkie.pl](mailto:biuro@chorobyrzadkie.pl) or please call: 22/757 81 97.

**Registration fee** is a small contribution covering the costs incurred by the Association during the organization of the conference. Registration fees do 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 (facultative),
- ✦ participation in events organized by Association members,
- ✦ accommodation, coffee breaks, breakfasts, lunches, dinners.

**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 organizer).

**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 by 1 May 2018 at the latest**

by fax: 22/757 81 97, @ e-mail: [biuro@chorobyrzadkie.pl](mailto:biuro@chorobyrzadkie.pl)

For additional information, please call: ☎ +48 601 300 452 📞 +48/22/ 757 81 97

The invitation and the online registration form are available on the website of the MPS and Rare Diseases Association - [http://chorobyrzadkie.pl/txt/konf\\_karta\\_2018.php](http://chorobyrzadkie.pl/txt/konf_karta_2018.php) and on the website of the Federation of Patients with Rare Diseases - <http://frd-cee.org/en/?s=aktualnosci>, registration form <http://chorobyrzadkie.pl/?s=2&p=ak2#konf2018en>

Questions concerning the conference may also be addressed to the following @ e-mail address: [biuro@chorobyrzadkie.pl](mailto:biuro@chorobyrzadkie.pl)

**Yours faithfully,**

**Teresa Matulka**

President of the Management Board  
of the Polish Association of Patients with MPS and Rare Diseases  
mob. +48 601 300 452

