



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

«Don't miss ♥ a rare disease»

27-30 June 2019

## Initial programme of the conference

### 27 June (Thursday)

#### Session for patient organizations and members of the Federation of Patients with Rare Diseases

- 13.30 -14.00 Registration of participants  
14.00 -14.10 Welcome address and session opening  
14.10 -15.30 New structural solutions in the healthcare for patients with rare diseases, experts' proposals  
15.30 -18.00 Briefing with the participation of representatives of patient organizations, public administration officials and experts  
19.00 -22:00 Welcome dinner for the guests of the conference

### 28 June (Friday)

- 7.30 - 8.50 Registration of participants  
8.50 - 9.00 Welcome and opening of the conference  
09.00 - 9.20 Rare diseases, diagnostics, comprehensive healthcare and welfare services

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

- Session I** 9.20 -11.00 Research in basic sciences for rare diseases  
**Session II** 11.20 -13.00 New methods in the diagnostics of rare diseases  
**Session III** 14.00 -18.00 Metabolic diseases - from pathophysiology to the clinic  
19:00 Barbecue dinner

### 29 June (Saturday)

- Session IV** 8.00 -13.00 Therapeutic methods and proposals in rare diseases

#### Sessions V and VI - Dysmorphology

- 14.00 -16.00 Dysmorphology session - lectures  
16.00 -18.00 Presentation of unexplained genetic cases  
19.00 Gala dinner

### 30 June (Sunday)

- Session VII** 9.00 -11.00 Diagnostic problems  
**Session VIII** 11.20 -13.00 Cooperation between a physician and a diagnostician - case presentations  
**Session XI** 14.00 -17.00 Organisation of diagnostics and treatment of rare diseases in different countries  
**Session X** 17.00 -18.00 Exchange of experiences and consultations concerning difficult cases of metabolic diseases  
18.00 -19.00 Dinner

#### Parallel sessions

#### Lectures for patients, parents, caretakers and therapists

### 29 June (Saturday)

- 9:30 - 11:30 New therapeutic proposals in the treatment of patients with selected rare diseases  
11:30 - 13:30 Diagnostic possibilities, specialised medical care  
14.30 - 16.30 Rehabilitation in rare diseases  
16.30 - 18.00 Long-term patient care  
19.00 Gala dinner

### 30 June (Sunday)

- 10.00 - 13.00 Specialist case studies and medical consultations  
14.00 - 18.00 Medical consultations for difficult and undiagnosed cases  
19.00 Dinner

