

Zalău, Sălaj, România
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The National Alliance for Rare Diseases in Romania warmly invites you to attend:
BALKAN CONGRESS FOR RARE DISEASES ROMANIA
Cluj- Napoca, June 26-27, Medical University "Iuliu Hatieganu"
"Share an inspired vision in RD".

Day 1

08:30 - 9:00 REGISTRATION

09:30-10:30 OPENING OF THE CONFERENCE

Expected speeches by the Minister of Health of Romania , Local Authorities, Rector of the Medical University of Cluj- Napoca, Orphanet Europe, Eurordis, European Commission, RONARD

10:30-11:00 COFFEE BREAK

11:00-13:00 PARALEL WORKSHOPS – chair Prof. Pop Victor SRGM, Conf. Dr. Vlad Gorduza - patient representatives, professionals, policy makers, industry and other important stakeholders:
(EURORDIS, RONARD, National Organizations from BALKAN AREA collaboration activity)
(Patients, Professionals' organizations: SRGM, Orphanet, etc.)

1. Diagnosis – chair Dr. Cristina Skrypynyk
2. Treatment and rehabilitation – chair. Dr. Ioana Rotaru
3. Social services- Dr. Hubert Soyer and Norber Hoedebeck Stuntebeck Germany
4. Education and Research – Prof. Dr. Victor Pop

Each workshop will have a chair, a monitor and a reporter.

12.30 – 13.00 Report the results in the plenary session.

13:00-14:00 LUNCH

14:00-16:00 PANEL SESSION

Prof. Segolene Ayme (ORPHANET, Rare Diseases Task Force, France), Conference chair

COMMISSION COMMUNICATION ON RARE DISEASES

Antoni Montserrat Moliner (EUROPEAN COMMISSION -DG SANCO), Conference co-chair

EU INITIATIVES TO IMPROVE THE ACCESS TO CARE

Anders Olauson (president EUROPEAN PATIENT FORUM)

Eric Tambuyzer (Genzyme Health politics): Rare disease at European level and global approach;

16:00-16:30 COFFEE BREAK

16:30-18:30 PROBLEMS ENCOUNTERED IN DIAGNOSIS AND MANAGEMENT OF THE RARE DISEASES IN BALKAN AREA – chair. Dr. Cristina Rusu, Iasi

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	<ol style="list-style-type: none"> Delays in diagnosis and insufficient specialized health care services for RD in Balkan area (screening, genetic tests availability, centers, etc.) Relevant experiences in different states
18:30-19:30	GALA DINNER
Day 2	
09:00-10:30	BEST PRACTICE GUIDELINES FOR CARE MANAGEMENT
	BEST PRACTICE AND COOPERATION IN BALKANS
9:30-10:30	Prof. Dr. Grigorescu Sido, Christel Nourissier, EURORDIS, co-chair
	<ul style="list-style-type: none"> French methodology to issue best practice guidelines and co-operate with physicians in Balkans Initiatives from Balkan countries
10:30-11:00	COFFEE BREAK
14:00-17:00	<p>RARE DISEASES MANAGEMENT- chair -Dr. Maria Puiu & Dr. Marie-Claude Hittinger & Ministry of Health France Interdisciplinary approach in management of the RD (CROMOZOMIAL, METABOLIC, NEUROLOGICAL, ENDOCRINE, ETC.)</p> <p>Maryze van Schoneveld (Pompe patient; International Pompe association) Neuromuscular disease, her experience in negotiating with authorities (funding); building a Patient society; her own experience with a genetic; life threatening disease;</p> <p>Prof. Anna Tylki-Szymanska: metabolic disorders; Polish experience</p> <ul style="list-style-type: none"> 12 SCIENTIFIC PRESENTATIONS (15'/ each.) Gabor Pogony, and Janos Sandor (Hungary)
17:00-17:30	COFFEE BREAK

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17:30-18:30	FROM RARE DAY TO EVERY DAY CARE Why and how to advocate for RD – Dorica Dan, RONARD - Patients advocacy groups - Professional advocacy groups
18:30–19:00	CONCLUSIONS AND HOMEWORK
19:00-20:00	DINNER