

Agenda

Conference: Integrated Care on Rare Diseases NoRo, 10 years of activity 28.06.2021

10.00 – 11.00 – Introduction

Moderator Lisen Julie Mohr – Frambu

- Introduction – Dorica Dan - NoRo Center – 10 years of challenges and achievements
- Message from Ministry of Foreign Affairs Norway
- Ministry of Health Romania, Dr. Ioana Mihăilă
- Open remarks: Terkel Andersen, President EURORDIS- Rare Diseases Europe
- Greeting's message Kjetil Orbeck, Chairman of Frambu Foundation
- Local authorities and partners' video messages: Ionel Ciunt, The Mayor of Zalău City, Dinu Iancu Sălăjanu, the president of County Council Sălaj, Dari Toma, The Prefect of Sălaj, Dr. Ligia Marincas, Director DSP Salaj, Prof. Dr. Maria Puiu, UMF Timisoara, Prof. Dr. Emilia Severin, UMF Bucharest;

10' comfort break

11.10 – 12.30 – Sustainable partnerships

Moderator Prof. Dr. Mihai Gafencu, UMF Timisoara

- “The EEA and Norway Grants – the background and goals for the funding”, Lisen Julie Mohr – Frambu Center, Norway
- 10 years of NoRo's contributions to EU-level work and exchange of good practices, Raquel Castro - Eurordis
- My cooperation and contacts the last 15 years with Dorica Dan, PWS Romania, professionals and families, Dr. Susanne Blickefeldt, Danemarca, IPWSO
- Why is PWS care a model for complex RD? Dr. Tony Holland, Cambridge University, IPWSO
- Frambu's experiences through these 10 years of partnership, KristianEmil Kristoffersen, CEO Frambu Foundation, Norway
- RareResourceNet – European network of Resource Centers, Anders Olaoson - President, Agrenska Sweden

Lunch break – 60 minutes

13.30 – 14.30 - Needs and priorities for RDs community at EU level

Moderator Dr. Cristina Skrypnik

- Needs and priorities for RDs community at EU level, Dr. Birute Tumiene, University of Vilnius
- Patient registry on HAE and the global network, Dr. Noemi Bara, UMF Tg. Mures
- Sharing experiences and good practice with all stakeholders, in different Countries, during pandemic, Domenica Taruscio, Director, National Centre for Rare Diseases, Istituto Superiore di Sanità, Italy
- ERN ITHACA, Anne Hugon - Project Manager ERN ITHACA
- RO-NMCAID - Romanian network of Centers of Expertise, part of ITHACA ERN, Dr. Chirita - Emandi Adela, UMF Timisoara

10' comfort break

14.40 – 16.00 - Case Studies: Integrated care for RDs

Moderator – Ovidiu Condurache și Ana Murray – Ashoka România

- Frambu Center for Rare Disorders
- Robert Hejdenberg "Ågrenska experiences shows that rare disease has an impact on all aspects of our life"
- NoRo – A Resource Center for RD Romania

- Vlasta Zmacek, EB House Croatia - video
- Marta Fonfria, CREER Center Spain- video
- " A model of integrated care management of patients with neurological diseases at Dr. Victor Gomoiu Center of Expertise for neurological pediatric diseases", Dr. Raluca Teleanu.
- "To all rare patients: We can't change your genetic condition, but we guide your life - geneticist's perspective", Plaiasu Vasilica, Regional Center of Medical Genetics Bucharest, INSMC Alessandrescu-Rusescu Romania
- "Integrated care in Obregia Center of Expertise for rare pediatric neurological disease, Romanian network for discussing rare cases and integration in the European context", dr Iliescu Catrinel

10' comfort break

16.10 – 17.30 – Access to innovation and care for people with rare diseases

Moderator: Dr. Marius Geantă

How can EU/ national policies influence the care and quality of life for patients?

How to improve screening in Romania? Patient registries?

What about a national program for genetic testing?

How prepared is the national health care system for the new types of therapies? Are the Centers of Expertise ready to embrace the new therapies?

How involved are the patient organizations in all this process?

How do our Centers of Expertise organize their activities to deliver integrated and efficient care?

Is Cross Border Health Care Directive known enough?

What is the future of health digital solutions in Romania?

Panel of experts: Lidia Onofrei - Ministry of Health, Dr. Domenica Taruscio - Director of Centro Nazionale Malattie Rare, ISS Italy, Zsuzsa Almasi- NoRo Center, Prof. Dr. Maria Puiu – UMF Timișoara, Dr. Adela Chiriță-Emandi - UMF Timișoara, Prof. Dr Emilia Severin – UMF București, Dr. Diana Miclea - UMF Cluj

Location:

Online on Zoom

Access link:

<https://us02web.zoom.us/j/82187371328?pwd=RjAxRG5xbFRVY01kSWc1S0c2YS9kUT09>

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Face to face at Brilliant City Zalău

<https://brilliantcity.ro/> , Adress: Str. 1 Decembrie 1918 Nr. 10/A Zalău

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