

12<sup>th</sup> European Conference  
on Rare Diseases &  
Orphan Products

HYBRID



15 & 16 MAY 2024

 Online side event **Romanian  
National Alliance for Rare Diseases**  
13 May, zoom meeting: 15.00 -17.00



  
Alianța Națională  
pentru Boli Rare ROMÂNIA **SATELLITE EVENT**  
**Monday, 13.05.2024, 15.00 – 18.00**

**Connection of European activities for RD with the National Plan for Rare Diseases and integration into the national health care system.**

**The goal** of the ECRD satellite meeting is: to inform and exchange the views of different stakeholder's about the link between the national policies on RD and the EU policy framework for RD and to raise awareness around the collaborative efforts that must be done for clear policy recommendations that can influence both EU and national policies.

**Introduction: 15.00 -15.20**

**Moderator** – Dorica Dan, President of RONARD, Vice-President EURORDIS

**Avril Daly, President of EURORDIS – Opening remarks**

**Session I: 15.20 – 16.50 Connecting European activities for rare diseases with the National Plan for Rare Diseases**

1. Message from the Romanian Presidency: **Conf. Dr. Diana Păun, Romanian Presidency, State Councilor for Health**
2. Top priorities of the Ministry of Health for improving the quality of life of patients with rare diseases in Romania in the next period. **Alexandru Rafila, Minister of Health Romania**
3. How do you think the provision of integrated care services for patients with rare diseases can be organized? What exactly do we need? **Valeria Herdea, President National Health Insurance House**

4. Access to clinical trials for patients with rare diseases in Romania. What is the current situation? How many innovative medicines are currently accessible to patients with rare diseases and rare cancers in Romania? **Razvan Prisada, President of the National Agency for Drugs and Medical Technologies**
5. The importance of a European Action Plan on rare diseases and rare cancers! Opportunities for integrating national and European actions. **Cristian Buşoi, MEP**
6. The importance of adopting a European Action Plan on rare diseases at the start of a new European policy cycle and how such a strategy can reduce inequalities in access to care for patients with rare diseases. **Nicolae Stăfănuţ, MEP.**
7. How can a cross-sectoral collaboration platform be initiated to develop a strategy for integrated care for persons with disabilities caused by rare diseases? **To be confirmed**
8. Access to innovative treatments for patients with rare diseases: where are we? How can we progress? **Bianchi Ioana, ARPIM Foreign Affairs Director**

**Break – 10 min**

### **Session II: 17.00 -18.00 Integration of good practices at European level into the national health care system**

**Moderator:** Emilia Severin, Vice-President of the National Council of Rare Diseases, UMVCD

#### **Centers of expertise for rare diseases, between opportunities and challenges. National networking and active participation in European networks.**

1. National Coordination Centre for Rare Diseases – interface between the national health system and the European one - Maria Puiu, Romanian representative in the Board for ERN of the Member States,
2. UMFT JARDIN – a project for the implementation of European recommendations, Ioana Streaţa, project coordinator JARDIN Romania, UMFCV
3. The role of ePAGs in ERN – Dorica Dan, Arabela Acălinei, Michaela Dan
4. Good practice examples:
  - Is it an advantage to be part of networks? Is it easy? Difficult? Centers of Expertise in zoom

#### **Conclusions of the session**