

# EMM 2019 Bucharest

16-18 May 2019

Crowne Plaza Bucharest

Thursday 16 May

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## Satellite meetings

**09.00-09.30** Registration- satellite meeting

**09.30-12.30** Eastern European Patient Organizations Workshop **ROOM: CROWN**

Share common best practices and challenges in Rare Disease policy, most Eastern European countries now have a national strategy for Rare Diseases and provide better healthcare services to people with rare diseases than in previous years. Patient associations are becoming more active, pushing Ministries of Health to consider EU legislation and best practices on rare diseases. However, the gap between EEC and EU member states remains a challenge and requires more attention, exchange of best practices and networking in the region. Share common best practice and challenges in RD policy in EE Countries can contribute to:

- Better understand the mechanisms that meaningfully engage people living with a rare disease and their representative in the region;
- Best practice exchange in organization of care, design, implementation and monitoring of care policies;
- Improved information and cooperation of patient organizations to face the challenges posed by the limited resources;
- Learn from each other about registry implementation, access to treatments, therapies, home care delivery, case management and other innovative projects developed in the region;

**++** Opening of the workshop and presentation of the participants / sharing best practices and challenges;

**Dorica Dan, Romanian National Alliance for Rare Diseases & EURORDIS, representatives from local and national authorities, EURORDIS & EPF;**

**++** National Alliances round introduction

**++** Rare Barometer Study results for EE Countries, Sandra Courbier **EURORDIS**

**++** Coordination of an ERN and National Strategy in Cseck, **Milan Macek, ERN Coordinator, Czech Republic**

**++** Funding opportunities for EE from EEA grants and the experience in rare diseases: Norwegian collaboration with Romania, Hungary, Bulgaria and Check Republic, **Lisen Julie Mohr, Frambu, Resource Center for RareDisorders; Norway**

**++** Solutions for the management of severe neuromuscular diseases through partnership between patient organization and professionals – **Isabela Tudorache, Parent Project Association Romania;**

## **++ Questions and answers & Conclusions**

**Closed meeting**