

EMM 2019 Bucharest

17-18 May 2019

Crowne Plaza Bucharest

Thursday 16 May

Satellite meetings

- 09.00-09.30 *Registration to satellite meetings*
- 09.30-12.30 Eastern European Patient Organisation's Workshop- Share common best practice and challenges in RD policy
- 9.30-12.30 ePAGs Advocates meeting (3 parallel sessions) – closed meeting
- 09.30-12.30 CNA Working Groups "Small EU countries (closed meeting)
- 09.30-12.30 CNA Working Group "Western Balkans" (closed meeting)
- 12.30-13.30 Lunch
- 13.30-18.00 CNA meeting (closed meeting)
- 13.30-16.00 ePAGs Advocates meeting (3 parallel sessions) – closed meeting
- 19.30 Dinner CNA and ePAG advocates

Friday 17 May

EMM 2019 Bucharest

- 08.30-09.30 *Registration to General Assembly and EMM 2019*
- 09.30-13.00 EURORDIS General Assembly (members only)
- 13.00-14.00 Lunch

Plenary session - Social services & integrated care

"Achieving Holistic Person-Centred Care to Leave No One Behind"

Chair: Valentina Rupel, Institute for Economic Research

- 14.00-14.30 Opening speeches:
- Terkel Andersen, President, EURORDIS
 - HRH Princess Maria of Romania
 - Dorica Dan, President, Romanian National Alliance for Rare Diseases
 - Sorina Pintea of Romanian Ministry of Health (tbc)

14.30-15.15

Launch of Position Paper

The ambition of EURORDIS is to have holistic care provided to the 30 million people living with a rare disease in Europe, and to their carers, by 2030. Our goal is to see people living with a rare disease integrated in a society that indeed leaves no one behind. We applaud all stakeholders for the progress achieved in the last decades. However, evidence demonstrates that people living with a rare disease and their carers continue to face serious challenges in everyday life and regarding social inclusion. It is urgent to address these unmet needs. The time to act is now. All stakeholders, working together, have the capacity to advance this change. Our objective with this position paper is to inspire that process, by presenting evidence on the unmet needs as well as by highlighting and recommending part of the strategies to address them.

Short presentations of the different aspects of the Position Paper

- Quality and Adequate Social Services and Policies, *Dorica Dan, EURORDIS & Romanian National Alliance for Rare Diseases, Romania*
- Integrated Care: Bridging Health and Social Care, *Avril Daly, EURORDIS & Retina International, Ireland*
- Equity of Rights and Opportunities, *Maria Montefusco, Nordic Centre for Welfare and Social Issues, Sweden*
- Which recommendations can have the greatest impact? *Mihai Tomescu, adviser of the Ministry of Work Romania*

Panel Discussion:

Dorica Dan, Avril Daly, Mihai Tomescu, Maria Montefusco and Cristian Busoi, MEP

- What are our 5 targets that will allow us to achieve holistic care for people living with a rare disease in Europe, and their carers, by 2030,
- How to start promote integrated/ holistic care at national level?
- What achievements/services do we already have that can be used for integrated holistic care for rare disease patients and the wider community?

15.15-16.00

Inequalities & Opportunities

EU Regulations and Directives give standards and added value to Europe, but are not always thoroughly implemented throughout the EU

Examples of policies that were successfully applied (or not) notably in Romania and other Eastern European countries compared to the rest of Europe (few slides, based on data: GPS and annul revenue, Health expenses, RD policy, National Alliances, HCP in ERN, Access to Medicines)

Speakers:

- *Romanian Agency for Medicines & Medical Devices, Marius Daniel Şişu, President (tbc)*
- *CNA WG Western Balkans, Ivana Badnjarevic NORBS, Serbia*
- *Patient Testimony, Bogdana Patrasc, Romania*

Panel Discussion

Ivana Badnjarevic, Anna Arellanesova, Rare diseases Czech Republic, Marius Daniel Şiş, Bogdana Patrasc,

- Exchange on experience with national policies
- Results of the survey on social impact of Rare Diseases – comparing regions of Europe (east/west)



- Discussion with the audience

16.00-16.30 Coffee break

16.30-17.15 **How to make the best use of the position paper for a bigger impact?**

Speakers:

- How to make your voice heard? *Rebecca Skarberg, OIFE, Norway*
- Case study on how to best use the position paper: Holistic care for rare diseases, using regional strategy and case management: *Encarna Guillen-Navarro, Hospital Clínico Universitario Virgen de la Arrixaca, Spain*

Panel Discussion

Alba Ancochea, Rebecca Skarberg, Encarna Guillen-Navarro, Katerina Konecna, MEP (tbc)

- How to use the position paper to advocate for holistic care?
- Discussion with the audience

19.30 Welcome dinner, Crowne Plaza

Saturday 18 May:

Workshops

9.30-12.30

1_ How to make the best use of the Social position paper?

Lead: Raquel Castro

How to make the best use of the position paper: What are the quick wins within our recommendations? Which recommendations can have the greatest impact? What are our 5 targets that will allow us to achieve holistic care for people living with a rare disease in Europe, and their carers, by 2030?

2_ Community Advisory Boards (CABs)

Lead: Rob Camp, François Houyez

How do you engage with developers of health technologies and treatments? Community Advisory Boards as a model

Understand what CABs are and how they operate

1. Learn successful examples of patient advocacy via CABs
2. The EuroCAB programme: State of Play as of May 2019
3. Create and operate your own CAB: how EURORDIS can help
4. EuroCAB programme

3_ European Reference Networks – The Eastern European Countries Dimension

Lead: Matt Johnson

1. State of the Art: Eastern Countries involved in ERNs
2. Ask the expert: Opportunities & Barriers Roundtable
3. Working Groups – Country Level Needs for Eastern Countries to participate in ERNs

4_ Foresight Study Rare 2030 (half day workshop)

Moderators: Anna Kole (EURORDIS) and Giovanna Giuffrè (ISINNOVA)

Share your vision for the future of rare disease policy in this interactive workshop. We will brainstorm the factors that most influence our future as people living with rare diseases in small groups and prioritize them together. The outputs of this workshop will contribute to a final set of Policy Recommendations as part of Rare2030, a foresight study on rare diseases.

12.30-13.30 Lunch

13.30-16.30

1_ Social (2d part)

Lead: Raquel Castro

2_ Community Advisory Boards (CABs) 2d part)

Lead: Rob Camp, François Houyez

3_ European Reference Networks – The Eastern European Countries Dimension (2d part)

Lead: Matt Johnson

4. Data sharing (half day workshop)

Lead : Sandra Courbier, Virginie Bros-Facer

Result of the survey on data sharing and presentation/discussion of recommendation

16.30 Farewell coffee

In Collaboration with:



With the support of:



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