Eastern Countries involved in ERNs - Opportunities & Barriers

ePAG Patient Representative's Perspective

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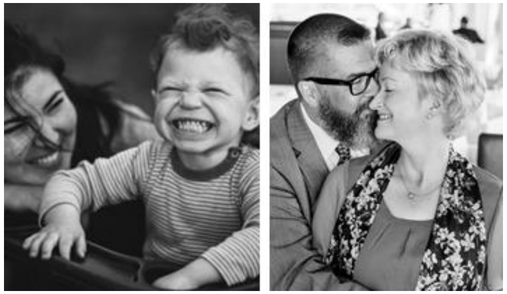
It is hard to understand
the complexity of Rare Diseases



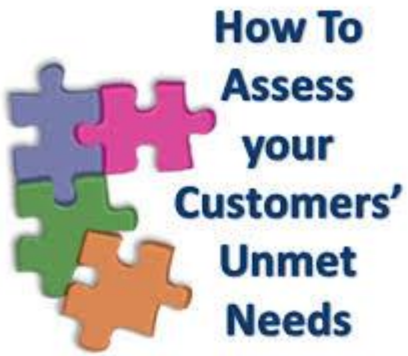
Eurordis Membership Meeting, Bucharest, 17.05.2019.

Needs

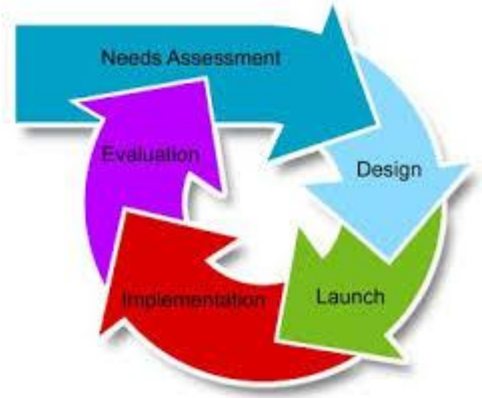
- screening for RD: prenatal/neonatal;
- education and training programs
- registries and statistics
- access to a genetic testing program
- medical & assistive devices
- social care, integrated care, information
- off-label treatment
- experts

Needs

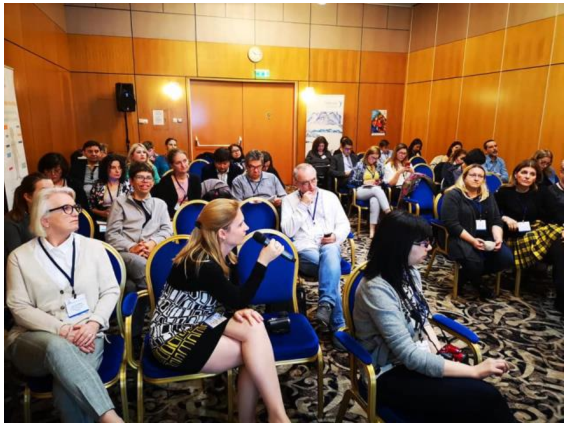
- timely diagnosis
- centers for assistance and care
- continuity of care
- complementary support services
- research
- specialization of the medical staff
- need for advice on how to access EU Grants
- possibilities to contact other patients with the same disease



Needs

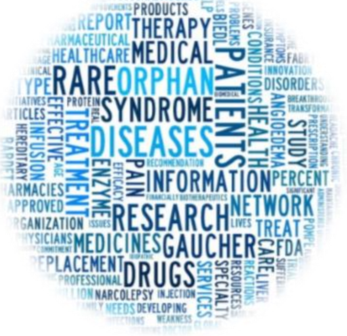


- A real functioning of the centers
- Therapeutic guidelines
- Training for therapeutic education
- Rehabilitation programs
- Case management
- Access to off-label medicines
- Specialized centers in RD
- Coordination of care



Opportunities

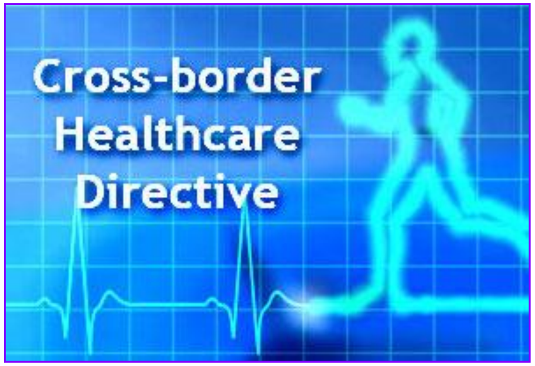
1. **Ensure “home for every RD”**
   - better understanding the needs of patients and families,
   - even more chances for very rare undiagnosed patients to find the diagnose,
   - clearer image of care services for patients with RD at EU level and in each MS
2. **Reduce costs at national level with sharing of resources**
   - better diagnose and lower prices for genetic tests and other intervention because of concentration and orientation of expertise
3. **New culture of patient centred view**
   - better collaboration among experts and patients,
   - better advocates for patients' rights,
   - better empowerment and awareness



Opportunities

4. Better quality of care

- more visibility to expert centers, patient networks,
- common clinical guidelines and common approach on RD care,
- gained knowledge and expertise,
- regular monitoring, independent assessments,
- better patient experience,
- better health outcomes



5. Better collaboration

- sharing of best practices, care pathways,
- team development and increased national and international cooperation among experts and patients,
- EU registries for RDs,
- Better coordination of patients and reduced waiting time for diagnostic and care

Barriers

1. At political level

- inequalities in terms of political support and commitment,
- unstable political environment,
- high rotation of civil servants,
- lack of ownership and clear responsibility,
- lack of communication among authorities

2. At the level of health care system

- different level of development in different MS,
- different level of expertise, brain drain,
- not enough and/or overworked specialist and multidisciplinary teams,
- inequalities in access to resources (health and care services, diagnostic tools, treatments approved, research funding),
- access to funding in general,
- bureaucracy and corruption (out of pocket payment)

Barriers

3. At the level of patient organizations

- different level of organizational development for PO,
- lack of time and human resources,
- lack of money, financial uncertainty,
- language barrier,
- lack of awareness, low member activity and participation,
- too much administration and bureaucracy,
- problems with willingness to cooperate, lack of trust,
- Conflicts with other services, professions

4. At the level of RD families

- lack of information,
- big financial burden


Thank
you