roPAG

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Workshop for patients advocates and experts on ERN – July 2018

- **GOAL:** to bring together patients and experts and inform them about the opportunities of working at EU level and to be involved in the ERNs;

- Matt Bolz - Johnson as the main invited expert from EURORDIS;
Our objectives

✓ to raise the awareness on Cross Border Health Care and ERNs

✓ to increase the interest of Ministry of Health to improve the access of HCPs & Centres of Expertise from Romania in ERNs

✓ to facilitate access to information about organizing National Coordination Hub and affiliation process to ERNs: as associate members or full members;
State of the art

- The level of awareness about ERNs at national level among the patient community and experts was still low.

- Health authorities didn’t understand the benefits of being part of ERNs and didn’t continue the accreditation process for CoE.
How?

1. 2 day workshop at NoRo Center in July 2018 with EURORDIS participation

2. 1st day was targeted to experts

3. the 2nd day for patients' representatives

4. 65 participants, 5 coordinators of Centres of Expertise that are already full members of the ERNs, 5 experts that declared their intention to apply for accreditation of their centre and apply in the next call of ERNs;
The main achievements:

- more people informed about Cross border organization of care for RD patient organizations
- more experts from Centres are willing to participate in the ERNs
- updated information about ERN’s call for associate members at national authorities level
- more interest of Ministry of Health to improve the access of Centres of Expertise from Romania in participation in the ERNs and to organize a National Coordination Hub.
- Patients are more interested to be involved in trainings and to become roPAGs (using the ePAG model) and to advocate for their rights (we had a first list in July 2018)
Why training?

- To increase the role of patients in organization of health care system at national level;

- To stimulate the recognition of expertise;

- To improve cooperation and collaboration between patients and experts in designing services according to patients’ needs;

- To be able to bridge the gaps between health, social and educational systems;

- We all need to learn to work together and advocate for a common vision;
**Goal:** To enable roPAGs to better collaborate with their CoE and transfer patients' needs into actions.

**The content** of the training program:

- **M1:** To develop **knowledge**
- **M2:** To build **effective partnerships with experts**
- **M3:** Communication with different stakeholders
- **M4:** Leadership

**How we do it in practice?** **workshops and working groups**

- Communication, planning, problem solving and negotiating skills;
- Knowledge guidelines
- Effective partnerships
- Co-creation
- Leadership
- RDSJ, HackRARE
Knowledge: Capacity building workshops to collect personal experiences and develop guidelines for integrated care/diseases and group of diseases;

Effective partnerships: roPAG training to build effective relationships and partnership with their CoE and involve them in writing/assessing/using the guidelines;

Communication: Communication with mass media

Leadership: Individual tailored mentoring programme to develop personal leadership style
## Training program

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<tr>
<th>No.</th>
<th>Module</th>
<th>Skills/ knowledge/ results</th>
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| M1  | Knowledge development                         | - Clarified roPAG role in a CoE  
- Common understanding and vision for care development  
- CoE roles and service improvement  
- GDPR and data protection  
  - group meetings  
  - meeting with NCRD |
| M2  | Building collaborations and effective partnerships | - Team work and partnership  
- Shared personal experiences  
- “Co-creation” guidelines for integrated care for 6 diseases and cooperation with CoE  
  - 2 workshops  
  - 3 working groups  
  - 2 group meetings |
| M3  | Communication                                 | - Presenting with impact  
- Influencers  
- Communication and digital solutions  
  - Participation at Rare Diseases School for Journalists, RDD, HackRARE; |
| M4  | Leadership                                    | - Influencing strategy  
- Sharing common vision  
- Mentoring program |
Results:

- Started to create a culture of patients involvement in training activities to become roPAGs;
- Organized trainings/meetings (congenital anomalies, metabolic diseases, rare rheumatological diseases);
- Produced 6 guidelines for integrated care for patients with: PWS, Williams, Pompe, Gaucher, Hunter, Fabry;
- Involved trained patients in Rare Diseases School for Journalists and HackRARE;
- Initiated the **Informal School for RDs** to sustain our activities from PROGENERARE Project AND INNOVCare project;
Networking
Success factors:

- The interest of participants at the workshop was higher because of the EURORDIS participation

- Good cooperation with professionals

- The presence of the Ministry of Health at the workshop was a success factor, both in terms of promotion and sustainability of our proposals

- The workshop had to be followed by several meetings with the Ministry of Health, workshops with patients and patient organizations and meetings/events with experts;

- Projects to organize the meetings in order to achieve our goals, we needed to mobilise and manage resources: time, money and human resources;

- THANK YOU!!!