



**Alianța Națională
pentru Boli Rare
România**

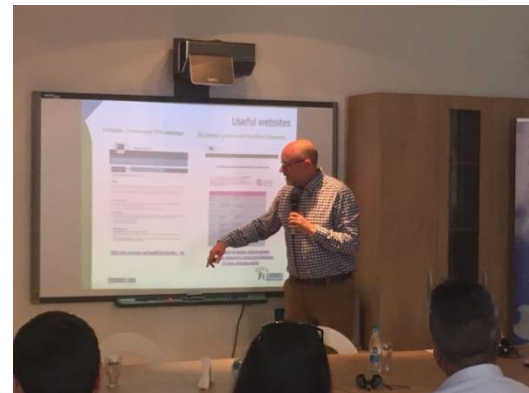


roPAG

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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;

roPAG Training Program

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 to develop:**
communication, planning, problem solving and negotiating skills;



roPAG development programme



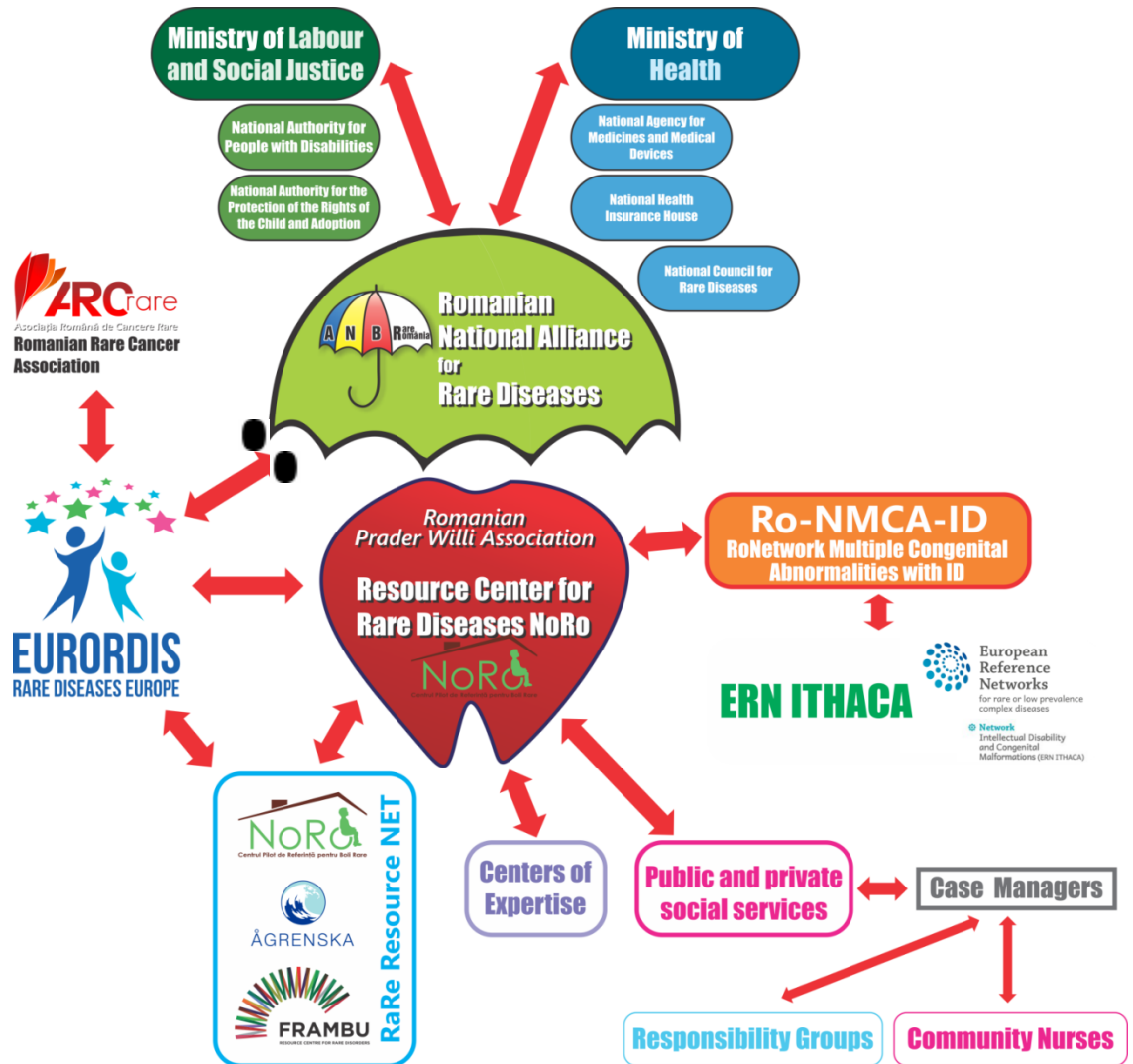
Training program

| No. | Module | Skills/ knowledge/ results |
|-----|--|---|
| M1 | Knowledge development | <ul style="list-style-type: none"> • Clarified roPAG role in a CoE • Common understanding and vision for care development • CoE roles and service improvement • GDPR and data protection <p>– group meetings – meeting with NCRD</p> |
| M2 | Building collaborations and effective partnerships | <ul style="list-style-type: none"> • Team work and partnership • Shared personal experiences • “Co-creation” guidelines for integrated care for 6 diseases and cooperation with CoE <p>– 2 workshops – 3 working groups – 2 group meetings</p> |
| M3 | Communication | <ul style="list-style-type: none"> • Presenting with impact • Influencers • Communication and digital solutions <p>– Participation at Rare Diseases School for Journalists, RDD, HackRARE;</p> |
| M4 | Leadership | <ul style="list-style-type: none"> • 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!!!

