

# RAISING AWARENESS OF ERNs AT NATIONAL LEVEL

## ITHACA

April 2019

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| Activity | Workshop for patients advocates and clinicians on ERNs  |
| Area     | training and education, communication and dissemination |
| Duration | 2 days  |
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### 1. SUMMARY

**i** The goal of the workshop was to bring together patients and experts and informed them, separately and together, about the opportunities of working at EU level and to be involved in the ERNs in order to improve the access to care for patients living with rare diseases.

The main achievements have been as follows:

- RD patient organisations are more informed about the organisation of cross border care for rare diseases
- More clinicians from expert centres are willing to participate in the ERNs,
- National health authorities have updated information about ERN's and the possibility of designating associated centres
- More interest from the Ministry of Health to increase the number of Romanian expert centres participating in the ERNs and to organize an ERN National Coordination Hub.
- Patients are more interested to be involved in trainings and to become roPAGs (replicating the ePAG model at national level) and to advocate for their rights.

## 2. INITIAL SITUATION

**i** The level of awareness on ERNs at national level among the patient community was low, health authorities did not understand how to organise the participation of Romanian centres in ERNs and clinicians did not see the benefits of being part of an ERN.

Our objectives were:

1. To raise the awareness on Cross border organization of care for RD patient organizations and experts from Centers of Expertise or experts willing to participate in the ERNs
2. To increase the interest of Ministry of Health to improve the access of Centers of Expertise from Romania in the ERNs
3. To facilitate access to information about organizing an ERN National Coordination Hub

We organized the event at NoRo Center as a 2-day workshop: 1st day was targeted to experts and the 2nd day for patients' representatives. We had in total 65 participants, 5 coordinators of Centers of Expertise that are already full members of the ERNs, 5 experts that intend to apply for accreditation of their center and apply in the next call of ERNs. The workshop was not big but impact oriented.

## 3. CONTRIBUTION TO PATIENT ENGAGEMENT AND/OR IMPROVEMENT OF CARE

**i** This was a patient-led meeting. We decided to move things forward by:

- identifying the expert centers that could join ERNs, following on the Ministry of Health declaration of having patients' mobility as a priority theme for EU Presidency, and made a proposal;
- drafting an action plan to train roPAGs
- reaching out to EURORDIS for advice on the action plan and also on how to set up an ERN National Coordination Hub.

In the second day, we had 3 new organizations that want to join RONARD – Romanian National Alliance for Rare Diseases. 19 patient advocates interested to be trained as roPAGs (patient advocates, working at national level) and replicate the experience of ePAGs at national level as roPAGs. Two of them would also like to be involved at EU level, as ePAGs.

The Minister of Health, Mrs. Sorina Pinteau and several Local Authorities, attended the meeting on the first day. Thanks to this event, she was able to better understand the importance of ERNs.

## 4. SUCCESS FACTORS

- i** • It is important first to identify clearly the specific objectives for the meeting to address the needs of the different target audiences and built the agenda with a clear focus.
- Being an ePAG patient advocate, with a good understanding of the landscape, the activities and goals of the ERNs and at the same time, having a strong network at national level, able to mobilize it in a meaningful way was also a big facilitator.
- Think ahead about several potential follow-up actions to keep the momentum and leverage on the energy and the main take-away of the meeting.
- 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 interest of participants at the workshop was higher because of the EURORDIS participation – a third party that brought a fresh perspective.

## 5. LESSONS LEARNED

- i** • The interest of participants at the workshop was higher because of the EURORDIS participation – a third party that brought a fresh perspective;
- 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;
- To organize the meetings in order to achieve our goals, we needed to mobilise and manage resources: time, budget and human resources;
- Patients and patient organizations at national level have important training needs to need to get updated information on ERNs, online and f2f;
- To create teams and mobilise the patients' voice, we need to organise face to face meetings and events;
- Experts need to be stimulated through recognition of their work by the hospital managers;
- National health systems should find ways to recognize and allocate funding to ring-fence experts' capacity and allow them to dedicate time to work for the ERNs activities;
- Experts involved in ERNs (also ePAG patient advocates) need "time recognition", ERN-related work time allocated as part of their job responsibilities, to facilitate their involvement in complex care and international communication;

- In Romania, we need more promotion on interdisciplinary teams and training for leadership facilitators.