

ePAG Satellite Meeting

Meeting Report

18 May marked the first time ePAG representations from all 24 European Reference Networks came together to share their expectations and experiences at the first ePAG Satellite Meeting, held prior to the EURORDIS Membership Meeting 2017 Budapest. It was an exciting and informative day for all, coming together as a community and making our first steps towards cross-ERN collaboration.

The ePAG Satellite Meeting was structured around 3 main sessions, all chaired by ePAG representatives including:

- Johan de Graaf (Nederlandse Hypofyse Stichting)
- Courtney Coleman (European Lung Foundation)
- Amanda Bok (European Haemophilia Consortium)

Supported by RD-Action and EURORDIS colleagues:

- Victoria Hedley (University of Newcastle, UK & RD-ACTION representative)
- Lenja Wiehe, Matt Bolz-Johnson and Ariane Weinman (EURORDIS ERN team)

The ePAG satellite meeting was held at a timely moment, three months since the European Reference Networks (ERNs) were officially launched and became operational in March 2017. As the ERNs are new and innovative, so are the European Patient Advocacy Groups (ePAGs), both ERN clinicians and ePAG representatives are working in a new environment and share similar opportunities and challenges. One important challenge is that both the clinical community and the patient community have started to collaborate in representing broader therapeutic fields bringing together clinical and patient groups that have not traditionally worked together.

In order to establish ePAGs based on common goals and values, the ePAG representatives have been engaging as partners to develop a participatory approach for patient representatives to be an equal and valued partner in the European Reference Network board or governance structures.

The strength of the ePAGs lies in the history, experiences, expertise, interests, values and judgements of each of the ePAG representatives.

However, it was also reported that some of ePAG groups have been facing challenges working together due to the diversity of the ERN community. Some ePAGs reported that they are successful, while others reported that communication between ePAG members could be improved. ePAG representatives also expressed that representing broader therapeutic fields as well as their specific disease can pose a challenge.

Moving forward together

During the meeting, most ePAG representatives said they felt that they have a voice and are listened to in their ERN and by the clinical leads. Most of them felt confident representing their disease area in their ERN.

It was evident that ePAG representatives bring a wealth of expertise and experience beyond their specific knowledge of their own rare disease. Their role is to bring the patient's perspective and the knowledge of what it is like to live with a rare disease on an everyday basis. ePAGs are not expected to be medical and or scientific experts.

It is important to share broader experiences and opinions to learn from each other and build from a successful base to bring new ideas of patient engagement into these clinical networks. Coming together as partners and learning from each other can help ePAG representatives strengthen their skills and feel more confident in representing their wider therapeutic area within their ERN.

Inherent in the ePAGs is a unique opportunity to take on a global view of the whole pathway from research to access to care.

Representing patients and capacity building in ERNs

The Satellite Meeting specifically focused on two key topics: 1. representation of the wider patient community in ERNs, and 2. ePAGs' capacity building within the ERN transversal activities framework.

The first part of the meeting focused on the role of ePAG representatives in representing patient communities. The themes that emerged from the discussions relate to the ePAG representatives' confidence or lack thereof in representing both their disease area within their ERN and their wider therapeutic areas. It was identified that further guidance and training on representing the wider patient community as well as on more technical aspects of ERNs is needed.

The second part of the meeting evolved around the theme 'ePAG Capacity Building: ERN Transversal Activities'. Three focus groups discussed issues pertaining to research, training/education, clinical guidelines and outcomes:

- 1) **Research & Registry Focus Group:** discussions centered on the role of patients in research which is not always recognized by the research community. Patient representatives felt they should have an increased role in steering research according to their needs and addressing social and quality of life research questions.
- 2) **Training & Education Focus Group:** The focus group felt strongly about education and training for all stakeholder groups including the patient community. Collaboration with ERNs to host training events in patient organization conferences was discussed of. The group also highlighted their role as ePAG representatives to increase awareness of guidelines among both professionals and patients.
- 3) **Clinical Guidelines & Outcomes Focus Group:** Participants suggested to create a thesaurus or glossary of terms for use around ERNs, and the development of Patient



Reported Outcome Measures (PROMs) to drive forward learning within the networks. The focus group also discussed the challenge of implementing common guidelines among a wide variety of countries that have different health policies.

Conclusions

It was agreed that EURORDIS would set up 3 Think Tanks on the above topics open to all ePAG representatives to share their experiences of working in their respective ERN working groups or task forces.

The ePAG satellite meeting also requested that EURORDIS develops an ePAG Guide to help steer the development of newly forming ePAG groups, clarifying expectations in communication and collaboration as a group and with the ERNs themselves.

