

All-ePAG meeting, 14-17 Nov 2022



European
Patient
Advocacy
Group

This year marks the 5th anniversary of the ERNs. Some of you have been involved in the Networks since their launch in 2017, others have joined later and some are newcomers that joined this year. Regardless of when you joined, if you are interested in understanding **how to get better at listening to your community to represent their perspective in the ERNs**, this year's all-ePAG meeting is for you. We have put together five short online sessions peppered throughout one week. They will take place from **Monday to Thursday, each day at 10.00-11.00 CET**. Have a look at the sessions and pick the ones that you are interested in!

1. EUROPEAN REFERENCE NETWORKS AND ePAGs 101

MON 14 NOV
10.00-11.00

Do you still have questions about your role as a patient advocate in the ERNs? This session has been designed specially for ePAG advocates who have been 1 year or less volunteering in the ERNs. Four fellow patient representatives will answer to your questions about the Networks, including any practical matters related to your role as an ePAG advocate. If you have been around for longer, but still want to mingle and meet the newcomers, this session is also for you!

Dorica Dan, ePAG ERN ITHACA
Graham Slater, ePAG ERN ERNICA
Isabella Brambilla, ePAG ERN EpiCARE
Simone Louise, ePAG ERN GUARD-HEART
Opening remarks: Yann Le Cam, EURORDIS

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3. HOW CAN I BEST CAPTURE MY COMMUNITY'S VOICE?

WED 16 NOV
10.00-11.00

Have you ever been asked as an ePAG advocate to participate in the development of a clinical practice guideline, contribute to develop a consensus statement, identify the unmet needs of your community or identify health or quality of life outcomes? In this hands-on session come explore what would be the best approach to collect and analyse your community's feedback. Our speakers will answer your questions and provide practical tips to make your life easier!

Angela Leburgue, ePAG ERN RARE-LIVER
Jessie Dubief, EURORDIS
Simon Eaton, ERN ERNICA & University College London (TBC)
Moderator: Lenja Wiehe, EURORDIS (TBC)

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5. LET'S HAVE A CHAT ON ...

THU 17 NOV
11.15-12.30

Grab a coffee and sit with one of our experts to have a chat on the European Health Data Space, the future Rare Disease Partnership, EURORDIS Ukraine Task Force and more! If you wish, you may jump from one table to another, our table hosts will be OK with table hopping.

Anastasiia Saliuk, EURORDIS (Ukraine Response/ Task Force)
Anja Helm, EURORDIS (Membership)
Birute Tumiene, Vilnius University Hospital Santariskiu Klinikos (ERN integration into national healthcare systems)
Jelena Malinina, EURORDIS (European Health Data Space)
Mari Murel, ERICA Project Manager (ERICA)
Roseline Favresse, EURORDIS
Opening remarks: Rita Francisco, EURORDIS

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2. WHY LISTENING TO YOUR COMMUNITY MATTERS

TUE 15 NOV
10.00-11.00

To represent the perspective and needs of the rare disease patient community in the ERNs, first ePAG advocates must gather the input from the community, analyse the results and use them to guide their work. This is indeed a central part of your role as ePAG advocates, and a challenging task too! How is this role perceived by the different actors directly involved in the ERNs? What does it take? What are the main roadblocks? How can it be effectively operationalised?

Jean-Yves Blay, EURACAN ERN Coordinator
Olivia Spivack, ERN CRANIO Project Manager
Petia Stratieva, ePAG ERN EYE
Moderator: Rita Francisco, EURORDIS

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4. HOW DO I COMMUNICATE ABOUT ERNs' ADDED VALUE AND ENGAGE MY COMMUNITY?

THU 17 NOV
10.00-11.00

The rare disease patient community is a diverse community organised around rare disease-specific local, national, European and international patient organisations as well as National Alliances bringing together the various rare disease patient organisations based in the same country. Join this session to listen to experiences from a national patient organisation, a European Federation and a National Alliance on how to communicate about the added value and benefits of the ERNs, and how to engage the patient community. You don't need to replicate exactly what others have done, but we promise that you will get some inspiring ideas!

Allison Watson, Ring 20 Research and Support UK & ePAG ERN EpiCARE
Ingunn Westerheim, Osteogenesis Imperfecta Federation Europe
Gabor Pogany, HUFERDIS, Rare Disease National Alliance of Hungary & ePAG ERN ITHACA Moderator: (TBC)

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