



Parallel session PS6: "Patient-Healthcare professional partnerships in ERNs: sharing successes and challenges"

22 November 11:40 – 13:00

<p>Session leaders:</p> <ul style="list-style-type: none"> ✓ Inés Hernando, ERNs and Healthcare Director, EURORDIS ✓ Guillaume Jondeau, VASCERN ERN Coordinator 	<p>Chairs:</p> <ul style="list-style-type: none"> ✓ Inés Hernando, ERNs and Healthcare Director, EURORDIS ✓ Guillaume Jondeau, VASCERN ERN Coordinator
<p>Speakers:</p> <ul style="list-style-type: none"> ✓ Janet Williams, ITHACA ERN, patients' representative ✓ Jill Clayton-Smith, ITHACA ERN, healthcare professional and ITHACA Coordinator ✓ Natascha Assies, VASCERN ERN, patients' representative ✓ Robert Damstra, VASCERN ERN, healthcare professional ✓ Graham Slater, ERNICA ERN, patients' representative ✓ René Wijnen, ERNICA ERN, healthcare professional and ERNICA Coordinator 	<p>EC support official:</p> <ul style="list-style-type: none"> ✓ Isabelle Dévé, Unit B3, DG SANTE

Aim of the parallel session:

Patient participation enhances the capacity of ERNs to improve health outcomes through representation of patients' needs in Networks' discussions and activities. ERNs must involve patients' representatives in their governance structure in order to ultimately improve the quality of care that patients will receive. They also provide new exciting opportunities for developing patient-healthcare professional partnerships in research. This is why ERNs success will depend to a large extent on the ability of healthcare professionals and patients'

representatives to develop trust and effective partnerships to co-build this success.

This session will aim at identifying what are the main facilitators and barriers for this collaboration and outline a set of recommendations to develop effective patient-healthcare professional partnerships in the framework of the ERNs.

Main issues to be addressed:

- Showcase the value of patient-healthcare professional partnerships in ERNs
- Present the experience and different perspective of patients representatives and healthcare professionals who are working together on the same activities/projects
- Reflect on lessons learned, barriers and facilitators to partnership
- Identify recommendations/good practices that can serve other ERNs and ePAGs

Format of the session:

- 5 min introduction of session and speakers (Chair)
- 45 min storytelling: the 3 tandems (patient representative + healthcare professional) to present their story. All to cover from both perspectives: facilitators, barriers, value and lessons learned/recommendations. Only 4 slides per story.
- 20 min of Q&A
- 5 min wrap-up