European Patient Advocacy Groups – ePAGs

What to expect and what is expected: the Patient Representative Role

Dr. Avril Kennan
• We are all past, current or future patients

• People living with rare diseases spend more time living as patients than most

• With that comes expertise!
Patient & Public Involvement (PPI) in care & research

Engagement

Participation

Involvement
European Patient Advocacy Groups (ePAGs)

Eurordis have been advocating for ERNs for 10 years

ERNs created on founding principles of patient-centred care, patient advocate empowerment, patient engagement

Mechanism of patient involvement is through the ePAGs:

86 patients in 24 ePAGs
# Objectives of ePAGs

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<tr>
<th>Key roles (Governance)</th>
<th>Key objectives (Care)</th>
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<td>• Present and represent the patient voice, providing patient experience</td>
<td>• Ensure transparency in quality of care, safety standards, clinical outcomes and treatment options.</td>
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<td>• To communicate and connect to our community</td>
<td>• Promote a patient-centric approach in both delivery of clinical care, service improvement and strategic development &amp; decision-making.</td>
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<th>Key roles (Monitoring &amp; Evaluation)</th>
<th>Key objectives (research)</th>
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<td>• Review effectiveness of network empowers patients, evaluate how network acts on feedback received</td>
<td>• Contribute to the definition of research priority areas based on what is important to patients and their families.</td>
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<td>• Ensure that patients are embedded in the research activities performed within the Network, including involvement in the assessment of clinical trials and in ethics committees.</td>
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The practicalities

• One ePAG per ERN

• Vision is for ePAG members to be involved in all committees and activities

• Open to Eurordis members & non-member patient groups in EU

• Communicate via RareConnect & conference calls

• EURORDIS provide management support & capacity development

• Initially based on elections. Now can express an interest in joining
Current ERNs

- Rare bone diseases
- Paediatric cancer
- Rare cancers (Adult solid cancers)
- Genetic Tumour Risk Syndromes
- Rare haematological diseases (including haematologic malignancies in adults)
- Rare cardiac diseases
- Rare connective tissue and musculoskeletal diseases
- Rare craniofacial anomalies and ENT (ear, nose and throat) disorders
- Rare endocrine diseases
- Rare eye diseases
- Rare gastrointestinal diseases
- Rare hepatic diseases
- Rare hereditary metabolic disorders
- Rare immunological & auto inflammatory diseases
- Rare malformations / developmental anomalies/and rare intellectual disabilities
- Rare multisystemic vascular diseases
- Rare neurological diseases
- Rare neuromuscular diseases
- Rare pulmonary diseases
- Rare renal diseases
- Rare skin disorders
- Rare urogenital diseases
- Transplantation in children
- Rare & complex epilepsies
The ERN-Skin ePAG
DEBRA International
DEBRA examples of patient involvement

Clinical practice guidelines

Patient registry

Research funding
What if I want to be involved?

- What is the level of commitment required?

- Will I receive training?

- Will I be funded?

- Where do I sign up?
  - [http://bit.ly/ePAGinterest](http://bit.ly/ePAGinterest) or email lenja.wiehe@eurordis.org
Being part of culture change

The will is there but patient involvement not yet integral

Patient organisations have huge power to effect change

We need to lead the way
Ask what your ERN can do for you—but ALSO ask what you can do for your ERN!

Emeline Dardoff – rare skin disease art competition winner
Thanks for listening!

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