



HAPO

HUNGARIAN ALLIANCE
OF PATIENT
ORGANIZATIONS

Contribution of ePAGs to enhance patients' rights: access, information and innovation

„Start by doing what's necessary then do what's possible and suddenly you are doing the impossible”

Saint Francis of Assisi

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<http://nemzetibetegforum.hu/>, www.rirosz.hu, www.eurordis.org, www.orpha.net



“Cross-border healthcare and centers of excellence...”, Brussels, 02.27.2018

European Reference Networks (ERNs)

ERNs aim to **improve access to diagnosis and treatment** by providing high-quality healthcare to patients who have conditions requiring a particular concentration of resources or expertise, such as rare diseases.

ERNs are networks of centres of expertise, healthcare providers and laboratories that are organised across borders

Expertise travels across borders, rather than the patient



- **Patient-centred**, involving patients from the start and as equal partners in all ERNs
- **Optimal framework** for multisystem rare diseases, every patient with a rare disease has a home under an ERN, leaving no one behind
- **Connect expert, expertise and creating a critical mass of cases and data**
- **Anchored into national health systems**
- **Vehicle that will pave the way for faster diagnosis and access to expert care**

Balanced Network Coverage

ERNs aim to be:

- Inclusive and foster a collaborative spirit
- Balanced and equal representation from its 'members' in all Member States.
- ERN Members to act as 'national gateway or hub' connecting the ERN to the national healthcare system, linking our local and regional hospitals and the ERN.



Membership Overview

Member State	No. ERNs / 24	Number HCP	Member State	No. ERNs / 24	Number HCP
Italy	23	189	Bulgaria	6	8
France	All	129	Romania	6	8
Germany	19	117	Slovenia	7	7
UK	22	105	Estonia	4	5
Netherlands	All	92	Croatia	3	5
Belgium	All	75% 71	Austria	3	4
Spain	15	35	Norway	3	4
Czech Republic	19	29	Ireland	4	4
Sweden	21	26	Latvia	2	2
Portugal	15	24	Luxembourg	2	2
Poland	16	21	Cyprus	1	1
Denmark	12	17	Malta	-	-
Finland	13	15	Greece	-	-
Hungary	12	14	Slovak Republic	-	5% -
Lithuania	11	20% 11	Total	-	945

Background

24 European Reference Networks (ERNs) were created on founding principles of patient-centred care, patient advocate empowerment, patient engagement

European Patient Advisory Groups (ePAGs):

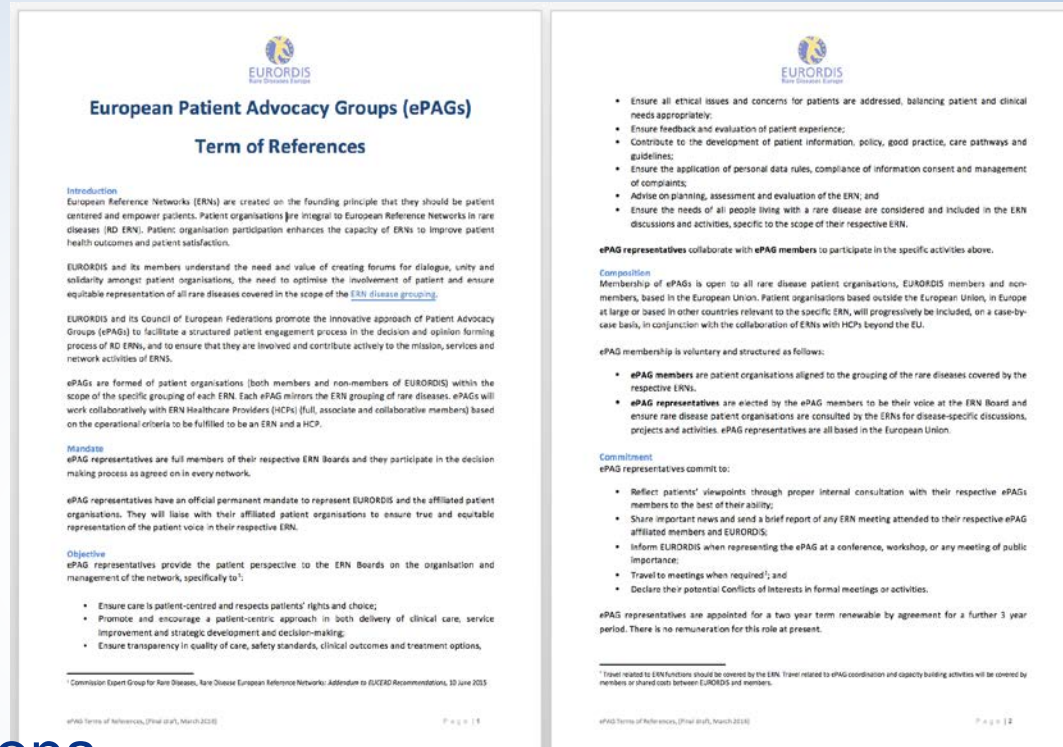
- **24 forums** for dialogue, unity & solidarity to optimise involvement of patients
- **Represent** patients to engage in application process and governance of rare diseases ERNs
- **Open** to members & non-member patient groups in EU
- **Aligned** with RD ERN scope
- **Composed** of >150 elected ePAG representatives & <1000 ePAG member organisations
- **Voting Members of ERN Boards, equal voice!**
- **Recruitment continue** for ALL disease specific clinical networks / committees and transversal working groups



Common objectives of ePAGs



- Ensure care is **patient-centred** & respects patients' rights & choice
- Ensure **transparency** in quality of care, safety standards, clinical outcomes & treatment options
- Ensure **ethical issues** for patients are addressed, balancing patient & clinical needs
- Contribute to the development of **patient information, policy, good practice, care pathways & guidelines**
- Advise on **planning, monitoring & evaluation** of ERN initiatives



ePAG representatives roles in ERNs

Key roles (Governance)

- **Present and represent the patient voice**, providing patient experience
- **To communicate and connect to our community**

Key objectives (Care)

- **Ensure transparency in quality of care, safety standards**, clinical outcomes and treatment options.
- **Promote a patient-centric approach** in both delivery of clinical care, service improvement and strategic development & decision-making.

Key roles (Monitoring & Evaluation)

- Review effectiveness of network **empowers patients, evaluate how network acts on feedback received**



Key objectives (research)

- **Contribute to the definition of research priority areas** based on what is important to patients and their families.
- **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.

ePAG Leadership Programme



Webinar

Capacity building

- 1.Virtual Healthcare;
- 2.Data Sharing;
- 3.Outcomes & Indicators;
4. Clinical Guidelines;
- 5.ERN & Orphan Drug Development

Transversal Focus Groups

Across ERNs

- 1.ERN Education & Training FG
- 2.ERN Research & Registries FG
- 3.ERN Outcomes & Guidelines FG

Peer Coaching

ePAG focused

Quarterly ePAG Coaching Groups with clinical lead

Mentoring Programme

individual focus

Mentoring Programme: Pilot with 12 mentors

Training courses

- 1.Presenting with Impact training;
- 2.Influencing without authority training

ePAG Mentoring Program



A 12 months long pilot mentoring relationship where **12 mentors and 17 mentees** dedicate a minimum of 2.5 hours every two months to the program

Aim #1

Carefully consider strategic health advocacy processes, roles, and responsibilities

Aim #3

Maintain or increase areas of impact in the board and committee environment

Aim #2

Explore strategies in collaborating with clinicians and patient representatives for improvement

Aim #4

Being conscious and aware of personal leadership strengths and areas of development

Aim #5

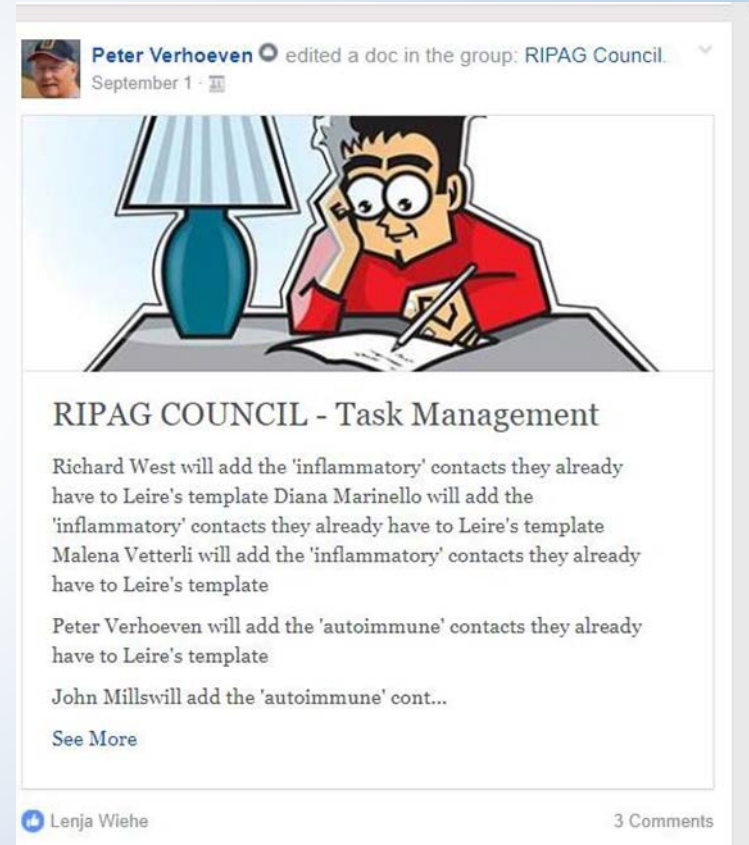
Identify tactics, tools and strategies that promote communication, cooperation, networking and coordination strategies

Facebook Workplace Initiative

An initiative launched by EURORDIS to create a common social media platform for ePAG representatives and patients organisations involved in the 24 ePAGs.

There are 48 communities for individual ePAG. Each ePAG community has two groups to:

- # Encourage communication across the ePAG Representatives group
- # Facilitate co-working within ePAGs through the creation/modification and sharing of documents
- # Encourage internal communication between ePAG representatives and to wider patient communities
- # Facilitate large scale communication of the ePAG Advocates group



Thank you for your attention!

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