



Update on ePAG activities and ePAG Leadership Training, *Lenja Wiehe*

CNA & CEF Joint Meeting, Paris, 3 November 2016

Content

1. European Patient Advocacy Groups (ePAG)
2. Online Communities
3. Patient Matchmaking Initiative
4. ePAG Leadership Programme

European Patient Advocacy Groups (ePAG) per disease grouping

Background

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

European Patient Advocacy Groups (ePAG):

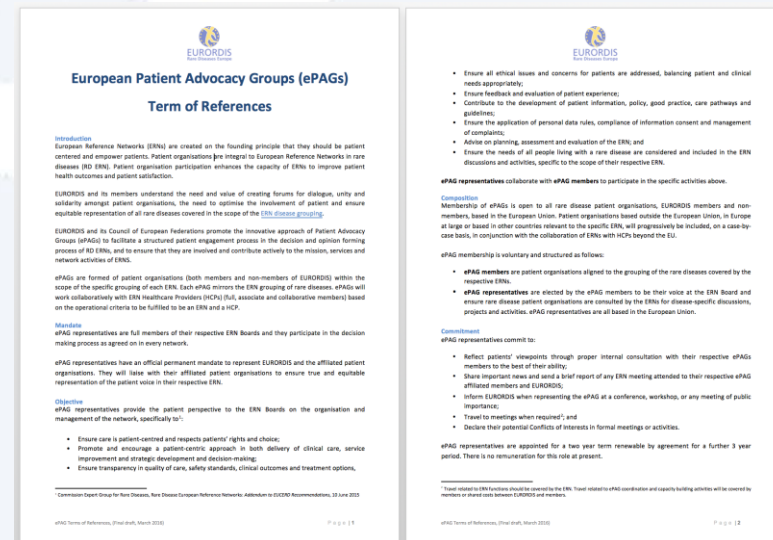
- **Forum** for dialogue, unity & solidarity to optimise involvement of patients
- **Represent** patients to engage in application process & governance of RD ERNs
- **Open** to members & non-member patient groups in EU
- **Aligned** with RD ERN scope
- **Composed** of elected ePAG representatives & ePAG member organisations
- **Established** where there is an ERN application & progressively expanded
 - Terms of Reference
 - Call for Expression of Interest (16 March 2016) & Elections of ePAG representatives (21 April – 4 May 2016)
- Process **launched** in May 2015 & ePAGs **announced** in May 2016

European Patient Advocacy 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 in the governance structure of ERNs

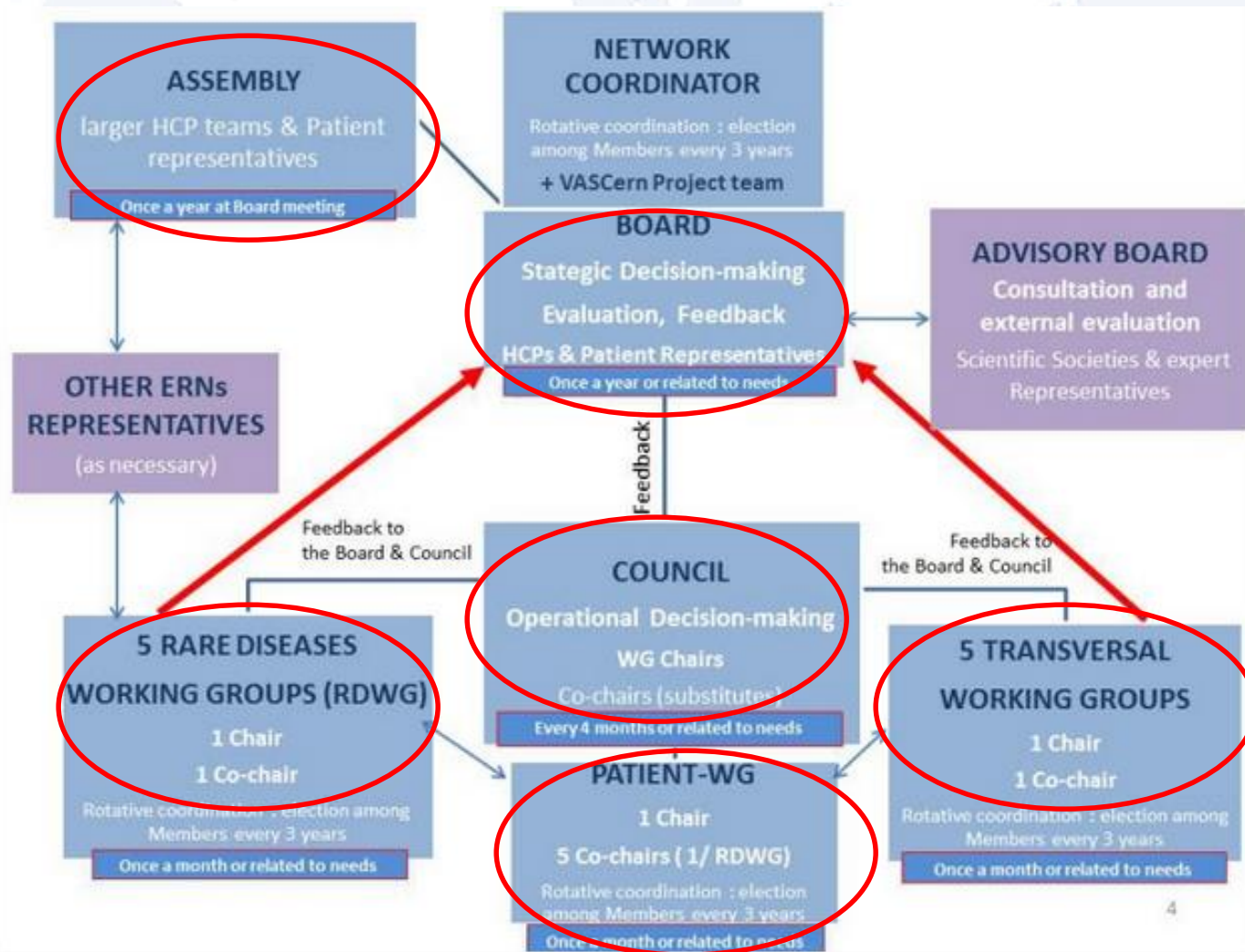
Different approaches to engage patients as formal members in ERNs:

- ePAG representatives can be **formal members** of:
 - **ERN Boards** & management committees:
 - Scientific Advisory Board, Steering Committee and Management Committee
 - **Clinical Committees** (single disease or sub-group of diseases) supporting ERN Boards
 - **Parent/Patient Advocacy Committee**

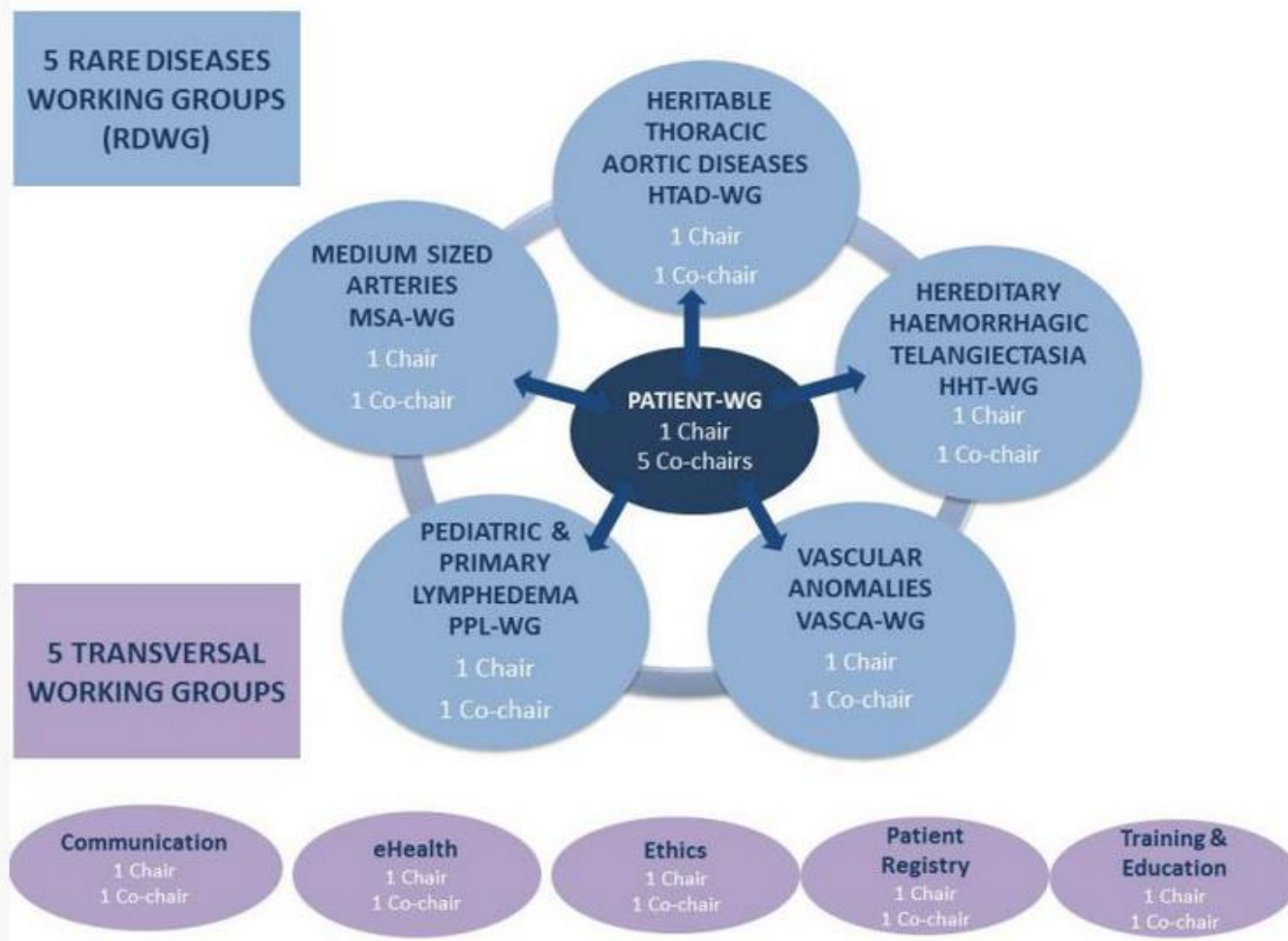
Example: Rare Multi-Systemic Vascular Diseases (VascERN) ePAG



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VASCern Patient-WG

Patient empowerment is important to collect the most pertinent information and allow patients to take part in making the management of their disease evolving in the most efficient manner.

Presentation

Members

Chair & EPAG



Paolo FEDERICI

[Associazione Fondazione Italiana HHT 'Onilde Carini', Italy](#)

HHT Onilde Carini is a support and mutual help among patients with hemorrhagic telangiectasia. It is a means of spreading knowledge of the disease among patients, their families, and among physicians. It is supporting clinical and genetic research to promote the care and treatment of patients with HHT. See: [leaflets](#)

Co-chair



Claudia CROCIONE

[HHT Europe](#)

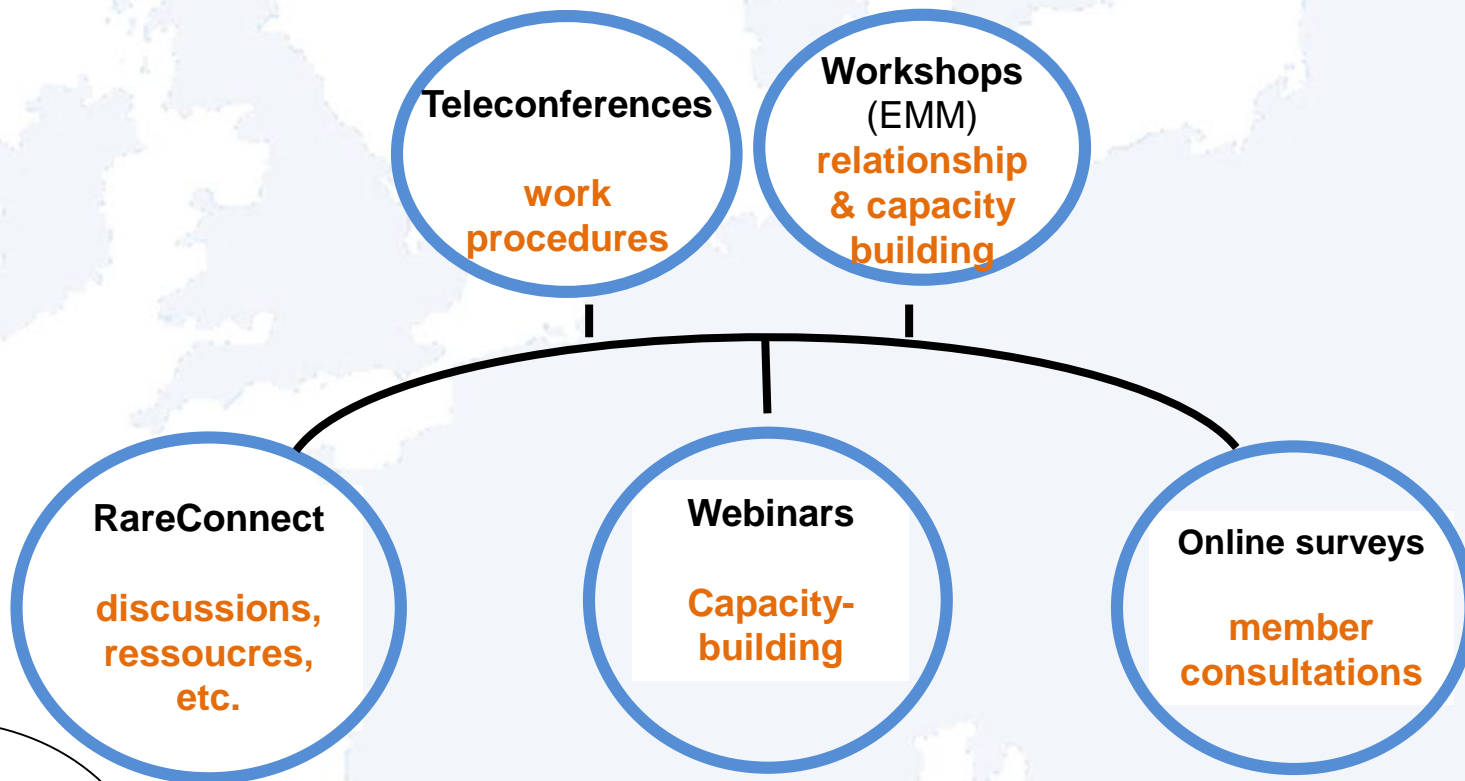
[Associazione Italiana Teleangectasia Emorragica - HHT ONLUS tonlus.org](#)

Means of ActionThe Objectives of **HHT Europe** are:

- To represent, protect and enforce rights and interests of people



Instruments of Engagement



behavior (13)

activity (20)

Involvement (36)

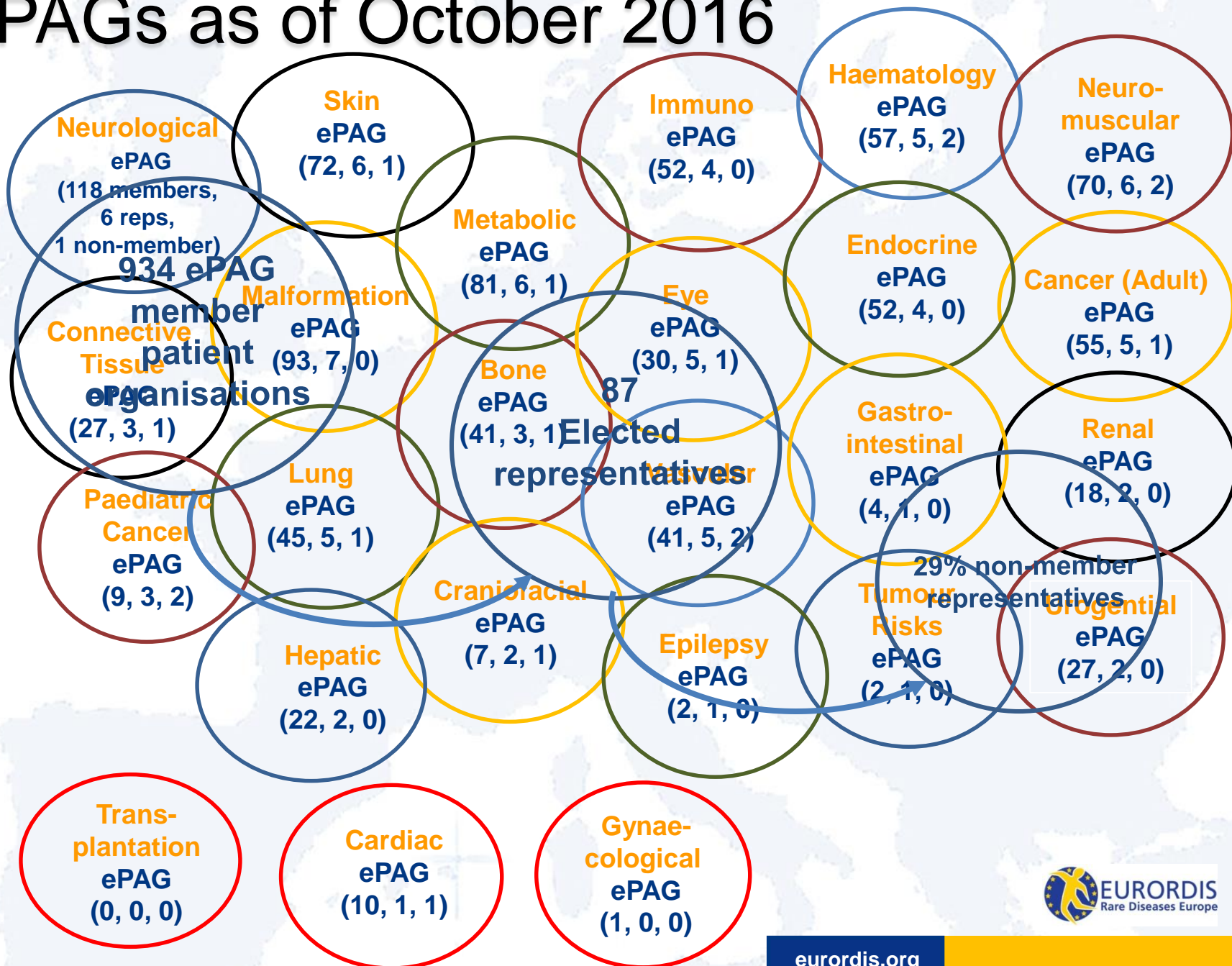
- genomics and the future of research into rare diseases
- barriers and enablers of cross border

- Health promotion of work
- recomm education



ePAG Patient Matchmaker Initiative for patient groups within ERNs

ePAGs as of October 2016



ePAG Representatives

- Need to engage **more patient representatives** in ERNs to participate in:
 - ✓ **Boards**
 - ✓ Sub-clinical committees (e.g. **Cranio**: 1. Craniofacial 2. Cleft lip palate 3. **ENT disorders**)
 - ✓ **Transversal task groups** (Ethics, Clinical Guidelines, Research, etc.), and *possibly*
 - ✓ **By Member State**
- ePAG representative elections 2017 or 2018
- Need to engage **more patient organisations** to achieve **fair representation** of diseases & member states

Patient Matchmaker Initiative

An online tool to connect patient organisations to ERNs

Aim:

- **Engage** patient organisations across the EU & beyond EURORDIS' membership to join an ERN
- **Match** patient organisations with ERNs according to their thematic groupings & across ERNs
- **Create** a virtual network of patient organisations for each ERN eventually covering all rare diseases & Member States
- **Map** patient organisations across the EU
- **Connect** ePAG representatives with ePAG member organisations and vice versa
- **Facilitate** collaboration & discussions between ePAG representatives, ePAG member organisations and clinicians to ensure fair representation of the patient voice in ERNs

Patient Matchmaker Initiative

- Launched in September 2016
- **163** additional member organisations since the matchmaker tool launched
 - ➔ **59% non EURORDIS** members
- Total **934** member organisations
 - ➔ **25% non EURORDIS** members
- Ongoing engagement with patient organisations via matchmaker

European Patient Advocacy Groups (ePAG) Registration Form for Patient Organisations

European Reference Networks (ERNs) provide a unique opportunity to take rare disease patient care to the next level. Before the year end, ERNs for rare diseases will be created in the categories listed further below, and will provide for the first time a unique opportunity to work cross border in Europe in healthcare where expertise is scarce. ERNs are required to involved patients and have open communication and engagement with the wider patient population.

If you are representing a patient organisation, this patient matchmaking tool is for you to register your patient organisation's interest in becoming a member of a patient stakeholder group called an ePAG that is linked to the specific ERN that you feel best represents your organisation. It is an online tool to enable patient organisations to be aligned and connected with these new ERNs in order to ensure an equitable patient voice within the system of ERNs.

Patients are involved in ERNs through elected patient representatives as well through these stakeholder groups. Patient representatives will directly liaise with member organisations in each of the stakeholder groups so to ensure that the patient voice is heard in the development, programming and evaluation of each ERN's initiatives and activities. In the coming months, EURORDIS will also look for additional patient representatives to be part of the governance of ERNs and ensure that representatives are part of all the sub-clinical areas and transversal groups of ERNs.

As a member organisation you will be involved in online ePAG communities and consulted on specific ERN relevant topics to reflect patients' viewpoints through consultations. You will receive information and updates on ERNs and be continuously informed about ERN activities.

Read more about ePAGs here: <http://www.eurordis.org/content/epags>

Rear more about ERNs here: <http://www.eurordis.org/european-reference-networks>

Name of patient organisation *

Short-answer text

Country *

Short-answer text

Private ePAG Online Communities (RareConnect)

ePAG communication via RareConnect

Aim: facilitate discussions and collaboration between ePAG representatives, ePAG member organisations & clinicians joining an ERN and across ERNs.

ePAG online communities:

- Connect representatives with each other in **24** private **'representatives'** communities
- Connect representatives & patient organisations in **24** closed **'advocates'** communities

The screenshot shows the 'Home' page of the 'Rare Cancers Representatives Community'. The page has a red header with a 'Home' button. Below the header is a breadcrumb trail: 'HOME > RARE CANCERS REPRESENTATIVES > HOME'. The main content area is white and contains the following text:

Welcome - Rare Cancers Representatives Community

WHAT IS RARE CANCERS REPRESENTATIVES ?

Welcome rare cancers ePAG Representatives!

The rare cancers ePAG Representative Online Community brings together the ePAG representatives of the rare cancers ePAG which corresponds to one of the 24 ERN groupings.

This community is for you to get in touch with, discuss and exchange information with other ePAG representatives. It is a private community which means that the information and discussions in this

The screenshot also shows the 'Home' page of the 'Rare Cancers Advocates Community'. The page has a grey header with a 'Home' button. Below the header is a breadcrumb trail: 'HOME > RARE CANCERS ADVOCATES > HOME'. The main content area is white and contains the following text:

Welcome - Rare Cancers Advocates Community

WHAT IS RARE CANCERS ADVOCATES ?

Patients are represented and active participants in the ERN development process via the European Patient Advocacy Groups. The rare cancers corresponds to one of the 24 ERN groupings.

The rare cancers online community brings together elected patient representatives and patient organisations who will ensure that the patient voice is heard in the development, programming and evaluation of ERN initiatives and activities.

ePAG communication via RareConnect

- Link to disease-specific RareConnect communities and vice versa for inclusion and out reach
- Launched in October 2016



Members have access to:

- group's description, updates & useful resources
- a space to ask questions & discuss
- a space to access all members, their profiles and their location within a global map



ePAG Leadership Programme

ePAG Leadership Model

A capacity-building programme for ePAG representatives to provide them with skills and knowledge to effectively engage in ERN governance

Objectives:

- **Module 1 ‘Capacity Building Seminars’:**
Develop knowledge & credibility
- **Module 2 ‘Peer Coaching Sessions’:** Build effective relationships, partnership approaches & networks
- **Module 3 ‘Board Presence & Personal Impact’:** Maximise board presence & personal impact of patient representatives
- **Module 4 ‘Mentoring’:** Support patient representatives to define & hone their personal leadership style



Leadership Competencies

No.	Leadership Competencies
Module 1	<p>Leading in ERNs:</p> <ul style="list-style-type: none">• Understanding of ePAG role & function in an ERN - governance, quality assurance & evaluation of service delivery• Common understanding of the vision & objectives of ERNs• Network functions & service improvement• Models for programmes and project development & delivery
Module 2	<p>Leading others:</p> <ul style="list-style-type: none">• Partnership working and clinical engagement• Influencing & persuading• Effective communication• Relationship skills (emotional intelligence part 1)
Module 3	<p>Leading the self:</p> <ul style="list-style-type: none">• Presenting with impact• Influencing without authority• Shaping culture, setting the strategy and decision making approach
Module 4	<p>Ongoing support:</p> <ul style="list-style-type: none">• Mentoring for political positioning & shaping strategic direction• Self-mastery (emotional intelligence part 2)• Defining personal leadership style• Situational leadership

Capacity Building Seminars (M1)

Open to all ePAG representatives:

- Bite size capacity building seminars - Ten minutes, Ten slides of training materials & supporting documents



Capacity Building Seminars (M1)

- **ePAG webinar series** based on RD Action workshops supporting the implementation of ERNs

i. Virtual Healthcare & Data Sharing

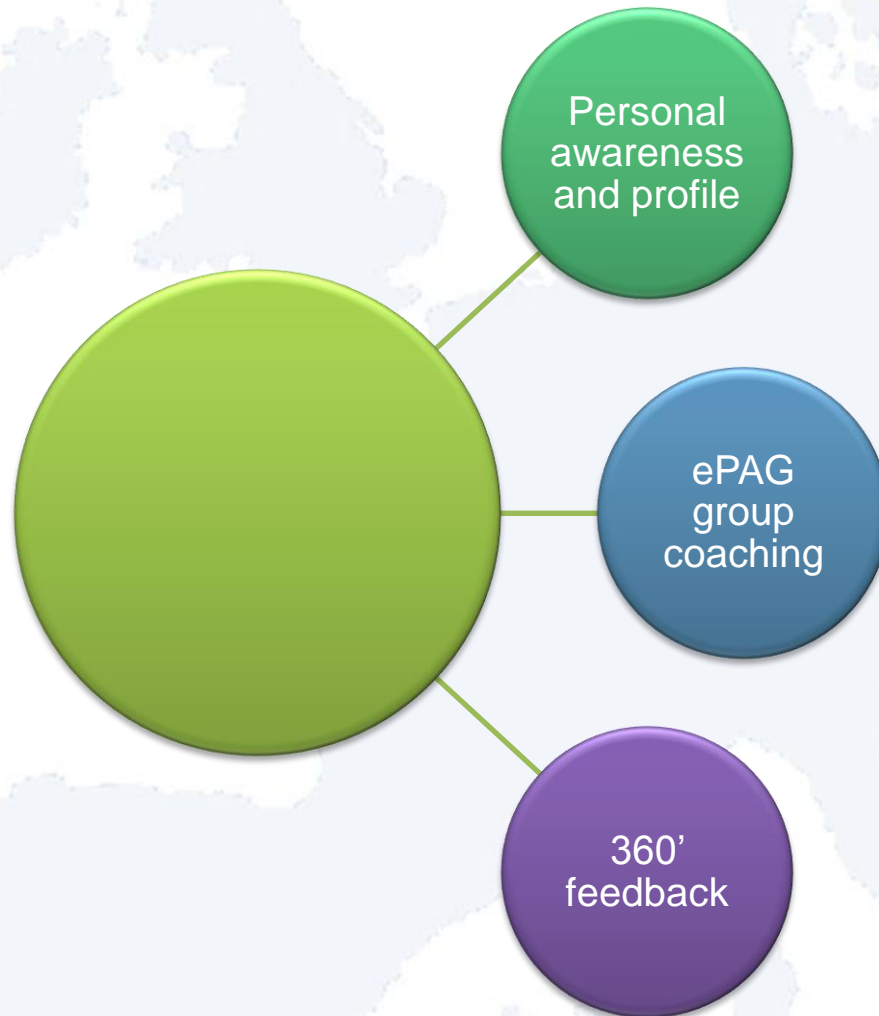
ii. ERNs & Registries

iii. ERNs & Knowledge Generation

iv. Integration of ERNs and Research Infrastructures

v. ERNs & Orphan Drug Development

Peer Coaching Sessions (M2)



- **One off** individual sessions
- **Bi-Monthly** ePAG discussions on ERN development with clinical leads
- **Quarterly** individual ePAG coaching sessions
- **Annual** 360' degree feedback sessions

Board Presence & Personal Impact (M3)

- Annual face-to-face training workshops during EURORDIS Membership Meeting
- **Save the date:** face-to-face workshops at the EURORDIS Membership Meeting **18 May, 2018**



Mentoring (M4)

Outline of mentoring sessions:



Stage 1
- Leadership
Profiling



Stage 2
- Call for
mentors and
partnering



Stage 3
- Ongoing
mentoring
sessions and
annual review

- **Aim** at understanding the nature of our leadership approach
- **Delivered** through individual mentoring support in the context of 'real life experience' of working within the ERN context

Summary

- Ensure **streamlined & comprehensive** patient representation in ERN governance structures
- Achieve **fair** patient representation across diseases and the EU via Matchmaker tool
- **Support** ePAG representatives with information, online communities and communication support
- **Build** the capacity of ePAG representatives to engage with & lead in ERN governance via Leadership Programme

Thank you



Daniel -Sanfilippo syndrome