

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

CNA & CEF Joint Meeting, Paris, 3 November 2016

Content

23/11/2016

- 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

23/11/2016



Background

European Reference Networks (ERNs) created on founding principles of patientcentred 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





eurordis.org

23/11/2016

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

European Patient Advocacy Groups (ePAGs)

Term of References

oblicition pain Materianse Networks (EINN) are created on the founding principle that they should be patient med and empower patients. Patient organizations pre-integral to European Reference Networks in rare ases (ID CEN). Patient organization participation enhances the capacity of EINs to improve patient th octoness and patient subjection.

EURORDIS and its members understand the need and value of creating forums for dialogue, u solidarity amongst patient organisations, the need to optimise the involvement of patient and equitable representation of all rare diseases covered in the scope of the <u>ERN disease grouping</u>.

RORDS and its Council of European Federations promote the innovative approach of Patient Advocacy oups (pPAGs) to facilitate a structured patient engagement process in the decision and opinion forming coses of RD RIMs, and to ensure that they are involved and contribute actively to the mission, services and twork activities of ERNS.

Alis are formed of patient organisations (both members and non-members of EURORDIS) within the pe of the specific grouping of each ENN. Each ePAG mirrors the ENN grouping of rare diseases. ePAGs will ris calibilitatively with ENN tentitations and vorketin (EVP) (bits, stancistic and collaborative members) based the operational criteria to be fulfilled to be an ERN and a HCP.

and/are AGR representatives are full members of their respective ERN Boards and they participate in the decisi aking process as agreed on in every network.

ePAG representatives have an official permanent mandate to represent EURORDIS and the affiliated patien organisations. They will lisis with their affiliated patient organisations to ensure true and equitable representation of the patient toxics in their respective RRN.

 $bblective PAG representatives provide the patient perspective to the ERN Boards on the organisation and management of the network, specifically to <math display="inline">^{\rm L}_{\rm T}$

Ensure care is patient-centred and respects patients' rights and choice; Promote and encourage a patient-centric approach in both delivery of clinical care, service improvement and strategic development and relative mainteents.

Ensure transparency in quality of care, safety standards, clinical outcomes and treatment options,

EUROPEIS - Ensure all ethical lauses and concerns for patients are addressed, balancing patient and cinit needs appropriately;

- Ensure feedback and evaluation of patient experience;
 Contribute to the development of patient information, polision
- guidelines; Ensure the application of personal data rules, compliance of information consent and management
- of complaints; Advise on planning, assessment and evaluation of the ERN; and Evaluation of all assess before the evaluation of the ERN; and
- discussions and activities, specific to the scope of their respective ERN.

ePAG representatives collaborate with ePAG members to participate in the specific activities abo

Membership of ePAGs is open to all rare disease patient organisations, EUROROIS members and nonmembers, based in the Europen Union. Patient organisations based outside the European Union, in Europe at large or based in other countries released to the specific ERW, will pergressively be included, on a case-bycase basis, in conjunction with the collaboration of ERNs with HCPs beyond the EU.

- ePAG membership is voluntary and structured as follows:
- ePAG members are patient organisations aligned to the grouping of the rare diseases covered by the respective ERNs.
- ePAG representatives are elected by the ePAG members to be their voice at the ERN Board and ensure rare disease patient organisations are consulted by the ERNs for disease-specific discussions, projects and activities. ePAG representatives are all based in the European Union.

Commitment ePAG representatives commit to:

- Reflect patients' viewpoints through proper internal consultation with their respective ePAGs members to the best of their ability;
- Share importain news and send a brief report of any DRN meeting attended to their respective ePAG affiliated members and EUROROIS;
 Inform EURORDIS when representing the ePAG at a conference, workshop, or any meeting of public
- Importance; Travel to meetings when required²; and
- Declare their potential Conflicts of Interests In formal meetings or activity

ePAG representatives are appointed for a two year term renewable by agreement for a further 3 year period. There is no remuneration for this role at present.

¹ Toxel islated to ENV functions should be covered to the ENV. Toxel islated to eAVG coordination and capacity building activities will be covered by members or shared cests between EUROPOS and members.

- 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

41 ePAG member organisations

Engagement with wider patient community Rafaella Restaino

Paolo Federici

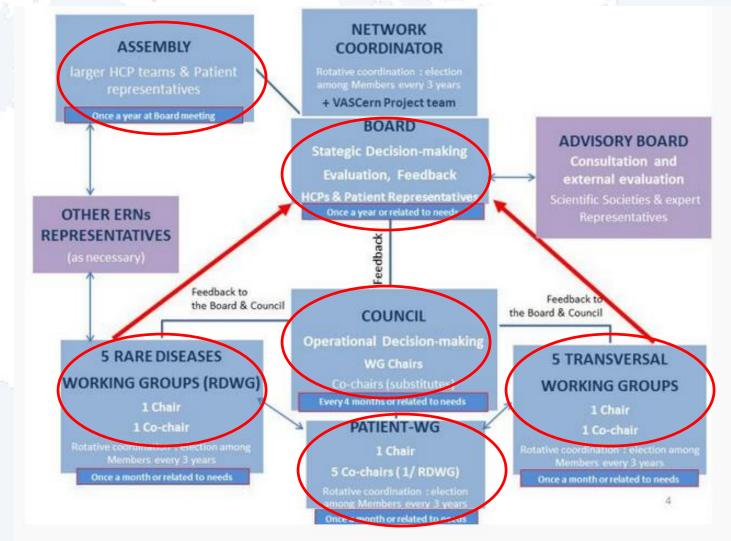
Patrice Touboulie

Christina Grabowski



eurordis.org

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



23/11/2016

eurordis.org

9

≀ORDIS

seases Europe

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



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

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



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

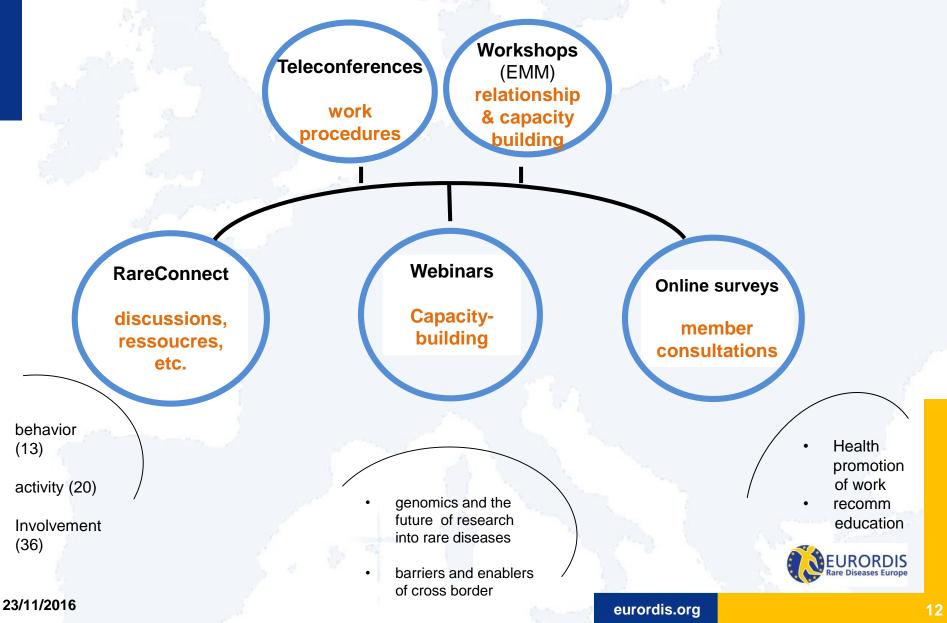
Associazione Italiana Teleangectasia Emorragica – HHT ONLUS tonlus.org

Means of ActionThe Objectives of HHT Europe are:

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

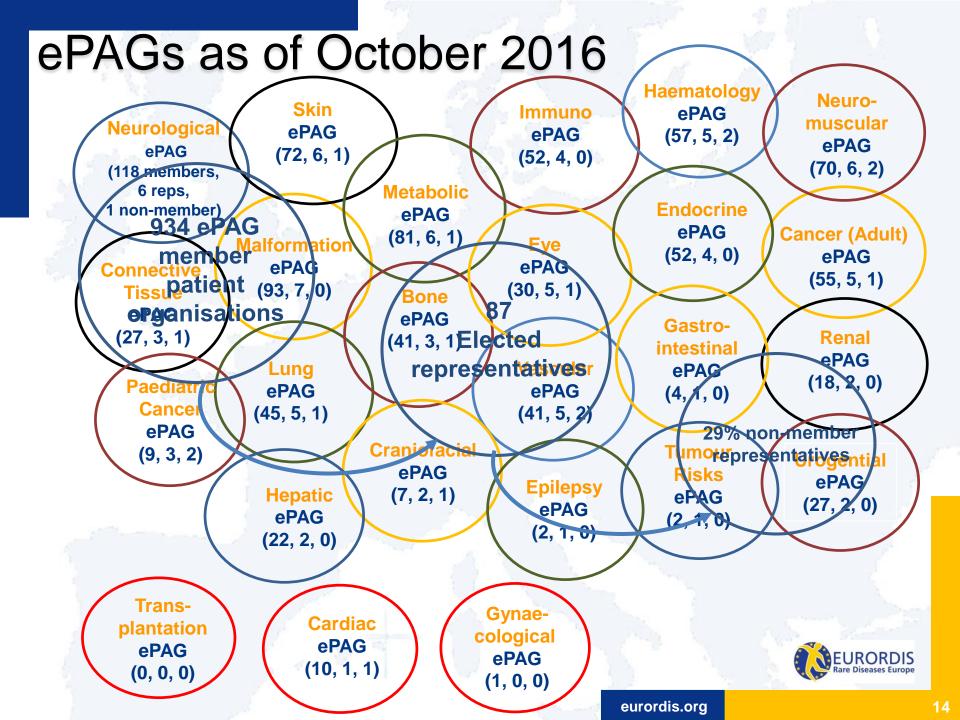


Instruments of Engagement



ePAG Patient Matchmaker Initiative for patient groups within ERNs





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
- PAG 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

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

- 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

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 liase 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 *

Ongoing engagement with patient organisations via matchmaker



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

Home

HOME > RARE CANCERS REPRESENTATIVES > HOME

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

HOME > RARE CANCERS ADVOCATES > HOME

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.

20

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 & home their personal leadership style



Leadership Competencies

No.	Leadership Competencies
Module 1	 Leading in ERNs: 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	 Leading others: Partnership working and clinical engagement Influencing & persuading Effective communication Relationship skills (emotional intelligence part 1)
Module 3	 Leading the self: Presenting with impact Influencing without authority Shaping culture, setting the strategy and decision making approach
Module 4	 Ongoing support: 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)



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



eurordis.org

0

Horse Riding