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## EPAG UPDATE

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**EURORDIS.ORG**

# Patient Centre & Empowerment

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



## European Patient Advisory Groups (ePAG):

- 24 forums 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 >150 elected ePAG reps & <1000 ePAG member organisations
- Voting Members of ERN Boards, equal voice!
- Recruitment continue for ALL disease specific clinical networks / committees and transversal working groups

# Patient & Clinical Partnership, Vilnius

## 9-10 March 2017

+50 number. ePAG Representatives attended Vilnius, funded by the EC as ERN representatives



# ERN Blueprint for Patient Involvement

## Input into ERN Board:

- Identify potential partners and existing stakeholders
- Strategic planning including expand network scope and coverage
- Monitors the activity, outcomes, and initiatives of the Network
- Established mechanisms to hear from and incorporate the voice and opinion of patients and families
- Develops and provides access to information adapted to the specific needs of patients
- Standardised common patient experience tool
- Improve the safety and quality of care base on patients experience

## Data Sharing:

- Promotes and/or facilitates the use of information and communication technology
- Virtual consultation and share expertise with local hospitals

Target  
Improvements  
in Rare  
Diseases

## Research Activities

### Research

- Set research priorities
- Supports collaborative research
- Disseminate research project information and results
- Recruitment to clinical trials and studies
- Shared registries and databases

## Knowledge Generation & Dissemination

### Knowledge Generation & Dissemination

- Establish patient pathways and cross-border pathways based on patient needs
- Develop, disseminate and implement guidelines and protocols
- Review and disseminates expertise, best practice and evidence
- Discuss new treatments, therapies, and health care technologies

## Training & Education

### Training & Education

- Provides education and training
- Share experience, exchange knowledge and best practice and expertise within ERN, between ERNs and wider community

## Specialist Advice

### Patient Care

- Inform patients and families about patient pathways
- Disseminates information on patient safety standards and safety measures
- Enabling reporting possible safety incidents or adverse events

Source: EC AMT Operational Criteria for Networks

# European Patient Advocacy Group Satellite Meeting



# ePAG Guide : Foster Engagement & Involvement

## Patient Representative Role in ERNs

Patient representatives, clinicians and researchers share a common ambition to find answers, treatments, and ultimately cures for people living with a rare disease, to enable them to lead better lives. Whilst we share this common ambition, we draw on different experiences, expertise and knowledge, and see the world from different perspectives. Understanding the patient representative's role in an ERN will enable the patient-clinician partnership to deliver on this shared ambition, successfully aligning these perspectives, experiences, expertise and knowledge and optimising the investment of resources – time, energy and funding – to fully unlock the true potential of ERNs.

The objective of patient representatives is to provide the patient perspective. The investment of their capacity, time and experiences for patient or carers representatives is at three levels:

1. Patients as a partner in their own care;
2. Patients contributing to the delivery of a common goal with each Network HCP Member, locally to their region or country;
3. Patients as a "Patient Resource" invested at a network and European level.

This Guide focuses practice guidance to optimise the invest of patients as a "Patient Resource" into ERNs, imparting their experiences and knowledge and to actively participate in the different groups, committees and boards. However, to do this successfully they will need to be actively involved in executive and clinical discussions and debates, and may need support to understand and digest technical, scientific, legal and medical terminology and concepts.

Patient representatives hold a privileged position in ERNs and have a valuable contribution to make into the strategic development and operational delivery of these networks. Recognising this by all – from patient representatives, clinicians and researchers - will be the deciding factor of the success of ERNs. The contribution and authority of clinicians and researchers have been honed-in and established throughout their professional lives and careers. Patient representatives' contribution draws on their real-world experience of living with a rare disease, understanding its impact on their health and wellbeing and on their family. Due to the rarity and complexity of many multisystem rare diseases, patients ultimately become the expert in their rare disease, through their real-world experience as many clinicians may only see one case in their career.

## Defining the Patient Representatives Role

Patient representatives have a wealth of experience that can be draw on in the operational delivery of ERNs. Defining the patient representative's role in ERNs, enables the patient representatives, clinicians and researchers, to hold share expectations of their contribution into the ERN discussions, and in turn optimises their involvement.

Patient representative's role can be defined, but not limited, to four fundamental functions:

1. Patient representatives hold the unique knowledge or personal experience of a specific disease, able to convey the needs and challenges of living with this disease into network discussions, decisions and activities.
2. They are the only stakeholders who hold a holistic view of the whole process – from diagnosis, care and treatment, from early research through to orphan drug authorisation - only patients have a stake in every stage of the research and healthcare pathways.
3. Patient representative are the only ones who can to ask 'the stupid questions' as these are often the most relevant and insightful questions that should be asked and are often not.
4. Hold skilled and experienced from other sectors, outside the medical/research field, that can offer a new or alternative perspectives into network discussions.

# Kick Off Meetings

European Reference Network	KOM date	Location	EURORDIS participation
Rare Neuromuscular ERN	Vilnius, Lithuania	10 March 2017	-
Transplantation ERN	Vilnius, Lithuania	10 March 2017	Yes
Rare Haematological ERN	Paris, France	26-27 Jan 2017	Yes
Rare Eye ERN	Tübingen, Germany	3-5 April 2017	Yes
Rare Pulmonary ERN	Frankfurt, Germany	5-6 April 2017	Yes
Rare Neurology ERN	Milan, Italy	15-16 April 2017	-
Rare Gastrointestinal ERN	Rotterdam, Netherlands	20-21 April 2017	Yes
Rare Liver ERN	Amsterdam, Netherlands	21 April 2017	Yes
Adult Cancer ERN	Lyon, France	21-22 April 2017	Yes
Rare Metabolic ERN	Frankfurt, Germany	24-25 April 2017	Yes
Rare Endocrine ERN	Leiden, Netherlands	27 March 2017	-
Rare Kidney ERN*	Heidelberg, Germany	22-23 May 2017	-
Rare Bone ERN	Rome, Italy	23-24 May 2017	Yes
Rare Skin ERN	Brussels, Belgium	25-26 May 2017	Yes

\* EURORDIS supported FEDER workshop in Amsterdam on 5 March 2017


# Kick Off Meetings

European Reference Network	KOM date	Location	EURORDIS participation
Genetic Tumour ERN	Copenhagen, Denmark	27-28 May 2017	Yes
Rare Connective Tissue ERN	Pisa, Italy	26-28 May	Yes
Rare Epilepsies ERN	London, UK	3 June 2017	Yes
Rare Urogenital ERN	Amsterdam, Netherlands	6 June 2017	Yes
Craniofacial & ENT	Rotterdam	10-11 June	Yes
Paediatric Cancer ERN*	TBC	June 2017	Yes
Rare Immunodeficiency, Auto-inflammatory and Autoimmune ERN	Edinburgh, Scotland	11 September 2017	Yes
Rare Cardiac ERN : Board Meeting	Barcelona, Spain	27 August 2017	Yes
Rare Malformations ERN	Manchester, UK	18 September 2017	Yes
Rare Vascular ERN	Paris, France	14 October 2017	Yes

\* EURORDIS supported Childhood Cancer International Conference in Rome on 12-14 June 2017



# Establish a Patient Advisory Committee (PAC)

  
**GUARD HEART Patient Advocacy Committee (PAC)**  
**Terms of References**

**GUARD HEART Patient Advocacy Committee (PAC)**

**Constitution**

The **GUARD HEART Patient Advocacy Committee** is established under the direction of GUARD HEART European Reference Network.

**Aims**

The aims of the **GUARD HEART PAC** are to:

- Representing the voice of patients within GUARD HEART ERN ensuring the needs of people living with a rare cardiac disease are included in the strategic and operational delivery of the network, and to;
- Create a bridge between the GUARD HEART ERN and the rare cardiac disease patient community, ultimately to improve access to high quality diagnosis, care and treatment.

Patient Advocacy Committee will deliver these aims through undertaking the following activities:


- Contribute to the development of patient information, treatment policies, good practice guidelines and care pathways
- Support the network to dissemination of information and communication to the wider patient community
- Contribute to the development of research priorities and ensuring they are informed by the needs of patients and families
- Provide advice on ethical issues on the application of personal data rules, compliance of information consent and management of complaints
- Engage with the appropriate patient communities for disease specific activities and projects

**Composition**

The GUARD HEART Patient Advocacy Committee is composed of elected or co-opted patient representatives, known as **ERNG** representative, who are to be their voice within GUARD HEART ERN. These **ERNG** representatives are all based in the European Union.

GUARD HEART PAC membership is voluntary. Membership of the GUARD HEART PAC is open to all patient representatives who are willing to be involved within the area of expertise of GUARD HEART ERN. The GUARD HEART PAC has 1 Chair, 1 Co-chair and 2 patient representatives per each of the 4 clinical network boards. Membership of the GUARD HEART PAC will be open to new patient representatives who will be nominated and active members of the clinical network boards and transversal thematic committees.

Rare Liver Patient Representative Council Terms of References, (First draft, June 2017)  
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**GUARD HEART PAC Members (additional members from those identified above)**

The initial composition of the patient representatives on the GUARD HEART ERN network groups are as following:

GUARD HEART PAC Members Names	Patient <b>QUESTIONS</b>	GUARD HEART Committees
Name (PAC Chair)		GUARD HEART Network Board
Name (PAC Co-chair)		GUARD HEART Network Board
...		Steering Committee
...		Rare familial Electrical Diseases Clinical committee
...		Rare familial Cardiomyopathies Clinical committee
...		Congenital Heart Defects Clinical committee
...		Other Rare Cardiac Diseases Clinical committee
		Ethics and Policy Issues working group
		Research and Funding working group
		Teaching and e-Learning working group
		Data Management and e-Health working group
		Knowledge Management working group

**Governance**

The GUARD HEART Patient Advocacy Committee

- 1 chair and 1 Co-chair representing the GUARD HEART PAC in the network board
- Patient representatives in the **diagnostic** specific clinical networks
- X thematic representatives for GUARD HEART thematic committees

They are elected among the patient representatives.

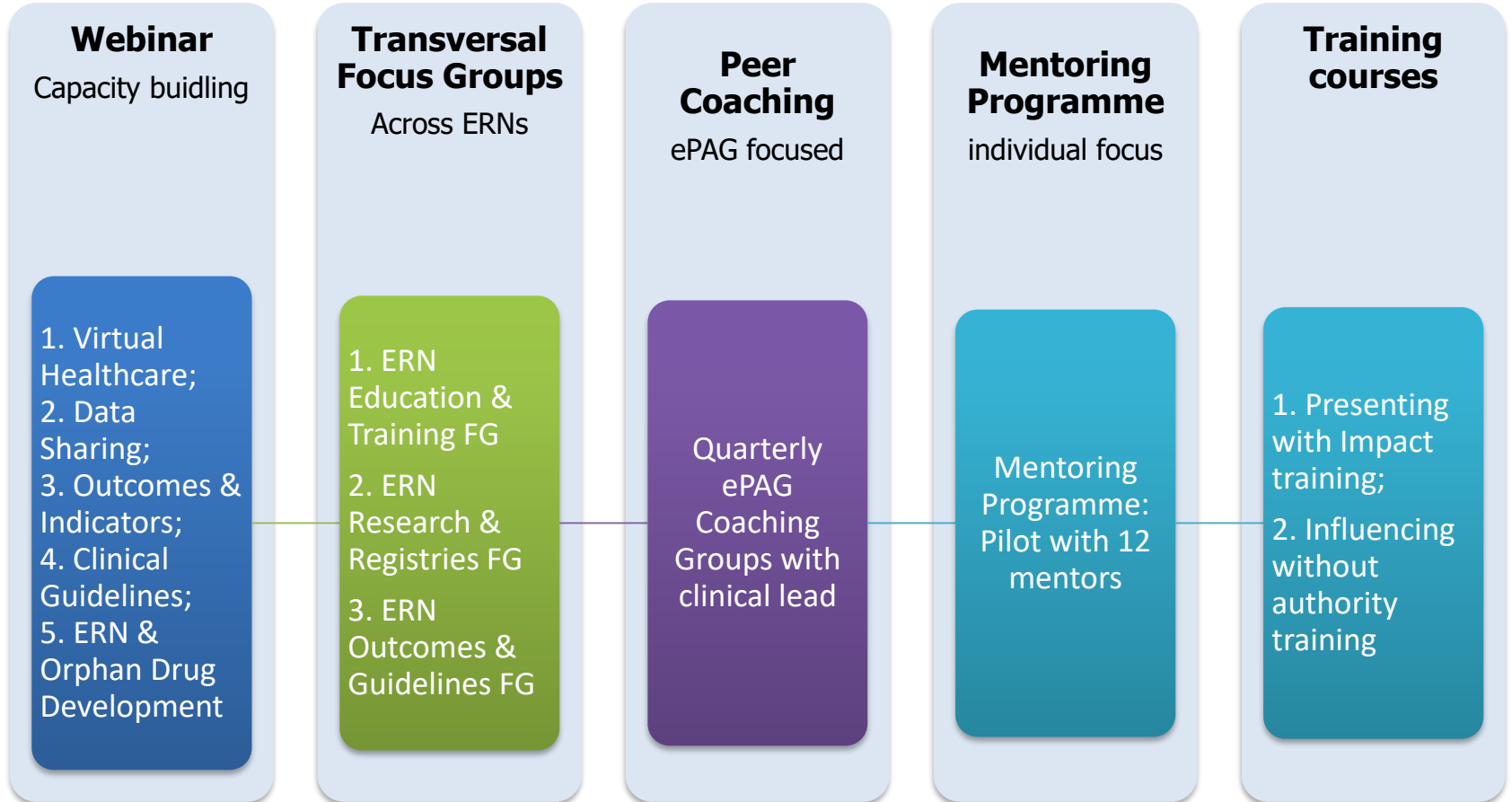
**Mandate**

The GUARD HEART PAC has an important role and missions in Governance, Ethical issues, Care, Research, Evaluation, and as expert patients in education of patients and families.

**Objective:** to ensure that the GUARD HEART PAC provides quality recommendations and feedback that genuinely reflects patient's viewpoints, members commit to:

Rare Liver Patient Representative Council Terms of References, (First draft, June 2017)  
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# ePAG Leadership Programme



# 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 #5**

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

## **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 #6**

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

# 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.

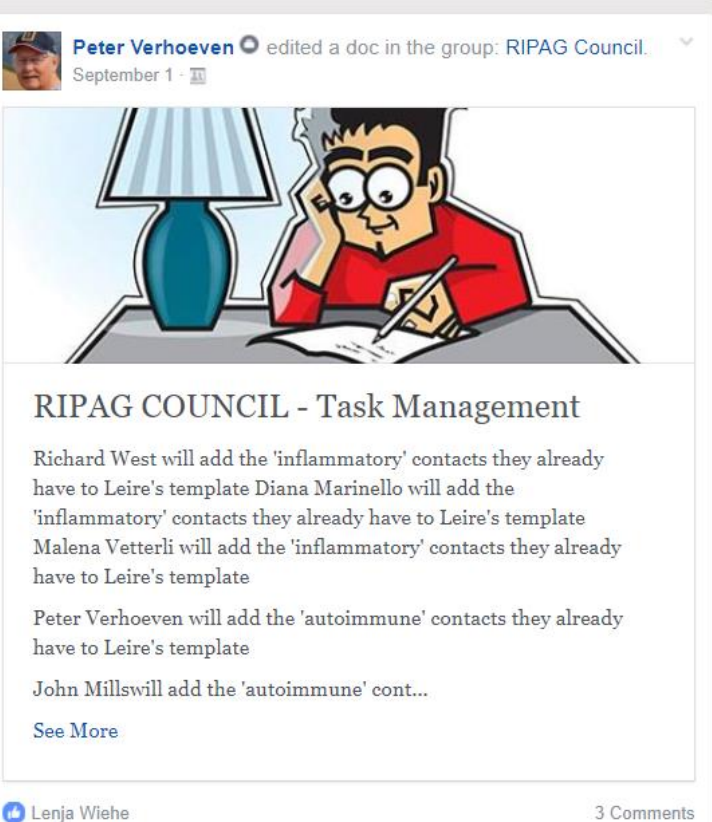
There are **48 communities** for individual ePAG. Each ePAG community has **two groups** to:

# 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 communications** from in the ePAG Advocates group



**Peter Verhoeven** edited a doc in the group: RIPAG Council. September 1 · 🌐

**RIPAG COUNCIL - Task Management**

Richard West will add the 'inflammatory' contacts they already have to Leire's template  
Diana Marinello will add the 'inflammatory' contacts they already have to Leire's template  
Malena Vetterli will add the 'inflammatory' contacts they already have to Leire's template

Peter Verhoeven will add the 'autoimmune' contacts they already have to Leire's template

John Millswill add the 'autoimmune' cont...

[See More](#)

Lenja Wiehe 3 Comments

# ERN Common Patient Experience Survey

Rare Barometer Voices is a **panel of people living with a rare disease who participate regularly in EURORDIS surveys** and studies available in 23 languages.

**Exploring the possible developing** this platform to be the centralised patient feedback mechanism across the ERNs will provide information in order:

- To **align strategic decisions and operational delivery of the ERNs with patients' needs and experiences**, specifically the development of healthcare pathways and treatment protocols;
- To **enable ERNs to capture the experience and feedback** of multisystem rare disease patients treated in one or multiple networks.



Avoiding duplication of efforts through **pooling of resources** to drive **economies of scale**;

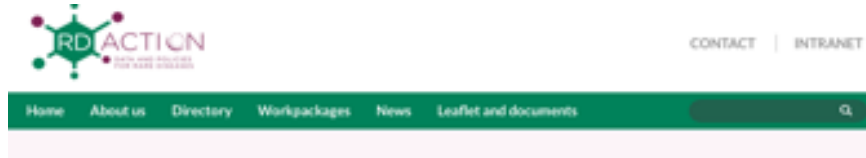


Ensuring **robust, comparable and independent validated data and results** by using the same survey methodology across ERNs;



Achieving **sufficient survey sample size and coverage** of the ERNs patient population.

# RD Action (Joint Action for Rare Diseases) Very Useful websites



## Coordination of European Reference Networks

This is a list of the approved Healthcare Providers (HCPs) coordinating the ERN in each Thematic Group; please see the official EC pages here.

UPDATE! To complement the official summaries provided by DG SANTE, you can read about the structure and goals of each ERN by clicking on NETWORK NAME, below



Network Name	Thematic Grouping	Coordinating HCP	Name of Coordinator	Website
<a href="#">BOND</a>	Rare Bone Disorders	Istituto Ortopedico Rizzoli, ITALY	Luca Sangiorgi	<a href="#">ERN-BOND</a>
<a href="#">CRANIO</a>	Rare Craniofacial anomalies and ENT disorder	Erasmus Medical Centre, Rotterdam - THE NETHERLANDS	Irene Mathijssen	<a href="#">ERN-CRANIO</a>
<a href="#">ENDO-ERN</a>	Rare Endocrine Diseases	Leiden University Medical Centre - THE NETHERLANDS	Alberto Pereira	<a href="#">ENDO-ERN</a>
<a href="#">EpiCARE</a>	Rare and Complex Epilepsies	UCL Institute of Child Health - UNITED KINGDOM	Helen Cross	<a href="#">EpiCARE</a>
<a href="#">ERKNET</a>	European Rare Kidney Diseases Reference Network	Heidelberg University Hospital - GERMANY	Franz Schaefer	<a href="#">ERKnet</a>
<a href="#">ERN-RND</a>	Rare Neurological Diseases	University Hospital Tübingen - GERMANY	Helm Graessner	<a href="#">ERN-RND</a>
<a href="#">ERNICA</a>	Rare Gastrointestinal Diseases (Rare Inherited & Congenital Anomalies)	Erasmus Medical Centre, Rotterdam - THE NETHERLANDS	Irene Wijnen	<a href="#">ERNICA</a>

<http://www.rd-action.eu/european-reference-networks-erns/coordination-of-rare-disease-erns/>

# Thank You

