

PATIENTS' INVOLVEMENT IN THE ERNs: the European Patient Advocacy Groups



Patient representatives and organisations are as integral to the strategic and operational outcomes of European Reference Networks in rare diseases (ERN) and play an **active role** in the networks' decision and opinion-making structures. To achieve this, EURORDIS created the European Patient Advocacy Groups (ePAGs) as forums to optimise the involvement of **patient representatives** of the rare disease community in the 24 ERNs.

ePAGs aim to represent the **voice of patients** within ERNs to ensure that the needs of people living with a rare disease are included in the strategic and operational delivery of the network. ePAGs create a bridge between the ERN and the patient community, to ultimately ensure that ERN services can answer to the **needs and expectations** of rare disease patients and therefore improve access to high quality diagnosis, care and treatment. ePAG Patient Advocates have an official permanent mandate to represent ePAG member organisations. They liaise with these organisations to ensure true and equitable representation of the patient voice by participating in the **Board** and sub-clinical committees of their respective ERN. ePAGs deliver these aims through their ePAG Patient Advocates undertaking the following activities inside the ERN:

- engage with the appropriate patient communities for disease specific **activities and projects** to represent their needs;
- actively participate to the ERN **Governance structures** and to the ERN activities;
- contribute to the development of information for patients and support the network in the **dissemination** of information and communication to the wider patient community;
- participate to the development of a monitoring process of the **outcomes** of the ERN;
- contribute to the development of **research priorities** and ensure they are informed by the needs of patients and families;
- provide advice on **ethical issues** on the application of personal data protection rules compliance of informed consent and handling of complaints.



Vera Guimaraes
LPCDR
Núcleo MCTD

Ana Vieira
LPCDR
Núcleo Sjögren

Alain Cornet
LupusEurope

Jürgen Grunert
Deutsche EDS
Initiative e. V.

Ilaria Galetti
FESCA

Charissa Frank
Bindweefsel.Be

ERN ReCONNET ePAG

One of the most relevant **added value** of the ERN ReCONNET is the **involvement** of Patients' Representatives within all the activities of the Network. In fact, an intense collaboration has been established with the ERN ReCONNET European Patient Advocacy Group (ePAGs).

Three ERN ReCONNET ePAGs Representatives are **voting members** of the Steering Committee, and each Representative represents one arm of the Network: Charissa Frank (Hereditary Connective Tissue Diseases), Ilaria Galetti (Rare Connective Tissue Diseases), Ana Vieira (Complex Connective Tissue Diseases).

In order to provide a structure to the patients' involvement in the ERN ReCONNET, a Patients Working Group has been created and Jürgen Grunert will act as **Senior Coordinator** and Ilaria Galetti as **Junior Coordinator**.

In addition, **Patients' Representative Disease Coordinators** (one per each disease) collaborate with Healthcare Providers Disease Coordinators and their role is particularly important for the activities related to the specific diseases both at European and National level

Diseases covered by ERN ReCONNET

- AntiPhospholipid Syndrome
- Ehlers-Danlos Syndrome
- Idiopathic Inflammatory Myopathies
- IgG4-Related Disease
- Mixed Connective Tissue Disease
- Relapsing Polychondritis
- Sjögren's Syndrome
- Systemic Lupus Erythematosus
- Systemic Sclerosis
- Undifferentiated Connective Tissue Disease

Clinical Patient Management System

The Clinical Patient Management System (CPMS) allows healthcare providers from all over the EU to organise **virtual consultations** and share experience together across national borders. This will provide patients with the **best expertise** available on diagnosis and treatments of rCTDs.



How to become an ePAG representative

ePAG patient advocates must come from a **patient organisation** in the EU and must adhere to the EURORDIS **Charter of Volunteers**. The number of patient advocates per ePAG is determined in collaboration with clinical coordinating teams of ERN applications and according to the scope of the respective ePAG membership. Patient advocates have already been elected to numerous ERNs but additional applications are welcome for all networks. Members and non-members of EURORDIS are encouraged to apply. If you are interested in becoming an ePAG advocate please contact lenja.wiehe@eurordis.org.

How to become an ePAG member organisation

Membership of ePAGs is open to **all rare disease patient organisations** (EURORDIS members and non-members based in the European Union). To register the interest of your patient organisation in becoming an ePAG member organisation you should fill out a form (available at <https://www.eurordis.org/content/epags>) indicating which ERN you wish to be affiliated to.

Network Coordinator Prof. Marta Mosca
Azienda Ospedaliero Universitaria Pisana
Via Roma, 67 - 56126 Pisa (Italy)

@ ern.reconnet@ao-pisa.toscana.it

<http://reconnet.ern-net.eu>



Subscribe to the ReCONNET Newsletter on website



Follow us on Twitter @ern_reconnet

Subscribe to our YouTube channel



ERN ReCONNET is one of the 24 European Reference Networks (ERNs) approved by the ERN Board of Member States. The ERNs are co-funded by the European Commission. The content of this publication represents the views of the authors only and it is their sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency (CHAFEA) or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.

ERN ReCONNET

European Reference Network on
Rare and Complex Connective Tissue
and Musculoskeletal Diseases

Patients' Involvement



European
Reference
Network

for rare or low prevalence
complex diseases



Network
Connective Tissue
and Musculoskeletal
Diseases (ERN ReCONNET)

Share. Care. Cure.

More info:

<http://reconnet.ern-net.eu>