

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>

Co-funded by the



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



Patient representatives and organisations are recognised by the European Commission Expert Group for Rare Disease, as integral to the strategic and operational outcomes of European Reference Networks in rare diseases (ERN) and should 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.

ePAGs deliver these aims through their ePAG Patient Advocates undertaking the following activities inside the ERN:

- assist the HCP Members of their ERN;
- contribute to the development of **information** for patients: treatment policies, good practice guidelines and care pathways to ensure they are patient centred by reflecting and meeting the needs of patients;
- participate to the development of a monitoring process of the **outcomes** of the ERN;
- support the network in the **dissemination** of information and communication to the wider patient community;
- 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;
- engage with the appropriate **patient communities** for disease specific activities and projects.



Do you want to be involved? Contact us!

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). The ERN ReCONNET ePAGs Patients Advocates identified are:



Alain Cornet
Lupus Europe



Charissa Frank
Bindweefsel.Be



Ilaria Galetti
FESCA



Jürgen Grunert
*Deutsche EDS
Initiative e. V.*



Ana Vieira
*LPCDR
Núcleo Sjögren*

Three ERN ReCONNET ePAGs Representatives are **voting members** of the Steering Committee, and each Representative represents one arm of the Network:

- Charissa Frank represents **Hereditary Connective Tissue Diseases**;
- Ilaria Galetti represents **Rare Connective Tissue Diseases**;
- Ana Vieira represents **Complex Connective Tissue Diseases**.

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

Patients' Representative Disease Coordinators collaborate with Healthcare providers Disease Coordinators and their role is particularly important for the activities particularly related to the specific diseases both at National and European level.

Diseases covered

Antiphospholipid syndrome
Idiopathic inflammatory Myopathies
IgG4-related disease
Mixed connective tissue disease
Relapsing Polychondritis
Systemic sclerosis
Undifferentiated connective tissue disease
Sjögren's syndrome
Systemic lupus erythematosus
Ehlers-Danlos Syndrome



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.



European
Reference
Network

Connective Tissue and Musculoskeletal
Diseases (ERN ReCONNET)

Contacts



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ERN ReCONNET



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ERN ReCONNET is one of the 24 European Reference Networks (ERNs) approved by the ERN Board of Member States. The ERNs are supported by the European Commission.

For more information about the ERNs and the EU health strategy, please visit ec.europa.eu/health/ern

