



Marta Mosca - ERN ReCONNECT

LUPUS EUROPE

They have created 24 Virtual Networks - There is some overlap in disease areas

To deliver high quality and homogeneous care across EU borders

Patient centred

Becoming a large network, it is constantly growing.

8 Member states. Also have affiliated members

Even if centres are not members they collaborate with ERN.

The purpose is not primarily research for doctors, the idea is to connect with patients.

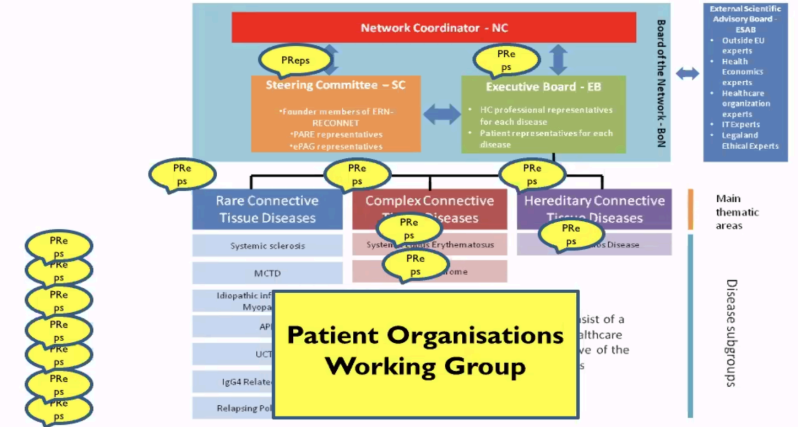
3 ePAGS are voting members of their steering committee

Bring their work to a national level and make a change.

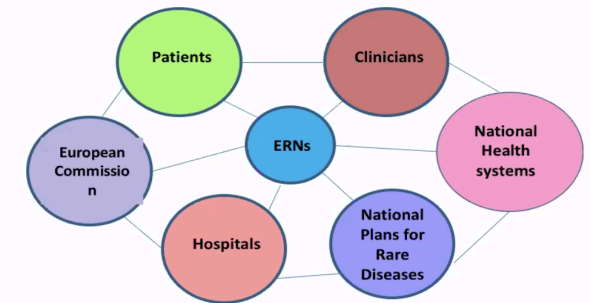
Convince the national health systems that their work is helpful and important.

Seek help from the broader medical community for the best patient care possible

Patients involvement



Stakeholders of ERNs



Meet with Marta Mosca ERN ReCONNET

- ▶ Kirsi - Finland has applied. MC- They are adding more and more but takes time hopefully completed in a few months
- ▶ Katy - Greece would like to be a member. MC- They have 2 centres from Athens applying. Can participate through being a Lupus Europe member.
- ▶ Illaria (FESCA) they are reviewing their epag internal constitution. Should have one per rare disease. Being involved in ReCONNET is a pleasure as Marta gives them a lot to do, so need more people. There are some limitations in becoming an epag, but they want more patient involvement.
- ▶ Ines - Only Doctors/centres can be in contact with the ERN? Not individual patients. MC - Clinical cases have to be through doctors. But sometimes it is directly the patient, especially in paediatrics (Telemedicine) It is a collaborative process, doctors and patients at the same level and valued opinions of both.
- ▶ Ines - Can we volunteer as an individual or through our organisation.? Illaria - Both. Alain can distribute patients according to their strengths. If they know anyone who would want to be a full ePAG for other rare diseases.
- ▶ Elfriede -are there any urgent topics? MC - Work on everything simultaneously, proof of concept for patient pathways is needed now. Webinars/education to patients very important. Think as a group on all the activities and identify 2/3 to be worked on in groups. We have worked as a group of patients (all diseases) and also in single disease areas. Engage as many patients as possible, so more work can be achieved simultaneously.
- ▶ How can we do better in our national groups to support you? Dissemination of the project (spread the word) to patients and doctors. Ask opinion of your doctor and they could pass it amongst their colleagues. LE surveys are very good and useful. Put your doctor in contact with ERN doctors.

- ▶ what we can do better to support each other in our work ?
- ▶ What we can learn from each other ?
- ▶ Any other learning?