

RIPAG is the Patient Advocacy Group for RITA, the European Reference Network on Rare Immunodeficiencies (PID), Autoinflammatory disorders (AID) and Autoimmune diseases (AI).

We represent the patient community for immune mediated diseases by participating in the ERN-RITA Working Groups, Council and Board.

The mission of RIPAG is to safeguard the patient centric profile of the ERN RITA and contribute to the ERN RITA according to the critical roles patients and patient's organisations play, as experts by experience and co-producers of knowledge in all ERN activities.



Plan

Plan, Expand, Deliver, Inform and Influence, those are the key areas we work on.

Expand



PLAN: We created a Terms of Reference document (ToR) explaining how we work and a plan defining our mission, vision and strategy.



Deliver

EXPAND: This phase currently has our focus. The whole idea of an ERN is to make excellent care available for patients in all European countries. Therefore, we have to include patient organisations from as many European countries as possible and in all three areas RITA covers: Primary Immunodeficiencies (PID), Autoinflammatory Disorders (AID) and Autoimmune diseases (AI). Being a big international patient organisation, IPOPI covered the entire PID community since day one. AID and AI were represented through EURORDIS and started with 3 people from the UK, one from Italy and one from The Netherlands. Currently, there are 12 Patient Advocacy representatives involved and some in the pipeline. They cover all three

Inform



Influence

areas through 12 patient organisations in Spain, Italy, France, The Netherlands, Finland, the United Kingdom, Ireland and Switzerland. We aim to be as inclusive as possible in getting patients from all over Europe involved and we are constantly on the lookout to get patient organisations on board.

DELIVER: Since we want to play an active role in all of ERN-RITA's activities, we try to ensure that representatives of RIPAG are actively participating in each of the RITA working groups so the patient's voice is heard in each one of them. The outcomes, so far, have been quite uneven and we call on the Working Group Chairs to ensure that patients are also part of the discussions in their working group.

INFORM: Not every single patient or patient organisation will be able to actively participate in all activities. Therefore, we have to work through an effective representation structure and ensure we frequently provide updates on our current activities. We are in the process of setting up a communication plan to achieve these goals.

INFLUENCE: The result of all of the above should be that we safeguard the patient centric profile of the ERN RITA and that we contribute to the ERN-RITA's activities and success. This would result in a better care for people living with a rare disease, in particular, those affected with an immune-mediated disease.

Want to know more? Want to get involved? Send an E-mail to contact-rita@ern-net.eu