



EURORDIS EMM 2021 European Patient Advocacy Groups

12th May 2021

[EURORDIS.ORG](https://eurordis.org)



1. What's the role of ePAG advocates?
2. What skills and experience are required?
3. Where can you engage?

What's the role of ePAG advocates?

1. Work in **partnership** with other patient advocates, clinicians and researchers involved in the ERN;
2. **Champion the diversity of views of the ERN patient community**, and not just to represent their own disease area nor their own experience;
3. **Disseminate** ERN information, primarily to the patient community, but as appropriate to other communities (e.g. healthcare providers)
4. Contribute to the development of **patient information, clinical practice guidelines, other clinical decision support tools and referral pathways**;
5. Contribute to the development of **research priorities** and ensure the needs of patients and families area taken into consideration;
6. Provide input on **ethical issues**, and balance patient and clinical needs appropriately;
7. **Scout** for or make recommendations for new patient organizations to cover disease groups or patients from other EU countries



What skills and experience are required?

- Have knowledge of, or experience of living with, one of the rare and complex conditions **included in the scope of the ERN**;
- **Willingness and motivation** to get involved, contribute actively to the discussions and work of the ePAG and the ERN working groups;
- Ability to work constructively with **other patient representatives and clinicians** from **different EU countries**;
- Ability to represent **the interests of all represented diseases** that are under the scope of the ERN, beyond their own disease.
- Ability to bring **independent judgement** from a patient representative perspective;
- Have an awareness of, and commitment to, **equality, diversity and inclusiveness**;
- High level of organisation and self-motivation;
- Understand the need for **confidentiality**;
- Able to **communicate in English** to be able to follow and contribute to meetings.
- Have **computer skills and equipment** to communicate through email, webinars, and videoconferences



Where can you engage?

EURO-NMD

(Rare Neuromuscular diseases)

GUARD Heart

(Rare & Low Prevalence Complex Diseases of the Heart)

- **Special Electrophysiology Conditions in Children**
- **Other Rare Cardiac Diseases**

ERN-RITA

(Rare Immunological disorders)

ERN LUNG

(Rare Respiratory diseases)

ERN RARE LIVER

(Rare Liver diseases)

- **Vascular liver diseases**

ERKNet

(Rare Kidney diseases)

- **CAKUT & Ciliopathies**

RND ERN

(Rare Neurological diseases)

- **Frontotemporal dementia**

RECONNET

(Rare and Complex Connective Tissue & Musculoskeletal Diseases)

- **Idiopathic Inflammatory Myopathies**
- **Undifferentiated connective tissue disease**
- **IgG4 related diseases**

ERN BOND

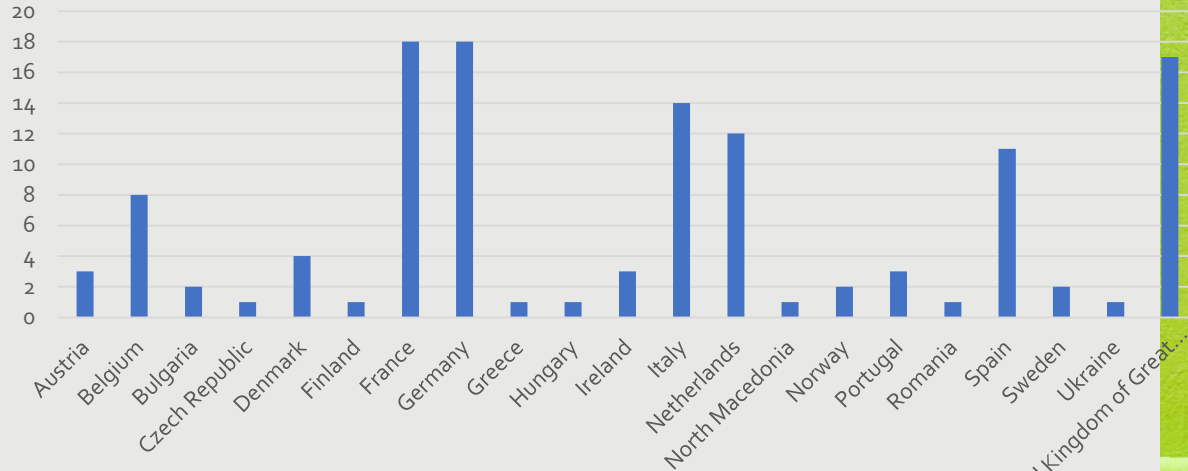
(Rare bone disorders)



Lenja

Where can you engage?

No. of ePAG advocates by country



Gaps: Croatia, Republic of Cyprus, Estonia, Latvia, Lithuania, Luxembourg, Poland, Slovakia and Slovenia.

Reinforced target countries: Eastern Europe



Where can you engage?

ERN ITHACA

(Rare congenital malformations and rare intellectual disability)

- Rare Genetic Intellectual Deficiencies

ERN EpiCARE

(Rare and complex epilepsies)

- Neonatal seizure

ERNICA

(Rare Inherited and Congenital (digestive and gastrointestinal) Anomalies)

- Intestinal failure
- Gastroenterological diseases

ERN SKIN

(Rare skin disorders)

- Severe cutaneous drug reactions

ERN CRANIO

(Rare craniofacial anomalies and ear, nose and throat (ENT) disorders)

- Odontologic disorders

VASCERN

(Rare Multisystemic Vascular Disease)

ERN eUROGEN

(Rare urogenital diseases & conditions)

ERN EYE

(Rare eye diseases)

ENDO-ERN

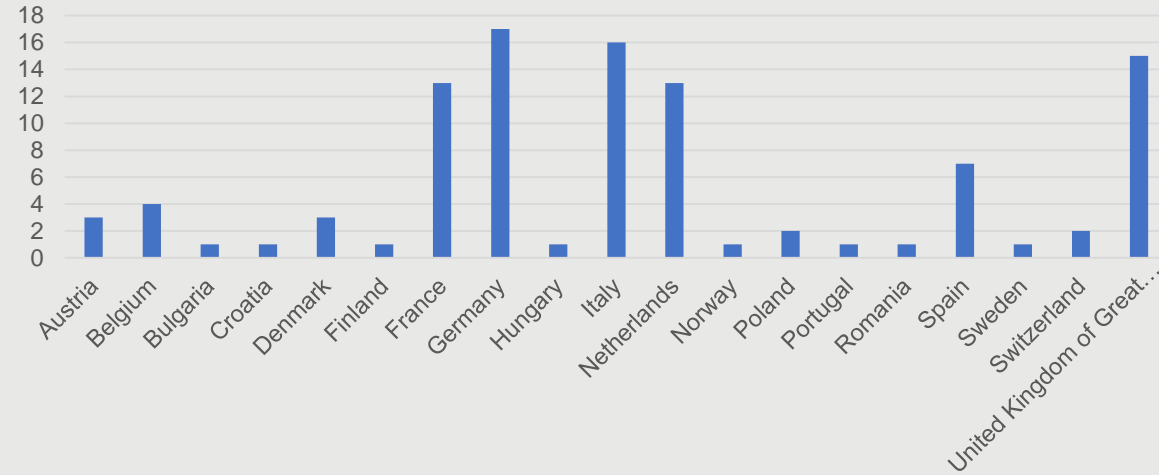
(Rare endocrine conditions)



Anne-Laure

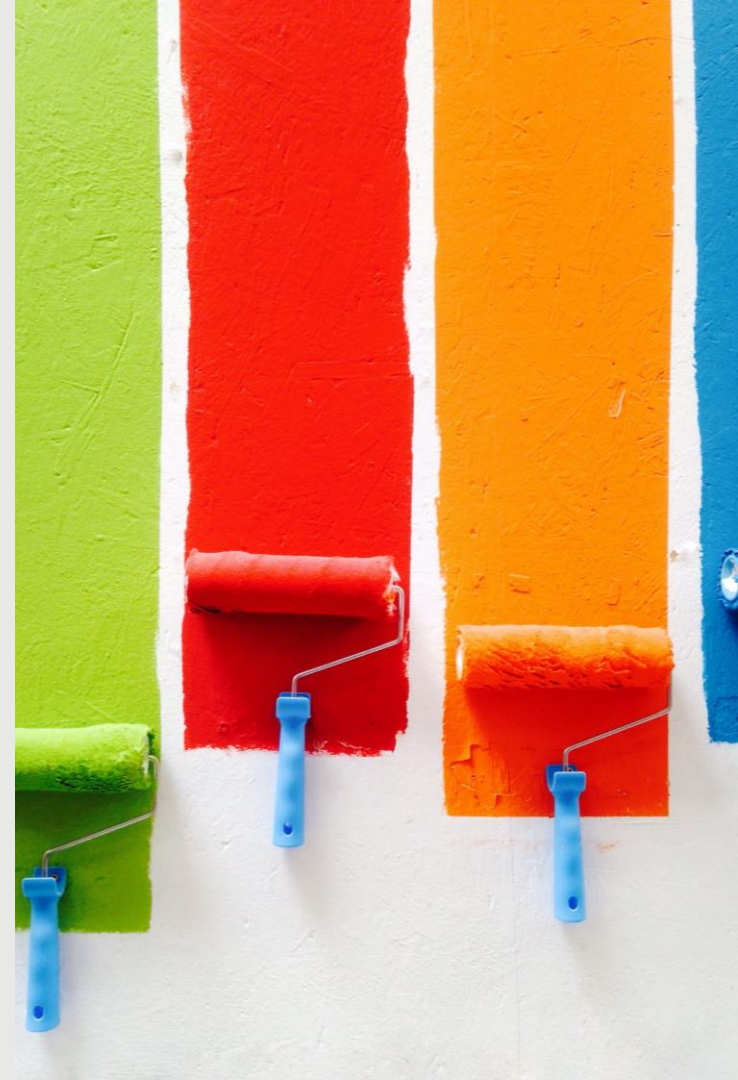
Where can you engage?

No. of ePAG advocates by country



Gaps: Bulgaria, Croatia, Republic of Cyprus, Czech Republic, Estonia, Finland, Greece, Hungary, Ireland, Latvia, Lithuania, Luxembourg, Malta, Portugal, Romania, Slovakia, Slovenia and Sweden.

Reinforced target countries: Eastern Europe



Thank you

