

The purpose of the ERNs

The European Reference Networks (ERN) were born from a directive of the EU commission for rare diseases to increase patients' rights in cross border healthcare.

Today more than 900 highly specialized healthcare providers from over 300 hospitals in 26 EU countries are engaged in the process together with over 300 patient representatives, called ePAG advocates, in 24 different ERNs. With patient empowerment and involvement, they are working towards an improved access to healthcare, safety and quality of diagnosis, care treatment for patients living with a rare condition etc.

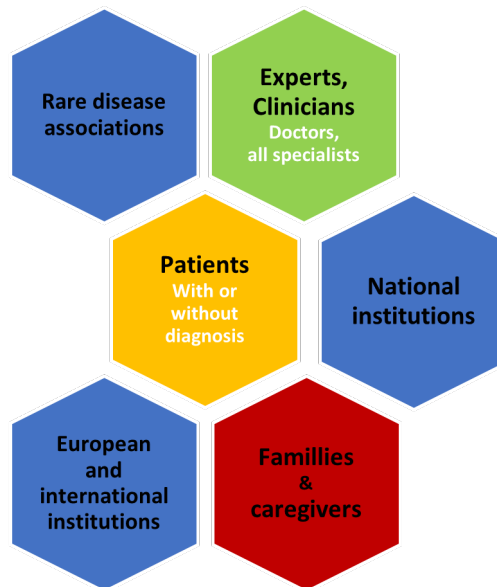
The European Organization for Rare Diseases, EURORDIS, leads and support the European Patient Advocacy Group (ePAG) with workshops, webinars and schools etc.

ERN ITHACA is a patient-centred network that meets the need for highly specialized, multidisciplinary healthcare for patients born with rare (multiple) congenital anomalies, rare intellectual and other neurodevelopmental disorders of genetic, genomic/chromosomal, or environmental origin, both diagnosed and undiagnosed.

Through sharing expertise, experience and resources, ERN-ITHACA aims to improve patient care, encourage further research and facilitate access to information about rare congenital malformations and intellectual disability.

Our Health Care Providers (HCPs) deliver each year the needed care for approximately 51,500 new patients diagnosed with rare developmental anomalies. The ERN ITHACA also has the largest number of entities, hence the largest scope and disease coverage amongst all ERNs.

Who can reach us?



The role of the Patient Council in ERN ITHACA


The European Patient Advocacy Groups (ePAGs) representatives in ERN ITHACA, referred to as the Patient Council, have an official mandate to represent the community of patients in the scope of ITHACA. They represent the voice and interests of the patient community and function as a bridge between them and the ERN clinicians. With the patient council's expertise and many connections within their own and other patient communities they ensure a true and equitable representation of the patient voice by participating in committees, boards and working groups (WG).

ePAG role-s are:

- to be that voice and participate in the creation of publications, studies, guidelines, databases with the collaboration of multiple authors from ITHACA's network and other ERNs.
- to ensure the quality of the Patient Council and Board face-to-face meetings, webinars and several bi-monthly online meetings are being held.

Why get involved?

- Bring your national expertise at the European level
- Participate in building bridges between professionals and patients across borders.
- Make your ideas heard, to build links and strengthen the networks of tomorrow.
- Represent the voice of patients in conferences, meetings etc.
- Contribute your expertise in an ERN work groups



ERN ITHACA for Intellectual disability, TeleHealth, Autism and Congenital Anomalies is led by **Prof. Alain VERLOES** at APHP-Robert DEBRE University Hospital, Paris France. It consists of 71 European Health Care Providers (HCPs) and their genetic departments from 25 out of the 27 EU Member States.

How can I become an ePAG advocate?

Involvement in ePAGs is open to all rare disease patient organisations in Europe.

The recruitment of advocates is ongoing to ensure that patients are fully represented in the governance of each and every ERN.

To apply to become an ePAG advocate in ERN ITHACA please contact:

Project Manager

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coordination@ern-ithaca.eu

Come and join us!

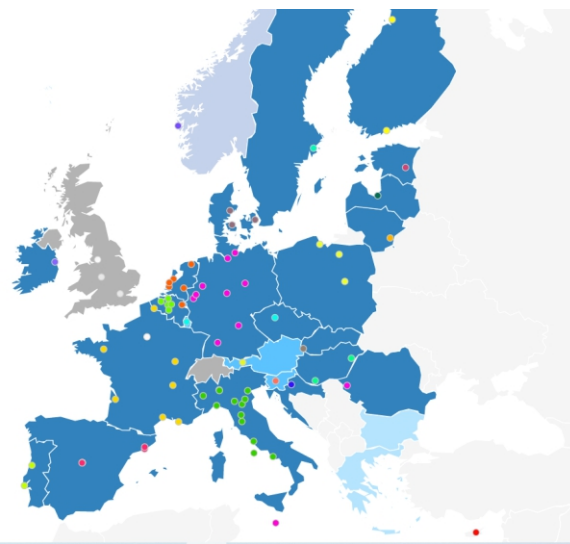
Let's go further together!

Feel free to get some information from the website!

www.ern-ithaca.eu



ITHACA Patient Council



European
Patient
Advocacy
Group



European
Reference
Network



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