

Open Academy Schools



Scientific Innovation & Translational Research

The Open Academy School on Scientific Innovation & Translational Research is a training programme, with the aim of deepening patient representatives' understanding of how pre-clinical research translates into real benefits for rare disease patients. The training consists of e-learning modules, pre-training webinars and in-person training.

Why attend?

Previous alumni have used the skills and knowledge gained from the training to:

- Successfully **advocate for national healthcare systems** to fund rare disease treatments.
- **Disseminate knowledge** within their organisation and continue to share experiences and best practices with alumni and other patient organisations.
- Use the information acquired to **maximise their own advocacy** and support work.
- **Reach out to research groups** working in the field of their rare disease with the aim to co-design or jointly submit proposals for research projects, ensuring the project meets the needs and priorities of the patients.
- Find academics, clinicians, and/or private partners to **drive forward a therapeutic development** such as repurposing an existing product.

“

They helped me deepen my knowledge in the development of new medicines and therapies but also in better communicating and better engaging with my stakeholders in order to be an equal stakeholder. ”

Iaria Galetti, Federation of European Scleroderma Associations, Italy

Programme features

The pre-training includes activities such as:

- E-learning modules on Sharing patient data, Genetics and Genomics, Genetic research to clinical diagnosis of Rare Diseases, and more.
- Introductory, thematic and networking webinars.

The training week consists of:

- **Subject-specific sessions** on topics such as Diagnostic care pathways; Translational research; Animal research; Ethics in Genomics; Patient Generated Data and more.
- **One day of joint sessions** with participants from the Open Academy School on Medicines Research and Development, focusing on patient engagement across the life-cycle of a medicine, with sessions designed to promote greater knowledge sharing.
- **Off-site visit and networking opportunities.**

EURORDIS covers patient representative's training costs, accommodation, meals during the training hours, welcome dinner and training materials. A limited number of fellowships will also be available to patient representatives to cover travel costs. Researchers and Observers are expected to cover their own travel and accommodation. Welcome dinner and meals during the training hours will be covered by EURORDIS.

Criteria

To take part, you must be a **rare disease patient advocate or PhD/up to 2yrs post PhD researcher**. As all training is conducted in English, a good level of the language is required. Patient representatives don't need to be a member of EURORDIS but must represent a patient organisation to apply. Researchers must represent a research institute or hospital.

The Open Academy Schools 2025 have been developed in collaboration with:

