



The **Open Academy School on Scientific Innovation & Translational Research** is a training programme offered by EURORDIS, with the aim of deepening patient representatives' understanding of **how pre-clinical research translates into real benefits** for rare disease patients. It is made up of e-learning modules, pre- and post-training webinars from January-June 2023 (estimated ~20 hours) and **in-person training taking place from 19-23 June in Barcelona.**

Why attend?

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

- 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.
- **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 to maximise their own advocacy and support work.

Programme features

The pre-training includes activities such as:

- **E-learning modules** on Sharing patient data, Genome editing, Genetic research to clinical diagnosis of Rare Diseases, and more.
- **Introductory and networking webinars.**

“ *The knowledge I gained helped me to see how to proceed in my advocacy efforts in the best way possible and helped me to influence change.* ”

Denica Velkovska, North Macedonia, SMA Europe

The training week consists of:

- **Three days of subject-specific sessions** on topics such as setting the landscape, going from diagnosis to translational research and from data to therapies.
- **Two days of joint sessions** with participants from the Open Academy School on Medicines Research & Development (formerly EURORDIS Summer School), focusing on patient engagement across the life-cycle of a medicine, with sessions designed to promote greater knowledge sharing.
- **Off-site visits and networking opportunities.**

Logistics

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.

Criteria

To take part, **you must be a rare disease patient advocate.** As all training is conducted in English, a good level of the language is required. Patient advocates participating must represent an organisation which is a member of EURORDIS. If this is not your case, you are still invited to apply but your organisation will be asked to apply to become a member of EURORDIS should you be selected.