



The **Open Academy School on Medicines Research & Development** is a training programme offered by EURORDIS, **designed to help participants become experts in medicines research and development**. 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:

- Successfully **advocate for national healthcare systems to fund rare disease treatments**.
- Register as a patient expert and **participate in activities in the European medicines Agency (EMA)** such as protocol assistance and scientific committees.
- **Contribute to Health Technology Assessment (HTA)** on a regional/national level.
- **Be involved in an ethics committee** in local hospitals or on a regional or national level.
- Disseminate knowledge within their organisation and continue to **share experiences and best practices** with alumni and other patient organisations.
- Participate in or **set-up a disease specific CAB (Community advisory board)** to help design clinical trials and identify the most relevant end points for patients.
- Use the information to **maximise their own advocacy and support work**.

## Programme features

The pre-training includes activities such as:

- **E-learning modules** on Pharmacovigilance, Market access & HTA, Ethics in Medicines Development, and more.
- **Introductory and networking webinars**.

“*The Open Academy trainings are very well structured, with patient relevant information that you actually can use. The content is delivered by real experts in their fields and is at the right level.*”

Alain Cornet, Belgium, Lupus Europe

The training week consists of:

- **Three days of subject-specific sessions** on topics such as Therapeutic development in rare diseases, Clinical Trials: Methodology, Design and Ethics and European Medicines Agency (EMA) – Regulatory pathways for Orphan drugs and Patient Engagement.
- **Two days of joint sessions** with participants from the Open Academy School on Scientific Innovation & Translational Research (formerly EURORDIS Winter 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. 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 researcher**. 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.

**19-23 JUNE 2023, BARCELONA**