Open Academy Schools



Medicines Research & Development

The Open Academy School on Medicines Research & Development is a training programme, designed to help participants become experts in medicines research and development. It is made up of e-learning modules and 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.
- **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.
- **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.

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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.



Programme features



The pre-training includes activities such as:

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

The training week consists of:

- Subject-specific sessions on topics such as Therapeutic development in rare diseases; Clinical Trials: Methodology, Design and Ethics; European Medicines Agency (EMA) Regulatory pathways for Orphan drugs; HTA and Compassionate Use; and Patient Engagement.
- One **day of joint sessions** with participants from the Open Academy School on Scientific Innovation & Translational Research, 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 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:













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