Call for Participants ERDERA Young Patients Training

May 2-3, 2025

Athens, Greece

Are you a young patient with a rare disease interested in healthcare and research? The ERDERA project invites **paediatric patients aged 12 to 18 years** to take part in a training event in Athens, designed to empower young patients with the knowledge and skills to actively contribute to paediatric and rare diseases research.

The training, organized by the **TEDDY Network** with the support of c4c-S, IMAGINE, EURORDIS, will provide tailored educational content in English. Training materials — including **child-friendly resources**, **videos**, **serious games**, **webinars**, **and podcasts** —will be developed with a participatory approach and made available for translation and adaptation into national languages.

What to Expect?

- **Pre-training assessment** Selected participants will complete an online test to assess their knowledge and interests, ensuring a personalized learning experience.
- Interactive sessions & play-to-learn activities Led by paediatricians, researchers, psychologists, patient representatives, Young Persons Advisory Group facilitators, and ethical/regulatory experts.
- Engagement in research Gain the skills to actively contribute to research projects, improve communication with stakeholders, and help shape future studies.
- **Future opportunities** Trained participants will be invited to take part in upcoming ERDERA activities and collaborations within European projects.

Who can apply?

This opportunity is open exclusively to young patients with rare diseases aged 12 to 18 years who are eager to learn about research and healthcare.





Training Topics:

- Rare and genetic diseases specificities Understanding the unique challenges of rare and genetic conditions in paediatric patients.
- Patients' and children's rights Ensuring ethical considerations and legal protections.
- Clinical and translational research challenges Ethical and legal aspects of paediatric research and the role of young patients.
- Patient engagement in clinical trials Involvement in trials, consent/assent issues, innovative methodologies (PROMs, PREMs), and the role of lay summaries.
- Orphan Medicinal Products in paediatrics Availability and access in the EU, pharmacovigilance, and off-label use in paediatric settings.

How to apply?

Just fill the **registration form**

Link to the registration form



Application deadline: April 12th, 2025

Join us in Athens to expand your knowledge and become an active voice in paediatric research!



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