2nd ERDERA Training for Young Advocates for Rare Diseases

April 23–25, 2026

Location : Institut *Imagine* (6th floor), entrance 24 boulevard du Montparnasse, 75015 Paris, France

Day 1 - Thursday, 23 April 2026

15:00 – 16:45 | Opening Session

- Welcome and Introduction to the ERDERA Training (15 min) – Rima Nabbout (Institut *Imagine*), Donato Bonifazi (TEDDY Network) and Barbara Alfandari (Institut *Imagine*)
- Introduction from the KIDS groups (30 min)
- The role of advocacy and patient organizations (30 min) – Gemma Rodriguez (EURORDIS)
- Drug development Introduction: from Research to Medicine (30 min) – Cécile Déal (Institut *Imagine*)

16:45 – 17:00 | Break

17:00 – 18:00 | Visit of Institut *Imagine*

Day 2 - Friday, 24 April 2026

8:30 – 10:00| Understanding Clinical Trials, Protocols and Pharmacovigilance in Pediatrics

- What is a Clinical Trial? (30 min) – Manika Kreka (KIDS Albania)
- An example of Clinical Trial Protocol (30 min) – Michaela Semeraro (AP-HP)
- Safety and Monitoring in Trials: pharmacovigilance in pediatrics, off-label use and side-effect monitoring (30 min) – Isabelle Desguerre (AP-HP)

10:00 – 10:15 | Break

10:15 – 12 :00 | Patient Engagement in Clinical Trials

- Active Patient Engagement in Clinical Trials: PROMs, PREMs and PIS (30 min) – Jessie Dubief (EURORDIS)
- Consent and assent in children: what's the difference? (30 min) – Ornela Cullufe (KIDS Albania)
- Consent/assent for processing personal data – Annagrazia Altavilla (Espace Ethique PACA-Corse, AP-HM)

12:00 – 13:00 | Lunch Break

13:00 – 14:00 | Rare and Genetic Diseases specificities

- Challenges in diagnosis, research and care (30 min) – Célia Cretolle and Léa Tricaud (AP-HP)

- Overview of rare and genetic diseases in pediatric patients (30 min) – Giulia Barcia and Emma Raimbault (AP-HP)

14:00 – 15:30| Round Tables: How Can Patients Participate in Translational Research Projects? Interactive exchange with young participants
Annagrazia Altavilla (Espace Ethique PACA-Corse, AP-HM), Suja Somanadhan (RAiN Ireland), Ines Salves (ANDO Portugal, ERN BOND) and Fatime Fejzullahi Derguti (KIDS Kosova)

15:30 – 15:45 | Break

15:45 – 16:45 | Introduction to INVENTS and the decision matrix – Donato Bonifazi (TEDDY Network)

16:45 | Free time to explore Paris

Day 3 - Saturday, 25 April 2026

08:30 – 09:00 | What is a Patient Registry? Case discussion: Retrospective vs Prospective studies Nicole Chemaly (AP-HP)

9:00 – 9:30 | Patient's and Children's Rights – Annagrazia Altavilla (Espace Ethique PACA-Corse, AP-HM), Leonardo Fiore (KIDS Bari) and Eirini Daskalopoulou (KRIKOS ZOIS)

9:30 – 10:15 | Clinical Trials and How young patients shape research – Advocate Empowerment –Yanis Mimouni (C-Path), Donato Bonifazi (TEDDY Network), Nicole Chemaly (AP-HP) and Mark Turner (c4c) and testimonials of Aaisha Seddika Mumminah, Charlotte Clerc and Valentina Jalby (INVENTS PEG)

10:15 – 10:30 | Break

10:30 – 12:00 | Working session: Young Patients as Partners in Research – Yanis Mimouni (C-Path), Donato Bonifazi (TEDDY Network), Nicole Chemaly (AP-HP) and Mark Turner (c4c)

- In groups, co-creation of a multi-national pediatric study outline (1h)
- Plenary wrap up (20 min)

12:00 – 13:00 | Lunch Break

13:00 – 14:15 | Closing session

- Key Learnings (30 min) – Emanuela Crea (TEDDY Network)
- Participant Feedback and evaluation session (30 min) – All participants
- Closing Remarks (15 min) – Rima Nabbout (Institut *Imagine*) and Donato Bonifazi (TEDDY Network)