Agenda - ERDERA Young Patients Training

Day 1 - Friday 2nd May, 2025

08:00 – 09:30 | Opening Session

- Welcome & overview of the TEDDY Network (15) **Donato Bonifazi**
- Introduction from the KIDS groups (45 mins) **All the groups**
- Welcome & introduction to the ERDERA training (15 mins) **Rima Nabbout**
- The role of advocacy and patient organizations (15 mins) **Dimitrios Athanasiou**

09:30 – 10:00 | Break

10:00 – 11:30 | Rare and Genetic Diseases Specificities

- Overview of rare and genetic diseases in pediatric patients (30 mins) **Persephone Augoustides-Savvopoulou**
- Challenges in diagnosis, research and care (30 mins) **Rima Nabbout**
- Case studies and interactive discussion (30 mins) **Bernadette Sheehan Gilroy**

11:30 – 12:00 | Break

12:00 – 13:30 | Patients' and Children's Rights

- Legal and ethical considerations in pediatric research (30 mins) **Silvia Torretta**
- The role of young patients in matters related to their health (30 mins) **Suja Somanadhan**
- Group discussion and real-world examples (30 mins) **Francesco La Penna**

13:30 – 14:30 | Lunch Break

14:30 – 16:00 | Translational Research Challenges

- Innovative therapies and the translational research journey with EPTRI (30 mins) **Donato Bonifazi**
- RD unmet needs and healthcare impact with prioritization in health and research decision-making (30 mins) **Dimitrios Athanasiou**
- Interactive session with case-based scenarios (30 mins) **Rima Nabbout**

16:00 – 16:30 | Break

16:30 – 18:00 | Shared activities from the TEDDY KIDS Network

- Establish a solid network: a perspective from a charity (30 mins) **Eleonora Passeri**
- Designing a paediatric multinational trial with kids (30 mins) **Ornela Cullufe**
- Participating in the TEDDY Network Board (30 mins) **Fiona Rako**

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KRIKOS ZOIS

Day 2 - Saturday 3rd May, 2025

08:00 – 09:30 | Patient Engagement in Clinical Trials

- Active Patient Involvement in Clinical Trials: PROMs, PREMs, and PISs. (30 mins) **Emanuela Crea**
- Consent/assent, clinical study protocol, and lay summaries (30 mins) **Silvia Torretta**
- Q&A and participant reflections (30 mins) **All**

09:30 – 10:00 | Break

10:00 – 11:00 | Orphan Medicinal Products & Pharmacovigilance

- Availability and access to orphan drugs in the EU (30 mins) **Dimitrios Athanasiou & Rima Nabbout**
- Pharmacovigilance and off-label use in pediatric settings (30 mins) **Sophia Trantza**

11:00 – 11:30 | Break

11:30 – 13:00 | Closing Session

- Key takeaways from the training (30 mins) **Francesco La Penna**
- Participant feedback and evaluation (45 mins) **All the groups**
- Closing remarks (15 mins) **Donato Bonifazi**

13:00 – 14:00 | Lunch Break

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