



Grant Agreement No. 101080823  
Start date: July 2023  
Duration: 60 Months

***Patient Expert Group  
face-to-face training meeting  
for paediatric patients***

## **PROGRAMME**

<https://invsnts-he.eu/>



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# Innovative methodologies based on in silico models and the secondary use of health data

2-3 November 2024  
Hotel Excelsior, Bari, Italy

Empowering young patients is crucial to involving them in research and healthcare decisions. The Paediatric Patient Expert Group (PEG), established under the European INVENTS project (HORIZON-RIA, N°101136365) by the TEDDY Network, is designed to educate adolescents with chronic conditions like arthritis and multiple sclerosis about biomedical research advancements.

Participants will learn about key concepts such as data collection, *in silico* models, and real-world data (RWD), which support faster drug development without the need for pediatric clinical trials. This training aims to provide young patients with the skills and knowledge needed to actively contribute to research and advocate for better healthcare services.

Participants will engage in training that covers ethical considerations, health data management, and innovative research methodologies. The PEG seeks to strengthen collaboration between patients, researchers, and healthcare professionals, ensuring more inclusive, patient-centered research. This initiative will help improve research and therapies for young patients worldwide who need effective treatments.

The course will be delivered in English and will equip participants to become well-informed contributors to the field of biomedical research.

## 2 November 2024 (Day 1)

### Morning Session

**9.00 – 9.10** Welcome greetings - TEDDY Network team

**9.10 – 9.25** Introduction: Overview of the PEG roles and responsibilities in the next two years of the INVENTS project – Vincent Damotte (with online participation from Stephanie Gentile and Enora Leroux)

### Module 1: General Training (9.30 – 12.30)

Facilitators: Yanis Mimouni, Francesco La Penna

*The module introduces general concepts related to rare and paediatric diseases, unmet medical needs, children's rights, ethical aspects, and the regulatory implications of health data collection and reuse.*

Lesson 1: **What is paediatric research, children's rights in health and research** – Silvia Torretta

Lesson 2: **Data collection and reuse** – Tim Friede

Lesson 3: **How innovation can improve paediatric clinical research, children's health, and well-being** – Donato Bonifazi



**13.00 – 13.45 Lunch**

### **Afternoon Session**

#### **Module 2: Disease/Product-Specific Training (14:00 - 16:00)**

Facilitators: Yanis Mimouni, Francesco La Penna

*The module provides insights into rare paediatric diseases and updates on the development of relevant medicinal products, such as treatments for juvenile idiopathic arthritis and multiple sclerosis.*

Lesson 1: **Rare paediatric arthritis in a nutshell, old, new, and upcoming medicines** – Marco Gismondi

Lesson 2: **Paediatric multiple sclerosis in a nutshell, old, new, and upcoming medicines** – Marta Simone

## **3 November 2024 (Day 2)**

### **Morning Session**

#### **Module 3: Research Methodology in INVENTS (9:00 - 12:00)**

Facilitators: Yanis Mimouni, Francesco La Penna

*The module covers traditional and innovative approaches to clinical trials, including in silico trials, virtual cohorts, and the use of real-world data.*

Lesson 1: **New methods using data** – Yanis Mimouni

Lesson 2: **New methods for prospective studies involving children** – Tim Friede

Closing Remarks: **Summary and next steps for participants as they continue their involvement in the INVENTS project** - Yanis Mimouni

## **Teachers and Facilitators details**

Vincent Damotte - Inserm

Silvia Torretta – Fondazione Gianni Benzi onlus

Tim Friede - University Medical Center Göttingen

Donato Bonifazi – TEDDY Network

Marco Gismondi - University of Bari

Marta Simone - University of Bari

Yanis Mimouni - Inserm

Francesco La Penna - TEDDY Network

