ERDERA
European Rare Diseases
Research Alliance

TEDDY EUROPEAN NETWORK OF EXCELLENCE FOR PAEDIATRIC RESEARCH

Welcome & overview of the TEDDY Network

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TEDDY NETWORK
European Network of Excellence for Paediatric Research

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TEDDY - EUROPEAN NETWORK OF EXCELLENCE FOR PAEDIATRIC RESEARCH

2005

TEDDY started under FP6 as a Network of Excellence (TEDDY NoE) to promote research and developement of children-tailored medicines.

2017

TEDDY became a nonprofit scientific association including members of several countries (both from and outside the EU)

Today

TEDDY is an independent research organisation, strongly connected with Patients, Universities, Companies, Scientific Associations and Regulatory Agencies

TEDDY Membership

European Network of Pediatric Research at the European Medicines Agency (EMA) (Enpr-EMA)

The operational objectives of Enpr-EMA include fostering collaboration, facilitating clinical trial recruitment, building competencies, avoiding unnecessary studies, stimulating high-quality research, and enhancing the European Research Area. TEDDY expresses one of the 12 members of the Coordinating Group of the Enpr-EMA.

European Network of Centres for Pharmacoepidemiology and Pharmacovigilance (ENCePP)

ENCePP is an initiative that brings together expertise and resources in pharmacoepidemiology and pharmacovigilance across Europe. ENCePP is coordinated by the European Medicines Agency. TEDDY actively participates in ENCePP activities, with the goal of advancing focused pediatric research initiatives.

Accelerating Clinical Trials in the European Union (ACT-EU)

TEDDY's involvement in Accelerating Clinical Trials in the EU (ACT EU), an initiative launched in 2022 by the European Commission, European Medicines Agency (EMA), and Heads of Medicines Agencies HMA to improve clinical trials in Europe. TEDDY contributes to three key Priority Actions: PA 1 (mapping trial activities), PA 3 (stakeholder platform for exchanging views), and PA 8 (accelerating guidance development) and expresses one member in the ACT-EU Multistakeholder Platform Advisory Board.

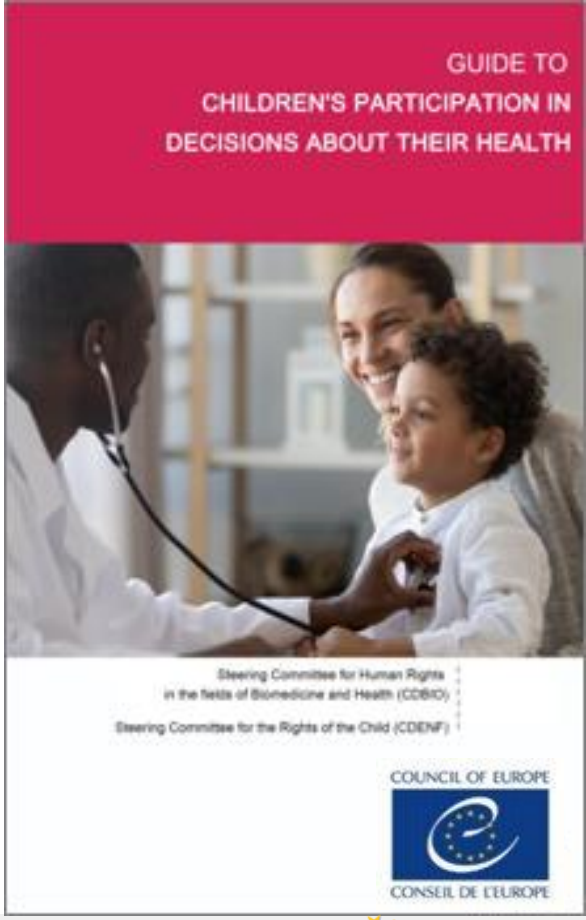
European Paediatric Translational Research Infrastructure (EPTRI)

TEDDY is a member of EPTRI, the only paediatric research infrastructure covering all phases of paediatric biomedical research, from discovery to clinical phases offering specific services in the field of paediatric research. EPTRI is organised in several thematic research platforms.

TEDDY KIDS Collaboration with the Council of Europe

The mission of promoting children's rights and active participation in decision-making processes, reached a milestone, when the TEDDY kids (from Albania, France, Greece, Italy, Latvia, and Malta) collaborated with the Council of Europe to develop the "Guide to the participation of children in decision-making processes regarding their health", released in 2023.

The Council of Europe (CoE) has developed the child-friendly version of the guide through a participatory methodology, involving children and adolescents from all over the EU, including members of the TEDDY KIDS Network from KIDS Bari and KIDS Albania.



A Council of Europe video made by children for children

TEDDY's Mission

To promote children well-being and ensure health protection and children’s integrity in clinical research and medical treatments as a fundamental children's right:

Promoting equal access of children to paediatric medicines and other products.

Promoting paediatric research for the advancement of novel therapies addressing unmet medical needs.

Engaging children and young patients in decisions related to their health.

Enhancing awareness among key stakeholders on children's health.

Ensuring active commitment of different stakeholders through collaborative networks and paediatric research projects.

TEDDY WORKING GROUPS

European Paediatric Medicines Needs

Off label uses mitigation

Paediatric Research Methodologies

Health Data & Real-World Evidence

Children Empowerment and Engagement

TEDDY KIDS Network

The TEDDY KIDS Network includes Young Persons Advisory Groups (YPAGs) across all Europe, focused on paediatric health. It empowers children in clinical research, ensuring their voices are heard throughout the process.

Children Participation in European Projects

TEDDY Network is committed to advancing paediatric healthcare by actively supporting children's participation in various collaborative projects across Europe.

ORPHADEV4KIDS (EU4H-2023-PJ, N°101161377) 2024/2027

This project aims to address the issue of orphan medical devices intended for paediatric use.

ERDERA (HORIZON-AG, N°101136365)2024/2030

The project aims to support patients affected by rare diseases by improving prevention, diagnosis, and treatment within the European rare disease healthcare framework.

INVENTS (HORIZON-RIA, N°101136365) 2024/2029

This project aims to optimize clinical drug development for small populations, including paediatric and rare diseases, by leveraging innovative methodologies based on in silico models and real-world data.

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

Last event: Patient Expert Group gace-to-face training meeting for paediatric patients
2-3 November 2024
Hotel Excelsior, Bari, Italy

OrphaDev4Kids project

Last event:
Kick-off Meeting of the Patient Expert Committee of the European project OrphaDev4Kids – University of Bologna, 15 March 2025

Patient Expert Committee Gives Patients a Voice

On March 15, 2025 their advice through the review of the survey was contributing to the future development of the medical device that can help patients with Cyanotic Congenital Heart Disease

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The International Children Advocacy Network (iCAN)

The iCAN Summit

The summit acts as a spotlight and gathering place for research, science, medicine, and friendship. Kids all around the world from different continents come to see how they are changing the world.

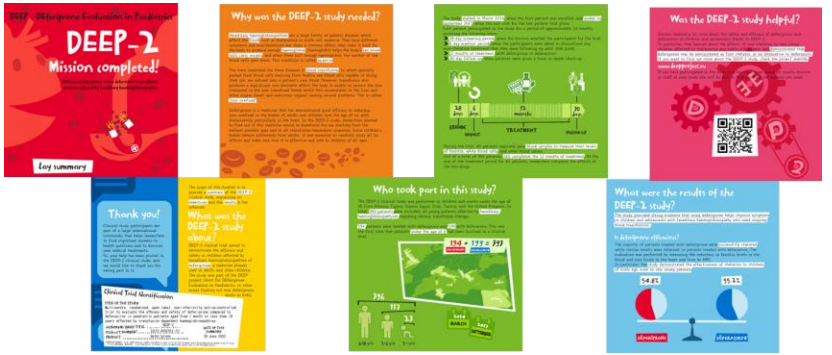
- 100 young people and patients (8-18 years) from 4 continents, 15+ countries, 37 iCAN chapters (KIDS groups) USA, Mexico, Canada, Italy, France, Germany, Albania, Turkey, South Africa, Uganda, Cameroon, United Kingdom, Spain, Kosovo, Poland, Greece and others.
- 100 Parents, siblings and caregivers of the 90 children, including their Chapter leaders
- Patient Organizations – EURORDIS, PTN.
- BigPharma companies – Pfizer, Novartis, Eli Lilly, BioCryst
- Partners – Georgia Institute of Technology, European Paediatric Translational Research Infrastructure, Regione Puglia, Università di Bari, Ospedale Pediatrico Giovanni XXIII, Il Nuovo Fantarca, TEDDY Network, CVBF.

TEDDY's commitment to children engagement

During the FP6 funded project TEDDY – Task-force in Europe for the Drug Development of the Young, a collection of short videos was created explaining to children different health related concepts and words, including why medicine for kids are different and what fever or antibiotics actually are.

Age-Appropriate Informative Materials

Development of Age-Appropriate Informative Materials: Creation of tailored materials to properly inform children and their families about the key concepts of drugs and their use in clinical studies, ensuring understanding and empowering participation (i.e. DEEP, GAPP, MODERATO clinical trials).



Age-Appropriate Informative Materials

The TEDDY Network has contributed with videos designed to inform children about clinical trials in a simple and accessible way.

Designed for children

Designed for Adolescents

TEDDY KIDS Network Members

The Network deeply relies on the strong bonds built between all partners, creating a strong European Network.

Its goal is to spread awareness and good practices in the field of youth empowerment and children advocacy, giving young patients the tools and knowhow to take decisions upon matters regarding their health, research and therapies