TEDDY WORKING GROUP CHILDREN ENGAGEMENT AND ADVOCACY

Working Group Chair:
Donato Bonifazi

TEDDY NETWORK
European Network of Excellence for Paediatric Clinical Research

The Children Engagement and Advocacy WG is dedicated to supporting educational initiatives focused on children and young patients to give them deep knowledge and expertise on how to interact in decision-making processes regarding their health. The WG oversees the TEDDY KIDS Network, supporting the creation of new KIDS (Kids Impacting Diseases through Science) groups and managing their activities across projects and initiatives. It facilitates meaningful youth participation in the yearly iCAN (international Children's Advisory Network) summits, supports Kids in activities beyond their own YPAG (Young Persons Advisory Group), and elects the Kids' representative to TEDDY's Board of Directors.

Mission

To empower children and young patients across Europe with the knowledge and tools to actively participate in decisions about their own health supporting the growth of the TEDDY KIDS Network and ensuring children's voices are heard at the highest level.

Objectives

- Empower children and adolescents to actively participate in pediatric health and research.
- Create and support YPAGs across Europe, providing resources and collaboration opportunities.
- Integrate youth perspectives into clinical research design and decision-making.
- Educate and inform young people about health and research.
- Foster networking and PPI (Patient and Public Involvement) in health research.
- Promote inclusion and diversity, ensuring representation of all backgrounds and rare conditions.

Main Activities

- Establish and support YPAGs across Europe under the TEDDY KIDS Network.
- Develop age-appropriate informational campaigns and educational tools including videos, booklets, and digital games to empower children in health decisions and research.
- Engage YPAGs and KIDS groups in surveys, consultations, and research reviews on paediatric health and research topics.
- Contribute to European institutional bodies including Enpr-EMA, Council of Europe, and ACT-EU on matters concerning children's health and paediatric clinical research.
- Participate in collaborative European research projects addressing unmet paediatric medical needs (i.e. ERDERA, INVENTS, OrphaDev4Kids) by involving Paediatric Patients Expert Groups.

TEDDY KIDS Network

The TEDDY KIDS Network includes Young Persons Advisory Groups (YPAGs) across Europe dedicated to strengthening the voice of children and young people in paediatric research, innovation, and healthcare decision-making. TEDDY Kids have a voice in the TEDDY Board of Directors, with one Kid representative appointed by other Kids, as outlined in the TEDDY Statute (Art. 13). Empowering children and young individuals by incorporating their perspectives in healthrelated decision-making is a fundamental right (art.24 EU – 2000/C 364/01).

The TEDDY KIDS Network includes the following YPAG groups:

- ANDO Portugal
- Eye YPAG London
- KIDS Albania
- KIDS Bari
- KIDS Kosova
- KIDS Munich
- KIDS rare Hellas
- KIDS Umbria
- KIDS RAiN
- POLPEDNET KIDS Warsaw

TEDDY Network Charter

Aim

- Promote children's empowerment as a priority in clinical research.
- Encourage young patients to actively participate in decisions affecting their lives.
- Reinforce children's specific knowledge and experience in health research.

Principles

- Right to Involvement: Children/young people participate in decisions impacting health and wellbeing.
- Insight Contribution: Young participants provide ideas and innovative solutions for pediatric needs.
- Collaboration with Sponsors: Sponsors review trial materials (protocols, summaries) and integrate meaningful input from children.

To learn more about the principles and commitments of the TEDDY Network, please consult the full Charter here.

TEDDY KIDS Network Agreement

This Agreement formalizes the collaboration between of all the participating YPAGs within the TEDDY KIDS Network in supporting children's involvement in paediatric research and healthcare decision-making.

By signing it, the YPAG becomes a new member of the TEDDY KIDS Network and agrees to:

- Uphold the TEDDY Network's principles of youth empowerment, inclusivity, and transparency.
- Actively participate in projects, campaigns, and consultations.
- Promote collaboration and share knowledge with other TEDDY KIDS Network members.

Objectives:

- Learn, Educate & Advocate: Advance knowledge to improve children's health.
- Engage Actively: Contribute to projects and stakeholder activities.
- Provide Insight: Highlight paediatric needs and priorities.
- Support Research Design: Contribute to child-focused research design.
- Be a Voice for Change: Represent children and families in research, policy, and international forums.

How to Join the Working Group

If you're interested in joining this working group, please contact
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and

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