



Enpr-EMA Annual Meeting

October 10th, 2023

Improve pediatric health, medicine, research,
and innovation by sharing children's voices
with iCAN, an International YPAGs Network

Donato Bonifazi
TEDDY Network Board Member
iCAN Advisory Board Member

E U R O P E A N N E T W O R K O F E X C E L L E N C E F O R P A E D I A T R I C R E S E A R C H

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CHILDREN RIGHTS

all the actions shall be carried out according with two fundamental principles



International Convention of
the Rights of the Child (UN)



THE “BEST INTERESTS” OF THE CHILD

THE “EVOLVING CAPACITIES” OF THE CHILD



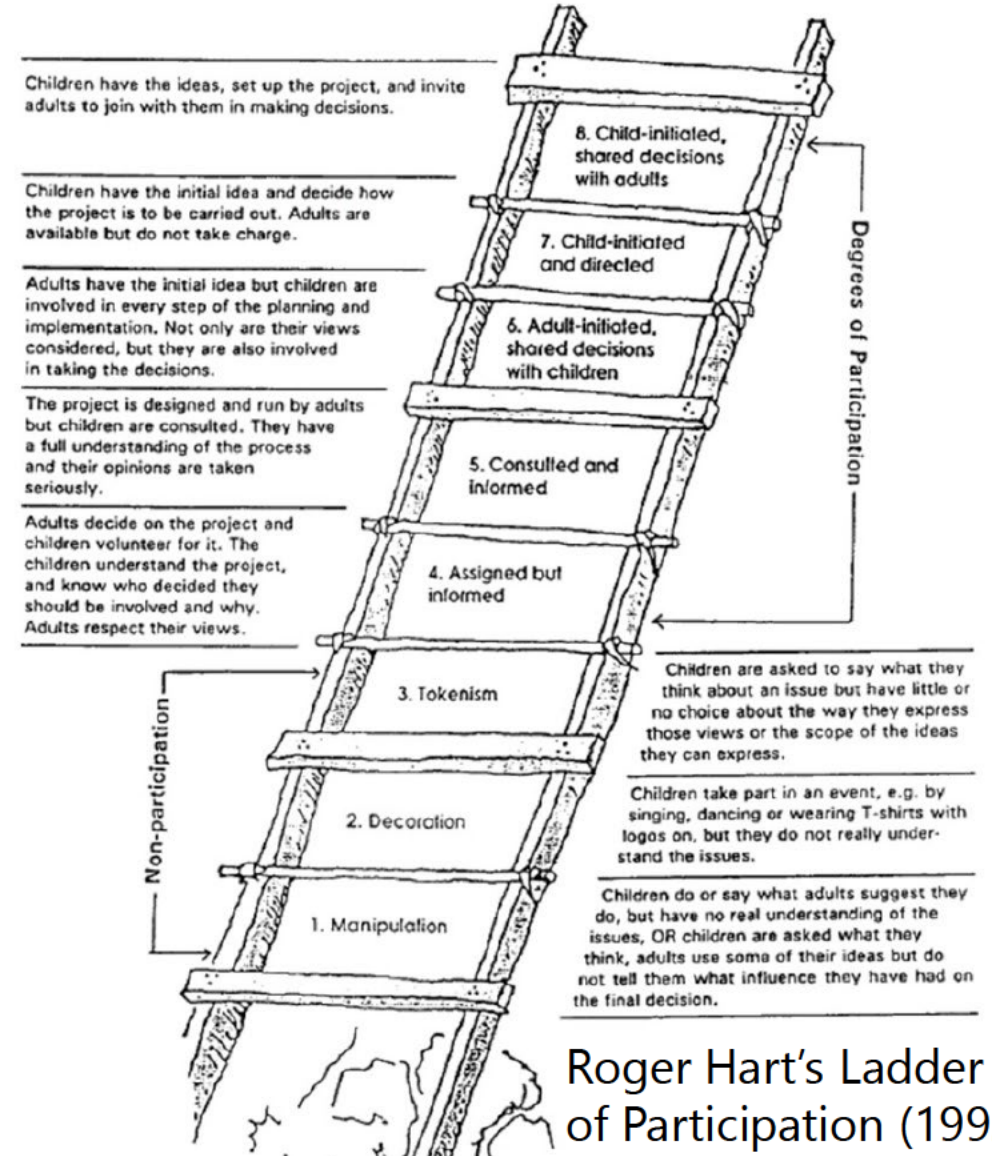
A CHILD MUST ENJOY ALL THE RIGHTS OF A PERSON
Children have the right to participate in any decision regarding them, including their health

Give voice to children! Not an easy task!

Young people and Children:
a new actor on the scene!



To the courtesy of Claudio Fracasso, MD, former Pediatric Clinical Director, 2023



Roger Hart's Ladder
of Participation (1992)

https://www.unicef-irc.org/publications/pdf/childrens_participation.pdf

Participation of children in decision-making processes regarding their health

The **involvement** of children is a **progressive process**, according to their evolving capacities, and implies **four levels of participation**:

1. being informed
2. expressing a view
3. influencing decisions
4. being the main decision-maker

Engaging with children to improve individual decision-making processes

ADVOCACY



ADVISORY



iCAN

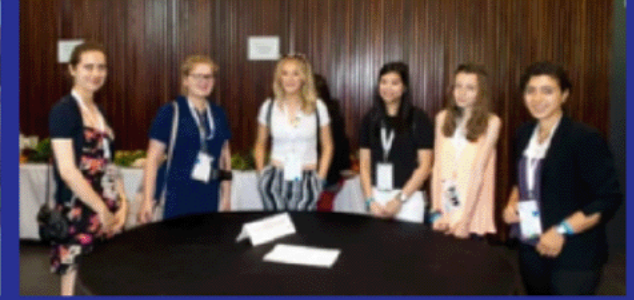
International Children's Advisory Network



www.iCAN.health

#iCANMakeADifference

The first International YPAGs Network - 2014



iCAN Chapters members are children

Youth Members:

- Ages: 8-18, with some slightly younger or older kids
- Health: affected by complex medical conditions or not

Common Goals:

- Give voice to their concerns and needs
- Being heard by individuals, industry, government agencies
- Make a difference in Pediatric healthcare

<https://www.icanresearch.org/>

What is iCAN?



A non-profit made up of 34 groups dedicated **to empowering every child**, everywhere by working to improve pediatric health, medicine, research, and innovation **by sharing children's voices**



A dedicated **platform for children and families** to give input and feedback into study designs, treatment plans, and educational materials of industry partners as well as hospitals, high schools, researchers, and non-profits.



HOW iCAN WORKS

the iCAN Seal of Approval*

The iCAN Chapters:

YPAGs or KIDS

Young Persons Advisory Group

Kids Impacting Diseases through Science

Ask the Experts Sessions

the annual **iCAN SUMMIT**

What iCAN Do?

iCAN Umbrella work

- 9 International Summit organised US/EU
- iCAN Curriculum by age group
- Educative Documents, Video, Games
- Encourage leadership
- Develop iCAN learning activities
- Partnership with the Pediatric Networks
- Foster a shared community
- The iCAN Seal of Approval*

Every iCAN Chapter is a unique, dynamic organization housed within the global iCAN umbrella!

Chapter Leader Lesson Plan

Discover Clinical Research

Clinical Research Terminology (ages 8-11)

How Are Medications Approved (ages 12-18)



MY CLINICAL TRIAL CENTER



PLAY TO LEARN!

My CTC game
explain in a

 **KiDS**Albania and  **KiDS**Bari



Let's play!



Promote Children participation in decision-making process

The TEDDY Kids

Strong motivation

Experts scientific
contribution

Attractive
(cartoon,

Involvement
external pa
and stakeh



Council of Europe Draft Guide to the participation of children in decision-making processes regarding their health



OBJECTIVES

- ▶ To highlight relevant **international frameworks and standards**
- ▶ To **provide examples of national legislation and good practices**
- ▶ To provide **guidance on how professionals can improve their practices** when involving children in individual decision-making processes affecting their health
- ▶ To identify other **measures** that healthcare and other relevant institutions may **apply to advance and facilitate involvement of children**

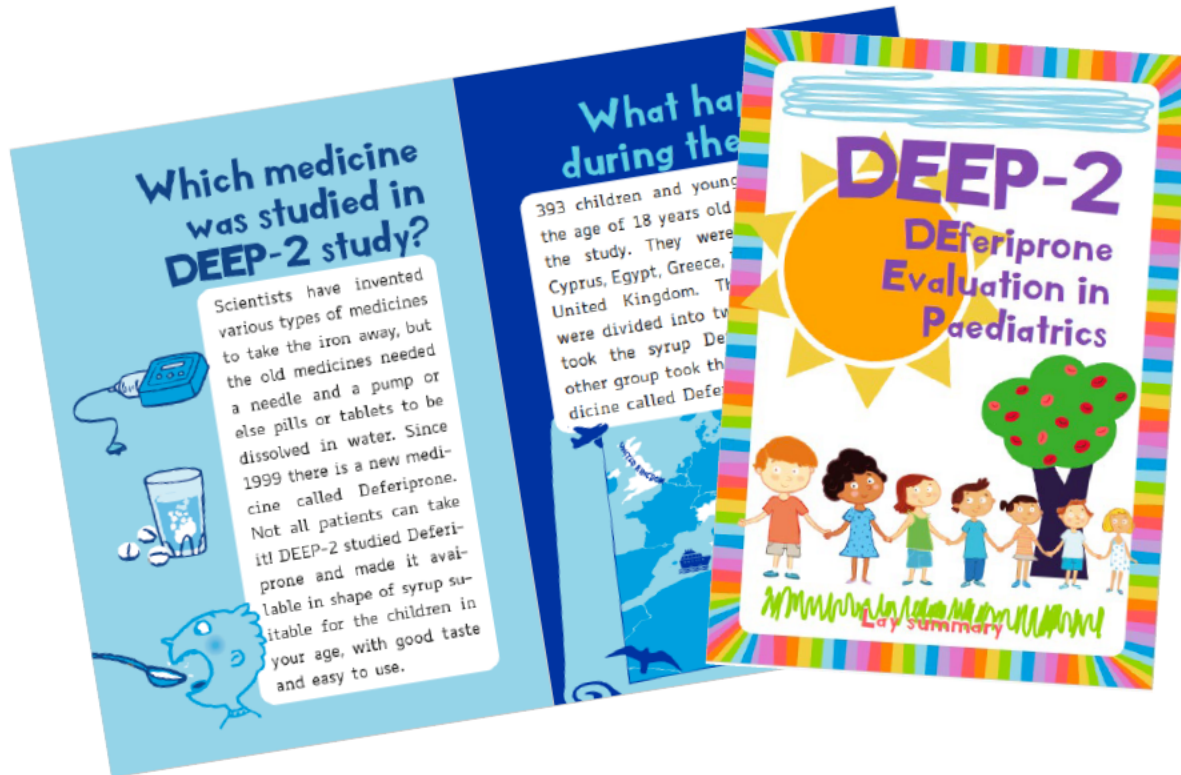
*Promoting children rights, needs, and resources, empowering children at every stage,
a Council of Europe initiative (2021-2022)*

DEEP-2 Clinical study Lay summary

Lay summary of the **DEEP-2 clinical study**, developed with the **expert contribution** of the TEDDY Kids, in collaboration with CVBF, sponsor of the study and coordinator of the DEEP Project.



DEFERIPRONE
EVALUATION IN
PAEDIATRICS



Children, giving a voice to other children

TEDDY has promoted **KIDS groups** that are part of the iCAN community **since 2017**

KiDSBari

KiDSAlbania



Young patients and healthy youngers, aged from 12 to 18 years, and more, who work together to give voice to children in the decision-making process involving health, medicine, and research.

TEDDY kids are specifically educated and empowered about **fundamental children rights and biomedical research**.

The iCAN Advocacy and Research Summit

Paediatric Rul

The summit acts as a spotlight and gathering place for research, science, medicine, and friendship

Kids all around the world from 4 different continents come to see how they are changing the world

NEXT Summit (2024) will be in EUROPE!

It will be in BARI!



Hot topics →

- Paediatric regulations
- Equal access to paediatric medicine

It will involve all KIDs and YPAGs in the world and will aim to implement new Groups in Europe

Thank You, from iCAN



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