

# Children's Participation and Decision-Making in Medical Matters

October 11-12, 2012  
Lund, Sweden



According to international and national agreements and conventions children have the right to express their views in all matters affecting them. This is a signal to parents, medical personnel and other responsible adults to consider the opinion of the child when making decisions that affect them. In medical treatment and research, however, the rights of children are often confronted with other interests that may impede on these basic rights, whereby the child's right to express their interests may not be considered. The role of children in clinical trials, for example, poses many questions regarding recruitment and participation due to concerns over risk, burden and safety of children and other ethical considerations.

This conference focuses on the bioethics of children's participation and decision-making in health care, scientific studies and clinical trials. The presentations will cover important questions such as:

- Who can make decisions for children and under what circumstances?
- How should children take part in /concerning their health?
- How should children's views be considered/included in the decision-making process?
- Under what premises should children be allowed to participate in clinical trials?
- Who can decide on their participation?
- Do we need special paediatric research ethics committees?

Participation is free of charge.

## DAY 1

15.30 – 16.00	<i>Registration and coffee</i>
16.00 – 16.10	<i>Opening and welcome</i>

### CHILDREN'S PARTICIPATION IN TREATMENT AND RESEARCH

Chair: Aaro Tupasela

16.10 – 16.30	<i>Children's rights and medical decisions - an overview</i> Ritva Halila, department director, Hjelt Institute, University of Helsinki, member of EGE
16.30 – 16.50	<i>Children's rights and risks - a Nordic perspective</i> Cecilia Sjölander, Child Ombudsman in Sweden
16.50 – 17.10	<i>Children's participation - parent's perspective</i> Ragna Marinósdóttir, director of Umhyggja– organisation for chronically ill children in Iceland, Iceland
17.10 – 17.40	<i>Discussion</i>
17.40 – 18.30	<i>Welcome Reception</i>

## DAY 2

### CHILDREN'S RIGHT TO PARTICIPATION IN DECISIONS ON MEDICAL CARE

Chair: Janne Rothmar Herrman

09.00 – 09.20	<i>How can children participate in decisions on therapy and clinical trials?</i> Kjeld Schmiegelow, general secretary of NOPHO
09.20 – 09.40	<i>What counts as participation? Some cautionary remarks</i> Linus Broström, researcher in Medical Ethics, Lund University
09.40-10.00	<i>Who decides on initiating, continuing or discontinuing treatment in extremely ill patients?</i> Anders Castor, child oncologist and head physician at Child and Youth Hospital, Lund
10.00 – 10.20	<i>Children's participation in the decision-making from a legal perspective</i> Titti Mattsson, professor in Public Law, Lund University
10.20-10.40	<i>Discussion</i>

10.40-11.00      *Coffee*

## **CHILDREN'S PARTICIPATION IN RESEARCH AND CLINICAL TRIALS**

Chair: Grethe Foss

- 11.00 – 11.20      *Children and medicines – ethical concerns in testing medicines on children*  
Kalle Hoppu, associate professor, Helsinki University Central Hospital
- 11.20 – 11.40      *Do we need paediatric ethical committees?*  
Göran Elinder, professor in paediatrics and paediatric, counsellor at the Regional ethical committee at Karolinska Institutet
- 11.40 – 12.00      *How are conflicts of interests in paediatric clinical trials – managed in the pharmaceutical industry?*  
Steinar Thoresen, medical director GlaxoSmithKline, Norway
- 12.00 – 12.30      *Discussion*
- 12.30 – 13.30      *Lunch*

## **REGULATING CHILDREN'S RIGHTS IN TREATMENT AND RESEARCH**

Chair: Ásgeir Haraldsson

- 13.30 – 13.50      *Regulations, guidelines and structure when you will perform scientific studies on children in Europe*  
Agnes Saint Raymond, European Medicines Agency, London
- 13.50 – 14.10      *Challenges for European Ethical Committees (EC) in overseeing research on children- data from the TEDDY-study*  
Annagrazia Altavilla, lawyer and associate Senior Lecturer at EEM -Bioethics research Centre- University of Aix-Marseille, France
- 14.10 – 14.30      *Ethical assessment of pediatric trials: examples of issues with risk assessment moral obligations for participation?*  
Inez de Beaufort, professor, Dept. Medical Ethics and Philosophy of Medicine, Rotterdam, Netherlands, member of EGE
- 14.30 – 15.30      *General discussion*
- 15.30                *Closing remarks*

**Venue: Pufendorfsalen, [Juridicum](#), Lund University,  
Lilla Gråbrödersgatan 4**



For more information about the conference contact the organizing committee:

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**The Nordic Committee on Bioethics** was founded in 1989 to promote Nordic cooperation and exchange of information between scientists, parliamentarians, opinion leaders and public officials in the area of bioethics.

The Committee has two members from each Nordic country and an observer from the Faroe Islands. Members are appointed for three years at a time by the Nordic Council of Ministers from the nominations of the Nordic countries.

The mission of the Nordic Committee on Bioethics is to foster co-operation between the Nordic countries by bringing together representatives from different backgrounds to discuss and analyse issues in bioethics in order to achieve greater awareness, promote common understanding and improve policy in this area.

**For more information:** [www.ncbio.org](http://www.ncbio.org)  
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