

## Outcomes in the Eye of the Beholder: Making critical decisions about our tiniest babies

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October 2010 - A group of European experts have taken an important first step towards harmonising decision-making regarding extremely premature babies across the European Union.

The meeting, organised by the [European Critical Care Foundation](#) in association with the [European Foundation for the Care of Newborn Infants](#) and [the Lancet](#), explored the wide range of medical and ethical challenges involved in the care of babies born before 26 weeks of gestation, identified both communalities and differences between European countries in the extent to which healthcare professionals share decision-making responsibilities with parents, as well as in the way emotionally difficult topics such as life-long disability and end-of-life care are approached.

The multidisciplinary meeting, held in Copenhagen, included thirty of Europe's leading neonatologists, obstetricians, neonatal nurses, midwives, psychologists, philosophers and religious leaders, as well as parents of premature babies representing European family support groups. **It was the first time that an expert gathering at this level has involved parents from several European countries.**

Approximately 10% of all children born in Europe every year are born prematurely (before 37 weeks), and the rate of premature births is increasing in all major European countries. Medical and technological advances in recent years allow babies born extremely prematurely or at 'threshold viability' (i.e. at 23-25 weeks or less gestation) to have a significant chance of survival, although the risk of subsequent severe disability remains very high.

The meeting delegates agreed that parents must play a crucial part when making treatment and care decisions, and that although a premature birth is an extremely stressful and highly emotional experience for a family, parents should be proactively involved in the decision-making process from (and even before) the moment of birth.

British neonatologist Professor Neil Marlow (University College London) who chaired the meeting, said: "This was a critical first step in developing coherent strategies for supporting parents in what are extremely difficult choices made at a time of intense stress. We have identified a paucity of support for research into the reasons for preterm delivery and the consequences, which for many families are be devastating. This poses a

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significant public health issue and should be high on the EU agenda”

Silke Mader, Chairwoman of the European Society for the Care of Newborn Infants and a mother who has first hand experience of the challenges of very preterm babies, said: “I believe that parents really felt able to speak up and be heard by professionals”.

There was also unanimous agreement that there is a severe lack of research into prevention of premature births and the disabilities caused by this, and that more funding is required in this area.

John Martin, President of the European Critical Care Foundation, said: “I lament the lack of interest from the pharmaceutical industry in developing treatments to prevent early birth and intrauterine growth retardation. The meeting called for the European Commission and National Governments to take action in creating new mechanisms that would encourage the pharmaceutical industry to be interested in the issue of preventing extremely premature births. This problem needs the application of science”.

The next step will be to explore in depth the important common issues raised at the meeting and strive for consensus, with the ultimate aim of producing a set of guidelines to be implemented across Europe.

#### **INFORMATION FOR MEDIA:**

Information about the event and background documents are available upon request.

For media enquiries, interviews and supporting materials, please contact:

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Documents are available in English

Interviews are available in the following languages: English, German, French, Spanish and Danish

#### **ABOUT ECCF**

Over the last 20 years, there has been a great improvement in survival from accidents, from heart disease and from infectious disease. Babies born small survive, and science offers even greater possibilities to improve the human condition. However, as science advances, so do the dilemmas in applying our new knowledge.

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Decisions made by doctors caring for critically ill patients do not only depend on medical knowledge, but also on a whole range of conditions often out of the doctor's control such as ethical, geographical or financial factors.

The European Critical Care Foundation (ECCF) is a pioneering new foundation established to initiate independent research into complex issues like these with the objective of improving the care of critically ill patients across Europe.

In a ground-breaking new approach, the ECCF brings together experts from the fields of medicine, law, philosophy, public policy as well as concerned parents' representatives to identify and address the issues that determine the survival and care of critically ill patients. ECCF focuses not on doctors and treatments, but on patients and results.

### **ABOUT EFCNI**

The European Foundation for the Care of Newborn Infants (EFCNI) is the first pan-European organisation to represent the interests of preterm infants and their families. It gathers together parents and medical professionals from different disciplines with the common goal of improving long-term health of newborn and preterm children by ensuring the best possible prevention, treatment, care and support.

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