

EFCNI www.efcni.org

The **European Foundation for the Care of Newborn Infants (EFCNI)** was set up in January 2008. It is the first time that people from diverse disciplines, who are all involved in the care of newborn infants and particularly preterm infants, have come together at European level.

EFCNI encourages all those involved or interested in this issue to interact and exchange ideas. It promotes mutual understanding and serves as a platform for the initiation, coordination and integration of all local and national activities involving the care of newborn infants, prevention of preterm delivery, long-term care of preterm infants and support for parents and relatives. EFCNI is particularly keen to establish a link between parents and doctors/scientists.

Why was EFCNI set up?

In spite of all the progress that has been made, children who are born ill, particularly preterm infants, are still a major challenge for the public health system and in many cases put a huge strain on their parents...

About 10% of all newborn infants come into the world too early and about 1-2% are born before the 32nd week of pregnancy (2 months early). These children have a high risk of future development disorders ranging from severe mental and physical impairment to attention deficit disorders and specific learning difficulties. Preterm infants are also particularly prone to secondary problems, such as an increased tendency to infection and respiratory infections. However, even infants born on their due date can fall ill before or during delivery (e.g. stroke or lack of oxygen) and suffer lifelong consequences.

Awareness of the problems and their long-term effects is low, both in society and within the public health system.

The situation facing doctors and scientists is that whilst improvements in intensive medicine have reduced the overall mortality rate of newborn infants, there has not been an equivalent reduction in secondary problems, such as neurological disorders. Therefore it is urgent that new ways of improving intensive neonatal medicine and developing new diagnostic and therapeutic measures to protect and nurture the brain are sought.

Researchers and neonatologists are thereby confronted with the problem that there is no lobby for children; this is the case for newborn infants in particular. For example, the amount of money currently spent in medical care to prolong the life of a newborn infant by one year, is only a fraction of that usually spent on adults.

At 10% of all births, the proportion of infants born prematurely is very high. Preterm infants, particularly those with a very low birth weight, suffer from various forms of impairment. However, compared to widespread diseases, such as high blood sugar and heart attack in adults, these problems are barely reflected in either state-funded or private research.

Whilst a comparison with other serious diseases is certainly problematic, particularly from the standpoint of those affected, it should nevertheless help to illustrate the above problem. A comparison with childhood cancers, for example, serves to illustrate how little public attention is paid to preterm delivery: approx. 0.2 in 100 children

develop cancer each year, whereas 2 in 100 children are born much too early (2 months). Everyone has heard of childhood cancer, yet apart from affected parents and health professionals, very few people are aware of the severe long-term effects of a preterm delivery.

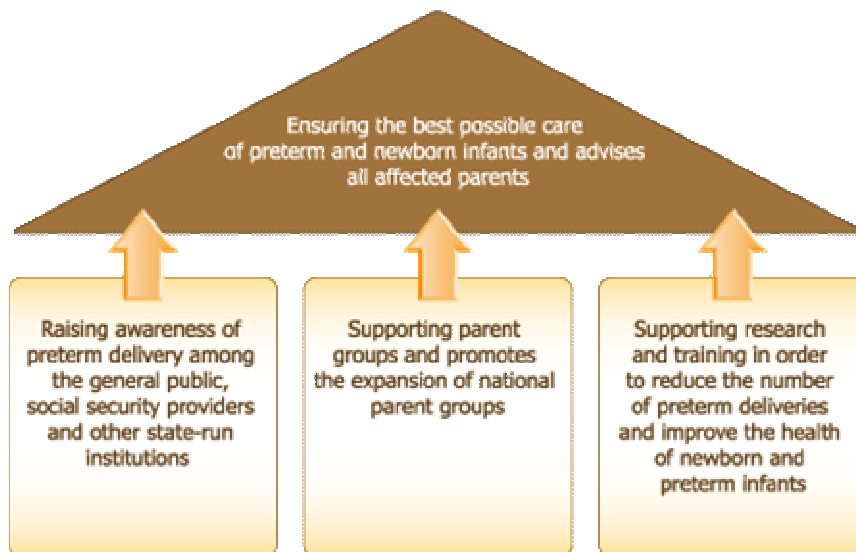
EFCNI is tackling these problems and, through public relations work and targeted lobbying, will ensure that they receive the attention they deserve.

Aims

By pooling the strengths of scientists, parents and their representatives, EFCNI aims ...

- to ensure the best possible care of newborn and preterm infants
- to provide parents with medical and psychological support
- to fund research into measures that will help to prevent preterm deliveries and the
 - Implementation of such measures.
 - to improve the long-term health of newborn and preterm infants

In order to achieve these aims, EFCNI operates at 3 levels:



If you would like further details of our aims, the constitution of the foundation can be downloaded as a pdf file [here](#).

Generation of public awareness of the issue

In order to raise public awareness of preterm delivery and bring it to the attention of society, EFCNI will ...

- Undertake selective lobbying and public relations work, including press conferences, professional articles, studies of the long-term effects and associated costs, etc.

The aim is to provide various target groups, such as the media, social security providers and politicians, with essential information and raise their awareness of preterm delivery.

- Provide a platform for discussion of the ethical issues surrounding preterm delivery, its prevention and the care of newborn infants.

Support of parent groups

In order to support parent groups and individual parents, EFCNI will ...

- Provide comprehensible and easily accessible information on psychosocial support for affected parents.
- Offer parents and parent groups access to a pan-European network of people and organisations involved in this field, so that they can exchange ideas and coordinate their activities
- Be a point of contact for questions and problems and an authoritative source of scientific information and help
- Keep a record of known and particularly striking cases of preterm delivery for information and reliable tracking purposes

Support of research and training

In order to guarantee first-class medical care for preterm and newborn infants, EFCNI will ...

- Initiate and promote basic and advanced training for all doctors, nurses and other professionals involved in the care of preterm and sick newborn infants in Europe
- Fund research projects which investigate preventive measures to reduce the number of preterm deliveries
- Fund neonatal and perinatal research projects that aim to improve the health of newborn and preterm infants
- Support European research and medical networks for improving the care of newborn infants.

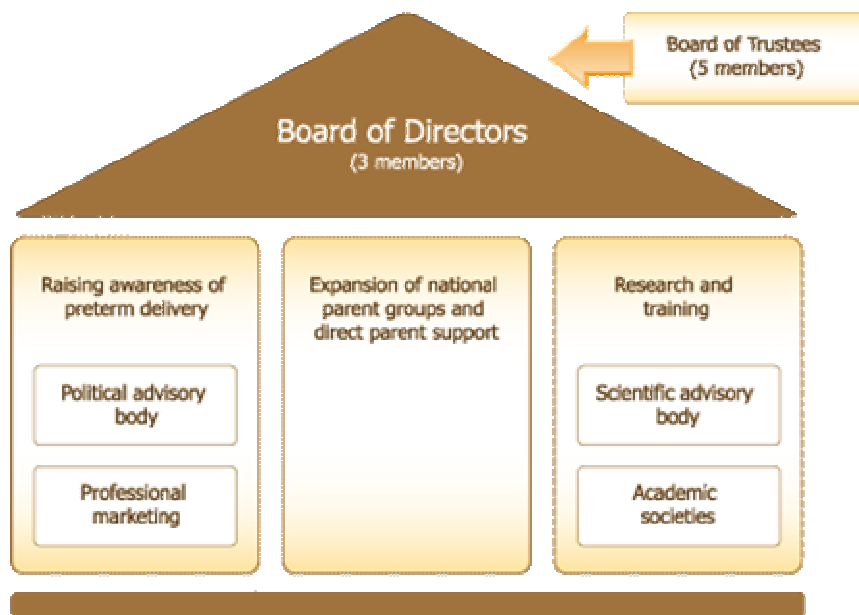
Benefits

As a platform, EFCNI connects the most diverse groups of people. They all have certain expectations and problems, which can vary widely. That is why EFCNI aims to provide parents, parent groups, doctors, researchers, private and institutional sponsors with relevant information and tailored support services.

Organisation

EFCNI consists of a Board of Directors and a Board of Trustees. The Board of Directors has three members and is responsible for representing and managing the foundation. The Board of Trustees has five members and assists the Board of Directors in an advisory, supportive and controlling role.

In taking the measures needed to achieve its aims, EFCNI is supported by political and scientific advisory bodies, academic societies and marketing specialists.



Board of Directors



Silke Mader, 36, Munich, Germany

President of the German Federal Association for Preterm Infants
[Bundesverband für Frühgeborene e.V.]
Mother of preterm twins one of whom died



Thomas Föringer, 43, Munich, Germany

Lawyer, lecturer, adviser, Business Angel



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