

Combining forces for preterm infants – the European Foundation for the Care of Newborn Infants (EFCNI)

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The European Foundation for the Care of Newborn Infants (EFCNI), founded in April 2008, is the first pan-European organisation and network to represent the interests of preterm and newborn infants and their families. It gathers together parents, healthcare experts from various disciplines, scientists, politicians and other stakeholders with the common goal of improving the short- and long-term health of preterm and newborn children. EFCNI is dedicated to improving the full spectrum of care by ensuring the best possible prevention, treatment, care and support, and promoting and protecting



the right to the best start in life.

EFCNI's latest project, the development of *European Standards of Care for Newborn Health*, is supported by over 50 health professional societies, parent organisations and other third parties and is a milestone for ensuring European-wide harmonised treatment for all infants.

Background

Worldwide, 15 million infants are born preterm annually.¹ In Europe, preterm birth is one of the leading causes for neonatal mortality and accounts for more than half of all infant deaths. Prevalence rates of preterm birth range from 5.2 to 10.4% – an average of 7.2% of all live births.² Alongside these differences in prevalence, the access and provision of neonatal care for patients differs widely across European countries.

Preterm and sick term-born infants are in a special situation. They are extremely young and their life depends fully on the care of others. In contrast to most other patient groups, they cannot speak for themselves at the time of treatment, nor have they had any prior chance to indicate their views on life.³ Due to this particular situation, neonatal patients are seen as a unit: the infant and his or her parents. Parents will continue to care for the infant for many years after hospital discharge. If the child passes away, the parents' lives will be changed forever.^{4,5}

In 2008, EFCNI was founded to improve the situation for preterm infants, sick newborn infants and their families, and to unite families over geographical and cultural boundaries to speak with one strong, growing voice. The purpose of the foundation is to strengthen and to empower the role of the parents by bringing together parents, healthcare professionals, policy-makers, organisations and scientists to ensure the best possible prevention, treatment, care and support for preterm and newborn children.

Before 2008, parent organisations already existed in several, but not all, European countries; cross-country coordinated activities and international exchange was lacking. Thanks to the work and empowerment of EFCNI, today parent organisations for preterm children exist in nearly all European countries playing an important role in:

1. providing a platform for affected families, sharing important information and creating a network

2. raising public awareness for the topic

3. carrying out policy work and linking with health professionals.

Impact and work of EFCNI

The pan-European cooperation began at a meeting in Rome in November 2008. Following EFCNI's invitation, 25 representatives from 18 nations came together to discuss options and goals for working together. The 'Declaration of Rome' was the first milestone; ten demands for preterm infants and their families were developed during this meeting and later handed over to politicians of the European Parliament.

World Prematurity Day

During this trailblazing meeting the decision was made to initiate an official day for preterm infants worldwide. The date, 17 November, was chosen because of the personal story of loss and hope of one of EFCNI's founders. The purpose of World Prematurity Day is to:

- raise awareness for preterm birth and its burden
- recognise and acknowledge the challenges encountered by families who have experienced preterm birth
- inform about prevention measures
- achieve the necessary health policy commitments to improve the care situation.

Parent organisation meetings

Since the initial meeting in 2008, 12 parent organisation meetings have been established by EFCNI (**FIGURE 1**). The aim of the regular meetings is to strengthen the networking between national parent organisations and to work together on a European level. To that purpose, best practice examples of the organisations are shared, and training and education sessions on different topics are provided to empower the organisations for

FIGURE 1

The 12th parent organisation meeting in 2016.



their national and international work. Sharing information on the current health-political situation in different countries informs and motivates future activities. Over the years, the meeting has developed into a global event with participants from other continents.

Policy and advocacy work

As a foundation with a European mission, EFCNI aspires to make maternal and newborn health a priority within Europe. Activities and events at EU level serve to raise political awareness for preterm birth as a health and societal topic. By informing European politicians and highlighting the importance of the issues for their home countries as well as showing solutions, a link between EU politics and national health agendas can be established.

The work with European third parties is an important step in stimulating European and national debate. EFCNI's EU activities include the initiation and co-organisation of workshops, conferences and meetings. In addition, EFCNI also advocates for investment into research in perinatology and neonatology, and harmonised training for health professionals.

An important landmark of EFCNI's policy work was the publication of a benchmarking report on preterm birth across Europe in 2010. The report *Too Little, Too Late* painted a compelling picture of the differences that exist in levels of care when it comes to maternal and newborn health in Europe.⁶ It showed that in most EU Member States, maternal and newborn health is not considered a public health priority, despite its obvious connection to health outcomes in adult life. To move from identification of the existing gaps and the provisions that EU Member States have made for newborn infants, to concrete proposals for improving the standards of care in Europe, the white paper *Caring for Tomorrow* was published in 2011.⁷ This report on maternal and newborn health, as well as follow-up and continuing care for preterm born children, highlighted some of the key concerns with regard to this growing patient group. The white paper identifies current challenges, makes recommendations and states clear rights for newborn babies and parents that should be considered in any healthcare strategy for maternal and newborn care.

Information and communication

EFCNI addresses a wide range of stakeholders in diverse countries and different communication channels have been used to build a base for reaching parents, healthcare professionals,



FIGURE 2 EFCNI at the first joint European Neonatal Societies Congress (jENS) in 2015 with the launch of the Socks for Life campaign.



politicians and others affected by or interested in prematurity. The EFCNI website (www.efcni.org) has tailored evidence-based and up-to-date information on preterm birth and newborn health, information on healthy pregnancy and valuable links to the global network. A monthly newsletter compiles news from the foundation and activities from collaborating partner organisations along with updates in recent research. EFCNI also publishes brochures and factsheets for families and healthcare professionals. All materials are freely available.

Campaigning

EFCNI has initiated several campaigns to share and unite the changes and impacts that are improving the situation for preterm babies and their families worldwide, for example:

- the EFCNI Changemaker Map, a platform for users to share events and milestones
- the Socks for Life campaign (FIGURE 2).

Current and future projects

European Standards of Care for Newborn Health

The differences and inequities in neonatal care across Europe are apparent and reinforced by the findings of the *Too Little, Too Late* report. The benchmarking report found that the availability of national guidelines and standards differed across countries.

This motivated EFCNI to initiate a project aimed at developing European reference standards for a wide range of neonatal health topics.

The European Standards of Care for Newborn Health project is an interdisciplinary European collaboration which brings together more than 220 individuals from 35 different countries and over 50 supporting organisations. The project combines the knowledge and experience of healthcare experts from obstetrics, neonatology, paediatrics, and psychology, parent representatives, industry partners and third parties with an interest in newborn health.

For this purpose newborn health is divided into 11 themes (FIGURE 3). Each of these themes corresponds to a working group – a topic expert group – that develops standards on this subject. The standards begin with the perinatal period and continue until well after discharge into early childhood.

Standards for each of the working groups are developed within this group before they are passed on to the project's steering committee, the Chair Committee. After discussion and approval by the Chair Committee, standards are sent out for consultation to the supporting organisations. After consultation, standards are submitted for endorsement and will be published on the project website (newborn-health-standards.org).

Breast milk banks

EFCNI has initiated a project to ensure the supply of breast milk for preterm infants, aiming to support hospitals in Germany, Switzerland and Austria to set up and operate breast milk banks on a national level. A position paper containing quality requirements for breast milk banks will be developed by a scientific advisory board composed of well-known experts in the fields of lactation, nutrition and neonatology.

European benchmarking report

Following on from the first benchmarking report in 2010, EFCNI intends to publish a new report with data from EU Member States and other selected European countries. The anticipated benchmarking report will show the current situation in the area of preterm health in Europe as well as preterm-related factors before, during and after pregnancy, aiming to increase awareness about the burden of prematurity and to promote and foster the implementation of European standards

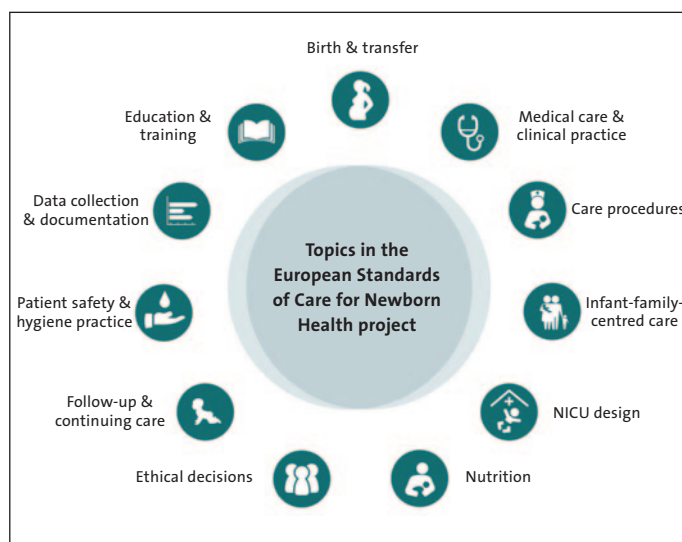


FIGURE 3 The 11 themes of the European Standards of Care for Newborn Health.

of care. The project will be supported by key opinion leaders and experts, scientific societies, national and international networks and selected industrial partners.

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