European Standards of Care for Newborn Health

Information brochure

european standards of care for newborn health

EFCNI european foundation for the care of newborn infants

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Babies born preterm do not only have a tough time during the first days or months of life. Preterm birth may affect us and our families for a lifetime.

Lukas Mader, born 1997,
at 25 weeks of gestation

1. Introduction and background

Medical treatment and care for preterm and ill newborn babies varies to a large extent between European countries. While in one country a high percentage of all babies born extremely preterm die, in other countries babies born at exactly the same age have a high chance of survival.

But the massive differences are not only limited to survival: In some countries, preterm birth is also more commonly associated with chronic motor and mental disabilities than in others. This effect is reinforced by the fact that, in some parts of Europe, follow-up care for these vulnerable children is not organised in a structural manner or is even non-existing.

With the high degree of inequity in healthcare provision, harmonised definitions and clear regulations for infrastructures, medical processes, care procedures, and capabilities of staff are needed in order to be able to compare and adjust the conditions of care in Europe. (1,2) There is a high and growing prevalence of preterm birth in Europe, and the short- and long-term medical and social consequences as well as the tangible and intangible burden for the patients, the families and for healthcare systems are immense.

Therefore, there is a compelling need to ensure that high-level care is equally accessible everywhere and for everyone.

The European Standards of Care for Newborn Health address the disparities in the organisation of care, the education of healthcare professionals, and the structure and provision of care for preterm and ill babies. (1)

The project promotes equitable and high levels of care for preterm and ill babies throughout Europe by a systematic approach in terms of a multi-stakeholder involvement from scratch, the involvement of patient (parent) organisations, the broadness of topics, and a multi-level dissemination strategy. Every single aspect of the project will have a significant impact on the lives of these vulnerable patients, their families, and eventually on the whole European society.

1. Chang HH et al. The Lancet. 2013 Jan;381(9862):223–34.
2. Gissler M et al. Inform Health Soc Care. 2010 Mar;35(2):64–79.


Multi-level dissemination strategy
The project is promoted to its stakeholders and audience at scientific congresses and parliamentary events. Moreover, the social media campaign "11 months – 11 topics" raises awareness of the different healthcare topics covered by the project and of the project itself among parents, healthcare professionals, and other stakeholders.
Multi-stakeholder involvement
The project joins forces with about 220 professionals of different areas and parent representatives from more than 30 countries. Additionally, NGOs, healthcare societies, media and industry representatives, as well as political decision makers have been involved in the project right from the beginning.
The project has been initiated and is coordinated by a parent organisation, and parent representatives are equal partners in the development process of the standards. To emphasize the role of parents as primary caregivers and partners in the care of their preterm baby is an important aspect in the project.
Role of parents
The project covers 11 key areas in newborn health which again are divided in several sub-topics. The key areas include care before and at birth, neonatal intensive care, ethical questions and education of health professionals, to name only a few.
Broadness of topics

2. Objectives

The reference standards are intended to serve as a benchmark and a groundwork for developing binding national guidelines, protocols, or laws (depending on the local situation). The project's long-term goal is to ensure equitable and high levels of care throughout Europe by facilitating and harmonising neonatal care and its neighbouring medical areas.

Driven by the power of parents, it is a true patient-centred project, and for the first time, patients are involved in absolutely every step in the development of standards.

3. Methodology of the project

3.1. Definition of a standard

Within the European Standards of Care for Newborn Health project, a standard is defined as a **systematically developed statement** with the purpose to **support decision making** of **physicians, nurses,** and **patients** for adequate care regarding specific health problems.

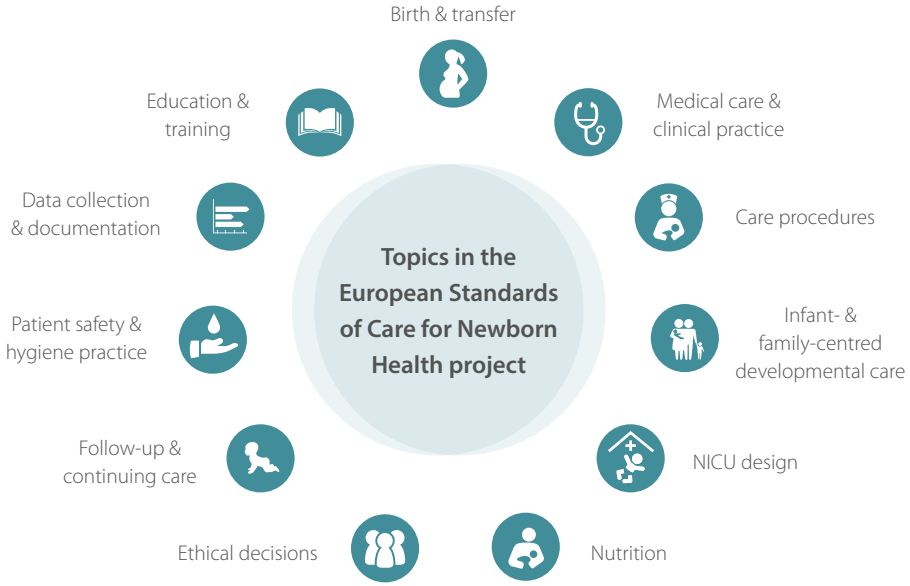
The standards developed within the project are reference standards that need to be translated into national binding guidelines/standards/recommendations (depending on the respective national situations).

3.2. The project members

Project members involved in the development process of these European reference standards include healthcare experts in obstetrics, neonatology, paediatrics, nursery, midwifery, and psychology, other experts like architects, and parent representatives. The members of this interdisciplinary project group are in regular contact, either by internet, phone or during face-to-face meetings to continuously work on the further development of the standards.

3.3. Newborn health – divided into 11 overarching topics

Eleven key areas (topics) of newborn health were identified. Within each topic, single issues for standardisation were selected and further topics are continuously being defined. Standards start with topics around birth and transfer and continue until well after discharge into early childhood.



3.4. The Topic Expert Groups

Each of the key areas (topics) is assigned to a Topic Expert Group (TEG), the project's thematic transdisciplinary working and writing groups that develop the respective standards connected to this topic. Every TEG consists of several members (experts from different disciplines and parent representatives) and is led by a Chair Team, which forms – together with the eight members of the EFCNI's Parent Advisory Board and the three Executive Board members of EFCNI – the Chair Committee. It steers the project, defines the project objectives, its design and methodology, develops the standard template, decides on the issues for standardisation and their prioritisation, and discusses and votes on the standards developed in the Topic Expert Groups.

3.5. Standard development process

Decision on standard topics by Chair Committee

Development of template for the standards by Chair Committee

Proof of content by the TEG's Chair team

Editing process regarding grammar and common wording together with Chair teams

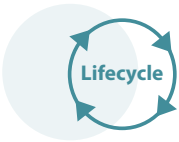
Review by the authors

Final formatting

Launch of the standards and the Call to Action in Brussels and publication on: https://newborn-health-standards.org

Implementation

Revision of the standards after a certain lifecycle and extension of the standard topics

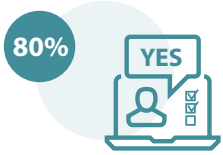


First standard draft written by one or more responsible authors as members of the TEG

Peer review process: At least one feedback loop with the TEG members and EFCNI

In case additional user perspective is needed: involvement of the Parents' Knowledge Forum and external experts

Voting on the standards by the Chair Committee; 80% yes votes needed



Support of the standards by healthcare societies, parent/patient organisations, and related Third Parties

This graphic illustrates the development process of the different standards starting with the decision on the standard topics until their official launch but goes beyond, including the lifecycle of the standards and extension of topics.

4. The 11 Topic Expert Groups

Birth & transfer

Medical care & clinical practice

Care procedures

Infant- & family-centred developmental care

Education & training

NICU design

Nutrition

Ethical decisions

Data collection & documentation

Patient safety & hygiene practice

Follow-up & continuing care

Birth & transfer

Access the **standards** here

The Topic Expert Group on Birth and transfer focuses on information and counselling of parents about potential risk factors for and signs and symptoms of preterm birth. Furthermore, organisational aspects of perinatal care are taken into account referring to different levels reflecting medical knowledge, organisation structure and staff capabilities. Management of the cord at the delivery of term and preterm infants are also part of the TEG. Moreover, standards on antenatal transport of the mother with her baby in the womb as well as on adequate intra- and inter-hospital transport of the newborn baby are developed.

Members of the TEG

Assoc Prof Ola Andersson, Sweden
Prof Annette Bernloehr, Germany
Amanda Burleigh, UK
Prof Irene Cetin, Italy
Dr Maurizio Gente, Italy
Dr Štefan Grosek, Slovenia
Dr Gilles Jourdain, France
Prof Franz Kainer, Germany
Prof Anna Locatelli, Italy
Dr Andrew Leslie, UK
Livia Nagy Bonnard, Switzerland
Asta Radzeviciene, Lithuania
Dr Nandiran Ratnavel, UK
Prof Heike Rabe, UK
Prof Rainer Rossi, Germany
Prof Matthias Roth-Kleiner, Switzerland
Prof Gerard A.H. Visser, The Netherlands
Prof Luc Zimmermann, The Netherlands

„If we had one wish, we would make sure that in the nearer future all pregnant women in Europe - regardless to the region they live in - will receive an optimal medical treatment during pregnancy and delivery. Women with pregnancy complications - although numbers may be small - should be transferred to specialists and/or specialised centres in a timely manner to enable optimal pre-, peri- and postnatal care. Parents should also be closely involved in perinatal care."

Chairs of the TEG

PD Dr Dietmar Schlembach, Germany

Professor Umberto Simeoni, Switzerland

Statements of the standards

Preterm infants receive **optimal umbilical cord management** for smooth transition at birth by waiting before clamping and cutting the cord for at least one minute.

In vigorous vaginally born **term infants, management of the umbilical cord includes waiting before clamping and cutting the cord** for at least three minutes or until the cord is pale and collapsed. For vigorous term infants born by caesarean section a one-minute wait is adhered to before clamping and cutting the umbilical cord.

Perinatal care is organised in specialist and non-specialist centres to ensure access to optimal, preferably evdence-based, care with respect to medical knowledge, organisation structure, and staff.

Infants are transferred by a dedicated, specialised medical service that offers a **quality** of care **similar to that promoted in a NICU**.

All (pregnant) women receive **timely information and counselling about potential risk factors for and sign and symptoms of preterm birth** and how to find appropriate healthcare advice.

Transfer of pregnant women for specialist care (for mother and/or newborn infant) is an essential component of perinatal care and is carried out in a timely, safe, and efficient manner.

Pregnant women and their partners receive complete and accurate personalised **information and support during pregnancy and childbirth** to achieve efficient, optimal and respectful **collaboration.**

Medical care & clinical practice

Access the **standards** here

The Topic Expert Group on Medical care and clinical practice develops standards on the prevention, diagnosis and management of the main medical conditions and challenges affecting preterm or ill babies. Additionally, standards on specific clinical procedure and techniques are developed.

Members of the TEG

Dr Delphine Arni, Australia
Assoc Prof Kathryn Beardsall, UK
Prof Frank van Bel, The Netherlands
Prof James Boardman, UK
Dr Kajsa Bohlin, Sweden
Prof Maria Borszewska-Kornacka, Poland
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Prof Mary Fewtrell, UK
Prof Andreas Flemmer, Germany
Prof Anne Greenough, UK
Prof Pierre Gressens, France
Prof Mikko Hallman, Finland
Dr Anna-Lena Hård, Sweden
Prof Ann Hellström, Sweden
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Álmos Paksi, Hungary
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Boróka Pénzes, Hungary
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Prof Elie Saliba, France
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Prof Ola Didrik Saugstad, Norway
Prof Andreas Stahl, Germany
PD Dr Martin Stocker, Switzerland
Dr David Sweet, UK
Prof Marianne Thoresen, UK
Prof Win Tin, UK
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Assoc Prof Daniele Trevisanuto, Italy
Prof Máximo Vento Torres, Spain
Prof Henkjan Verkade, The Netherlands
Dr Eduardo Villamor, The Netherlands

„We can observe a lot of progress within the field of medical care and clinical practise over the last decades. This reaches from better medication to integrating parents into clinical procedures. Networking amongst professionals has improved neonatal care and will continue to do so if we collaborate on a European level. Establishing guidelines will enable us to make structural changes all over Europe and make an impact on society."

Chairs of the TEG

Professor Luc Zimmermann, The Netherlands

Professor Lena Hellström-Westas, Sweden

Professor Giuseppe Buonocore, Italy

Statements of the standards

Neonatal services provide a **high standard of care** in terms of **diagnosis and treatment of necrotising enterocolitis (NEC)** and infant/family experience and strive to continuously improve care and outcomes for NEC.

Measures are taken to identify, prevent, and manage **hypoglycaemia** in newborn infants who are at risk for impaired metabolic adaptation **within the first 72 hours of life**, including those with prolonged fetal distress, growth restriction, maternal diabetes, asphyxia, maternal beta-blocker medication.

Newborn infants with suspected **early onset infection** receive prompt **diagnosis and effective treatment of sepsis** while avoiding overuse of antibiotics.

Prophylactic supplementation with **vitamin K** for all infants is given **to prevent vitamin K deficiency bleeding (VKDB).**

All newborn infants are **assessed for neonatal jaundice** with the aim of implementing effective prevention of severe hyperbilirubinaemia.

Support of postnatal transition to extrauterine life is based on internationally consented guidelines, which are based on scientific evidence, and is performed in an appropriate structured and equipped environment by trained personnel.

Newborn infants at risk of **Respiratory Distress Syndrome (RDS)** receive appropriate perinatal care including place of delivery, **antenatal corticosteroids**, guidance around optimal strategies for delivery room stabilisation, and ongoing respiratory support.

Programmes for **preventive measures** such as control of oxygen supplementation and promotion of optimal nutrition are established as well as **screening programmes** for detection, documentation and treatment of **sight threatening retinopathy of prematurity (ROP)** in all units caring for very preterm infants.

Bronchopulmonary Dysplasia (BPD) is best prevented using evidence-based strategies, including continuous distending pressure or non-invasive ventilation to maintain patency of airways and avoiding invasive mechanical ventilation and intermittent **hypoxemia** when possible, minimally invasive early administration of **exogenous surfactant**, aiming at **volume targeted ventilation and early caffeine**, administration of systemic steroids in infants still requiring mechanical ventilation during their 2nd postnatal week, and supporting parental involvement in preterm infant care starting shortly after birth.

Newborn infants who have suffered from severe **hypoxic-ischaemia receive early evaluation and appropriate postnatal management** including therapeutic hypothermia and monitoring.

In order to improve evaluation and outcomes of newborn infants at risk of **brain injury, management includes neurological monitoring** using a structured, age-appropriate neurological assessment and a range of devices to evaluate brain haemodynamics, oxygen transport, brain function, and imaging as required.

Management of newborn infants with **persistent pulmonary hypertension (PPHN)** in a specialised centre improves mortality and morbidity.

Care procedures

Access the **standards** here

The Topic Expert Group on Care procedures works on topics reflecting the range of care needs of preterm and ill babies and summarises appropriate techniques.

Members of the TEG

Johann Binter, Austria
Dr Fátima Camba, Spain
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Dorottya Gross, Hungary
Ingrid Hankes-Drielsma, The Netherlands
Eva Jørgensen, Denmark
Anna Kalbér, Germany
Thomas Kühn, Germany
Marianne van Leeuwen, The Netherlands
Dr Maria López Maestro, Spain
Elsa Silva, Portugal
Xenia Xenofontos, Cyprus

Our heartfelt thanks go to our former Chair Odile Frauenfelder, The Netherlands for her valuable contribution.

„Care procedures play an important role in an infant's and a family's daily life in neonatal units and help the neonatal team to make decisions about the continuation or any change in the care and treatment. It is very important for the neonatal staff to recognise the necessity of the tests and procedures in order to protect infants' sleep and reduce pain, discomfort and other disturbances. High quality care procedures always go along with the involvement of parents and the encouragement of parents' embracement in daily care plays a fundamental role in infants' neurodevelopmental outcome and family's bonding. Unfortunately, the involvement of parents and families is not the same in every European country. We wish that organisations, governments, hospital managers and caregivers will invest more in the provision of high-quality care procedures and constantly promote the implementation of standards."

Chairs of the TEG

Monique Oude Reimer-van Kilsdonk, The Netherlands

Foteini Andritsou, UK

Statements of the standards

The process of **taking blood samples** is carried out exclusively by experienced and specially trained healthcare professionals, under individualised developmental supportive care to **minimise stress and pain** for the preterm infant.

All infants receive care that provides the individualised **positioning support and comfort**.

Skin is protected, injuries are minimised, infections are prevented and comfort is promoted during skin care and other routine procedures, with regard to the individual needs of the infant.

Environmental **management of temperature and humidity** is necessary to optimise the management of newborn infants.

Sleep of all infants is **respected.**

Appropriate **mouth care** is given to infants according to their individual needs and to minimise aversive responses.

Inserting and managing feeding tubes in infants is performed by a trained person and adjusted to infant´s needs and comfort.

The procedure of **weighing** an infant is individualised to **minimise stress** and adapted to the clinical condition and may be **carried out alongside or by the parents**.

All infants in neonatal and paediatric units receive optimal **comfort to minimise stress** and **pain**, supported by their parents.

Nappy change is performed with a technique that **minimises skin damage, discomfort, and physiologic instability**.

All **mothers are supported** to **feed their infants exclusively with human milk** (expressed mother's milk or donor human milk) during the hospital stay and after discharge.

All infants receive appropriate **activities of daily living (ADL)**, commencing with low-stress cleaning and moving to methods that support self-regulation once the infant is stable, alert and interactive.

Infant- & family-centred developmental care

Access the **standards** here

The Topic Expert Group on Infant- and family-centred developmental care develops standards for the implementation of neonatal care that is centred around the baby and the baby's family to optimally support the baby's development.

Members of the TEG

Dr Sari Ahlqvist-Björkroth, Finland
Natascia Bertoncelli, Italy
Dr Nils Bergman, Sweden
Prof Zack Boukydis, Hungary (†)
Sylvia Caballero, Spain
Prof Charlotte Casper, France
Mandy Daly, Ireland
George Damhuis, The Netherlands
Dr Manuela Filippa, Italy
Paula Guerra, Portugal
Prof Petra Hüppi, Switzerland
Dr Kai König, Switzerland
Birgitte Lenes-Ekeberg, Norway
Siri Lilliesköld, Sweden
Dr Rosario Montirosso, Italy
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Prof Jacques Sizun, France
Dr Kari Slinning, Norway
Dr Inga Warren, UK
Dr Björn Westrup, Sweden

Our heartfelt thanks go to our former Chair Dr Björn Westrup, Sweden for his valuable contribution.

„Infant- and family-centred developmental care aims to improve infant and parental long-term health by acknowledging the importance of parental involvement and individualised care based on infant behaviour. Providing family access to the NICU 24/7 and supporting the parents to be involved in the care of their infant as primary caregivers from the beginning of hospitalisation is fundamental and supported by scientific evidence. We observe that in some countries parents are still treated as visitors. However, family access and involving the parents in the care of their infant is also a matter of ethics and of human rights. Adjusting the clinical setting to infant and family needs requires a mind-shift of hospital administrations and staff but the concept of infant- and family-centred developmental care will eventually prove successful not only in Europe but beyond and be supported by further scientific evidence."

Chairs of the TEG

Professor Pierre Kuhn, France

Associate Professor Anna Axelin, Finland

Statements of the standards

A **managed acoustic environment** reduces stress and discomfort for infants.

Parents are members of the caregiving team and, with individualised support, assume the **primary role in the provision of care of their infant**, and are active partners in decision-making processes.

An individual **case management plan for each newborn infant** is established, in collaboration with parents, to plan and coordinate needed investigations and procedures, ensure the acquisition of needed parental competences prior to discharge and to plan follow-up and continuing care.

Infant- and family-centred developmental care (IFCDC) competence is ensured by providing **formal education and recurrent training** for hospital and unit leadership, healthcare professionals, and other staff working or visiting the neonatal unit.

Parents (and substitutes designated by the parents) have **continuous access** and are able to remain with the infant throughout the **24 hours.**

Skin-to-skin contact between mother or father and newborn infant is initiated as early as possible and maintained continuously.

The family receives care in an environment where their **socioeconomic, mental health and spiritual needs are supported**.

The hospital **sensory environment** is adjusted to the infants' sensory expectancies and perceptual competences.

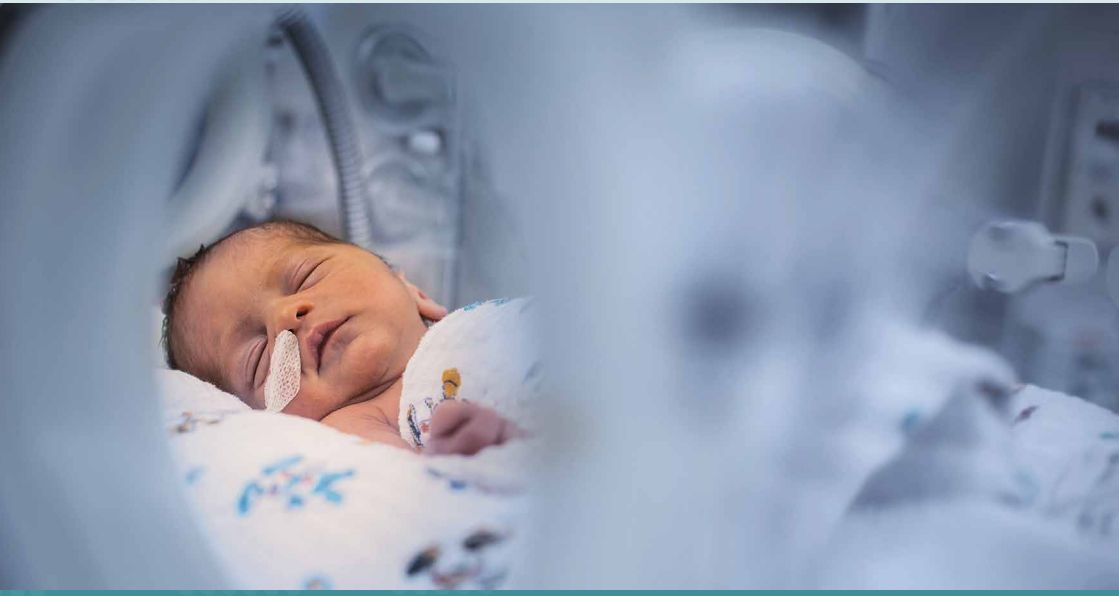
The **fostering of early bonding between parents and their newborn infant** is pursued through strategies which promote early contact for the parent-infant dyad.

Healthcare professionals receive **counselling and regular clinical supervision** in **communicating** with and providing **emotional support for parents**.

NICU Design

Access the **standards** here

The Topic Expert Group on NICU design works on standard topics reflecting infrastructural and design issues which optimally support the provision of high-quality and family-integrated and developmentally supportive care.



Members of the TEG

Prof Sidarto Bambang Oetomo, The Netherlands
Delphine Druart, Belgium
Katarina Eglin, Germany
Prof Uwe Ewald, Sweden
Prof Fabrizio Ferrari, Italy
Prof Peter Fröst, Sweden
Teresa Garzuly-Rieser, Austria
Dr Erna Hattinger-Jürgenssen, Austria
Silke Mader, Germany
Dr Tomasz Makaruk, Poland
Dr Thilo Mohns, The Netherlands
Prof Jacques Sizun, France
Prof Robert White, USA

Our heartfelt thanks go to our former Chair Dr Boubou Hallberg, Sweden for his valuable contribution.

„The field of NICU Design is a fast evolving and very important area. Originally, NICUs were not built to have the parents present 24/7 and we are still facing huge differences regarding quality and facilities in NICUs across Europe. So it is all about to re-build and re-think and to use architecture as some kind of medicine. It is not about a nice design but about creating facilities to bring parents and their children together so the NICU becomes a good place for the patients' wellbeing and treatment."

Chairs of the TEG

Dr Atle Moen, Norway

Associate Professor Bente Silnes Tandberg, Norway

Statements of the standards

A NICU is **designed to support safety and healing** through **unrestricted parental presence**, use of **sensory supportive material and optimal working facilities**, promoting close collaboration between families and staff in caring for the ill infant.

Neonatal care is optimised by utilising **key design elements to promote the family as primary care givers throughout the stay.**

A physical environment that **facilitates parent-infant closeness and skin-to-skin** care is considered in NICU planning.

Nutrition

Access the **standards** here

The Topic Expert Group on Nutrition works on standards relating to the special feeding requirements of preterm and ill born babies during their stay in the hospital and after discharge.

Members of the TEG

Prof Magnus Domellöf, Sweden
Prof Nicholas Embleton, UK
Prof Hans van Goudoever, The Netherlands
Dr Darius Gruszfeld, Poland
PD Dr Susanne Jonat, Germany
Prof Alexandre Lapillonne, France
Alison McNulty, UK
Dr Peter Szitanyi, Czech Republic

„Nutrition has a tremendous impact on the long-term outcomes of preterm infants, especially on those born with a very low birth weight. It affects their growth and their organ development, including brain development. It is important to establish consistency all over Europe concerning standards for nutritional care of preterms and to include the different stakeholders from healthcare professionals to parents in this process."

Chairs of the TEG

Professor Berthold Koletzko, Germany

Professor Mary Fewtrell, UK

Statements of the standards

All units treating preterm and ill term infants **develop and implement guidelines on nutritional care** and aim at establishing nutrition support teams, inform and train all healthcare professionals regarding the use of these guidelines on nutritional care, and monitor implementation.

Growth monitoring and assessment of nutritional status is performed using **suitable equipment** and appropriate **growth charts** in order to optimise nutritional support and outcomes.

Preterm infants are given **supplements to reduce nutritional deficits**.

In very preterm infants (<32 weeks of gestation)/ very low birthweight infants (<1500 g birthweight), **parenteral nutrition** should start on the **first day after birth**, usually using standard solutions, and should continue until sufficient enteral feeding is established.

Parents develop appropriate **knowledge and skills in feeding** their preterm infant.

Standards are established for the safe use of **human donor milk when mother's own milk is not available**.

Formula for preterm infants promotes growth and functional outcomes approaching those of preterm infants fed fortified mother's milk.

Early enteral feeding is established, based on a standard protocol, preferably with mother's own breast milk.

Early nutrition, preferably using **human milk**, is established and **feeding difficulties, growth, and breastfeeding are monitored** during and after hospitalisation.

Mothers are **informed about the benefits of breastfeeding**, **encouraged and supported to provide their own breast milk** for their infant. However, staff should be sensitive to maternal choice and avoid putting pressure on women who are unable to provide any or sufficient MOM or who choose not do so.

Ethical decision making & palliative care

Access the **standards** here

The Topic Expert Group on Ethical decision-making and palliative care works on standards related to challenging decision-making processes in neonatal care.

Members of the TEG

Elsa Afonso, Spain/UK
Prof Hans-Ulrich Bucher, Switzerland
Dr Laurence Caeymaex, France
Prof Nicholas Embleton, UK
Dr Milivoj Novak, Croatia
Dr Daniel Nuzum, Ireland
Prof Jochen Peters, Germany
Karl Rombo, Sweden
Yannic Verhaest, Belgium
Dr Daniel Wood, UK

Our heartfelt thanks go to our former Chair Professor Gorm Greisen, Denmark for his valuable contribution.

„The scope of intensive neonatal care is expanding and great efforts have been made in neonatal intensive care units to reduce neonatal mortality. But in this process it is essential that the dignity and integrity of babies and their families are protected with due attention to minimising unnecessary suffering. The medical facts must be clarified as well as possible, but equally important, the family has to be involved. Only by involving parents, their life conditions and views can be known, as well as their wish to contribute to any decision."

Chairs of the TEG

Professor Jos Latour, UK

Dr Marina Cuttini, Italy

Statements of the standards

Parents and healthcare professionals share all relevant information such as the conditions, prognosis, and choices for care of the infant, as well as the social situation, values, and preferences of parents.

The **rights of infants, parents, and families in difficult decisions** are respected by healthcare professionals. The values behind any decisions that may compromise those rights are transparent.

Decisions of withholding or withdrawing life support are based on **shared decision-making** between parents and healthcare team taking into account the **best interest of the infant and family** in the context of the clinical situation and legal frameworks.

Interdisciplinary neonatal palliative care safeguards the quality of life of the infant and the family when a **life limiting condition** is diagnosed.

Follow-up & continuing care

Access the **standards** here

The Topic Expert Group on Follow-up and continuing care looks at the care and treatment of babies after discharge from hospital and defines central areas of assessment to identify any problems early in order to enable interventions and optimal management of healthcare needs.

Members of the TEG

Prof Laura Bosch, Spain
Prof Catherine Cassiman, Belgium
Dr Christiaan Geldof, The Netherlands
Prof Mijna Hadders-Algra, The Netherlands
Dr Ingmar Fortmann, Germany
Dr David Göttler, Germany
Prof Christoph Härtel, Germany
Prof Egbert Herting, Germany
Dr Bregje Houtzager, The Netherlands
Dr Shelley Hymel, Canada
Dr Julia Jäkel, USA/Germany
Prof Mark Johnson, UK
Prof Samantha Johnson, UK
Prof Eero Kajantie, Finland
Dr Anne van Kempen, The Netherlands
Dr Karen Koldewijn, The Netherlands
Prof Liisa Lehtonen, Finland
Prof Johannes Liese, Germany
Silke Mader, Germany
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Dr Veronique Pierrat, France
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Dr Gert van Steenbrugge, The Netherlands
Dr Irma van Straaten, The Netherlands
Dr Jacqueline UM Termote, The Netherlands
Prof Tracy Vaillancourt, Canada
Mónica Virchez Figueroa, Spain
Prof Brigitte Vollmer, UK
Dr Marie-Jeanne Wolf-Vereecken, The Netherlands

Our heartfelt thanks go to our former Chair Dr Aleid Leemhuis, The Netherlands for her valuable contribution.

"Future follow-up should have a stronger focus on the multiple factors playing a role in academic achievement of preterm infants. This includes health, participation in sports, executive function, parental scaffolding and social cognition, emotion understanding and social skills and better liaison with education services. We also know that integrating and getting on with siblings or peers from kindergarten to school is crucial to provide long-term support and happiness for at risk children. Coordinating and managing appointments by a case manager assisting distressed parents is important. Care and research should go hand in hand. It is not always clear which interventions may be of benefit to the infant and families and at which age they should start. Comparing programmes and setting up cross-border research on interventions is a good way to proceed."

Chairs of the TEG

Professor Dieter Wolke, UK/Germany

PD Dr Britta Hüning, Germany

Statements of the standards

Preterm infants are **immunised according to their chronological age,** regardless of gestational age and weight at birth. In very preterm infants, **immunisations are started and monitored in hospital,** once the target age for the first immunisation (usually 8-12 weeks) is reached.

Parents receive **comprehensive and integrated care** for their high-risk infant **after** discharge home.

Standardised **hearing screening** is conducted using **Automated Auditory Brainstem Response (AABR)** technology before one month of age, and where necessary diagnostic investigations are completed before three months and early interventions are started within the first six months.

Standardised assessment of **neurological status** and **motor development** is conducted in the first two years and repeated at transition to school.

Standardised assessment of **communication, speech, and language development** is conducted by two years of age and repeated at transition to school.

Developmental progress and school readiness of infants born very preterm or with risk factors are assessed 6-12 months prior to initial entry into formal schooling, and **education** professionals receive **training** about the potential **special educational needs** of children born very preterm or with risk factors.

Peer and sibling relationships are evaluated as part of a standard follow-up programme.

Behaviour, emotional and attention problems are assessed at two years of age and again at the time of transition to school.

Respiratory health is evaluated as part of a follow-up care programme.

Mothers of infants born very preterm or with pregnancy complications and their partners are **counselled on the risk of recurrence** in future pregnancies, and offered strategies to prevent recurrence, both before conception and during a subsequent pregnancy.

Families receive a **comprehensive discharge management** plan to facilitate transition from the hospital to home.

Standardised **cognitive assessment** is conducted by two years of age and repeated at transition to school.

Standardised **visual assessment** is conducted by age 3.5 to 4 years and repeated by age 5 to 6, at which age additional attention is payed to **visual information processing dysfunctions**.

All very preterm infants and their families are offered **preventive responsive parenting support** after discharge home.

Key cardiometabolic risk factors (in particular blood pressure, abdominal obesity and physical inactivity) are **monitored** from childhood to adult life.

Targeted **screening of parental mental health** is undertaken six months after discharge and at two years, during regular follow-up visits for the child.

Patient safety & hygiene practice

Access the **standards** here

The Topic Expert Group on Patient safety and hygiene practice works on topics related to the prevention of healthcare-associated infection, therapeutic errors, hygiene, and safety culture.

Members of the TEG

Dr Susana Ares Segura, Spain
Dr Alessandro Borghesi, Italy
Maria Josep Cabañas Poy, Spain
Prof Daniele De Luca, France
Dr Cécile Dubois, France
Prof Christoph Fusch, Germany
Estrella Gargallo, Spain
PD Dr Eric Giannoni, Switzerland
Prof Christoph Härtel, Germany
Hans Härting, Austria
Assoc Prof Jan Janota, Czech Republic
Martin Jessie, Germany
Dr Ulrik Lausten-Thomsen, France
Dr Nolwenn Le Saché, France
Silke Mader, Germany
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Prof Norbert Pateisky, Austria
Dr Josep Perapoch, Spain
Prof Christian F. Poets, Germany
Roland van Rens, The Netherlands
Prof Rainer Rossi, Germany
Dr Jens-Christian Schwindt, Austria
Ass Prof Heleen van der Sijs, The Netherlands
Dr Cynthia van der Starre, The Netherlands
Nicole Thiele, Germany
Dr Tobias Trips, Germany
Lucie Žáčková, Czech Republic

Our heartfelt thanks go to our former Chair Team Professor Pierre Tissières, France and Dr Onno Helder, The Netherlands for their valuable contribution.

„For too long patient safety and hygiene in treatment and care had been neglected. Measures taken in this regard have made significant and tremendous improvements in the safety of newborns and preterm babies, resulting in better long-term outcomes.

Most adverse events or errors cannot be solved at the individual level but rather at the system level. Medical teams on the frontline must be provided with a system that is designed to make it easy for the teams to do the right thing. It is the responsibility of healthcare leaders and policy-makers to ensure the implementation of such a highly reliable system."

Chairs of the TEG

Associate Professor Marije Hogeveen, The Netherlands

Dr Eva Schwindt, Austria

Statements of the standards

Incident reporting systems must be mandatory for all neonatal wards and have to be **embedded in comprehensive safety programmes** to effectively improve healthcare safety.

Hand hygiene is practiced consistently according to the guidelines in order to reduce the spread of hand carried pathogens.

Each hospital has **central venous catheters insertion and maintenance bundles**, that are consistently applied to reduce the incidence of central line-associated bloodstream infections.

Neonatal services implement bundles of care designed to **prevent necrotising enterocolitis (NEC)**.

Vascular access is achieved in a competent, skillful, and safe manner.

High standards of **environmental hygiene and cleaning** are ensured to reduce the occurrence of infection and complications.

Medication errors are monitored and evaluated to reduce the exposure of infants to avoidable therapeutic risks.

Patient screening for multidrug-resistant bacteria in neonatal intensive care units (NICUs) is part of infection prevention and control programmes.

Nurse staffing levels reflect the needs of the infants they are caring for, which include one to one nursing during intensive care and one to two nursing during intermediate care.

Safe use of equipment in neonatal care is ensured using standardised operating procedures and systematic monitoring and reporting of incidents.

Patient safety and quality improvement activities are fully integrated in clinical practice.

The **risk of ventilator associated pneumonia (VAP) is minimised** by systematic application of care bundles.

Physiological monitoring is provided to any infant admitted to a NICU, which is tailored to the individual clinical situation.

High **personal hygiene standard** is ensured to reduce the risk of nosocomial infections.

Data collection & documentation

Access the **standards** here

The Topic Expert Group on **Data collection and documentation** works on standards related to the acquisition and use of perinatal and neonatal data.

Members of the TEG

Vilni Verner Holst Bloch, Norway
Mandy Daly, Ireland
Prof Mika Gissler, Finland
Prof Wolfgang Göpel, Germany
Prof Dominique Haumont, Belgium
Dr Kjell Helenius, Finland
Prof Jos Latour, UK
Dr Ashna Hindori-Mohangoo, The Netherlands
Prof Helmut Hummler, Germany
Dr Begoña Loureiro Gonzalez, Spain
Prof Neena Modi, UK
Dr Miklós Szabó, Hungary
Prof Roger Soll, USA
Dr Liis Toome, Estonia
Dr Eleni Vavouraki, Greece
Ben Wills-Eve, UK
Dr Jennifer Zeitlin, France

Our heartfelt thanks go to our former Chair Professor Gérard Bréart, France for his valuable contribution.

"Data collection and documentation frequently fail to meet the immediate expectations of parents and later needs of former neonatal patients. However, recent technological advances offer enormous opportunities in efficient data usage: optimal use of data can improve provision of care and subsequent patient outcomes. In general, there are two major challenges in data collection and documentation in Europe: the accessibility of data and the comparability of data. First, not all relevant data are regularly available. Second, the heterogeneity of healthcare systems is the bane of all international comparisons in quality of healthcare. We give recommendations for avoiding pitfalls in interpreting this type of data and to encourage the use of already existing comparative databases with a good methodological basis."

Chairs of the TEG

Dr James Webbe, UK

Dr Nicholas Lack, Germany

Statements of the standards

Information on the **quality** of neonatal healthcare is **collected, accessible, and understandable** at national, regional, and hospital level.

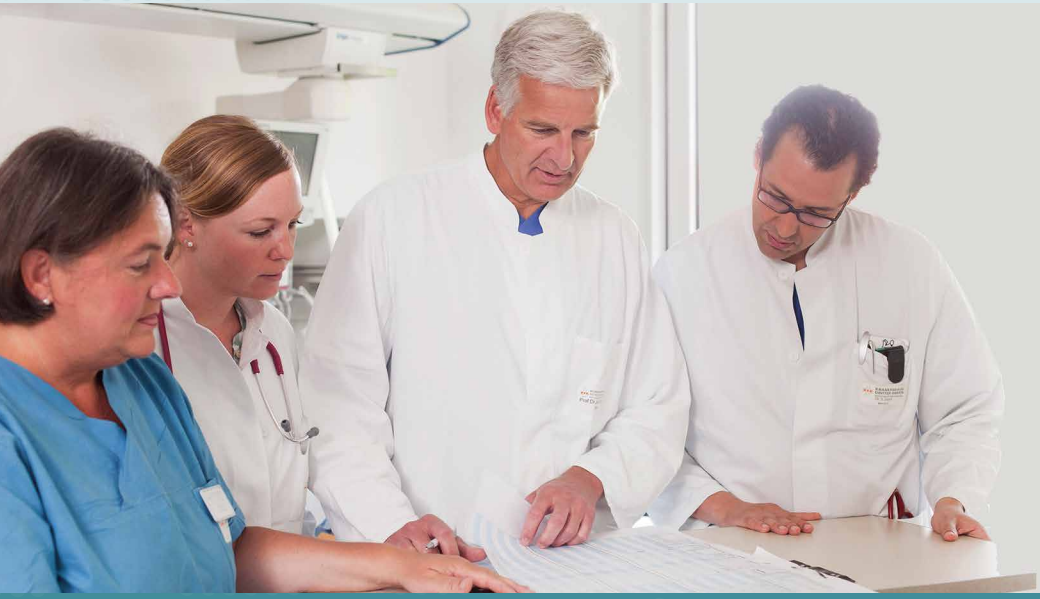
Quality and health indicators in neonatal healthcare **comply with published standards** and help to increase comparability.

Recording, collating and reporting quality indicators in a standardised manner supports comparisons of care nationally, within Europe and beyond.

Education & training of the multidisciplinary team working in neonatology

Access the **standards** here

The Topic Expert Group on Education and training of the multi-disciplinary team working in neonatology develops standards related to education and training requirements for neonatal health practitioners. The focus of the standards lies on how education and training shall be structured and which topics are relevant in curricula.



Members of the TEG

Charlotte Bouvard, France
Dr Marina Boykova, Russia/USA
Prof Karl Heinz Brisch, Germany
Prof Duygu Gözen, Turkey
Prof Moshe Hod, Israel
Thomas Kühn, Germany
Dr Trudi Mannix, Australia
Prof Karel O'Brien, Canada
Marni Panas, Canada
Dr Julia Petty, UK
Dr Mirjam Schuler Barazzoni, Switzerland
Natascia Simeone, Italy
Dr Dalia Stoniene, Lithuania
Dr Inge Tency, Belgium
Nicole Thiele, Germany
Dr Inga Warren, UK

Our heartfelt thanks go to our former Chair Professor Charles C. Roehr, UK/Germany and Dr Morten Breindahl for their valuable contributions.

„The new standards will be an important guide for policy makers, regulators and education providers. The goal is that babies and their families in Europe will consistently, and sustainably, receive evidence-based care, delivered by a multidisciplinary team who has received high-quality specialist education and training. With healthcare delivery across Europe based on those principles, we can be confident that babies and their families will have improved outcomes and lead happy and healthy lives."

Chairs of the TEG

Professor Linda Johnston, Ireland/Canada

Professor Willem de Boode, The Netherlands

Assistant Professor Agnes van den Hoogen, The Netherlands

Dr Florian Langhammer, Germany

Statements of the standards

All healthcare professionals develop and maintain **competencies to provide safe and effective care** through regular **simulation-based learning**.

All healthcare professionals have access to and undertake **continuing professional development** to deliver safe and effective healthcare.

Every healthcare professional caring for infants and their families delivers **care based on the best available evidence**, integrated with clinical expertise, available resources and the wishes of the family.

All doctors providing care to infants and their families receive **training** using a **competency based** curriculum and assessment framework.

All **parents** are provided with a **training programme** to facilitate their development as confident caregivers.

Every **healthcare professional** is given access to and undertakes regular neonatal **resuscitation training**.

All **nurses** providing care to infants and their families have access to and undergo **education and training** using a **competency based** curriculum and assessment framework.

Every healthcare professional has access to **interprofessional education** that enhances the delivery of practice in the care of infants and their families.

5. Launch of the standards

The European Standards of Care for Newborn Health were officially launched in the European Parliament in Brussels in November 2018 in an event titled: "Mission: impossible – Take responsibility for newborn health in Europe". In total more than 100 participants, ranging from politicians, the project's experts and supporters, parent representatives, as well as several key stakeholders from organisations like the World Health Organization (WHO) and European healthcare societies joined the launch event.

6. Awards and recognitions

Silke Mader became Ashoka fellow in 2015 with the goal of pushing the European Standards of Care for Newborn Health project forward. In 2017, the project was recognised as Landmark of Germany – Land of Ideas. In the course of the launch of the standards, THE LANCET Child & Adolescent Health published an editorial "Putting the family at the centre of newborn health" in their 2019 January issue. In the meanwhile the European Standards of Care for Newborn Health were mentioned in several publications and various presentations at diverse congresses and conferences all around the world.

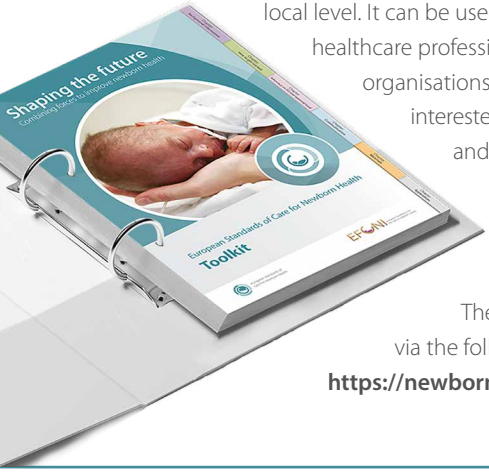
ASHOKA

Germany
Land of Ideas
Landmark 2017

7. Next steps

With the launch of the standards, the project is not finished but continues with the implementation process. For a sustainable change of newborn health practices and structures in line with the new standards, various steps are undertaken to support and accelerate their implementation.

In September 2019, the toolkit 'Shaping the future – Combining forces to improve newborn health' was launched. The toolkit aims to facilitate and support the implementation of the European Standards of Care for Newborn Health on a national, regional, and local level. It can be used by various stakeholders like parent organisations, healthcare professionals, healthcare societies, payers, non-governmental organisations, policymakers, politicians, the media, and other interested parties. This practical handbook provides knowledge and background information about the standards, ideas, tools, and step-by-step advice. Many practical examples serve as an inspiration in order to raise awareness and engage with national stakeholders.



The toolkit is a digital, interactive resource and is available via the following link:

https://newborn-health-standards.org/downloads/

Parent organisations all around Europe (and beyond) as well as individual healthcare professionals and healthcare professional societies have taken the initiative to implement the standards on a national level with diverse projects: expert roundtables, whole conferences on the standards, as well as political events were organised to name only a few. In some countries working groups were established, which now compare the actual practices with the European reference standards with the aim of adapting national guidelines, protocols, or laws (depending on the national situation).

If you need support in implementing the standards or if you are already working on the national implementation of the European Standards of Care for Newborn Health, please inform us about your initiatives via **standards@efcni.org**

We hope that all relevant stakeholders will join forces and work together on the implementation of the standards in order to ensure the best start in life for all babies across Europe, and beyond.

Find more information online:

To download the standards or to get more information about the background, methodology, topics, and experts involved, please visit: **www.newborn-health-standards.org**

8. Supporting organisations

We warmly thank the following healthcare societies and organisations for supporting the

developed European Standards of Care for Newborn Health (in alphabetic order):










We warmly thank the following parent organisations for supporting the developed European Standards of Care for Newborn Health (in alphabetic order):

9. Funding

We thank the European Standards of Care for Newborn Health project's industry partners for their financial support for the project:

Thanks to AstraZeneca for supporting the project from 2021 until 2023.

Thanks to Baxter for supporting the project from 2017 to 2019 and from 2021 until 2022.

Thanks to Philips Avent for supporting the project until 2014 to 2019.

Thanks for Philips for supporting the project from 2018 until 2019.

Thanks to Prolacta Bioscience® Inc. for supporting the project from 2021 until 2023.

Thanks to Shire for supporting the project from 2014 until 2018.

Thanks to Takeda for supporting the project from 2019 until 2020.

A hero isn't always big and strong. A hero is simply one who has the strength and courage to overcome overwhelming circumstances.

Unknown

10. EFCNI donation programme

There are many ways to make donations. Find out which one is the most suitable for you:

Donate now: single donations

With one single donation you will improve the situation for preterm and ill born babies in many ways. Every donation, big or small, helps us to provide support where it is needed most.

Become a Member of the I-Care Programme

With a monthly donation or with a one-time annual donation of at least 50 Euros you become a member of the EFCNI I-Care Programme. Your non-earmarked donation will be used for our donation projects in Europe and worldwide.

Become a Bodyguard

With a donation of 1,000 Euros or more you can become a ***Bodyguard*** for the smallest children and implement your very own project.

Give a donation instead of a gift

Joyful moments but also sad occasions are part of everyone's life. These moments can be reason to think about people in need.

Corporate Giving

Donate the proceeds of your corporate event to EFCNI and demonstrate your social commitment.

Despeena, born at 24 weeks weighing 820 grams

We would like to thank all donors for their generosity and commitment to improving maternal and newborn health in Europe. All contributions, however small, help us to achieve our goals and will make a vital difference. If you wish to make a donation, please send it to the following EFCNI bank account:

Bank fuer Sozialwirtschaft

Account owner: EFCNI

BIC: BFSW DE33 XXX

IBAN: DE18 3702 0500 0008 8109 00

EFCNI is a registered charity certified by the Munich Tax Office as eligible for support, tax reference number 143/235/22619 and therefore can issue donation receipts.

Please quote your address in the reference line so that we can issue a donation receipt*.

Our donation receipt template is officially accepted by the German tax authorities. To reduce administration, EFCNI will issue donation receipts from 25 Euros or more (annual donation amount). Nevertheless, if you need a donation receipt for a smaller donation from us, please do not hesitate to contact us: **donations@efcni.org**

EFCNI can issue donation receipts in English but cannot guarantee an acceptance of this receipt by your designated tax authority.

*The legal basis for this data processing is article 6 paragraph 1 b) GDPR. For more information, please visit: **www.efcni.org/dataprotection**

11. Imprint

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Visit us on

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About EFCNI

The European Foundation for the Care of Newborn Infants (EFCNI) is the first pan-European organisation and network to represent the interests of preterm and newborn infants and their families. It brings together parents, healthcare experts from different disciplines, and scientists with the common goal of improving long-term health of preterm and newborn children. EFCNI's vision is to ensure the best start in life for every baby.

For more information: ***www.efcni.org***

EFCNI european foundation for the care of newborn infants

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