



European Standards of Care for Newborn Health

Project report



european standards of
care for newborn health

EFGNI european foundation for
the care of newborn infants



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, 21 years old,
born at 25 weeks of gestation**

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Foreword EFCNI Executive Board







Since we conceptualised the European Standards of Care for Newborn Health project in September 2013, we have been asked why we work so hard on standards in newborn health and whether there is still a need for improvement in this area in Europe. We live in a part of the world where the majority enjoy free healthcare and highly developed medical standards. Do not the youngest patients in our healthcare systems benefit from this security and institutional reliability?

There has been great progress within the field of neonatology over the last decades and survival rates for preterm babies are increasing. In parallel, for a range of reasons, we are facing a continuously increasing number of preterm births. A significant proportion of children born preterm live with long-term consequences affecting their physical and mental development, which also affect their families. Optimal care can offset many of these issues; providing support for families after birth and into the future helps to ensure a supportive environment for the growing child.

The heterogeneity of the European Union, with wide disparities in its economies and political systems and in provision and organisation of healthcare, make common standards of care difficult to apply. For preterm and ill newborn babies, who form the largest but also the weakest and most vulnerable patient group in Europe, this variation is especially wide, despite the wealth of scientific evidence to support practice. Preterm birth is the leading cause of neonatal mortality and morbidity. (1) Standards and effective policies that enhance equity

and quality of healthcare in this field are likely to be highly beneficial.

When EFCNI initiated the European Standards of Care for Newborn Health project, the idea was to serve as a neutral project platform and coordinator, while supporting a multi-stakeholder network to develop reference standards to serve as a benchmark and blueprint for the development of standards in each individual country. We believe that the partnership we have established with all relevant stakeholders in maternal and newborn health all over Europe has developed evidence-based best practices and qualitative outcome indicators that will significantly improve health outcomes of preterm infants in Europe and beyond. Together with this ever-growing network of healthcare professionals and parent representatives, who voluntarily contributed their extensive knowledge and experience, we have realised a comprehensive set of almost 100 standards to be disseminated and implemented across Europe and beyond.

Thanks to the invaluable support of our partners and the many dedicated members of our network, and their belief and commitment in the project, we now provide the infrastructure to give newborn health medical, political, and societal priority.

Together we can advance newborn health in Europe and beyond.

Yours,



Silke Mader
Chairwoman of the
EFCNI Executive Board



Nicole Thiele
Vice Chair of the
EFCNI Executive Board



Professor Neil Marlow
Member of the
EFCNI Executive Board



Greetings

MEP Professor Dr Angelika Niebler

EFCNI Parent Advisory Board

International partnering healthcare societies

Dr Dietmar Schlembach - Chairman of the Trustee Board of EFCNI



Professor Dr Angelika Niebler

Member of the European Parliament

Approximately one in ten babies is born too soon. Worldwide. In Europe, about 500,000 babies are born preterm every year. These infants represent Europe's largest child patient group and their number is continuously growing, yet their voice has still to be heard. Together with their parents, these children experience enormous physical, emotional, and financial challenges, costs entailed by preterm birth. If we want to pave the way for progressive and efficient healthcare politics, we must take medical and socio-economic aspects into account. Health is a very important issue for Europe's citizens and thus, European recommendations and research on health are a priority for European institutions, in particular the European Parliament.

In our globalised world, we rely on international exchange and cooperation in an ever growing number of aspects regarding our daily lives. Health and the field of science and research are especially relevant in this matter and we need collaboration and an exchange of knowledge to implement research findings in order to improve prevention and treatment in the future.

The European Standards of Care for Newborn Health project is a role model for transnational, and interdisciplinary exchange of knowledge, to spread thorough understanding and use of evidence-based findings in neonatal care but also to develop strategies in reforming our routines in caregiving and therapeutic measures towards high-value, equitable healthcare.





As a Member of the European Parliament, as well as a woman and a mother, I welcome the commitment of EFCNI, its partners, and supporters in pushing forward European Standards of Care for Newborn Health. Children are our future and the future of our societies. It is crucial to address the needs of preterm and ill babies and to turn the spotlight on the various maternal and newborn health policies and practices in place within Europe's Member States. As patron of EFCNI, I am delighted to be able to actively support this path-breaking project to ensure that Europe's children receive the best start in life.

Yours,

Professor Dr Angelika Niebler
Member of the European Parliament



EFCNI Parent Advisory Board

When we initially started to become advocates for preterm babies and their families within our national parent organisations, we found it hard to imagine that one day, parents could be considered as equal partners in the care of their preterm or ill newborn infants. What seems natural at first sight, has often enough been a long and tedious process with years of persuasive efforts. We are therefore particularly proud to see that the day has come to present the results of the truly patient-centred European Standards of Care for Newborn Health project. It incorporates the unique perspective of parents, their experiences, views and feelings into recommendations for newborn care. With joy and gratefulness, we have been contributing to this milestone project that has the potential to become a ray of hope for families worldwide.

As members of the EFCNI Parent Advisory Board, we represented the parents' voice in the project's steering group, the Chair Committee. Together with EFCNI's Executive Board and the Chairs and Vice Chairs of the project's Topic Expert Groups, we actively and equally developed, discussed, and voted on the standards. Characterised by mutual understanding and attentiveness, the project was a unique platform for us to be heard as ambassadors for the smallest and most vulnerable patients, to share our long-standing competences as parent and patient representatives and to see these thoughts reflected in the standards.

We also recognise that this is just the beginning. In fact, the actual work only starts now with putting the standards into everyday practice in our countries. We will make every effort for their successful implementation, hand in hand with healthcare professionals, hospitals, other parents and politicians, and will support others to follow our example. Although every experience is individual, we are united by the same objective and by our willingness to improve the situation for the next generation of preterm babies and their families. The European Standards of Care for Newborn Health project is an important step on this journey and our goal is that families worldwide will benefit significantly from our efforts and experience their life-long effects.

We are ready for this change, so let's get started!

Yours,





Mandy Daly

Mandy Daly
*Co-Founder and Director of
Advocacy and Policy Making, Irish
Neonatal Health Alliance (INHA),
Ireland*



Paula Guerra

Paula Guerra
*Co-Founder and Executive
Board Member, XXS -
Associação Portuguesa de
Apoio ao Bebê Prematuro,
Portugal*



Tomasz Makaruk

Dr Tomasz Makaruk
*Founder and Chairman,
Fundacja Wczesniak
Rodzice-Rodzicom,
Poland*



Nagy Livia

Livia Nagy Bonnard
*Co-Founder, Melletted a
helyem - Right(s) beside you,
Hungary*



Gert van Steenbrugge

Dr Gert van Steenbrugge
*Past Director, Vereniging van Ouders
van Couveusekinderen (VOC),
The Netherlands*



Eleni Vavouraki

Dr Eleni Vavouraki
*Co-Founder and President,
Ilitominon,
Greece*



Y Verhaest

Yannic Verhaest
*Chairwoman, Vlaamse
Vereniging voor Ouders van
Couveusekinderen (VVOC),
Belgium*



Mónica Virchez

Mónica Virchez Figueroa
*President, Prematura,
Spain*

International partnering healthcare societies

Our societies are committed to putting the smallest and most vulnerable patients in the centre of care and to respecting the rights of newborns wherever they are born. We therefore support and promote the European Standards of Care for Newborn Health that will help reduce health inequalities in Europe and beyond.

The uniqueness of this lighthouse project is that it considers so many different perspectives, from healthcare professionals, parents, to non-governmental organisations, and other stakeholders. Members from many different professional societies contributed to this unprecedented multi-disciplinary project. Coming from the fields of perinatology, obstetrics, gynaecology, nursing science, neonatology, and paediatrics, they shared their expertise and worked united towards the completion of these standards. In a joint effort, they set a new framework, giving clear guidance on how to improve the health of newborn babies through providing the highest possible standard of care. By defining a profound evidence base for clinical practice, the standards will in the long term lead to better medical treatments and improve outcomes.

In this endeavour, education and training of healthcare professionals will play a major role. Harmonising

existing neonatal training programmes, taking evidence-based practices into account, needs to be promoted. Given the complexity of the healthcare needs and the range of healthcare providers involved in the care of neonatal patients, interprofessional education is mandatory for multidisciplinary teams to effectively work together. With its focus on research-driven practice, the project advances neonatal and paediatric intensive care and provides a decisive impulse for a European-wide and international collaboration between researchers, practitioners, and societies. Furthermore, the project sheds light on important, but currently still neglected issues and "soft skill" topics, for instance infant- and family-centred developmental care or ethical decision-making. By putting these topics on the top of the agenda, the project takes forward the scientific discussion.

Overall, the standards pay tribute to the current shift towards patient-centred care practices that demonstrably have beneficial effects for both patients as well as for medical teams. Welcoming this development, we strongly advocate for the standards and will support their national implementation to the best of our ability in our daily practice.

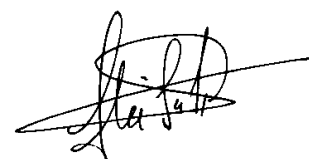
Yours,

Council of International Neonatal Nurses (COINN)

A handwritten signature in blue ink that reads "Carole Kenner".

Dr Carole Kenner
President of COINN

European Association of Perinatal Medicine (EAPM)

A handwritten signature in black ink that reads "Elie Saliba".

Professor Elie Saliba
President of EAPM



European Board & College of
Obstetrics and Gynaecology (EBCOG)



Professor Jacky Nizard
President of EBCOG

European Society for Paediatric
Gastroenterology Hepatology
and Nutrition (ESPGHAN)



Professor Raanan Shamir
President of ESPGHAN

European Society for Paediatric
Research (ESPR)



Professor Charles C. Roehr
President of ESPR

European Society of Paediatric
Neonatal Intensive Care (ESPNIC)



Professor Pierre Tissières
Medical President of ESPNIC

Union of European Neonatal &
Perinatal Societies (UENPS)



Professor Corrado Moretti
President of UENPS

Dr Dietmar Schlembach - Chairman of the Trustee Board of EFCNI



For us professionals involved, contributing to the European Standards of Care for Newborn Health project has been a unique opportunity to share best practices and to put maternal and newborn health, especially the often underestimated issue of preterm birth, high on the agenda. As Chair of the Topic Expert Group on Birth and transfer, and as member of the project's editorial team as well as Chairman of EFCNI's Trustee Board, I have accompanied the development of the standards from the very beginning and have seen the great efforts and achievement of bringing key stakeholders together. The international, transdisciplinary exchange with parents and colleagues, both practitioners and researchers, was eye-opening for everyone involved and has been crucially decisive and enriching. Having started from the scratch, it is thanks to the voluntary commitment, insistence, and perseverance of these people that we are now able to present the first European reference standards that will shape the future of newborn care. With regard to my discipline, maternal-fetal medicine and obstetrics, the project, for example, encounters the specific challenges of identifying high-risk pregnancies early and of ensuring a proper but yet individualised treatment of pregnant women and newborn infants by specialists at the most suitable hospital.

At the same time, the project enhances understanding of the emotional rollercoaster parents are facing and presents multifaceted, evidence-based ways to intelligently and empathetically support them in case of pregnancy and birth complications – not only from a medical point of view but also, for example, by providing comprehensive information and by facilitating communication between parents and healthcare professionals.

It is now up to us healthcare professionals, to enable this desired change of mind and to incorporate the recommended practices into our daily work. We did not make it easy on ourselves in developing feasible, patient-centred standards and admittedly sometimes struggled for solutions. The more I am confident that the final result will work out in practice. The project has also built a strong network of multipliers for the implementation of the standards into national healthcare systems and has fostered the interlocking of the disciplines and countries. Thinking ahead, I can only encourage my colleagues to now turn these reference standards into tangible reality and to let them sustainably shape our future work.

Yours,

Dr Dietmar Schlembach
Chair of the Topic Expert Group on Birth and transfer and member of the editorial team of the European Standards of Care for Newborn Health project, Chairman of the Trustee Board of EFCNI





**What makes
this project so
unique?**





What makes this project so unique?

To 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), Europe needs **new ideas and solutions** with respect to newborn health. The European Standards of Care for Newborn Health project presents such a solution by providing **European reference standards** for this health area.

With its **transdisciplinary focus** and **international composition** of the working groups, the project sets new benchmarks for the care of preterm and newborn babies and can serve as a role model for countries in Europe and worldwide. About **220 experts** from more than **30 countries** committed to take up the challenge and dedicated their free time to work on this ambitious project over several years. More than **80 healthcare societies and associations** as well as **parent organisations** confirmed the need for such reference standards and accepted EFCNI's invitation for endorsement of the project. Through its **multi-stakeholder approach**, the perspective of parents, healthcare professionals, and relevant third parties were equally considered, aiming at identifying current best practice. **Industry partners** were involved in the project by supporting it **financially**. Their representatives could join the Chair Committee meetings in an observing role and they were welcome to share their knowledge and expertise without exerting influence.

Driven by the **power of parents**, it is a true **patient-centred project, initiated by patient (parent) representatives for patients**. For the first time,

patients were involved in absolutely every step in the development of standards. In the project, parents and healthcare professionals work together in an open and respectful partnership to **pave the way for change** and set newborn health on the international and national agendas.

By addressing newborn health from different angles, the **complexity** of the wide range of topics in neonatal care was taken into account. For the first time, standards were not only developed for the (medical) care of patients but go further beyond to areas like NICU design, follow-up and continuing care, infant- and family-centred developmental care, and even ethical decision-making.

The project is also unique because it aims at achieving and catalysing a **systematic change** for **harmonisation and quality improvement** of newborn care by changing the **framework conditions** in the respective countries. This mind change was worked on in a **multi-level dissemination, implementation, and scaling strategy** reaching from political events, to a big social media campaign, to presentations of the project on congresses, and to training of patient representatives.

On a political level, addressing European Standards of Care for Newborn Health will stimulate a new debate that can help questioning existing structures, identify gaps and deficiencies, and advance national healthcare systems.



The project stands out, because it will promote 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. All this together will have a significant impact on the lives of these vulnerable patients, their families, and finally to the whole European society.



Background

Numbers and key facts on preterm birth

The need for European Standards of Care for Newborn Health

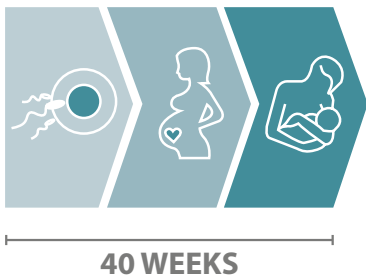
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4

Numbers and key facts on preterm birth

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. (2) Although survival rate for preterm infants is continuously improving thanks to advances made in medical science, preterm birth is a remaining challenge with different trends in Europe. While the preterm rate decreased between 2004 and 2010 in countries like Norway, Sweden, Germany, and Denmark, it increased in countries like the Czech Republic, Portugal, Ireland, and Italy, and remained on a steady level in several other countries. (2)

PRETERM BIRTH



A baby is born preterm, when it is born

before 37 weeks of gestation.

DEPENDING ON THE LENGTH OF PREGNANCY, IT IS DIFFERENTIATED:

extremely preterm:

less than 28 weeks of pregnancy

very preterm:

28 to 31 weeks of pregnancy

moderate to late preterm:

32 -37 weeks of pregnancy

1 baby in 10

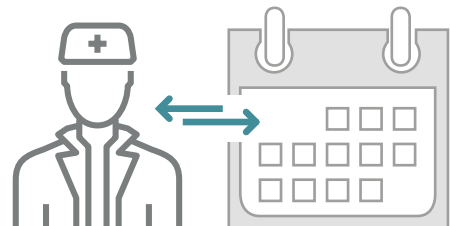


is affected by preterm birth

Prematurity can affect health throughout the whole life



REGULAR FOLLOW-UP ASSESSMENTS ARE IMPORTANT



Babies born preterm face higher risks of poorer long-term neurodevelopmental outcomes

e.g. cerebral palsy, visual and hearing impairments and mortality



PREMATURITY

is the main cause of death under 5 years

THE EARLIER a baby is born THE HIGHER is the risk for poorer long-term outcomes

not every

preterm born baby has a poor long-term outcome



Risks and possible causes for preterm birth (1)

Lifestyle factors	Medical conditions	Demographic factors
Smoking	Infections (urinary tract, vaginal)	Aged under 17, or over 35
Alcohol consumption	High blood pressure	Low socioeconomic status
Drug use	Diabetes	Ethnicity
High stress level & long working hours	Clotting disorders	
Late/no prenatal care	Underweight	
Lack of social support	Obesity	
	Multiple pregnancy	
	Women having experienced preterm birth before	
	Uterine or cervical abnormalities	

Several preconditions have been linked to increasing the risk of preterm birth. Nevertheless, in several cases no cause can be identified and not all preterm births can be attributed to known risk factors. (1)



More research into the unknown risk factors of preterm birth is needed

Potential consequences of preterm birth

Preterm birth can result in various long-term impairments regarding both the physical and mental development of the child. Yet, preterm birth also takes its toll on society, creating a financial burden on the affected families (3) and the healthcare system as such, since later morbidity poses significant economic costs in terms of health, education, and social care. (4)

Outcomes and long-term consequences of preterm birth (5)

Outcomes of preterm birth

- Physical disabilities, e.g. cerebral palsy
- Learning disabilities
- Behaviour problems
- Psychiatric disorders
- Respiratory diseases
- Cardiovascular diseases
- Visual diseases



Long-term consequences of preterm birth

- Reduced educational attainment
- Reduced earning potential
- Reduced social integration
- Poor adult health

In general, one can say the lower the gestational age at birth, the less developed the organs and therefore the higher the risk for long-term disability. (6) Additionally, although the use of evidence-based practices has been shown to improve survival without severe morbidities for very preterm babies, not every preterm baby in Europe receives evidence-based treatment. (8)



All around Europe, babies born preterm should have access to evidence-based care

Despite the increasing numbers of preterm births on a global level, what seems to constitute a general trend, there is a wide variation in the number of preterm births in European countries. Many countries maintained or even reduced rates of singleton preterm birth over the past 15 years, challenging the belief that rising rates of preterm births are the norm. (7)



More country specific research into socio-economic and socio-medical preconditions and structures is needed to eventually elaborate efficient preventive measures.

The need for European Standards of Care for Newborn Health



Current situation

The current state of the art in healthcare provided for preterm and ill babies throughout Europe today draws a very heterogeneous picture. 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 even worsened 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 inequality 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. (4,8) However, even though the discrepancies are known, an elaboration of a European comprehensive framework containing common definitions, rules, and procedures regarding the core areas of neonatal care has been missing, resulting in a greatly varying quality of maternal and newborn healthcare, depending a lot on the place of birth and the respective maternity unit, national or regional clinical practices, and health system structures.

Considering the high and growing prevalence of preterm birth in Europe and its 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, there is a compelling need to ensure an equitable provision of and access to high-level care.

Even though the disparities in health outcome and survival are known, an elaboration of a European comprehensive framework containing common definitions, rules, and procedures regarding the core areas of neonatal care remains unsettled.



Why standardised care

In daily clinical practice, standards ensure access to the best possible care for as many patients as possible since they direct decision-making and reflect best scientific evidence as well as practice experience. Consequently, due to the lack of standards and respective guidelines, care strongly depends on medical routines of single hospitals or healthcare professionals on duty. (9) Some of these are not even scientifically substantiated but have become unwritten rules within clinical routines.

Europe's variations in health outcome among preterm and ill babies can only be overcome by providing harmonised definitions and clear regulations for infrastructures, medical processes, care procedures, and capabilities of staff, as well as quality indicators, allowing to compare and adjust the conditions of care. (4,8)

“

All neonatal units caring for preterm and ill babies need standards to advocate for high quality newborn care across the world.

Prof Nicholas Embleton, Neonatologist, UK

”

Development and implementation of standards of care – a national issue

The European Union is a confederation of states with different responsibilities between European institutions and national governments. According to EU-law, health is a national issue, while the EU's role is to complement these national policies. (10,11)

Generally speaking, national expert panels, specialised bodies, or professional healthcare societies are responsible for the development of national guidelines on health and care.

On a cross-national level the respective European associations are in charge of guideline development, but there are still gaps in several medical areas such as neonatology. However, because of the differences of national health systems and structures, European-wide standards can always only serve as a reference for the development, adjustment, or update of national standards.

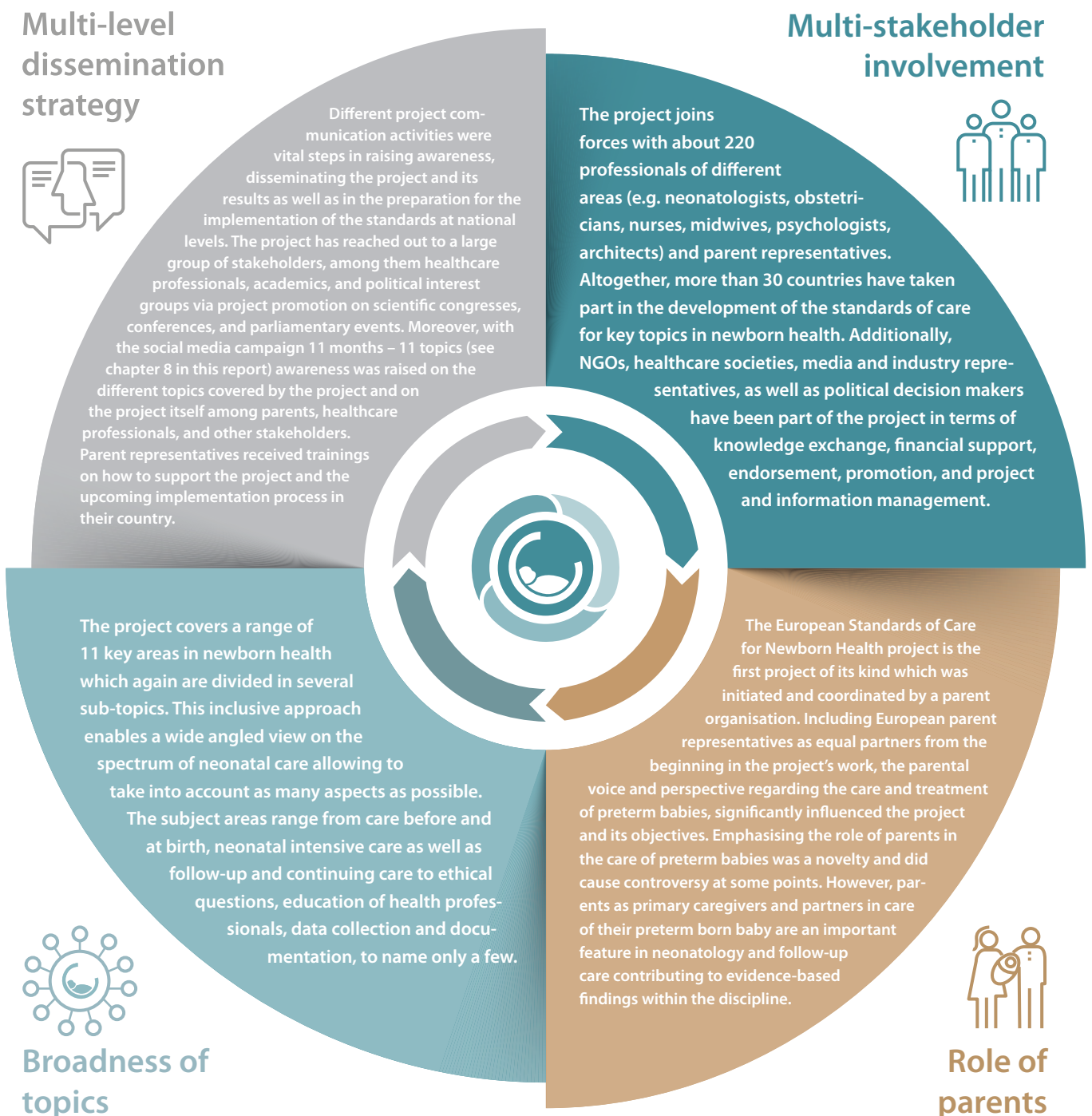


Project goals and objectives

The European Standards of Care for Newborn Health project aims to address the disparities in provision and quality of care existing in Europe by developing reference standards, which are basically covering the most important topics associated with preterm birth and neonatal morbidity. These European standards are intended to be used as a source for a national development of respective binding and implemented guidelines, protocols, or laws (depending on the local situation).

In the long run, the project's mission is to ensure equitable and high levels of care throughout Europe by facilitating and harmonising neonatal care and its neighbouring medical areas.

In order to achieve this, the project follows a systematic approach in terms of:





Origin and history of the project

5

Origin and history of the European Standards



Research and preparation phase

**2008/2009:
The Declaration of Rome**

In spring 2009, the Declaration of Rome, a catalogue of 10 demands for improving the treatment and care of preterm babies which had been formulated in 2008 by EFCNI and partnering parent organisations, is revealed and handed over to Professor Dr Angelika Niebler, Member of the European Parliament (MEP).

**2010:
Benchmark Report Too little, Too late –
Why Europe should do more for preterm infants**

The EU benchmarking report provides a compelling picture of the impact of preterm birth across 14 European countries and reveals a troubling lack of European-wide harmonised standards of care.

**2011:
Call to Action for Newborn Health**

In the 10 points Call to Action for Newborn Health the EU and national policy makers, payers, patient organisations, healthcare professionals, academics, industry, and the public are called upon to work in partnership to ensure the best start in life for every baby born in Europe. As one consequence of the call, the European Standards of Care for Newborn Health project was started.

**2011/2012:
Caring for Tomorrow – the EFCNI
White Paper on Maternal and Newborn
Health and Aftercare Services**

The paper gives recommendations on how to improve existing healthcare plans for maternal and newborn health which are feeding into the development of harmonised European Standards of Care for Newborn Health.

Raising awareness

Campaigns Socks for Life

Congresses

of Care for Newborn Health project

2014

2015

2016

2017



2014: Kick-off in the European Parliament

In April 2014, the project is officially started with a "Socks for Life" arts exhibition in the European Parliament. The visitors of the exhibition including the Vice President of the European Parliament symbolically sign a large poster together with 80 parent and healthcare organisations, to show their support for the development of the European Standards of Care for Newborn Health.

Development of the standards

Yearly Chair Committee Meetings

Starting in September 2014, the Chair Committee meets every year for several days to work on the methodology, publication and communication strategies, the working structure for the Topic Expert Groups and the role of the Chair Committee, to define the areas for which standards are needed, to develop a template to be used for drafting the standards, and to discuss on the implementation strategy.

2016: The project is named in the Editorial of the Lancet

In the Editorial of the Lancet on the unfinished agenda of preterm births the European Standards of Care for Newborn Health project is named in the context of improving survival and minimising long-term sequelae.

2015: Workshop at the EU Parliament

Under the lead of MEP Professor Dr Angelika Niebler and MEP Dr Peter Liese, a workshop is organised at the European Parliament being titled: "Maternal and Newborn Health – shaping Europe's future". In this workshop the European Standards of Care for Newborn Health as well as maternal health related topics are addressed and explained by healthcare professionals, representatives of the WHO, and patient representatives to members of the parliament.

Editing phase

2017: The project is selected as Landmark 2017 of Germany - Land of Ideas

This award honours the innovative character of the project, its translational approach that sets new benchmarks for the care of preterm and newborn infants Europe-wide.

Education and training



Parent workshops



Level I



Level II



EFCNI Academy for healthcare professionals



11 months - 11 topics



Co-organisation of jENS in Budapest



Co-organisation of jENS in Venice

2018

from 2019 on



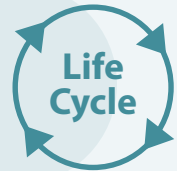
Voting

The whole Chair Committee is invited to vote on every single standard. A percentage of 80% is required, with the percentage representing the amount of "yes" votes among all "yes" and "no" votes. Abstentions are not included in these calculations. The response rate is 97%, and all standards pass the vote with a percentage of 93-100% "yes" votes!

Support

The standards together with the new Call to Action for Newborn Health in Europe are sent to European healthcare societies and parent organisations to ask for their support and endorsement respectively, as this will strengthen the standards as well as the Call to Action and assist their implementation.

Life cycle of the standards and extension of topics



2018: Launch and publication of European Standards of Care for Newborn Health project in Brussels

The project and its first 96 European Standards of Care for Newborn Health are launched at a parliamentary session in the European Parliament in Brussels. Together with the standards, a new Call to Action for Newborn Health is launched.

Implementation

Quality measurement



Level III



Level IV



Pilot: How to build up a human milk bank



Co-organisation of jENS in Maastricht





Developing process – teaming up for change

Project design and methodology

6

Project design and methodology

The European Standards of Care for Newborn Health project was initiated to minimise differences and to ensure quality in future neonatal care. The project design followed this principle in order to provide universal reference standards that can be adapted at a national level.



Challenges faced within the project

Challenges faced within the project	Approach to overcome the challenges
Bringing together diverse stakeholders (both locally and disciplinary)	<ul style="list-style-type: none"> • Creation of mutual understanding between countries as well as professions • Consideration of different mind-sets, cultural and historical backgrounds
Complexity of the wide range of topics in neonatal care	<ul style="list-style-type: none"> • Inclusion of the multi-professional team involved in neonatal care, and associated topics • Chair Committee agrees on, defines, and prioritises the standard topics • Division of newborn health into 11 overarching themes
Translating scientific evidence and medical practice into feasible, understandable standards	<ul style="list-style-type: none"> • Explanations of the need for the standard in the rationale • Development of one common template presenting the standards in one table, substantiated by references to scientific evidence • Structuring the standard template so that it clearly contains the target groups for the diverse standard components • Inclusion of grading of the evidence for every standard component
Taking country-specific differing legal regulations into account	<ul style="list-style-type: none"> • Involvement of parent representatives, parent organisations, healthcare experts, and healthcare societies from different countries and backgrounds • Development of European reference standards that need to be adapted to the respective national situations
Ensuring practicability of the standards in the European context by deciding level of standards (minimum versus current best practice standards)	<ul style="list-style-type: none"> • Differentiation between standard components, initial steps which are comprehensively applicable, and recommendations that leave room for further development



The project members

Project members involved in the development process of European reference standards included healthcare experts from obstetrics, neonatology, paediatrics, nursery, midwifery, and psychology, other experts like architects, and parent representatives. In total, about 220 experts, including 19 parent representatives, from more than 30 countries worked together on a voluntary basis. Industry partners supported the project financially. Their representatives could participate at the Chair Committee meetings as observers and were welcome to share their knowledge and expertise without exerting influence. Parent/patient organisations and academic and professional societies were invited to show their support for the development of the standards by endorsing the need for cross-country standards as well as the development of such standards and with this, the entire project, which was done by more than 80 organisations. The final set of standards was then also sent out for support. At the moment of printing this report, 108 healthcare professional societies and 50 parent organisations have declared their support for the developed standards. Further organisations are cordially invited to join the supporters.

Newborn health – divided into 11 overarching topics

In the European Standards of Care for Newborn Health project, 11 key areas (topics) of newborn health were identified. For each topic, issues for standardisation were selected. Standards start with the perinatal period* and continue until well after discharge into early childhood.



*The perinatal period commences at 22 completed weeks (154 days) of gestation and ends seven completed days after birth. (Perinatal and maternal health are closely linked.) Source: http://www.who.int/maternal_child_adolescent/topics/maternal/maternal_perinatal/en

The Topic Expert Groups

Each of the key areas (topics) was assigned to a Topic Expert Group (TEG), the project's thematic transdisciplinary working and writing groups that developed the respective standards connected to this topic. Every TEG consisted of several members (experts from different disciplines and parent representatives) and was led by a Chair Team. Overlapping topics of the different TEGs were elaborated in a personal meeting, where all Chairs presented the topics of their TEGs. These overlaps were addressed by cross referencing between the single standards.



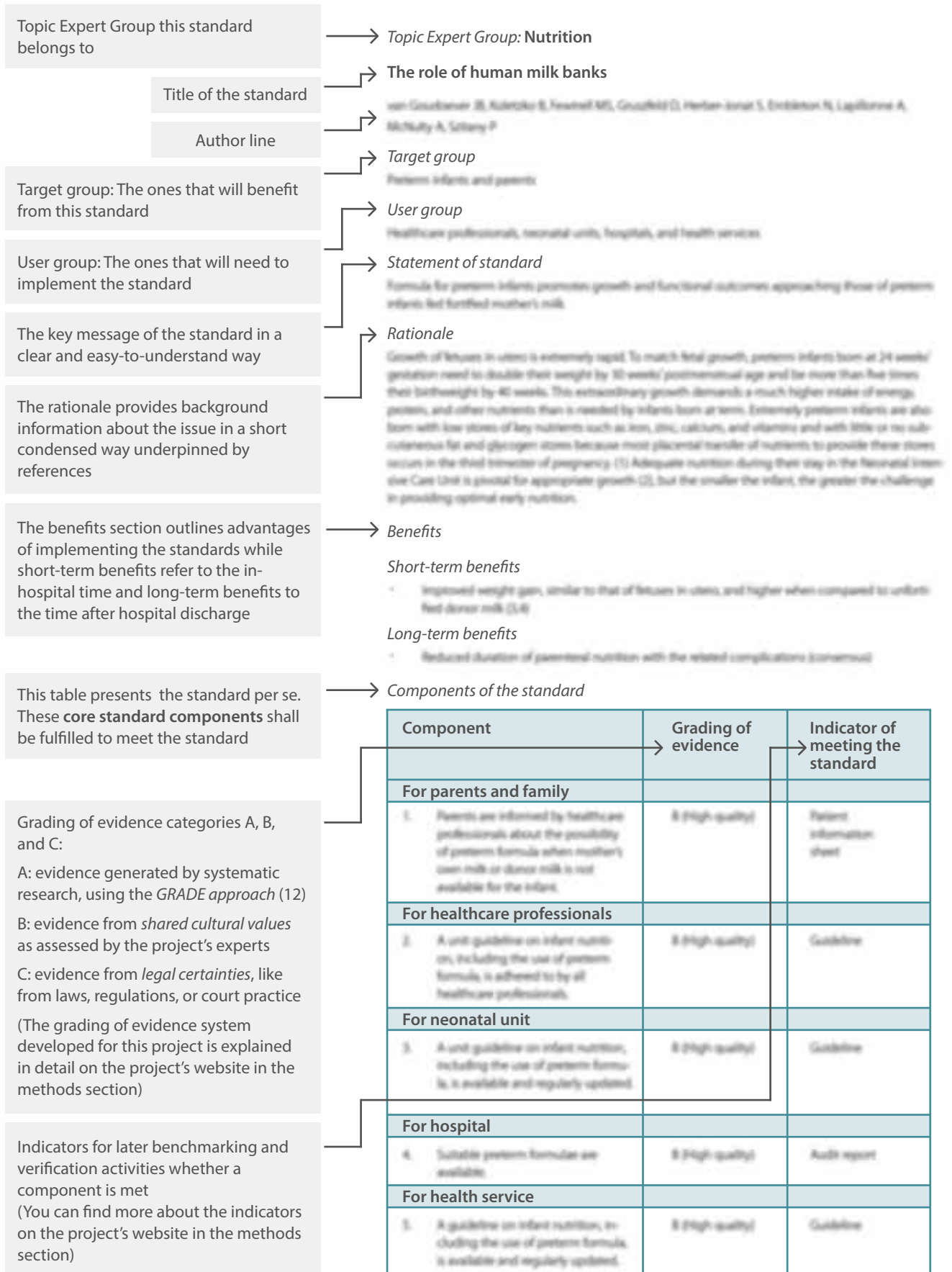
The Chair Committee

The central decision-making body of the project was formed by the Chair Committee. It consisted of 36 members: 25 Chairs of the different TEGs, eight members of the EFCNI's Parent Advisory Board, and the three Executive Board members of EFCNI. For important consultations, discussions, and decisions, the Chair Committee members met annually in personal meetings, the Chair Committee Meetings. Decisions that needed to be taken in between were discussed virtually and taken by online surveys. The Chair Committee steered the project, defined the project objectives, its design and methodology, developed the standard template, decided on the issues for standardisation and their prioritisation, recognised overlapping standards in the 11 broad topics, discussed and voted on the standards developed in the Topic Expert Groups, and paved the way for their implementation.



The standard template

To facilitate a harmonised format and structure of the standards, a specific template was created by the Chair Committee for the standard development process.





Where to go – further development of care

Further development	Grading of evidence
For parents and family	
• Parents are verbally informed by healthcare professionals.	⊕ (High quality)
For healthcare professionals	
• Develop and implement a guideline on infant nutrition.	⊕ (Low quality)
For neonatal unit	
• N/A.	⊕ (High quality)
For hospital	
• Develop and implement a guideline on infant nutrition, including	⊕ (High quality)
For health service	
• Support research on preterm formula to improve health.	⊕ (High quality)

If hospitals already meet all core components of the standard, this table provides additional aspirational targets for further development; these are not part of the standard per se

The standards of this project represent a high level of care. For those hospitals where the components or some of the components seem to be beyond the current levels of care, the table "Getting started" introduces initial steps that can be easily and immediately taken along a path towards meeting the components of the standard one day; these are not part of the standard per se

Getting started

Initial steps	
For parents and family	
• Parents are verbally informed by healthcare professionals about the possibility of	
For healthcare professionals	
• Attend training on infant nutrition, including the use of preterm formula.	
For neonatal unit	
• Develop and implement a guideline on infant nutrition, including the use of preterm.	
For hospital	
• Support healthcare professionals to participate in training on infant	
For health service	
• Develop and implement a guideline on infant nutrition, including the use of preterm.	

Additional information can be given in the "Description" section of the template

The "Source" section shows the scientific evidence behind the standard

All standards are first launched in November 2018. In case of revisions, the number of edition will increase, and the new release date will be displayed here

Description

Growth of tissues in utero is extremely rapid. To match fetal growth, preterm infants born at 24 weeks' gestation need to double their weight by 20 weeks' postmenstrual age and be more than five times their birthweight by 40 weeks.

Source

1. Agostoni C, Bernasconi G, Cavallaro G, Costa M, Demerouti E, Dini F, et al. Enteral Nutrition Supply for Preterm Infants. *Consensus Report from the European Society of Pediatric Gastroenterology, Hepatology and Nutrition Committee on Nutrition*. *Pediatr Gastroenterol Nutr*. 2015;60(2):126-40.

2. Day W, Henrick A, Cavallaro G, Fong C, Gifford M, Kulkarni S, et al. Postnatal growth in preterm infants and neonatal health outcomes: a systematic review. *Acta Paediatr Scand*. 1992; 2012;101(10):1274-80.

First edition, November 2018

Lifecycle

5 years/next revision: 2023

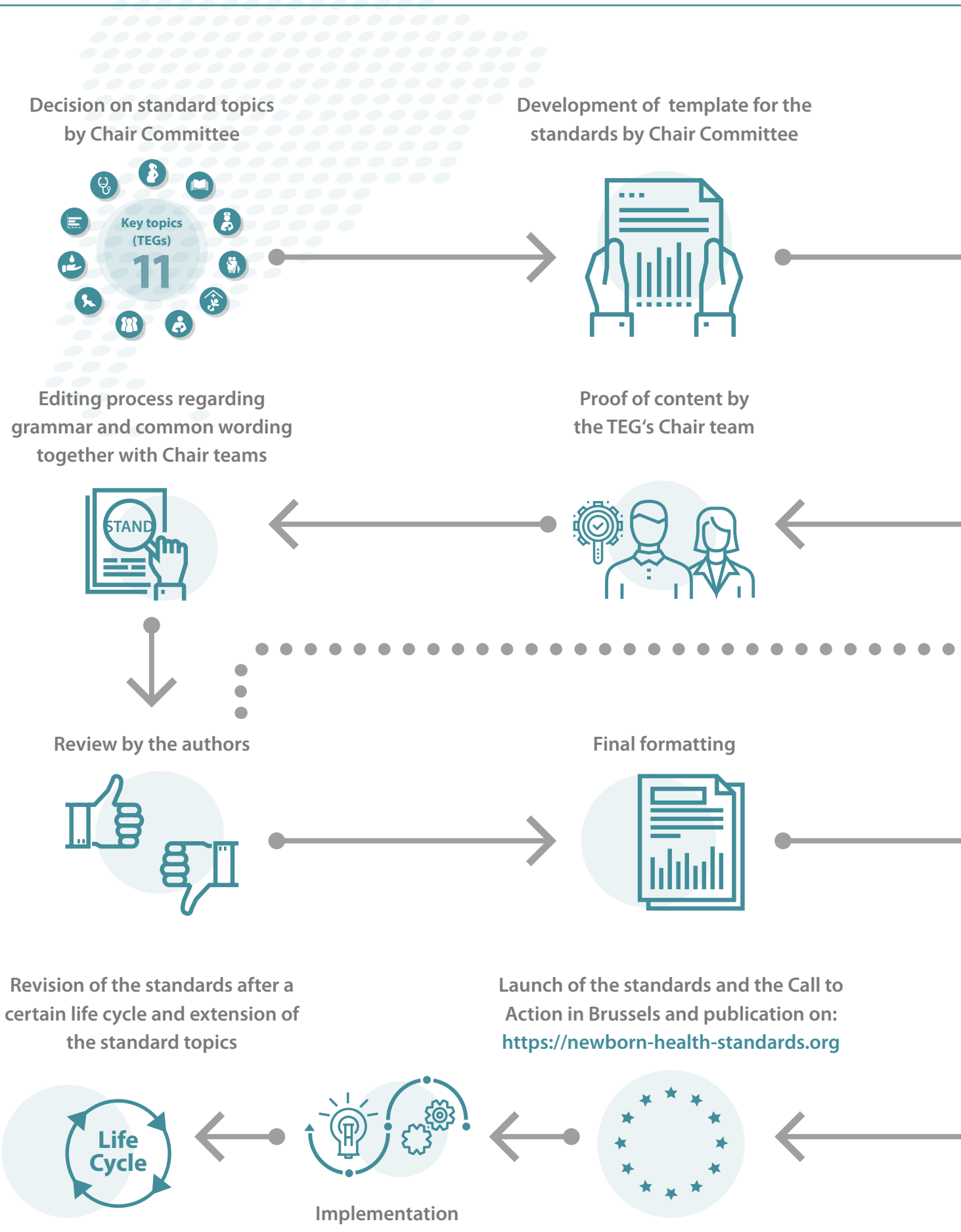
Recommended citation

ESPGAN, van Goudswaam JG, Kokkalis B, et al. European Standards of Care for Neonatal Health: The role of preterm formula. 2018

The standard will be considered for review latest at this time point. The lifecycle of each standard can be three, five, or ten years

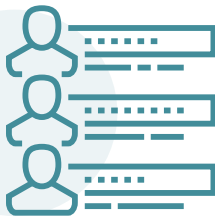
The recommended citation of each standard

Standard development process





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

80%



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



During the life-span of the project, 96 standards have been developed by about 220 experts from all over Europe. 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 planned life-cycle of the standards and extension of topics.



Results

The project in numbers

The 11 Topic Expert Groups

Call to Action for Newborn Health in Europe





THE PROJECT IN NUMBERS

Duration of the project / development of the standards 01/2013 – 12/2018 (72 months)



TOTAL
NUMBER OF
STANDARDS

96



Project
managers
at EFCNI

Number of
standards with
80% majority
(yes)



96



TRAFFIC ON THE
ESCNH HOMEPAGE

1.134
PER MONTH

108

NUMBER OF PROFESSIONAL
SOCIETIES / ASSOCIATIONS
WHO SUPPORT THE STANDARDS

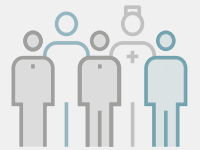
NUMBER OF PARENT
ORGANISATIONS WHO
SUPPORT THE STANDARDS

50



217 experts
involved (of
which 19
were
parents)

~220

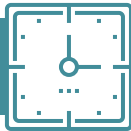


Number of factsheets
distributed

1640



Working hours



25.700 h*

Industry
partners

7

5

Chair Committee
Meetings



3

Editing Meetings



122

95

MEN / WOMEN



Have a look at the project website for more information about the background, methods, topics, and people involved. You will also find all project standards for download. Visit us at: www.newborn-health-standards.org

31
Countries involved

*this number is based on researches and estimates



The 11 Topic Expert Groups

Birth & transfer



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. 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



Prof Annette Bernloehr, Germany
Dr Morten Breindahl, Sweden
Prof Irene Cetin, Italy
Dr Maurizio Gente, Italy
Dr Štefan Grosek, Slovenia
Dr Gilles Jourdain, France
Prof Franz Kainer, Germany

Dr Andrew Leslie, UK
Livia Nagy Bonnard, Switzerland
Asta Radzeviciene, Lithuania
Dr Nandiran Ratnavel, UK
Prof Rainer Rossi, Germany
Prof Matthias Roth-Kleiner, Switzerland
Prof Gerard A.H. Visser, The Netherlands



*Dr Dietmar Schlembach,
Germany*



*Professor Umberto
Simeoni, Switzerland*

„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.”

Statements of the standards

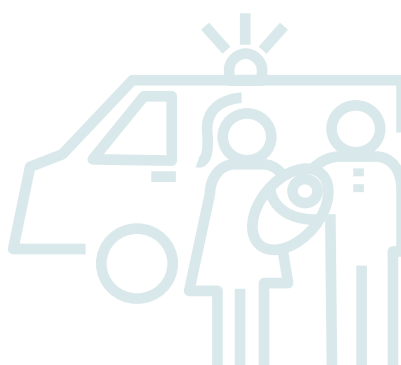
Infants are transferred by a dedicated, specialised medical service that offers a **quality** of care **similar to that promoted in a NICU**.

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.

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

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

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, standard on specific clinical procedure and techniques are developed.



Members of the TEG



Dr Kathryn Beardsall, UK
Prof Frank van Bel, The Netherlands
Dr James Boardman, UK
Dr Kajsa Bohlin, Sweden
Prof Maria Borszewska-Kornacka, Poland
Dr Jeroen Dudink, The Netherlands
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
Prof Egbert Herting, Germany
Prof Anton van Kaam, The Netherlands

Prof Claus Klingenberg, Norway
Prof Berthold Koletzko, Germany
Dr Rene Kornelisse, The Netherlands
Prof Boris Kramer, The Netherlands
Dr Gianluca Lista, Italy
Prof Rolf F. Maier, Germany
Dr Tuuli Metsvaht, Estonia
Prof Delphine Mitanchez, France
Dr Deirdre Murray, Ireland
Prof Eren Özek, Turkey
Dr Adelina Pellicer Martínez, Spain
Dr Serafina Perrone, Italy
Prof Christian F. Poets, Germany
Prof Heike Rabe, UK
Prof Irwin Reiss, The Netherlands

Prof Mario Rüdiger, Germany
Prof Elie Saliba, France
Prof Ola Didrik Saugstad, Norway
Prof Andreas Stahl, Germany
Dr Michael Steidl, Germany
Dr Martin Stocker, Switzerland
Dr David Sweet, UK
Prof Marianne Thoresen, UK
Prof Win Tin, UK
Dr Justyna Tołkoczko, Poland
Dr 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

Measures are taken to identify, prevent, and manage **hypoglycaemia** in newborn infants who are at risk for impaired metabolic adaptation, including those with 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.

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

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.

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

Bronchopulmonary Dysplasia (BPD) is prevented using evidence-based strategies including avoiding mechanical ventilation, minimally invasive administration of **exogenous surfactant**, **volume targeted ventilation** and **early caffeine**, and administration of systemic steroids in infants still requiring ventilation during their 2nd postnatal week.

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 well as long-term follow-up of neuro-motor function as required.

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



Care procedures

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
Monica Ceccatelli, Italy
Dorottya Gross, Hungary
Ingrid Hanks-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

Chairs of the TEG



*Monique Oude Reimer-van Kilsdonk,
The Netherlands*



*Odile Frauenfelder,
The Netherlands*

„The involvement of parents and families is not the same in every European country. Changing daily care at the bedside needs good management in a broad perspective - not only for caregivers but also in management at a community and national level. We wish that organisations such as governments, hospital managers and caregivers will invest more in the provision of high-quality care procedures and constantly promote the implementation of standards. High-quality care goes along with the involvement of parents. Therefore, healthcare professionals ought to regard parents as an essential part of the team”

Statements of the standards

The process of **taking blood samples** is carried out using optimal comfort strategies to **minimise stress and pain** using an individualised supportive technique.

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**.

Infants are **exclusively fed with human milk** during their hospital stay and mothers are supported to **exclusively breastfeed 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

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 Bertonecchi, Italy
Dr Nils Bergman, Sweden
Prof Zack Boukydis, Hungary (†)
Sylvia Caballero, Spain
Dr 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
Dr Carmen Pallás Alonso, Spain
Dr Milica Rankovic-Janevski, Serbia
Prof Jacques Sizun, France
Dr Kari Slinning, Norway
Dr Inga Warren, UK



*Dr Björn Westrup,
Sweden*



*Professor Pierre Kuhn,
France*

„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 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.”

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

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



*Dr Atle Moen,
Norway*



*Dr Boubou Hallberg,
Sweden*

„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.“

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

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

Dr Susanne Herber-Jonat, Germany
Prof Alexandre Lapillonne, France
Alison McNulty, UK
Dr Peter Sztanyi, Czech Republic



*Professor Berthold Koletzko,
Germany*



*Professor Mary Fewtrell,
UK*

„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.”

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.

Parenteral nutrition is commenced on the **first day after birth**, usually using standard solutions, and continued until sufficient enteral feeding is established.

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.

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

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

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

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

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

Mothers are **encouraged and supported to provide their own breast milk** for their infant.





Ethical decision making & palliative care

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
Dr Marina Cuttini, Italy
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



*Professor Jos Latour,
UK*



*Professor Gorm Greisen,
Denmark*

„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.“

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

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
Dr Christiaan Geldof, The Netherlands
Prof Mijna Hadders-Algra, The Netherlands
Prof Christoph Härtel, Germany
Prof Egbert Herting, Germany
Dr Bregje Houtzager, The Netherlands
Dr Britta Hüning, Germany
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 Els Ortibus, Belgium
Dr Anne-Marie Oudesluys-Murphy, The Netherlands
Dr Vilhelmiina Parikka, Finland
Dr Veronique Pierrat, France

Dr Federico Prefumo, Italy
Prof Alessandra Sansavini, Italy
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
Dr Brigitte Vollmer, UK
Dr Marie-Jeanne Wolf-Vereecken, The Netherlands

"Future follow-up should have a stronger focus on the multiple factors playing a role in academic achievement of premature 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*



*Dr Aleid van
Wassenauer-Leemhuis,
The Netherlands*

Statements of the standards

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

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

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

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

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

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

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

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.

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.

Mothers of infants born very preterm or 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.

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 paid to **visual information processing dysfunctions**.

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.

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





Patient safety & hygiene practice

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
Dr Eric Giannoni, Switzerland

Prof Christoph Härtel, Germany
Dr Jan Janota, Czech Republic
Dr Ulrik Lausten-Thomsen, France
Dr Nolwenn Le Saché, France
Silke Mader, Germany
Dr Paolo Manzoni, Italy
Dr Josep Perapoch, Spain
Prof Christian F. Poets, Germany

Roland van Rens, The Netherlands
Prof Rainer Rossi, Germany
Dr Heleen van der Sijs, The Netherlands
Dr Cynthia van der Starre, The Netherlands
Nicole Thiele, Germany
Dr Tobias Trips, Germany
Lucie Žáčková, Czech Republic



*Professor Pierre Tissières,
France*



*Dr Onno Helder,
The Netherlands*

„For too long hygiene in treatment and care had been neglected. Measures in this regard have made significant and tremendous improvements reducing infections in newborns and preterms, resulting in better long-term outcomes. By continuously improving safety in the units and a responsible work approach we can create a safer environment for preterm infants.“

Statements of the standards

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.

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.

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

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

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

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

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.

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

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

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

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





Data collection & documentation

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



Prof Mika Gissler, Finland
Prof Wolfgang Göpel, Germany
Prof Dominique Haumont, Belgium
Dr Ashna Hindori-Mohangoo, The Netherlands
Vilni Verner Holst Bloch, Norway
Prof Helmut Hummler, Germany

Dr Begoña Loureiro Gonzalez, Spain
Dr Miklós Szabó, Hungary
Dr Liis Toome, Estonia
Dr Eleni Vavouraki, Greece
Dr Jennifer Zeitlin, France



*Professor Gérard Bréart,
France*



*Dr Nicholas Lack,
Germany*

"Parents' concerns in data collection and documentation are typically overlooked. There should be more data reflecting parents' demands and expectations. 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. Hence, it is important to 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."

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.





Education & training of the multidisciplinary team working in neonatology

The Topic Expert Group on Education and training of the multidisciplinary 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
Marni Panas, Canada
Dr Julia Petty, UK
Dr Mirjam Schuler Barazzoni, Switzerland

Nataschia Simeone, Italy
Dr Dalia Stoniene, Lithuania
Dr Inge Tency, Belgium
Nicole Thiele, Germany
Dr Inga Warren, UK

„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 Charles C. Roehr,
UK/Germany*



*Dr Agnes van den Hoogen,
The Netherlands*



*Dr Morten Breindahl,
Sweden*

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 **inter-professional education** that enhances the delivery of practice in the care of infants and their families.



Call to Action for Newborn Health in Europe

The *UN Convention on the Rights of the Child* has been ratified by 196 countries and proclaims that "the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth". Article 6 affirms every child has the right to life, survival, and development. Furthermore, children have a right to be cared for by their parents and should not be separated from them, as far as possible (Articles 7 and 9). However, upholding the Rights of the Child in reality remains a major challenge.

The *European Standards of Care for Newborn Health* help support these rights from the beginning of life by serving as a reference for the development and implementation of binding standards and guidelines on a national and international level. **European and national policy makers, hospital administrators, insurers, professional and patient associations, and industry** should work together to bring the standards into practice and to ensure quality, equity, and dignity for the smallest.

Therefore, we call for action to:



Identify women at risk for preterm birth early and avoid transfers that result in increased morbidity and mortality and the separation of mother and baby by providing treatment in specialised perinatal centres where maternal and newborn care are located together.



Commit to evidence-based healthcare by providing modern health technology and an adequate number of staff. Easily comprehensible information for parents on treatment and care procedures needs to be available all times.



Provide sufficient specialist staff, particularly nurses and midwives, to ensure optimal care for babies.



Support parents of newborn babies in their role as primary caregivers from admission to hospital, promote infant- and family-centred developmental care and ensure parents 24-hour access to their baby.



Follow guidelines and recommendations on clinical environment and interior design to reduce stressful events for the vulnerable baby and provide facilities for parents and families that are sensitive to their needs and allow privacy with their baby.



Make adequate resources available to support optimal nutritional care that meets the baby's individual needs from the first day of life. Mother's own milk should always be the first choice and breastfeeding needs to be supported.



Promote shared decision-making between healthcare professionals and parents in ethically challenging situations. This includes providing psycho-social support for both, parents and healthcare professionals throughout the process.



Support coordinated, specialised, and effective follow-up and continuing care services for babies and children at risk for later developmental difficulties, as well as for their families. This provides targeted and evidence-based preventive measures to optimise child health and development as an important basis for the health and well-being of the whole family.



Ensure patient safety and adherence to hygiene practices by providing evidence-based information, equipment, and training for staff, parents, and visitors. **This includes creating a blame-free error-reporting culture** to improve healthcare quality and prevent adverse effects of care and treatment procedures.



Define and provide national and European-wide comparable datasets on pregnancy, birth, maternal, newborn, and child healthcare from conception into adulthood.



Ensure continuous education and training for all healthcare professionals working in maternal and newborn healthcare, including regularly updated curricula and training in sensitive communication and open interaction with parents.



Establish national frameworks for strategies to minimise risks before, during, and after birth.



Define indicators for long-term health and developmental outcomes and create quality measurement tools to allow benchmarking within and between hospitals and countries.



Support research into maternal and newborn health, develop and implement clinical guidelines and protocols to ensure evidence-based care, reduce mortality and morbidity, and improve quality of life.



Project communication

Goals and target group

Features of the project communication

Two campaigns accompanying the project

Live communication



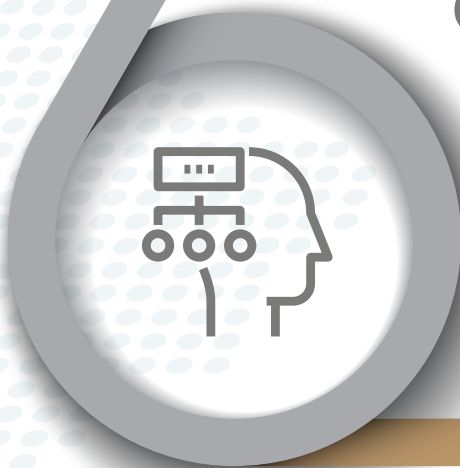
Goals and target group

A project's communication strategy contributes to its awareness and dissemination. Additionally, it is a tool to gain support and to inform all stakeholders about its goals and the current status of the project. Yet communication goes beyond information - offering the option for dialogue in order to reduce possible reservations and oppositions which might occur within the working process. EFCNI's understanding of communication does also imply to educate, motivate, and inspire project partners, supporters, and other interested third parties.

Information

All parties involved need to be exhaustively informed about objectives and strategies, the current working progress, results, decisions, and developments.

Main objectives



Coordination

Focusing and canalising all activities on the one common goal, developing, launching, and endorsing the standards project, is key.



Motivation

Whilst reservations are reduced, communication strategies shall enforce commitment, loyalty, and identification with the project leading to action in the individual countries.



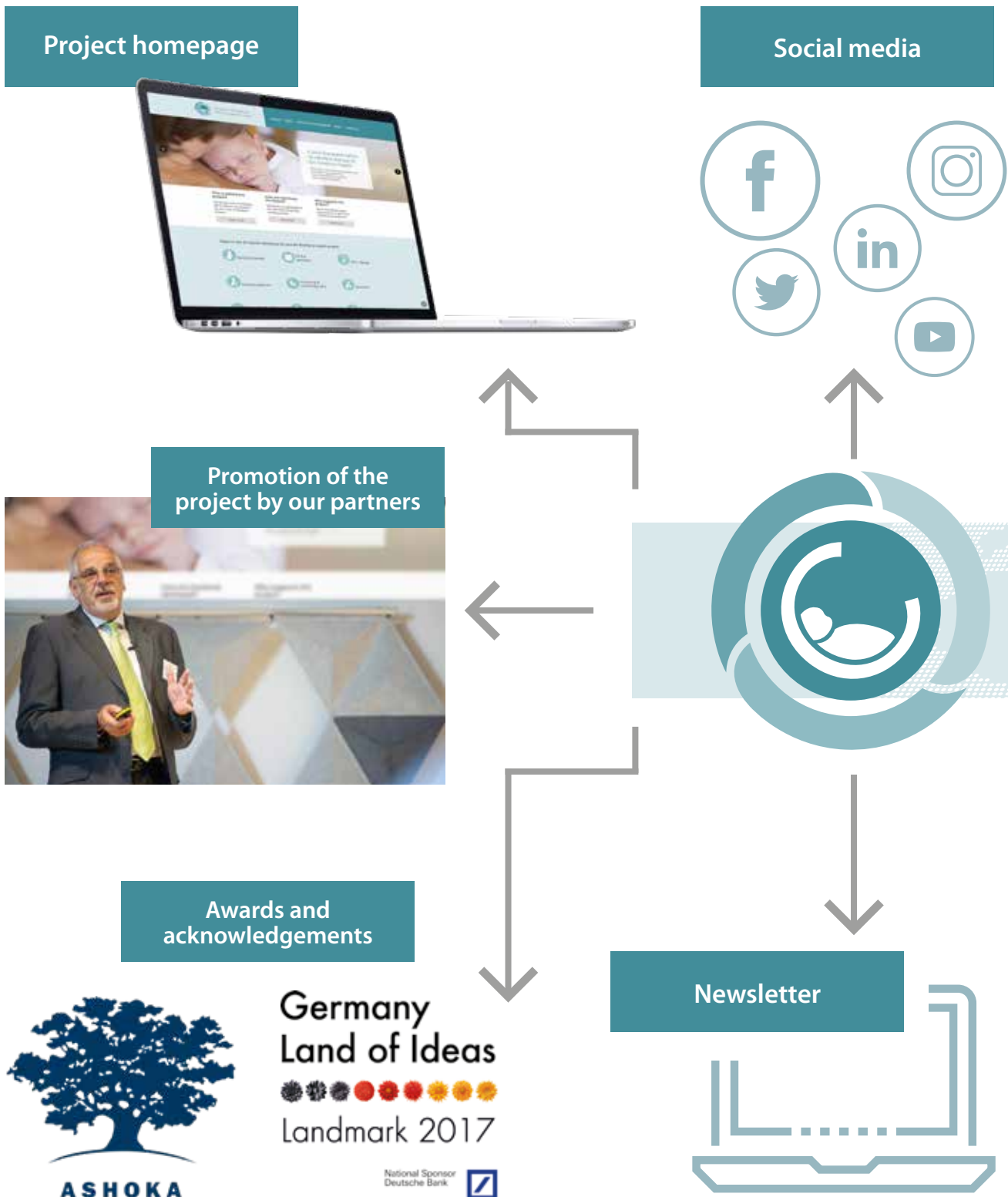
Target Group



Healthcare professionals, parent and patient organisations, affected parents, interested public, media, third parties (like NGOs and expert societies), politicians, payers as well as other relevant stakeholders in industry, science, and society

Features of the project communication

A **multichannel approach** is followed within the communication strategy in order to reach a large target group and to link all forms of communication and messages about the project together. This includes website content, news about regular updates on the project, interviews, background features, videos, factsheets, and promotional materials both online and in print media, talks at scientific conferences and congresses, as well as political events.





Presentation of the project at numerous events and congresses



Print materials



Communication tools

Image video



Political events



Two campaigns accompanying the project

Socks for Life

The international Socks for Life campaign was initiated as awareness campaign in 2013 with the aim of reaching the general public. In the campaign, the socks line with nine normally sized baby socks next to one tiny pair stand metaphorically for the 1 baby in 10 that is born preterm, showing how small and fragile this newborn is compared to the term born peers. Once the awareness was raised to the needs of the babies who wear the tiny pair of socks, the Socks for Life campaign was developed further to show the necessity for standards in newborn care. In 2015, at the 1st joint Congress of European Neonatal Societies (jENS) in Budapest, Hungary, giant posters spread around the whole exhibition area together with small booklets visualised 11 demands to healthcare professionals and made them visible to all congress visitors. In April 2014, at the kick-off event for the European Standards of Care for Newborn Health project, the Socks for Life exhibition was presented in the European Parliament, and a banner was signed by all visitors to the exhibition, committing their support for the development of standards in newborn care.





11 Months - 11 Topics



With the campaign "11 Months - 11 Topics", launched in 2016, EFCNI's social media and online communication focuses from February to December on one newborn health standard topic. They correspond to the subjects of the eleven Topic Expert Groups of the European Standards of Care for Newborn Health project. Every month, the work of the different Topic Expert Groups and the corresponding standard topics is explained by sharing related publications, news, interviews or guest articles. The intention of "11 Months - 11 Topics" is to reach out explicitly to health professionals and policy makers, but also to lay persons who are to benefit from the dissemination of the standards in the long run, namely the preterm babies and their parents, relatives, and friends. With this campaign, extensive information and best practice examples are shared in order to raise awareness of the need for standards.

Every year there were different repetitive components, which were supplemented by up-to-date information, e.g. research articles. Exemplary, it is shown how the month May, featuring NICU design, changed its look and feel during the three years the campaign has been running so far:



Live communication

Events as part of the campaigns

The project has been actively promoted and introduced to a wide public on several occasions. Over the years, the project was continually promoted by EFCNI on national and international conferences and congresses e.g. at the jENS congress of which EFCNI is since 2015 one of the co-organisers, at the annual Parent Organisations Meetings, as well as to industry partners and medical experts on meetings, or in workshops and trainings.

Since the project's kick-off, several political events have taken place on a European and national level, which helped to put the topic newborn health on the political agenda and emphasised the need for harmonised European Standards of Care for Newborn Health.





Awards

Ashoka Fellowship

Selected Landmark 2017 of Germany – Land of Ideas

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In 2015, EFCNI's Chairwoman Silke Mader was publicly recognised by Ashoka, an international non-profit organisation and network that promotes social entrepreneurship by affiliating individual social entrepreneurs into the Ashoka organisation. For more than 30 years and in more than 80 countries, Ashoka has been supporting pioneers who solve societal problems with innovative approaches. Honouring Silke Mader's merits within EFCNI and as a driving force of socially impactful visionary projects, Silke Mader became an Ashoka Fellow in 2015, with the goal of pushing the European Standards of Care for Newborn Health project forward. She received this most valuable promotion for social entrepreneurs in a festive ceremony in the presence of the Nobel Peace Prize winner Kailash Satyarthi, himself an Ashoka Fellow.

The selection committee explained their decision by Silke Mader's untiring commitment in giving the most vulnerable patients and their families a voice and working towards structural change in the care of newborn babies, especially in the European Standards of Care for Newborn Health project. The jury highlighted her endeavour to sensitise organisations, institutions, and other stakeholders in this health field for the importance of standards and to raise public awareness for standards in newborn care in the European institutions and national policy makers. The jury also praised Silke Mader's efforts in building a network and bringing key stakeholders together in this project.

Ashoka continues to support Silke Mader and EFCNI through their worldwide, vast like-minded support network for social visionaries and pro bono strategic coaching and consulting services. Effectively, being part of this prestigious fellowship benefits the European Standards of Care for Newborn Health project.

Selected Landmark 2017 of Germany – Land of Ideas

Germany Land of Ideas Landmark 2017



National Sponsor
Deutsche Bank



In 2017, the innovative character of the project was honoured by an award that further increased the public visibility and media attention for the upcoming standards. The European Standards of Care for Newborn Health project was one of the awardees in the competition “Landmarks 2017 in the Land of Ideas” by the initiative “Germany – Land of Ideas”.

Founded by the German federal government and the Federation of German Industries (BDI) in

2005, with the aim of making Germany visible and identifiable domestically and internationally as a powerful innovator and creative force, the joint initiative holds a yearly “contest of ideas” which offers creative minds from all over Germany a stage for their innovative projects. The selection committee praised the project’s translational approach that sets new benchmarks for the care of preterm and newborn infants, improving Europe-wide children’s chances for a better future and subsequently reducing tangible and intangible costs for individuals and society. The fact that for the first time, patients initiated the development of standards and were involved in absolutely every step of the process was emphasised. Following the official award ceremony in Berlin, EFCNI was invited to the Bavarian State Chancellery, where the Minister of State Dr Marcel Huber highlighted the European Standards of Care for Newborn Health project. The award demonstrated that the project itself was highly recognised on a political level.





Training of parent representatives



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Training of parent representatives

Over the last years, the European parent organisations have become influential stakeholders in the area of newborn care. In order to let the parents become ambassadors for the project, it requires training and detailed information on the project, its background, its aims, the need for standards, and of course also on the standards themselves. This enables them to promote the standards and support national stakeholders (e.g. healthcare professionals, hospital directors, insurance companies, policy makers, and third parties) to use these standards as reference for creating national binding guidelines, thus implementing them into real life practice in each hospital nationwide.





Since 2016, EFCNI has invited parent representatives to the EFCNI office to train them in terms of advocacy and policy for the European Standards of Care for Newborn Health project, and will continue these trainings for the coming years.



2019 and beyond

Level IV workshop:

- Sharing best practice examples on activities to implement standards
- How to use the toolkit for promoting and supporting the implementation of the standards

European wide implementation of the standards



4



Next steps – the EFCNI implementation strategy

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Next steps – the EFCNI implementation strategy



With the launch of the standards in Brussels in November 2018, the project is not finished but continues with the implementation process. In the upcoming years, EFCNI will support healthcare professional societies, parent organisations, individual institutions, and organisations in bringing the standards into practice in Europe and hopefully in the future even beyond.

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.



EFCNI is fully aware of the fact that the implementation of the newly developed standards will be a lengthy and exhausting process, but it will be worth it, as it will help to save millions of babies all around Europe and let them thrive! Therefore, we hope that in the future 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.

Let them
thrive!





Epilogue

A large, bold, white number '12' is centered on a teal background. The background features a halftone dot pattern of small, light blue circles that is denser on the left side and fades towards the right. A thin white horizontal line is positioned above the number, and another thin white horizontal line is positioned below the number.

12

Epilogue

Over the past 40 years neonatal care has been transformed. Neonatal mortality has tumbled from 20 to 2 per thousand livebirths. There has been an explosion in research and understanding of the problems of transition after birth, the diseases that affect newborn infants, the potential harm posed by some well-meant interventions, and, most importantly, the critical importance of parents in ensuring the very best outcomes; all have led a revolution both in how care is delivered and in the humanity of the clinical service. From being a discipline primarily focused on saving lives after birth, neonatology today should be part of an integrated care pathway from fetal life to childhood, involving multiple disciplines and relishing its role in supporting parenthood as the primary influence on the infant. Gone should be the restrictions placed on parental and family visiting, paternalistic attitudes and opaque management plans. In should be inclusivity and transparency. Neonatology is a major modern medical advance in which success lasts a lifetime.

All neonatal services struggle to keep up with the rapid pace of medical advance to ensure they deliver high quality, evidence-based and up-to-date care. For many services it is a major challenge to integrate the information explosion of research and opinion. The European Standards of Care for Newborn Health are designed to reduce this load by providing recommended standards across most areas of care, agreed by experts and, importantly, initiated and endorsed by parents. Aware of the need to engage health systems at all levels, the standards include recommendations for hospitals and health services, who may not be aware of the level of evidence or need to support neonatal services to minimise mortality and optimise outcomes. Care should always be focused on outcomes.

Why do we need such standards? There is much variation in measures of care and outcomes between European countries, within countries themselves and between similar hospitals. Some of this will be due to environmental and social influences, but a very significant proportion will be down to our care. The European Standards of Care for Newborn Health are a call to action for all members of society to focus on ensuring that each birth receives the best care and attention possible, and that policy and resources are found to maintain this progress, for sick and premature infants in particular. We must deliver a healthy future for all births.

How should we use the resources in these standards? Developing a neonatal service is a continual challenge. For that reason, alongside the key components for each standard, we have suggested where the process may be started at each level of the health system.



The simple act of developing information for parents focuses the mind on how a service component will be introduced and monitored. At first this seems an impossible task, and the thought of a huge textbook about what can happen in a neonatal admission seems unnecessary and overly correct, but the provision of a resource where parents can find information about what to expect from their care is a critical step in service improvement, transparency, and safety. It also allows parents to develop confidence in their neonatal team. The standards also tell us what we should aspire to in the very best services we deliver.

We would wish that parents and neonatal teams work together to use the standards as a framework for quality assurance across Europe and that individual national professional groups adopt them as measures of excellent care. The views of experts and evidence underpinning our care and practice change over time. The standards are not a textbook but a live series of recommendations that will be developed and added to as time goes on. We hope that EFCNI can continue to nurture and develop the elements of each standard so that as practice changes, the recommendations are as up-to-date as possible, including review within 3-5 years or more frequently. Translating evidence into practice provides the best care.

What is the next step? The state of European neonatal care at present is only really reflected in mortality; no other common measures are used to determine how well we are doing. Although critically important, mortality has reduced dramatically and other outcomes, affecting respiratory, neurological, and other body systems, have assumed greater importance. Using a single indicator is therefore not useful. I would like to see the next piece of work take the standards and develop from them important service outcome indicators that we may use to benchmark our care. Publishing these benchmarks widely is an important step in understanding the factors that lead to variation and uncertainty, and reducing the anxiety that all parents face following a birth, particularly if their infant is sick or premature. The European Standards of Care for Newborn Health are an important step in the right direction.



Professor Neil Marlow
*Member of the EFCNI Executive Board
and member of the editorial team of the European
Standards of Care for Newborn Health project*



Acknowledgement



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The Chair Committee





Birth & transfer

Chair Team



Dr Dietmar Schlembach, Germany

Dietmar Schlembach (MD) is an expert in Maternal-Fetal Medicine and Obstetrics. Since May 2014, he is Head of the Department of Obstetrics and Gynecology at Vivantes Clinic Berlin-Neukölln, Department of Obstetrics and Gynecology.

He addresses the specific problems and treatment of pregnancy complications (such as hypertensive disorders and intrauterine growth restriction) as well as prenatal diagnosis and therapy. His clinical and research focus is screening, diagnosis and treatment of hypertensive disorders and intrauterine growth restriction, preterm birth and prenatal diagnosis and therapy of fetal abnormalities.

He is currently board member of the German Society of Gynecology and Obstetrics and secretary of the Working Group Obstetrics and Prenatal Medicine of the German Society of Obstetrics and Gynecology. He's also secretary of the German Society of Prenatal- and Obstetric Medicine. Since 2015, he is Chairman of the Trustee Board of EFCNI.



Professor Umberto Simeoni, Switzerland

Umberto Simeoni is Professor of Paediatrics at Faculté de Biologie et de Médecine, University of Lausanne and Director of the Division of Pediatrics and of the Developmental Origins of Health and Disease (DOHaD) Research Unit at CHUV University Hospital in Lausanne Switzerland.

His research is oriented towards the Developmental Origins of Health and Disease (DOHaD), with a special focus on the developmental programming of the cardio-vascular system in conditions of perinatal disease, such as intrauterine growth-restriction, preterm birth or exposure to maternal overweight/obesity and gestational diabetes. He also is highly interested in perinatal bioethics.

He authored and co-authored more than 200 referenced articles, several books on neonatology, and more than 300 invited lectures. Umberto Simeoni is Past-President of the European Association of Perinatal Medicine and of the Société Francophone DOHaD. He also is a member of the Scientific Advisory Board of EFCNI.



EFCNI Parent Advisory Board member



Livia Nagy Bonnard, Switzerland

Livia Nagy has been one of the founding members of the Hungarian association Melletted a helyem Egyesület (Right(s) beside you). The association brings together doctors, medical professionals, policy makers, NGOs and the parents of preterm children in order to improve the quality of care. She deals mainly with parental support, especially giving advice to parents who have special needs children.

Her work has been involved in different forums for parents of special needs children from 2006 onward. Though born in Hungary, she now lives on the French Swiss border, so she has a deep insight into the NICU system in Hungary, France and Switzerland. She is a mother of 4 children, 3 girls, and a premie boy who was born at gestational week 27 and who suffered from PVL. Livia is a trained nurse, she worked mostly with babies and children in cardiac departments and a CICU (cardiac intensive care unit).

Livia Nagy Bonnard is a member of the Parent Advisory Board of EFCNI.

Topic Expert Group members

Professor Annette Bernloehr, Germany

Dr Morten Breindahl, Sweden

Professor Irene Cetin, Italy

Dr Maurizio Gente, Italy

Dr Štefan Grosek, Slovenia

Dr Gilles Jourdain, France

Professor Franz Kainer, Germany

Dr Andrew Leslie, UK

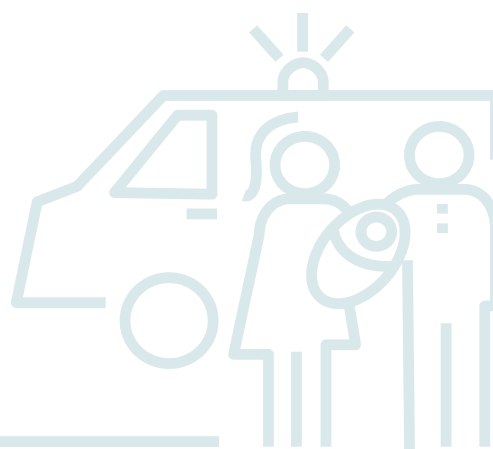
Asta Radzeviciene, Lithuania

Dr Nandiran Ratnavel, UK

Professor Rainer Rossi, Germany

Professor Matthias Roth-Kleiner, Switzerland

Professor Gerard A.H. Visser, The Netherlands





Medical care & clinical practice

Chair Team



Professor Luc J.I. Zimmermann, The Netherlands

Luc J.I. Zimmermann is Professor of Paediatrics and Neonatology at the Faculty of Health, Medicine & Life Sciences at Maastricht University since 2003. He also is a staff neonatologist and since 2005 Chief of the Division of Neonatology at the Academic Hospital Maastricht.

From an early stage in his professional career he developed a distinct research interest on the development of the preterm lung, on which he did his PhD and continued his further research.

In 2006 he became Chairman of the Department of Paediatrics and Division Leader in the Research Institute GROW (Oncology and Developmental Biology). He is past president of the European Society of Paediatric Research (ESPR). Since 2017, he is a member of the Trustee Board of EFCNI.



Professor Giuseppe Buonocore, Italy

Giuseppe Buonocore, MD, is professor of Paediatrics, Director of the Unit of Paediatric Neonatology and Chairman of Paediatrics and Neonatology at the School of Specialisation in Paediatrics of the University of Siena.

He is author of more than 200 scientific publications in international journals with IF and Co-Editor of the well known textbook "NEONATOLOGY: A Practical Approach to Neonatal Diseases", Springer-Verlag Publisher. The focus of his research lies in the mechanisms of neonatal brain injury, the role of free radicals in neonatal diseases and in birth asphyxia. He is also interested in ethics in perinatology and in foetal and neonatal pain prevention.

Besides being a member of the EFCNI Scientific Advisory Board, he is President of the Italian Academy of Paediatrics, College of University Professors of Paediatric (IAP-COPED). He is former President of the European Society for Paediatric Research (ESPR), as well as of the Union of European Neonatal and Perinatal Societies (UENPS), and currently honour Member of Ibero-American Society of Neonatology (SIBEN).



Professor Lena Hellström-Westas, Sweden

Lena Hellström-Westas, MD, PhD, is Professor of Perinatal Medicine at Uppsala University, Sweden and Senior Consultant in Neonatology at the Department of Neonatology at the Uppsala University Hospital. She is medical Co-Director at the Karolinska NIDCAP center and scientific advisor in neonatology to the Swedish National Board of Health and Welfare.

Her research on amplitude-integrated EEG monitoring started with a focus on early prediction of outcome in asphyxiated infants and preterm infants. Additionally, her research interests include seizure detection, sleep and pain assessments.

She is also a member of the Swedish Neonatal Society and the European Society for Pediatric Research and a member of EFCNI's Scientific Advisory Board.

Topic Expert Group members

Dr Kathryn Beardsall, UK

Professor Frank van Bel, The Netherlands

Dr James Boardman, UK

Dr Kajsa Bohlin, Sweden

Professor Maria Borszewska-Kornacka, Poland

Dr Jeroen Dudink, The Netherlands

Professor Mary Fewtrell, UK

Professor Andreas Flemmer, Germany

Professor Anne Greenough, UK

Professor Pierre Gressens, France

Professor Mikko Hallman, Finland

Dr Anna-Lena Hård, Sweden

Professor Ann Hellström, Sweden

Professor Egbert Herting, Germany

Professor Anton van Kaam, The Netherlands

Professor Claus Klingenberg, Norway

Professor Berthold Koletzko, Germany

Dr Rene Kornelisse, The Netherlands

Professor Boris Kramer, The Netherlands

Dr Gianluca Lista, Italy

Professor Rolf F. Maier, Germany

Dr Tuuli Metsvaht, Estonia

Professor Delphine Mitanchez, France

Dr Deirdre Murray, Ireland

Professor Eren Özek, Turkey

Dr Adelina Pellicer Martínez, Spain

Dr Serafina Perrone, Italy

Professor Christian F. Poets, Germany

Professor Heike Rabe, UK

Professor Irwin Reiss, The Netherlands

Professor Mario Rüdiger, Germany

Professor Elie Saliba, France

Professor Ola Didrik Saugstad, Norway

Professor Andreas Stahl, Germany

Dr Michael Steidl, Germany

Dr Martin Stocker, Switzerland

Dr David Sweet, UK

Professor Marianne Thoresen, UK

Professor Win Tin, UK

Dr Justyna Tołłoczko, Poland

Dr Daniele Trevisanuto, Italy

Professor Máximo Vento Torres, Spain

Professor Henkjan Verkade, The Netherlands

Dr Eduardo Villamor, The Netherlands





Care procedures

Chair Team

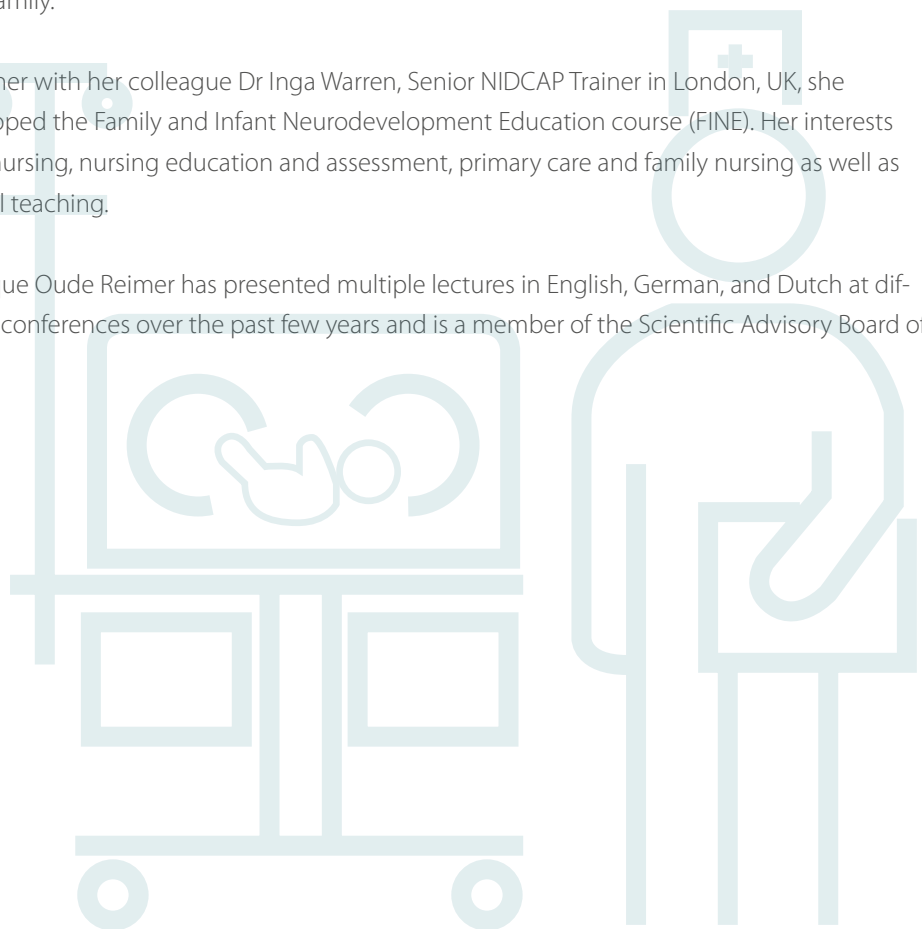


Monique Oude Reimer-van Kilsdonk, The Netherlands

Monique Oude Reimer is a NIDCAP trainer at the Erasmus MC-Sophia Children's Hospital, Rotterdam and Co-Director of the Sophia NIDCAP Training Centre, Rotterdam, The Netherlands. Currently, she works as a Clinical development consultant at NICUs all over the world, where she supports the units in all their efforts to implement individualised care for the patients and their family.

Together with her colleague Dr Inga Warren, Senior NIDCAP Trainer in London, UK, she developed the Family and Infant Neurodevelopment Education course (FINE). Her interests lie in nursing, nursing education and assessment, primary care and family nursing as well as clinical teaching.

Monique Oude Reimer has presented multiple lectures in English, German, and Dutch at different conferences over the past few years and is a member of the Scientific Advisory Board of EFCNI.





Odile Frauenfelder, The Netherlands

Odile Frauenfelder is a senior nurse practitioner specialised in the field of maternity and child care. In 2018, she obtained her second master's degree in Quality and Safety in Patient care at the University of Nijmegen.

Her interests as a neonatal nurse practitioner lie primarily in the care of extreme preterm infants, not restricted to the medical and nursing care but also including the care of the parents during their stay at the NICU. In addition to her clinical work, Odile is also active in other fields as advisor. In the past, she was the Nursing President from ESPNIC (European Society for Paediatric and Neonatal Intensive Care) and President of the Dutch Association for Nurse Practitioners (V&VN VS).

She has established an extensive network amongst professionals involved in the care of the extreme preterm infants and beyond in the Dutch healthcare and political world. Odile is member of the registration commission for Dutch nurse practitioners and a member of the advisory board for the Dutch Dentists registration commission. Odile is knowledge ambassador of the city of Rotterdam and since 2010, a member of the Scientific Advisory Board of EFCNI.

Topic Expert Group members

Johann Binter, Austria

Dr Fátima Camba, Spain

Monica Ceccatelli, Italy

Dorottya Gross, Hungary

Ingrid Hanks-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





Infant- and family-centred developmental care

Chair Team



Dr Björn Westrup, Sweden

Björn Westrup, MD, PhD, is a senior consultant in neonatology and Director of the Karolinska NIDCAP Training & Research Center at Astrid Lindgren Children's Hospital, Karolinska University Hospital and lecturer at Karolinska Institute, Stockholm, Sweden.

His fields of research are mainly medical and physiological aspects of developmentally supportive care, family-centred care and iron metabolism. He performed two randomised controlled clinical trials in the field of family-centred care and has been pioneering the development of the most advanced stage of family-centred developmental care: couplet care – a care model that minimises the separation of infant from its mother by, if needed, providing medical care also for the mother together with her infant in the neonatal unit.

For his expertise in changing the care and designing nurseries to become more family oriented, Björn Westrup is a frequent invited speaker at scientific conferences and is regularly hosting leadership teams that in the planning stage of building new nurseries, are visiting his unit to seek his advice. He is a member of the Scientific Advisory Board of EFCNI.



Professor Pierre Kuhn, France

Pierre Kuhn, MD, PhD, is a professor of paediatrics at the University Hospital of Strasbourg, France, and was an invited researcher at the Karolinska Institute in Stockholm, Sweden. He works as senior neonatologist and has the position of head of the NICU at the University Hospital Strasbourg.

He is also a researcher in neuroscience at the Centre National de la Recherche Scientifique. He is involved in research evaluating mainly the impact of the hospital environment on the sensory systems and the brain development of infants born very preterm. His research focuses also on the evaluation of infant- and family-centred developmental care strategies.

Pierre Kuhn has published in national and international journals and books. He is a board member of the Société Française de Néonatalogie and is coordinating the Group of Reflection and Evaluation of the Environment of Newborn infant (GREEN) in France. In addition, he is also the president of the perinatal network in the Alsace region. Pierre Kuhn is a member of the Scientific Advisory Board of EFCNI.



EFCNI Parent Advisory Board member



Mandy Daly, Ireland

Mandy Daly is a parent of a preterm infant born in 2006 and is a co-founder and Director of Advocacy and Policy Making with the Irish Neonatal Health Alliance (INHA). She has been advocating for improved, family-centred and standardised neonatal care in Ireland for the past 11 years.

The INHA network created and facilitates the collaborative platform for Irish healthcare professionals, educators, industry partners, government officials and researchers to partner together. Mandy holds the patient collaborator role on several national and international research projects.

She oversees neonatal curriculum reviews, lectures to neonatal, medical and nursing students and is active on several health system review projects. Mandy Daly is a member of the Parent Advisory Board of EFCNI and is a board member of the NIDCAP Federation International.



Paula Guerra, Portugal

Paula Guerra is one of the founders of the Portuguese preemies association XXS – Associação Portuguesa de Apoio ao Bebê Prematuro, being an executive board member of XXS since the creation of the association in November 2008. She has two daughters, one born in 1993 as a term baby and a second one, an extremely preterm born girl, born in 2001 with 26 weeks of gestation and 615g of weight.

Since 1993, Paula Guerra worked in IT development departments of three different Portuguese banks and she is since 2010 the Head Talent Management of the IT Department in one of those Portuguese banks. She is a member of the Parent Advisory Board of EFCNI.

Topic Expert Group members

Dr Sari Ahlqvist-Björkroth, Finland

Nataschia Bertoncelli, Italy

Dr Nils Bergman, Sweden

Professor Zack Boukydis, Hungary (†)

Sylvia Caballero, Spain

Dr Charlotte Casper, France

George Damhuis, The Netherlands

Dr Manuela Filippa, Italy

Professor Petra Hüppi, Switzerland

Dr Kai König, Switzerland

Birgitte Lenes-Ekeberg, Norway

Siri Lilliesköld, Sweden

Dr Rosario Montirosso, Italy

Dr Carmen Pallás Alonso, Spain

Dr Milica Rankovic-Janevski, Serbia

Professor Jacques Sizun, France

Dr Kari Slinning, Norway

Dr Inga Warren, UK





NICU design

Chair Team



Dr Atle Moen, Norway

Atle Moen is a consultant neonatologist at Oslo University Hospital, Rikshospitalet. He worked for more than 10 years at the Drammen Hospital, part of Vestre Viken Hospital Trust as consultant in paediatrics and neonatology, Clinical Director Neonatology and Medical Director of the Department of Paediatrics. In Drammen Hospital, he planned and implemented a new single room level II NICU in 2012.

His scientific focus is neonatology, healthcare management, paediatrics, and patient safety. Atle Moen is a member of the Scientific Advisory Board of EFCNI.



Dr Boubou Hallberg, Sweden

Boubou Hallberg, MD, PhD, is the Head of Neonatology at the Neonatal Department of the Karolinska University Hospital in Stockholm, Sweden and affiliated to Karolinska Institute.

His research focuses on new strategies for preventing neonatal brain injury. He is PI/clinical lead for the EU-funded projects PreventROP, NEMO, NeoOpioid and BIHIVE. Additionally, he is involved in family-centered and couplet care in neonatology and also directs his attention towards staff and parental interaction and the process of designing an optimal neonatal intensive care unit to support this process for the past several years.

He is also a member at the Swedish Neonatal Society, European neonatal brain club and director of the working group for centralisation and transport. Boubou Hallberg is a member of the Scientific Advisory Board of EFCNI.



EFCNI Parent Advisory Board member



Dr Tomasz Makaruk, Poland

Tomasz Makaruk is the founder and Chairman of the Polish Premature Baby Foundation (Fundacja Wczesniak Rodzice-Rodzicom), which has existed since 2004, shortly after he became a father to a preemie born in week 29 at 1600 g.

He holds a PhD in Economics from the Warsaw School of Economics and also completed a course in Managing Professional Service Firms at Harvard Business School Executive Education. During his work with the Premature Baby Foundation, Tomasz Makaruk was also the co-creator of a highly successful fundraising campaign for the organisation in 2010.

Over the past 15 years, he has worked in both management and executive positions within the marketing departments of top international corporations. He also co-owns and manages a marketing firm specialised in building brand loyalty. He is an active communicator and in addition to keeping a blog on marketing and economics, he has written a number of articles that have appeared in the press. Tomasz Makaruk is a member of the Parent Advisory Board of EFCNI.

Topic Expert Group members

Professor Sidarto Bambang Oetomo, The Netherlands

Delphine Druart, Belgium

Katarina Eglin, Germany

Professor Uwe Ewald, Sweden

Professor Fabrizio Ferrari, Italy

Professor Peter Fröst, Sweden

Teresa Garzuly-Rieser, Austria

Dr Erna Hattinger-Jürgensen, Austria

Silke Mader, Germany

Dr Thilo Mohns, The Netherlands

Professor Jacques Sizun, France

Professor Robert White, USA





Nutrition

Chair Team



Professor Berthold Koletzko, Germany

Berthold Koletzko is Professor of Paediatrics at LMU – Ludwig-Maximilians-University Munich and Head of the Division Metabolic and Nutritional Medicine at Doctor von Hauner Children's Hospital, LMU University of Munich, Germany.

He has coordinated several international research consortia, including the EarlyNutrition Project, the Early Nutrition eAcademy South East Asia and the ESPEN Project on Disease Associated Malnutrition in Children, served as scientific advisor in the European Parliament Committee on Consumer Protection as well as in the Innovation Initiative of the Chancellor of the Federal Republic of Germany. He previously was member and rapporteur of the European Commission Scientific Committee on Food.

Professor Koletzko is author of >900 scientific journal publications. He is further President of the Federation of International Societies of Paediatric Gastroenterology, Hepatology & Nutrition (FISPGHAN) and Managing Director of the Early Nutrition Academy. He also is a member of the Scientific Advisory Board of EFCNI.





Professor Mary Fewtrell, UK

Mary Fewtrell is Professor of Paediatric Nutrition and Honorary Consultant Paediatrician at the UCL Great Ormond Street Institute of Child Health, London, UK, Clinical Lead for Nutrition at the UK Royal College of Paediatrics & Child Health, and a member of the European Food Safety Authority Infant Nutrition working group. She was previously Chair of the ESPGHAN (European Society for Paediatric Gastroenterology Hepatology and Nutrition) Nutrition Committee.

Her research interest span the main areas of paediatric nutrition including the programming of health outcomes by early nutrition and growth, primary prevention and treatment of obesity and practical aspects of infant nutrition, including breastfeeding, lactation, and complementary feeding.

Mary Fewtrell is author of numerous scientific articles and a regular speaker at conferences. She is also co-editor and author of EFCNI publications on breastfeeding preterm infants.

Topic Expert Group members

Professor Magnus Domellöf, Sweden

Professor Nicholas Embleton, UK

Professor Hans van Goudoever, The Netherlands

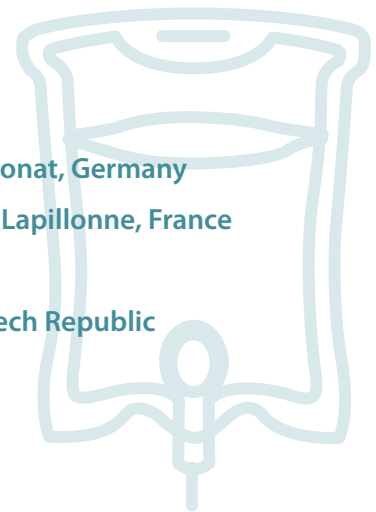
Dr Darius Gruszfeld, Poland

Dr Susanne Herber-Jonat, Germany

Professor Alexandre Lapillonne, France

Alison McNulty, UK

Dr Peter Sztanyi, Czech Republic





Ethical decision-making and palliative care

Chair Team



Professor Jos Latour, UK

Jos M. Latour is Professor in Clinical Nursing at Plymouth University in Plymouth, UK and at Hunan Children's Hospital, Changsha, China. His clinical post is based at Musgrove Park Hospital in Taunton, Somerset, UK, where he is leading the Clinical School for the Somerset region.

His research lines are related to empowerment and involvement of parents in healthcare, end-of-life care, and paediatric sepsis. His major research programme is called the EMPATHIC study (EMpowerment of PARENTS in THE Intensive Care) and is currently implemented in NICUs and PICUs in many countries around the world. He is actively involved in the promotion of evidence-based and evidence-informed care. His vision is to narrow the gap between research, education, and clinical practice.

Jos Latour has published widely in peer-reviewed journals, books and chapters. He is associate-editor of Pediatric Critical Care Medicine and editorial board member of several other international peer-reviewed journals and is a member of the Scientific Advisory Board of EFCNI.



Professor Gorm Greisen, Denmark

Gorm Greisen is a Clinical Professor of Pediatrics at the Institute of Clinical Medicine, Copenhagen University, Denmark and consultant neonatologist at the Department of Neonatology at The Juliane Marie Centre, Rigshospitalet.

His research focuses on causes of brain injury in preterm infants, cerebral blood flow and cerebral oxygenation, systematic follow-up studies to evaluate outcomes later in life, growth before and after birth and the consequences of growth in the perinatal period for later health, as well as interventions in the newborn period to improve health later in life, and the ethics of medical research.

He is currently engaged in an attempt to test the clinical value of monitoring cerebral oxygenation by near-infrared spectroscopy in extremely preterm infants (the SafeBoosC project) with a group of neonatologists in 17 European countries. Gorm Greisen is also a member of the Scientific Advisory Board of EFCNI.



EFCNI Parent Advisory Board member



Yannic Verhaest, Belgium

Yannic Verhaest is Chairwoman of the Belgian parent organisation VVOC (Vlaamse Vereniging voor Ouders van Couveusekinderen). She joined the VVOC in 2007 as an active board member and became Chairwoman in 2013. She is mother of two children, the oldest born at 30 weeks of gestation.

She is a clinical psychologist, psychoanalytic psychotherapist, infant mental health specialist and works as psychotherapist and researcher at the UPC KU Leuven, at PraxisP (therapy centre of the Faculty of Psychology and Educational Science of KU Leuven), as well as affiliated staff of the Centre for Psychoanalysis and Psychodynamic Psychology at the University of Leuven.

She has been representing Belgium within EFCNI since the first joint parent organisations meeting in 2008. She collaborates closely with EFCNI to improve prevention of preterm birth and for the best possible care for preterm infants and their families in Belgium and Europe. She is a member of the Parent Advisory Board of EFCNI.

Topic Expert Group members

Elsa Afonso, Spain/UK

Professor Hans-Ulrich Bucher, Switzerland

Dr Laurence Caeymaex, France

Dr Marina Cuttini, Italy

Professor Nicholas Embleton, UK

Dr Milivoj Novak, Croatia

Dr Daniel Nuzum, Ireland

Professor Jochen Peters, Germany

Karl Rombo, Sweden

Dr Daniel Wood, UK





Follow-up and continuing care

Chair Team



Professor Dieter Wolke, UK/Germany

Dieter Wolke PhD Dr rer. nat. h.c. is Professor of Developmental Psychology and Individual Differences at the Department of Psychology and Division of Health Sciences at the University of Warwick. He leads the Lifespan Health and Wellbeing Group.

His research focuses on developmental pathways leading to developmental psychopathology, social and emotional development, biological at risk children (very preterm children), school and sibling bullying, infant regulatory problems (crying, feeding, sleeping) and parenting. His particular interest is on how preterm birth affects brain and psychological development and quality of life. He is involved in a range of follow-up studies of preterm children in the UK and Germany including the EPICure Study, the Bavarian Longitudinal Study and Avon Longitudinal Study (ALSPAC) and in the Scientific lead of RECAP preterm, a EU Horizon 2020 project with 20 partners.

He has published widely and is on the editorial boards of a number of journals and several scientific boards, e.g. of EFCNI's Scientific Advisory Board.



Dr Aleid van Wassenaer-Leemhuis, The Netherlands

Aleid van Wassenaer-Leemhuis MD, PhD, is paediatrician and the head of the follow-up programme of NICU graduates at the Emma Children's Hospital, Amsterdam University Medical Center. She is consultant to the Expertise Center for post discharge developmental support (EOP-NI, Expertise centrum Ontwikkelingsondersteuning voor Prematuren).

Within national and international collaborations, she is involved in research in multi-disciplinary groups mostly aiming at improving long-term health and neurodevelopmental outcomes of preterm infants and infants born after fetal growth restriction. This concerns primary, secondary and tertiary prevention of neurodevelopmental disabilities, mostly within the age group 0 to 13.

Aleid van Wassenaer-Leemhuis participated in the core writing group of the Dutch guideline on aftercare for preterm and small for date neonates which was a joined effort of the preventive primary healthcare, the Dutch society of paediatrics and the Dutch association of parents of preterm infants. She also is a member of EFCNI's Scientific Advisory Board.

EFCNI Parent Advisory Board member



Dr Gert van Steenbrugge, The Netherlands

Dr Gert van Steenbrugge is father of two preterm children, born respectively at 34 and 26 weeks of pregnancy. He is former director of the Dutch parent organisation VOC ('Vereniging van Ouders van Couveusekinderen').

He holds a Ph.D. in biochemistry and worked for many years in biomedical research. Having this background, his special interest and activities for the VOC organisation has always been focused at medical advocacy work. In close cooperation with care providers he is involved in aftercare and follow-up programmes, was member of several guideline committees, participates in research groups and represented parents in the Call-to-Action NL platform, a local continuation of the EFCNI initiative.

Along with parents and professionals, he was the founder of the 'Neokeurmerk', a quality mark for the Neonatology and the Mother and Child centres of the Dutch hospitals. This programme is based on the parent perspective, with the focus on developmental and family-centered care. Gert van Steenbrugge is member of the Parent Advisory Board of EFCNI.



Mónica Virchez Figueroa, Spain

Mónica Virchez Figueroa is mother of triplets born in 29 weeks of gestation in London, UK. She has been supporting professionally the organisation PREMATURA in Spain for many years.

She is a clinical psychologist as well as a trainer in baby massage, infant reflexology, skin-to-skin care. She has a post-degree-course in prematurity at the Italian Hospital in Argentina. In her daily work, she is in contact with issues like: attachment, bonding, skin-to-skin care, baby massage, breastfeeding, follow-up, pregnancy, baby body language, stress and burnout in mothers with multiple births, Brazelton, and NIDCAP. She has working experience in the development of small babies and children as well as support of parents and families of preterm infants.

She is a member of different Spanish and European associations and foundations related with prematurity and multiple births. She is in regular contact with professionals from other countries. She is a member of the Parent Advisory Board of EFCNI.

Topic Expert Group members

Professor Laura Bosch, Spain

Dr Christiaan Geldof, The Netherlands

Professor Mijna Hadders-Algra,
The Netherlands

Professor Christoph Härtel, Germany

Professor Egbert Herting, Germany

Dr Bregje Houtzager, The Netherlands

Dr Britta Hüning, Germany

Dr Shelley Hymel, Canada

Dr Julia Jäkel, USA/Germany

Professor Mark Johnson, UK

Professor Samantha Johnson, UK

Professor Eero Kajantie, Finland

Dr Anne van Kempen, The Netherlands

Dr Karen Koldewijn, The Netherlands

Professor Liisa Lehtonen, Finland

Professor Els Ortibus, Belgium

Dr Anne-Marie Oudesluys-Murphy,
The Netherlands

Dr Vilhelmiina Parikka, Finland

Dr Veronique Pierrat, France

Dr Federico Prefumo, Italy

Professor Alessandra Sansavini, Italy

Dr Irma van Straaten, The Netherlands

Dr Jacqueline UM Termote,
The Netherlands

Professor Tracy Vaillancourt, Canada

Dr Brigitte Vollmer, UK

Dr Marie-Jeanne Wolf-Vereecken,
The Netherlands



Patient safety and hygiene practice



Chair Team



Professor Pierre Tissières, France

Pierre Tissières, MD, PhD, is Professor of Paediatrics at the University Paris South, and Director of the Pediatric Intensive Care and Neonatal Medicine at the Paris South University Hospitals. He is leading the Human Pathogens Interactions in Sepsis Group at the Department of Microbiology, from the Institute of Integrative Biology of the Cell, Paris Saclay University.

He is specialised in molecular immunology and neonatal critical care. Pierre Tissieres's current research is mainly focusing on the immune response of neonates and preterm infants to gram negative sepsis.

Pierre Tissières is the president-elect of the European Society of Paediatric and Neonatal Intensive Care. He is a member of the Scientific Advisory Board of EFCNI.



Dr Onno Helder, The Netherlands

Dr Onno Helder is a nurse scientist at the Erasmus MC-Sophia Children's Hospital, Rotterdam, The Netherlands and lecturer at the Rotterdam University of Applied Sciences. He gained his PhD from the Medical Faculty of Erasmus University Rotterdam and currently works as a senior clinical researcher in addition to his lecturer post.

His research interests are infection prevention, implementation strategies, and developing technical innovations that facilitates healthcare professionals' workflow and patient safety. He has contributed to improvements in the BSc nursing program at Rotterdam University of Applied Sciences, and initiated several multi institutional research projects.

Onno Helder is a member of the Scientific Advisory Board of EFCNI.



Topic Expert Group members

Dr Susana Ares Segura, Spain

Dr Alessandro Borghesi, Italy

Maria Josep Cabañas Poy, Spain

Professor Daniele De Luca, France

Dr Cécile Dubois, France

Professor Christoph Fusch, Germany

Estrella Gargallo, Spain

Dr Eric Giannoni, Switzerland

Professor Christoph Härtel, Germany

Dr Jan Janota, Czech Republic

Dr Ulrik Lausten-Thomsen, France

Dr Nolwenn Le Saché, France

Silke Mader, Germany

Dr Paolo Manzoni, Italy

Dr Josep Perapoch, Spain

Professor Christian F. Poets, Germany

Roland van Rens, The Netherlands

Professor Rainer Rossi, Germany

Dr Heleen van der Sijs, The Netherlands

Dr Cynthia van der Starre, The Netherlands

Nicole Thiele, Germany

Dr Tobias Trips, Germany

Lucie Žáčková, Czech Republic





Data collection and documentation

Chair Team



Professor Gérard Bréart, France

Gérard Bréart is a perinatal epidemiologist and Professor of Public Health at the Pierre et Marie Curie University in Paris, France. He also holds adjunct faculty positions at the Department of Maternal and Child Health, School of Public Health, University of North Carolina, USA and the Department of Epidemiology, School of Public Health and Tropical Medicine, Tulane University, USA.

His research focuses on different aspects of women's and children's health, in particular on preterm birth, fetal growth, organisation of care and efficacy and effectiveness of interventions.

From 2008 to 2011, Gérard Bréart served as Director of the Institute of Public Health at INSERM. He is past President of the Association of French-speaking Epidemiologists (1989-1993) and of the French Society of Perinatal Medicine (1999-2001). Gérard Bréart has also been involved in large national and international studies such as the ENP, the EURO-PERISTAT, EPICARD, and EPIPAGE and has published numerous articles in leading journals.



Dr Nicholas Lack, Germany

Nicholas Lack is a statistical consultant, currently employed as section head of statistical methods, perinatology, neonatology, gynaecology and breast cancer surgery at the Bavarian Institute for Hospital based Quality Assurance (BAQ) in Munich, Germany. He has gained over 35 years of international experience in maternal and child health in government health administration assignments in the UK and Germany.

His specialty lies in benchmarking of hospitals with respect to quality of care. For over 15 years he has been involved in international collaborations such as cross-country comparisons of perinatal health (EURO-PERISTAT working group of European indicators of perinatal health) and causal analysis of rare obstetric events and their prevention (International Obstetrics Surveillance System - INOSS). Since 2014 he is a statistical consultant for the Rotarian RFPD Maternal Child Health (MCH) Project in Nigeria.

Besides different lecturing jobs in the field of statistics and health education, he has published on the topics of funnel plots for quality comparisons, the epidemiology of perinatal mortality as well as on methodological difficulties of cross-country comparisons of indicators of maternal child health-care. He also is a member of the Scientific Advisory Board of EFCNI.



EFCNI Parent Advisory Board member



Dr Eleni Vavouraki, Greece

Eleni Vavouraki is a pulmonologist with a PhD in pulmonary rehabilitation; she is also specialised in Complementary and Alternative Medicine. After becoming an aunt of triplets that were born very prematurely (26+4), she together with the triplet's parents co-founded the association Ilitominon, of which she is the President since 2011.

She has a wide teaching experience as a professor at Faculty of Health and Caring Professions of the Technological Educational Institute of Athens for 23 years. She is now working as a medical advisor in a Natural Products company, meanwhile she is teaching postgraduate courses in the Medical School of the University of Thessaly.

She is also member of Therapeutic Riding Association of Greece, a NGO where children with disabilities (mainly due to prematurity) are helped to cope by improving their physical and psychological condition. Eleni Vavouraki is a member of the Parent Advisory Board of EFCNI.

Topic Expert Group members

Professor Mika Gissler, Finland

Professor Wolfgang Göpel, Germany

Professor Dominique Haumont, Belgium

Dr Ashna Hindori-Mohangoo, The Netherlands

Vilni Verner Holst Bloch, Norway

Professor Helmut Hummler, Germany

Dr Begoña Loureiro Gonzalez, Spain

Dr Miklós Szabó, Hungary

Dr Liis Toome, Estonia

Dr Jennifer Zeitlin, France





Education and training of the multidisciplinary team working in neonatology

Chair Team



Professor Linda Johnston, Ireland/Canada

Linda Johnston is Dean of the Lawrence S Bloomberg Faculty of Nursing at the University of Toronto, Honorary Professor at the University of Hong Kong and Suzhou University, China, and Adjunct Professor at the Vanderbilt University, USA.

Her programme of research over the last 20 years has focused primarily on the assessment, and management, of pain in babies requiring neonatal intensive care. A particular focus was, on those babies with complex surgical conditions requiring a prolonged hospitalisation and multiple procedures. More recently her work has begun to explore the longer term physical, emotional and social outcomes for surgical babies and their families who experience a neonatal intensive care stay.

She is a Fellow of the American Academy of Nursing and the European Academy of Nursing Science. She co-convoked the 8th International Neonatal Nursing Conference in Belfast, auspiced by the Council of International Neonatal Nurses. Linda Johnston is also a member of the Scientific Advisory Board of EFCNI.



Professor Charles C. Roehr, UK/Germany

Since 2017 Charles C. Roehr is Associate Professor at the University of Oxford and he holds a university position as Privatdozent (Assistant Professor of Paediatrics) at the Charité Berlin, Germany since 2012.

He has a keen interest in studying neonatal transition at birth and to improve the various methods of non-invasive respiratory support/ ventilation (NIV) applied to neonates. Another interest of his is medical education and postgraduate training. For many years, he has conducted national and international seminars on different neonatal topics.

In his role as President of the European Society for Paediatric Research (ESPR), deputy chair of the European Scientific Collaboration of Neonatal Resuscitation Research and Chair of Paediatric and Neonatal Intensive Care Section of the European Respiratory Society (ERS), he is keen to promote neonatal education, resuscitation research and respiratory health throughout Europe and beyond. He is also a member of EFCNI's Scientific Advisory Board.



Dr Agnes van den Hoogen, The Netherlands

Agnes van den Hoogen is a nurse scientist at the University Medical Centre of Utrecht (UMCU) – Wilhelmina Children's Hospital in Utrecht, The Netherlands. She is a postdoc researcher, neonatal nurse at Neonatology at Wilhelmina Children's Hospital, UMCU and lecturer at the University of Utrecht. Next to teaching at the University of Utrecht, she is also engaged in various other educational activities.

Her research interests lie in epidemiology of neonatal infection, prevention, and antibiotic use. Another interest of hers is education at the University of Utrecht in clinical health science and mentoring students in their master degrees of neuro science and cognition, medicine, and clinical health science.

Agnes van den Hoogen is actively involved as a committee member in the Council of International Neonatal Nurses (COINN), WHO committees and is past president of the European Society for Pediatric and Neonatal Intensive Care (ESPNIC). She also is a member of the Scientific Advisory Board of EFCNI.



Dr Morten Breindahl, Sweden

Morten Breindahl is Head of Patient Flow "Extremely preterm infants" at Karolinska University Hospitals in Danderyd, Solna and Huddinge, Stockholm, Sweden. He is also Senior Consultant and Medical Director of NeoPETS (the Neonatal and Paediatric Emergency Transport Service), and holds a PhD in paediatric infectious diseases.

In this capacity, he has joined a comprehensive reformation of the healthcare system at Karolinska University Hospital focusing on Value Based Care and treatment including new organisational structures, leadership, and cooperation principles.

He was the Congress President of the 2nd (2016) and 3rd (2017) edition of the international congress „Transport of High Risk Neonates – When skill, equipment and professionalism make the difference“. Furthermore, Morten Breindahl is a member of the Scientific Advisory Board of EFCNI and the past President of the European Society for Neonatology (ESN).

Topic Expert Group members

Charlotte Bouvard, France

Dr Marina Boykova, Russia/USA

Professor Karl Heinz Brisch, Germany

Professor Duygu Gözen, Turkey

Professor Moshe Hod, Israel

Thomas Kühn, Germany

Dr Trudi Mannix, Australia

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





Currently, there are no cross-European guidelines for newborn health. The development and publication of reference standards is an important step towards harmonising treatment and care for preterm and ill babies across Europe and the world.

**Prof Christian F. Poets,
Neonatologist, Germany**



Editorial team



Written by about 220 experts, the standards differed in wording and grammar. In order to finetune the documents, the editorial team consisting of Professor Neil Marlow, Dr Dietmar Schlembach, Silke Mader, Dr Johanna Walz, Dr Verena Lindacher, Valerie Matthäus and Philine Altbäumer, came together in three different meetings for a total of 11 days. Via skype calls it was possible to include additionally almost all international Chairs of the different TEGs into the editing process. We warmly thank the whole editorial team for their very valuable contribution to harmonising and finalising the standards!



1st Editing Meeting 2017



3rd Editing Meeting 2018



2nd Editing Meeting 2018

of Care for Newborn Health and endorsing the Call to Action for Newborn Health in Europe (in alphabetic order):





Supporting parent organisations



We warmly thank the following parent organisations for supporting the developed European Standards of Care for Newborn Health and endorsing the Call to Action for Newborn Health in Europe (in alphabetic order):



The project members of EFCNI

Behind the scenes of the European Standards of Care for Newborn Health, an amazing project team has ensured a smooth development and management process throughout all stages of the project and has handled the cooperation between all stakeholders.

The Executive Board of EFCNI



Silke Mader

Silke Mader is the Chairwoman of the Executive Board and co-founder of EFCNI. In 1997, her twins were born in the 25th week of pregnancy, and were not given the appropriate care. Unfortunately, one of them died a few days after birth. During her time in hospital and afterwards, Silke Mader was faced with the non-existence of support of any kind, the absence of public awareness, and the lack of information and education for parents during pregnancy. Her motivation is to prevent parents from making similar experiences in such painful situations. As the conditions throughout Europe are distressingly similar and preterm children urgently need a voice within Europe and worldwide, she decided to take on the role of chair on the Executive Board of EFCNI.

She is author and editor of many other publications on topics related to maternal and newborn health.

In 2012 Silke Mader was awarded the "Prix Courage" by ZDF television programme "ML mona lisa" in cooperation with the cosmetics company Clarins. 2013 she received the Medal for Particular Services to Bavaria in a United Europe. Since 2014 she is Honorary Lecturer at the School of Nursing and Midwifery, Queen's University Belfast, Northern Ireland. In 2015, she has been awarded as social entrepreneur and Ashoka Fellow and in 2016 she received the Bavarian State Medal for Services concerning Health and Long-term Care.



Nicole Thiele

Nicole Thiele joined EFCNI in 2010 and holds the position of Vice Chair of the Executive Board. She is a Fellow of the European Patients' Academy (EUPATI), has a diploma as European Secretary/ESA and holds a university degree in Economics, Management, Business Administration, and EU Public Affairs. Living and working abroad has provided her with extensive experience in different positions within multi-national companies.

With her family experiencing the consequences of an extremely preterm birth nearly 50 years ago, she is personally committed to driving forward the prevention of preterm birth, the continuous improvement of treatment and care as well as the philosophy of family-centred developmental care and parental involvement, to give every baby the best start in life.

She has developed a variety of educational and information materials and is author, (co-) author, and (co-) editor of several publications on the topic.



Professor Neil Marlow

Neil Marlow trained in clinical medicine at Oxford and University College Hospital London. His first research post was in Manchester where he carried out one of the first and largest single observer outcome studies following low birthweight. Since that time, he has continued to focus on the sequelae of perinatal events and in particular neuropsychological outcomes. Neil Marlow was appointed Professor of Neonatal Medicine at University College London in September 2008, having held the chair of Neonatal Medicine in Nottingham since 1997.

He leads the national EPICure studies, funded by the UK Medical Research Council (MRC), focused on long-term outcomes for extremely preterm infants. He also runs several local studies and collaborates both nationally and internationally on a range of neonatal trials. Neil Marlow is the current Chair of the NHS England Clinical Reference Group for Neonatal Critical Care, and Chair of the Neonatal Critical Care Transformation Review. He is a member of the executive board of EFCNI.

EFCNI employees involved in the project over time

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A hero isn't always
big and strong.

A hero is simply one
who has the strength
and courage to overcome
overwhelming
circumstances.



Unknown





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“The collaboration of health-care professionals, parents, and scientists from different countries and disciplines is invaluable to improve care for preterm babies and their families across Europe. Together we can move mountains.”

Dr Inge Tency, Midwife, Belgium

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*Despeena, born at 24 weeks
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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.

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