

Celebrating
10 years of

EFGNI



EFCE NI 2008 – 2018

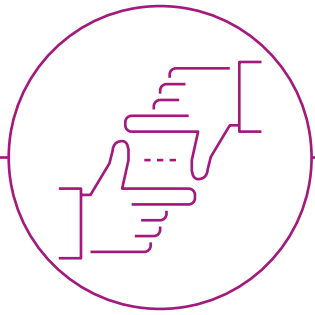
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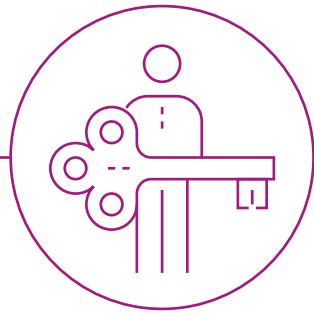
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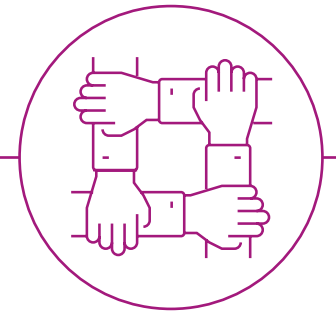
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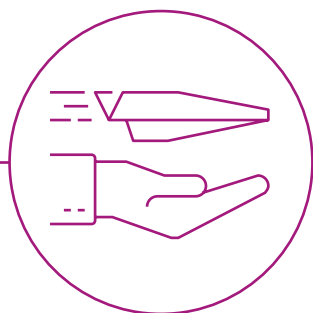
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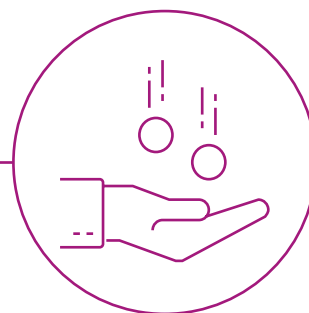
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Welcome



Dear readers, friends and allies,

Who would have known when we founded EFCNI in 2008, that one day we would be celebrating our tenth anniversary? Some might have doubted it I suppose. But here we are and I am overwhelmed when I look back on ten intense, eventful and inspiring years.

I would like to take the chance to express my heartfelt thanks to everyone supporting EFCNI because in doing so they supported preterm babies and their families. They supported a mind change amongst political decision makers and amongst several members of the faculty. I remember times when it was regarded common sense to assume a preterm infant could not feel pain simply because of being born preterm and not yet developed to sense anything. I remember times when nursing a newborn with breast milk was not regarded a priority in nutrition. I remember times when parents felt like intruders when they wanted to see their own child in the NICU and when physical contact between parents and their newborn child was not implicit. I do remember all these things because I experienced them first hand as a mother of preterm twins. Luckily a lot has changed since then but then again there is still a lot to be changed and – as we live in a globalised world – I learned that not every baby benefits from improvements in clinical practices. May it be because of economic status or due

to their place of birth, may it be because of a lack of information or due to a slow change of routines. For EFCNI this means to keep on working for a change because, with the ever growing network we have established over time, we can achieve so much. My thanks go to all the health professionals providing us with invaluable expert knowledge and support, to our partners in the national and EU parliaments for putting preterm birth on the political agenda, to our corporate partners helping us realise our projects, to our parent organisations who are doing wonderful work all over the world raising awareness for preterm birth and to all those who contribute their bit to support our vision: the best start in life.

I wish you an enjoyable and insightful read.

Yours,

Silke Mader

Co-Founder and Chairwoman of EFCNI



Foreword



Approximately one in ten babies is born premature. Worldwide. In Europe, about 500,000 babies are born preterm every year. They 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 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.

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 and exchanging knowledge on an interdisciplinary and international level. Children are our future and the future of our societies. It is crucial to address the needs of preterm and ill born children and to turn the spotlight on the various maternal and newborn health policies and practices in place within Europe's Member States. I am delighted to be the patron of EFCNI and to actively support the foundation to ensure that Europe's children receive the best start in life.

Yours,

A handwritten signature in black ink, reading "Angelika Niebler".

Professor Dr Angelika Niebler

Member of the European Parliament



Origin & history

The history of EFCNI starts with a very personal experience: in 1997 founding member Silke Mader was pregnant, expecting twins. What was supposed to be a happy and exciting experience, turned out to be a tragically life-changing one: due to severe pre-eclampsia the babies were delivered at 25 weeks of pregnancy which one of them, her daughter, did not survive. She passed away after one week. Silke's son is now a young man, attending university. But it was a long, and not seldom, troubled road for the entire family to get there. Already during her time in the clinic, Silke Mader received little information about her own physical condition, the wellbeing of her children, appropriate treatment and care for her and her babies, nor was there any psychological support for Silke Mader and her family after discharge. This experience made her take action and she joined a local parent initiative in Munich, Germany.

Some years later, after having become head of the national parent organisation in Germany, Silke Mader felt the need to found an organisation that pushes a social change forward. The idea of establishing a group that acts politically on a European level seeking to achieve significant changes in the healthcare system was born. Together with likeminded supporters Professor Matthias Keller, neonatologist, Jürgen Popp, a fellow affected father who had previously lost triplets due to preterm birth, and lawyer Thomas Föringer, they took steps to bring fighting for preterm babies and their families to a European agenda: On 8 April 2008, EFCNI was officially founded. The initiators also immediately contacted European national parent organisations, motivating them to join forces on a cross-border initiative to improve the situation of preterm babies and their families.



Since its establishment in 2008, EFCNI has grown into a renowned organisation and advocate for preterm babies, ill newborns and their parents in Europe and meanwhile even beyond.

Silke Mader's personal story

When my husband and I got to know we were expecting twins, we were extremely happy and looking forward to a future with two lovely children. But from the first day my pregnancy was difficult. After week 24 I felt so bad that I asked for a general check-up where I was diagnosed with HELLP¹-Syndrome. I was immediately admitted as an emergency, and after four days in hospital the doctors told us our twins needed to be delivered at 25 weeks of gestation. Apparently my own state of health was very poor, too. Something I had never been informed about. Not only my children's but also my own life was at stake. My husband sat for more than 4 hours without any information and no one spoke to me either. On February 17, 1997 Lena (290 g) and Lukas (515 g) were born and admitted to the NICU². It was not before 2 days later that I could take a look at my children - on a photo. The only person who congratulated me on our babies was the nurse in my Intensive Care Unit. She woke me up and said: "Congratulations on your twins." I will never forget this because nobody else had done so. On the 4th day I got to see my children for the first time. Everybody tried to prepare me for the "shocking picture" of our babies. I had no idea what they meant, but as soon as I saw my daughter I knew what they tried to tell us. Lukas was small, yet he had a nice colour, Lena however, had high frequency ventilation and she was so extremely small.

She was covered in bruises because of the infusion therapy. This sight made me cry and I wanted them to stop the treatment immediately so they showed me out of the NICU. Again I was not offered any psychological support. Neonatologists and nurses did their best at this time and I am very grateful for this, but it was unbelievable that we got no support in this traumatic nightmarish situation. After 6 days Lena died. Contrary to our expectations Lukas was getting better and better. For us it felt like Lena gave him her power. But in our hearts our big worry remained that Lukas would not survive either and I was always extremely anxious. One day, a nurse said if I didn't stop crying she would not allow me to visit my son. Some days later I entered the NICU and heard that Lukas had his first skin-to-skin care with a nurse that night, because he had been crying. Another time, I came to the NICU and Lukas had a fresh nappy before I was able to change it. Back then, changing the diaper was the highlight of the day for me and I was so disappointed and could not believe that the nurses did all these things without including and respecting us as parents. I spoke to the head of the unit that I wanted to see Lukas every day and have physical contact with my son. She was honestly shocked about my feelings and discussed the treatment and care routines with her team. Eventually it became better for us. Nevertheless, we never received any psychologic counselling.



When Lukas had been moved from the NICU to the local neonatal unit (SCBU), these communication disasters started all over again.

Lukas was in a three bed room with mixed twins and no one seemed to understand how that made us as bereaved parents of one twin-baby feel. Quite the contrary, I was told I should be happy that Lena died because for sure she would have been disabled if she had survived. Before and after discharge, Lukas had small hernia surgeries, but no other big problems. Albeit, my husband and I became ill and depressed and we noticed that Lukas' development did not appear healthy. Not only did he not start to crawl and walk, he was also way smaller than his peers. Eating was also a problem until he was five years old. It was not before we went to get a second opinion concerning Lukas' health and development that a physician told us he needed immediate surgery and physiotherapy and it wasn't clear if he will learn to walk. For Lukas' hip surgery we stayed in hospital for 3 months – again without any psychological support. The situation finally improved when Lukas began to walk and started riding therapy. For all these years I felt like I was the co-therapist and not Lukas' mother. Not only was I faced with the non-existence of support in any sense, there was also no public awareness at all and a lack of information and education for parents during pregnancy. My experiences made me actively participate in the Munich-based local



parent group in 1999, which I later headed from 2001 on. In 2003 I became Chairwoman of the German umbrella organisation "Das Frühgeborene Kind e. V.". I learned that the situation throughout much of Europe is distressingly similar to what my husband and I – and our son – went through. In the end I decided to quit my job as a pre-school teacher and to assume chair functions in EFCNI. I founded the foundation in 2008 together with experts and affected parents. What we want to promote is an awareness that support for preterm babies and their families goes beyond survival – it is important to accompany them and their families after discharge as well. Today, I can look back on many achievements both, personally and professionally. My son Lukas attends university, he enjoys an active lifestyle and has become a healthy young man – against all odds. With EFCNI we have developed European Standards of Care for Newborn Health and I can observe that the situation for parents of hospitalised babies has improved in many places across Europe and beyond. Still, there is plenty to do! However, with ten years of experience and a strong network backing us up, I believe that we can make these changes happen.

¹ HELLP: Haemolysis Elevated Liver enzyme levels Low Platelet count-Syndrome; a variant of pre-eclampsia

² NICU: Neonatal Intensive Care Unit

Early beginnings

EFCNI has, over time, established an internationally thriving network of individuals, parent organisations, healthcare societies and other supportive partners from the academic or the corporate field, working committedly together. But like Rome wasn't built in a day, it took many years, persistence – some might even say stubbornness – courage and also one or two setbacks, for the foundation to get where it is today. The following section will recall the achievements of EFCNI's work in its ten years of existence staring off from its very beginnings. Looking back on the first events made us realise that many projects, stand points or recent developments departed in the very first year of EFCNI's existence.



2008



2018

First Parent Organisations Meeting

In November 2008, EFCNI invites 25 parent representatives from 14 organisations to meet in Rome and discuss: "What can we do to achieve our common goals?" When EFCNI was founded, Silke Mader's idea was to establish an international network, empowering parents and helping them to become well informed dialogue partners who could represent their children's interests on eye-level with healthcare professionals and political decision makers.

This very first Parent Organisations Meeting marks the beginning of this pan-European network and is the forerunner of the annual Parent Organisations Meeting that now welcomes more than 70 participants from more than 30 countries. This gathering in Rome turns out to be very efficient, the group drafts a first basic outline of the joint aims and objectives, World Prematurity Day is founded (back then called International Prematurity Awareness Day) and the Declaration of Rome is set up.





From a parent's and a partner's point of view:

Dr Gert Jan van Steenbrugge

*Parent Advisory Board of EFCNI, Past director of the Dutch parent organisation VOC
(Vereniging van Ouders van Couveusekinderen), The Netherlands*



Ten years ago, I had a very special experience in Rome, where I had the honour to attend the founding meeting of the still growing family of parents and healthcare professionals united in the EFCNI. What impressed me the most during that meeting were the big differences and inequalities among the participating countries, in terms of the medical care of preterm babies, social care of parents and the access of parents to the ward and to their child in the incubator. But even more impressive was the way all parents shared a very strong involvement in their volunteering activities to improve the care for vulnerable preterm babies and the way they were inspired by the experiences of parents and organisations in other countries.

It is amazing what has been reached by EFCNI and their partners after years of empowering parents and supporting a great number of organisations. As a consequence, the earlier inequalities are diminished and will undoubtedly be further reduced by the implementation of the European Standards of Care for Newborn Health which are launched in November 2018.

I am proud to be part of the strong and influential EFCNI network and impressed by the progress that has been made during the first ten years of its existence!



The Declaration of Rome

In spring 2009, the Declaration of Rome, a catalogue of 10 demands for preterm babies which had been formulated by EFCNI and partnering parent organisations on their first joint meeting in Rome the previous year, is revealed and handed over to Professor Dr Angelika Niebler, Member of the European Parliament (MEP). Silke Mader presents the catalogue of demands that covers a broad spectrum of newborn care, represents the parental perspective, and clearly urges for a social change. Since this event MEP Professor Dr Angelika Niebler has become a supporter for the cause of preterm and newborn health in Brussels and the patron of EFCNI.

"I am pleased that a foundation based in Bavaria makes an issue out of this subject. As a mother myself I can support the ten requests unconditionally and will try to make them a priority on a European level", so Professor Dr Niebler.

These 10 claims can be seen as the precursor of the European Standards of Care for Newborn Health project which was later, precisely in 2013, initiated by EFCNI. It also is one of the first written and printed documents by EFCNI.



DECLARATION OF ROME

1. Prioritise and raise awareness of the needs of preterm and newborn infants with illnesses
2. Research and implement measures for the prevention of preterm births
3. Consider the development and implementation of medical guidelines for the start of resuscitation of preterm infants in hospitals
4. Develop and implement independently controlled guidelines and quality standards for the treatment and care in hospitals of preterm and newborn infants with illnesses
5. Improve specialised and appropriate aftercare for developing pre-term and newborn infants with illnesses
6. Develop and implement structured programmes and systems to document medical check-ups and aftercare for preterm and newborn infants with illnesses
7. Improve psychological and social care for parents of preterm and newborn infants with illnesses, in hospital and after discharge, by specialised healthcare professionals
8. Provide research funds for studies to improve the treatment, care and neonatal outcomes of preterm and newborn infants with illnesses
9. Consider prolonged maternity leave and maternity grants (financial support) for parents of preterm and newborn infants with illnesses
10. Provide appropriate schooling and educational support for developing preterm and newborn infants with illnesses



Milestones & achievements

2008 to 2018, ten years, in which EFCNI managed to position itself within the spectrum of newborn health. Finding its way was challenging and one goal accomplished led to the next task. The foundation has been active in varied fields, may it be to raise awareness, to create a powerful network, or to inform and educate and to develop standards for newborn health. The following lists some of our reached milestones.

Publications



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

To get a better insight into the situation regarding preterm birth in Europe, the EU Benchmarking report “Too little, too late? – Why Europe should do more for preterm infants”, is compiled and published in 2009/2010. The 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. It fosters several national and European policy initiatives to improve the quality of maternal and newborn health.

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

To address the need for change, EFCNI publishes the White Paper “Caring for Tomorrow” in 2011/2012 which highlights some of the key concerns regarding the growing patient group affected by preterm birth. The paper is a starting point and gives recommendations on how to improve existing healthcare plans for maternal and newborn health covering preconceptional care, newborn health, as well as follow-up and continuing care providing background information, and identifying challenges. Bringing together healthcare professionals to work on this broad spectrum is unique. The recommendations of the White Paper are feeding into the development of European Standards of Care for Newborn Health.



2011 | Call to Action for Newborn Health

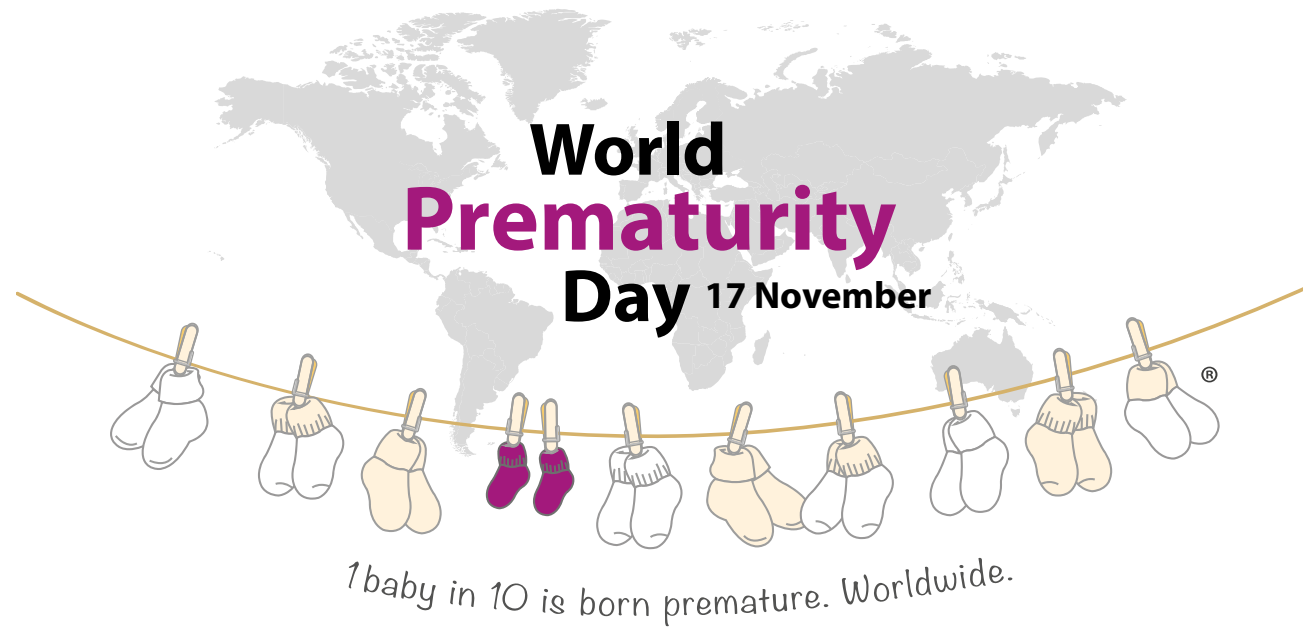
Complementary to the White Paper, a Call to Action is created. The 10 points Call to Action for Newborn Health, initiated by EFCNI and the European national parent organisations, is launched in November 2011 in the European Parliament. The EU and national policy makers, payers, patient organisations, 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 a consequence of the call, the interdisciplinary European Standards of Care for Newborn Health project is started with the aim of developing European reference standards for improved care for preterm and ill babies.

Our information material

The foundation also provides information factsheets, developed in close collaboration with experts in perinatal and neonatal health. EFCNI is proud to be able to distribute this information for instance on Parenteral nutrition, Breastfeeding a preterm infant, Respiratory syncytial virus (RSV), or on Pre-eclampsia, in a steadily growing number of languages. This reduces language barriers and makes vital knowledge about pregnancy complications or neonatal health accessible to both, experts and parents.

Over time, EFCNI has produced a large record of publications, from information brochures to factsheets, to posters and flyers to scientific papers and position papers. Please visit our website on www.efcni.org/activities/publications to get an overview of our offer. Your very own copy is just a few clicks away.





2008 | World Prematurity Day

17 November has become one of the most important days in our calendar. On this day we celebrate World Prematurity Day to raise awareness of the challenges and burden of preterm birth globally. The day is initiated by EFCNI and partnering European parent organisations during the first Parent Organisations Meeting in Rome in 2008. The date, 17 November, is chosen as it is the birthday of the daughter of the first Trustee Board chair of EFCNI. He and his wife had previously lost triplets due to preterm birth, so the birth of their healthy baby sure was a reason to celebrate. Back then this day is named International Prematurity Awareness Day. The community around 17 November soon grows bigger when

the African organisation LittleBigSouls, the March of Dimes (USA) and the National Premmie Foundation (Australia) join the celebrations and make World Prematurity Day, as it is re-named in 2011, an intercontinental movement. Meanwhile, countless individuals and organisations like the World Health Organization, Save the Children and many more from over 100 countries join forces with activities, special events and commit to action to help address preterm birth and improve the situation of preterm babies and their families. In 2016, EFCNI is featured in the editorial of The Lancet, for its commitment in pushing neonatal health and care forward and its specific role in initiating World Prematurity Day.



World
Prematurity
Day 17 November



World
Prematurity
Day 17 November

10
years

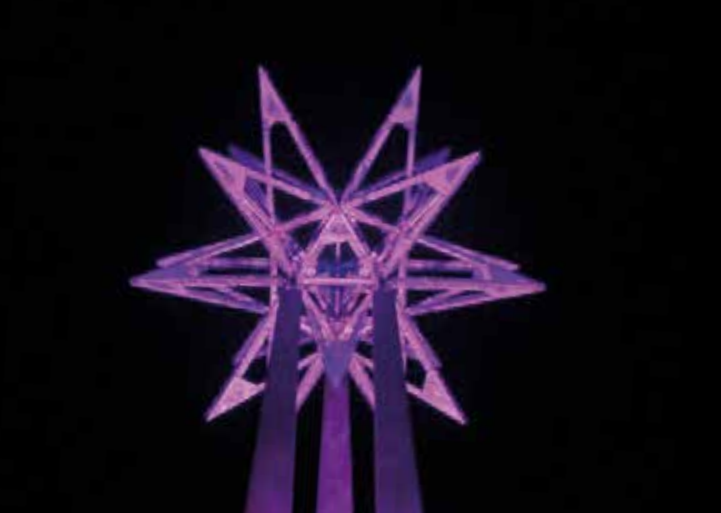
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More than
100
countries celebrate
World Prematurity Day



2009 | Charity Concert

In the year after its founding, EFCNI runs a big fundraising campaign supported by celebrity TV Chef Stefan Marquard, the Swedish Singer Jakob Samuel and fellow-countryman composer and songwriter Robert Wells. At a press conference followed by a charity concert, the topic of preterm birth is provided a stage and this pressing issue receives a large media coverage.





“



Robert Wells

*Ambassador of EFCNI,
Composer, pianist and songwriter, Sweden*

When I became father of a preterm son, I learned what parents of preterms and ill newborns have to go through in such a situation. Writing and composing music helped me come to terms with this emotionally challenging time but I also decided to use my contacts and my name to found the charity organisation 'Tummeliten' so to raise awareness for preterm birth in Sweden. I have been active in charity and fundraising for over 15 years now, working together with many international celebrities for the good cause of supporting children worldwide and had the honour to collaborate with the Swedish Queen Silvia's World Childhood Foundation. To go public, I wrote the charity song 'Sing me another song' which I gifted EFCNI. Both as affected father and as an artist I am very happy to join forces with EFCNI.

”

Socks for Life



1 baby in 10 is born premature. Worldwide.

2010 | Socks for Life

EFCNI initiated Socks for Life as a worldwide and year-round campaign inviting everyone to interact, raise awareness for preterm birth while, at the same time, creating opportunities for fundraising. Socks for Life has been re-invented several times and has been accompanying EFCNI now for many years and in many different contexts. The socks make their first prominent appearance at the UENPS Congress in Istanbul (including a quite adventurous journey to Turkey) and have been ambassadors for preterm babies worldwide since then. In the campaign the socks line with 9 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. The socks also stand for the needs of preterm or ill newborn babies, both physical and emotional, that help them grow and develop from the NICU up to adulthood.



In 2013 Socks for Life is used as a communication tool for an art-campaign to raise awareness for the challenges of preterm birth.

In 2015 the campaign starts to support the European Standards of Care for Newborn Health project.





2016 | Starker Start für kleine Helden (A strong start for little heroes)

Starker Start für kleine Helden is a large-scale German speaking initiative which EFCNI initiates in 2016. Our aim here is for once to promote World Prematurity Day but also to support Neonatal Intensive Care Units in Germany, Austria, and since 2017 also in Switzerland, in the organisation of their individual events on that special day. Interested units can sign up to participate and, for this purpose, receive a comprehensive action package including small gifts for parents of hospitalised babies and visitors of the unit. In its first year an impressive number of 150 clinics join the campaign. By including Switzerland in the following year, the number of participating units rises to 170.





Projects

2013 | European Standards of Care for Newborn Health

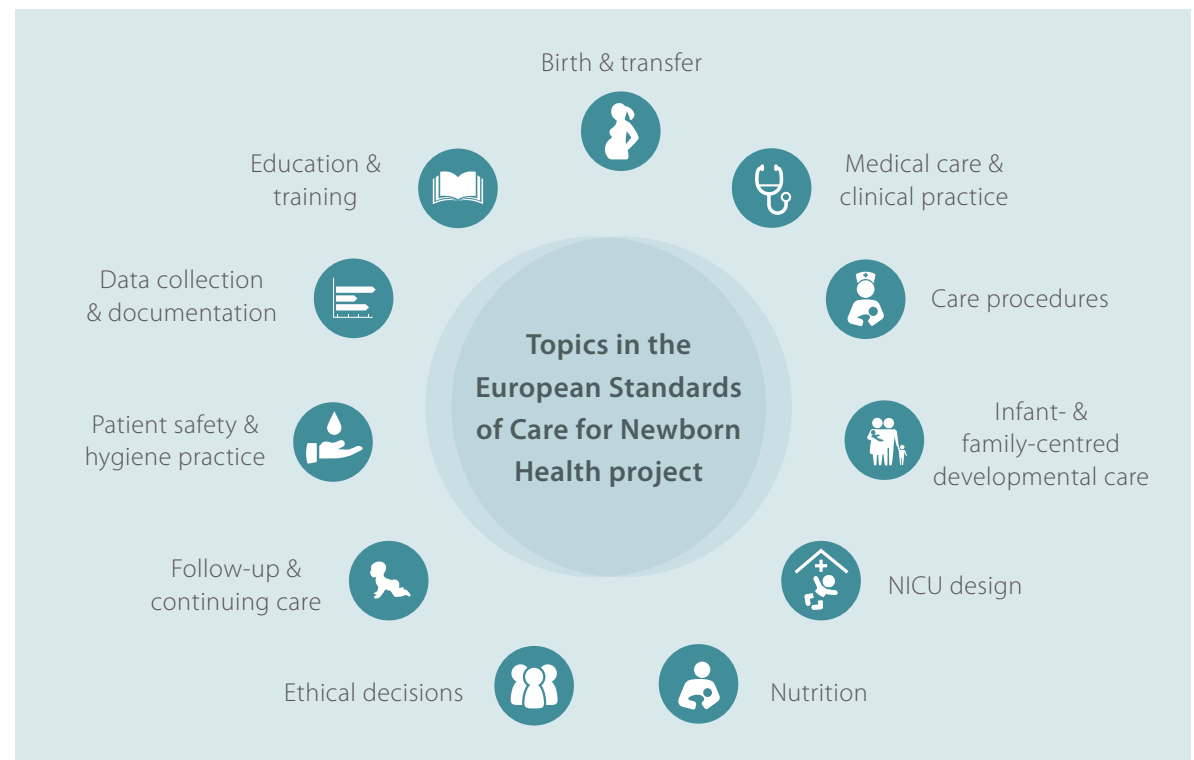
In September 2013, the preparation and research phase for the European Standards of Care for Newborn Health project starts. The official launch of this unique large scale project takes place in April 2014 with an event in the European Parliament.

The European Standards of Care for Newborn Health project is an interdisciplinary collaboration to develop standards of care for key topics in newborn health. Since the initiation of the project, EFCNI has been working together with about 220 experts from more than 30 countries and over 80 supporting organisations. The vision behind the project is that all babies receive equitable access to evidence-based, current best practice treatment and care no matter where in Europe they are born.

Currently, there are no cross-European standards for newborn health and till today, the organisation, structure, and provision of care as well as the education of healthcare professionals vary widely across Europe. These discrepancies and the current lack of harmonised standards within Europe, causing increased mortality and morbidity in one place while babies in other places survive, thrive and are able to live a self-determined, healthy life, shall be diminished and eventually removed.



european standards of
care for newborn health



The European Standards of Care for Newborn Health project addresses these disparities by developing European reference standards to contribute to improved care for all newborns.

In the project, which is initiated and coordinated by EFCNI, 11 Topic Expert Groups develop evidence-based standards referring to current best practice and experience. The thematic spectrum of these standards ranges from “Birth and transfer”, “Medical care and clinical practice”, “Nutrition” or “Education and training” to “Follow-up and continuing care” in early childhood. All standards are discussed and voted upon by the project’s steering group, the Chair Committee. At the moment of printing this report more than 100 healthcare professional societies and over 50 parent organisations have declared their support for the developed standards. The standards are published on the project website www.newborn-health-standards.org. The official launch of the around 100 standards takes place in November 2018 at the European Parliament in Brussels.

In 2016, the project is featured in the editorial of The Lancet, for its commitment in pushing neonatal health and care forward.



In 2017, the project is awarded one of the most innovative Landmarks 2017 of the initiative Germany – Land of Ideas.

“

Dr Dietmar Schlembach

Chairman of the Trustee Board of EFCNI

Head of the Department of Obstetrics and Gynecology

Vivantes Clinic Berlin-Neukölln, Germany



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. The international, transdisciplinary exchange with parents and colleagues, both practitioners and researchers, was eye-opening for everyone. 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.

”

The NICU of the future: design meets function

Our knowledge of how hospitalised term and preterm infants perceive, relate and are influenced by their surrounding environment has improved significantly during the last 20 years. Infants are negatively influenced by environmental stress that may destabilise respiratory and circulatory function. During intensive care treatment they may be exposed to toxic stress from painful procedures and a stressful physical environment with the absence of parents as caregivers and regulators of the infant's stress response. Toxic stress in preterm infants has been shown to influence gene expression through epigenetic mechanisms that may permanently change stress responses throughout childhood and maybe into adult life. Stress and permanent changes in gene expression seem to be a pathway for the finding of structural changes in the brain and suboptimal neuro-developmental outcome later in childhood.

In the traditional open-bay NICU with many infants in one large single room it is difficult for parents to be present for more than a few hours every day. Still an infant needs the parents 24/7 ready to sooth, comfort and regulate stress response whenever painful or stressful procedures are carried out. Designing a NICU of the future is therefore both an architectural, a medical and an ethical challenge

for the healthcare system. This responsibility and challenge has to be recognised by NICU staff, hospital administrators, hospital planners and architects.

The NICU of the future must provide a protective physical environment for the infant. The little patient is dependent on parents for regulation through skin-to-skin contact, breastfeeding, parental speech and olfactory stimuli. The experience from units with such an environment is that parents become the infant's best advocates: they protect their child from overstimulation, overdiagnosis and overtreatment. They are also able to support the infant developmentally and physically through days and weeks of painful and stress provoking intensive care treatment.

I once asked the father of a 27 weeks gestation preterm girl how he felt when he was handling his tiny baby girl and if he was afraid of doing something wrong. His answer was very simple; You do not need to worry at all; this child is my life and I would never ever do anything that could harm her. This is probably how most parents feel, and an important job for the staff is to educate and to empower parents and let them provide care and support for their child through stressful and potentially painful procedures.



Dr Atle Moen

Consultant in neonatology
at the Department of
Neonatology, Rikshospitalet,
Oslo University Hospital,
Norway

There are both scientific studies and practical experience of measures helping parents to stay in the unit with their child. Parents should be included in the care of their infant from day 1 and recognised as important members of the team caring for the child. Parents are not visitors to their infant, expected to leave when caring measures or procedures are performed. They should be introduced into daily care and as they get more experienced they can also be included in tasks and procedures traditionally considered nursing procedures like feeding through nasogastric tubes or replace the tube when it falls out.

Parents need protection from visual insight and have their own protected place next to their infant. They need at least a comfortable adjustable chair to sit in with their infant, but space for a full electrically adjustable hospital bed increases presence and skin-to-skin time significantly. Noise from alarms, loud speech or noise from medical equipment may contribute to a feeling of stress and discomfort. Not being able to turn off the light is also an obstacle for long-term presence of parents.

It is also a prerequisite for parental presence within a social security system to provide some economical compensation when they are absent from work to care for their infant.

NICU staff with experience from traditional open bay units with limited possibilities for parental presence often argue that it is stressful and not good for parents to stay too long in the unit, and that parents should go home or to work to “relax”. It is then important to remember that the reason



parents are stressed or unable to stay may very well be the physical environment and the verbal and non-verbal signals parents gets from the staff rather than fatigue of being with their child. When both staff attitudes and the physical environment support parental presence, studies show that most parents prefer to stay with their infant for most or all of the day's 24 hours.

In 2012 the NICU at Drammen hospital in Norway opened a new 17 bed NICU. The NICU cares for infants inborn from 28.0 weeks. Infants born even earlier or requiring surgical or advanced intensive care were born at the regional unit and transferred to Drammen when stable enough to tolerate the transport.

Until 2012 the Drammen hospital unit was a traditional open bay unit. In the new unit all infants and parents are allowed to stay together from birth until discharge. Each room has an outer area for the infant incubator and an inner area for parents with two high quality hospital beds 105 cm wide electrically adjustable to support parents giving skin-to-skin care. At day time there is no physical separation between the parents and infant area and all equipment (CPAP, pumps, ventilators) are mounted on flexible arms allowing easy transfer of the child from the incubator to the parents bed without disconnection for skin-to-skin care as often and as long as parents feel comfortable.

Each patient area includes a separate bathroom for parents. During night time there are flexible folding doors to lock off parents sleeping area, while there is still direct access to the infants caring area for nurses without interrupting parents.

Both parents are provided 3 daily meals in an area outside the room but inside the NICU unit where they are also offered the possibility of a relaxation area. All patient rooms have wireless network connection, but there is no TV inside the patient rooms to avoid disturbance of the child. Parents are allowed to use their computers for work and relaxation in the patient room but preferably with earphones.

The unit has wireless monitoring from the patient room directly to a phone in the nurse pocket with audio and visual alarms.

The main idea of the unit was not to build single rooms for infants; it was to provide a physical environment that optimises protection of the child and provides parents with an environment that makes it possible for them to stay 24/7 if they wanted.

The experience so far has been positive. More than 90% of parents appreciate the opportunity to stay with their infant and participate in care. Most parents stay more than 20 hours daily and sleep over night in the room. We regularly observe infants transferred from the regional unit with high oxygen requirements and frequent apneas that within hours reduce their oxygen requirements and improve cardiovascular stability due to less stress from sound and light.

It is challenging and sometimes difficult for the staff to change their way of thinking and work this close with parents present all the time. These challenges must be acknowledged in the process and preparations should start years





before the actual change of the caring environment. When moving to a new unit the most difficult part is to change the culture from a paternalistic culture of caregiving where we as staff “know best” to a relationship between staff and parents where shared decision making is the cornerstone of patient care. Shared decision making does not leave medical decisions to parents, but it is a fact that most of our treatment and daily practical decisions are based on local traditions and personal preferences and not on hard scientific evidence. These types of decisions may be explained and discussed with parents. Parents living together with their infant represent a superior continuity of care compared to staff going home after an 8 hours shift. Therefore, parents can often provide supplemental information about the state of the child that may reduce the need for blood tests, x-rays and other measures. After a few days, parents know their infant much better than the staff and therefore also may solve issues of instability or discomfort differently than doctors and nurses are used to.

The NICU of the future should envision the world from the infant’s point of view. NICU design must support the infant’s physical and developmental needs through a most critical and stressful period of life. In order to do that it must be designed to make it possible for parents to do their important job as the infant’s primary caregivers and advocates by staying in the unit and live together with their infant as much as they are able to, not limited by environmental stressors or staff attitudes.



2015 | EPICE/SHIPS

SHIPS is a European research collaboration building on the EPICE cohort which includes 6792 babies born before the 32nd week of gestation in 2011 and 2012 in 19 regions in 11 European countries. EFCNI is involved as partner adding patient perspectives and personal experiences to the research process and leading the activities for parental involvement as well as dissemination and outreach in SHIPS for example by developing informative materials, a social media strategy and promoting news and studies concerning the project.

A SHIPS Parent Advisory Board with now 16 parent representatives from the international EFCNI network was constituted. EFCNI makes sure there is regular personal contact between researchers and the national parent organisations on EFCNI's Annual Parent Organisations meeting and meeting with the project's Parent Advisory Board.



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 633724



2016 | RECAP preterm

RECAP preterm brings together European child to adult cohorts and a group of highly experienced organisations. The expertise of the partners covers a wide and complementary range of fields, including life course epidemiology, methodology, neonatology, paediatrics, early-life stressors, non-communicable disease research, epigenomics, economics, psychology, and mental health as well as e-learning technologies, eHealth/mHealth applications, communication, dissemination and project management. EFCNI's role in RECAP preterm lies particularly in leading all activities regarding dialogue, dissemination, and sustainability by reaching out to the scientific community, clinicians, healthcare professionals, patient organisations, the general public, policy makers, and other potential stakeholders at the national, European, and international level to increase the visibility as well as the health and societal impact of RECAP preterm. A particular focus will be placed on parents in the interaction and dissemination strategy in particular to identify and answer user-driven research questions and policy needs.



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 733280.

“

Dr Jennifer Zeitlin

Programme coordinator of SHIPS, Institut national de la santé et de la recherche médicale (INSERM), France



I think it is of very great value that EFCNI is actively involved in follow-up projects like SHIPS. These programmes ensure a thorough and long-term monitoring of infant development and EFCNI makes sure that parents' experiences and viewpoints are considered and that parents and health experts know about the importance of follow-up.

”

EFCNI as partner and coordinator in research:

Operating and networking on an international level from its beginning, the foundation could over time expand its area of accountability and became involved in national and transnational research projects. Thus, EFCNI is strongly incorporated in several scientific projects.

The SHIPS and the RECAP project are targeting long-term improvements in preterm health and quality of life of children born very preterm.



2016 | Human milk banks project

Spreading knowledge about the benefits of breastfeeding for both mother and child as well as the nutritious value of breast milk is paramount to EFCNI. EFCNI strongly promotes that breastfeeding is the best for every newborn. Nonetheless, sometimes breastfeeding and sustaining a steady milk supply can be very difficult especially for mothers of preterm babies, or the provision of own mother's milk might not be possible for a certain time because of a medical treatment the mother might receive. To ensure the supply of own mother's milk and donor milk for preterm babies, EFCNI initiates an international project in 2016 with the aim to support clinical centres in Germany, Switzerland and Austria in the setup and operation of human milk banks on a national level. For this purpose, a position paper containing recommendations for the support of milk banks as well as a toolkit for interested institutions has been developed by a project Scientific Advisory Board, composed of well-known experts in the fields of lactation, nutrition, obstetrics, and neonatology. The successful project is also cited in several publications. Moreover, in 2018, EFCNI hosts its first workshops on the topic in Frankfurt and Munich under the umbrella of the EFCNI Academy. Since it came into being, the milk banks project has been mentioned in national publications on the topic of breastfeeding.



Congresses and conferences



2009

EFCNI's first
medical congress
in Berlin



2010

UENPS Congress
in Istanbul



2013

Workshop in the
EU Parliament
in Brussels



2015

International G7/20
Parliamentarians' Conference
in Berlin

One incentive for EFCNI's founding is to step beyond the status of a parent self-help group addressing medical professionals and political decision makers. So, in order to gain access to healthcare professionals and representatives from the healthcare policy spectrum, EFCNI places itself in a position where it can inter-

act and make itself heard. Networking with medical experts, industry partners and politicians has been key in this regard. In 2009, the foundation hosts its first medical congress on preterm birth in Berlin. In 2013, EFCNI holds a conference together with the WHO at the Representation of the Free State of Bavaria to the



2015

jENS congress
in Budapest

European Union. Over time, the foundation managed to make the importance of the parent perspective in the provision of care clear and became a sought after speaker at conferences and congresses. It is a very special honour to be invited to speak at the International G7/20 Parliamentarians' Conference in Berlin in 2015.



2017

jENS congress
in Venice

On the occasion of its 10th anniversary, EFCNI hosts its own conference in Munich.



2018

The same year, EFCNI is co-organiser of the first jENS congress in Budapest. This congress marks a turning point in the history of medical congresses in the area of newborn health as it opens the doors for parental representatives to participate at a medial forum as visitors and also as contributors and speakers.

Awards

Ten years of EFCNI were coined by permanence, perseverance and persistence. Co-founder and Chairwoman Silke Mader kept her drive despite the obstacles and discouragements, she was confronted with along the way. If one door closed she and her team would try a different approach. This paid off and EFCNI and Silke Mader's commitment were awarded several times.



2013

Silke Mader is an awardee for the Prix Courage



2013

Silke Mader is awarded the Medal for Particular Services to Bavaria in a United Europe



2014

Silke Mader becomes Honorary Lecturer at the School of Nursing and Midwifery, Queen's University Belfast, Northern Ireland



2015

Silke Mader becomes an Ashoka Fellow



2016

Silke Mader wins the Iconic Innovative Trailblazer of the Decade award by the All Ladies League



2016

Silke Mader is honoured with the Bavarian States Medal for Health and Care



2017

EFCNI is awarded as distinguished place in a land of ideas by the initiative Deutschland – Land der Ideen

“



Matthias Scheffelmeier

*Partner at Ashoka Germany, Co-director Ashoka Europe,
CEO SEND e.V., Germany*

When it comes to systemic change we must not forget how important all the small initial steps are to eventually make change happen. It's a long way from an idea to a paradigm shift that takes creativity, commitment, and persistence. Silke Mader and her entire team at EFCNI have continually, by little and little, created awareness for the need for change in newborn health and established a network that puts ideas into practice.

”

Networking and empowerment

An alliance is always stronger than a lone fighter – it is as simple as that but cannot be emphasised enough: Thus, the ever growing network of EFCNI is the backbone of the foundation. It enables knowledge exchange, establishes contacts and places EFCNI in a position where it can make others benefit from those contacts and gained skills.

EFCNI-WHO conference “Caring for Tomorrow” on 5 March 2013 in the Representation of the Free State of Bavaria to the European Union, Brussels, Belgium



PHOTO: from left to right, Professor Dr Luc J.I. Zimmermann, Professor Dr Angelika Niebler, Professor Dr Matthias Keller, Silke Mader, Dr Dietmar Schlembach, Mandy Daly, Professor Dr Marleen Temmerman, Professor Dr Kypros H. Nicolaides

Since its early beginnings, the foundation has been aiming at bringing everyone involved in newborn health on the same table and to support and empower each other. The initial Parent Organisations Meeting in Rome in 2008 started the networking process amongst parent representatives but it almost immediately continued on a political and academic level.

Besides cooperating with parent organisations, EFCNI strives to combine forces and foster collaboration with the medical and scientific community. We are grateful to partner with healthcare professionals, scientists and their respective societies in many interdisciplinary projects, congresses, conferences, workshops or roundtables, always searching to improve and implement high-quality treatment and care, and improving the situation for pregnant women and newborns.

“



Professor Luc J.I. Zimmermann

Member of the Trustee Board of EFCNI

Past President of the European Society for Paediatric Research (ESPR)

Head of the Department of Paediatrics, School for Oncology and Developmental Biology (GROW), Maastricht UMC, The Netherlands

EFCNI brings together healthcare professionals, parents, and politicians with a single aim: To combine forces to improve standards of care, to nurture the development of needed infrastructure and to guarantee every baby the best start in life. The foundation is our link to other stakeholders in the field and we greatly appreciate their achievements.

”

“

Dr Peter Liese

Member of the European Parliament



It is of crucial importance to improve the quality of life of preterm infants and their families and to prevent preterm birth. Millions of families can benefit from improvements in this area, and money that we invest to improve the conditions or to avoid preterm birth is very well spent because it will improve conditions for these human beings throughout all their lifespan.

”

From 2009 onwards Professor Dr Angelika Niebler, Member of the European Parliament (MEP) has been supporting EFCNI as its patron. Together with her likeminded fellow, MEP Dr Peter Liese, they establish in 2010 an informal interest group within the EU Parliament, to place the important but often overlooked topic maternal and newborn health on the political agenda.

To raise awareness among their fellow colleagues, the interest group supports for instance a Socks for Life art exhibition (2013) as well as the kick-off event for the European Standards of Care for Newborn Health project (2014) and realises gatherings in the Representation of the Free State of Bavaria to the European Union and a parliamentary workshop on the topic of newborn health, set in the EU-Parliament (2015).





Healthcare societies, supportive organisations,

Global

ALL Ladies League / ALL
Ashoka
Council of International Neonatal Nurses / COINN
Early Nutrition eAcademy / ENeA
Every Newborn Action Plan led by WHO and UNICEF
Fetal Medicine Foundation / FMF
Global Alliance to Prevent Prematurity and Stillbirth / GAPPS
Global Breastfeeding Initiative
Healthy Newborn Network, an initiative of Save the Children's Saving Newborns Lives (SNL) program
International Consortium for Health Outcomes Measurement / ICHOM
International Federation of Gynecology and Obstetrics / FIGO
International Postgraduate Organization for Knowledge Transfer, Research and Teaching Excellent Students / IPOKRATES
Newborn Individualized Developmental Care and Assessment Program / NIDCAP
Partnership for Maternal, Newborn and Child Health / PMNCH
World Association of Perinatal Medicine / WAPM

Europe

Alliance for Childhood
Biomedical Research in Europe / BioMed Alliance
Confederation of Family Organisations in the European Union / COFACE
Early Life Nutrition Network
eNewborn
EUPATI
Eurochild
Euro-Peristat
Europe Against Infant Brain Injury / EURAIBI

European Academy of Paediatrics / EAP
European Association of Perinatal Medicine / EAPM
European Board and College of Obstetrics and Gynaecology / EBCOG
European Board of Neonatology / EBN
European Critical Care Foundation / ECCF
European federation of Critical Care Nursing associations / EfCCNa
European Federation of Nurses Association / EFN
European Hospital and Healthcare Federation / HOPE
European Lung Foundation / ELF
European Parliamentary Forum on Population and Development / EPF
European Patients' Forum / EPF
European Reference Network on Rare inherited and congenital abnormalities / ERNICA
European Respiratory Society / ERS
European Society of Intensive Care Medicine / ESICM
European Society for Paediatric Gastroenterology Hepatology and Nutrition / ESPGHAN
European Society of Paediatric Neonatal Intensive Care / ESPNIC
European Society for Paediatric Research / ESPR
Neonatal estimation of brain damage risk and identification of neuroprotectants / NEOBRAIN
PEARL – Pain in Early Life
Union of European Neonatal and Perinatal Societies / UENPS

National

Austria

Berufsverband Kinderkrankenpflege Österreich /BKKÖ
Österreichische Gesellschaft für Kinder- und Jugendheilkunde / ÖGKJ
Österreichisches Hebammen-Gremium / ÖHG

Bulgaria

Alliance of Bulgarian Midwives / ABM

and research partners

Germany

Arbeitsgemeinschaft Gestose-Betroffene
Ausbildungszentrum Laktation und Stillen
BabyCare - FB + E Forschung, Beratung + Evaluation GmbH
Berufsverband der Kinder- und Jugendärzte / BVKJ
Bildungsinstitut Fachbereiche Gesundheitswesen / BFG
Bundesverband Bunter Kreis
Deutsche Gesellschaft für Baby- und Kindermassage DGBM
Deutsche Gesellschaft für Gynäkologie und Geburtshilfe / DGGG
Deutsche Gesellschaft für Perinatale Medizin / DGPM
Deutsche Gesellschaft für Pränatal- und Geburtsmedizin / DGPGM
Deutsche Stiftung Kranke Neugeborene / DSKN
Erich Saling-Institute of Perinatal Medicine
German Neonatal Network / GNN
Gesellschaft für Neonatologie und Pädiatrische Intensivmedizin / GNPI
Harle.kin – Nachsorge in Bayern
Mutter-Kind-Hilfswerk
Neven Subotic Stiftung (WASH projects in Ethiopia)
projekt Anna – Kinderhilfe Kaliningrad (projects in Kaliningrad)
Sichere Ausbildung für Eltern / SAFE
Stiftung Ambulantes Kinderhospiz München
Stiftung für das behinderte Kind
Stiftung Kindergesundheit
Uplift-Aufwind (projects in Kyrgyzstan)
Welcome

Kazakhstan

Club "28 petel"

Latvia

Latvijas Neonatologu biedriba

Spain

Red de Salud Materno Infantil y del Desarrollo / Red SAMID

Sociedad Española de Neonatología

Switzerland

amiamusica

Berufsverband Schweizerischer Still- und Laktationsberaterinnen / BSS

Schweizer Berufsverband der Pflegefachfrauen und Pflegefachmänner / SBK

Schweizer Gesellschaft für Gynäkologie und Geburtshilfe / SGGG

Schweizer Gesellschaft für Neonatologie

Switzerland

National Institute for Health Research – Clinical Research Network Children / NHS

Tommy's

USA

Foundation for Premature Infants

International Neonatal Consortium – Critical Path Institute

March of Dimes

National Perinatal Association

Research Partners

Conect4children – Collaborative Network for European Clinical Trials For Children

Global Research in Paediatrics / GRIP

iPLACENTA – Innovation in Modelling Placenta for Maternal and Fetal Health

Medicines in pregnancy: predicting harms and benefits of antenatal corticosteroids

NeoCirc – neocirculation

SCENE – Separation and Closeness Experiences in the Neonatal Environment

SHIPS – Screening to improve Health In very Preterm infants in Europe

RECAP preterm – Research on European Children and Adults born Preterm



● Parent and patient organisations

● Healthcare societies, supportive organisations, and research partners



Parent and patient organisations

Argentina

Prematuros Grupo Crisálida

Australia

Life's Little Treasures Foundation
L'il Aussie Prens Foundation
Miracle Babies Foundation
National Premmie Foundation / NPF
Preterm Infants' Parents' Association / PIPA

Austria

FRÜH R LEBEN
Kleine Helden

Belarus

Baby Story
The RANO

Belgium

Néonid
Vlaamse Vereniging voor Ouders van
Couveusekinderen / VVOC

Brazil

Prematuridade

Bulgaria

Our Premature Children

Canada

Canadian Premature Babies Foundation-
Fondation Bébés Prématués Canadiens

Chile

Asprem - Asociación de padres de prematuros
Neovidas

China

Home for Premature Babies

Colombia

Fundación Milagros de Vida

Croatia

Klub roditelja nedonoščadi "Paličiči"

Cyprus

Friends of Neonatal Intensive Care Unit
Association Cyprus / FNICU
Mora Thavmata

Czech Republic

Nedoklubko o.s.

Denmark

Dansk Præmatur Forening

Dominican Republic

Pequeñas Vidas

Egypt

Our Dream

Estonia

MTÜ Enneaegsed lapsed

Finland

Kevyt / MLL Meilahden yhdistys ry

France

SOS Préma

Germany

Bundesverband „Das frühgeborene Kind“ e.V.

Ghana

LittleBigSouls
African Foundation for Premature Babies &
Neonatal Care / AFPNC

Greece

Ilitominon

Hungary

Koraszülöttekért Közhasznú Egyesület / KORE
Melletted a helyem Egyesület – Right(s) beside you
Association

Iceland

Fyrirburar

Ireland

Irish Neonatal Health Alliance / INHA
Irish Premature Babies

Israel

Lahav Association

Italy

Associazione Prematuri Alto Adige –
Frühgeborene Südtirol
Genitin Onlus
Piccino Picciò Onlus
Progetto Pulcino Onlus
Vivere Onlus

Latvia

Esmu Klat

Lithuania

Neišnešiotukas
Padedu Augti

FYR of Macedonia

Lulka

Mexico

Con Amor Vencerás
Nacer temprano... VIVIR EN GRANDE
Pequeño NuNu

Netherlands

Kleine Kanjers VOF
Vereniging Nee-eten!
Vereniging van Ouders van Couveusekinderen / VOC
Stichting Prematurendag

New Zealand

The Neonatal Trust

Nigeria

LittleBigSouls

Northern Ireland

TinyLife

Norway

Prematurforeningen

Poland

Fundacja Świadomi Rodzice
Fundacja Wcześniak Rodzice-Rodzicom

Portugal

Associação Pais Prematuros
XXS – Associação Portuguesa de Apoio ao Bebê
Prematuro

Romania

Asociația Prematurilor – Premies Association
Asociația Unu și Unu
Baby Care Sibiu

Russia

Fund “Give Sunshine”
Pravo Na Chudo – Right for a miracle

Serbia

Mali div - LittleGiant

Slovakia

Malíček

Spain

Asociación de Padres de Niños Prematuros / APREM
Asociación Valenciana de Padres de Niños
Prematuros / AVAPREM
Federación Nacional de Asociaciones de Prematuros
/ FNAP
Prematura

Sweden

Prematurföreningen Mirakel
Riksförbundet Svenska Prematurförbundet
Stiftelsen Tummeliten

Taiwan

Premature Baby Foundation of Taiwan / PBF

Turkey

El Bebek Gül Bebek Derneği

Ukraine

Ranni Ptashky (Early Birds) –
Ukrainian Premie Parent Association
Velvet Hearts

United Kingdom

Bliss
Children's Liver Foundation / CLDF
LittleBigSouls

Uruguay

Asociacion Uruguay de Padres con hijos
Prematuros / AUPAPREM

USA

Graham's Foundation
Hand to Hold
National Perinatal Association
Preeclampsia Foundation
Premie Parent Alliance

Vietnam

Newborns Vietnam

Global

International Federation of Spina Bifida and
Hydrocephalus / IFSBH
International Patient Organisation for Primary
Immunodeficiencies / IPOPI



● Parent and patient organisations

● Healthcare societies, supportive organisations, and research partners

EFCNI's goal: parents as partners

As making the patients' voice heard is paramount for EFCNI, the foundation puts a lot of effort in the training and set-up of national parent organisations.

"Self-help groups are important, but they usually aim at helping the individual. If we want to make a societal change, and improve the situation for every newborn, we need to think in larger terms. The parents have to be able to identify and address the right people in the right way", states Silke Mader.

After many years of experience EFCNI has developed guiding principles for defining a fair, equal and transparent interaction between parents, professionals, researchers and other stakeholders that ensures a long-term and mutually fruitful partnership.



What makes parent representatives so important?

- They build a link between patient community, professionals and other parties involved
- They increase the understanding for real-life challenges as well as patient needs, expectations, and priorities
- They act as spokesperson and networker to drive forward the need for specific treatments, services, or mind changes
- They conduct community awareness and educational programmes on the health topic and rights of patients
- They operate as change maker through constructive dialogue with political decision makers and opinion leaders
- They serve as information resource for patients' rights, advance directives and ethical issues.

“



Paula Guerra

*Parent Advisory Board of EFCNI, Co-founder of XXS –
Associação Portuguesa de Apoio ao Bebê Prematuro, Portugal*

Being the mother of a preterm born girl, I have been living the impact that preterm birth has on the children, their families and the society in general. Thanks to the good care my daughter received at the neonatal unit, she is now a healthy girl. It is important to support parents in such frightening situations, to inform them so they know their children's needs and rights. Informed parent's involvement crucially contributes to better responses to preterm babies and their follow-up.

”



Empowering parents

EFCNI has been organising international meet ups with parent organisations not only for networking but also to exchange know-how and experience.



In the meantime, the annual Parent Organisations Meeting has become a time honoured tradition. Once a year, EFCNI invites parent representatives from all over the world to the Parent Organisations Meeting. Started in 2008 with 25 participants from 14 organisations, now more than 70 attendees from about 30 countries come together for sharing ideas, exchanging experiences and learning from and discussing with invited experts. Since the very beginning, EFCNI has been organising workshops and trainings for the participants. The overall goal of these

meetings is to strengthen and professionalise the parental commitment and to foster exchange between organisations to improve the situation for preterm babies and their families. In addition to the annual Parent Organisations Meetings, EFCNI organises several workshops throughout the year to train parent representatives in different topics e.g. on the implementation of the European Standards of Care for Newborn Health in the health systems of their countries, in fundraising, social media management, media relations, research or project management.

Since 2014, the EFCNI Award ceremony has become another tradition of the annual Parent Organisations Meetings.



Each year, EFCNI honours parent organisations for their outstanding efforts and dedication in the field of maternal or newborn health with this trophy which is by the way made of acrylic glass and weighs 2 kilos (4 pounds).



2014

XXS – Associação Portuguesa de Apoio
ao Bebé Prematuro, Portugal

Our Premature Children, Bulgaria

Vivere / Piccino Piccio, Italy



2015

Vlaamse Vereniging voor Ouders van
Couveusekinderen (VVO), Belgium

Ilitominon, Greece

Fundacja Wczesniak
Rodzice-Rodzicom, Poland



2016

Neišnešiotukas, Lithuania

malicek, Slovakia

Nedoklubko, Czech Republic

Con Amor Vencerás, Mexico



2017

SOS Préma, France

Melletted a helyem Egyesület, Hungary

Irish Neonatal Health Alliance, Ireland



2018

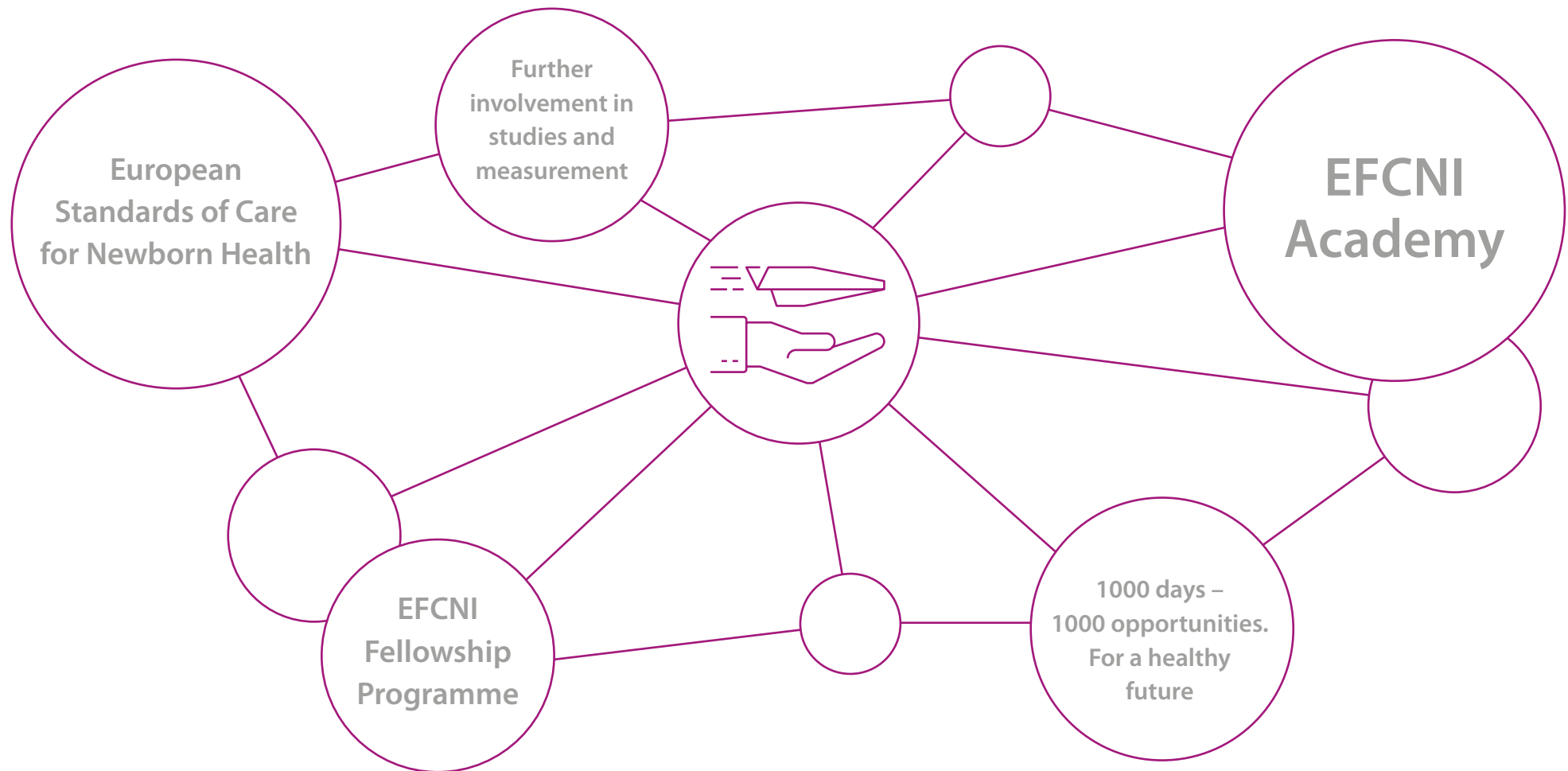
Bundesverband "Das frühgeborene Kind" e.V., Germany

TinyLife, Northern Ireland

Ranni Ptashky (Early Birds), Ukraine

Outlook & future plans

As a foundation aiming at improving neonatal and maternal health at an international level, EFCNI has the incentive to continually expand its network, its capacities and its opportunities to shape the future for every newborn. With our ongoing and upcoming projects, we want to gain and exchange knowledge, share best practice examples and keep on empowering the patient voice.



Outlook on the European Standards of Care for Newborn Health project

With the launch of the standards in autumn 2018 in Brussels, the implementation process of the standards has started. EFCNI will support institutions, organisations, parent groups and other involved or interested parties in bringing the standards into practice in the different countries. A toolkit will offer templates and guidance for media relations, information and endorsing activities. Expansion as well as revisions of the standards according to their individual life-cycle are going to be a regular task of the project.

1000 days – 1000 opportunities. For a healthy future

The first 1000 days of life are a unique window of opportunity to support child development and long-term health. At this point there is only limited awareness and knowledge regarding this important period of time across both parents and healthcare professionals. Hence, the foundation wants to raise awareness for the first 1000 days of life by informing and educating the various target groups. EFCNI's differentiation niche in this regards, is the focus on specific topics such as nutrition, life-style, breastfeeding, infant and family-centred developmental care, early support, skin-to-skin contact, and societal/financial frameworks.

Further involvement in studies and measurement

As platinum partner of the International Consortium for Health Outcomes Measurement (ICHOM), EFCNI supports the development of worldwide health outcome measurements that matter most to families of hospitalised and preterm neonates. A standardised measurement is developed by a transdisciplinary working group consisting of patients, health professionals, researchers, outcomes measurement experts and policy makers. The foundation is proud to have Professor Andreas Flemmer (Ludwig Maximilian University, Munich) chairing this project.

EFCNI Academy

EFCNI announces the launch of the EFCNI Academy in autumn 2018 at the congress of the German Association for Neonatology and Paediatric Intensive Care (GNPI) in Rostock, Germany. The EFCNI Academy will offer a wide range of trainings and workshops in line with the European Standards of Care for Newborn Health. At this stage the academy is designed as a standardised training concept with different modules for healthcare professionals. It will become a central pillar in sensitising and training healthcare professionals for the implementation of the standards in their daily practice.

The first German-speaking workshops organised in autumn 2018 under the umbrella of the EFCNI Academy focus on establishing and organising human milk banks. These workshops in collaboration with the Ludwig Maximilian University of Munich, are primarily aimed at physicians, nursing consultants and further healthcare professionals who intend to set up a human milk bank. Renowned experts give insights into the work of already established human milk banks and share their experiences from a clinical and nursing perspective. Further workshops with different cooperation partners and experts will follow and will, beyond providing trainings for healthcare professionals, also raise further awareness for the importance and practicability of the European Standards of Care for Newborn Health.

An EFCNI Fellowship programme

is being designed for the professionalisation of parent- and patient representatives. The parents and patients shall receive targeted information, courses and workshops on topics like networking, fundraising, policy and advocacy work as well as a professional PR, whilst the health professionals shall be trained in relation to their discipline and standard topic, e.g. human milk banks, parenteral nutrition, for paediatric nutritionists or lactation consultants and many more.

Organisational structure



Trustee Board

Thomas Föringer
Germany

Silke Mader
Germany

Dr Michael Poschmann
Germany

Dr Dietmar Schlembach (Chair)
Germany

Professor Luc J. I. Zimmermann
The Netherlands

Honorary Member
Professor Hercília Guimarães
Portugal

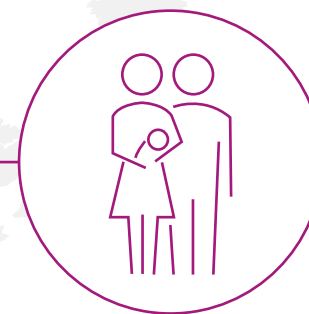


Executive Board

Silke Mader (Chair)
Germany

Professor Neil Marlow
United Kingdom

Nicole Thiele
Germany



Parent Advisory Board

Mandy Daly
Ireland

Paula Guerra
Portugal

Dr Tomasz Makaruk
Poland

Livia Nagy Bonnard
Hungary

Dr Gert Jan van Steenbrugge
The Netherlands

Dr Eleni Vavouraki
Greece

Yannic Verhaest
Belgium

Mónica Virchez
Spain



Scientific Advisory Board

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Germany

Professor Fiona Alderdice

United Kingdom

Professor Mats Blennow

Sweden

Dr Morten Breindahl

Sweden

Professor Giuseppe Buonocore

Italy

Professor Olaf Dammann

Germany/USA

Professor Gian Carlo Di Renzo

Italy

Professor Mats Eriksson

Sweden

Professor Ursula Flderhoff-Müser

Germany

Professor Andreas Flemmer

Germany

Odile Frauenfelder

The Netherlands

Professor Gorm Greisen

Denmark

Professor Pierre Gressens

France

Dr Boubou Hallberg

Sweden

Professor Dominique Haumont

Belgium

Dr Onno Helder

The Netherlands

Professor Ann Hellström

Sweden

Professor Lena Hellström-Westas

Sweden

Professor Moshe Hod

Israel

Professor Petra Hüppi

Switzerland



Scientific Advisory Board

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Sweden/Norway

Professor Linda Johnston
Northern Ireland

Professor Berthold Koletzko
Germany

Professor Pierre Kuhn
France

Dr Nicholas Lack
Germany

Professor Hugo Lagercrantz
Sweden

Professor Jos Latour
The Netherlands

Dr Atle Moen
Norway

Professor Kypros Herodotou Nicolaides
United Kingdom

Monique Oude Reimer van Kilsdonk
The Netherlands

Dr Carmen Pallás-Alonso
Spain

Professor Christian F. Poets
Germany

Professor Heike Rabe
United Kingdom

Professor Charles Christoph Roehr
Germany/United Kingdom

Professor Mario Rüdiger
Germany

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Spain

Professor Ola Didrik Saugstad
Norway

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The Netherlands

Dr Stefan Verlohren
Germany

Professor Gerard H. A. Visser
The Netherlands

Dr Axel von der Wense
Germany

Dr Björn Westrup
Sweden

Professor Dieter Wolke
United Kingdom

“

Professor Kypros Herodotou Nicolaides

Scientific Advisory Board of EFCNI

Professor of Foetal Medicine, King's College, London, UK,

Professor of Foetal Medicine, University College, London, UK,

Founder of the Fetal Medicine Foundation (FMF)



It is a true honour for my colleagues and myself to be part of EFCNI's Scientific Advisory Board. I am glad that I can contribute with my expertise and actively support EFCNI and the power set free by parents. Only by joining forces, and by working in open, honest partnership with patients and across disciplines and professions, can we reach the best for mothers, babies and their families.

”



Team

The story of EFCNI has become a story of success thanks to a committed and well attuned team. What started as a one-woman-show in 2008, was continued with the valuable work of Nicole Thiele from 2010 on. However, with an ever growing network, an increasing amount of projects, campaigns and ideas to improve newborn

Executive department



Silke Mader



Nicole Thiele

Administration and finances department



Aurelia Abenstein



Sylvie Baranger-Strobel

Scientific department



Dr Johanna M. Walz



Simone Cramer



Philine Altebäumer



Valerie Matthäus

and maternal health, EFCNI needed more (wo)manpower. Today, 15 committed employees, ranging from experts in public health and pharmacy, social sciences and communication to graphic design and office administration are handling the many different tasks at EFCNI. Last but not least, Snoopy, our office dog, does his bit to keep the office-spirits up!

Communications department



Judith Eckstein



Sarah Fügenschuh



Christine Schwaiger

Design department



Laura Staudt



Diana Hofmann-Larina

Working students



Phillip Heinrich



Manuel Kreitmair

Security & feel good management



Snoopy



We would also like to express our sincere thanks to all our former EFCNI team members for their work and support.

Acknowledgements

We express our warm gratitude to our Boards who have been instrumental in guiding EFCNI's mission with their insights, unique expertise and strong personal involvement.

We would like to sincerely thank the partnering healthcare societies, associations, parent and patient organisations and all our networking partners for their confidence in EFCNI and for their continued support over the past years.

We are extremely grateful to our committed community of voluntary supporters of healthcare professionals, parent and patient representatives, and the many individuals who have been contributing to the cause of EFCNI and to the cause of preterm birth and newborn health with their invaluable advice, expertise, knowledge and skills. Without them, EFCNI would not be where it is today.

Our heartfelt thanks go particularly to

Our patron

Professor Dr Angelika Niebler, Member of the European Parliament

Our ambassadors and supporters

René Böll, Artist/ painter, Germany

Stefan Marquard, (Celebrity-) Chef de Cuisine, Germany

Jakob Samuel, Musician and Songwriter, Sweden

Christine Strobl, 3rd Mayor of Munich, Germany

Robert Wells, Musician, Composer and Songwriter, Sweden

The European Parliamentary Interest Group for Maternal and Neonatal Health

Founding members and chairs

Professor Dr Angelika Niebler, Member of the European Parliament

Dr Peter Liese, Member of the European Parliament

and the Members of the Interest Group

Our partners

AbbVie, Ashoka, Baxter, Bird & Bird, Bübchen, Carry Each Other Stiftung für frühgeborene Kinder, Chiesi, Clarins, Comeo, Dräger, DSM, Ferring, Hans Werner Melchior, Hill+Knowlton Strategies, Hogan Lovells, Kolja Stegemann, Lyomark, MCA Scientific Events, Martina Merz, Medela, Natus, Nestlé, Nestlé Nutrition Institute, Novartis, Perkin Elmer, Philips, Philips Avent, Shire, Talent Coaching Klaus Siefert, Thermo FisherScientific, UCB, and Vygon.

Closing words



Back in 2010, when I met Silke Mader, I was instantly excited about the concept of EFCNI and wanted to make my contribution to giving preterm babies and their families a voice. Looking back at the past 8 years, working for EFCNI was – and continues to be – a challenging but also a very gratifying task, especially now that we start seeing the fruits of our hard work.

I grew up in a family affected by an extreme preterm birth, so I am aware of the traumatic consequences a preterm birth can have on parents, siblings, and the entire family (even across generations). I am therefore convinced that we must support the afflicted families from the first moment the baby is born, and must ensure that our babies receive equitable access to quality care so they can thrive beyond survival and develop to their best potential.

EFCNI started out as a small group of people wanting to make a change in newborn health, and today we have become a quite large organisation with 16 employees who work every day with incredible personal commitment, creativity and joy. Our network grew as well, from a handful of parents and healthcare professionals to a strong, dedicated international network of supporters.

It makes me proud to be part of this network and to see what we already accomplished: EFCNI managed to put preterm birth on the political agendas, nationally and globally, we

addressed numerous healthcare professionals, clinic administrators, policy makers, researchers and industry representatives, advocating for change in newborn health. In the more recent years, we also started to partner in research projects and initiated own projects to increase the knowledge in newborn health by developing, for example, the first European Standards of Care for Newborn Health (ESCNH) and the new EFCNI Academy offering evidence-based medical education to healthcare professionals. All of these individual projects contribute to our goal to make change happen.

A big thank you to all our partnering parent and healthcare organisations, our scientific and medical advisors, our corporate partners and supporters for 10 remarkable years of trust, kindness, friendship, and support. We absolutely couldn't have done it without you, nor can we take the next steps without your support, your expertise and knowledge. We are looking forward to the next 10 years of collaboration – let's give preterm babies and their families a voice, now and in the future.

Sincerely yours,

A handwritten signature in blue ink, reading 'Nicole Thiele'.

Nicole Thiele

Vice Chair of the Executive Board



Thanks to your donation, EFCNI is able to help

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



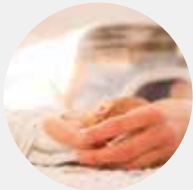
Donate now: single donations

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



Become a Member of the I-Care Programme

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



Become a Bodyguard

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



Give a donation instead of a gift

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



Corporate Giving

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



*Despeena, born at 24 weeks
weighing 820 grams*

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

Bank fuer Sozialwirtschaft

Account owner: EFCNI

BIC: BFSWDE 33 MUE

IBAN: DE 66 700 205 00 000 88 10 900

EFCNI is a registered charity certified by the Munich Tax Office as eligible for support, certificate dated 26.08.2016, tax reference number 143/235/22619 and therefore can issue donation receipts.

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

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

donations@efcni.org

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

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

Chronic



- First public celebration of *International Prematurity Awareness Day*

- EFCNI hosts first own congress on preterm birth in Berlin

- Benchmark Report *Too little, too late* published in Brussels
- Nicole Thiele joins EFCNI as first employee
- Starting a network of supporters in the EU Parliament
- Introducing the international *Socks for Life* campaign; the small socks line becomes the signature feature

2008

- Founding of EFCNI in April 2008
- Developing a distinctive design and logo
- EFCNI releases charity song *Sing me another song* composed and donated by Swedish composer and songwriter Robert Wells

- 17th November declared as *International Prematurity Awareness Day* on first Parent Organisations Meeting in Rome, Italy



2009

2010

- First election of the Parent Advisory Board
- EFCNI exhibits at the *European Academy of Paediatric Societies (EAPS)* in Copenhagen





- Publication of the *A healthy pregnancy* brochure, adding the spectrum of maternal health to the foundation's portfolio
- **EFCNI is supporting organisation, technical editor and co-author of *Born too Soon – The Global Action Report on Preterm Birth***

competence centre
for maternal and
newborn health and
aftercare services



- EFCNI moves into its new Munich headquarters



european standards of
care for newborn health

- Silke Mader is awarded the *Prix Courage*
- **Start of the large-scale project *European Standards of Care for Newborn Health (ESCNH)***

2011

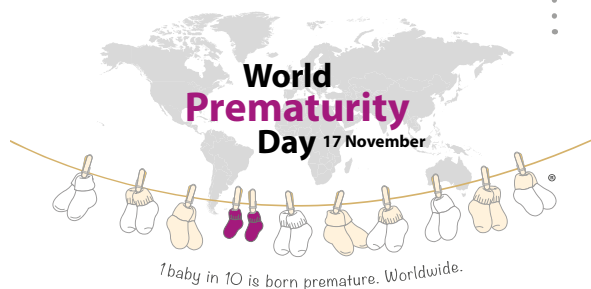
- *International Prematurity Awareness Day* is renamed in *World Prematurity Day*
- **White Paper *Caring for Tomorrow* includes perinatology, neonatology and follow-up care in one paper for the first time**

2012

- *World Prematurity Day* is celebrated together with supranational cooperative partners
- EFCNI is patient representative at the World Health Organization (WHO)
- ***World Prematurity Day* gets its own logo and partner organisations initiate purple lightings of landmarks all over the world**

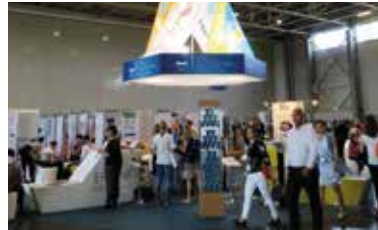
2013

- Silke Mader is awarded the *Medal for Particular Services to Bavaria in a United Europe*
- **EFCNI and the WHO give a joint conference on maternal and newborn health at the Bavarian representation in Brussels**





- **Launch and kick-off event for**
● *European Standards of Care for*
● *Newborn Health (ESCNH) at the EU*
● **Parliament with an art exhibition**
- Silke Mader becomes honorary lecturer
● at the *School of Nursing and Midwifery,*
● Queen's University Belfast, Northern
● Ireland



- Co-organiser of the first Congress of joint European Neonatal Societies (jENS) in Budapest, Hungary – the first medical congress actively integrating parent representatives



- Silke Mader is honoured with the *Bavarian State Medal for Health and Care*
- Start of the transregional *Milk Banks Project*
- Launch of the *A Strong Start for Little Heroes* campaign





- EFCNI gets involved in further EU-funded research project *Research on European Children and Adults born Preterm (RECAP preterm)*

- 14th Parent Organisations Meeting
- Launch of the *European Standards of Care for Newborn Health in Brussels*
- On the occasion of its 10th anniversary, EFCNI hosts a national congress on *Neonatology of the future* in Munich, Germany

2017

- EFCNI is awarded as a *Landmark 2017* by the initiative *Germany - Land of Ideas*
- Co-organisator of 2nd *jENS Congress* in Venice, Italy
- Publication of Position Paper *Involvement of parent representatives in neonatal research*



2018



10 years of EFCNI
2008 – 2018

Imprint

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EU Transparency Register ID Number: 33597655264-22

Visit us on



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