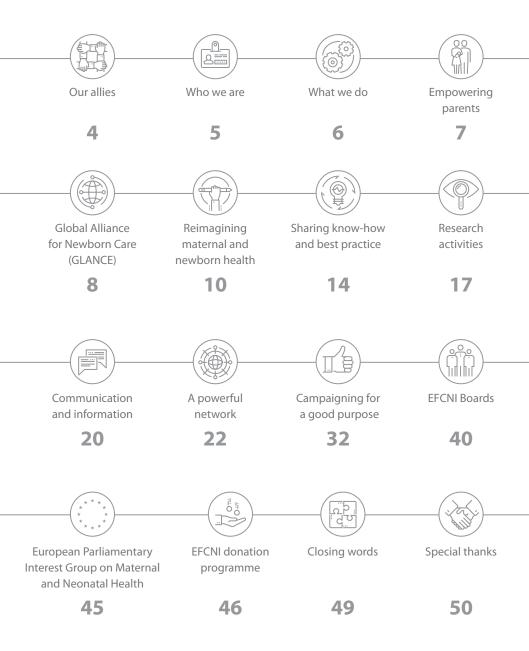
hor the hest start in life



Content





Our allies



Professor Dr Angelika Niebler

Member of the European

Parliament

Approximately one in ten babies is born too soon. Worldwide. Preterm babies represent Europe's largest child patient group and their number is continuing to grow, yet their voice has still to be heard. These children, together with their parents, experience enormous physical, emotional and financial challenges. They also represent an added burden on our often struggling healthcare systems.

Health is a very important issue for Europe's citizens and thus a priority for European institutions, in particular the European Parliament.

As a Member of the European Parliament, as well as a woman and a mother, I welcome the work of EFCNI. The foundation addresses the needs of preterm and newborn children and turns the spotlight on the various maternal and newborn health policies and practices in place within Europe's Member States. As a patron of EFCNI, I am delighted to be able to actively support the foundation in Brussels to ensure that Europe's children receive the best start in life.



Dr Eleni Vavouraki

Co-founder and President of the Greek Parent Organisation Ilitominon Member of the EFCNI Parent Advisory Board

EFCNI has strengthened the political impact of national parent organisations by uniting them in a strong network. The parents' voice is powerful and together we can make a change for preterm babies.



Professor Luc J. I. Zimmermann

Senior Medical Director of EFCNI
Past President of the European Society for
Paediatric Research (ESPR)

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.

Who we are

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.

To achieve our aims, we are focusing on the following three areas:



Preconception and maternal care

We want to ensure widely accessible pregnancy information and the provision of effective, equitable high-quality care for all women of reproductive age.



We aim at continuously improving treatment and care for all preterm babies and ill newborns as well as support for their families.





Follow-up and continuing care

We seek to improve the long-term health and quality of life of preterm babies and ill newborns. This also includes the provision of medical, psychological, socio-pedagogical, and financial support for these children and their families.





What we do

EFCNI is an advocate for preterm babies, ill newborns, and their families. Our work is dedicated to improving the situation of pregnant women and newborns in Europe across the full spectrum of care, promoting and protecting the right to the best start in life. Our work is based on the following three pillars:

Establishing a powerful network

We combine forces of all stakeholders involved and foster collaboration to achieve our common vision by:

- Partnering with parents, healthcare professionals, scientists and their respective societies as well as with policy-makers, international non-profit and private sector organisations
- Empowering national parent organisations through networking events, special trainings and workshops

Raising awareness

We call attention to the growing challenge of preterm birth and its significant impact on children, families, and our society by:

- Running awareness campaigns
- Constructive dialogue with political decision-makers and opinion-leaders
- Making the patient's voice heard in the healthcare setting

Sharing best practice

We develop and disseminate knowledge to improve and implement high-quality treatment and care by:

- Coordinating interdisciplinary projects
- Providing easy-to-understand and widely accessible information for families and professionals
- Participating in research and providing advice from the patient's perspective
- Organising and hosting conferences, workshops, and roundtables
- Developing factsheets and position papers
- Strategic Consultancy of companies in dealing with parent organisations

Empowering parents



Participants of the 1st Parent Organisations Summit in Freising, Germany, January 2020

Parent Organisations Summit

The annual *Parent Organisations Summit* (formerly known as Parent Organisations Meeting) has become a time-honoured tradition. Once a year, EFCNI invites parent representatives from all over the world to an international gathering. Initiated in 2008 with representatives of 14 organisations, now up to 100 attendees from more than 30 countries come together to share ideas, exchange experiences, gain new skills in workshops, and discuss with invited experts. The overall goal is to provide a platform to strengthen and professionalise parent organisations, in order to advocate and act as well informed dialogue partners, representing the interests of families.



EFCNI Award

Every year, EFCNI honours parent organisations for their outstanding commitment towards preterm birth. The festive annual EFCNI Awards ceremony takes place as a side event at the Parent Organisations Summit.

Professionalising parent organisations

Besides workshops and trainings for the participants of the Parent Organisations Summit, EFCNI hosts 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 on a national level, in fundraising, social media management, media relations, research or project management.





Global Alliance for Newborn Care (GLANCE)





The *Global Alliance for Newborn Care (GLANCE)* is a global network to represent the interests of babies born too soon, too small or too sick and their families. Initiated and coordinated under the umbrella of EFCNI, GLANCE aims at including parents from all parts of the world to exchange knowledge and experience. GLANCE aspires to decrease the burden of afflicted families and their preterm and sick newborns to help them thrive beyond survival.

GLANCE was founded and became a registered trade mark in 2018.

In July 2019, GLANCE welcomed its 14 international parent and patient representatives for the Founding Committee Meeting with the goal to lay the foundation for the first steps of GLANCE.





Every baby born receives the best start in life. Worldwide.

Reimagining maternal and newborn health



EFCNI Benchmark Report and White Paper

EFCNI's efforts to improve the quality of maternal and newborn health worldwide started with policy activities in the European Parliament and the publication of:

2010 | Benchmark Report

Too little, Too late – Why Europe should do more for preterm infants

2011 | Caring for Tomorrow the EFCNI White Paper on Maternal and Newborn Health

and Aftercare Services

The reports and further evidence showed that the organisation, structure, and provision of care, as well as the education of healthcare professionals vary widely across Europe. Although much progress has been made to improve survival and outcomes in the past years, there were no cross-European guidelines for newborn health so far.

To address these disparities, EFCNI started a milestone project in 2013 to develop *European* Standards of Care for Newborn Health.

European Standards of Care for Newborn Health





In November 2018, EFCNI launched the European Standards of Care for Newborn Health in the European Parliament in Brussels and online on the project website **www.newborn-health-standards.org**, where they can be downloaded free of charge. The aim of the European Standards of Care for Newborn Health is to ensure that babies receive the best possible care no matter where they are born.

In an interdisciplinary collaboration over five years, about 220 renowned international health-care experts, patient representatives and further stakeholders from over 30 countries developed reference standards for newborn health. In addition, the standards are supported by over 170 healthcare professional societies and parent organisations (June 2020).

In order to cover the complexity of neonatal care, the following 11 overarching key topics were indentified: starting from birth and transfer, to medical care and clinical practice, ethical decision-making and palliative care, to follow-up and continuing care.







It is an unique project, as for the first time, such standards have been initiated by a patient organisation. Additionally, parent representatives (speaking for the little patients - preterm and ill babies) have been involved in every step in setting up this new framework and working hand in hand with healthcare professionals. Only the voluntary contribution and commitment of the involved experts and patient representatives made this project possible.

In 2017, the project was awarded one of the most innovative Landmarks by the initiative Germany – Land of Ideas. Furthermore, the standards were featured within several publications and the Lancet Child & Adolescent Health issued a full editorial on the standards. All around Europe, diverse initiatives by parent representatives in collaboration with healthcare professionals that aim to implement the standards on a national level have been started since the official launch of the standards.

The project is continuously supported financially by the project industry partners AbbVie, Takeda and Nestlé Nutrition Institute. Thanks to the industry partners that supported the project in the past: Dräger from 2013 to 2015, Shire from 2014 to 2018, Philips Avent from 2014 to 2019, Baxter from 2017 to 2019 and Philips from 2018 to 2019.

The European Standards of Care for Newborn Health and further materials (e.g. brochures, project report, toolkit, graphics) are available for download:

www.newborn-health-standards.org

European Standards of Care For Newborn Health - Toolkit

The toolkit *Shaping the future – Combining forces to improve newborn health* is available for download and aims to facilitate and support the implementation of the European Standards of Care for Newborn Health.

Changes in healthcare policies start at a national and even quite often a regional or local level and every one of us can make a difference.

This toolkit is giving guidance on how to identify actions required in the specific country and is giving help put standards of care for newborn health into practice.

The toolkit provides knowledge and background information about the standards, ideas, tools, and step-by-step advice. Many practical examples serve as an inspiration in order to raise awareness and engage with national stakeholders.

Measuring patient-focused health outcome As platinum partner

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 preterm and hospitalised neonates.

The transdisciplinary working group is led by Professor Dr Andreas W. Flemmer (Div. Neonatology University Children's Hospital and Perinatal Center, Ludwig Maximilian University, Munich, Germany). It consists of international clinical and registry leaders, as well as patient representatives. They review current measurement initiatives, existing literature and gather patient input through guided discussions and validation surveys. A series of teleconferences facilitates consensus building on the proposed standard set.

The standard set on preterm and hospitalised neonates will allow healthcare providers to use the clinician and patient-reported outcomes to evaluate the quality of care, develop care plans and treatment pathways. The standardised outcome data can be used for global benchmarking, to learn from each other and improve care protocols.



Official Launch Event of the standards at the European Parliament in Brussels, Belgium, November 2018
From left to right: Prof. Dr Dr Dieter Wolke, Dr Martin Weber, Prof. Dr Mats Eriksson, Silke Mader, Prof. Dr Andreas Flemmer,
Prof. Dr Angelika Niebler, Dr Eleni Vavouraki, Livia Nagy Bonnard, Prof. Dr Charles Christoph Roehr, Dr Jennifer Zeitlin





Sharing know-how and best practice

EFCNI Academy





The EFCNI Academy is an international education programme for healthcare professionals under the umbrella of the European Foundation for the Care of Newborn Infants (EFCNI). Lectured by the most experienced professionals in the care field, the EFCNI Academy offers high-quality training including workshops, seminars, and conferences with the mission to provide and share the highest standard of care for maternal and newborn health.

Established in 2018 with the motto 'Learn and share for better care', the EFCNI Academy started with training opportunities in the field of nutrition, namely on the setup and organisation of human milk banks. The range of workshops and topics is continuously being extended.



Workshop on the setup and organisation of human milk banks, Hamburg, Germany, October 2019

Within the EFCNI Academy, workshops on the setup and organisation of human milk banks were carried out in 2018 and further workshops take place in Germany in 2019 and beyond. During the one-day workshops, experts give insight into the work of established human milk banks and share their experiences and expertise. The workshops are intended for neonatologists, nurses, lactation consultants, as well as other healthcare professionals who are interested in the setup and operation of a human milk bank.

Expert meetings

In order to achieve clinical and structural improvements for preterm and ill babies, EFCNI organises roundtables on a defined healthcare topic. Renowned experts come together to exchange views, discuss the current state of evidence and develop recommendations. The outcome, professional standpoints, and proposed solutions are documented in summaries or position papers.

Examples of topics covered by EFCNI roundtables and position papers so far:

- Camera systems for live streaming in the neonatal intensive care unit (NICU)
- Neonatal parenteral nutrition
- Respiratory syncytial virus (RSV)
- Setup and organisation of human milk banks

Download the position papers at: www.efcni.org/downloads



Meeting of the project scientific advisory board on the setup and organisation of human milk banks, Munich, Germany, April 2017

The scientific advisory board of EFCNI's milestone project to support clinical centres in the setup and organisation of human milk banks on a national level, consisted of renowned experts in the fields of lactation, nutrition, obstetrics, and neonatology from Germany, Austria and Switzerland. In a number of meetings, they developed a position paper with recommendations for the support of human milk banks as well as a toolkit with examples of best-practice, concrete instructions, and different templates.





Conferences and congresses

EFCNI is a frequent speaker at scientific conferences and congresses in the field of maternal and newborn health and puts the patient perspective on the scientific agenda, for example at the Annual Meeting of the German Society for Neonatology and Paediatric Intensive Care Medicine (GNPI), the Congress of the European Academy of Paediatric Societies (EAPS), the Congress of joint European Neonatal Societies (jENS), and the World Congress of Perinatal Medicine (WCPM).

EFCNI is also actively involved in the development of scientific programmes of key congresses in close collaboration with research societies, e.g. of the *Congress of joint European Neonatal Societies* (*jENS*). In addition, EFCNI organises its own scientific congresses in cooperation with healthcare experts.

The Congress of joint European Neonatal Societies (jENS) is the first international neonatology congress in which patient representatives team up in an equal partnership with healthcare professionals to develop and contribute to the scientific programme. Since the first jENS congress in Budapest in 2015, as well as in the following years, EFCNI has been one of the organising societies and part of the executive committee. In several pre-courses and (plenary) sessions, EFCNI brings parent and patient perspectives to the scientific discussion.





EFCNI at jENS congress,

Maastricht, Netherlands 2019

On our website we provide a detailed overview on all important conferences and congresses in this field and marked those where you can meet EFCNI. View more at: www.efcni.org/conferences-congresses

Research activities

EFCNI research participation



EFCNI continuously expands its research activities. To this end, the foundation works in close collaboration with the EFCNI Parent Advisory Board, parent organisations, healthcare professionals, and other relevant stakeholders. The aim is to incorporate the parents' perspective and experience into different projects in the field of maternal and newborn health. In addition, there has been a growing interest by researchers and research institutions to take the patient perspective in healthcare research into account.

In 2017, EFCNI conducted a survey among 50 parent organisations worldwide and developed a position paper on the involvement of parent representatives in neonatal research.

The publication highlights current challenges and gaps as experienced by EFCNI and its partner organisations and suggests principles towards an infrastructure and framework that will lead to a beneficial partnership between both parties. This shall serve as a basis for a structured and meaningful involvement of parent representatives in future research projects.



Working meeting of the former EFCNI Parent Advisory Board in Freising, Germany, January 2017





EU-funded research projects

As a partner in national and transnational research projects, EFCNI was and is strongly involved in several EU-funded projects targeting long-term improvements in preterm health and quality of life of children born very preterm:



Duration: 2017 - 2021

www.recap-preterm.eu

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



Duration: 2018 - 2024

www.conect4children.org

This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 777389.



Duration: 2018 - 2023

www.ed.ac.uk/usher/research/ projects/co-opt

This project has received funding from the Wellcome Trust Clinical Career Development Fellowship.

Research on European Children and Adults born Preterm (RECAP preterm)

The project intends to build a bridge from data collection to data sharing by developing a digital platform for harmonising and exploiting data of different European cohort studies with babies, children and adults born preterm, as well as incorporating data from Nordic registries.

EFCNI is leading the work package on "Dissemination, Translation and Sustainability".

conect4children (c4c)

c4c is a large collaborative European network that aims to facilitate the development of new drugs and other therapies for babies, children and young people.

As a Third Party, EFCNI adds the patient perspective and experiences and provides input to the development of educational materials addressed to patients and parents.

Consortium for the study Of Pregnancy Treatments (Co-OPT)

The project studies the use of antenatal corticosteroids treatment (ACT) by using large datasets in order to predict harms and benefits of this treatment.

EFCNI assists in identifying members for a parental advisory board who consults on the project.

Brain injury in the premature born infant: stem cell regeneration research network (PREMSTEM)

EFCNI has the role of work package leader in the project representing preterm infants and their families. Furthermore, the goal is to increase the visibility and impact of PREMSTEM on health and society by disseminating the knowledge gained in the project.

With the help of fifteen partners from eight countries, PREMSTEM researches if stem cells can be used to regenerate the brain damage caused by preterm birth. To 'rebuild' the damaged areas of the brain, scientists will use human stem cells taken from umbilical cord tissue.

TREOCAPA – Prophylactic treatment of the ductus arteriosus in preterm infants by acetaminophen (paracetamol)

TREOCAPA is a clinical trial that studies the effect of paracetamol on the closure of the ductus arteriosus in preterm infants. The ductus arteriosus is a vessel that allows the blood to avoid the lungs when the baby is still in the womb. After birth this connection needs to close, which often does not happen in preterm babies.

EFCNI set up and maintains a parent advisory board for this trial, which adds the patient perspective and experiences to this project. Also dissemination is the responsibility of EFCNI.



Duration: 2020 - 2024

www.premstem.eu

PREMSTEM is funded by the European Union's Horizon 2020 Research and Innovation program, Grant Agreement number 87472. 2020-2025.



Duration: 2021 - 2024

This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 777389. The Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA.





Communication and information



Our websites

The EFCNI website provides tailored, evidence-based and up-to-date information on topics related to pregnancy, preterm birth, and newborn health, as well as valuable links to our network. View more at:

www.efcni.org

The European Standards of Care for Newborn Health are featured on a separate website and are freely accessible via:

www.newborn-health-standards.org

Information about GLANCE (The Global Alliance for Newborn Care) is available from World Prematurity Day, 17 November 2019 at:

www.glance-network.org

Our newsletter

In our monthly newsletter, we compile news about our projects, feature remarkable activities from our network partners as well as latest research news.

Sign up for our newsletter at: www.efcni.org/newsletter

Social media

Via our social media channels, we promote current information and recent findings related to preterm birth and newborn health, as well as recommendations for a healthy pregnancy and child development.



Follow us on **f** in **O**









Our brochures

Our brochures and factsheets provide the most important information in a nutshell, concisely highlight key points and answer the most important questions on the specific topic.

Examples:

Bonding and care for preterm babies

This brochure explains developmental care and why parents are the most important persons in their child's

A healthy pregnancy

The brochure provides an overview of the most important topics during pregnancy. Valuable information and tips support parents-to-be in giving their baby the best conditions for a good start in life.

Breast milk for preterm babies

This brochure addresses parents of preterm babies offering extensive advice on how to breastfeed their baby plus valuable information on the benefits of breast milk regarding nutritious aspects and emotional bonding.

Our factsheets

Our factsheets cover several preterm birth and maternal health topics, e.g. the *Respiratory Syncytial Virus* (RSV), Pre-eclampsia, Breastfeeding a preterm baby, or Parenteral nutrition for very preterm and ill babies.



All EFCNI brochures and factsheets (in different languages) are available for free download at: www.efcni.org/downloads





A powerful network





Parent and patient organisations

Global

International Federation of Spina Bifida and

Hydrocephalus (IFSBH)

International Patient Organisation for Primary

Immunodeficiencies (IPOPI)

National

Argentina

Prematuros Grupo Crisálida

Australia

Life's Little Treasures Foundation (LLT)

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

Brazilian Parents of Preemies' Association

Prematuridade

Bulgaria

Our Premature Children Foundation (OPCF)

Canada

Canadian Premature Babies Foundation (CPBF) · Fondation Bébés Prématurés Canadiens (FBPC)

Life with a Baby (LWAB)

Colombia

Fundación Milagros de Vida

Costa Rica

Fundación para Padres de Niños Prematuros Costa Rica

(FUNDAPREMA)

Croatia

Klub roditelja nedonoščadi "Paličići"

Cyprus

Thermokoitida Agapis

Mora Thavmata

Czech Republic

Nedoklubko z.s.

Denmark

Dansk Præmatur Forening

Dominican Republic

Pequeñas Vidas

Egypt

Our Dream Project

Estonia

MTÜ Enneaegsed lapsed

Finland

Keskosvanhempien yhdistys Kevyt (MLL Meilahden

yhdistys ry, KEVYT)

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 Egyesulet – Right(s) beside you

Association

Iceland

Fyrirburar

Ireland

Irish Neonatal Health Alliance (INHA)

Israel

LAHAV - For the premature babies in Israel

Italy

Associazione Prematuri Alto Adige – Frühgeborene

Genitin Onlus

Piccino Picciò Onlus

Progetto Pulcino Onlus

Vivere Onlus

Parent and patient organisations

Latvia

Esmu Klāt

Lithuania

Neišnešiotukas Padedu Augti

The Republic of North Macedonia

Lulka

Mexico

Con Amor Vencerás

Nacer Temprano... Vivir en grande

Pequeño NuNu

Moldavia

Vitae

The Netherlands

Hellp Stichting Kleine Kanjers VOF

Vereniging Nee-eten!

Vereniging van Ouders van Couveusekinderen (VOC)

New Zealand

The Neonatal Trust

Nigeria

LittleBigSouls

Northern Ireland

TinyLife

Norway

Prematurforeningen

Poland

Fundacia Świadomi Rodzice

Fundacia Wcześniak Rodzice-Rodzicom

Koalicja dla Wcześniaka

Portugal

Associação Pais Prematuros

Nascer Prematuro

XXS – Associação Portuguesa de Apoio ao Bebé

Prematuro

Romania

Asociatia Prematurilor Asociatia Unu si Unu

Baby Care Sibiu

Russia

The Charity Fund "Give Sunshine"

Pravo Na Chudo – Right for a miracle

Providenie Charity Foundation for Premature Babies

and Their Parents

Serbia

Mali div – LittleGiant

Slovakia

Malíček

Spain

Asociación de Padres de Niños Prematuros (APREM)

Federación Nacional de Asociaciones de Prematuros

(FNAP)

PREMATURA

Sudan

Le Yahia Sweden

Prematurföreningen Mirakel

Riksförbundet Svenska Prematurförbundet

Taiwan

Premature Baby Foundation of Taiwan (PBF)

Tansania

Doris Mollel Foundation (DMF)

Turkey

El Bebek Gül Bebek Derneği

Ulkraina

Ranni Ptashky (Early Birds) – Ukrainian Preemie Parent

Association

United Kingdom

Dlice

Children's Liver Disease Foundation (CLDF)

Leo's Neonatal LittleBigSouls

Uruguay

Asociacion Uruguaya de Padres con hijos Prematuros

(AUPAPREM)

USA

Graham's Foundation

NICU Parent Network

Hand to Hold

Preeclampsia Foundation

Vietnam

Newborns Vietnam

Healthcare societies, supportive organisations, and research partners

Global

ALL Ladies League (ALL)

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

Global Sepsis Alliance (GSA)

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 Gynaecology and Obstetrics

International Neonatology Association (INA)

International Paediatric Association (IPA)

International Postgraduate Organization for Knowledge Transfer, Research and Teaching Excellent Students (IPOKRaTES)

National Perinatal Association (NPA)

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

Furochild

Euro-Peristat

Europe Against Infant Brain Injury (EURAIBI)

European Academy of Paediatrics (EAP)

European Association for children in hospital (EACH)

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 Medicines Agency (EMA)

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

European Society for Paediatric Research (ESPR)

Neonatal estimation of brain damage risk and identification of neuroprotectants (NEOBRAIN)

Pain in Early Life (PEARL)

Union of European Neonatal and Perinatal Societies (UENPS)

National

Albania

Albanian Pediatric Society (APS)

Austria

Berufsverband Kinderkrankenpflege Österreich (BKKÖ)

Österreichische Gesellschaft für Kinder- und Jugendheilkunde (ÖGKJ)

Österreichische Gesellschaft für Prä- und Perinatale Medizin (ÖGfPPM)

Österreichisches Hebammengremium (ÖHG)

Belaium

Belgische Vereniging voor Neonatologie (BVN) -Groupement Belge de Néonatologie (GBN)

Belgische Vereniging voor Kindergeneeskunde (BVK) -Société Belge de Pédiatrie (SBP)

Kind en Gezin - Child and Family

Vlaamse Beroepsorganisatie van Vroedvrouwen (VBOV)

Vlaamse Vereniging voor Obstetrie en Gynaecologie

Bulgaria

Alliance of Bulgarian Midwives (ABM)

Association for Maternal Fetal Medicine

Bulgarian Neonatology Association

Bulgarian Pediatrician Association

Canada

Canadian Association of Neonatal Nurses (CANN)

Croatia

Croatian Society for Neonatology and Neonatal Intensive

Cvprus

Cyprus Society of Perinatal Medicine

Cyprus National Bioethics Committee

Czech Republic

Czech Association of Nurses

Czech Neonatology Society

Denmark

Speciel interessegruppe i neonatalsygepleje (SIG-Neonatalsygepleje) - Special Interest Group of Neonatal nursing in Denmark (SIG-Neonatal)

Estonia

Eesti Naistearstide Selts (ENS) - Estonian Gynaecologists`

Society

Eesti Lastearstide Selts (ELS) - Estonian Pediatric

Association

Eesti Ödede Liit - Estonian Nursing Union

Eesti Perinatoloogia Selts (EPS) - Estonian Perinatal Society

Finland

Suomen Lastenlääkäriyhdistys Ry - Finnish Pediatric Society (FPS)

France

Société Française de Néonatologie (SFN)

Société Française de Pédiatrie (SFP)

Association Nationale des Puéricultrices(teurs) Diplômé(e)s et des Etudiants (ANPDE)

Georgia

Association of Neonatologists of Georgia

Germany

Arbeitsgemeinschaft Gestose-Betroffene

Ausbildungszentrum Laktation und Stillen

Arbeitsgemeinschaft für Geburtshilfe und Pränatalmedizin in der DGGG e.V. (AGG)

BabyCare - FB + E Forschung, Beratung + Evaluation

Bayerische Arbeitsgemeinschaft für Qualitätssicherung in der stationären Versorgung (BAQ)

Berufsverband Kinderkrankenpflege Deutschland e.V.

Berufsverband der Kinder- und Jugendärzte (BVKJ)

Bildungsinstitut Fachbereiche Gesundheitswesen (B.F.G.)

Bundesverband Bunter Kreis

Deutsche Gesellschaft für Baby- und Kindermassage

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 Pädiatrische Gastroenterologie und

Gesellschaft für Neonatologie und Pädiatrische

Harl.e.kin – Nachsorge in Bayern

Mutter-Kind-Hilfswerk

Intensivmedizin (GNPI)

Ernährung (GPGE)

Neven Subotic Stiftung (WASH projects in Ethiopia)

projekt Anna – Kinderhilfe Kaliningrad (projects in

Kaliningrad)

Sepsis Stiftung

Sichere Ausbildung für Eltern (SAFE)

Stiftung Ambulantes Kinderhospiz München (AKM)

Stiftung für das behinderte Kind

Stiftung Kindergesundheit

Uplift-Aufwind (projects in Kyrgyzstan)

wellcome

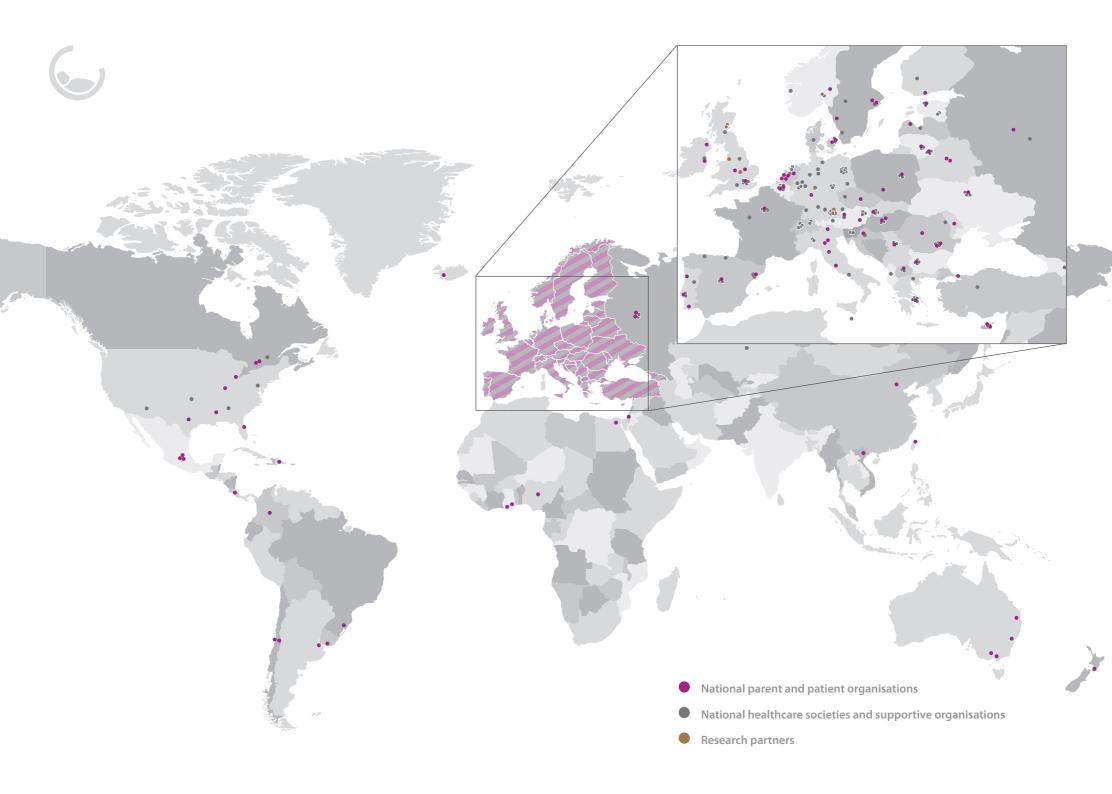
Department of Pediatrics, Hippokration, General Hospital, Aristotle University

Hellenic Midwives Association

Hellenic Pediatric Society

Hellenic Society of Obstetrics and Gynecology (HSOG)

Hellenic Society of Perinatal Medicine (HSPM)



Hungary

Hungarian Society of Perinatology

Hungarian Society of Perinatology and Obstetric Anesthesiology

Ireland

Irish Neonatal Society

Italy

Societa' Italiana di Anestesia, Analgesia e Terapia Intensiva Pediatrica (S.I.A.A.T.I.P.) - Italian Society of Anaesthesia, Analgesia and Paediatric Intensive Care

Società Italiana di Medicina Perinatale (SIMP)

Societá Italiana di Neonatologia (SIN) - Italian Society of Neonatology

Kazakhstan

Club "28 petel"

Kosovo

Neonatal Society of Kosovo

Latvia

Latvijas Neonatologu biedrība

Lithuania

Lietuvos akušerių ginekologų draugija (LAGD) - Lithuanian Association of Obstetricians and Gynecologists (LAOG)

Lietuvos akušerių sąjunga - Lithuanian Midwives Union

Lietuvos neonatologijos asociacija - Lithuanian Neonatology Association

Lietuvos pediatrų draugiją - Lithuanian Pediatric Society Lietuvos slaugos specialistų organizacija (LSSO) -

The Republic of North Macedonia

The Lithuanian Nurses' Organisation

Macedonian Neonatal Association

Macedonian Association of Perinatal Medicine (MAPM)

Malta

Maltese Pediatric Association

The Netherlands

Neonatal Section of the Dutch Pediatric Association Section Intensive Care of the V&VN - Nurses Netherlands

Norway

Helse Bergen - Haukeland University Hospital, Department of Neonatology

Norsk Perinatalmedisinsk Forening (NPF) - Norwegian Perinatal Society

The Norwegian Pediatric Association

Poland

Polskie Towarzystwo Ginekologów i Położników -Polish Society of Gynecologists and Obstetricians

Polskie Towarzystwo Neonatologiczne -Polish Neonatal Society

Portugal

Associação Portuguesa de Enfermagem Pediátrica e Neonatal (APEPEN)

Sociedade Portuguesa de Neonatologia (SPN) -Portuguese Neonatology Society

Sociedade Portuguesa de Obstetrícia e Medicina Materno-Fetal (SPOMMF) - Portuguese Society of Obstetrics and Maternal-Fetal Medicine

Romania

Asociatia de Neonatologie din Romania (ANR) -Romanian Neonatology Association

Asociația Română de Medicină Perinatală -Romanian Society of Perinatal Medicine

Autoritatea Națională de Management al Calității în Sănătate (ANMCS) -Romanian Authority of Health Management Quality

Societatea de Obstetrica si Ginecologie din Romania (SOGR) – Romanian Society of Obstetrics and Gynecology

Russia

Russian Society of Obstetricians and Gynaecologists Russian Society of Neonatology

Serbia

Udruženje ginekologa i opstetričara Srbije, Crne Gore i Republike Srpske (UGOSCGRS) - Association of Gynaecologists and Obstetricians of Serbia, Montenegro and Republic Srpska

Serbian Society of Perinatal and Neonatal Medicine

Slovakia

Slovenska Komora Sestier a Porodnych Asistentiek (SKSaPA) - Slovak Chamber of Nurses and Midwives

Slovakian Neonatal Pediatric Society

Section of Neonatal Nurses of Slovak Nurses and Midwives Organisation

Slovenia

Slovenian Pediatric Society

Slovenian Association of Perinatal Medicine

Spain

Asociación Española De Pediatría (AEP)

Red de Salud Materno Infantil y del Desarrollo (Red SAMID)

Sociedad Española de Enfermería Neonatal (SEEN)

Sociedad Española de Neonatología (SENeo)

Iniciativa para la Humanización de la Asistencia al Nacimiento y la Lactancia (IHAN) – UNICEF

Sweden

Svensk Förening för Barnanestesi och Barnintensivvård (SFBaBi) - Swedish Association of Paediatric Anaesthesia and Intensive care

Svenska Neonatalföreningen - Swedish Neonatal Society Swedish Association of Paediatric Nurses

Switzerland

amiamusica

Berufsverband Schweizerischer Still- und Laktationsberaterinnen (BSS)

Schweizer Berufsverband der Pflegefachfrauen und Pflegefachmänner (SBK)

Schweizer Gesellschaft für Gynäkologie und Geburtshilfe (SGGG) - Gynécologie suisse

Schweizer Gesellschaft für Neonatologie (SGN) -Swiss Society of Neonatology

Schweizerischen Gesellschaft für Pädiatrie (SGP) -Swiss Society of Paediatrics

Turkey

Turkish Neonatal Society

Ukraine

Association of Neonatologists of Ukraine

National committee of neonatal and perinatal medicine of Ukrainian Academy of Pediatrics

Ukrainian Association of Obstetricians and Gynaecologists

United Kingdom

British Association of Perinatal Medicine (BAPM)

National Institute for Health Research – Clinical Research Network Children (NIHR)

Tommy's

The Neonatal Society

Neonatal Nurses Association (NNA)

Royal College of Paediatrics and Child Health (RCPCH)

Scottish Neonatal Nurses' Group

USA

The Foundation for Premature Infants International Neonatal Consortium – Critical Path Institute

March of Dimes NEC Society

Research Partners

concentris - Germany

Fundació Sant Joan de Déu – Spain

Institut National de la Sante et de la Recherche Medicale (INSERM) – France

Ludwig-Maximilians-University (LMU) Munich – Germany

Nederlandse Organisatie voor Toegepast Natuurwetenschappelijk Onderzoek (TNO) – The Netherlands

Philipps University Marburg – Germany

University of Dundee – UK

University of Edinburgh – UK

University of Liverpool – UK

University of Warwick – UK



Campaigning for a good purpose



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 was initiated by EFCNI and partnering European parent organisations during the first Parent Organisations Meeting in Rome in 2008.

The date 17 November was chosen at the first EFCNI Parent Organisations Meeting in Rome, Italy. That day, one of the founding members of EFCNI became proud father of a daughter, after previously having lost triplets due to preterm birth. A new awareness day was born. In 2010, the US organisation March of Dimes, the African organisation LittleBigSouls, the Australian National Premmie Foundation, and EFCNI joined together across continents to celebrate this special day.

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 was 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. In 2018, organisations worldwide celebrated the 10th anniversary of World Prematurity Day. Each year, the day is commemorated under a global theme.

Campaign website:

www.efcni.org/worldprematurityday





A Strong Start for Little Heroes

A Strong Start for Little Heroes is a large-scale initiative which EFCNI initiated in 2016. The aim is to support neonatal intensive care units in Germany, Austria, and Switzerland in the organisation of their events on World Prematurity Day on 17 November.

More than 170 hospital units take part in this activity every year. They receive a comprehensive action package including promotional material, presents for parents of hospitalised infants, and give-aways for visitors.





Socks for Life

Socks for Life is a year-round established campaign to raise awareness for preterm birth worldwide and to visualise commitment. Everyone is warmly invited to join the movement.

Campaign website: www.efcni.org/socksforlife



11 Months – 11 Topics



Campaign website: www.newborn-health-standards.org/campaign/

The campaign 11 Months – 11 Topics by EFCNI features the eleven main topics of the European Standards of Care for Newborn Health. From February to December, EFCNI focuses its social media and online communications on one of these eleven newborn health standard topics. Every month, EFCNI shares publications, research news, interviews, guest articles, and best practice examples about the respective topic.

The aim of the campaign is to support the dissemination and implementation of the standards. It is targeted particularly to health professionals, policy makers, and further key stakeholders, but also to families affected by pretern birth.

Wash your hands - it's easy

Hand hygiene matters, both in hospital settings and at home. To raise awareness for better hand hygiene, EFCNI, in collaboration with the Neven Subotic Foundation, launched the campaign *Wash your hands - it's easy*. Both foundations carry out joint activities around Global Handwashing Day (15 October) and provide several materials like a card game for children, posters on proper handwashing in five easy steps, as well as materials for healthcare professionals.



Campaign website: www.efcni.org/washyourhands



Pre-eclampsia awareness campaign: act early! screen early!

May is Pre-eclampsia awareness month and 22 May is World Pre-eclampsia Day: EFCNI's pre-eclampsia awareness campaign *act early! screen early!* raises awareness for this severe and dangerous pregnancy complication throughout the month of May. Coordinated by EFCNI, affected women and healthcare professionals share their experience and advice in videos and social media messages. Supporters of this cause can choose from the campaign materials to set up their own message and engage in the campaign, using the hashtag #ActEarlyScreenEarly.



World Breastfeeding Week campaign



For many years, EFCNI has been actively supporting *World Breastfeeding Week*, an initiative by the World Alliance for Breastfeeding Action (WABA), promoting the many long-term health benefits of breastfeeding. EFCNI strongly advocates for a breastfeeding-friendly society and develops annual international campaigns in collaboration with parent organisations and experts such as midwives, nurses and lactation consultants to educate about the benefits of breastfeeding and addressing the needs of breastfeeding women.

Campaign website: www.efcni.org/world-breastfeeding-week

EFCNI Boards

The Trustee Board has four active members. The Board makes decisions in all fundamental matters. It advises, supports, and supervises the foundation's Executive Board.

EFCNI's Executive Board consists of three members. The Board represents the foundation and conducts the day-to-day business in accordance with the Trustee Board's guidelines and resolutions.

The Parent Advisory Board consists of ten elected members who support EFCNI with their knowledge and experience from parenting preterm babies and from their work for national parent organisations in their home countries.

The Scientific Advisory Board brings together internationally renowned medical experts and scientists and provides EFCNI with expert knowledge in the fields of medicine.

Trustee Board

Thomas Föringer Silke Mader Dr Michael Poschmann Dr Dietmar Schlembach

Germany Germany Germany

Honorary Member Professor Hercília Guimarães Portugal



Dr Dietmar Schlembach

Chairman of the

Trustee Board

The treatment and care mothers and newborns receive during pregnancy, birth, and neonatal period depends to a great extent on the organisation, structure, and provision of services which vary widely across Europe. EFCNI is addressing these disparities and works together with specialists towards offering solutions. Information exchange, sharing best practice across borders, or developing standards of care are important elements to pave the way for better prevention and improvement of peri- and neonatal care at a European level. As a Chair of the Trustee Board, I am happy to contribute my knowledge and experience to help expediting our vision - the best start in life for every newborn. Every small step we achieve is a giant leap for our newborns.

Executive Board

Silke Mader Professor Neil Marlow Nicole Thiele
Germany United Kingdom Germany



Professor Neil Marlow

Member of the

Executive Board



Nicole Thiele
Vice Chair of the
Executive Board

I felt it was important to support the foundation from its very beginnings because the parental voice and perspective are critical to improving service, delivery, and effectiveness. I value the foundation's philosophy of uniting all stakeholders in neonatal health to fight for the same cause. Such interdisciplinary collaboration is vital to improve health and outcome for preterm babies and their parents everywhere. I am honoured to contribute my knowledge as a member of the Executive Board to continue this important work for newborn babies throughout Europe.

Making the patient's voice heard is a key focus of EFCNI's daily work: In our case, the patients are too small and too fragile to speak for themselves, to claim their rights or to demand what is best for them to develop to their full potential. By combining our forces, we can give these children and their families the strong voice that is needed to ensure a shift in minds as well as towards effective and sustainable healthcare systems.

Parent Advisory Board

Oleksandra Balyasna Selina Bentoom Livia Nagy Bonnard Mandy Daly Paula Guerra **Portugal** Ukraine Ghana Hungary Ireland Nina Nikolova Asta Radzevičienė Dr Eleni Vavouraki Gigi Khonyongwa-Alison McNulty Fernandez Northern Ireland Bulgaria Lithuania Greece **USA**



Mandy Daly

ACII, DLDU,
Dip. Holistic Nutrition & Dietetics
Director of Advocacy and Policymaking Irish Neonatal Health
Alliance (INHA)

I am a proud member of EFCNI's Parent Advisory Board and grateful to be part of EFCNI's broad network. Through this network, I have close contacts to other national parent organisations, but also to healthcare experts and others active in the field of maternal and newborn care. Here, we learn from each other, empower each other, and work hand in hand to bring good practice into our countries. EFCNI creates a strong link between all of us for a better future for those we love most – our children.



Scientific Advisory Board



Professor Kypros Herodotou Nicolaides Professor of Fetal Medicine, King's College, London, Professor of Fetal Medicine, University College, London

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.

Northern Ireland



Odile Frauenfelder RN Msc MA

Neonatal nurse practitioner
Vice president of the
national register of the
Dutch Nurse Practitioners
(until December 2019)
Project team member
of ICHOM data set in the
Netherlands

Quality improvement in healthcare is only possible if it is a joint effort of professionals and patients - EFCNI brings these two together. It is therefore a privilege to be part of EFCNI's Scientific Advisory Board. Working together with an international group of professionals and parents in an interdisciplinary approach is fruitful in making the world of neonatology better for newborn babies, their parents and families.

| Professor Michael Abou-Dakn Germany | Professor Ursula Felderhoff-Müser Germany | Dr Onno Helder Netherlands |
|---|---|--|
| Professor Fiona Alderdice United Kingdom | Professor Andreas Flemmer Germany | Professor Ann Hellström Sweden |
| Professor Mats Blennow Sweden | Odile Frauenfelder Netherlands | Professor Lena Hellström-Westas Sweden |
| Professor Giuseppe Buonocore Italy | Professor Hans van Goudoever Netherlands | Professor Moshe Hod Israel |
| Dr Morten Breindahl Denmark | Professor Gorm Greisen Denmark | Dr Agnes van den Hoogen Netherlands |
| Professor Olaf Dammann USA/Germany | Professor Pierre Gressens France | Professor Petra Hüppi Switzerland |
| Professor Gian Carlo Di Renzo Italy | Dr Boubou Hallberg Sweden | Professor Bo Jacobsson Sweden/Norway |
| Professor Mats Eriksson | Professor Dominique Haumont | Professor Linda Johnston |

Belgium

| Professor Berthold Koletzko Germany | Dr Carmen Pallás-Alonso Spain | Dr Inge Tency Belgium |
|--|---|---|
| Professor Pierre Kuhn France | Professor Christian F. Poets Germany | Professor Pierre Tissières France |
| Dr Nicholas Lack Germany | Professor Heike Rabe United Kingdom | Dr Aleid van Wassenaer-Leemhuis Netherlands |
| Professor Hugo Lagercrantz Sweden | Professor Charles Christoph Roehr Germany | Dr Stefan Verlohren Germany |
| Professor Jos Latour United Kingdom | Professor Mario Rüdiger Germany | Professor Gerard H. A. Visser Netherlands |
| Dr Atle Moen Norway | Professor Manuel Sanchez Luna Spain | Dr Axel von der Wense Germany |
| Professor Kypros Herodotou Nicolaides United Kingdom | Professor Ola Didrik Saugstad Norway | Dr Björn Westrup Sweden |
| Monique Oude Reimer-van Kilsdonk Netherlands | Professor Umberto Simeoni Switzerland | Professor Dieter Wolke United Kingdom |

Sweden





European Parliamentary Interest Group on Maternal and Neonatal Health

Founding members and chairs



Dr Peter LieseMember of the

European Parliament

Germany



Professor Dr Angelika Niebler

Member of the

European Parliament

Germany

It is of crucial importance to improve the quality of life of preterm babies and their families and to prevent preterm birth. Millions of families can benefit from advancements in this area. Money that we invest to change the conditions or to avoid preterm birth, is very well spent because it will make a difference in the life of these human beings.

MEP Dr Peter Liese



EFCNI donation programme

Thanks to your donation, EFCNI is able to help. There are many ways to make donations:



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.



Dr Wolf-Henning Becker Elbe Center for Prenatal Medicine, Hamburg

For me, as a perinatologist, it is my heartfelt wish to improve maternal health not only in Germany but worldwide. To me it is an important concern to reduce the risk of pre-eclampsia in pregnant women, which also means reducing the risk of preterm birth. EFCNI's entire donation programme aims at preventive measures in pregnancy, at family-centred care for preterms and ill newborns and at trainings for healthcare professionals. I am proud to be a member of the EFCNI donation programme supporting Silke Mader and her team in order to allow every newborn the best start in life.

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 07.01.2020, 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







Closing words



Silke Mader
Chairwoman of the
Executive Board

We feel thrilled and fortunate that in the past ten years we have been able to build a collaborative network of stakeholders working together to make newborn health a priority across Europe. Parent representatives, healthcare professionals and politicians now have one common objective: allowing every baby in Europe and even beyond. Recently, we founded the Global Alliance for Newborn Care (GLANCE) to establish a voice for newborns across the world.

We are grateful to our partners, who have been supporting and working with us to operate effectively at both national and European level to raise awareness, change attitudes and standardise practices. Together, we took our vision one step further: the development of European Standards of Care for Newborn Health.

My sincere thanks go to everyone who has been working with us in the past and who is committed to the cause of preterm and newborn health in Europe. I wish to extend a warm welcome to all those who want to join our network to contribute their dedication, knowledge and experience. Together we can speak with one strong voice and make a significant change on behalf of our children's future.

Special thanks

We would like to thank Christian Klant Photography, Foto Video Sessner GmbH, Klinikum Dritter Orden Munich, Martina Herstus/Nedoklubko, Quirin Leppert, Vivantes Klinikum Neukoelln Berlin, Irini Kolovou, Irish Neonatal Health Alliance (INHA), Neven Subotic Stiftung, St. Joseph Krankenhaus Berlin Tempelhof, and Vera Dammberg for supporting EFCNI with photographs. Further images: EFCNI, Hofmann-Larina Photography, Shutterstock.

We would like to express our gratitude to all partners of EFCNI as well as to all donors and volunteers.

Special thanks to our Corporate Partners and Corporate Project Partners (2020):

Platinum Partner:



Premium and Premium Project Partners:











Silver Partners:







Project Partners:



















