

For the
best
start in
life

EFCUNI european foundation for
the care of newborn infants





Our allies



Professor 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

*Past President of the European Society for Paediatric Research (ESPR)
Member of the EFCNI Trustee Board*

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 reducing preterm birth rates, and improving long-term health of preterm and newborn children. Our vision is to ensure that every baby born receives the best start in life.

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.

Treatment and care

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

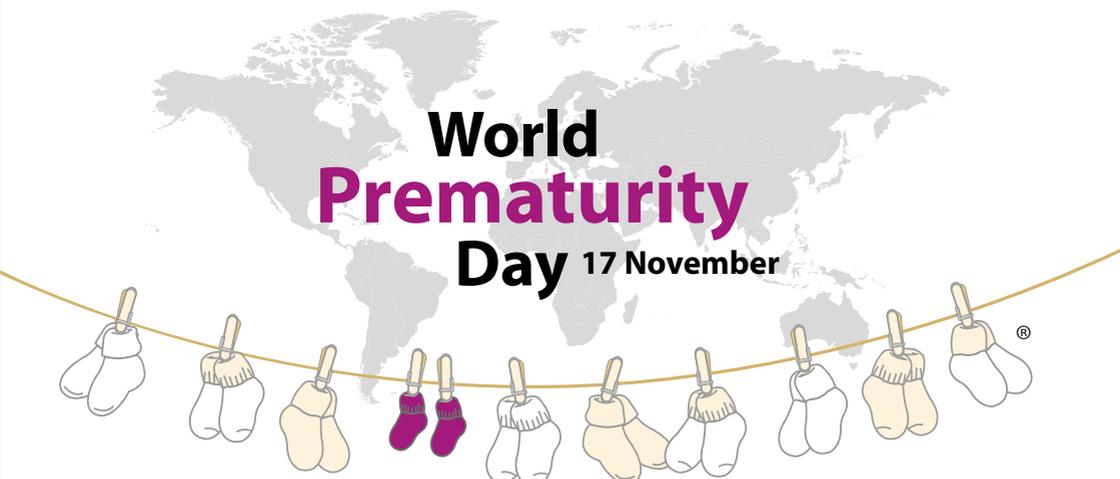
Sharing best practice

We gather and multiply information to improve and implement high-quality treatment and care by:

- Coordinating interdisciplinary projects
- Providing easy-to-understand and widely accessible information for free 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



Our milestones



World Prematurity Day 17 November

1 baby in 10 is born premature. Worldwide.

World Prematurity Day

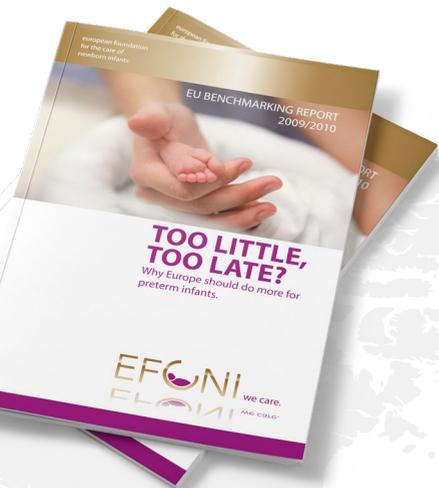
World Prematurity Day on 17 November is one of the most important days in the year to globally raise awareness of the challenges and burden of preterm birth. The day was initiated by EFCNI and partnering European parent organisations in 2008.

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 from more than 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.

Further information and a download section with graphics in about 40 languages are available at: www.efcni.org/worldprematurityday



EU Benchmarking Report

The EU Benchmarking Report 2009/2010 *Too Little, Too Late - Why Europe should do more for preterm infants* provides a compelling picture of the impact of preterm birth across 14 European countries. It reveals a troubling lack of European-wide harmonised standards of care and coordinated national and European policy initiatives to improve the quality of maternal and newborn health.

EFCNI White Paper

Caring for Tomorrow - the EFCNI White Paper on Maternal and Newborn Health and Aftercare Services from 2011/2012 aims at highlighting some of the key concerns with regard to the growing patient group affected by preterm birth. The paper is a starting point and source of support on how to improve existing healthcare plans for maternal and newborn health.



Call to Action for Newborn Health

The 10 points *Call to Action for Newborn Health*, initiated by EFCNI and European national parent organisations, was launched in November 2011 in the European Parliament. The EU and national policy makers, payers, patient organisations, healthcare professionals, academics, industry as well as the public were called upon to work together to ensure the best start in life for every baby born in Europe.



A consequence of these activities was the start of EFCNI's cross-country and interdisciplinary project to develop *European Standards of Care for Newborn Health*.

Empowering parents



Parent Organisations Meeting

Once a year, EFCNI invites parent representatives from all over the world to the Parent Organisations Meeting. Initiated in 2008 with representatives of 14 organisations now more than 70 attendees from about 30 countries come together to share ideas and experiences. Since the very beginning, EFCNI has been organising workshops and trainings for the participants. The overall goal of this meeting is to professionalise the parental commitment and to foster exchange between organisations to improve the situation for preterm babies and their families.

Workshops

EFCNI organises several workshops throughout the year to train parent representatives in different topics e.g. in fundraising or project management.



EFCNI Award

Every year, EFCNI honours parent organisations for their great commitment towards preterm birth. The annual EFCNI Awards ceremony takes place at the Parent Organisations Meeting.

European Standards of Care for Newborn Health



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 in 2013, the foundation has been working together with about 220 experts from over 30 countries and over 80 supporting organisations.

The organisation, structure, and provision of care as well as the education of healthcare professionals vary widely across Europe. Currently, there are no cross-European guidelines for newborn health. The *European Standards of Care for Newborn Health* project addresses these disparities by developing reference standards to contribute to better care for all European babies.

On 28 November 2018, the standards are launched at the European Parliament in Brussels and online on the project website, where they can be downloaded free of charge. The central demands of the project are presented in a Call to Action, which calls upon policy makers, hospital administrators, insurers, professional societies, patient associations, and industry to work together to pave the way for the implementation of the standards at national level.

Germany Land of Ideas



Landmark 2017

Nationaler Förderer
Deutsche Bank



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

The project is possible thanks to the voluntary contribution and commitment of the project members and the financial support by the project industry partners AbbVie, Baxter, Nestlé Nutrition Institute, Philips Avent, and Shire. Thanks to Dräger for supporting the project from 2013 till 2015.

More information about the project at: www.newborn-health-standards.org



Measuring patient-focused health outcome



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. A standardised measurement is developed by a transdisciplinary working group consisting of patients, health professionals, researchers, outcomes measurement experts and policy makers.

A standardised measurement is developed by a transdisciplinary working group consisting of patients, health professionals, researchers, outcomes measurement experts and policy makers.

Agenda setting

Roundtables

In order to realise clinical and structural improvements for preterm babies, EFCNI organises roundtables with renowned experts who come together to exchange views, discuss the current state of evidence and develop recommendations.

Examples of roundtables: Implementation of web camera systems in the neonatal intensive care unit, parenteral nutrition, chronic lung diseases, setup of human milk banks.

The scientific committee of EFCNI's milestone project to support clinical centres in the setup and operation 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.



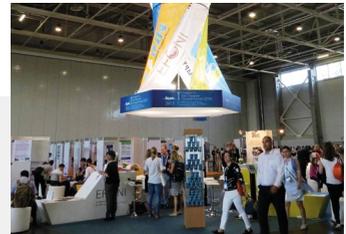
Scientific congresses

EFCNI is a frequent speaker at various scientific congresses in the field of maternal and newborn health and puts the patient perspective on the scientific agenda. EFCNI is also actively involved in the development of scientific programmes of key congresses in close collaboration with research societies and the congress organisers, e.g. the *Congress of joint European Neonatal Societies (jENS)*.

Examples of congresses:

- Annual Meeting of the German Society for Neonatology and Pediatric Intensive Care Medicine (GNPI)
- Congress of the European Academy of Paediatric Societies (EAPS)
- European Congress of Perinatal Medicine (ECPM)
- International Congress of the Union of European Neonatal and Perinatal Societies (JENPS)
- World Congress on Maternal Fetal Neonatal Medicine (WMFNM)
- World Congress of Perinatal Medicine (WCPM)

The *Congress of joint European Neonatal Societies (jENS)* is the first international congress on neonatology in which patient representatives contribute to the congress programme and form an equal partnership with healthcare professionals. Since the first jENS congress in Budapest in 2015, followed by the 2nd edition in Venice in 2017, and the 3rd jENS congress in Maastricht in 2019, EFCNI has been a member of the organising societies and the executive committee. So far, EFCNI has chaired several pre-courses, sessions, and a plenary session.



EFCNI's role in current research



EFCNI steadily expands its activities in carrying out their own research. To this end, the foundation works in close collaboration with the EFCNI Parent Advisory Board, parent organisations, supported by the expertise of 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 consider the patient perspective in healthcare research.

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 future structured and meaningful involvement of parent representatives in research projects.



EU-funded research projects

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



Screening to improve Health in Very Preterm Infants in Europe – SHIPS: SHIPS is a European research collaboration building on cohort studies including 6,800 infants born preterm in 2011 and 2012 in 11 European countries. It creates new knowledge about the efficiency of follow-up programmes and how guidelines for effective follow-up can be developed. The project aims to

identify problems early in order to drive forth interventions and optimal management of health care needs.

EFCNI adds the patient perspective and experiences to the research process and coordinates the activities for parental involvement, dissemination and outreach.

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

Research on European Children and Adults born Preterm (RECAP preterm): RECAP preterm intends to improve health, development, and quality of life of children and adults born very preterm or with a very low birth weight. The project's innovative element is to build a bridge



from data collection to data sharing: a digital platform for harmonising and exploiting data of European cohort studies with babies, children, and adults born preterm as well as Nordic registry data. This broadened data basis shall ensure improved understanding, diagnosis, and evidence-based personalised prevention of mental and somatic disorders associated with preterm birth.

EFCNI is 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 both visibility and impact of RECAP preterm.

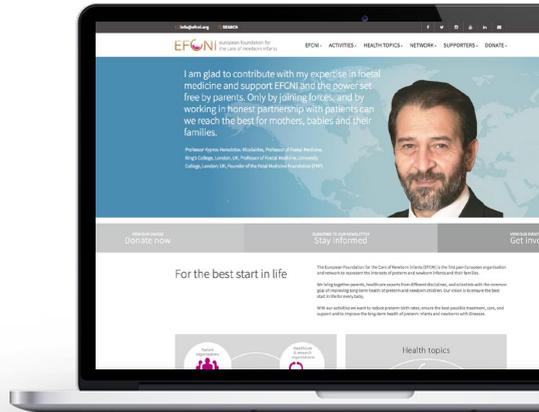
This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 733280.

Our information tools

Our website

We provide 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



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.

Feel free to 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     

3th edition | 2018

EFCNI european foundation for the care of newborn infants

EFCNI NETWORK ABOUT US NEWS

 The Parent Organisations Meeting at the end of January marked the start of the new EFCNI year. Filled with workshops and plenty of activities for networking and exchange, like the World Caffe discussion event, we were inspired by the talks of our speakers. By sharing their expertise and practice, e.g. on creating a paid position in a national parent organisation in Bulgaria, they encouraged others to make an impact in their own countries. Furthermore, 2018 is a special year for us. Your EFCNI team

EFCNI

 FREISING
14th Parent Organisations Meeting

As a time-honoured tradition, January was that time of year again where EFCNI hosted its by now 14th Parent Organisations Meeting (POM) in Freising, Germany. About 60 participants from Europe, Africa, Canada, and North America, in total from more than 30 countries, gathered to discuss preterm health topics, to share knowledge and experiences, and to motivate each other.

[READ MORE](#)

NETWORK

 Extension of maternal leave in Brazil

The Brazilian government has decided to double the length of paid maternity leave for mothers of preterm infants. Our partnering parent organisation Prematuridade significantly influenced the legislative procedure by creating a task force composed of politicians from different parties to join forces to improve the legal situation.

[READ MORE](#)

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:

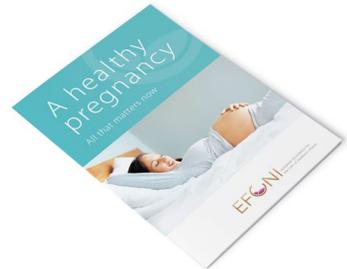
Bonding and care for preterm babies

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



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 right from the womb.



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 are available for free download at:
www.efcni.org/downloads



A powerful network for newborns



- 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 Prems 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

Asociatia Prematurilor – Premies Association
Asociatia Unu si 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 Preemie Parent Association
Velvet Hearts

United Kingdom

Bliss
Children's Liver Foundation / CLDF
LittleBigSouls

Uruguay

Asociacion Uruguaya de Padres con hijos Prematuros /
AUPAPREM

USA

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

Vietnam

Newborns Vietnam

Global

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

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 Still-birth / 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

Har.le.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 biedrība

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

Our campaigns

Socks for Life

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

Further information and graphics in about 40 languages are available at:
www.efcni.org/socksforlife

Socks for Life



1 baby in 10 is born premature. Worldwide.

EFCNI Changemaker Map

The EFCNI Changemaker Map appreciates the work of all those who make a difference to preterm babies, ill newborns and their families.



On www.efcni.org/changemakermap we warmly invite you to add your individual event and milestone. Once added, the input goes online and makes change visible all around the world.

Wash your hands - it's easy



Wash your hands - it's easy

To raise awareness for better hand hygiene, EFCNI, in collaboration with the Neven Subotic Foundation, launched the campaign *Wash your hands - it's easy*. For the joint initiative the foundations created among others posters depicting proper handwashing in five easy steps.



The posters and further material are available for free download at:
www.efcni.org/washyourhands





EFCNI Boards

The Trustee Board has five 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 eight 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.

Executive Board

Silke Mader
Germany

Professor Neil Marlow
United Kingdom

Nicole Thiele
Germany



Professor Neil Marlow

*Member 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.



Nicole Thiele

*Vice Chair of the
Executive Board*

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.

Trustee Board

Thomas Föringer
Germany

Silke Mader
Germany

Dr Michael Poschmann
Germany

Dr Dietmar Schlembach
Germany

Professor Luc J. I. Zimmermann
Netherlands

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.

Parent Advisory Board

Livia Nagy Bonnard
Hungary

Mandy Daly
Ireland

Paula Guerra
Portugal

Dr Tomasz Makaruk
Poland

Dr Gert van Steenbrugge
Netherlands

Dr Eleni Vavouraki
Greece

Yannic Verhaest
Belgium

Mónica Virchez
Spain



Mandy Daly

*Director of Advocacy & Policy
Making at Irish parent
organisation 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.

EFCNI Boards

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.

Professor Michael Abou-Dakn
Germany

Professor Fiona Alderdice
United Kingdom

Professor Mats Blennow
Sweden

Professor Giuseppe Buonocore
Italy

Dr Morten Breindahl
Denmark

Professor Olaf Dammann
USA/Germany

Professor Gian Carlo Di Renzo
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Professor Mats Eriksson
Sweden

Professor Ursula Felderhoff-Müser
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Professor Andreas Flemmer
Germany

Odile Frauenfelder
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Professor Moshe Hod
Israel

Dr Agnes van den Hoogen
Netherlands

Professor Petra Hüppi
Switzerland

Professor Bo Jacobsson
Sweden/Norway

Professor Linda Johnston
Northern Ireland



**Odile Frauenfelder,
RN, Ma ANP**

*Student Master of Science
in Quality and Safety in
Patient Care
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 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

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Professor Mario Rüdiger
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Professor Gerard H. A. Visser
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Dr Atle Moen
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Professor Manuel Sanchez Luna
Spain

Dr Axel von der Wense
Germany

Professor Kypros Herodotou Nicolaidis
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



European Parliamentary Interest Group on Maternal and Neonatal Health



Dr Peter Liese
*Member of the
European Parliament*

It is of crucial importance to improve the quality of life of pre-term babies 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.

Founding members and chairs

Professor Angelika Niebler
Germany

Dr Peter Liese
Germany

Members

Biljana Borzan
Croatia

Karin Kadenbach
Austria

Dr Andreas Schwab
Germany

Esther de Lange
Netherlands

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Poland

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Ireland

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.

Donations



**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 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**

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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 to have the best start in life.

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 could make it possible to take 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

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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 (2018):

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the care of newborn infants

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