

For the
best
start in
life

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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 Parent and Patient 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:

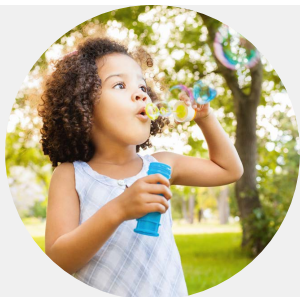


Preconception and maternal care

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

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.

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.

Trustee Board

Professor Ursula
Felderhoff-Müser
Germany

Thomas
Föringer
Germany

Silke
Mader
Germany

Dr Michael
Poschmann
Germany

Dr Dietmar
Schlembach
Germany

Honorary Member Professor Hercília Guimarães Portugal

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.

Executive Board

Silke Mader
Germany

Nicole Thiele
Germany

Professor J.I. Luc Zimmermann
Netherlands

The **Parent and Patient 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 and patient organisations in their home countries.

Parent and Patient Advisory Board

Fabiana Bacchini
Canada

Oleksandra Balyasna
Ukraine

Selina Bentoom
Ghana

Estela Coutinho
Portugal

Gigi Khonyongwa-
Fernandez
USA

Doris Mollel
Tanzania

Nina Nikolova
Bulgaria

Kylie Pussell
Australia

Asta Radzevičienė
Lithuania

Dr Eleni Vavouraki
Greece



Find out more about EFCNI's organisational structure:
www.efcni.org/about-us



Scientific Advisory Board

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

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
Italy

Professor Mats Eriksson
Sweden

Professor Andreas Flemmer
Germany

Odile Frauenfelder
Netherlands

Professor Hans van Goudoever
Netherlands

Professor Gorm Greisen
Denmark

Professor Pierre Gressens
France

Dr Boubou Hallberg
Sweden

Professor Dominique Haumont
Belgium

Dr Onno Helder
Netherlands

Professor Ann Hellström
Sweden

Professor Lena Hellström-Westas
Sweden

Professor Moshe Hod
Israel

Dr Agnes van den Hoogen
Netherlands

Professor Petra Hüppi
Switzerland

Professor Bo Jacobsson
Sweden/Norway

Professor Linda Johnston
Northern Ireland

Professor Minesh Khashu
United Kingdom

Professor Berthold Koletzko
Germany

Professor Pierre Kuhn
France

Dr Nicholas Lack
Germany

Professor Hugo Lagercrantz
Sweden

Professor Jos Latour
United Kingdom

Dr Atle Moen
Norway

Professor Kypros Herodotou Nicolaides
United Kingdom

Monique Oude Reimer-van Kilsdonk
Netherlands

Dr Carmen Pallás-Alonso
Spain

Professor Christian F. Poets
Germany

Professor Heike Rabe
United Kingdom

Professor Charles Christoph Roehr
Germany

Professor Mario Rüdiger
Germany

Professor Manuel Sanchez Luna
Spain

Professor Ola Didrik Saugstad
Norway

Professor Umberto Simeoni
Switzerland

Dr Inge Tency
Belgium

Professor Pierre Tissières
France

Dr Aleid van Wassenae-Leemhuis
Netherlands

Dr Stefan Verloren
Germany

Professor Gerard H. A. Visser
Netherlands

Dr Axel von der Wense
Germany

Dr Björn Westrup
Sweden

Professor Dieter Wolke
United Kingdom



Professor Kypros Herodotou Nicolaides

Professor of Foetal Medicines, King's College, London, UK; Professor of Foetal Medicine, University College, London, UK; Founder of the Fetal Medicine Foundation (FMF)

”

I am glad to contribute with my expertise in foetal medicine and support EFCNI and the power set free by parents. Only by joining forces, and by working in honest partnership with patients can we reach the best for mothers, babies, and their families.





Paula Guerra

*Co-founder of XXS-
Associação Portuguesa de
Apoio ao Bébê Prematuro*



Kobi V. Ajayi

*Founder & CEO EDEN
Foundation, Nigeria, and
mom of a former 33-week
preterm infant*

”

It is important to support parents in the NICU. They should know their childrens' needs and rights and also collaborate with health professionals. Informed parent's involvement crucially contributes to better responses to preterm babies and their follow-up. ”

”

At EFCNI, there are no geographical barriers to the support they provide to local organizations working on the frontlines for preterm infants and their families. As a parent organization, we have gleaned onto EFCNI's support to create sustainable partnerships with key organizations in Nigeria to serve communities through a family-centered care lens. ”



Empowering parents



Participants of the 3rd Parent Organisations Summit in Freising, Germany, May 2023

Parent Organisations Summit

The annual *Parent Organisations Summit* 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.

Professionalising parent organisations

Besides workshops and trainings for the participants of the *Parent Organisations Summit*, EFCNI offers several workshops as well as digital meetings or webinars throughout the year to train parent and patient representatives in different topics e.g. on the implementation of the European Standards of Care for Newborn Health on a national level, in fundraising, research or project management.



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.

More information about the Parent Organisations Summit can be found here:

www.efcni.org/parent-organisation-meeting



Global Alliance for Newborn Care (GLANCE)



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 babies born too soon, too small or too sick to help them thrive beyond survival.



Learn more about GLANCE:

www.glance-network.org

Follow us on



Zero separation. Together for better care!

With the international campaign “Zero Separation. Together for better care! Keep preterm and sick babies close to their parents”, GLANCE reacts to the development of neonatal units adopting a separation policy, limiting or prohibiting access of parents to neonatal care units due to the COVID 19 pandemic. In cooperation with our international network, we developed a long-term campaign to support parents of hospitalised newborns and healthcare professionals in neonatal care units with the aim to enable infant and family-centred developmental care in line with COVID-19-precautions.

COVID-19

Zero separation. Together for better care!

Keep preterm and sick babies close to their parents.

#TogetherForBetterCare
#ZeroSeparation

Close contact and early, exclusive breastfeeding helps a baby to thrive. A woman with COVID-19 should be supported to breastfeed safely, hold her newborn skin-to-skin and share a room with her baby. (Source: webinar series/ infographic)

World Health Organization
www.who.int/images/default-source/health-topics/coronavirus/pregnancy-breastfeeding-who-pregnancy-4.jpg



More information on our COVID-19 activities can be found here:
www.glance-network.org/covid-19



Communication and information

EFCNI provides evidence-based and up-to-date information, tailored for different audiences, on topics related to pregnancy, preterm birth, and newborn health, as well as valuable links to our network.

In our newsletter, we share news about our projects, feature remarkable activities from our network partners as well as the latest research news in neonatal and maternal healthcare.

Through our social media channels, we not only inform about our latest campaigns, and recent findings related to preterm birth and newborn health, we connect and grow our network of partner organisations as well as our community of parents, former patients and healthcare professionals.

Follow us on



EFCNI publishes a wide range of information materials, such as position papers for advocacy groups and health policy experts, informative brochures, toolkits, factsheets, and posters for parents and patients, parent organisations, and healthcare professionals. All materials offer information tailored to the target group, reflect the latest state of knowledge, are educational and a joy to look at.



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



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



Campaigning for a good purpose

Raising awareness, providing information, and increasing our impact is what our campaigns are about. Yet, we also support our partner parent organisations by developing materials they can use to inform and engage with their own networks. Our campaigns are either centred around awareness days, e.g. World Prematurity Day or are focused on health educational topics like the value and benefits of human milk or the promotion of healthy nutrition during the first 1000 days of a child's life. Further, we raise awareness around pregnancy-related issues like pre-eclampsia or immunization during pregnancy or around particular diseases like the Respiratory Syncytial Virus (RSV).

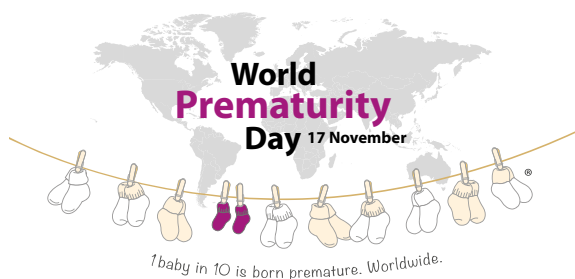
Our campaigns inform, empower, and support parents and caregivers of preterm born children, families, parent groups, medical experts, educators, political decision-makers, and many more to drive newborn and maternal health.



For more information please visit:
www.efcni.org/activities/campaigns



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 meeting of parent organisations in Rome in 2008. 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.



© Martina Herstus for Nedoklubko



Learn more about World Prematurity Day here:
www.efcni.org/activities/campaigns/wpd



More than

100

countries celebrate
World Prematurity
Day

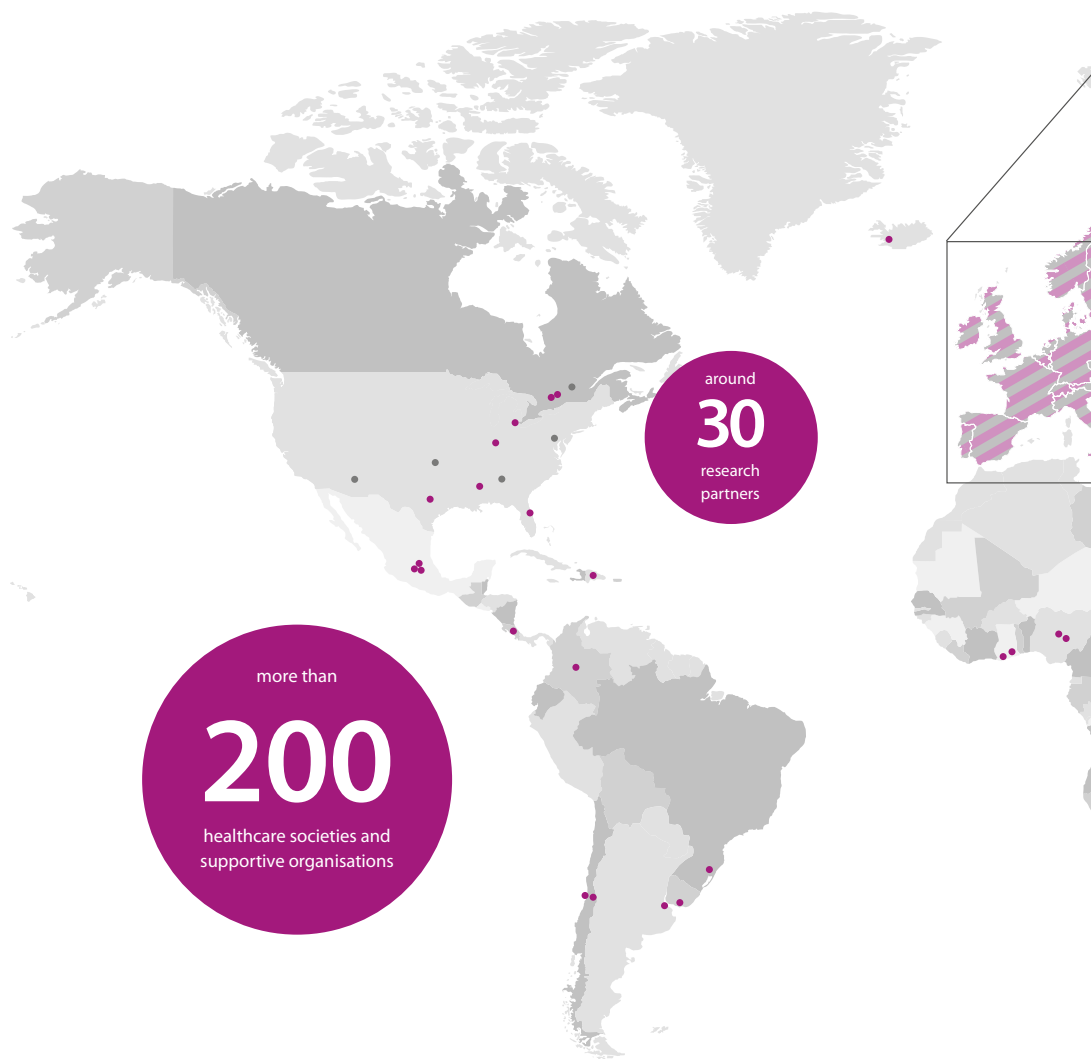
#WorldPrematurityDay

Find an overview of worldwide events at: www.efcni.org/worldprematurityday

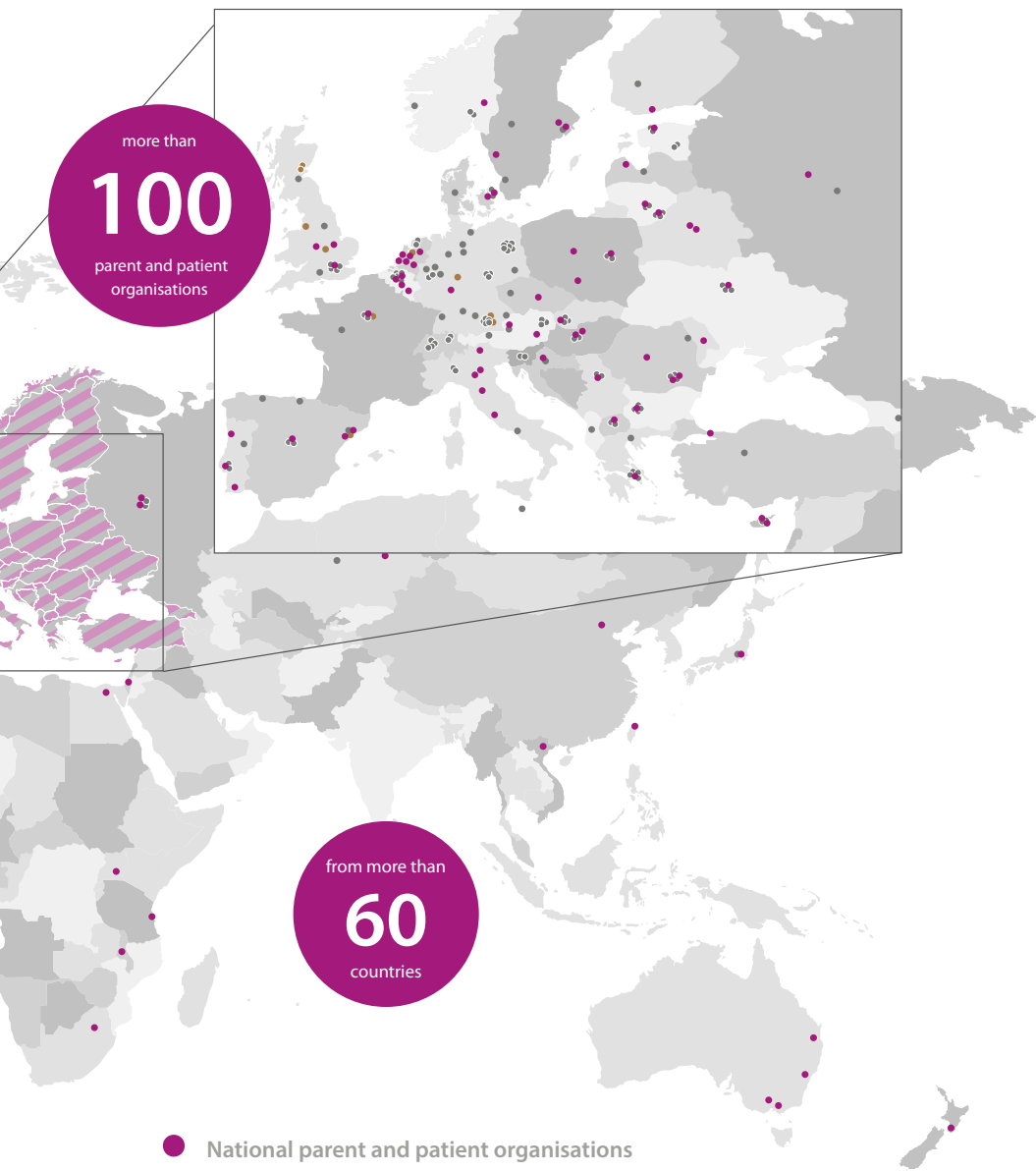




A powerful network



For more information on EFCNI's global network please visit:
www.efcni.org/network



for newborn infants

European Standards of Care for Newborn Health



european standards of
care for newborn health



The European Standards of Care for Newborn Health (ESCNH) are developed in an interdisciplinary European collaboration with a focus on the treatment and care of preterm and ill newborns from hospital to school age. The ESCNH serve as a basis for the development of binding national guidelines, protocols, or laws. Over 100 healthcare societies and more than 50 parent organisations have officially endorsed the ESCNH. As medical care is a fast-developing area, the ESCNH are updated regularly and new standards of yet neglected or uprising medical areas are worked on simultaneously.

In September 2022, six new standards were launched at the UENPS congress in Krakow. Areas covered by our new standards are:

- cord management of term and preterm infants,
- management of NEC,
- immunisation of preterm infants,
- error management and
- quality indicators.

Additionally, 20 standards were reassessed in a comprehensive revision process, which included an expert and a public consultation. In April 2023, the revision cycle of the remaining 76 standards has started. The entire process including again an expert and a public consultation is expected to end in the second half of 2024.

Implementation

Since the launch of the ESCNH in the European Parliament in 2018, they received much attention and international experts in neonatal care expressed great interest to support their implementation.



Learn more about the ESCNH project:
www.newborn-health-standards.org





One best practice example for efficient implementation is the translation of the entire set of standards into Italian by the Italian Society of Neonatology (SIN) and Vivere ONLUS, the Italian National Coordination of Parents' Associations. Making the ESCNH available in Italian promises to change the understanding of adequate neonatal care by including more people in the conversation. Finally, it will support NICUs across Italy in putting the ESCNH into daily practice.

To facilitate the implementation further, a task force was set-up by the Italian Society of Neonatology (SIN) including several professionals from different disciplines, together with parent representatives. The task force aims to raise awareness among professionals and families on the existence of the Italian ESCNH and their application.

11 Months – 11 Topics

The campaign *11 Months – 11 Topics* by EFCNI features the eleven main topics of the ESCNH. 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 healthcare professionals policy makers, and further key stakeholders, but also to families affected by preterm birth.



Campaign website:
www.efcni.org/11-months-11-topics/





The EFCNI Academy is an international education programme for healthcare professionals under the umbrella of the EFCNI. With input from the most experienced professionals in the field, the EFCNI Academy offers high-quality training and educational materials ranging from workshops and seminars to factsheets and videos. Our aim is to improve the standard of care for maternal and newborn health by sharing state of the art knowledge and best practices from and to healthcare professionals.

E-learning opportunities

By better understanding the importance of human milk for infant health, it will be possible to improve health outcomes of newborn infants on a short- and long-term basis. In our free of charge e-learning series, experienced high-level speakers provide you with up-to-date insights on this important topic. The modules are designed for junior to senior level healthcare professionals in general, and medical specialists and nursing staff working in the field of paediatrics, neonatology or infant nutrition in particular, and those wishing to update their scientific knowledge on the topic.

Register now!

Enteral Preterm Nutrition

Webinar series for junior to senior level healthcare professionals on the benefits of human milk for infant health.

THIS WEBINAR SERIES IS CME ACCREDITED BY THE EUROPEAN ACCREDITATION COUNCIL FOR CONTINUING MEDICAL EDUCATION (EACCME).

U.E.M.S.

This webinar series is supported by



EFCNI Academy
Learn, and share for better care



EFCNI
European Foundation for the care of newborn infants



European Society for Paediatric Research

Educational material for healthcare professionals

We are offering information material, educational videos and factsheets targeted to all healthcare professionals maintaining preterm infants. Our material was developed together with internationally renowned experts in the field of maternal and newborn health.



Videos and factsheets are available for topics such as Retinopathy of Prematurity (ROP), thermoregulation in preterm born babies as well as parenteral nutrition and resuscitation. All our materials are available free of charge.

Retinopathy of Prematurity

Factsheet



Thermoregulation in preterm infants

Factsheet



RSV – a risk for all children under two years of age

Factsheet



Parenteral Nutrition

Factsheet



Learn more about the EFCNI Academy:
www.efcni.org/activities/efcni-academy

Conferences and Congresses



Further, EFCNI is 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.



Learn more about the participation of EFCNI at congresses and conferences:
www.efcni.org/activities/conferences-congresses



Research activities

EFCNI continuously expands its research activities. Supporting research projects and promoting scientific evidence is key to our mission. To this end, the foundation works in close collaboration with the Parent and Patient Advisory Board, parent organisations, healthcare professionals and other relevant stakeholders. EFCNI's work relies on generating new knowledge on maternal and newborn health, particularly in the field of neonatal care. Evaluating the impact of follow-up screening programmes and infant and family-centred developmental care is part of EFCNI's primary research interest. We are looking for new angles and innovative problem-solutions from the patient's/parents' perspective.

EU-funded research projects



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



Mark Turner

Neonatologist, Researcher and co-lead of the pan-European paediatric clinical trials research networks, connect4children (c4c); Professor of Neonatology and Research Delivery, University of Liverpool

” Research is needed to improve the care that newborn babies receive. Research needs to be based on the needs of parents and what is acceptable to parents. EFCNI is a fantastic partner for researchers. EFCNI makes the right connections between researchers and families. EFCNI makes sure the voice of parents is heard before and during research. ”



Learn more about our research activities:

www.efcni.org/research-overview-page



Involvement of parent representatives in neonatal 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 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



The position paper can be downloaded here:

www.efcni.org/downloads



EFCNI initiated research activities



ResQ Family: Impact of **Respiratory** Syncytial Virus Hospitalisation on **Quality of Life of Families** – A Multi-Country Study

There is still little information available on how severe RSV infection leading to hospitalisation of the infant, impacts the quality of life of affected families. For the ResQ Family project, an online questionnaire was used to survey parents or caregivers of children up to 24 months currently or recently hospitalised due to RSV infection.

The main aim of the study is to evaluate how RSV infection with hospitalisation affects the parents' quality of life. The goal is further to provide scientific evidence on the burden of RSV and raise awareness among all relevant stakeholders including healthcare professionals and patient representatives, decision-makers and the general public.



Get more information on the ResQ Family project here:

www.efcni.org/activities/resq-family





Infant and family-centred developmental care in times of COVID-19 – A global survey of parents’ experiences”

The COVID-19 pandemic has created exceptional challenges, especially for the care of preterm, sick and low birthweight infants. While most restrictions were necessary, some have impacted the provision of healthcare, including infant and family-centred developmental care (IFCDC). Hospitalised newborns and their families, have been severely affected by separation policies with so far unforeseen short and long-term consequences. Hence, EFCNI conducted a global online-survey to explore parents’ experiences with regard to the disruptions and restrictions on different elements of IFCDC during the first year of the COVID-19 pandemic. Parents of newborns in need of special/intensive care shared their experiences regarding prenatal care, parenatal access, infant nutrition and breastfeeding, health communication, as well as mental health.

Zero separation. Together for better care!

Infant and family-centred developmental care in times of COVID-19 – A global survey of parents’ experiences

Project Report available now!



Find out more about this project and get access to the full project report here:

www.efcni.org/health-topics/covid-19-faq



Policy Work

EFCNI is working hard to advance newborn and maternal health through policy discourse. To this end, the foundation also engages in policy work.

European Parliamentary Interest Group on Maternal and Neonatal Health

The group was founded in May 2011 by Prof. Dr. Angelika Niebler together with her parliamentary colleague Dr. Peter Liese.

The Group seeks to bring a diverse group of Members of the European Parliament (MEPs) together for open dialogue and advocacy to help ensure the best possible start in life for all babies born in Europe.

Founding members and chairs



Dr Peter Liese

*Member 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





Policy papers and roundtables

Our engagement in the policy-making process is reflected in organising and hosting roundtables with various stakeholders, and in policy papers targeted at decision-makers.



Find out more about EFCNI's position papers, toolkits and policy papers:
www.efcni.org/activities/projects

Patients' and Consumers' Working Party, European Medicines Agency

EFCNI is an organisation representative member of the Patients' and Consumers' Working Party (PCWP). PCWP provides recommendations to the European Medicines Agency and its Human Scientific Committees on matters of direct or indirect interest to patients in relation to medicines for human use and monitor the overall interactions between EMA and patients and consumers.



Find out more about EFCNI's representation at the PCWP:
www.efcni.org/european-medicines-agency



EFCNI donation programme

*Despeena, born at 24 weeks
weighing 820 grams*



Giving our children the best start in life is both, a task and an obligation for our society. The right environment, care and support for the babies and their parents from the first moment on and during the early years makes a crucial difference to a child's good health and life.



There are many ways to make donations. Find out which one is the most suitable for you. Your support will help EFCNI to work towards our common vision – the best start in life for every baby:

www.efcni.org/donation-programmes



For direct donations:

Donate now

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



Closing words



Silke Mader
*Chairwoman of the
Executive Board*

We feel thrilled and fortunate that we have been able to build a collaborative network of stakeholders working together to make newborn health a priority across Europe. The past two years during the pandemic have made us even more aware of the value of such a strong and supportive network. Parent representatives, healthcare professionals and politicians now have one common objective: allowing every baby in Europe to have the best start in life. With GLANCE, the Global Alliance for Newborn Care, we have furthermore established 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), St. Joseph Krankenhaus Berlin Tempelhof 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 (2023):



For more information about our supporters:

www.efcni.org/supporters

Platinum Partner:



Premium Partners:



Silver Partners:



Bronze Partner:



Project Partners:



The EFCNI 2023 policy and advocacy training workshop for patient and family representatives is supported by a restricted grant from Pfizer.





competence centre for maternal and newborn health and aftercare services

Germany
Land of Ideas



Landmark 2017

Nationaler Förderer
Deutsche Bank



European foundation for
the care of newborn infants

Hofmannstrasse 7A
81379 Munich, Germany

phone: +49 (0)89 890 83 26-0
fax: +49 (0)89 890 83 26-10

info@efcni.org
www.efcni.org

