





Dear friends and supporters of EFCNI,

November is, quite possibly, the busiest month in the year for us. On 17 November, we celebrated World Prematurity Day with the help of friends and partners all across the globe. It was an emotional day, allowing us to celebrate those born too soon as well as the professionals who often go above and beyond to support families with a baby in the NICU. We are happy to see how many people and organisations came out in support of this year's motto, "Zero Separation"!

This month, we also presented our report on parents' experiences with a hospitalised newborn during the COVID-19 pandemic. To be frank, it is a harrowing read and shows that, in many countries, families have been severely affected by separation policies – with so far unforeseen short and long-term consequences. Infant and family-centred developmental care must be continued, even in times of a pandemic.

As the year draws to a close, we want to thank you, once more, for your continuous support.

Please stay healthy and safe,

Silke Mader and the EFCNI team

### **EFCNI**

WORLD PREMATURITY DAY 2021

Zero Separation. Act now! Keep parents and babies born too soon together.

We look back on World Prematurity Day 2021 on 17 November with a sense of pride – the day was, in our estimate, a huge success! Together with our friends and partners, we managed to raise awareness for the challenges of preterm birth and



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celebrate those born too soon and their families. All over the globe, parent organisations, motivated individuals, healthcare societies, and corporate partners hung up banners, organised webinars, illuminated buildings and landmarks in purple – and found countless other ways to creatively celebrate the day. They also worked tirelessly to draw attention to the challenges of the COVID-19 pandemic which particularly affected (and continues to affect) preterm babies and their families. It is truly humbling and moving to hear our calls for "zero separation" echoed across the globe! So, thank you to everyone who participated in big and small ways – you have truly made a difference and helped to put the issue of preterm birth on national agendas. Let's keep up the work and keep advocating on behalf of those born too soon, too small, or too sick.

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#### STRONG START FOR LITTLE HEROS

### Hero power on World Prematurity Day

We did it again! On the occasion of World Prematurity Day, almost 170 hospitals in Germany, Austria, and Switzerland joined our Project "Strong Start for Little Heroes" and raised awareness for the needs and challenges of preterm born babies and their families. Many thanks to all supporters for your great commitment and your wonderful campaigns. It is a pleasure to have you by our side! PS: Everyone who is interested in our lottery can access detailed information on our website. Closing date for participation is 15 December 2021.

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NEW RSV CAMPAIGN PAGE

### Are you RSV aware?

Respiratory Syncytial Virus (RSV) is literally on everyone's lips at the moment, and rightly so. In many places, paediatric clinics are overflowing with babies and toddlers suffering from RSV infections. This is because the RS virus, which normally occurs seasonally, has triggered a veritable RSV wave unusually early this summer. Experts are concerned and speak of an "immunity debt" after many people avoided contact and did not build up immunity due to strict COVID-19 protective measures last winter, allowing the pathogens to spread more quickly as protective measures declined and countries reopened. Although the number of RSV cases continues to rise, many people are still unfamiliar with this common but less-known respiratory disease. That is why we have launched a new campaign page with easy-to-understand information about the virus to raise awareness about RSV, especially among expecting and new parents, healthcare providers and caregivers. Visit our new page and help us spread the word about RSV to protect all infants from this serious virus! Thanks

to our corporate partner Sanofi Pasteur for their support of this project.

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#### TALKING ABOUT PRETERM BIRTH

# Looking back and forward at the same time – Instagram Live with Silke and Lukas Mader

In honour of World Prematurity Day, EFCNI's Chairwoman Silke Mader and her son Lukas stopped by "Hallo Hebamme" ("Hello Midwive"), a project heralded by Anja Stern and Marie Kuon, two midwives based in Heidelberg. In an Instagram Live session, Silke and Lukas Mader talked about their family's experience with preterm birth, what motivates their work on behalf babies born too soon, and World Prematurity Day. They also presented the new parent brochure on preterm birth which was developed jointly with the working group "Arbeitsgemeinschaft für Geburtshilfe und Pränatalmedizin" ("Working group on obstetrics and prenatal medicine") and the parent organisation "Das frühgeborene Kind e.V." ("The preterm child"). The Instagram Live session is still available for viewing. Please note that the video is in German.

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#### **PERTUSSIS**

"The pertussis vaccination during pregnancy closes a gap in protection for babies", says PD Dr. Holger Maul in a new interview

EFCNI talked to PD Dr. Holger Maul, chief physician at the Asklepios Hospital in Barmbek, Germany, about the benefits of the pertussis vaccination during pregnancy. In the interview, Dr. Maul, an experienced gynaecologist, explains why pertussis can be potentially deadly for babies and why the vaccine constitutes a good preventive measure. He also describes how the pertussis antibodies are transferred from mother to unborn child and discusses how medical staff can best go about educating patients about the vaccine. The interview is in German.

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#### **DIGITAL CONGRESS**

30th Congress of the German Society for Perinatal Medicine (DGPM)



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From 24 to 27 November, the congress will take place in digital form. The varied scientific programme of the congress includes presentations of the latest scientific results on topics in obstetrics and neonatology with interesting case presentations and expert discussions on developments in practice and clinic. The DGPM is considered the most important forum in the German-speaking perinatal-medical community. We are very pleased to be part of this renowned event with a lecture on the latest global evidence on infant- and family-centred developmental care in the pandemic by Chairwoman Silke Mader and a poster session with EFCNI's Dr. Julia Hoffmann on parenteral nutrition in German perinatal centres. She will present an analysis of barriers in clinical application as a guide for practice-oriented solutions.

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#### **INFANT HEALTH POLICY SUMMIT 2021**

#### What a fruitful event!

On the occasion of the seventh annual Infant Health Policy Summit 2021, health care providers, parents, policymakers and other stakeholders met to explore highly relevant topics in the field of infant health. Rare diseases, the value of safety and innovation for neonates, and the market of human milk banks were only some of the elaborated topics. Dr. Johanna Kostenzer, head of EFCNI's scientific department, was also part of the round and presented the results of our COVID-19 report on the global impact of the pandemic on neonatal care. The event was recorded and can be accessed on-demand.

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### **Network**



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HOSPITALISED NEWBORNS

# PROMOTING THE WELLBEING OF HOSPITALISED BABIES IN FRANCE

In cooperation with the French Neonatology Society, our partner parent organisation in France, "SOS Préma", developed the "Hospitalised Newborn Charter". This project was developed under the high patronage of the French Health Ministry and aims to improve newborn care in French hospitals. The Charter defines, in 10 points, the essential needs of the baby. It is based on "attachment theory" which shows that, for optimal development socially, emotionally, and cognitively, a newborn baby must establish an ongoing relationship with their parents. The theory insists on the fact that developmental care at the hospital integrates parents as partners in care, thus promoting a "zero separation" approach. The "Hospitalised Newborn Charter" is already supported by

several notable French medical associations. Please note that the Charter is in French.

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#### **EDUCATING PARENTS ABOUT PRETERM BIRTH**

# New parent brochure on preterm birth launched in Germany

We are happy to announce that on 5 November, a new parent brochure on preterm birth was officially presented. The brochure is geared towards pregnant women as well as families and aims to inform them about preterm birth. It addresses questions about possible causes, consequences for the baby, and explains to parents what happens if they are about to experience a preterm birth. The brochure is the result of a cooperation with the working group "Arbeitsgemeinschaft für Geburtshilfe und Pränatalmedizin" ("Working group on obstetrics and prenatal medicine"), the parent organisation "Das frühgeborene Kind e.V." ("The preterm child"), and EFCNI. It is available as free download. Please note that it is written in German.

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#### Science



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#### ZERO SEPARATION IN TIMES OF COVID-19

# Urgent call for holistic approach to unrestricted infant- and family-centred developmental care

World Prematurity Day 2021 draws attention to the particular challenges faced by preterm babies born during the still-ongoing COVID-19 pandemic. In contrast to international agreements, which underline the right to health and the right of children to be close to their parents, separation policies have been implemented in many neonatal intensive care units (NICUs) across countries, impacting the quality of care for preterm, sick, and low birth weight infants in the NICU. This is why, in a Lancet commentary, we call for policy makers, public health experts and health professionals to take immediate action to achieve zero separation and infant- and family-centred developmental care. Every baby born too soon, too small, or too sick should receive high-quality care for the best start in life.

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# Which actors in the health system need to be addressed to make RSV prevention work for all infants?

Recently, EFCNI's Chairwoman Silke Mader and a group of experts, led by the long-standing expert and paediatric infectiologist Prof. Louis Bont, published a review article on the Respiratory Syncytial Virus (RSV) in the journal "Emerging Themes in Epidemiology". RSV is one of the most common causes of acute lower respiratory tract infections (LRTI) in children under two years of age and a leading cause of hospitalisation in this age group. Currently, there is no prevention available for all infants: however, some new prophylactic agents will soon be on the market. The article looks at the challenges these new opportunities pose to our healthcare systems. A major concern of the authors is the timely availability of RSV prophylaxis for all infants. Read more about the authors' motivations and suggestions for creating an enabling environment for the timely implementation of new passive immunisation strategies.

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#### READING RECOMMENDATION

# New research on preterm teenagers and their parents out now!

Looking for an interesting read? Prof. Dr. Michaela Gross-Letzelter just published a new anthology on families with a preterm child or teenager. The book's focus lies on the results of a long-term study which conducted its next phase in 2020 when parents with a preterm teenager were interviewed for their experiences. What is more, the volume also analyses the situation of families who lived through a preterm birth during the COVID-19 pandemic. Apart from the medical, care, and psycho-social aspects of preterm birth, the anthology also gives room to the personal story of Barbara Mitschdörfer, Chairwoman and founding member of the German parent organisation "Das frühgeborene Kind e.V." ("The preterm child"). In her contribution, Mitschdörfer recounts her journey from becoming a preterm mother to empowering self-help activism and advocacy work. Please note that the volume is in German.

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## European Standards of Care for Newborn Health

WEBSITE RELAUNCH

Looking good! Design update for the website about the European Standards of Care for



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### Newborn Health (ESCNH) now online

We did it! The past six months, we worked quietly behind the scenes to update the website about the European Standards of Care for Newborn Health (ESCNH) – and we are finally done! Today, we proudly present its new features and some highlights: If you want to share important information on the standards and their current developments, you are now able to just click on the social media icons at the top of each page and share it effortlessly with your community. Additionally, our new tile-based structure of parent pages promises optimised user experiences. You can also find lots of new content, for example on the current and future development of new standards, within the eleven topics of care. Head over to the website, surf around, and let us know what you think.

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#### PARENTERAL NUTRITION

# How Sweden turned standardised parenteral nutrition solutions into clinical practice

The use of standardised and individual parenteral nutrient (PN) solutions is a much-debated subject in neonatal clinical practice. In Sweden, they already turned standardised solutions into a standard approach a few years ago when it comes to applying PN solutions in neonatal nutritional care. The individual PN solution is used in specific cases when patients require individualised nutritional care. In an interview with pharmacist Dr. Mattias Paulsson from the Uppsala University Hospital, we had the great opportunity to find out how this implementation process of standardised parenteral nutrition took place, what the reasons and the preconditions were to take this step, and how it affects the day-to-day running of the clinical units.

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NEW INSIGHTS ON PARENT-INFANT BONDING

# Investigating the benefits of parentadministered oral stimulation in preterm infants

Reaching the transition from tube to oral feeding is a milestone in the development of preterm infants that is not always easily achieved. However, oral motor therapy has been proven to increase the baby's feeding skills and thereby facilitates this transition. Between March 2017 and May 2019, an Italian research team evaluated whether there is a difference in the transition time to full oral feeding between parent-administered and professional-administered premature infant oral motor intervention (PIOMI). The results indicate no statistically significant differences in the transition time but high parental

satisfaction and family-bonding benefits. The findings therefore allow to consider parent-administrated PIOMI more broadly.

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#### SKIN-TO-SKIN CARE

# Study results encourage early skin-to-skin care in extremely low birthweight infants

Although the benefits of early skin-to-skin care (SSC) for preterm and extremely low birth weight (ELBW) infants are well known in neonatology, there are still implementation problems in some health centres. Unfortunately, these particularly unstable and vulnerable infants are not consistently offered the promising option of SSC due to safety concerns and discomfort of the care team. With the goal of increasing SSC rates within the first 72 hours of life in ELBW infants to 80% within one year, a multidisciplinary team of neonatologists identified barriers and developed targeted interventions to facilitate early SSC care, using the Institute of Healthcare Improvement's quality improvement methodology. At the end of the study, after extensive training of parents, staff and providers, the initiative was successfully completed with an SSC rate of 84%. The feared increase in the rate of severe intraventricular haemorrhage (IVH) did not occur despite the increased SSC rate during the project period, further encouraging the practice of early SSC among staff.

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### **EFCNI-Academy**



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#### **E-LEARNING SERIES**

# Learn more about the importance of enteral nutrition in preterm infants

What is the connection between preterm birth and cardiovascular diseases? How does nutrition impact the neurological development of newborns and how can human milk in particular promote the healthy development of very preterm babies? These and other questions are addressed by renowned experts in our e-learning series available now on the EFCNI Academy's website. We invite doctors and nursing staff working in the field of paediatrics, neonatology, or infant nutrition to register and take part in this free, CME accredited, online training. The modules are accredited by the European Accreditation Council for Continuing Medical Education (EACCME) and are supported by the European Society for Paediatric Research (ESPR).

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### GLANCE - Global Alliance for Newborn Care



**BIG LAUNCH EVENT** 

Report on global parent survey about the impact of the pandemic on neonatal care released in a live webinar

On 11 November, EFCNI and GLANCE could finally present the results of the global parent survey and released the project report "Zero separation. Together for better care! Infant and family-centred developmental care in times of COVID-19 – A global survey of parents' experiences" in a digital launch event. Representatives of the foundations as well as international supporters of the project and affected parents contributed with insightful presentations and made the extent of the separation policies comprehensible by sharing their perspectives as scientists, researchers, and parents. The full report is now available for download on our website. In addition, a recording of the webinar can be accessed via our website as well.

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#### NEW PARENT ORGANISATION IN NIGERIA

### Welcome to the network, "EDEN Foundation"!

We are happy to welcome a new parent organisation as partner and friend to our network: The "EDEN Foundation" from Nigeria! After experiencing a preterm birth, and overcoming the physical and psychological tolls that came with it, Kobi Ajayi found her calling in activism and established the organisation in 2019 with the aim to improve the health outcomes of mothers as well as small and sick newborns in rural and underserved regions in sub-Saharan Africa. The name of the foundation references, of course, the Biblical Garden of Eden with its promises of health and wholesomeness, but is actually an acronym of the foundation's strategic goals to Educate families, Direct and provide resources, Empower mothers with skills and knowledge, and, lastly, Nurture families to survive and thrive. Welcome to the network, "EDEN Foundation"! We are excited to have you.

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