





Dear friends and supporters of EFCNI,

As you are surely aware, 17 November is World Prematurity Day – and we celebrated again in style. This year's motto was "A parent's embrace: a powerful therapy. Enable skinto-skin contact from the moment of birth", calling for the implementation of infant- and family-centred developmental care in neonatal care. It was a wonderful day which shone a light on those born too soon and their families as well as the challenges these families often face. We also honour those working in neonatal care for their efforts and dedication. Thus, it was heartening to see that communities all over the globe came together to raise awareness and call for more parental involvement in the care of the smallest patients.

Kangaroo Mother Care (KMC) was an important topic this month as well, and in this edition, we highlight new findings and developments on skin-to-skin practices, particularly the new WHO guidelines for the care of preterm and low-birth-weight infants. Standards of care prove helpful when advocating for the implementation of certain practices and routines, which is why we are excited to bring you important updates about the European Standards of Care for Newborn Health (ESCNH).

Many thanks for your continuous support!

Please stay healthy and safe,

Silke Mader and the EFCNI team

#### **EFCNI**



### A parent's embrace: a powerful therapy. Enable skin-to-skin contact from the moment of birth

We are proud to say that World Prematurity Day 2022 was a big success! As in previous years, it was an emotional day which celebrated those born too soon and their families while drawing attention to the challenges that come with preterm birth. This year, the global community also called for the implementation of Kangaroo Mother Care (KMC) and skin-to-skin contact from the moment of birth. Social media platforms bristled with activity as families shared stories and pictures. Roundtables and conferences took place, often in a hybrid setting, allowing people to log on from all parts of the world as experts and advocates discussed the current state of neonatal care in conference venues across the globe. Parent organisations set up local events and festivities, bringing communities together. Purple was the colour of the day with purple balloons, streamers, clothing, and food widely shared. We are truly grateful to those who participated for their invaluable contributions to World Prematurity Day. We know that we could not have done it without you! We would also like to extend our heartfelt thanks to the global group of organisations involved in planning and preparing World Prematurity Day 2022. Your enthusiasm, focus, and energy meant that this year's WPD was set up for success from the start. Check out an overview of this year's activities and feel free to send us more information and pictures of your events as well.

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#### NEW WHO RECOMMENDATIONS LAUNCHED

Updated guidelines could revolutionise the way clinical care is provided to the most fragile infants

The newly updated WHO guidelines for the care of preterm and low-birth-weight infants advise that skin-to-skin contact, an important aspect of kangaroo mother care, should start immediately after birth for babies born too soon and/or too small without incubation. This marks a significant change from earlier recommendations and common clinical practice. In a live-webinar on World Prematurity Day, dedicated to the launch of these guidelines, EFCNI's Chairwoman Silke Mader had the honour and great opportunity to contribute the parental perspective on this aspect of neonatal care. The guidelines are now freely available online.

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**Q&A RECORDING ON KMC NOW AVAILABLE** 

Learn more about Kangaroo Mother Care (KMC) and skin-to-skin care practices



Are you a (neonatal) healthcare professional, a nurse, or a parent of a hospitalised or preterm baby and would like to learn more about KMC approaches and their implementation in daily intensive care practices? Watch our Q & A on KMC and skin-to-skin practices where we talk about the benefits of starting these interventions as early as possible, discuss challenges and lessons learned, and provide impulses to implement KMC in a neonatal intensive care unit. The session was jointly hosted by the Canadian Premature Babies Foundation (CPBF), our Brazilian partners at Prematuridade.com, and EFCNI. Learn from our experts Dr. Nathalie Charpak and Diane K. E. Schultz.

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STRONG START FOR LITTLE HEROES – DEADLINE FOR RAFFLE ACTION IS 15 DECEMBER

### Take part in our raffle and win prices for your neonatal intensive care unit

Participating clinics as part of the "Strong Start for Little Heroes" campaign organised outstanding activities to raise awareness for World Prematurity Day 2022. With lots of imagination and creativity, neonatal intensive care units across Germany, Austria, and Switzerland managed to draw the public's attention to the challenges of preterm birth and to make the situation of affected babies and their families more present in society. A special thank you goes out to all units for contributing to such a special day! We encourage all participants to sign up for the raffle. Registration is still possible until 15 December. Good luck! Please note this campaign is set up in German.

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VOICES OF RSV

# New video series with testimonials from affected families and caregivers

Due to a severe wave of respiratory illnesses in infants and young children, France activated an emergency plan just last week. We are also receiving reports from the USA and other countries in the northern hemisphere of worrying numbers of ill infants in emergency rooms and paediatric hospitals due to the increasing cases of Respiratory Syncytial Virus (RSV) infections. Very young infants and preterm babies are particularly affected – and their families and caregivers suffer with them. In our new video series "Voices of RSV", we have given affected parents and caregivers as well as nurses and doctors a voice to tell their own RSV story. Behind every RSV-afflicted preterm baby is a very personal illness story that touches many people – first and foremost, of course, the family but also the hospital staff caring for the child.

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### **Network**

The F.I.N.E. Conference for Healthcare Professionals: Neurodevelopmental Care is Essential!









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DIGITAL F.I.N.E. CONFERENCE FOR HEALTH PROFESSIONALS

# Romanian parent organisation ARNIS continues digital F.I.N.E. trainings

Since 2018, EFCNI's Romanian partner parent organisation ARNIS has been educating healthcare professionals in the Family and Infant Neurodevelopmental Care Education (F.I.N.E.) programme, a programme coordinated by Dr. Inga Warren, via a digital platform. Until today, around 300 Romanian medical professionals were trained at Level 1 of the F.I.N.E. course. Recently the organisation also hosted and organised a digital conference, bringing together key opinion leaders as well as graduates of the course to discuss and facilitate the implementation of the programmes' principles in the NICU. Focussing on neurodevelopmental care, the very well-attended event provided intriguing insights and stimulated exciting debates amongst the attendees.

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13TH INTERNATIONAL CONFERENCE ON KANGAROO MOTHER CARE (KMC)

# Experts from around the world came together to exchange knowledge in the field of KMC

It was a pleasure to attend the 13th International Conference on Kangaroo Mother Care from 21 to 24 November in Madrid. Four days packed with workshops and lectures from worldwide experts on the latest KMC practices are behind us, and EFCNI Chairwoman Silke Mader had the honour to contribute to the diverse congress programme with a session on the importance of parent organisations for the dissemination of Kangaroo Mother Care. Moreover, the World Health Organisation (WHO) presented the new guidelines on providing KMC for preterm born infants, with Silke Mader contributing the parental perspective in this area. We were thrilled to meet old friends and new ones and to work together with the KMC community towards the best possible care for preterm born babies and their families. We are looking forward to the next conference.

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### Science



# First respiratory syncytial virus (RSV) cases have already occurred and the trend is rapidly increasing

EFCNI is looking for voluntary participants in France, Germany, Italy, and Sweden to take part in a multi-country study. The study aims to explore parents' and caregivers' experiences related to the challenges caused by RSV infection and hospitalisation of their children (< 2 years). By sharing how parents have dealt with their child's RSV episode, they can help to increase our understanding of the disease and begin to make a change in the quality of life for affected children and their families. Check it out to learn how you can help make a difference!

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#### **NEW EFCNI PUBLICATION**

### Stronger together – A call for collaboration

How can we achieve participation of all relevant actors in health research and why is this important? The advantages and benefits of a collaborative research approach by the involvement of all relevant actors has been outlined in an editorial in the American Journal of Physiology, published on the occasion of World Prematurity Day 2022. The recognition of parents and caregivers in the medical care of their children underlines the paradigm shift from "research about" to "research with" and contributes to closing the gap between the reality of people's lives and health research. Read more about how participatory research approaches can be established right from the start in order to identify unmet though important needs for a specific research question.

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ADVERSE HEALTH EFFECTS OF A MOULDY HOME ENVIRONMENT

### Early exposure to residential moisture damage associated with persistent wheezing

Moisture damage and mould at home are associated with poor respiratory outcomes in childhood with possible long-term health consequences. A new study on the adverse child health consequences of a mouldy or moisture-damaged home has just been published in the Pediatric Allergy and Immunology Journal (PAI). Children who are born in a home environment with dampness and signs of mould were at higher risk of developing persistent wheezing in early childhood. As persistent wheezing is further strongly associated with asthma and reduced lung function later in adolescence and adulthood, these findings

emphasize the importance of providing a healthy home environment right from the start.

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PARENT ADVISORY BOARD MEETING FOR THE INSPIRESTUDY

# Insightful meeting on neonatal blood transfusions in Europe took place

In October, the 2nd Parent Advisory Board Meeting in 2022 for the INSPIRE-study (International Neonatal tranSfusion PoInt pREvalence study) took place. Parent representatives and members from the Neonatal Transfusion Network (NTN) met online to discuss and share experiences regarding neonatal blood transfusions in Europe. The discussion results and parents' input will be used for further activities within the implementation of the study. Our sincere thanks go to all participants for their valuable contributions.

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#### NOTHING ABOUT ME WITHOUT ME

### Call for contributions on patient and public involvement (PPI) in paediatric health research

Contribute to the upcoming Special Issue by EFCNI in the Children Journal "Nothing about me without me – Addressing, and overcoming current and future challenges in paediatric health research by involving all actors". We are looking for innovative contributions in the field of stakeholder participation, involvement, and co-creation in paediatric health research.

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### European Standards of Care for Newborn Health



EAPS CONGRESS IN BARCELONA

# The role of standards in improving health outcomes for preterm infants

EFCNI was honoured to chair a session at the 9th Congress of the European Academy of Paediatric Societies (EAPS) this October. Together with EFCNI's Senior Medical Director Prof. Luc Zimmermann, Chairwoman Silke Mader led a session on the role of standards in improving and assessing health outcomes for preterm infants. Senior Project Manager Isabel

Geiger opened the session with a presentation on the European Standards of Care for Newborn Health (ESCNH). Geiger discussed the revision process built into the lifecycle of each individual standard, using the public and expert consultation phases held this summer for 20 such standards as example. She also introduced six newly-adopted standards after explaining the rigorous development process. The main theme of the session was that standards of care should move with social and medical developments to keep reflecting the state of the art and enabling patients and health professionals to achieve the best outcomes.

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#### DIGITAL WORKSHOP

# Learning from the best: How to implement the European Standards of Care for Newborn Health

As the European Standards of Care for Newborn Health (ESCNH) continue to grow and evolve, the question of how to implement them successfully across Europe takes on an even greater importance. This is why a group of representatives from Portugal and Italy got together with EFCNI this November to discuss implementation strategies. The meeting was held in the form of a digital workshop. Attendees included members of the respective national neonatology associations, nurse associations, parent organisations as well as NIDCAP representatives from these countries. When it comes to implementation efforts, both Italy and Portugal serve as best practice examples, so EFCNI was keen to learn from their experiences since plans for an implementation manual are underway. Thank you to all participants for sharing their insights.

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### **EFCNI-Academy**



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CME ACCREDITATION RUNS OUT IN JANUARY 2023

### E-learning series "Enteral Preterm Nutrition"

How does nutrition impact the neurological development of newborns, and how can human milk in particular promote the healthy development of very preterm babies? What exactly makes human milk the superfood that contributes to growth and disease prevention and helps minimise mortalities? These and other questions are addressed by renowned international experts who share latest insights and studies on the importance of human milk nutrition for preterm infant health. We warmly invite healthcare professionals, nursing staff, and interested learners to sign up and participate in this free online training!

Note that CME accreditation is only possible until the end of January 2023.

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### GLANCE - Global Alliance for Newborn Care



@ GLANCE

INFANT- AND FAMILY-CENTRED DEVELOPMENTAL CARE

Session on infant- and family-centred developmental care before and during the COVID-19 pandemic

An interdisciplinary session at the EAPS Congress in Barcelona, chaired by GLANCE founder Silke Mader, provided the great opportunity to present the implications for infant- and familycentred developmental care before and during the COVID-19 pandemic. In their talks, the speakers shed light on the parents' situation during the often-rigorous separation from their newborn in the NICU and also how healthcare professionals can support parents as allies and partners now and in the future. After all, it takes science-based, not fear-based, policies in neonatal and maternal healthcare.

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