



Dear friends and supporters of EFCNI,

World Breastfeeding Week is only a few days away, and we are busy finalising our outreach activities. This year's theme is "Protect and promote breastfeeding for the best start in life", an important message which highlights the importance of breastmilk for newborns.

We are also gearing up for the fifth jENS Congress – the Congress of joint European Neonatal Societies where EFCNI is involved in the organisation. This year, the congress takes place in Rome, and we look forward to connecting with old and new friends while discussing the latest developments in neonatology. Lastly, we want to direct your attention towards a new publication on the importance of nurturing care, published jointly by the WHO and UNICEF.

Many thanks for your continuous support!

Happy reading,

Silke Mader and the EFCNI team

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WORLD BREASTFEEDING WEEK 2023

Join our World Breastfeeding Week awareness campaign from 1 to 7 August

In celebration of World Breastfeeding Week 2023, EFCNI organises a campaign again between 1-7 August with the aim to raise awareness about the health benefits of breastfeeding for preterm or sick newborns and their mothers. This year's World Breastfeeding Week is about recognising the importance of

establishing and maintaining breastfeeding-friendly facilities and support systems. They are crucial for protecting, promoting, and assisting breastfeeding, not only at the workplace but also in communities, health facilities, the public, and particularly in critical environments like hospitals and NICUs. Join us with our message "Protect and promote breastfeeding for the best start in life" and find social media graphics in different languages, a poster, infographics, and much more to raise awareness during World Breastfeeding Week.

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REGISTER NOW - STILL FREE SPOTS AVAILABLE

Join us and sign up for our campaign "Strong start for little heroes" 2023

It is still possible to sign up for our campaign "Strong start for little heroes" ("Starker Start für kleine Helden")! We warmly invite neonatal intensive care units in Germany, Austria, and Switzerland to register for this activity. As in previous years, we will provide all participating clinics with a comprehensive package facilitating their activities to draw attention to World Prematurity Day 2023. Included are greeting cards for former preterm born babies, gift sets for parents, and much more. Among all participating neonatal units, we will give away great prizes. So do not wait and sign up! Registration is still open until 15 August. Please note this campaign is set up in German.

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JENS 2023

From evidence-based research to scientific innovations: The future of neonatology starts here!

From 19 to 23 September, the fifth Congress of joint European Neonatal Societies (jENS) will take place in Rome, Italy. Organised by ESPR, UENPS, and EFCNI, the congress addresses a diverse range of topics from developments in neurology to neonatal infectious diseases to perinatal practices. Pre-congress courses are scheduled for 18 and 19 September. EFCNI will be on-site with a booth and lots of interesting material while also organising and chairing several sessions on the benefits of parent and patient involvement in neonatal research and care. We look forward to seeing you in Rome!

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PICAPP IN HUNGARY

New app supports families of preterm infants on their NICU journey

Becoming parents to a preterm infant is often a traumatic experience. Many families report feeling overwhelmed, and filtering through available information can be an additional burden in what is already an extremely emotional and stressful situation. In Hungary, our partner parent organisation Melletted a helyem Egyesület (Right(s) beside you Association) developed a free app which aims to support parents as they navigate the NICU with their preterm infant. The app offers evidence-based information on preterm birth to help parents educate themselves. It also features journaling functions and allows parents to log growth rates, weight gain, time spent kangarooing, and other activities. These data can be sent easily to specialists who treat the infant to facilitate individualised care.

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OPEN LETTER TO EUROPEAN UNION

Call to secure access to medical devices for children and patients with orphan diseases

Along with representatives of 21 other European associations, EFCNI chairwoman Silke Mader signed an open letter by the European Academy of Paediatrics to the EU Commission. The reason: the EU Medical Device Regulation 745/2017 aimed to improve the evaluation and safety of high-risk medical devices. However, its implementation has led to the withdrawal of medical devices from the EU market due to an unintended massive increase in time and costs for manufacturers – especially for those who produce devices for small patient groups. As a result, the paediatric and rare diseases community in the EU is currently facing the loss of important medical devices. The open letter calls for immediate action to secure continued access to essential medical devices.

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WE ARE LOOKING FOR PARTICIPANTS AND SPEAKERS

Upcoming multi-stakeholder meeting on perinatal asphyxia in September

If you have experiences with perinatal asphyxia or have been involved in preclinical studies and clinical trials on this topic, then please join the following event! The conect4children (c4c) network, of which EFCNI is a partner, organises an international multi-stakeholder meeting ahead of the 5th jENS Congress this

year and is currently looking for participants and speakers. Patient representatives are particularly encouraged to get involved. The meeting will take place on 18 and 19 September 2023 and offers five interesting sessions of lectures and panel discussions on the topic of perinatal asphyxia. Participants include international experts, such as researchers in the field of neonatal preclinical studies and biomarkers, representatives from regulatory agencies and pharmaceutical companies as well as patients, parents, and their advocates.

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Science



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COMPREHENDING THE NEEDS OF PARENTS

Coping with bereavement in the NICU after infant loss

Parental grieving in the NICU following infant loss was the subject of a recent systematic review from Canada. Healthcare professionals can support parents by involving them in joint decision-making and clear communication. Understanding parents' needs helps to improve care, e.g. ethical decisions in end-of-life care can profoundly impact parental bereavement. What is more, healthcare professionals play a crucial role in helping parents cope with their grief. Facilitating meaningful moments, creating memories, and involving parents have also shown to be beneficial during mourning. The review also emphasised the value of clear and compassionate communication, private goodbye spaces, and shared decision-making.

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TWIN PREGNANCIES

Need for improvements in Twin Anaemia Polycythemia Sequence screening

A recent case study from the US highlights the ethical challenges concerning the screening and handling of Twin Anaemia Polycythemia Sequence (TAPS). This disease can occur in monochorionic twin pregnancies and is characterised by anaemia in one twin and polycythaemia in the other twin. The cause is an unwanted small surface connection in the placenta, which results in a transfer of red blood cells from one baby to the other. It means that neither twin's blood is in a healthy state, leading to many serious short- and long-term complications. Preterm births are also likely. The study describes a representative example of the burden of a mother and her twins affected by TAPS, demonstrating the importance of early diagnosis and support. The authors emphasise the need for

advanced research in this field and adjustments to the screening guidelines to improve patient care and family support.

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FDA APPROVES NEW DRUG

A medical milestone to prevent RSV in babies and toddlers

Last week, the U.S. Food and Drug Administration (FDA) approved a new drug for preventing lower respiratory tract disease caused by Respiratory Syncytial Virus (RSV) in newborns and infants born during or entering their first RSV season, and in children up to 24 months of age who remain at risk of severe RSV disease through their second RSV season. This marks a significant turning point in the fight against an infectious disease that has affected countless lives. With its far-reaching impact, many children will benefit from the new preventative option in the upcoming season, alleviating a significant strain on both health system and families. Its approval is a monumental milestone in giving every child a better chance to grow up without the burden of RSV.

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European Standards of Care for Newborn Health



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INFANT- AND FAMILY-CENTRED DEVELOPMENTAL CARE

Rebuilding after the earthquake – The power of parental involvement in Turkey

The devastating earthquake which ravaged parts of Turkey in February this year has also severely affected hospitals in their capacity to care for the tiniest patients and their families. Thanks to the initiative of our partner parent organisation in Turkey, El Bebek Gül Bebek, two NICUs saw their family rooms renovated and refurbished. These rooms enable families to stay with their infant in the hospital, thus supporting Zero Separation and family bonding. Congratulations to El Bebek Gül Bebek on completing this wonderful project!

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IMPLEMENTATION

Learning from success stories: Second digital workshop held

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Last month, EFCNI organised and held the second digital workshop focused on how to implement the European Standards of Care for Newborn Health (ESCNH). It provided a platform for those already engaged in putting the ESCNH into practice in their countries to reflect on their progress and share insights with others wanting to achieve the same. Representatives of the task forces working on implementing the ESCNH in Italy and Portugal spoke about their experiences and explained which steps they took to advance the endeavour. Participants discussed paths towards implementation as well as roadblocks and ways to circumvent them. Thank you to everyone for the lively debate, and see you at the follow-up meeting next year!

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LAST CHANCE TO JOIN THE REVIEW PROCESS

Public consultation phase: only a few days left

After a consultation period of four months, the public consultation of 76 standards closes on Monday, 31 July 2023. Healthcare professionals, parent representatives, and all other stakeholders are cordially invited to take this unique opportunity to shape neonatal care by participating in the review process. We wholeheartedly thank everyone who has already participated for their support and are looking forward to receiving further insightful feedback.

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THERMOREGULATION

New video series on temperature management in newborns

Preterm infants often struggle with maintaining a stable body temperature in the normal range. This is why professional temperature management is crucial from the first moments of life onwards. Katrin Klebermass-Schrehof, associate professor at the Medical University Vienna, spoke with EFCNI about the role of thermoregulation in neonatal care in our new interview series. In the videos, she explains, for instance, why temperature management should form part of care routines during the "Golden Hour" and what hospitals can do to ensure newborns do not lose heat.

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THE VITAL FIRST YEARS

New progress report from WHO and UNICEF highlights the need to step up investment in early nurturing care

The first years of a child's life provide unique opportunities to improve lifelong health, nutrition, and well-being. This is why a new progress report from WHO and UNICEF calls to step up investment in nurturing care. It tracks against the 2018 global Nurturing Care Framework, a guidance document for supporting the healthy physical, intellectual, and emotional development of young children. According to the progress report, political commitment to early childhood development has increased. Nearly 50% more countries have developed related policies or plans, and services have expanded. However, more investments are needed to scale up services and demonstrate impact, especially among vulnerable populations. This includes ensuring adequate support for children with developmental difficulties and promoting the psychosocial well-being of caregivers.

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

This online newsletter is issued by EFCNI - European Foundation for the Care of Newborn Infants. Share your comments, suggestions and feedback by emailing news@efcni.org. If you wish to unsubscribe, please click [here](#).

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EFCNI is a non-profit organisation established under German public law | Tax reference number 143/235/22619.

