



Dear friends and supporters of EFCNI,

It is with immense gratitude and humility that I share the news of being awarded the Cross of the Order of Merit of the Federal Republic of Germany, the highest honour our country bestows. This recognition is a testament to the decades of tireless work and dedication on behalf of preterm and hospitalised infants and their families. It is a collective achievement, reflecting the unwavering commitment of our entire community.

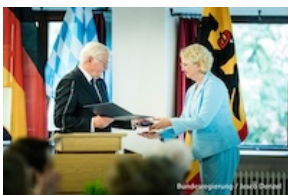
In this edition of our newsletter, we are also thrilled to welcome our new Senior Medical Director, Professor Helmut Hummler, whose expertise and vision will undoubtedly strengthen our mission. We also celebrate the recent passing of new EU regulation on human milk, a significant step forward in ensuring optimal nutrition and care for our most vulnerable infants.

These milestones inspire us to continue our advocacy with renewed vigour, knowing that our efforts are making a tangible difference in the lives of many. Together, we will keep striving for excellence in neonatal care and support for families. Thank you for accompanying us on this journey!

Warm regards,

Silke Mader and the EFCNI team

EFCNI



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SILKE MADER RECEIVES GERMANY'S HIGHEST HONOUR

## Federal Cross of Merit for outstanding commitment to preterm and newborn health

Silke Mader, co-founder and Chairwoman of EFCNI, was awarded the Cross of the Order of Merit of the Federal Republic of Germany for her tireless work on behalf of preterm babies and their families. She was presented with Germany's highest honour by President Frank-Walter Steinmeier at a festive ceremony in Weiden in the Oberpfalz region of Bavaria (Upper

Palatinate) on 27 June. Mader's unwavering commitment to improving maternal and newborn care was born out of a harrowing personal experience and has driven her to fight for major improvements in healthcare for the tiniest and most vulnerable, and ultimately for a better start in life for all children. Read more about her remarkable journey in our official press release (German and English).

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© Helmut Hummler

#### NEW ADDITION TO THE TEAM

### A warm welcome to Professor Hummler, EFCNI's new Senior Medical Director

We are thrilled to announce that Professor Helmut Hummler will join EFCNI as Senior Medical Director in September 2024. He will take over from current Senior Medical Director, Professor Luc Zimmermann, who retires at the end of the year. A graduate of the University of Tübingen, Professor Hummler trained in neonatology in Miami and has held prominent roles in Germany and Qatar. He has published over 150 articles, focusing on neonatal lung injury and mechanical ventilation, and has introduced family-centred care standards internationally. Professor Hummler has received numerous awards for his contributions to neonatology. His extensive experience and dedication to quality care will greatly advance EFCNI's mission to support preterm and hospitalised infants and their families.

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#### NEW RULES FOR SAFER ACCESS TO HUMAN MILK

### European Council implements new regulation on substances of human origin (SoHO), ensuring better protection for donors and recipients

The Council of the European Union has adopted new rules to broaden the scope of SoHO, now including human milk and intestinal microbiota. This step will greatly improve the safety and quality of these substances used in healthcare, significantly benefitting newborn health. The new regulation covers every step from registering and testing donors, to collecting and processing SoHO, to applying them to humans, and monitoring clinical outcomes. These changes will better protect donors, recipients, and children born through medically assisted reproduction. The goal is to improve the current legal framework and make it more adaptable to scientific and technical progress. For over a decade, EFCNI, alongside international high-level experts in the field of human milk, has been advocating for a common regulatory framework in the EU, significantly contributing to the success of the newly implemented regulation.

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## STRONG START FOR LITTLE HEROES 2024

### The campaign “Strong start for little heroes” enters the next round – Join us and sign up!

We are happy to announce that our campaign “Strong start for little heroes” (“Starker Start für kleine Helden”) is starting again! 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 2024. 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! Please note this campaign is set up in German.

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## Network



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## PODCAST RECOMMENDATION

### Series 2 of “Unexpected Beginnings: The Neonatal Unit” podcast is available

Hosted by Caroline Verdon and Kerry McCarthy, both of whom have personal experience with neonatal units, “Unexpected Beginnings” provides first-hand insights into the subject. By sharing stories from other parents and interviewing doctors, surgeons, mental health experts, and other professionals, this podcast aims to make parents feel more supported and less isolated, while also offering guidance to valuable resources and information. The episodes explore a wide range of topics, from mental health to common conditions affecting neonatal babies. Thanks to funding from Leeds Hospitals Charity and the support of Leeds Teaching Hospitals NHS Trust, Series 2 premiered on 18 December 2023 and has since released an episode monthly.

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## KNIGHT OF MERIT

### Recognising the power of advocacy in neonatal care

Monica Ceccatelli, Vice President of our Italian partner parent organisation “Vivere Onlus” and President of “Piccino Piccino” (the Italian association of parents of preterm infants) was awarded the prestigious “Cavaliere al Merito” of the Italian Republic. This honour recognises her unwavering dedication to the defence of preterm infants and those in need of urgent

medical care. Her tireless efforts have had a significant impact on the lives of countless families and children. Thank you for your dedication and commitment throughout the years – congratulations! Please note that the article is in Italian.

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## EDUCATION OPPORTUNITY

### Providing education and training to healthcare professionals in Ukraine

Our partner parent organisation in Ukraine, “Early Birds”, has been providing extensive training and education programmes on skin-to-skin contact in the neurodevelopmental care course developed for healthcare professionals in Ukraine. Collaborating with the Ukrainian Academy of Paediatric Specialties, the National Health Service of Ukraine, the National University of Health of Ukraine, COINN (The Council of International Neonatal Nursing/ Council of International Neonatal Nurses), EFCNI, and others, “Early Birds” offered a range of webinars with renowned experts on topics such as Kangaroo Mother Care, skin-to-skin contact, and improving care with the help of the European Standards of Care for Newborn Health. Speakers also discussed how medical professionals can improve communication with families and addressed strategies to mitigate shortages in staff and resources. Please note that the recording is in Ukrainian.

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## Science



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## RESQ FAMILY

### A child’s hospitalisation due to RSV can impact the well-being of the entire family

It can be difficult to distinguish between a common cold and an RSV infection. That is why it can come as a shock to parents when their child suddenly develops a severe case of RSV and must be hospitalised. Caught up in worrying about the sick child, feeling guilty about not being there for the other family members, and concerns about missing out at work, parents experience a very challenging situation. The ResQ Family study uncovers how parents are affected and which country-specific gaps in support for parents need to be closed in the future.

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## CANNABIS AND NEONATAL HEALTH

### A warning about the adverse effects of cannabis



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## use during pregnancy

An estimated 50% of women who use cannabis continue their use during pregnancy, leading to major health risks for the baby. These include a higher risk of preterm birth and low birth weight. A cohort study from Spain examined pregnant women for 10 years and developed approaches to motivate them to stop using cannabis during pregnancy. The findings reveal that early detection of use and subsequent counselling opportunities for discontinuation are the most effective ways to support these mothers and prevent health problems for the unborn child.

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## European Standards of Care for Newborn Health



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### MEDICAL CARE AND CLINICAL PRACTICE

## Improving medical care and clinical practice for all newborns across Europe through reference standards

Explore our two insightful videos on “Medical care and clinical practice”, one of the topics of the European Standards of Care for Newborn Health (ESCNH). In the first video, Chair Professor Luc Zimmermann and Vice Chairs Professor Lena Hellström-Westas and Professor Guiseppa Buonocore discuss the necessity of European-wide standards to harmonise care and improve outcomes for preterm and ill newborns. The second video focuses on the essential steps for implementing these standards, emphasising stakeholder engagement and providing the necessary tools for improvement.

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### PREVENTING BRONCHOPULMONARY DYSPLASIA

## The protective effects of mother’s own milk and donor milk for preterm infants with BPD

Breast milk is essential in reducing the incidence and severity of Bronchopulmonary Dysplasia (BPD) in preterm infants. A study conducted at Hospital General Universitario Gregorio Marañón in Madrid compared the effects of mother’s own milk (MOM) and preterm donor milk (PDM) on BPD incidence. The findings indicate no significant difference between the two, suggesting that PDM is a viable alternative when MOM is unavailable. The research also highlights that preterm infants with BPD 2-3 show lower growth despite adequate nutrition, underscoring the need for targeted nutritional strategies. Breastfeeding provides significant protective benefits against BPD and reduces hospital readmissions in the first six months of life.



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## NICU DESIGN

### Building a new NICU in Nicosia, Cyprus

Our partner parent organisation in Cyprus, Mora Thavmata, has successfully pushed for a new NICU in Nicosia. The old NICU, opened in 1985, currently operates at 150% capacity, a situation that is no longer tenable. The new building will provide ample space and, following the guidance of the European Standards of Care for Newborn Health for NICU design, support infant- and family-centred developmental care and improved medical care and clinical practice. The new NICU will include a family room, a breastfeeding room, and upgraded facilities for medical and nursing staff. Parental presence, currently limited to only a few hours a day, will be facilitated by the new design as well as extensive Kangaroo Mother Care and skin-to-skin contact. At the beginning of June, the President of the Republic of Cyprus, Mr. Nicos Christodoulides, officially laid the foundation stone, and construction has begun.

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## GLANCE - Global Alliance for Newborn Care



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## GLOBAL COLLABORATION

### WHO initiatives for follow-up care of small and sick newborns

The survival and development of small and sick newborns (SSNs) remain a critical issue worldwide, with progress lagging in many regions. The “Every Newborn Action Plan” (ENAP) highlights the potential of intrapartum and postnatal care to save nearly three million lives annually. Despite consensus on the importance of both hospital and community care, there are no WHO guidelines for SSN follow-up, especially suited for low- and middle-income countries. To address this, the WHO is developing comprehensive guidelines with input from four expert review teams and a technical consultative group. Over 50 international experts, including EFCNI Chairwoman Silke Mader and Doris Mollel of the Doris Mollel Foundation in Tanzania, convened in Geneva to discuss follow-up care from discharge to five years of age. The meeting united key stakeholders to review evidence and plan next steps. The guidelines are expected by late 2024 or early 2025, with EFCNI and partners committed to active dissemination.

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## KANGAROO MOTHER CARE



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## Not a privilege but a right – Kangaroo Mother Care is a lifesaving intervention

We released a statement on the importance of Kangaroo Mother Care (KMC), a low-cost, high-outcome intervention that involves continuous skin-to-skin contact, exclusive breastfeeding, and timely NICU discharge. KMC significantly reduces infant mortality and infections, enhances growth and brain development, and strengthens family bonds while also alleviating the burden on healthcare professionals. Alarming, some hospitals charge families for this essential care, a practice we strongly oppose. Join us in advocating for every newborn's right to lifesaving KMC.

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The EFCNI 2024 policy and advocacy training workshop for patient and family representatives is supported by a restricted grant from Pfizer.

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EFCNI - Hofmannstraße 7A - 81379 München - Germany

Tel: +49 (0)89/89083260 - Fax: +49 (0)89/890832610 - E-mail: [info@efcni.org](mailto:info@efcni.org)

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