

Dear friends and supporters of EFCNI,

Preterm birth is not just a medical challenge; it is a lifelong journey. In this issue, we share the inspiring story of Lukas Mader, born at just 515 grams, highlighting the realities many preterm children face beyond the NICU.

We also celebrate a major step forward in maternal and neonatal health. Thanks to strong advocacy, the WHO has now included skin-to-skin contact and breastfeeding in its Core Outcome Set for epidemics – ensuring these life-saving practices are prioritised in future research.

Finally, we look ahead to the 38th Fetus as a Patient Congress, where I will share my personal perspective on pre-eclampsia. This global event brings together experts to advance maternal-foetal care and strengthen collaboration.

By raising awareness, advocating for change, and sharing knowledge, we can shape a better future for newborns worldwide.

Warm regards,

Silke Mader and the EFCNI team

EFCNI

NEW AWARENESS CAMPAIGN

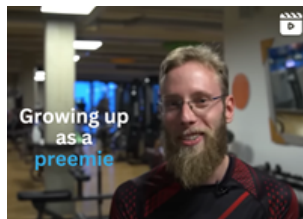
HDFN is rare – be aware – ask for specialist care



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Haemolytic disease of the foetus and newborn (HDFN) is a rare but serious condition that requires early detection and specialist care. It occurs when a mother's red blood cells are incompatible with those of her unborn baby and can lead to severe foetal anaemia. To raise awareness and provide resources for patients and expectant parents, EFCNI and the Allo Hope Foundation have launched an awareness campaign featuring expert insights and personal experiences from affected families. We are delighted that Professor Stefan Verlohren is supporting this campaign with video testimonials on the monitoring and management of HDFN. You can find his statements, more information about HDFN, and moving personal stories on our newly launched campaign page.

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BORN EARLY – ALWAYS BEHIND?

Growing up as a preemie

Being born preterm is not just a medical event – it is a lifelong journey that shapes individuals and their families. Lukas Mader, born 28 years ago weighing just 515 grams, shares his inspiring story of resilience and the unique challenges preterm babies face beyond the first few months of life. Discover how these “little big fighters” defy the odds in the compelling documentary “Born early – Always behind?”.

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JOIN THE 38TH FETUS AS A PATIENT CONGRESS

Shaping the future of maternal-foetal medicine

From 14-16 May 2025, the 38th Fetus as a Patient Congress in Ljubljana, Slovenia, will bring together leading international experts in maternal-foetal medicine, obstetrics and neonatology to explore the latest advances in foetal diagnosis, therapy, and perinatal care. This congress serves as a key platform for scientific exchange, bridging research with clinical practice, while fostering multidisciplinary collaboration to address the evolving challenges in the field. During the plenary sessions on Friday, 16 May, our Chairwoman Silke Mader will share her patient perspective and personal experience of pre-eclampsia and its consequences, offering valuable insights for healthcare professionals. Don't miss this opportunity to connect, collaborate, and advance the field. Register by 1 March 2025 for early bird rates!

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SUPPORTING NEURO-DEVELOPMENT

Building a brighter start: NeuBriC's approach to preterm infant care

The transition from neonatal intensive care to home presents unique challenges for preterm infants and their families. The NeuBriC programme, developed by our Greek partner parent organisation "Iitominon", offers a structured, multidisciplinary approach to improving neurodevelopmental outcomes from birth through early infancy. Combining evidence-based training for healthcare professionals and practical support for parents, NeuBriC integrates trauma-informed and family-centred care into NICU practice. In our latest guest article, Dr Eleni Vavouraki and Pani Pantelides share their insights into how this initiative is shaping neonatal care in Greece and promoting long-term well-being for both infants and their families.

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SUPPORTING INFORMED DECISIONS

Understanding twin pregnancy screening: A guide for parents

Twin pregnancies present unique challenges that require careful monitoring. While the ISUOG Practice Guidelines offer crucial guidance for healthcare professionals, expectant parents often struggle with their complexity. To bridge this gap, Stephanie Ernst, founder and director of our partner parent organisation "The TAPS Support Foundation", and Professor Asma Khalil, St George's Hospital, London, developed the "Patient Guide to Twin Pregnancy Screening". This resource translates medical terminology into accessible language to help parents understand key screening processes, potential risks, and the importance of early chorionic presentation. By empowering families with clear, evidence-based information, the guide ensures they can make informed decisions with their healthcare providers, fostering confidence and better outcomes for both babies and parents.

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VOLUNTEER-LED PROJECTS IN TURKEY

Bringing comfort and support to preterm babies and their families

To support preterm babies and their families in Turkey, our partner parent organisation “El Bebek Gül Bebek” has launched three powerful initiatives: The Nest and Cover Project, Angel Muge, and the New Parents’ Kit. These projects provide essential resources, emotional support, and practical solutions to families facing the challenges of neonatal intensive care, while also offering a sense of reassurance and community. From specialised nesting solutions and handmade clothing to vital breastfeeding support, these efforts are making a real difference in NICUs across Turkey.

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Science



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NEONATAL CARE IN EMERGENCIES

The challenges of implementing Essential Newborn Care (ENC) in crisis settings

Preterm birth remains the leading cause of under-five mortality, underscoring the extreme vulnerability of neonates. This fragility is further amplified by the rising incidence of natural disasters and armed conflicts worldwide. A recent literature review explored the barriers to providing essential newborn care in such challenging environments and identified effective strategies for protecting the lives of the most vulnerable. Initiatives such as the establishment of breastfeeding tents and the creation of dedicated neonatal units within crisis healthcare settings, staffed by specifically trained personnel, have shown significant potential to reduce neonatal mortality. These findings emphasise the critical need for tailored interventions to ensure that essential newborn care is accessible, even in the most adverse conditions.

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PREECLAMPSIA INTERVENTION

Aspirin can lower pre-eclampsia risk

A recent study from Eastern Asia highlights the effectiveness of



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a first-trimester screening and low-dose aspirin in reducing the risk of pre-eclampsia by up to 48% in high-risk pregnancies. This intervention, deemed safe and well-tolerated, also offers additional benefits, such as a reduction in perinatal mortality. The study's findings suggest a promising global application for improving maternal and infant health outcomes.

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RESQ FAMILY EXPERT VIDEO SERIES

Experts call for action to advance RSV prevention

As RSV hospitalisations rise again, especially among infants and young children, the ResQ Family “Expert Video Series” provides key insights into the burden faced by affected families. In five short clips, country-specific experts from France, Germany, and Sweden, along with two international messages, present key study findings on the impact of RSV hospitalisations on daily life - covering topics such as work productivity, parental emotions, RSV awareness, and health literacy. Each video concludes with actionable steps to improve RSV prevention and a call to action to better protect children and their families from the far-reaching consequences of RSV.

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European Standards of Care for Newborn Health



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STUDY PROTOCOL

Developing of a self-assessment tool to reduce inequality in neonatal healthcare

The quality of neonatal care varies not only between European countries but also between healthcare facilities within the same country. To ensure that every newborn receives the best possible care for their start in life, the European Standards of Care for Newborn Health (ESCNH) were developed. However, their implementation remains challenging, as some healthcare providers do not recognise the need for change. To address this, a new ESCNH self-assessment tool is being developed with the support of diverse experts. This free, publicly available resource will enable healthcare professionals to identify areas for improvement and enhance the quality of neonatal care accordingly.

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GLANCE - Global Alliance for Newborn Care



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EMPOWERING FAMILIES, SAVING LIVES

ATTA Breastmilk Community: Supporting newborns through donor human milk

ATTA Breastmilk Community unites parents, healthcare workers, and caregivers to prevent newborn deaths and support maternal mental health. Since its inception in 2021, ATTA has dispensed over 1,005 litres of donor breast milk from more than 150 mothers, benefiting 600 newborns. With community support, ATTA saves fragile infants and trains healthcare professionals in newborn care and donor milk handling. Operating in Uganda as the Alyssa Marie Foundation Limited, a nonprofit organisation, ATTA runs a community-led human milk donation service, ensuring that every baby in need receives the nutrition to survive and thrive.

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WHO CORE OUTCOME SET

Measuring maternal and neonatal health in future epidemics

Epidemics pose significant risks to maternal and neonatal health, but inconsistent reporting of outcomes has hindered evidence-based decision-making. A new Core Outcome Set (COS) developed by the World Health Organization (WHO) aims to standardise the measurement of key maternal and neonatal health outcomes during epidemics. The final COS includes seven core maternal and eleven main neonatal outcomes, as well as seven complementary maternal and four complementary neonatal outcomes. Thanks to strong advocacy, skin-to-skin contact and breastfeeding are now among the core neonatal outcomes – a crucial step in protecting newborn health in times of crisis. While challenges remain, this milestone ensures that these critical practices will be measured in future research and surveillance efforts.

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