



Dear friends and supporters of EFCNI,

As we prepare to celebrate World Prematurity Day on 17 November, the urgency of advocating for preterm and sick babies is clearer than ever. This year's theme, focusing on equitable access to quality care, reminds us of the vital work that remains to be done around the world.

To further support families, we are proud to introduce Neopedia, an exciting project launching in spring 2025. This global, multilingual platform will provide trusted information to families navigating the challenges of preterm and sick baby care. Developed in collaboration with experts and parent organisations worldwide, Neopedia will become a vital resource for those in need.

As we approach World Prematurity Day, let's unite in raising awareness and pushing for the changes needed to ensure that every baby has the best possible start in life.

Thank you for your continued support as we work together to improve newborn care.

With best regards,

Silke Mader and the EFCNI team

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WPD TOOLKIT

Introducing the 2024 World Prematurity Day social media toolkit

Ahead of World Prematurity Day on 17 November, we are pleased to offer a comprehensive social media toolkit to support awareness raising efforts. This resource provides customisable

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graphics, key messages, and essential information to help individuals and organisations effectively highlight the challenges of preterm birth. Whether used by healthcare professionals, parent groups, or advocacy organisations, the toolkit offers a versatile way to engage audiences and promote the need for equitable access to high-quality care for preterm infants. It equips users with the tools necessary to amplify their message and foster greater understanding and support for preterm babies and their families. We also invite you to join our upcoming live chat on the social media platform X (formerly Twitter) on 14 November at 3 pm CET. This engaging discussion will focus on “Access to quality care everywhere”, addressing the challenges of preterm birth and the vital role of healthcare professionals and families.

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STRONG START FOR LITTLE HEROES

Inspirations for celebrating World Prematurity Day 2024 in Germany, Austria, and Switzerland

Are you still looking for activity ideas for World Prematurity Day? Or are you already planning your event but could use some inspiration, practical tips or templates? Our “Strong Start for Little Heroes” campaign page, specifically for Germany, Austria and Switzerland, offers a wide range of materials to help you raise awareness. These includes social media graphics and banners, infographics, and quote cards. The site also features a digital toolkit with text templates and suggestions on how to use the campaign materials in your communications. Additionally, participants have the chance to enter a raffle for engaging in activities. We look forward to seeing the creative efforts and celebrations in these regions! Please note that all materials are provided in German.

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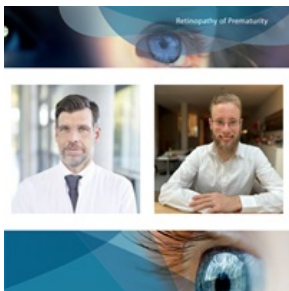
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COMING SOON: NEOPEDIA

A new source of support for families of preterm and sick babies

We are excited to announce the development of Neopedia, a global website designed to support families of preterm or sick babies with reliable, accessible, and multilingual information. This collaborative project brings together the expertise of parent organisations and specialists from around the world, all united in providing vital resources for families navigating the neonatal journey. Stay tuned and sign up to be notified when Neopedia launches in spring 2025!

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LIFELONG IMPACT OF RETINOPATHY OF PREMATUREITY

ROP through the eyes of an expert and a preterm adult

Retinopathy of Prematurity (ROP) is a lesser-known eye disease that profoundly affects those born preterm. From infancy to adulthood, its impact is far-reaching. In an exclusive interview, Professor Armin Wolf, a renowned specialist in ROP, sheds light on the complexities of managing this condition. Lukas Mader, an adult who has lived with ROP since his preterm birth, shares his personal journey, reflecting on the challenges and successes along the way. Both emphasise the critical importance of early detection and ongoing follow-up care in minimising complications and improving long-term outcomes.

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Network



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10TH CONGRESS OF THE EUROPEAN ACADEMY OF PAEDIATRIC SOCIETIES

Global experts exchange knowledge in paediatrics and neonatology

It was a pleasure to attend the 10th Congress of the European Academy of Paediatric Societies (EAPS) in Vienna. Looking back on three days of engagement with leading paediatric researchers from around the world, this event was a vibrant hub of knowledge, collaboration and innovation. EFCNI's Chairwoman Silke Mader and Professor Luc Zimmermann had the honour of chairing the scientific session "Care of the preterm infant" with intriguing presentations on skin-to-skin care, delayed cord clamping and thermoregulation. In addition, Professor Zimmermann presented in the EAPS poster session the perspectives of healthcare professionals and parents on the current state of eleven core topics in preterm care. All in all, it was a great pleasure for us to meet our partners on-site to elaborate on future projects and milestones to improve preterm and newborn care in the future.

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PATIENT NAVIGATOR PROJECT 2024

Expanding care for maternal and child health in Romania

ARNIS, the Romanian Association of Long Hospitalised Newborns, is pioneering the introduction of Patient Navigators in maternity wards, a role previously limited to oncology. These



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Navigators will support families of high-risk newborns, helping them understand diagnoses, treatment options, and necessary care. By the end of November, the programme will have produced the first 10 accredited patient navigators through 180 hours of theory and practice, awarding government-accredited diplomas. ARNIS has also partnered with a university in Cluj-Napoca to study the impact of Navigators in neonatal care. Although still in progress, this initiative represents a significant step forward for maternal and child health in Romania.

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FAMILY SUPPORT & EMPOWERMENT

Czech parent organisation “Nedoklubko” offers bi-annual magazine for NICU families

The Czech parent organisation Nedoklubko has published the 18th issue of its magazine “Nejste v tom sami” (“You Are Not Alone”), dedicated to the vital concept of Zero Separation. The bi-annual magazine, which is distributed to all NICUs in the Czech Republic, is a valuable resource for parents of preterm babies. The latest issue focuses on the importance of keeping babies and mothers together and shows how healthcare professionals in the country are embracing this approach. With practices such as skin-to-skin care, or bonding, implemented even for babies born at 28 weeks, the magazine advocates for this crucial aspect of neonatal care. It also features an insightful interview with EFCNI Chairwoman Silke Mader who shares her views on Kangaroo Mother Care and the importance of Zero Separation in ensuring the best start in life for preterm infants.

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RESHAPING THE LANDSCAPE OF MATERNITY CARE

Professor Kypros Nicolaides awarded Austria's prestigious Semmelweis Prize

We are delighted to share that Professor Kypros Nicolaides, a global pioneer in foetal medicine and a long-standing member of our EFCNI Scientific Advisory Board, has been awarded the Semmelweis Prize – Austria's most distinguished medical honour. Recognised for his groundbreaking contributions to prenatal care, including pioneering diagnostic techniques and life-saving surgical interventions, Professor Nicolaides continues to inspire with his dedication to transforming obstetric care and advancing foetal health worldwide. Congratulations from the entire EFCNI team for this well-deserved recognition!

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PUBLICATION OF RESQ FAMILY PRESS RELEASE

ResQ Family press release highlights impact of RSV hospitalisations on families

As the colder months approach, so does another season of Respiratory Syncytial Virus (RSV). Hospitalisation of children due to RSV places a heavy burden on families and has a significant impact on their quality of life. We are delighted to announce our latest German press release from EFCNI's ResQ Family project, which explores the far-reaching effects of RSV on family well-being. Parents report experiencing anxiety, guilt, and disruption of their professional obligations, compounded by long travel distances to clinics and additional costs. These factors add to the stress and anxiety of working parents. By raising awareness, we aim to advocate for the health of vulnerable infants and support their families. Read more about the study's findings in our official press release, available in German and English.

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NEW RESEARCH PROJECT

LIFT-UP Preterm improves health outcomes for very preterm populations using innovative tools

Building on the foundation of the RECAP Preterm Cohort Platform, the LIFT-UP Preterm project brings together researchers, healthcare professionals, and parent representatives to advance Randomised Controlled Trials (RCTs) in very preterm populations. By leveraging the Platform's extensive study cohorts, this project enables the tracking of long-term health intervention outcomes, supporting a more sustainable use of health data for this under-represented group. One of the project's proof-of-concept studies, TREOCAPA-long-term, illustrates this potential by following up on participants from the original TREOCAPA study to assess neurodevelopmental progress in early childhood.

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MATERNAL HEALTH

The impact of vitamin D deficiency on pregnancy outcomes

A major meta-analysis of more than 28,000 pregnant women reveals that vitamin D deficiency significantly increases the risk of low-birth-weight infants (LBWI). Although no clear association with preterm birth or small-for-gestational-age (SGA) was found, the global rise in vitamin D deficiency underscores the urgent need for regular monitoring and intervention.

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IMPROVING THE NICU EXPERIENCE

Developmental care as a key to improving environment and care

Developmental care is a set of interventions using skin-to-skin care, parental involvement and exclusive breastfeeding to improve the well-being of hospitalised infants and their parents. A new study from China examined the impact of developmental care on the length of an infant's stay in the neonatal intensive care unit (NICU). The study shows that developmental care can significantly improve care procedures in the NICU, enhance the NICU environment and enable earlier discharge from hospital.

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European Standards of Care for Newborn Health



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SPEAK OUT ON RSV

Expertise, personal stories, and a call to action – Protecting our most vulnerable from RSV

In our latest Speak out session, experts and parents came together to shed light on the serious threat that RSV (Respiratory Syncytial Virus) poses for infants and other vulnerable groups. Watch as affected parents Dina Hediger and Dr Barbara Plagg share their personal experiences with their hospitalised children and hear from virologist Dr Lindsay Broadbent about the latest in RSV research and prevention. This eye-opening discussion calls for improved public health education, equitable access to life-saving interventions, and a collective shift to make RSV prevention a public priority.

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PATIENT SAFETY & HYGIENE PRACTICES

Improving patient safety and hygiene practices in neonatal care through European reference standards

The importance of patient safety and hygiene in neonatal care cannot be overstated. Infants in neonatal units are particularly vulnerable, and lapses in hygiene can lead to serious infections. In two new videos, Associate Professor Marije Hogeveen and DDr Eva Schwindt, Chair and Vice Chair of the Topic Expert Group on “Patient safety and hygiene practices”, provide insight into the need for European-wide standards. These standards not only provide healthcare professionals with a reliable

framework to ensure consistent and safe care, but also aim to improve neonatal outcomes by reducing errors and preventing infections. Implementing these guidelines is key to creating safer environments for both infants and healthcare providers.

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SUPPORTING MULTIPLES

Expanding the scope: How the European Standards of Care for Newborn Health (ESCNH) can benefit multiples

The European Standards of Care for Newborn Health (ESCNH) have been instrumental in improving outcomes for preterm and high-risk newborns across Europe. However, one area remains under-represented: the unique challenges faced by twins, triplets, and other multiples. In a recent abstract accepted at the 7th World Congress on Twin Pregnancy and the 19th ISTS Congress, Stephanie Ernst, founder of Dutch partner parent organisation "The TAPS Support Foundation", and Monique Oude Reimer-van Kilsdonk, Senior NIDCAP Trainer at Erasmus MC Hospital in Rotterdam, explore how the ESCNH could be expanded to address the specific needs of multiples. By focusing on infant- and family-centred developmental care and follow-up and continuing care, the authors highlight the potential of the existing standards to improve long-term outcomes and reduce health risks for these vulnerable babies.

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INFECTION PREVENTION

Simulation training boosts infection prevention in neonatal care

A recent study from the Federal University of Minas Gerais, Brazil, focuses on the power of simulation-based training in neonatal care. By focusing on infection prevention practices for central venous catheters, the research demonstrated significant improvements in caregiver compliance. The educational intervention not only improved adherence to critical procedures such as hand hygiene and skin antisepsis but also empowered healthcare teams to provide safer care to vulnerable newborns. This innovative approach underscores the importance of ongoing education in reducing infection risks in Neonatal Intensive Care Units.

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GLANCE - Global Alliance for Newborn Care

WHO RECOMMENDATIONS



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Protecting newborns: WHO calls for GBS screening in pregnancy

The World Health Organization (WHO) has issued new guidelines recommending that pregnant women be screened for Group B Streptococcus (GBS), a bacterium which poses a serious risk to newborns. With nearly 400,000 infants affected worldwide each year, GBS screening can be crucial in preventing serious infections such as sepsis and meningitis. The recommendations outline two key prevention strategies – universal and risk-based screening – to improve neonatal health outcomes.

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LITTLE READERS READ-A-THON

Promoting reading and language exposure in the neonatal setting

The Life's Little Treasures Foundation in Australia held a successful Little Readers Read-a-thon, now in its fifth year. The initiative encourages parents to read to their preterm babies in the NICU, supporting brain development, bonding and reducing parental stress. This year, 74 neonatal units participated, including 54 from Australia and 20 from countries around the world, including New Zealand, USA, UK, Hong Kong, Lebanon, France, Canada, Portugal, Israel, China, Iran, Qatar, and Ireland.

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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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