



Dear friends and supporters of EFCNI,

World Breastfeeding Week, observed annually in August, emphasises the importance of breastfeeding for all newborns, especially preterm and critically ill infants. This year's theme, "Protect and promote breastfeeding for the best start in life", highlights the need for robust support systems in hospitals, workplaces, and public spaces to ensure every newborn gets the best possible start in life.

At the same time, we must address the unique challenges of neonatal palliative care. Some extremely preterm infants require compassionate end-of-life care, making antenatal counselling and ethical decision-making crucial. Improving palliative care practices helps support families and healthcare providers during these challenging times.

Thank you for your dedication to improving neonatal health.

Warm regards,

Silke Mader and the EFCNI team

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WORLD BREASTFEEDING WEEK 2024

## Protect and promote breastfeeding for the best start in life

For the 10th consecutive year, EFCNI is leading the World Breastfeeding Week campaign to underscore the invaluable health benefits of breastfeeding for all newborns, with a special focus on preterm and sick babies and their mothers. This year, under the message "Protect and promote breastfeeding for the best start in life", we advocate for better breastfeeding support systems for everyone, everywhere – in workplaces, health facilities, public places, and critical settings like hospitals and

neonatal units. Join us in this crucial awareness campaign from 1-7 August! To access our resources, including social media graphics in 27 languages and the EFCNI factsheet “Breastfeeding a preterm baby”, please visit campaign page.

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## BEST PRACTICES IN NEONATAL CARE

### First joint UENPS and EFCNI congress: “Do’s and Don’ts in Neonatology”

Our inaugural “Do’s and Don’ts in Neonatology” congress, co-organised with the Union of European Neonatal and Perinatal Societies (UENPS), successfully brought together doctors, nurses, midwives, and parent and patient representatives in Ljubljana, Slovenia. The congress saw participants engage in detailed presentations and practical workshops, discussing and sharing best practices in neonatal care. Key highlights included an in-depth analysis of immediate skin-to-skin contact, nutritional fortification, and the crucial role of parenteral nutrition for preterm and critically ill newborns. With a focus on improving health outcomes for newborns, this congress has set a high standard for future events in the series and promises to be an invaluable resource for all involved in neonatal care.

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## REGISTER NOW – STILL FREE SPOTS AVAILABLE

### Join us and sign up for our campaign “Strong start for little heroes” 2024

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 hospitals with a comprehensive package to facilitate their awareness raising activities on World Prematurity Day 2024. This includes greeting cards for former preterm babies, gift sets for parents, and much more. We will also be giving away great prizes among all participating neonatal units. So do not wait – sign up now! Registration is open until 15 August. Please note that this campaign is conducted in German.

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## Network

### PREVENTING RSV IN GERMANY

STIKO recommends passive immunisation to



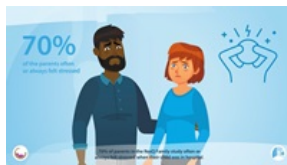
© Robert Koch-Institut (RKI)

## protect all children from severe RSV infections

Respiratory syncytial virus (RSV) poses a significant risk to young children worldwide and is a leading cause of respiratory infections in infants, particularly those born preterm. For the first time, the Standing Committee on Vaccination (STIKO) in Germany now recommends passive immunisation as the standard measure to protect all children from severe RSV infections. This RSV prophylaxis provides protection against RSV infections immediately after administration and lasts for the entire RSV season. Please note that the text is in German.

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## Science



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## RESQ FAMILY SHORT MOTION VIDEO RELEASED

### When RSV strikes: Understanding the family impact

Respiratory syncytial virus (RSV) is a common infection in children under the age of two. The course of this viral disease can be unpredictable and may require sudden hospitalisation, especially in newborns. An infant's hospitalisation due to RSV can dramatically change family life, affecting the entire family in numerous ways. As part of the ResQ Family project, which aims to shed light on the overall burden faced by affected families in four European countries, a short motion video has been released. This video highlights parental feelings during the stressful situation of a child's hospitalisation and raises awareness about the disease and the quality of support structures provided by healthcare systems. The video is available with subtitles in five languages.

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## EMPOWERING PATIENTS

### Exploring a new self-management tool for pregnant women to prevent preterm birth

The risk of preterm birth can be reduced through healthy behaviours such as adequate nutrition and physical activity. However, it can be challenging for mothers to stick to exercise or diet plans throughout pregnancy. This is why a team of South Korean scientists developed a new self-management self-efficacy tool to assess the capabilities and risks of each individual woman. Healthcare professionals can then adapt health interventions accordingly and potentially prevent adverse pregnancy outcomes.

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### ETHICAL DECISION-MAKING & PALLIATIVE CARE

#### Pioneering standards in ethical decision-making and neonatal palliative care

This month, we present two videos featuring Professor Jos Latour and Dr Marina Cuttini, in which they address critical aspects of ethical decision-making and palliative care within neonatal health. In the first video, they discuss the necessity of European-wide standards to ensure consistent and compassionate care for critically ill newborns and their families. The second video dives into the implementation of these standards, highlighting the importance of collaboration between healthcare professionals and families, ongoing educational initiatives, and team discussions. The European Standards of Care for Newborn Health (ESCNH) for “Ethical decision-making and palliative care” are designed to equip healthcare providers with the skills and knowledge to manage ethically complex situations while maintaining the well-being of patients and their families.

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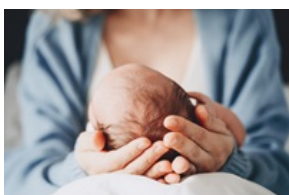
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### END-OF-LIFE CARE FOR EXTREMELY PRETERM INFANTS

#### Tailored approaches for the most vulnerable

Extremely preterm infants (EPI) represent a small yet critical group in NICUs, facing unique end-of-life care (EOLC) challenges. Despite their limited numbers, EPIs account for a significant portion of neonatal deaths, requiring specialised approaches to EOLC. Our latest research news explores the complexities from antenatal counselling to NICU decision-making, emphasising ethical considerations and the need for improved guidelines to support families and healthcare providers. Discover the intricacies of EOLC for extremely preterm infants and the vital importance of compassionate, informed care.

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### COMPREHENSIVE SUPPORT

#### Holistic perinatal palliative care at St. Josef Hospital, Vienna

St. Josef Hospital in Vienna offers an exceptional perinatal palliative care programme designed to support families facing the birth of a child with life-limiting conditions. Their dedicated interdisciplinary team of medical and psychological professionals collaborates closely with parents from diagnosis to

post-birth care, ensuring a self-determined and dignified experience. Through comprehensive birth plans, continuous emotional support, and personalised palliative care, they help families create meaningful moments during an immensely challenging period.

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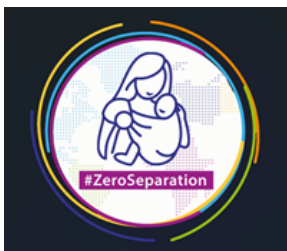
## SPEAK OUT ON (CO-)TWIN LOSS

### Advocating for change: Insights from the January Speak out session

In January, the European Standards of Care for Newborn Health (ESCNH) hosted their first Speak out session on (co-)twin loss. The four esteemed speakers emphasised the critical role of healthcare professionals in creating a supportive environment, offering comprehensive guidance, and leading parents through each stage of care. Additionally, the panel highlighted the necessity for systemic changes to prevent caregiver burnout. The session concluded by highlighting the importance of the family's voice in driving policy and structural change within the healthcare system, advocating for the transformative shifts needed to better support bereaved families. Thank you to Michelle LaFontaine, Professor Nicholas Embleton, Elsa Silva, and Dr Gudrun Simmer for participating and sharing their expertise.

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## GLANCE - Global Alliance for Newborn Care



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## SUCCESSFUL GLOBAL CAMPAIGN

### Zero Separation. Together for better care!

This year's "Zero Separation" campaign by GLANCE has come to a successful close, for now. The campaign advocates for infant- and family-centred developmental care, promoting 24/7 NICU access for parents to be with their baby around the clock. By focusing on NICU design, parent support, and Kangaroo Mother Care (KMC), we have raised awareness and disseminated information via social media. We extend our gratitude to everyone who has participated, supported with translations and content, shared materials, and helped shine a spotlight on this critical issue. We look forward to continuing the campaign next year!

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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)  
EU Transparency Register ID Number: 33597655264-22 - Chairwoman of the Executive Board: Silke Mader

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