



Dear friends and supporters of EFCNI,

May was a truly busy month for us! We held our annual Parent and Patient Organisations Summit in Freising, Germany, and connected with our community of partner parent organisations. It was again a rewarding experience to spend three days networking, teaching and learning from one another, and exchanging ideas – all with the goal to improve neonatal care for the tiniest patients and their families.

As another step in this direction, and to support the WHO in its endeavours to implement (immediate) Kangaroo Mother Care across the globe, we now offer up-to-date, comprehensive information on this topic on our website, including a new expert interview.

Lastly, to mark its 10th anniversary, an updated version of the original report entitled “Born Too Soon: Decade of Action on Preterm Birth” was launched this month. It unites a large and international coalition of advocates to call for reducing the burden of preterm birth by providing equitable and accessible healthcare for babies, women, and families worldwide.

As always, many thanks for reading,

Silke Mader and the EFCNI team

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#### PARENT ORGANISATIONS SUMMIT

EFCNI hosted the annual international meeting of parent and patient organisations

This May kicked off with an eventful, successful, and inspiring Parent Organisations Summit (POS). Every year, EFCNI invites the international community of parents of preterm born infants to connect and network, exchange experiences, learn from one another, support each other, and, last but not least, make and maintain empowering friendships. With exciting presentations and hands-on workshops, this summit is always an opportunity to gain motivation and exchange ideas with like-minded people from all over the world.

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## CHANGING OF THE GUARD

### New EFCNI Parent and Patient Advisory Board elected

After four years of dedicated service to our community, it was once again time to elect a new Parent and Patient Advisory Board (PPAB) at our recent Parent Organisations Summit in Freising. We thank our former members from the bottom of our hearts for their invaluable contributions and advice, and for their tireless efforts to improve newborn health in their countries. At the same time, we warmly welcome our new PPAB and look forward to working together to improve neonatal care.

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## NEW FACTSHEET

### Launch of new factsheet on fortification in preterm and sick infants

We are happy to announce the launch of our newest asset for parents/caregivers and the broad public: The new EFCNI factsheet on “Fortification: nutritional additives for preterm and sick babies”, which was first presented at the 55th Annual Meeting of the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) in Vienna. Supported by Priv. Doz. DDr. Christoph Binder, a well-known expert in the field of paediatric nutrition, and our Parent and Patient Advisory Board member Gigi Khonyongwa-Fernandez, we provide an overview of the areas of application as well as types and components of fortification in preterm and sick babies. The aim of this factsheet is to raise awareness on the important topic of fortification in preterm and sick babies’ nutrition.

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## 55TH ANNUAL MEETING OF ESPGHAN IN VIENNA

### Experts from around the world exchange knowledge in the field of paediatric nutrition

It was a pleasure to attend the 55th Annual Meeting of the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) in Vienna. Looking back on three days of connecting and exchanging knowledge with leading researchers from all over the world in the field of paediatric nutrition, this year's congress was very special for us: For the first time, patient organisations were involved in the scientific programme on-site and EFCNI's Chairwoman Silke Mader had the honour to contribute to the Patient Forum with a presentation on Human Milk Regulation in the EU. Besides, we launched our new factsheet on fortification for preterm-born and sick babies and attended the ESPGHAN Patient Organisation Meeting with an important take-home message: Strong collaborations between healthcare professionals and patient organisations are needed to work towards the best possible health outcomes for children and babies, and: The more we empower the patient, the better!

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## SUPPORT FOR NICUS IN SLOVAKIA

### Partner parent organisation Malíček gifts Neobeds and other items to NICUs in Slovakia

With the help of donations, the organisation was able to hand over 13 so-called Neobeds to neonatal intensive care units. These beds provide nests in which newborns from 500 g to 3,500 g can “grow into the soft and protective hands” of their parents. The nests may also help to optimise the positioning of newborns and can positively affect the psychomotor development of this at-risk group of babies. Additionally, Malíček were able to donate special transport Neobeds, which eliminate the shocks caused by transfers and provide greater safety and comfort to the baby. The donation packages also included incubator mats, mini pacifiers for the smallest babies, a professional breastmilk pump, accessories for the First Baby Photo Project as well as books and magazines for parents of preterm and at-risk babies on the wards. Please note that the linked article is in Slovakian but offers a translation option.

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## PRELIMINARY RESULTS OF INTERNATIONAL RSV STUDY

### New RSV prophylaxis could significantly reduce hospitalisation rates

New preliminary results from the international HARMONIE study suggest that Nirsevimab, a monoclonal antibody immunisation, could help prevent a large number of infants with RSV infections requiring hospital care. Nirsevimab is a long-acting antibody that is currently being tested. It is designed to protect all infants from birth to the start of the first RSV season with a single dose. The HARMONIE trial aims to provide more information about the effect of this antibody in helping to prevent severe RSV disease and hospitalisation of infants due to RSV. The preliminary results were presented at the 41st Annual Meeting of the European Society for Paediatric Infectious Diseases (ESPID).

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## PREMSTEM CO-CREATION ACTIVITIES

### Get involved in the PREMSTEM co-creation activities and contribute to stem cell research

How can the groundwork for societal and professional acceptance to perform clinical trials in stem cells in preterm infants be established? And have you ever been offered to participate in a clinical trial but decided not to take part, for whatever reason? The PREMSTEM project, which is conducting research into stem cells to find a therapy to treat brain injury in preterm born babies, is currently running co-creation interviews with people from outside the project team, including parents and healthcare professionals. As part of these discussions, they are hoping to talk to a parent of a preterm born baby who was offered a clinical trial for their child but choose not to take part and adults who were born preterm and could have been eligible for a clinical trial as a baby. If you fit this profile and would like to be involved in such a conversation, please get in touch with PREMSTEM via the contact form on their website. Don't miss your chance to contribute to stem cell research!

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## INTRODUCING THE NOMINATE PROJECT PAGE

### New research project on most relevant outcomes in the management of HDFN and the impact on parents and newborns

Hemolytic Disease of the Fetus (HDFN) is a very rare disease that can occur if the red blood cells of a pregnant woman and her fetus are not compatible. Through a process called maternal

alloimmunization, the mother's immune system identifies the red blood cells of her fetus as foreign and produces antibodies against them, which may result in fetal anemia. The NOMINATE research project aims to identify both existing and new research outcomes in the field of HDFN management and specifically, to understand the impact of this disease on parents and newborns. The project is led and funded by EFCNI's Premium Partner Janssen. EFCNI ensures patient involvement at all stages of the project, supports in raising awareness for rare diseases like HDFN and is involved through creating a patient advisory board. The perspective of parents and other family representatives is a central component of the NOMINATE project, supporting to build up a network of people affected by the disease in Europe.

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## THE POWER OF TOUCH

### Impact of sensory-based intervention in the NICU on parents and their preterm born babies

Co-occupation refers to sharing a space and engaging in activities together. This is especially important between parents and their children during their stay in the NICU. Parental involvement in activities such as feeding, playing, and gentle touching has many benefits. In a study by Richter and colleagues, 35 families were included in an intervention based on the SENSE programme, which helps parents understand sensory stimulation of preterm infants during their NICU stay. The study looked at the effects of sensory activities provided by different people and found that babies who had more interactions with their parents rather than volunteers or healthcare professionals were less sleepy. Their parents also felt less anxious and stressed.

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## European Standards of Care for Newborn Health



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## EVERY FEEDBACK COUNTS

### Public consultation for revision process is open

We invite all healthcare professionals, parent representatives, and other stakeholders to participate in the open (public) consultation of the European Standards of Care for Newborn Health (ESCNH). This year, 76 standards encompassing eleven topics are up for reassessment. The aim of the public consultation is to enable the wider community to contribute to the ESCNH and to further improve quality. The consultation form for each standard can be accessed via an online survey, which is available under the respective topic at our revision page. We very much appreciate your feedback!



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## EFCNI-Academy



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### NEW EDUCATIONAL MATERIALS

#### Making the case for (immediate) Kangaroo Mother Care

Kangaroo Mother Care (KMC), as defined by WHO, includes continuous and prolonged skin-to-skin contact, exclusive breastfeeding or breastmilk feeding, and timely discharge from hospital. It is a neonatal care practice which benefits all newborns and which can, as recent data show, be initiated even before the newborn is considered clinically stable. In order to raise awareness about the advantages of KMC particularly for preterm, low birth-weight, and hospitalised infants, we have set up a new EFCNI Academy page on the topic which contains further detailed information as well as additional reading. On the page, you will also find our latest interview with Dr. Carmen Pallás Alonso, a pioneer in the field of KMC, who spoke with EFCNI about how KMC promotes neonatal health and empowers families.

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## GLANCE - Global Alliance for Newborn Care



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### A LIFESAVING TECHNIQUE

#### Global Position Paper and Implementation Strategy on Kangaroo Mother Care released by the WHO

Kangaroo Mother Care (KMC) significantly improves survival and health outcomes for preterm and low birthweight babies. Data demonstrates that it can increase preterm survival rates by as much as a third, reduce infections, prevent hypothermia, and improve feeding and growth. It also empowers and reassures mothers and families who take a leading role in providing care for their infants. To support wider uptake of Kangaroo Mother Care and help countries expand KMC for babies born early or small, the WHO released two new resources, developed in collaboration with a multi-country, multi-stakeholder working group. EFCNI had the great honour of contributing to this landmark report with its expertise from the parent community.

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## BORN TOO SOON: DECADE OF ACTION ON PRETERM BIRTH

### Launch of new report sets an ambitious agenda to reduce the burden of preterm birth

The report "Born Too Soon: Decade of Action on Preterm Birth" was launched at the International Maternal Newborn Health Conference (IMNHC 2023) in Cape Town this month. 70+ organisations in 45+ countries, including EFCNI, worked together on the report to show new data: scientific evidence, country learnings, and the powerful lived experiences of parents and families of preterm babies. This report calls for urgent and collective actions to ensure every woman and every infant born preterm can survive and thrive. We invite you to download the report and share!

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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.

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