



Dear friends and supporters of EFCNI,

Summer is here – and with it, several opportunities to participate in activities aimed at improving the outcomes for preterm infants and their families. For instance, we are extending the public consultation phase for the European Standards of Care for Newborn Health (ESCNH) until the end of July. All stakeholders in the fields of maternal and newborn care are invited to provide feedback on those individual standards currently under review. Together we can ensure that the ESCNH continue to reflect the state of the art in neonatal care.

What is more, registration is now open for hospitals in Germany, Austria, and Switzerland to join our campaign “Strong start for little heroes” which raises awareness for those born preterm.

Finally, we are celebrating the arrival of baby Paul, a preterm simulation doll, in Lithuania, thanks to the tireless advocacy of our partner parent organisation Neišnešiotukas.

As always, thank you for reading!

Please stay healthy and safe,

Silke Mader and the EFCNI team



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EFCNI AT THE GNPI IN HAMBURG

EFCNI involved in interdisciplinary and diverse congress programme

For the 49th time, the annual meeting of the GNPI (Gesellschaft für Neonatologie und pädiatrische Intensivmedizin / Society for Neonatology and Pediatric Intensive Care Medicine) took place, this year in Hamburg. EFCNI had the gratifying opportunity to contribute actively to the intriguing congress programme. Founder and Chairwoman Silke Mader co-chaired three sessions on topics ranging from exceptional situations in the NICU to ethical issues in neonatology to nutrition and breastfeeding. She also presented on regulation of human milk banks in the EU, a project in which EFCNI has been heavily and proactively involved for several years. A truly successful and inspiring gathering! Note the linked article is available in German and English.

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FORTIFICATION

Launch of the German version of our factsheet on fortification in preterm and sick infants

We are happy to announce the launch of the German version of the EFCNI factsheet on “Fortification: nutritional additives for preterm and sick babies” (“Anreicherung: Ergänzung der Nahrung von Frühgeborenen und kranken Babys“), our newest asset for parents/caregivers and the broader public, which was first presented at the GNPI congress in Hamburg. Mother’s own milk is the preferred option for infant nutrition. However, preterm, sick, or low birthweight infants need nutrients to ensure optimal growth and development. One way to meet these additional needs is the fortification of breastmilk. Supported by Priv. Doz. DDr. Christoph Binder, a well-versed 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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NEW CAMPAIGN ON HDFN

HDFN is rare – Be aware – Ask for specialist care

Hemolytic Disease of the Fetus and Newborn (HDFN) is a rare pregnancy condition which occurs when the mother's red blood cells are not compatible with the red blood cells of her unborn baby (the fetus). To increase awareness for this condition and to facilitate communication between medical, specialised experts and patients, EFCNI developed a campaign addressing health professionals as well as women at risk of HDFN and women affected in a previous pregnancy, with targeted information. We are delighted that Professor Kypros Nicolaides supports this campaign with video statements on the risk assessment and monitoring of HDFN. You will find his statements and much more information on our newly published project page. The campaign is supported by Janssen.

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EMPOWERING PARENT REPRESENTATIVES

Three-day workshop on policy and advocacy with parent and patient representatives from all over the world

Coinciding with the “Love Your Lungs” week, our policy and advocacy workshop on RSV (Respiratory Syncytial Virus) was held in Munich from 23 to 25 June. Representatives of parent and patient organisations from all over the world came together to share their experiences on RSV in their individual countries and learned new policy and advocacy tools and skills over the course of three days. We would like to express special thanks to our speakers Dr. Eleni Vavouraki from Ittominon, Alison McNulty from TinyLife, and Fabiana Bacchini from the Canadian Premature Babies Foundation for their interesting and engaging sessions during the workshop.

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STRONG START FOR LITTLE HEROES 2023

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 2023. 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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NEW POSITION PAPER

RSV: disease burden, challenges, and opportunities in children in Germany, Austria, and Switzerland

At the 49th annual meeting of the Society for Neonatology and Pediatric Intensive Care Medicine (GNPI) in Hamburg last week, we presented our new RSV position paper. It was developed in close collaboration with leading experts from the fields of paediatrics, neonatology, immunology as well as paediatric nursing and parent representatives. The topic of RSV in children in the DACH region (Germany / Austria / Switzerland) was comprehensively discussed in several roundtable meetings, and, as a consequence, a call to action for decision-makers was developed. In particular, our experts stress the importance of raising awareness already now in preparation for the upcoming RSV season in autumn. Please note that the website and materials are in German.

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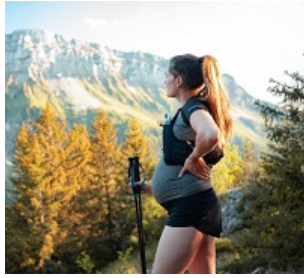
THE POWER OF ADVOCACY

Hello, Paul! Highly realistic preterm simulation doll Paul joins first hospital in Lithuania

Our partner parent organisation in Lithuania, Neišnešiotukas, had reason to celebrate this month: Thanks to their advocacy, Paul, a hyper-realistic preterm simulation doll, made his way to Lithuania. He now supports doctors, nurses, and other hospital staff in training medical procedures and practising how to treat a tiny patient in high-pressure situations. Initial feedback by healthcare professionals has been overwhelmingly positive, and it is hoped that Paul will further improve the quality of care preterm infants receive in Lithuania. Congratulations and welcome, Paul, to Lithuania!

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Science



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MATERNAL HEALTH

New tool developed to detect and prevent excessive gestational weight gain

A group of researchers developed a practical questionnaire to help doctors, nurses, and midwives identify pregnant women at risk of excessive gestational weight gain (GWG) during pregnancy. Seeing that excessive GWG is linked to adverse health outcomes for mothers and infants, hopes are that this tool will help with its prevention. Results from the validation analysis were promising, as the questionnaire seems to accurately identify individuals at risk of excessive GWG. This proactive approach can potentially help with timely interventions, leading to better maternal and newborn health. The Technical University Munich and EFCNI's research team, including Senior Project Manager Dr. Julia Hoffmann, collaborated on this study.

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NEWBORN HEALTH

Improving outcomes and empowering families with Kangaroo Mother Care

The World Health Organization (WHO) launched a Global Position Paper and an accompanying Implementation Strategy on Kangaroo Mother Care (KMC) last month. Taken together, these publications explain how KMC, a neonatal care practice, can be a life-saving intervention, especially for preterm and low birth-weight infants. They illustrate new findings and evidence-based recommendations for preterm care and call for systemic change in how maternal and newborn care are organised and conducted. Our latest research news summarises both papers and links to further educational material on the topic.

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DIGITAL PANEL MEETING

INSPIRE – International guideline initiative for neonatal transfusion clinical practice recommendations

This month, EFCNI and two parent representatives from our Romanian partner parent organisation ARNIS (Romanian Association of Long Hospitalized Newborns) and our Portuguese partners from XXS joined a digital panel meeting with international experts from the Neonatal Transfusion Network (NTN) to discuss current practice and summarise evidence from clinical trials on neonatal red blood cell transfusions. In the past, randomised trials were already

completed and published, aimed at defining how to safely use red cell transfusion in preterm infants. Moreover, several surveys have shown wide variation in clinical practice, emphasising the need for an international guideline. The NTN has therefore formed a Steering Committee to develop clinical practice recommendations for neonatal transfusions – the INSPIRE study. The role of EFCNI, ARNIS, and XXS in this project is to give feedback and input from the patient and parental perspective.

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RESQ FAMILY STUDY PROTOCOL

First publication released as part of EFCNI's ResQ Family project

For many families, life suddenly changed after their child needed to be hospitalised because of a severe infection with Respiratory Syncytial Virus (RSV). It is important to give these parents a voice and discuss the burden, the challenges as well as the unmet needs during these trying times. With the ResQ Family study, we investigate comprehensively the experience of caregivers of children who were hospitalised for RSV by applying a participatory research approach. We have now successfully published a study protocol which provides the scientific basis of the project. It defines the study design and objectives, describes the involvement of relevant stakeholders, and explains the recruitment of the study population. Please help us raise awareness about the global impact of RSV by sharing our research with your community!

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European Standards of Care for Newborn Health



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JOIN THE REVIEW PROCESS

Public consultation phase extended until the end of July

In order to ensure that the European Standards of Care for Newborn Health (ESCNH) remain up-to-date, each individual standard has its own lifecycle. Once the lifecycle is completed, a review becomes mandatory. Currently, 76 standards have concluded their lifecycle and now require revision to confirm that they continue to reflect the state of the art. We invite all healthcare professionals, parent representatives, and other stakeholders working in neonatal care to participate in the review process. The public consultation is open until the end of July. Please share your expertise with us!

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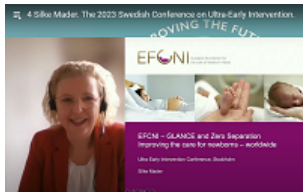
27 JUNE – WORLD MICROBIOME DAY

Learn about microbiomes and enteral preterm nutrition from our experts

Microbiomes play an important role in the health of infants born too soon, too small, or too sick, as they often struggle with a disrupted microbiome development which can lead to health issues. To support the microbiome and healthy development of newborns, effective measures are exclusive breastfeeding as well as feeding expressed breastmilk, i.e. mother's own milk (MOM) or donor human milk. Watch our videos to learn more about the microbiome and its effects on neonatal outcome. Moreover, our e-learning series on enteral preterm nutrition shows the many benefits of human milk for newborns and the specifics of enteral nutrition for preterm infants.

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GLANCE - Global Alliance for Newborn Care



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ULTRA-EARLY INTERVENTION CONFERENCE 2015-2023

Watch the recordings for free now

“Always Together – Caring for newborn babies together with their parents in skin-to-skin contact and Mother-Newborn Couplet Care from the time of birth” was the theme of this year's Swedish Conference on Ultra-Early Intervention (UEI), which is co-organised by Dr. Björn Westrup, a member of the GLANCE Chair Committee. Chairwoman Silke Mader attended the conference digitally and gave a talk on the results of separation policies in NICUs worldwide during the COVID-19 pandemic and how this affected neonatal care in the short and long term. The UEI Conference was founded with the goal to show the importance of infant- and family-centred developmental care. Over the years many interesting and enlightening presentations have been held there by inspirational speakers. If you would like to experience some of them yourself, you can now watch the recordings of the 2015-2023 UEI Conferences for free.

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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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