





Dear friends and supporters of EFCNI,

February finds us quite busy again. We are in the middle of preparing the Chair Committee Meeting of the European Standards of Care for Newborn Health (ESCNH), which will take place in the very beginning of March. Experts from across Europe and beyond will come together to discuss the future of the ESCNH over the course of three days. We are also still looking for participants in our multi-country survey on how families experienced hospital stays due to their child's RSV infection. And last but not least, we want to wish a happy birthday to our long-time friend and patron Professor Angelika Niebler, MEP, who celebrated her 60th birthday this month.

As always, many thanks for your unwavering support!

Please stay healthy and safe,

Silke Mader and the EFCNI team

## **EFCNI**



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PARTICIPANTS NEEDED

# RSV season is not over yet

RSV season is in full swing and continues to be a serious issue for affected families and children. EFCNI is still looking for participants, particularly from Italy and Sweden, to take part in the ResQ Family Survey – a multi-country study that aims to explore parents' and caregivers' experiences related to the challenges caused by RSV infection and hospitalisation of their children (< 2 years). By sharing their experiences of how they have dealt with their child's RSV episode, they can help to increase our understanding of the disease and begin to make a change in the quality of life for future affected children and their

families. The survey is also an opportunity for parents to tell their story and make their voices heard.

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#### STRONG START FOR LITTLE HEROES

## Congratulations to the winners of the raffle 2022

We say "Congratulations" to the winners of the raffle as part of the campaign "Strong start for little heroes" 2022! Many clinics celebrated World Prematurity Day in a particularly creative way and sensitised the public for the challenges and needs of preterm born babies and their families. A total of 23 neonatal intensive care units participated in the raffle, and we received so many wonderful pictures, summaries, and reports of celebrations. Picking 7 winners was therefore quite difficult. We would like to thank all participating hospital wards and their extraordinary staff from the bottom of our hearts for their outstanding commitment and creativity. We are looking forward to the campaign 2023 and your participation! Please note this campaign is set up in German.

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### **Network**



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### WARM CONGRATULATIONS

# A very happy birthday to our patron Angelika Niebler

We congratulate Professor Dr. Angelika Niebler from the bottom of our hearts on her 60th birthday. Being a patron of EFCNI since 2008, she has supported our work and efforts from the very beginning. As a member of the European Parliament, and as a woman and mother, she has consistently put maternal and newborn health on the political agenda with dedication and commitment. In doing so, she has always backed EFCNI's vision: to ensure the best start in life for every baby. A sincere thank you for your commitment to continuously improving the situation for pregnant women, mothers, and babies across Europe. We look forward to our further cooperation and wish you all the best on your special day and in the future!

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MEET EFCNI IN LISBON

7th ReSViNET Conference in Lisbon





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We are delighted to participate in the "RSVVW'23 – A Global Conference on Novel RSV Preventive and Therapeutic Interventions" from 22-24 February 2023 on-site in Lisbon, Portugal. The aim of the conference is to share knowledge on current research into Respiratory Syncytial Virus (RSV) as well as to bring together leading researchers, decision-makers, and representatives of governmental organisations from around the world. EFCNI is proud to present the methodology and some preliminary results of our latest research project "ResQ Family" to the experts on-site. The European study explores families' experiences related to the challenges caused by RSV infection and hospitalisation of children – a topic on which sufficient information is still scarce. We are looking forward to meeting many new and known allies on the topic of RSV in Lisbon.

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## Science



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#### 2023 LANCET SERIES ON BREASTFEEDING

# More than a meal – breastfeeding as collective responsibility

Earlier this month, Richard Horton, Editor in Chief of the Lancet, and a panel of experts launched a new three-paper Lancet Series on the value of breastfeeding with a focus on how governments and public health sectors can stage interventions to protect its health benefits. The series frames breastfeeding as a collective responsibility which should be protected and promoted and aims to start a global conversation on how to achieve this. The video of the launch event includes talks by international experts as well as a panel discussion followed by a live Q&A and can still be watched by following the link below.

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### EXTREME AND VERY PRETERM BIRTH

# Analysing health-related quality of life after preterm birth

Compared to children born at term, preterm born children have a higher risk of developing serious complications such as bronchopulmonary dysplasia (BPD) and severe non-respiratory morbidities. A study conducted in 11 European countries with more than 3,600 children aged five years showed that extremely preterm children have a particularly lower health-related quality of life (HRQoL). The study results also underline the complex impact of very and extremely preterm births on a physical, mental, and social level for the children themselves and their families. EFCNI contributed to this study as co-author and part of the SHIPS Research Group.

# European Standards of Care for Newborn Health



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#### CHAIR COMMITTEE MEETING

# Mapping out the road ahead for the European Standards of Care for Newborn Health

In order to plan the next steps for the European Standards of Care for Newborn Health (ESCNH), the Chair Committee and the Parent, Patient and Public Advisory Board (PPPAB) will convene between 1 and 3 March 2023 in Freising, Germany. Topics to be discussed include the upcoming lifecycle for 76 individual standards and implementation tools and strategies. Dr. Gina Ancora of the Italian Society of Neonatology (SIN) has also been invited to talk about SIN's plans to implement the ESCNH in Italy.

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#### **EDUCATION & TRAINING**

# Strengthening neonatal and obstetric healthcare in Ukraine

Oleksandra Balyasna, founder of our Ukrainian partner parent organisation "Ranni Ptashky – Early Birds", and member of EFCNI's Parent Advisory Board, organised a seminar on communication between doctors and patients. The seminar forms part of a programme established by the Polish Medical Mission to strengthen neonatal and obstetric healthcare in Ukraine to counter effects of the on-going war. Speakers of diverse backgrounds address a range of questions on patients' rights, successful collaboration with the patient community, and respectful and empathic communication. More than 1,600 healthcare professionals already participated in the seminar and received credits and a certificate.

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# **EFCNI-Academy**

#### **THERMOREGULATION**

# Keeping preterm and hospitalised infants warm

Thermoregulation, i.e. an infant's ability to control their body temperature, is a significant aspect in determining neonatal health. In order to raise awareness for the importance of



monitoring body temperature, especially in preterm and hospitalised infants, and to support healthcare professionals in this endeavour, we have developed a factsheet, available in seven languages on our website. There you will also find several video interviews with experts on the topic.

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## GLANCE - Global Alliance for Newborn Care



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#### **CONFERENCE**

## Discussing the future of maternal and newborn health

EFCNI's chairwoman Silke Mader will attend the International Maternal Newborn Health Conference in Cape Town, South Africa, from 8 to 11 May 2023. She will present the results of our global survey of parents' NICU experiences during the COVID-19 pandemic. The conference will bring together experts on maternal and neonatal health from across the globe to discuss how to strengthen the quality of care delivered to mothers and newborns as well as tools and strategies with which to do so.

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**PHILIPS AVENT** 

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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EFCNI - Hofmannstraße 7A - 81379 München - Germany
Tel: +49 (0)89/89083260 - Fax: +49 (0)89/890832610 - E-mail: <a href="mailto:info@efcni.org">info@efcni.org</a>
EU Transparency Register ID Number: 33597655264-22 - Chairwoman of the Executive Board: Silke Mader

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