



Dear friends and supporters of EFCNI,

We hope you had a fantastic start into 2023. Looking ahead, we are excited about the interesting projects, campaigns, and collaborations awaiting us this year – all with the objective to improve outcomes for preterm and hospitalised babies and their families.

This spirit is clearly driving the many wonderful ventures we report on in this newsletter. For instance, the European Standards of Care for Newborn Health (ESCNH) welcomed new members to the Chair Committee and the Parent, Patient and Public Advisory Board, thus ensuring that the parental voice continues to be heard and considered. New guidelines on how to respond to neonatal seizures were published, acknowledging that this health issue should be approached in a more systematic manner. And finally, our 4th RSV roundtable brought together experts from a range of disciplines and countries to discuss how to prevent the spread of the Respiratory Syncytial Virus and treat it in case of infection.

As always, many thanks for your continuous support!

Please stay healthy and safe,

Silke Mader and the EFCNI team

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## ORGANISATIONAL CHANGES

### Updates in the Scientific Affairs Department

The beginning of the new year also brings some significant changes in the internal structure of EFCNI as we will reorganise our growing Scientific Affairs Department into two departments.

This measure will enable us to channel our energies more efficiently into research efforts and advocacy work. We want to thank our current Head of Scientific Affairs, Dr. Johanna Kostenzer, for her years of dedication to EFCNI and hard work on behalf of preterm and hospitalised infants. During her tenure, the Scientific Affairs Department embarked on many complex research projects, collaborated with other research partners in different studies, and developed helpful education materials for healthcare professionals and lay persons alike. She leaves us at the beginning of February to pursue new opportunities. Dr. Christina Tischer will then head the team "Scientific Affairs and Research", and our colleague Aisling Walsh-Papageorgiou will lead the team "Policy and Advocacy". While we will miss Dr. Kostenzer greatly, we are also excited about the path ahead and the room for growth this reorganisation opens up.

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## PARTICIPANTS WANTED

### Study on the impact of Respiratory Syncytial Virus (RSV) hospitalisation on quality of life of families continues

RSV is a traumatising and far-reaching infection, often leading to extended hospital stays and impacting the quality of life of families. Yet, little data is available on how families experience hospitalisation due to RSV. EFCNI's effort to fill this knowledge gap continues in the form of the ResQ Family study, a multilingual, multinational exploration of the experiences of parents or caregivers concerning the challenges they faced with the RSV infection and the hospitalisation of their children. The survey has reached many participants across France, Germany, Italy, and Sweden. We are looking for further volunteers in Sweden. The ResQ Family survey remains open through the RSV season until April of 2023. If you are from Sweden, Italy, France, or Germany and fit our criteria for participation, consider taking the ResQ Family survey today to help make a difference for future affected families of RSV.

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## Network



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## NEW GUIDELINES ON NEONATAL SEIZURES

### The International League Against Epilepsy (ILAE) developed expert-based recommendations for the treatment of neonatal seizures

Seizures are common in neonates, but there is substantial management variability. Hence, the International League

Against Epilepsy (ILAE) Clinical Practice Guideline group has developed guidelines and expert-based consensus recommendations for the treatment of neonatal seizures. These guidelines and recommendations are based on a systematic review and, if no sufficient evidence was available, on expert-based consensus via Delphi. The Clinical Practice Guideline group consisted of an international team of experts, including neurologists, neonatologists, paediatricians, epileptologists, and a parent representative. EFCNI Chairwoman Silke Mader had the great opportunity to be involved in developing these guidelines by representing the parent perspective.

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## TRANSITIONAL CARE FORUM

### Rethinking transitional care for preterm and hospitalised infants

During the 30th United European Gastroenterology Conference in Vienna, participating medical societies and patient organisations set up an international and multidisciplinary meeting to discuss the state of transitional care for patients. Preterm and hospitalised infants are faced with particular challenges, not just with transitioning from hospital to home. They also transition from different levels of care and from one healthcare system to another. EFCNI, represented by Parent Advisory Board member Livia Nagy Bonnard, discussed with other participants how to account for the needs of this particular patient group. The forum plans to develop and publish a joint call to action in the next two years. Thank you to Livia Nagy Bonnard for reporting from the forum.

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## Science



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## FOURTH EXPERT ROUNDTABLE ON RSV IN CHILDREN

### Disease burden, opportunities, and challenges of paediatric RSV in Austria, Germany, Switzerland

On 18 January, the fourth digital roundtable on the Respiratory Syncytial Virus (RSV) was hosted by EFCNI. An RSV infection may cause a wide range of diseases, from mild upper respiratory illness to life threatening lower respiratory tract infections. During the expert roundtable, key experts in paediatrics, neonatology, and obstetrics from Germany, Austria, and Switzerland discussed the disease burden, opportunities, and challenges related to paediatric RSV. The project will result in a position paper to underline the severity of paediatric RSV, possibilities of prevention and care, and the importance to raise

awareness. We sincerely thank the entire expert group for their valuable contributions and are very much looking forward to continuing the work on this important project. Further details can be found on our updated project website (in German).

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## KEEPING PARENTS AND THEIR BABIES CLOSE

### International study on facilitators and barriers to integrated family care and its challenges

Separating mother and child during a hospital stay can have severe consequences for the health of both. Family-integrated care (FICare) is therefore crucial for parent and newborn health. The CROWN Study Group, of which EFCNI chairwoman Silke Mader is one of the study authors, investigated the facilitators and barriers to parent-infant closeness and zero separation. Neonatal healthcare professionals from 19 countries were interviewed and confirmed that parent-infant separation is very common (93%), regardless of an ongoing pandemic such as COVID-19. Four aspects that facilitate zero separation and parent-infant closeness were highlighted, the 'four Cs': Culture, Collaboration, Capacities, and Coaching. Read more about these necessary strategies for overcoming challenges and managing change.

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## European Standards of Care for Newborn Health



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## THANK YOU

### A powerful network

The European Standards of Care for Newborn Health (ESCNH) are an interdisciplinary and international collaboration to develop reference standards in eleven areas of neonatal care with a particular focus on the needs of preterm and hospitalised infants. Thanks to our partners, we are able to work continuously on this important project. This year will be another busy year for the ESCNH as 76 individual standards enter their scheduled revision phase, and we map out more strategies to implement them across Europe. We would therefore like to thank our industry partners AstraZeneca, GE HealthCare, Janssen, Nestlé Nutrition Institute, Prolacta Bioscience, and Sanofi for supporting the ESCNH.

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## NEW MEMBERS



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## Welcome to our newest experts aboard the European Standards of Care for Newborn Health (ESCNH)

Three new experts have joined the teams behind the ESCNH as co-chairs of different Topic Expert Groups (TEGs). What is more, the Parent, Patient and Public Advisory Board was newly elected as well and now constitutes of eight new representatives. We welcome all incoming members and look forward to insightful discussions and fruitful collaborations as the ESCNH continue to grow and evolve. At the same time, we want to thank all outgoing representatives for their hard work and dedication over the years.

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### CONFERENCE REPORT

## Managing the "grey zone" in Hungarian hospitals

The Hungarian Society of Neonatology and our Hungarian partner parent organisation "Melletted a helyem Egyesület" ("Right(s) Beside You") held a conference on the topic of the "grey zone", a term which describes situations where the available medical evidence is so ambivalent as to leave healthcare professionals without clear guidance on which treatment would be the best option for the patient. Conference participants ultimately concluded that a national guideline is necessary and suggested the European Standards of Care for Newborn Health as reference framework. Thank you to Livia Nagy Bonnard for this guest article.

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## EFCNI-Academy



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### E-LEARNING OPPORTUNITY IN 2023

## Learn about enteral preterm nutrition from our experts – no registration required

To make our e-learning series on enteral preterm nutrition as easily available as possible, no more prior registration will be necessary to access all webinars and talks. As of February, the content can be retrieved via our website. Learn about the many benefits of human milk for newborns and the specifics of enteral nutrition for preterm infants from the comfort of your own home, customised to your interests and individual schedule. Note that CME accreditation is only available until the end of January.

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## GLANCE - Global Alliance for Newborn Care



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### NEW PARENT ORGANISATION IN UGANDA

## Welcome, "Preterm Infants Parent Network Uganda", to our network

We are happy to announce that a new partner parent organisation has joined our networks at EFCNI and GLANCE. "Preterm Infants Parent Network Uganda" (PIPNU) was formed in March 2022 by two fathers, Kateregga Bazilio and Mpanga Arnold, during the Kangaroo sessions at Mulago Specialized Women and Neonatal Hospital. The network is made of parents, infants, healthcare specialists, and adult preemies. The support which the network offers starts when the mother becomes aware that her pregnancy is high-risk and that her baby may be born preterm. It continues while the family has an infant in a Neonatal Intensive Care Unit (NICU) and also provides post-discharge support. Currently, the network is following up with over 900 parents through community visits and daily phone calls. Over 50 parents are trained in topics such as home neonatal care support and Kangaroo Mother Care each week in hospitals in the central region. Reduction of preterm birth rates through sensitisation is another objective. PIPNU's vision is a Uganda where no parent goes through the experience of prematurity alone by 2024. A warm welcome to PIPNU from our side and all the best on your path ahead!

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### Special thanks to our corporate partners for their kind support:

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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.

This online newsletter is issued by EFCNI - European Foundation for the Care of Newborn Infants.  
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EU Transparency Register ID Number: 33597655264-22 - Chairwoman of the Executive Board: Silke Mader

EFCNI is a non-profit organisation established under German public law | Tax reference number 143/235/22619.