





Dear friends and supporters of EFCNI,

With more and more people receiving the COVID-19 vaccine, we are starting to be hopeful that an end to the global pandemic may soon be in sight. As preliminary results from our worldwide survey suggest, parents and their newborns have been particularly affected by the pandemic as well as the strain it put on healthcare systems everywhere. Safety precautions taken by hospitals to prevent infections have led to separations of parents from their babies right after birth. Yet, new research confirms that for babies the benefits of kangaroo mother care outweigh the risks of a possible COVID-19 infection by far. On a similar note, we asked Dr. Britta Hüning why follow-up appointments are an important aspect of newborn health and how the global COVID-19 pandemic has forced parents and healthcare professionals alike to find new ways to provide care for preterm and sick babies.

Many thanks for your continuous support!

Please stay safe and healthy,

Silke Mader and the EFCNI team

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ACT EARLY! SCREEN EARLY!

One-month Pre-eclampsia awareness campaign ends with a highlight for all

May marks the month of pre-eclampsia awareness which EFCNI has been supporting with its own campaign for several years now. "Act early! Screen early!" has received a lot of support this year from healthcare professionals, medical societies, patient organisations, and individual supporters, which makes us very happy and for which we want to say

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thank you - especially to those who supported our flashmob on World Pre-eclampsia Day, 22 May, which reached tens of thousands of people. As the campaign draws to an end, we would like to point you to a special highlight: A live webinar is now available on-demand for the next few months after the event! It features excellent presentations by Professor Kypros Nicolaides on prediction and prevention of pre-eclampsia, Professor Stefan Verlohren on the prediction of adverse outcomes associated with pre-eclampsia, and EFCNI founder Silke Mader on the consequences of pre-eclampsia from a patient perspective.

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NEW PRESS RELEASE

Raising awareness for pertussis vaccine during pregnancy

In April, EFCNI successfully launched a new awareness campaign in Germany about the possible dangers of pertussis (the whooping cough) for preterm and newborn babies. The campaign highlights how vaccinating pregnant women from 28 weeks of gestation onwards can help to protect the baby against pertussis while still in the womb. In order to alert German media to this health topic as well as inform about the campaign itself, EFCNI published a press release which explains the issue and presents the campaign to the interested public. Please note that the press release is written in German.

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PREEMIE HEALTH TALKS

Analysing parents' experiences of neonatal care during the pandemic

On 5 May 2021, EFCNI's Head of Scientific Affairs, Dr. Johanna Kostenzer was invited to speak at the "Preemie Health Talks" organized by the Canadian Premature Babies Foundation CPBF. In her talk, Kostenzer focused on the impact of the COVID-19 pandemic on intensive care for newborns. She discussed some preliminary results of the global study which EFCNI conducted in order to explore parents' experiences of neonatal care during the pandemic. Follow the link to watch the entire video of Kostenzer's talk.

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Network



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Romanian hospitals competing for new kangaroo chairs

The benefits of practicing kangaroo care are well established and range from lower cortisol levels and less parental stress to even a 40% reduction of neonatal mortality. Knowing about the importance of skin-to-skin contact, one of our partner parent organisations, "Unu Si Unu", organised an online voting competition which gave six Romanian hospitals the chance to win special kangaroo chairs by expressing their motivation and desire to encourage kangaroo care in their facility. Parents and friends supported the competing hospitals with enormous enthusiasm and "Unu Si Unu" had to stop the voting after only two days and already 6,000 comments. In total, five chairs from a German manufacturer were donated to two of the competing hospitals. We, the team of EFCNI, are happy that we could help our friends at "Unu si Unu" with the purchase and transport of these chairs!

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NEW EUPATI FELLOW

The European Patients' Academy – EUPATI – gains a new fellow from the EFCNI network

Livia Nagy, founding member of the Hungarian parent organisation "Melletted a Helyem Egyesület" ("Right(s) beside you") and EFCNI Parent Advisory Board Member, has successfully completed the EUPATI fellowship programme. This is a programme which provides education and training to patients and patient representatives, so they can meaningfully contribute to medicine research and development. In addition, it improves the availability of medical information for patients and other stakeholders. In an interview with EFCNI, Livia Nagy shares some insights into the programme and how she wants to use her newly gained qualification in the future.

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NICU PARENT NETWORK MEMBERS ACTION MEETING

NICU families particularly affected by COVID-19

On 4-5 June 2021, the NICU Parent Network (NPN) will hold its annual member meeting, and this year, COVID-19 constitutes the main focus. After all, the pandemic has affected NICU families in particularly complex and lasting ways. EFCNI's Silke Mader and Dr. Johanna Kostenzer will attend the meeting and take the opportunity to discuss some of the preliminary results of our global parent survey about parents' experiences of neonatal care during the COVID-19 pandemic. During the session on 4 June, Kostenzer will present some of

the findings and then, joined by Silke Mader, participate in a live Q&A. Register for the event by following the link below. Non-members are always welcome, too!

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MPROVE ACADEMY

Improving communication between parents and professionals after preterm birth

Parents often have to navigate challenging situations after the preterm birth of their baby, making effective, respectful, and informative communication between parents and medical professionals all the more important. Yet, for many parents, communicating with hospital staff is a difficult experience with many frustrations on both sides. An online session organised by the MProve Academy sought to address the question of how parents and medical staff can engage and communicate successfully with each other. Held on 6 May, MProve Academy brought together over 60 participants from all over the world who represented different medical professions. Three parent representatives from the EFCNI network related their real-life experiences as preterm parents. The commitment to improve parents' experience in the NICU was clear and it was agreed by all that one of the most important things that professionals can do is get to know each family and their individual circumstances.

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NEONATAL CARE IN TIMES OF COVID-19

COVID-19 restrictions in neonatal care impede bonding between parents and baby

Our partner parent organisation in the United Kingdom, "Bliss", has conducted and published a survey of parents and NHS Trusts to evaluate the impact of COVID-19 restrictions on neonatal care in the country. Entitled "Locked Out: The Impact of COVID-19 on Neonatal Care", the report details how parents with a baby in the NICU during the pandemic are often only allowed limited access to and time with their baby. As the report shows, these restrictions hinder bonding and attachment between parents and baby and also negatively affect the parents' mental health. "Bliss" is now using the report to call on the government to set out a national plan for return to full, unrestricted access for parents to their baby in neonatal care as soon as possible.

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RESEARCH SUPPORT

Representing the parent voice in research projects

Does your organisation have a great research project in the works? Are you looking for a strong parent or patient voice? Then we invite you to get in touch with us for a possible research collaboration. We believe in cooperation as a fast-track to social development and are excited to work together with co-applicants to achieve common research goals. Over the years, EFCNI has participated in many different projects in the field of neonatal care and gained a lot of experience in this field. We have summarised our experiences and expectations for such a partnership – please have a look.

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© RECAP preterm

E-LEARNING OPPORTUNITY

Register now for the RECAP summer school

Don't miss this great opportunity! The RECAP Summer School offers focused training on working with very preterm cohorts as well as collaborative research principles and techniques. It is geared towards researchers in the fields of neonatology, epidemiology, and psychology and starts on 1 July. Registration is free. Lecturers from across Europe will discuss their research into very preterm birth cohorts and their work with the RECAP preterm platform. There will also be ample time and opportunity to discuss your own research plans.

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NEW STUDY ON ROOMING-IN

The health-promoting power of parental involvement

A recently conducted international study explores the availability and advantages of different NICU designs that aim to support parental presence in the hospital. By analysing data from 10 neonatal networks of 11 high-income countries, the survey provides evidence on the health-promoting effects of infant-parent rooms that enable parents to be present 24 hours a day. Read our research news for more in-depth details on the benefits of rooming-in in NICUs.

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KANGAROO MOTHER CARE DURING COVID-19

Benefits of kangarooing outweigh risks of COVID-19 infection, new study finds

In an effort to protect families as well as medical staff from a possible COVID-19 infection, many hospitals started to prohibit kangaroo mother care (KMC) between parents and their newborn after birth. In an open access study published in February of this year in "The Lancet", a team of researchers investigated how this practice affected newborns' health outcomes. They conducted a two-scenarios-analysis and compared the risk of not implementing KMC to neonatal deaths from COVID-19. The results are clear: The undeniable survival benefit of KMC far outweighs the risk of death because of the virus. As the researchers argue, public health policies must therefore be reconsidered.

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THE BENEFITS OF SKIN-TO-SKIN CARE

Involving fathers in skin-to-skin care directly after birth is beneficial for both fathers and newborns

It is still a routine practice in many parts of the world to separate babies from their parents after a C-section. A recent study investigates three different caregiving models after an (elective) C-section: cot, fathers' arms or skin-to-skin contact between father and baby. Overall, the results suggest that skin-to-skin contact between fathers and their newborn babies is beneficial and should be supported when mothers are not available themselves, for example after a C-section.

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European Standards of Care for Newborn Health



© Britta Hüning

FOLLOW-UP CARE IN TIMES OF COVID-19

"The worst thing you could do is to just cancel the appointment!"

Follow-up and continuing care are a central element of the European Standards of Care for Newborn Health. For many families with preterm or sick babies, the global COVID-19 pandemic has made it quite challenging to balance follow-up appointments with staying safe as the virus spreads. Dr. Britta Hüning (University Hospital Essen, Germany) discusses with EFCNI's Dr. Annika Brunck the difficult situation in which families and healthcare professionals find themselves during

COVID-19. An expert paediatrician and neonatologist, Dr. Hüning offers suggestions and advice on how to navigate follow-up care safely.

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EUROPEAN NEONATOLOGY CURRICULUM

The "European Training Requirements in Neonatology" received an important update

The European Union of Medical Specialists (Union Européenne des Médecins Spécialistes – UEMS) recently adopted an update of the "UEMS 2021.18 European Training Requirements in Neonatology" (ETR Neonatology). Professor Charles Roehr, president of the European Society for Paediatric Research (ESPR) and chair of the Topic Expert Group on Education and Training, was named as writing group lead for the work on the ETR Neonatology. The curriculum references the European Standards of Care for Newborn Health and emphasises the need to train neonatal staff in key areas such as family care and care of the newborn baby, transport of the newborn baby, cardiorespiratory intensive care, and resuscitation. EFCNI's co-founder and Chairwoman of the Executive Board. Silke Mader, was also asked to read and comment on the curriculum. The result is a pan-European training curriculum for neonatal care which takes the parents' perspective into account.

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EFCNI-Academy



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THERMOREGULATION

The factsheet on thermoregulation is now also available in Russian

For babies, getting too hot or too cold after birth can be a serious danger – especially if they are born too soon, too small, or too sick. Keeping a baby's temperature within the normal range is key. In order to support parents and healthcare professionals alike, we developed a factsheet on thermoregulation, or control of body temperature. We are happy to announce that the factsheet is now also available in Russian! Ypa!

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Don't miss the chance to take part in our elearning series "Enteral Preterm Nutrition"

Renowned experts from the fields of neonatology and infant nutrition share their expertise on enteral nutrition for preterm infants and talk about the importance of human milk. We warmly invite healthcare professionals, nursing staff, and interested learners to participate in the online training – sign up now! All modules are CME-accredited and free of charge.

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GLANCE - Global Alliance for Newborn Care



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ZERO SEPARATION

Adults born prematurely reflect on the impact of separation policies in NICUs

The following two months of the "Zero Separation" campaign will be dedicated to the impact and personal experiences of adults who were born preterm and affected by separation policies in the neonatal ward. To gain insights into whether, and if so, how this practice influenced the lives of former preterm infants, we will look at research findings on possible long-term consequences of separation policies and talk to former patients. Campaign materials such as banners and graphics for social media promotion are again available in 28 languages and can be downloaded from our website. We appreciate your support!

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

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