





Dear friends and supporters of EFCNI,

Summer is showing it's best side and some exciting, eventful months as well as new projects are laying ahead of us. With Chiesi, we warmly welcome our new Silver Partner and look forward to the collaboration to thrive newborn health. Right after the summer holidays, we are excited to finally meet old and new friends again at the 12th International Congress of Union of European Neonatal & Perinatal Societies (UENPS) in Krakow as well as the 9th Congress of the European Academy of Paediatric Societies (EAPS) in Barcelona with EFCNI on-site. Moreover, we start into autumn with our new research project ResQ Family, exploring the experiences of parents and caregivers related to the challenges of RSV infection in their children in four European countries.

Many thanks for your continuous support!

Please stay healthy and safe,

Silke Mader and the EFCNI team

# **EFCNI**



**NEW PARTNERSHIP** 

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Warm welcome to Chiesi as our new Silver Partner

We are delighted to announce that Chiesi has joined us as a new Silver Partner of EFCNI. Chiesi is an international, research-focused biopharmaceuticals group that develops and markets innovative therapeutic solutions in respiratory health, rare diseases, and speciality care. The company's mission is to improve people's quality of life and act responsibly towards both the community and the environment, hence it has been B Corp

certified since 2019. We very much look forward to the collaboration.

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## **EMA PCWP MEMBERSHIP**

# EFCNI is new member of the European Medicines Agency 'Patient's and Consumer Working Party'

We are excited to announce that EFCNI is a member of the European Medicines Agency "Patient's and Consumer Working Party" (PCWP) from 2022 to 2025. During this period, we will actively contribute to EMA's work to improve maternal and newborn health by providing feedback and input on patient-related issues, particularly related to sick and preterm born infants and their families. We are happy that Dr. Johanna Kostenzer, Head of Scientific Affairs, and Aisling Walsh, Senior Project Manager for Maternal and Newborn Health will represent EFCNI as members of the PCWP.

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PROPOSAL FOR EU REGULATION ON SUBSTANCES OF HUMAN ORIGIN OUT NOW!

# The European Commission has published a proposal for a regulation on substances of human origin - including human milk

EFCNI welcomes the proposal for a regulation on substances of human origin - including human milk - which has the potential to bring important improvements for vulnerable infants in need of donor human milk. In case this proposal gets adopted by the European Parliament and the Council, the regulation will replace the Tissues and Cells Directive from 2004.

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PERTUSSIS VACCINATION FOR PREGNANT WOMEN

# Informing about protection for the newborn

Pertussis/Whooping cough is a widespread and highly contagious infectious disease that can quickly become dangerous, especially for preterm and newborn babies. However, vaccination of the expectant mother at the beginning of the 3rd trimester transfers the antibodies to the unborn baby via the umbilical cord. The baby is then born with its own first protection against whooping cough until it can be vaccinated

itself. To inform pregnant women about this form of protection, we have developed a poster for free download that clearly presents the benefits of vaccination. The poster can also be ordered in a print version. Find more information on our website. Please note that this campaign and its materials are in German.

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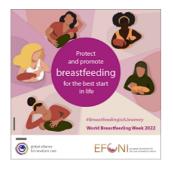
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### **REGISTER NOW - STILL FREE SPOTS AVAILABLE**

# Join us and sign up for our campaign 'Strong Start for little Heroes' 2022

It's still possible to sign up for our campaign 'Strong Start for little Heroes' (Starker Start für kleine Helden)! 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 2022. Included are greeting cards for former preterm born babies, gift sets for parents and much more. Among all participating neonatal units, we are going to give away great prices. So do not wait and sign up! Registration is still open until 15 August. Please note this campaign is set up in German.

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### WORLD BREASTFEEDING WEEK 2022

# Join our World Breastfeeding Week awareness campaign from 1-7 August

In light of World Breastfeeding Week 2022, EFCNI will organise a campaign again between 1-7 August with the aim to raise awareness of the health benefits of breastfeeding, focusing in particular on the situation of preterm or sick newborns and their mothers with their specific challenges. This year's World Breastfeeding Week is about advocating for restoring the breastfeeding rates to pre-pandemic levels, strengthening breastfeeding support systems as well as providing breastfeeding-friendly environments for women and families in the post-pandemic world. Join us with our message 'Protect and promote breastfeeding for the best start in life' and find social media graphics in different languages, a poster and much more to raise awareness during World Breastfeeding Week.

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## Network



© UFNPS

# 12th International Congress of UENPS in Krakow

The congress season is just around the corner and we cannot wait to get a taste of congress air again starting in September. Even though the virtual meetings of the last few years have been very productive, we are more than excited to finally meet with old and new friends in person again at the UENPS in Krakow, Poland. The 12th International Congress of the Union of European Neonatal & Perinatal Societies (UENPS) is themed "Everyday Practical Challenges in Neonatology" and will bring together like-minded and interested people from all over the world, both locally and remotely. We are beyond happy to participate with a plenary session and welcome you on-site with our own EFCNI stand. We hope to see you there!

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#### MEET EFCNI IN BARCELONA

# 9th Congress of the European Academy of Paediatric Societies

#EAPS2022 will deliver cutting-edge science from world-renowned experts under the theme "Shaping the Future of Child Health". Join us at this premier paediatrics event between 7-11 October 2022 in Barcelona, Spain & Online! Hear from over 250 established professionals and be the first to discover the cutting-edge developments in the field presented in 200 sessions and 1200 posters. Do not miss the opportunity to discuss novel discoveries, the newest therapeutic techniques, and diagnostic tools as well as the most up-to-date research in paediatrics. EFCNI will be present and contribute to the congress programme. We are very much looking forward to welcoming you at our booth!

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## Science



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## PARTICIPATE IN RSV RESEARCH

# Online survey about Respiratory Syncytial Virus (RSV) and potential vaccination

How familiar are you with RSV and possible vaccinations? The RSV patient network (RSV-PN) of ReSViNET Foundation has developed a questionnaire to gain insight into the level of knowledge about RSV among parents of infants and young children, pregnant women and their partners, and adults over 60 years of age, to learn more about possible vaccination considerations. This 10-minute, anonymous online survey is being conducted as part of the EU-funded "PROMISE" project to

improve the understanding of what makes infants and older adults more susceptible to RSV. PROMISE is working closely with the RSV-PN to raise awareness of the disease and provide factual and transparent information on treatment and prevention options. Take part in this RSV research by answering the multilingual online survey to better assess your knowledge about RSV vaccines and potential concerns. Thank you for participating and sharing!

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### NEW EFCNI RESEARCH PROJECT - RESQ FAMILY

# ResQ Family: Impact of Respiratory Syncytial Virus hospitalisation on Quality of life of Families – a multi-country study

Getting ready for autumn! This time of the year not only stands for colourful leaves and golden light, but also marks the usual beginning of the Respiratory Syncytial Virus (RSV) season for our little ones. By the age of two years, almost all infants will be infected with RSV at least once. Although most cases are mild, we cannot predict which infants might become seriously ill and require treatment in hospital. When the RSV infection takes a severe course, it may result in the need for mechanical ventilation, long-term complications and a significant burden on the entire family. Currently, there is a lack of evidence on how severe RSV infection leading to hospitalisation of children impacts the quality of life of affected families. To close this knowledge gap, EFCNI is conducting a study in four European countries (Germany, Sweden, Italy and France) aiming to explore the experiences of parents and caregivers related to the challenges of RSV infection in their children (< 2 years). Recruitment of study participants will start in September 2022. Stay tuned!

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NEW RESEARCH PROJECT - END OBESITY

# First 1000 days - Strategies to Prevent Childhood Obesity

The first 1000 days, the period between conception and the child's second birthday, are decisive for the child's long-term development and health status. Research showed that certain factors such as an unhealthy maternal lifestyle during pregnancy as well as an unfavourable early infant nutrition negatively influence the child's risk for obesity in later life. The EndObesity project is aiming at investigating effective strategies to prevent childhood obesity. Based on basic research on risk factors, targeted prevention strategies will be developed, implemented and comprehensively evaluated with the overall goal to improve the children's risk for childhood obesity as early as possible.

EFCNI is supporting the project as a third party and will, together with the valuable contribution of the parent network, represent the patient perspective.

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## **ADVERTORIAL**

How does parent-baby bonding help with baby growth in the NICU?

Kangaroo Care is an essential part of family-centred care, it has been shown to improve physiological response and decrease pain response in preterm and very preterm infants. Additional benefits for parents have been observed such as reduction in stress and increased parent-baby bonding. Watch the video to see how a well-recognised NICU design works to support daily care and families.

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# European Standards of Care for Newborn Health



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### THE BUTTERFLY PROJECT

A project to support healthcare professionals in interacting with parents who have experienced co-twin loss

How can I accompany parents who have lost a child in a multiple pregnancy through this difficult time? The Butterfly Project addresses precisely this question by offering support to healthcare professionals in better understanding how parents feel after they have experienced co-twin loss and provides them with a guide on how to manage this difficult situation as professionals. To support the healthcare staff in interacting and communicating with parents who have lost a baby in a multiple pregnancy, the project also offers a 4-hour online course providing guidance in terms of how healthcare staff can better support parents and the kind of feelings and issues that they deal with. In our interview, Professor Nicholas Embleton provides more insights into the project and the course.

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## **NEW VIDEO SERIES**

All you ever wanted to know about the European Standards of Care for Newborn Health

© EFCNI

The European Standards of Care for Newborn Health (ESCNH) are one of our longest and most comprehensive projects. But what exactly are these standards all about? What are they supposed to achieve, how were they developed and what is the future of this project? Our video series gets to the heart of all these questions - and more. Quickly and understandably. Have a click!

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## ITALIAN TASK FORCE

# Italian Society of Neonatology founded Task Force to drive the implementation of the European Standards of Care for Newborn Health in clinical settings

The Task Force joins several professionals from different disciplines, together with representatives of parent organisations and desires to collaborate with other parents and professionals from all over Europe, with the support of EFCNI. One objective is to co-construct criteria for the definition of a "Preemie Friendly" Hospital", i.e., a hospital able to empathise with the newborn's family, where zero separation between newborns and their parents is implemented, where NICUs are open 24/7 to parents, where care is based on the best scientific evidence and is multidisciplinary, where partnership with parents is promoted, skin-to-skin contact and breastfeeding are supported, and as far as possible, where NICUs are designed to maximise comfort for newborns, families and staff. Other goals of the Task Force are to promote ESCNH diffusion, among professionals and at the institutional level, and to include them in the academic and postacademic education.

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# GLANCE - Global Alliance for Newborn Care





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## ZERO SEPARATION – TOGETHER FOR BETTER CARE

# New campaign material available

Our global campaign on infant and family-centred developmental care in the NICU has been providing information and materials for parents and professionals alike since the beginning of the pandemic. We invite you to visit our website, where you will find new social media graphics in 28 languages that you are welcome to use to support family-centred care, as the pandemic has led to major cut-backs in this area, worldwide. Join us and make a statement for families and NICU staff!

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## **REGISTER NOW**

# Workshop on 'The first 1000 days - a formative phase in a child's life'

This year we invite again all midwives, nursing staff and physician assistants to a half-day face-to-face workshop on the topic of "The first 1000 days - a formative phase in a child's life" on October 5, 2022 in Frankfurt am Main. During this event, renowned experts from the fields of nutrition and medicine will give an insight into the areas of prevention, screening, nutrition and lifestyle for pregnant women, mothers, newborns and children. Registration is still possible until 30 September. Further information as well as the workshop itself are in German.

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## CME ACCREDITED WEBINAR SERIES

# Register and take part in our free, e-learning opportunity on enteral preterm nutrition

How does nutrition impact the neurological development of newborns, and how can human milk in particular promote the healthy development of very preterm babies? What exactly makes human milk a true superfood that contributes to growth and disease prevention and helps minimise mortalities? These and other questions are addressed by renowned international experts who share the latest insights and studies on the importance of human milk nutrition for preterm infant health. We warmly invite healthcare professionals, nursing staff and interested learners to sign up and participate in this free, CME accredited online training!

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