



Dear friends and supporters of EFCNI,

The Respiratory Syncytial Virus (RSV) season is upon us in the northern hemisphere, and with it comes the start of our first year of live congresses and events since the start of the COVID-19 pandemic. These include the RSV Symposium in Belfast, the EAPS congress in Barcelona, and of course the congress of the Union of European Neonatal and Perinatal Societies (UENPS) that took place at the start of September.

We have also been quite busy producing new assets for a range of topics focused on RSV infection and best practices for keeping informed and safe. Further, we worked on multiple video series discussing topics ranging from why “Human Milk Matters” to the emotional testimonials of families who have experienced first-hand their children being hospitalised due to RSV.

Many thanks for your continuous support!

Please stay healthy and safe,

Silke Mader and the EFCNI team

EFCNI

OBITUARY

We mourn the sudden passing of Professor Heidelise Als

We were shocked and saddened by the sudden passing of Professor Heidelise Als. She was a pioneer and trailblazer for Infant and Family-Centred Developmental Care (IFCDC) and the originator of NIDCAP (Neonatal Individualised Developmental Care and Assessment



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Program), she has made a meaningful, lasting contribution to improving the health outcomes of hospitalised infants worldwide. Professor Heidelise Als has been a long-time supporter and a true source of inspiration for EFCNI. We will miss her greatly.

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NEW PARTNERSHIP

Warm welcome to Janssen as Premium Partner of EFCNI

With this new partnership, EFCNI and Janssen aim to raise awareness of rare alloimmune diseases such as haemolytic disease of the foetus and newborn (HDFN), a condition where maternal and foetal blood types are incompatible which – in severe cases – leads to anaemia, jaundice, severe brain haemorrhage or even death of the newborn. We look forward to working with Janssen to fight these threats to newborns and their parents!

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ADVERTORIAL - RAISING AWARENESS OF RSV

Do you recognise the “Sounds of RSV” in babies?

For many countries in the northern hemisphere, September marks the start of the respiratory syncytial virus (RSV) season. RSV is a common, contagious virus that infects the nose, throat and lungs, making it hard for an infant to breathe. Most children will contract RSV infection in their first two years, and although it usually only causes mild, cold-like symptoms, some serious cases can be life-threatening. For babies who are at high risk, such as babies born prematurely, recognising the symptoms of RSV infection is therefore critical.

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“ARE YOU RSV AWARE?”

New RSV campaign gives parents a 360° view of the common and unpredictable Respiratory Syncytial Virus

It's cold season again and therefore also RSV season. But not every cough is a harmless cold. With our new comprehensive and multilingual campaign, we want to educate parents about the common RS virus, because only with knowledge can we counter this unpredictable virus, which is a major burden for families, doctors and the health system every year. For this, affected families have shared their very personal “RSV Stories” in emotional testimonial videos. These moving images are complemented by general RSV information, easy-to-understand infographics and our RSV parent booklet with valuable first-hand advice from parents and doctors on how to recognise an infection and what parents can do to protect all infants from RSV. All materials are now available to download and share in English, French, German, Italian and Spanish. Spread the word, not the virus!

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VIDEO SERIES

Experts break down complex facts about human milk

We spoke with experts in the field of nutrition, neonatology, neuroscience, and political science to learn about the tremendous importance of human milk on the healthy development of newborns, especially those born too soon and too small. In our playlist, you can find out what they told us about fortification, special nutritional measures for preterm babies, or the role of milk banks.

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STATEMENT ON EU REGULATION

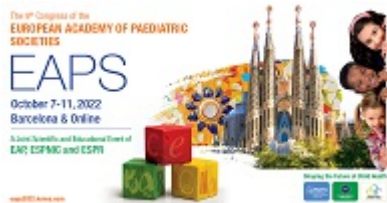
The regulation of human milk in the European Union enters next stage

In July 2022, the European Commission adopted the proposal for a regulation on standards of quality and safety for substances of human origin (SoHo) intended for human application. Previously unregulated at EU level, this new proposal has extended its scope of SoHo to “human breast milk”. EFCNI welcomes and supports the aims of ensuring safety and protection for recipients

and donors by clarifying regulatory aspects of donor human milk. Find our full statement and requests to the European policymakers to guarantee that the highest level of safety for preterm and sick infants are met on our project website.

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Network



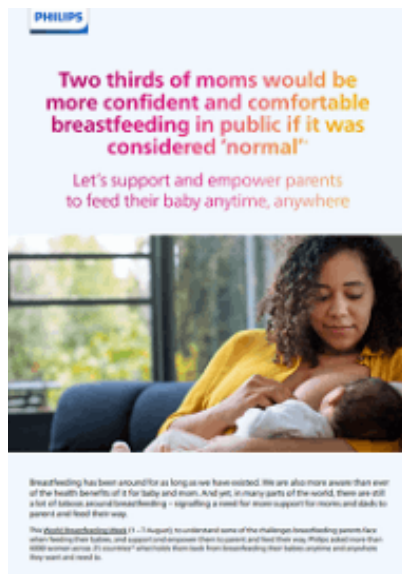
© Philips/Pregnancy+ App

MEET EFCNI

The congress season 2022 is in full swing: meet us at the EAPS Congress in Barcelona!

We are delighted to be participating in the 9th Congress of the European Academy of Paediatric Societies (EAPS) from 7-11 October 2022 on-site in Barcelona. EFCNI will be contributing to the diverse congress programme with two sessions focusing on the patient- and parent perspective in neonatal care.

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BREASTFEEDING IN PUBLIC

Survey shows: Breastfeeding in public remains problematic for many women

Breastfeeding has been around for as long as we have existed. We are also more aware than ever of the health benefits of it for babies and mums. And yet, in many parts of the world, there are still a lot of taboos around breastfeeding. The results of a survey conducted on the Pregnancy Plus app, in which 6000 women from 25 countries participated, show there's still work to be done to support and empower moms in their choice to breastfeed in public.

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Science

LAUNCH OF THE RESQ FAMILY ONLINE SURVEY



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Impact of Respiratory Syncytial Virus (RSV) hospitalisation on Quality of life of Families – a multi-country study

By the age of two years, almost all infants will be infected with RSV at least once. When the RSV infection takes a severe course, affected children often require hospital care. There is little data on how severe RSV infection leading to hospitalisation of children impacts the quality of life of affected families. EFCNI is looking to fill in this gap with voluntary participants to take part in a study that explores parents' or caregivers' experiences with the challenges caused by RSV infection and hospitalisation of their children (< 2 years). By sharing your experiences of how you have dealt with your child's RSV episode, you can help to increase our understanding of the disease and begin to make a change in the quality of life for affected children and their families.

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ANNUAL PREMSTEM MEETING IN UTRECHT

In-person meetings returning in full force

The first full in-person meeting of the PREMSTEM project took place in Utrecht, The Netherlands, on 7-8 September. As a work package leader in the project, EFCNI was happy to finally be able to meet other members of the consortium and presented an update on the progress of communication and patient engagement in the project. It was great to receive live updates on the progress within the other work packages including stem cell labelling to see where these end up in the large animal models, the impact of stem cell treatment on myelin in different regions of the brain, the long-term outcomes of perinatal brain injury in preterm born sheep and the development of the ultrafast ultrasound technology.

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European Standards of Care for Newborn Health



NEW STANDARDS LAUNCHED

European Standards of Care for Newborn Health are progressing

After an intensive development and coordination phase, six new standards were launched at the 12th UENPS

Congress in Kraków. Now topics such as cord management of term and preterm infants, management of NEC, the immunisation of preterm infants, error management, and quality indicators are being covered. The launch was also preceded by an extensive revision process of 20 existing standards last year.

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GLANCE - Global Alliance for Newborn Care



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GLOBAL TRENDS IN PRETERM BIRTH FROM 1990-2019

How did the global incidence and mortality of preterm newborns change over the years?

Preterm birth remains to be a severe health threat, with one in ten babies born too soon worldwide. Due to the higher risk of infections and other complications, preterm birth is still the leading cause of death in children under five years. However, incidence and mortality rates differ significantly across continents, countries and regions. In a recent study from China, researchers analysed global trends from 1990 to 2019 regarding the incidence and mortality of preterm birth by using pre-existing data from the 2019 Global Burden of Disease study. Deaths and incident cases decreased globally, but on a regional and national level, preterm birth rates also increased. Further research is needed to find the underlying reasons and measures to prevent preterm birth worldwide.

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EFCNI-Academy



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NEW FACTSHEET FOR HEALTHCARE PROFESSIONALS

NEONATAL PARENTERAL NUTRITION

Parenteral nutrition is a life-saving therapy for some preterm and sick newborns but can be accompanied by certain risks. While evidence-based recommendations on how to provide safe and optimal parenteral nutrition are available, the practical implementation may deviate from these recommendations. With our newly developed factsheet supported by experts, we provide healthcare professionals with comprehensive advice on safety measures and recommendations for optimal and safe

parenteral nutrition according to the evidence-based guidelines.

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NEW FACTSHEET FOR HEALTHCARE PROFESSIONALS

RSV - A RISK FOR ALL CHILDREN UNDER TWO YEARS OF AGE

Respiratory Syncytial Virus (RSV) is a virus whose infections may lead to a variety of diseases, from mild upper respiratory illness to life threatening lower respiratory tract infections. While most RSV cases are mild, we cannot predict the course of the disease and which infants get seriously ill and have to be hospitalised. With our brand-new factsheet we offer healthcare professionals a summary on burden, symptoms, risk factors, transmission, treatment, prevention and communication recommendations supported by experts in the field of paediatric infectiology.

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