



In May, we focused on the topic of NICU design and on how to welcome parents to neonatal units. We asked healthcare professionals and parents what needs to be considered when designing a neonatal intensive care unit. We launched a factsheet and new website content providing information for parents in the NICU. One of our partners successfully advocated 24/7 opening hours for parents in their country. Welcoming parents in neonatal units is possible. Let's put it into practice together.



Your EFCNI team

Parents of Premies Day 2016

The first Sunday in May is dedicated to parents of preterm born infants. On *Parents of Premies Day*, individuals, organisations, and hospitals realise countless activities dedicated to parents of preterm infants. This year, EFCNI created a social media series featuring the ten most important rights of parents and newborns. EFCNI has developed these rights in close collaboration with partnering parent organisations. We also published a new [factsheet](#) and website content on [Parents in the NICU](#). In a very personal [interview](#) EFCNI's Chairwoman Silke Mader spoke about her experiences as a mother of a preterm child in the late 90s.

[EFCNI Rights of parents and newborns](#)



Review on Parents of Premies Day by Graham's Foundation

1 May 2016 marked the fifth annual Parents of Premies Day, the global day of awareness created by [Graham's Foundation](#) to recognise the courage and commitment it takes to stay strong when a preterm birth turns a family's world upside down. Christa Terry from Graham's Foundation gives a short recap on their activities.

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Interview with a mother of a preterm baby

On the occasion of Parents of Premies Day, we spoke to Mindy, mother of four. One of her children was born preterm. In the interview Mindy describes her experiences during her son's stay in the NICU.

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New collaboration partner DSKN

We welcome our new collaboration partner *Deutsche Stiftung Kranke Neugeborene* (German Foundation for ill Newborns). Founded in 2014, the aim of the charitable foundation is to improve the provision of healthcare not only of preterm infants but also of ill newborns.

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EFCNI at the European Congress of Obstetrics and Gynaecology

From 19 to 21 May 2016, the 24th European Congress of Obstetrics and Gynaecology took place in Torino, Italy. About 700 participants saw the EFCNI booth. Besides this, we had the honour to participate in this congress with an own session on preeclampsia and its prevention and treatment.

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EFCNI at the SHIPS project meeting

From 14 to 15 March 2016, the team of the SHIPS research project organised the second project meeting in Porto, Portugal. EFCNI gave a presentation about the involvement of parent representatives in the research project assessing the impact of follow-up screenings and prevention programmes in preterm born children.

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Video in French

We proudly present the video of our 12th Parent Organisations Meeting with French subtitles. EFCNI warmly thanks our partnering parent organisation *SOS Préma* for the translation!

[View more](#) (Youtube)



New content on the EFCNI website

During the last weeks, we launched new content on the EFCNI website. We proudly present the new section on *Parents in the*

NICU including a factsheet for (affected) parents for free download. Another new section deals with *The neonatal intensive care unit* including a description of the equipment in the NICU.

- [*The neonatal intensive care unit*](#)
- [*Parents in the NICU*](#)



EFCNI at the ESPGHAN Congress

The 49th Annual Congress of ESPGHAN was held from 25 to 28 May 2016, in Athens, Greece. EFCNI had the honour to participate in this congress to provide information on the nutrition of preterm born babies. We were proud to have our Greek partner *Ilitominon* with us.

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Meet EFCNI @ these congresses

We will participate in several [congresses](#) within the coming months and would be happy to see you there!

Meet the EFCNI team @

- [*42. Jahrestagung der Gesellschaft für Neonatologie und Pädiatrische Intensivmedizin \(GNPI\) from 02 to 04 June 2016 in Frankfurt a. M., Germany*](#)
- [*25th European Congress on Perinatal Medicine from 15 to 18 June 2016 in Maastricht, Netherlands*](#)
- [*15th World Congress in Fetal Medicine from 26 to 30 June 2016 in Palma de Mallorca, Spain*](#)
- [*Conference Nutrition and nurture in infancy and childhood bio-cultural perspectives from 23 to 25 August 2016 in Dalarna, Sweden*](#)
- [*Conference The Power of Programming 2016 – Developmental Origins of Adiposity and Long-term Health from 13 to 15 October 2016 in Munich, Germany*](#)
- [*6th Congress of the European Academy of Paediatric Societies from 12 to 25 October 2016 in Geneva, Switzerland*](#)
- [*Global conference on maternal infant health from 4 to 6 November 2016 in Florence, Italy*](#)



From Louise with love - letter to

French deputies

The French parent organisation *SOS Préma* has realised two remarkable projects to raise awareness for this topic respectively to improve the situation for preterm born infants: a moving postcard, written by the preterm born baby Louise (born at 26 weeks of gestation), and a two-day advanced training with 300 participants from all across France.

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Conference for healthcare professionals and therapists

During March and April 2016, *Lahav Association* from Israel collaborated with the *Children's Medical Center MEDIKIDS* and held two Academic Conferences for healthcare professionals and therapists.

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Padedu augti helps establish first Lithuanian mother's milk bank

Inga Budriene, Chairwoman of our Lithuanian partner organisation *Padedu augti* presents a variety of innovative projects, ranging from the establishment of Lithuania's first mother's milk bank, a *mind nesting box*, for emotional support of families, their project *Tree of Life*, and a guidebook for parents of preterm children.

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Vivere Onlus achieves 24 hours parental access to Italian NICUs

Vivere Onlus is an Italian national coordination of associations for neonatology. In February, they held the first joint assembly, a major two-days work meeting in Padua, Italy. In addition, in May, the *Italian Ministry of Health* signed a recommendation paper which had been developed by the *Technical Operating Table for the promotion of breastfeeding (TAS)*, the *Italian Society of Neonatology (SIN)*, and *Vivere Onlus*. This effected a change towards 24 hours parental access to Italian NICUs. Congratulations!

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Sharing tears and hopes - an emotional Mother's Day event

To celebrate Parents of Premies Day and Mother's Day, the parent organisation *El Bebek Gul Bebek* from Turkey put together an event full of joy, tears, and further awareness.



follow-up programmes for children born very preterm by studying their impact on the children and families followed in the *EPICE* cohort. EFCNI is contributing to the *SHIPS* project by providing a link between researchers and parents. Visit the new project website for more information about the study, the *EPICE* cohort, the participating regions, and latest research results from the study.

www.epiceproject.eu

Study on mothers' experiences with expressing breast milk

Ikonen and colleagues recently published a study in the *American Journal of Maternal/Child Nursing* describing mothers' experiences with expressing breast milk for preterm infants or infants small for gestational age. They concluded that expressing breast milk should be considered as a helpful factor for mothers and that the separation between mother and infant should be avoided.

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Recommendations for psychological support of NICU parents

Under the lead of Guest Editors Sue L. Hall, MD, MSW, FAAP and Michael T. Hynan, PhD, the *Journal of Perinatology* publishes a set of recommendations on the support of parents and staff working in the NICU. The recommendations were developed by a workgroup of multidisciplinary professional organisations and NICU parents. The articles are published as open access articles that can be read and downloaded without a subscription to the journal.

[View more](#) (Journal of Perinatology)

Update of webpages for patients and consumers

The *European Medicines Agency* (EMA) is pleased to announce an update to their webpages dedicated to *patients and consumers*. The aim was to update the content, highlight existing helpful information as well as to launch the ongoing series entitled '*EMABasics*' in the *training and resources section*.

[View more](#) (European Medicines Agency)

Mark your calendar

Receive an overview on [congresses and conferences in 2016](#) and find out where to meet EFCNI.

[Awareness days in 2016](#)



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