



News

6th/7th edition 2017

This double issue for the summer season is full of real life stories. Two dedicated paediatricians travelled to Nepal to provide surgical aid to children with spastic cerebral palsy. In another interview about a topic close to our heart, an expert in palliative care and crisis intervention and her team provide encompassing support for families of severely and terminally ill children. We also devoted this edition to nutrition, our campaign for this year's *World Breastfeeding Week*, and give you an update on cutting-edge research in this field. We wish you a refreshing summer.



Your EFCNI team

Launch of SHIPS project factsheet

We are happy to present you the brand new factsheet about *Screening to Improve Health in Very Preterm Infants in Europe (SHIPS)*. The EU-funded project will assess the impact of screening programmes on health, care and quality of life for very preterm infants and their families. Have a look at the clearly designed factsheet to learn more about the aim and scope of SHIPS, its supporting partners and the structure of the project including its four inter-related studies.

[Download the factsheet](#)

World Breastfeeding Week 2017

This year's *World Breastfeeding Week* (1st week of August) was all about "working together for the common good". We invited partnering parent organisations to join a common campaign to highlight the unmet needs and the most valuable support mothers received while breastfeeding. Parents of preterm babies from 16 countries shared their breastfeeding experiences with us and we created an illustrative poster to visualise their answers.

[Download the poster](#) for free from our website.

[View more](#)

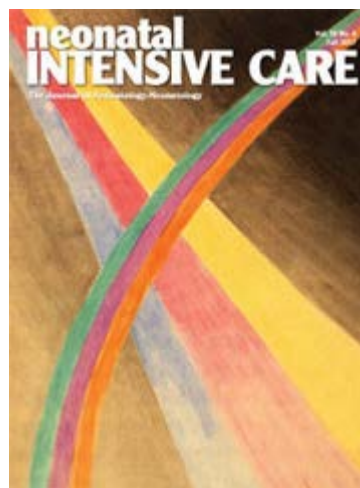
Enrolment of patient families in neonatal clinical trials

A nice example for the cooperation of patient voices beyond borders: in the current issue of the *Neonatal Intensive Care Magazine*, Deb Discenza, the head of US-based *PreemieWorld LLC*



presents her findings about how to increase the enrolment of patient families in neonatal clinical trials for preterm labour. To build a strong network of parent-led support groups, she also brings the *Preemie Parent Alliance (PPA)* and EFCNI into the discussion by doing an interview with Nicole Thiele, Vice Chair of EFCNI and Keira Sorrells, President of PPA.

[View more](#) (pp. 37-39; *Neonatal Intensive Care Magazine*)



Welcome to the EFCNI community

We are pleased to welcome *The RANO (The Early)* from Belarus to our network. The parent organisation unites parents of preterm babies all over the country. Fully led by parents, it expresses the parental voice at local and national levels and represents the interests of preterm infants and their families at all levels: individual, family, social, and political. We look forward to working together.

[View more](#)



A Strong Start for Little Heroes - fully booked

Great response to our long scale initiative for World Prematurity Day. About 170 units subscribed for the second edition of *A Strong Start for Little Heroes 2017*. What is new this year? Participants will get an enhanced event package including - among other things - a drawing book and crayons for children and a guidebook for parents on bonding and care of preterm infants.



[View more](#)

Baxter: New corporate partner

EFCNI is proud to announce the new partnership with *Baxter*. The US-based company has become one of EFCNI's premium partners 2017. Baxter has been assisting clinicians in treating patients' diverse nutrient needs since the 1940s, when the company first introduced liquid proteins in the form of amino acids. Since then, Baxter has continued to advance parenteral nutrition (PN) therapy.



[View more](#)

Support EFCNI while buying online

From now on, it is easy to shop for a good cause and to support preterm and newborn babies. If you have an *Amazon* account, you can support EFCNI *without any extra expenses* for you via this [Amazon Smile website link](#). *Amazon* will donate 0,5 percent of your purchase sum to EFCNI. We will use the money to realise further charity projects for preterm infants. Please note: this service is only

available for customers with an account on amazon.de.

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Meet EFCNI @ these congresses

We will participate in several symposia and congresses within the coming months and would be happy to see you there!

Meet the EFCNI team @

- [*ISSHP European Congress*](#) from 6 to 9 September 2017 in Berlin, Germany
- [*3rd annual National Conference on clinical studies*](#) from 7 to 8 September 2017 in Stockholm, Sweden
- [*7th Symposium for Developmental Care in Neonatology and Pediatrics - EADCare*](#) from 28 to 29 September 2017 in Paris, France
- [*5. Gießener Neonatologie Symposium*](#) from 13 to 13 October 2017 in Gießen, Germany
- [*13th World Congress of Perinatal Medicine \(WCPM\)*](#) from 26 to 29 October 2017 in Belgrade, Serbia
- [*2nd Congress of the joint European Neonatal Societies \(jENS\)*](#) from 31 October to 4 November 2017 in Venice, Italy



Baby Story brings Socks for Life to Belarus

The organisation [*Baby Story*](#) has successfully brought the [*Socks for Life*](#) campaign to Belarus. In a creative way, they are realising a bunch of remarkable *Socks for Life* charity projects. In one of them, they asked people to write warm words and wishes for preterm babies on *Socks for Life* cards and put them inside 50 pairs of hand-knitted woollen socks. They then handed over these little gifts to preterm born children in a city hospital in Minsk.

[View more](#) (*Baby Story*)



Commitment without borders – medical help for children in Nepal

In 2016, paediatrician Dr Sibylle Poschmann and her husband Dr

Michael Poschmann, a paediatric- and neuro-orthopaedic surgeon, travelled to Nepal in order to provide surgical aid to children with spastic cerebral palsy within the scope of their own medical aid project. Besides improving the care of Nepalese children with impairments the aim of their initiative was also to teach local physicians in terms of indication. In conversation with EFCNI, Dr Poschmann portrays her experiences and impressions from this undertaking.

[View more](#)



Parents and doctors as equal partners - communication seminar

In July, *Early Birds (Ranni Ptashky)*, the *Ukrainian Preemie Parent Organisation*, held their first communication seminar for parents and doctors in Kiev, Ukraine. More than 200 doctors and parents from all over the Ukraine came to participate with the aim to create a fruitful dialogue and to learn about new ways of communication for an equal partnership between doctors and parents.

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Brothers for Life

The Swedish singer and songwriter Joakim Bertilsson has recorded an emotional song dedicated to two preterm born brothers. The artist is the godfather of the two boys Matteo and Malcolm.

[View more](#) (Youtube)



11 months - 11 topics: Ethical decision-making and palliative care

Talking about ethical decision-making and palliative care in July, we tackled questions like shared decision-making, communication processes, and decisions related to the transition from curative to palliative care.

- [Parent statement](#) (Facebook)
- [Caring for children at the end of life - a guest article by Christine Bronner](#)
- [Global Alliance to Prevent Prematurity and Stillbirth \(GAPPS\)](#)
- [The Sands Guidelines - Sands Stillbirth & neonatal death charity](#)
- [The Butterfly project: supporting parents who have lost a](#)



Ethical decision-making
and palliative care

EFCNI

[baby from a multiple pregnancy](#)

- [Confronting the Sorrow and Silence of Stillbirth, Healthy Newborn Network website](#)
- [Approaching the third decade of paediatric palliative oncology investigation, The Lancet Child & Adolescent Health](#)
- [Reducing stillbirth rates in Europe, EFCNI White Paper \(2010\), chapter 13 \(pp 85-87\)](#)

Variability in stillbirth and in-hospital mortality across Europe

As stillbirth and in-hospital mortality rates associated with very preterm births vary widely across Europe, Draper et al. have conducted an encompassing Europe-wide study that aims to determine to which extent the variation in stillbirth and in-hospital mortality rates among very preterm infants remains unchanged. The study takes up the results from the EPICE cohort study and revealed an almost twofold difference across European regions.

[View more](#)



How to involve parents in neonatal critical care decision-making

Having a newborn baby cared for on a neonatal intensive care unit is a difficult time for parents. For some, this becomes particularly painful when they are faced with decisions around whether or not to continue life-sustaining treatment or withdrawing this support. A study by Shaw et al. published in *Sociology of Health & Illness* analysed decision-making conversations between doctors and parents of critically ill newborn babies.

[View more](#)



Attitudes and values regarding end-of-life decision-making in extremely preterm infants

A Swiss study investigated factors influencing the approach to life-sustaining measures for extremely preterm infants taking the perspective of healthcare professionals, affected parents and the Swiss population into account. The qualitative study revealed differences concerning moral and medical standpoints amongst the three groups of interviewees, but showed consent in a consistent involvement of parents in the decision-making process.

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Survival rates of extremely preterm infants in France depend on place of birth

According to the findings of the recently published study by Diguisto et al., the provision of active antenatal care for infants born before 25 weeks of gestation in France differs from region to region which significantly influences survival rates of this patient group and results in higher mortality and morbidity rates as compared to international standards. Thus, the researchers urge to identify and address these points of inequality and to propose national guidelines for France as they already exist in other countries.

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Expert interview about ethical decision-making and palliative care

The members of the Topic Expert Group on “Ethical decision-making and palliative care” in the *European Standards of Care for Newborn Health* are working on standards in this important field. We had the opportunity to ask Professor Gorm Greisen, one of the two Chairs of this group. For him it is essential to practise shared decision-making and to “focus on communication - this means not only informing parents about the situation of the infant, but also listening to them to understand their aspirations and values”.



[View more \(YouTube\)](#)

Expert interview about NICU design

Why do we need to develop standards on the design of the neonatal intensive care unit (NICU)? We asked Professor Boubou Hallberg from Sweden and Dr Atle Moen from Norway. As members of the Topic Expert Group on *NICU design* of the *European Standards of Care for Newborn Health* project, they are working on standards to optimally support the provision of family-integrated and developmentally supportive care.



[View more \(YouTube\)](#)

11 months - 11 topics: Nutrition

Following our hot topic in August, "Nutrition", we collected news about nutrition and special feeding requirements of preterm and ill born babies during their stay in the hospital and after discharge.

- [Interview with Anne Sunder-Plaßmann on the setup of a milk bank](#)
- [Parent statement \(Facebook\)](#)
- [EFCNI project on the setup and operation of milk banks](#)
- [EFCNI Position Paper: Recommendations for the support of milk banks in Germany, Austria and Switzerland \(in German\)](#)
- [EFCNI Toolkit for the setup and operation of milk banks \(in](#)



Nutrition

EFCNI

[German\)](#)

- [Introduction of parenteral nutrition by Professor Berthold Koletzko](#)
- [Report by the Dutch organisation Nee-Eten!](#)
- [Organisation Feeding Matters](#)
- [Room for improvement in breast milk feeding after very preterm birth in Europe: Results from the EPICE cohort. Study Maternal & Child Nutrition](#)
- [World Breastfeeding Week 2017 Pledges](#)
- [Videos for parents from the "Deutsche Stiftung Kranke Neugeborene" \(in German\)](#)
- [Mobile apps to support breastfeeding](#)

Milk banks from Madrid to Kaunas

In line with our topic of the month *Nutrition*, we introduce a small selection of remarkable milk banks in Europe. Clinics e.g. in Spain, Northern Ireland, Lithuania and Slovakia show that the setup and operation of a milk bank is possible no matter where.

[View more](#)



ESPGHAN: Position paper on complementary feeding

The *European Society for Paediatric Gastroenterology, Hepatology, and Nutrition* (ESPGHAN) published a position paper that considers different aspects of complementary feeding, focussing on healthy term infants in Europe. The paper covers topics such as the timing, the content, and the method of complementary feeding.

[View more](#)



Diet and physical activity based interventions in pregnancy

Half of all women of childbearing age worldwide are overweight or obese. This puts mothers and babies at risk, both in pregnancy and in later life. In a study published in the *British Medical Journal (BMJ)*, a team of researchers from the *International Weight Management in Pregnancy (i-WIP)* Collaborative Group around Professor Khan therefore assessed if diet and physical activity

based interventions have an effect on limiting gestational weight gain and on the health of mothers and their infants.

[View more](#)

Managing complications in pregnancy and childbirth

The newly updated and easy-to-use manual “Managing complications in pregnancy and childbirth” by the *World Health Organization (WHO)* is arranged by symptoms (e.g. vaginal bleeding in early pregnancy) including a corresponding diagnosis table. The clinical action steps are based on clinical assessment with limited reliance on laboratory or other tests and most can be performed in a variety of clinical settings (e.g. district hospital or health centre).

[View more](#) (*World Health Organization*)

Neurodevelopmental outcome in children born extremely preterm

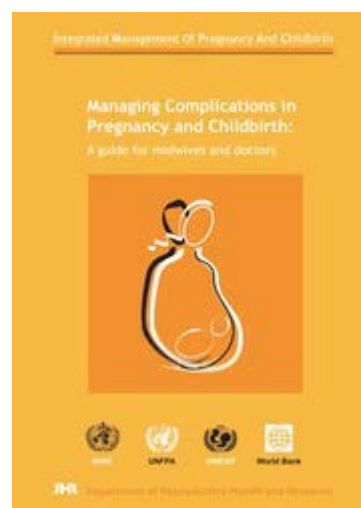
An Australian study examining the neurodevelopmental outcome at the age of 8, in cohorts of children born extremely preterm, has revealed unexpected results: even though the survival rate of extremely preterm born children has significantly increased over time, developmental morbidity did not decline in equal measures. Researchers draw from this study that long-term assessment of neurodevelopment has been underestimated for too long.

[View more](#)

Every Women Every Child Progress Report

The first Progress Report on the *Every Woman Every Child Global Strategy for Women’s, Children’s and Adolescents’ Health*, “Progress in Partnership,” was launched in July 2017 at the UN’s High-Level Political Forum on Sustainable Development in New York, USA.

[View more](#) (*Every Woman Every Child*)



No coherence between preterm birth

and anxiety and mood disorders

It has been assumed that very preterm and/or very low-birth weight (VP/VLBW) birth is associated with an increased risk of mood and anxiety disorders in adulthood. A recent study by Jaekel et al. now examined the risk for mood or anxiety disorders in a longitudinal whole-population study.

[View more](#)



Very preterm birth and parents' quality of life

Parents of preterm children experience increased distress early in their children's lives. Wolke et al. have now conducted a prospective whole-population study to assess the quality of life of parents of very preterm or very low birth weight adults compared to that of parents of term individuals. The study highlighted that parental quality of life was not predicted by their children's preterm birth, disability or academic achievement and the like but rather by their children's mental health.

[View more](#)



Self-reported mental health problems among adults born preterm

A recent, comprehensive study analysing self-reported mental health problems of adults born preterm, is supporting the view that there is a universal appearance of mental health problems among adults born preterm. Their findings showed that adults born preterm reported more internalising and avoidant personality problems - especially preterm born women and those preterms born small-for-gestational age.

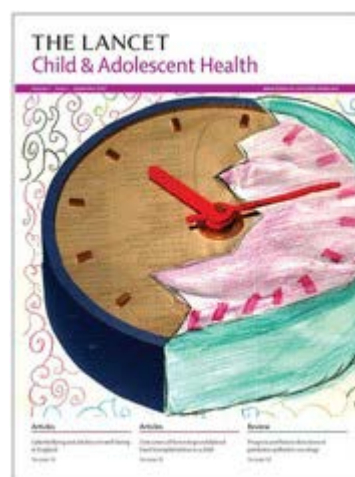
[View more](#)



First issue of The Lancet Child & Adolescent Health

The inaugural issue of the new scientific magazine *The Lancet Child & Adolescent Health* is now online. In celebration of the official launch, the full-text content is available for free with online registration and covers issues like cyberbullying, ZIKA, art therapy for children, and much more.

[View more](#) (*The Lancet Child & Adolescent Health*)



Mark your calendar

Receive an overview on [congresses and conferences in 2017](#) on maternal and newborn health.

[Awareness days 2017](#)



Landmark 2017 in the Land of Ideas

EFCNI is one of the most innovative "Landmarks 2017" of the initiative [Germany – Land of Ideas](#).

[View more](#) (website [Germany - Land of Ideas](#), in German)

Germany
Land of Ideas



Landmark 2017

Nationaler Förderer
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