



News

3rd edition 2017

It is already May - time flies fast. This is true also to preterm infants. Even as adults they benefit from an early starting and evidence-based follow-up. In this edition, we are focussing on this important newborn health topic. We asked researchers, doctors, and parents what they are thinking about *Follow-up and continuing care* and show some positive and encouraging stories from the exciting time after discharge from hospital.



Your EFCNI team

## Silke Mader meets Federal President of Germany

Together with the Minister-President of Bavaria Horst Seehofer and his wife, the Federal President Frank-Walter Steinmeier and his wife gave a reception at the Court Church of All Saints at the Munich Residence for fellow citizens who are doing volunteer work. Being invited to the reception, our Chairwoman Silke Mader had the great honour to meet the German Federal President and the Bavarian Minister-President in person who took the time for a personal conversation. Their motivating words will encourage and accompany us in our future work!



[View more](#) (Facebook)

## 4th project meeting of SHIPS research consortium

At the end of March, the partners of the *Screening to Improve Health in Very Preterm Infants in Europe (SHIPS)* project met in Nijmegen, the Netherlands, for their 4th meeting. Whereas the first part was dedicated to agree on a common scientific publication strategy, the second day focused on EFCNI and the plans with regard to continuing project communication activities and outreach for the upcoming year.



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## Welcome to our network: Baby Story from Belarus

A warm welcome to our new partner *Baby Story* from Belarus. This non-governmental charity organisation supports and advocates for



В ПОМОЩЬ НЕДОНОШЕННЫМ МАЛЫШАМ  
И ДЕТЯМ С ДОПОЛНИТЕЛЬНЫМИ ПОТРЕБНОСТЯМИ  
FOR CHILDREN BORN PREMATURE  
OR WITH ADDITIONAL NEEDS

the rights and interests of children born preterm. *Baby Story* sees its role to link vulnerable children and families with relevant professionals and stakeholders who cooperate to create the system of coordinated community support improving the situation of preterm children in Belarus.

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## The first EFCNI Bodyguard

Only a few weeks after the launch of the EFCNI donation programme, we can thankfully announce that we have gained our first *Bodyguard*: Dr Till Dresbach, Senior Physician for pediatrics and youth medicine at the University Hospital Bonn, Germany, also representing his team, decided to support EFCNI with 1,000 euros.

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## Thought-provoking symposium on end-of-life decision making

Even today, ethical decision-making processes and palliative care often remain a taboo subject in neonatology. The symposium "Frühstgeborene am Lebensende" ("End-of-life decision-making in extremely preterm infants") at the *Zurich University Hospital* tackled this challenge in stimulating talks and critically addressed the status quo from very different angles. EFCNI Chair Silke Mader spoke about the question on how parents could be involved in critical care decisions. We very much appreciated the invitation and the open discussions in this thought-provoking meeting.

[View more](#) (invitation flyer, in German)



## 1st World Congress on Maternal Fetal Neonatal Medicine

EFCNI was one of the auspices of the *1st World Congress on Maternal Fetal Neonatal Medicine* from 24 to 26 April 2017 in London, UK. The conference focused on issues like periconceptional medicine, great obstetrical syndromes, and fetal and neonatal growth restriction. Silke Mader talked about "How parents can be involved in making critical care decisions" in the pre-course on Preterm Neonatal Resuscitation. More than 1,500 congress participants attended the high-level talks and the inviting exhibition hall, which was located close to iconic buildings in the heart of London.

[View more](#) (congress website)



## 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 @



- [50th ESPGHAN Annual Meeting of the European Society for Paediatric Gastroenterology, Hepatology and Nutrition from 10 to 13 May 2017 in Prague, Czech Republic](#)
- [43. Jahrestagung der Gesellschaft für Neonatologie und Pädiatrische Intensivmedizin \(GNPI\) from 8 to 10 June 2017 in Dresden, Germany](#)
- [8th Europaediatrics Congress from 7 to 10 June in Bucharest, Romania](#)
- [16th World Congress in Fetal Medicine from 25 to 29 June 2017 in Ljubljana, Slovenia](#)

## NICU goes mobile - apps for parents

Within the last three years a number of mobile apps targeted at parents of preterm infants were released. The core of nearly all of them is the tracking of the baby's development in combination with a digital diary. Most of them promise additional benefits for users. In line with our topic of the month, we give an overlook about the market.

[View more](#)



## Juvenile commitment - tiny caps, big sign

The young Greek Prokopis was born at 32 weeks of pregnancy and spent 17 days in the NICU. Now, a couple of years later, he decided to make caps for preterm infants. With these caps, he wants to encourage parents and say "Everything will be ok".

[View more](#) (Facebook)



## Thank you, Gert

On 1 April 2017, the Dutch Association of Parents of Premies, *Vereniging van Ouders van Couveusekinderen (VOC)*, said farewell to their long standing director, Dr Gert Jan van Steenbrugge. EFCNI has been working closely together with him for more than nine years. We are very grateful for his work and commitment to preterm born children, their families and the care teams around them. Gert will stay a valuable member of the EFCNI Parent Advisory Board. We wish him all the best for the future and look forward to working together on our common projects!

[View more](#) (EFCNI Parent Advisory Board)



## Campaign „Let's help together“

Do good while you shop: Our Estonian partner organisation

*Enneaegsed lapsed* is collaborating with one of the largest malls in Tallinn, Estonia. The centre started a charity campaign called “Let’s help together” (“Aitame koos”) to collect donations from visitors of the shopping mall for five charity organisations. In a charity event in February, the donations were handed over to the five organisations. *Enneaegsed lapsed* is now using the donations to support breastfeeding in maternity hospitals in Tallinn and Tartu. A great and successful cooperation!

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## Opening of new UK NIDCAP Centre

In April, the new UK NIDCAP Centre (*NIDCAP: Newborn Individualized Developmental Care and Assessment Program*) at *University College London Hospital* officially opened its doors. The inauguration was celebrated in the presence of Director Professor Neil Marlow, Trainer Gillian Kenney and Senior Trainer Inga Warren (picture by NIDCAP France). The co-directors are Drs Judith Meek and Angela Huertas. Warm congratulations to the entire team!



[View more](#) (Facebook)

## Fast, faster, Malicek

Make way for the running season with charity marathons around the world. Doing good by doing sports is an ideal way to raise money for preterm children. In April, 34 volunteers joined the *12th CSOB Marathon*, one of the biggest running events in Slovakia with 12,000 runners. They represented our partner organisation *Malicek*. The donated money will now be used to support physical therapies for two families of preterm infants. Thumbs up!

[View more](#) (Facebook, in Slovakian)



## 25 years of commitment for the smallest patients

Time to celebrate: This year, our German collaboration partner, the Federal association “*Das frühgeborene Kind e.V.*” is having its 25th anniversary. Today, the organisation represents more than 70 member groups active in child health and support throughout Germany. We warmly congratulate you - keep up the good work!

[View more](#) (website of the association, in German)



## 11 months - 11 topics: Follow-up & continuing care

In line with our communication series *11 months - 11 topics*, we

feature one special newborn health topic per month. April was dedicated to *Follow-up and continuing care*. Please find below some highlights of this field - among others guest articles on the SHIPS research project, on a Hungarian follow-up programme, and some research news.

- [Follow-up programme at the Budapest Early Intervention Centre](#)
- [Follow-up of the POPS cohort in the Netherlands](#)
- [Programme Babylotse by the Foundation SeeYou in Hamburg](#)
- [Parent statement on the SHIPS project](#) (Facebook)
- [Researcher statement](#) (Facebook)
- [Fruehgeborene-bildung.de](#) (in German)

## Interview on Follow-up and continuing care

The care after discharge from hospital and during childhood has a crucial impact on the development of preterm born infants. We asked Dr Aleid van Wassenaer-Leemhuis and Professor Dieter Wolke, representing the Chair Team of the Topic Expert Group on *Follow-up and continuing care*, some questions on important issues in the field.

[View more](#) (Youtube)

## "We all benefit from high-quality follow-up programmes"

In her guest article, Mandy Daly from the [Irish Neonatal Health Alliance](#) calls for effective, high-quality follow-up programmes. She highlights the need for scientific determination of the diverse programmes to improve the health and quality of life of children born very preterm all across Europe. This is the overriding aim of the EU funded SHIPS project.

[View more](#)

## Unique programme for follow-up care for preterm and high-risk babies

Professor Felderhoff-Müser and Dr Britta Hüning demand that „continuing family-centred care after discharge of all preterm infants and high-risk neonates should become routine care”. In their contribution to our monthly topic “Follow-up and continuing care”, the two physicians give us a valuable insight into their unique follow-up care programme for preterm born and ill born infants and their parents at the *Essen University Hospital*, Germany.



Follow-up and continuing care

EFCNI



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## Caesarean section and effects on breastfeeding patterns

Hobbs et al. published a new cohort study in *BMC Pregnancy and Childbirth* to examine the association between mode of birth on breastfeeding initiation, duration and difficulties in the first four months after delivery. The authors found that women who gave birth by planned c-sections were more likely to have no intention to breastfeed or to discontinue breastfeeding before 12 weeks postpartum.

[View more](#)

## Mental health of extremely low birthweight survivors

*The Psychological Bulletin* recently published a study by Mathewson et al. which analysed all available literature on the mental health of individuals born at extremely low birthweight or extremely preterm up until mid-2016. The authors found out that parents and teachers of very small born children report significantly more often inattention and hyperactivity, oppositional disorders, autistic symptoms, and social difficulties.

[View more](#)

## Ultra-early Intervention conference: Free handouts

This year's *Stockholm Conference on Ultra-early Intervention*, organised by the *Karolinska NIDCAP Training and Research Center*, took place under the heading *Parental voice and music in neonatal intensive care*. The organising committee recently published handouts of the given presentations.

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## EMA consultation on orally inhaled products (OIP)

Do not miss the public consultation by the *European Medicines Agency (EMA)* on the [concept paper](#) on revision of the guideline on the requirements for clinical documentation for orally inhaled products (OIP) including the requirements for demonstration of therapeutic equivalence between two inhaled products for use in the treatment of asthma and chronic obstructive pulmonary disease (COPD) in adults and for the treatment of asthma in children and adolescents. Comments should be provided using this [template](#). The completed comments form should be sent to [respiratoryDG@ema.europa.eu](mailto:respiratoryDG@ema.europa.eu) by **22 June 2017**.

[View more](#) (EMA Website)

## Mark your calendar

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

[Awareness days 2017](#)



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