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Spring has arrived, we can finally store away the thick coats and crack on with fresh energy. April started with a very joyous event – the 10th anniversary of EFCNI and you can tell, a lot has happened since EFCNI's founding ten years ago. This month's lighthouse projects give evidence of how much has changed in terms of follow-up and continuing care for example. You also get an insight into how assessment is carried out in the SHIPS research project. This issue features a petition to promote Patient Safety across Europe, which anyone can sign and support. So let's get active on behalf of neonatal care!



Your EFCNI team

Our charity projects

Thanks to our wonderful supporters, we could implement several charity projects in favour of preterm or ill born babies and their families. In the year of our 10th anniversary, we asked our donors and beneficiaries to tell us more about their experiences in projects that have been carried out together with EFCNI, like a new parents' room at the *Catholic Children's Hospital Wilhelmsstift* in Hamburg, Germany.

[View more](#)



Dr Stepha Stehert
Chief Physician, Kath. Kinderkrankenhaus Wilhelmsstift Hamburg, Germany
Managing Director, Foundation Seehtu, Hamburg, Germany

Press for Progress in Women's Health!

If we team up we can make a change. Our partner organisation from Ghana, the African Foundation for Premature Babies and Neonatal Care (AFPNC), has set up an event to raise awareness for maternal rights and to improve women's and child health. This is a pressing issue in the Western African Region not only but especially concerning mothers giving birth preterm.

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Follow-up of preterms – why, what, when and how?

Preterm born children face higher risks of health and developmental problems than their term born peers. We asked the members of the SHIPS project which abilities they assess in their daily clinical work, which time slots regarding age are important and how assessment actually looks like.

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International Neonatal Scientific Workshop

From 11 to 12 April 2018, the Annual International Neonatal Scientific Workshop took place in Maryland, USA. The workshop was organised by INC, a global collaboration formed to forge a predictable regulatory path for evaluating the safety and effectiveness of therapies for neonates. EFCNI contributed to the workshop by introducing a survey aimed at affected parents to determine their attitudes towards the data collection in the field of neonatal research.

[View more](#)

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 @

- *[51st Annual Congress of the European Society for Paediatric Gastroenterology, Hepatology and Nutrition \(ESPGHAN\)](#) from 9 to 12 May 2018 in Geneva, Switzerland*
- *[44. Jahrestagung der Gesellschaft für Neonatologie und Pädiatrische Intensivmedizin \(GNPI\)](#) from 7 to 9 June 2018 in Rostock, Germany*
- *[World Congress in Fetal Medicine](#) from 24 to 28 June 2018 in Athens, Greece*
- *[XXVI. European Congress of Perinatal Medicine \(ECPM\)](#) from 5 to 8 September 2018 in St. Petersburg, Russia*
- *[8th International Congress of UENPS](#) from 3 to 5 October 2018 in Bucharest, Romania*

2008 - 2018 - EFCNI turns 10





Comforting your baby in intensive care

Did you know that babies can feel as much pain as adults, perhaps even more? Babies' nerve endings are closer to the surface of their skin, making them more sensitive to touch. A new booklet by Professor Linda S. Franck from the School of Nursing at the *University of California San Francisco*, helps parents to learn about infant pain and the important role parents can play, in partnership with the healthcare team, to keep their baby comfortable during intensive care. It is now available free-of-charge on their website.

[View more](#) (*University of California San Francisco*)



Digital support for parents at home

Our partnering organisation *TinyLife* has launched a website dedicated to parents during their first weeks at home together with a preterm baby. *Life at home* offers practical advice and lots of short videos of parents and professionals.

[View more](#) (*TinyLife*)



Support the Declaration for Patient Safety

EFCNI endorses the *Declaration for Patient Safety* by Health First Europe (HFE). Adverse events, such as healthcare-associated infections or surgical errors, occurred in 4 – 17 % of hospitalisations in Europe. Most of them are preventable. The EU Member States must protect patients from preventable harm: patient safety is a milestone of quality and safety within healthcare, the absolute precondition for preventing errors and adverse events and especially important for preterm born or ill babies. Act now for a safer healthcare across EU.

[Sign the petition](#)



All things neonatal - Neopodden, the Karolinska podcast

Want to add a new podcast to your feed? For Swedish speakers we recommend Neopodden, the new podcast run by Karolinska University Hospital. After one year of preparation the first seven episodes have now gone online. Each episode invites you to listen

to what patients, former patients and healthcare professionals experience(d) in the NICU. Unfiltered, and spot on from their perspective.

Listen to Neopodden [here](#) (in Swedish)



Pre-eclampsia Awareness Month: Stay informed

As May is Pre-eclampsia Awareness Month with 22 May being World Pre-eclampsia Day, we will dedicate the entire month to informing about this pregnancy complication. Who is at risk, what are the symptoms and how does the screening test and the treatment of symptoms work?

[View more](#)



11 months - 11 topics: Follow-up and continuing care

April was dedicated to the newborn health topic: Follow-up and continuing care. The related Topic Expert Group of the *European Standards of Care for Newborn Health* project therefore focuses on the period after discharge from hospital. We have compiled some background information and remarkable projects in this field.

- [Topic announcement \(Facebook\)](#)
- [Standard topics of Follow-up and continuing care \(Facebook\)](#)
- [Developing standards on Follow-up and continuing care \(website of European Standards of Care for Newborn Health project\)](#)
- Website content on [Going home](#)
- [Health advice for preterm born grown-ups](#)



Lighthouse projects: Follow-up and continuing care

During April we kept on highlighting lighthouse projects. These projects realised by members of our network or others active in neonatal care are remarkable examples how *Follow-up and continuing care* can be put into practice:



„Tiny miracles” - the first Family Centre in Sofia, Bulgaria

As one lighthouse project for family-centred care we would like to introduce “Tiny miracle” – the first Family Centre in Sofia, Bulgaria

for preterm born children and their parents. In her guest article, Petya Bankova from the responsible parent organisation *Our Premature Children*, describes the services they offer and the challenges they face.

[View more](#)

Sociomedical follow-up care in Germany offered by "Bunter Kreis"

Another remarkable project: The follow-up care facilities of the federal association *Bunter Kreis e. V.* support families with ill or preterm born babies. Nurses specialised in follow-up care help the families to face the daily challenges. In his guest article, Andreas Podeswik, chairman of the federal association, introduces their services which are free of charge for the families.

[View more](#)

From a rocky road to a joyful life

In his exclusive interview, Dr Kai König, Paediatrician & Neonatologist at Medicum Wesemlin, Switzerland, stresses the importance of a multi-disciplinary follow-up care for preterm born infants. From his point of view, every patient has to be treated according to their individual needs.

[View more](#)

Against all odds

In 1989, Gert van Steenbrugge became father of Anja who was born at 26 weeks of gestation, weighing only 800 gr. More than 20 years later, she successfully completed her vocational education and has a bright future ahead. We had the chance to ask father and daughter some questions about their experiences with the challenges of preterm birth, with a special focus on the topic follow-up and continuing care.

[View more](#)



Lung function in school-aged children born extremely preterm

Some babies born too early show signs and symptoms later in life that may be long-term consequences of preterm birth. To look at

this in more detail, follow-up studies are of great importance. Their results provide a scientific basis for follow-up and continuing care. A study from Sweden recently analysed lung function in 6½-year-old children born at less than 27 weeks. These extremely preterm born children had suffered from immature lungs after birth, and almost all of them had developed Bronchopulmonary dysplasia (BPD), a chronic neonatal lung disease.

[View more](#)

Survey on the use or non-use of rhEPO in European NICUs

If you are a neonatologist and affected with recombinant human erythropoietin (rhEPO) use or non-use in NICU patients as a preventive measure, we would like to invite you to participate in an online survey, led by Professor Rolf F. Maier from the Marburg University Hospital, Germany: www.surveymonkey.de/r/3K3R887 Because this topic addresses an issue very close to the heart of the aims of our foundation, we would very much appreciate your help in generating new knowledge on this important topic.

[View more](#)

News from the EMA

The *European Medicine Agency (EMA)* has completed its review of retinoid medicines, and confirmed that that retinoids can harm the unborn child and must not be used during pregnancy.

[View more](#) (LinkedIn)

Mark your calendar

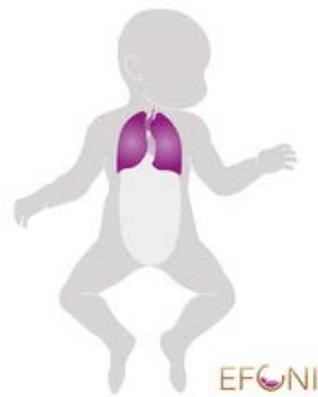
Receive an overview on [congresses and conferences in 2018](#) on maternal and newborn health.

[Awareness days](#)

Landmark in the Land of Ideas

EFCNI is one of the most innovative *Landmarks 2017* of the initiative *Germany – Land of Ideas*.

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



Germany
Land of Ideas



Landmark 2017

Nationaler Förderer
Deutsche Bank



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