



New year, new events and encounters. We are still energised and overjoyed by the recent 13th Parent Organisations Meeting. It was enriching to meet good friends, fellows, cooperation partners and new faces at our annual gathering of international parent organisations. Filled with this positive spirit, we are dedicating ourselves to the upcoming projects, meetings, congresses, and to the new edition of our communication motto *11 months – 11 topics*. Be part of it and let us move forward together!



Your EFCNI team

13th Parent Organisations Meeting

The 13th Parent Organisations Meeting, powered by EFCNI, took place from 27 to 29 January 2017 in Freising near Munich. With about 75 participants from more than 30 countries, it was our biggest international meeting of parent organisations so far. EFCNI had the honour to welcome parents and healthcare professionals from Ghana, Belarus and Brazil for the first time. This meeting has proven that this family is growing and becoming even more international.



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New parent organisations in the EFCNI network

EFCNI is proud to announce that the Russian *Give Sunshine fund* from Moscow and the *African Foundation for Premature Babies & Neonatal Care (AFPNC)*, based in Ghana, have become new partners of the foundation. Svetlana Koval and Selina Bentoom represented their organisations at the 13th Parent Organisations Meeting in Freising. We warmly welcome them in our fast growing international network.



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New look: "11 months - 11 topics" continues

Thanks to your positive feedback on *11 months – 11 topics*, we will continue this communication motto also in 2017. In a new design, we focus our social media and online communication once again on one newborn health topic per month for the eleven months from



February to December. In this newsletter, we start with the first topic, *Data collection and documentation*. If you would like to offer us a contribution for one of the monthly topics, you are warmly invited to send it to news@efcni.org

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Research on European Children and Adults born Preterm (RECAP)

In February 2017 the newly formed research consortium *RECAP - Research on European Children and Adults born Preterm* met for a two-day meeting in Utrecht, the Netherlands. The meeting was organised to bring all partners together for the first time to outline the next four years with tasks and milestones as well as to discuss challenges to be tackled. EFCNI is involved in RECAP in the area of representing the voices of parents and adults born preterm in the project and to involve all relevant stakeholders via dissemination activities.

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Professor Michael Abou-Dakn enters Scientific Advisory Board

EFCNI welcomes Professor Michael Abou-Dakn, MD, as new member of the EFCNI Scientific Advisory Board. He is head of the Gynaecology and Obstetrics Department at *St. Joseph's Hospital Berlin Tempelhof*. His specialist areas include special perinatology and obstetrics. The breastfeeding expert is past president of the *WHO/UNICEF Baby-friendly Hospital Initiative* in Germany, and a member of organisations including the *National Breastfeeding Committee*.

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Where to go in 2017: A guide to this year's congresses

To help you navigate your way through the jungle of scientific conferences and congresses, we present you some of our personal highlights in 2017. If you are planning your agenda for this year, you may get some inspiration from our overview.

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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 @

- [*9th International DIP Symposium on Diabetes, Hypertension, Metabolic Syndrome and Pregnancy from 8 to*](#)



12 March 2017 in Barcelona, Spain

- [The 8th Stockholm Conference on Ultra-Early Intervention on 23 March in Stockholm, Sweden](#)
- [Symposium „Frühstgeborene am Lebensende: gesellschaftliche, medizin-ethische und rechtliche Aspekte“ on 21 April in Zurich, Switzerland](#)
- [1st World Congress on Maternal Fetal Neonatal Medicine from 24 to 26 April 2017 in London, UK](#)
- [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](#)

Lithuanian President visits NICU of the country's largest hospital

Our collaboration partner *Padedu Augti* from Lithuania succeeded in placing preterm birth high on the political agenda. Last year, the Lithuanian President Dalia Grybauskaite had become a patron of their charity project "Silent Christmas Night". Being a proud supporter, the President of Lithuania then visited the country's largest healthcare institution to gain a personal picture of the medical care of preterm babies.

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Norwegian parents meet at Ministry of Health

The Norwegian parent organisation *Prematurforeningen* had written to the Ministry of Health about their concerns for babies born preterm and their parents. In a meeting in January at the Ministry of Health, they discussed these concerns with the Norwegian Secretary of State, Anne Grethe Erlandsen. In addition, Vilni Verner Holst Bloch was recently elected the new Chairman of *Prematurforeningen*. Congratulations!

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Journées des Soignants - Parents inspire healthcare professionals



For more than seven years, the French parent organisation SOS *Préma* has been organising *Journées des Soignants* (Days of Care) with the goal of gathering together parents of preterm infants and healthcare professionals. The intention behind this is to inform doctors, nurses and the entire staff in the NICU about the feelings, experiences, fears and needs of parents. This helps to initiate a mind change in neonatology towards family-integrated care.

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Scientific programme of jENS congress 2017 out now

We are delighted to contribute to the newly released scientific programme of the *2nd Congress of joint European Neonatal Societies (jENS)*. Come to Venice from 31 October to 4 November and listen to inspiring speakers at the EFCNI sessions on “Pain reduction – does a partnership with parents reduce pain in newborns?”, “Family centred developmental supportive care – evidence or philosophy?” or “Digital patient care – the new dimension?”, and much more.

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Data collection and documentation

Data collection and documentation are crucial for the implementation of evidence-based medical and care procedures. That is one of the reasons why EFCNI focuses on this important newborn health issue following our communication motto *11 months - 11 topics*. In the weeks of February, we have been featuring expert interviews, new research on the use of big data in neonatal care, and other related content. Follow us on social media and stay tuned!

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Data collection and documentation

EFCNI

Homogeneous data in a heterogeneous environment

All research projects depend on high-quality data collection and documentation. Dr Jennifer Zeitlin and Anna-Veera Seppänen from the *SHIPS* project gave an exclusive interview on the challenges of a pan-European project in this field and how preterm infants from all European countries may benefit from cross-border projects.

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Dr Nicholas Lack on Data collection and documentation

“As a statistician, I am a Numbers Man and of course the topic that I deal with is mind-blowing”, says Dr Nicholas Lack. This video clip marks the start of our interview series of *11 months - 11 topics*. Together with Professor Gérard Bréart, Dr Nicholas Lack is Chair of the Topic Expert Group on Data collection and documentation of the *European Standards of Care for Newborn Health* project.

[View more](#) (YouTube)



The Core Outcomes in Women’s and Newborn Health (CROWN) Initiative

The Core Outcomes in Women’s and Newborn Health (CROWN) initiative is an international initiative, led by journal editors, to harmonise outcome reporting in women’s health. The vision of the initiative is to encourage develop and promote core outcome sets for every condition in women’s and newborn health by 2030. Warm thanks to Professor Khalid Saeed Khan for providing us with a recap of CROWN.

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Simulated NICU: big data and tiny patients

DeRienzo and colleagues from *Mission Health System*, North Carolina, recently published a study in the *Journal of Perinatology* on the prediction of the need for health staff depending on specific conditions of a preterm baby by simulating a neonatal intensive care unit (NICU). Moreover, the relationship between length of stay, cost and clinical outcomes was analysed.

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Study reveals long-lasting effects of kangaroo mother care

Charpak and colleagues recently published a follow up study of their original work investigating the benefits of kangaroo mother care in the scientific journal *Pediatrics*. The study indicates that kangaroo mother care has significant long-term protective effects even 20 years after the intervention.

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Paediatric drug development: EMA consultation - guideline ICH E11(R1)

We would like to remind you of the public consultation on the *ICH E11(R1) guideline on clinical investigation of medicinal products in the paediatric population: Step 2b* by the European Medicines Agency (EMA). The document open for consultation is available by



clicking [here](#). Comments should be submitted using this [template](#).
The deadline for comments is **13 April 2017**. The completed
comments form should be sent to ich@ema.europa.eu

Mark your calendar

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

[Awareness days](#)



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