



Dear friends and supporters of EFCNI,

The new year started off well with our Parent Organisations Meeting, where about 100 participants from more than 30 countries met in the Munich area to exchange ideas, attend workshops and to network. Read more about this meeting and other interesting and recent EFCNI activities below.

Many thanks for your interest and support,

Your EFCNI Team

EFCNI



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PARENT ORGANISATIONS MEETING

A time-honoured tradition

In January, EFCNI hosted its meanwhile 15th Parent Organisations Meeting (POM) in Freising, Germany. From 25 to 27 January, about 100 participants from Europe, Africa, and North America (in total from more than 30 countries) discussed preterm health topics, shared knowledge and experiences, networked, and motivated each other.

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RECENTLY ELECTED AND EXTENDED BOARD

Welcome to the new EFCNI Parent Advisory Board

Following the elections at the Parent Organisations Meeting in Freising in January, it is our pleasure to announce the newly

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elected members of the future EFCNI Parent Advisory Board. Heartfelt congratulations to our eight European and two overseas Board Members. Warmest thanks also go to the former Board for their great support.

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WELCOME ON BOARD

Support for EFCNI's communication and administration teams

In spring, two new team members joined the EFCNI team: Communications Manager Sandra Hermsdorf and Team Assistant Coralie Lesenechal. A warm welcome to both of you!

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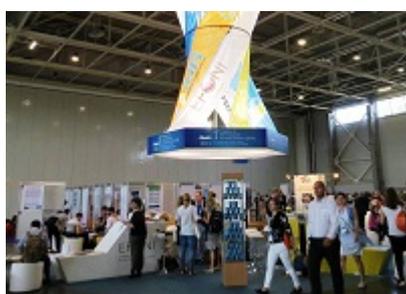
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A STRONG START FOR LITTLE HEROES

Successful campaign to raise awareness for preterm born babies will take place for the fourth time

In 2018, more than 170 hospital units in Germany, Austria and Switzerland participated in the third edition of A Strong Start for little Heroes and organised various events to support children and families affected by preterm birth around World Prematurity Day on 17 November. This year, the campaign will take place for the fourth time.

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CONGRESSES AND CONFERENCES

Meet EFCNI at these events in 2019

EFCNI will participate in a number of meetings, conferences, and congresses in 2019 and will be co-organiser of the 3rd Congress of joint European Neonatal Societies (jENS) in Maastricht. On our website we provide a detailed overview on all important neonatology events and marked those where you can meet EFCNI.

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Network

DEVELOPMENTAL CARE FOR LITTLE PATIENTS



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Family and Infant Neurodevelopmental Education (FINE) training in Romania

“Preterm babies and ill newborns are properly treated from the medical point of view, but the human dimension is often neglected”, says Corina Croitoru, President of Unu si Unu. By supporting FINE trainings in Romanian hospitals, her organisation aims to change this situation.

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BOOK REVIEW

Breastfeeding and breast milk – from biochemistry to impact

The book explores the multifaceted, multidisciplinary, and complex world of breastfeeding, breast milk, and lactation. Overall, 30 distinguished authors from all over the world, each a specialist within their field, provide a factual, scientifically robust overview of the key topics.

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FIRST WORLD NIDCAP DAY 2019

Raising awareness for infant- and family-centred developmental care

On 20 March, the NIDCAP Federation International (NFI) celebrated the first World NIDCAP Day. The aim is to raise awareness for the importance of NIDCAP, improving the hospital stay of newborns and families worldwide. NIDCAP is a child and family-centred programme promoting individualised developmental care for newborns and their families. It positively effects the healthy development of preterm and ill babies.

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Science



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NEW PUBLICATION

A parental view on cluster randomised controlled trials in newborn babies

In a recent article, published in the scientific journal ACTA PAEDIATRICA on behalf of the EFCNI Parents Advisory Board, gives recommendations about the conduct of cluster randomised controlled trials in babies in particular.

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FINAL PROJECT MEETING IN ROME

Screening to Improve Health in Very Preterm Infants in Europe (SHIPS) project

At the end of January, all members of the SHIPS (Screening to Improve Health in Very Preterm Infants in Europe) project met in Rome, Italy, for the last project members meeting. The project – originally planned to end in August 2018 – had been extended until the end of January 2019.

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MEETING OF RECAP PRETERM CONSORTIUM

RECAP preterm brings together European child to adult cohorts and a group of highly experienced organisations

In January, the RECAP preterm consortium (Research on European Children and Adults born Preterm) met in Rome to wrap up and evaluate the project's second working year. 85

professionals from various fields of medical research gathered to discuss the project's milestones and deliverables.

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REGULATORY SCIENCE STRATEGY

Call for expert feedback

The European Medicine Agency (EMA) has published its draft on a “Regulatory Science to 2025” strategy for public consultation. Stakeholders are now invited to send their comments by 30 June 2019 via an online questionnaire.

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REGISTER NOW

3rd Congress of joint European Neonatal Societies (jENS) takes place in Maastricht

Since the launch of the jENS congress in 2015, EFCNI has been a member of the organising societies and the executive committee. At the 3rd edition, EFCNI will again present pre-courses and several own scientific sessions covering topics that are important and relevant to parents.

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European Standards of Care for Newborn Health



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INFORMATION AT A GLANCE

Brochure about European Standards of Care for Newborn Health

Would you like to know more about the newly released European Standards of Care for Newborn Health that will shape the future of newborn health in Europe? Then our information brochure on the standards is just right for you.

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TRAINING FOR PARENT ORGANISATIONS

Workshop on the implementation of the standards



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Training and knowledge about the European Standards of Care for Newborn Health are key for their implementation in the different countries. This is why EFCNI was thrilled to recently welcome another group of parent organisation representatives from 12 countries for a training workshop.

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STANDARDS OF CARE FOR NEWBORNS

How Norway implements high-quality care

Our Norwegian partner parent organisation Prematurforeningen chaired a seminar at Rikshospitalet, Oslo, as a national follow-up of the launch of the European Standards of Care for Newborn Health. Experts in neonatology offered a broad overview of care procedures in Norway and gave insights into recent achievements, ongoing implementation of quality care and pointed out, where improvements are feasible.

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CAMPAIGN ENTERS 4TH YEAR

11 Months – 11 Topics to promote the European Standards of Care for Newborn Health

The 4th edition of the campaign “11 Months – 11 Topics” sheds light on the newly released standards and provides new features like an overview on the standard topics, whole sets of standards for download as well as selected standards “in brief”.

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DATA COLLECTION AND DOCUMENTATION

Registries of babies treated for Retinopathy of Prematurity (ROP)

Within our monthly topic of data collection and documentation in February, we featured the Retina.net ROP registry from Germany and the SWEDROP registry from Sweden and talked to the medical experts in charge.

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BIRTH AND TRANSFER

Delaying cord clamping – beneficial for ill or preterm born babies

Focusing on the topic of birth and transfer, we talked to Rianne Rotink, CEO of the start-up Concord Neonatal. They introduced a new solution enabling medical staff to provide care immediately after birth with the umbilical cord still intact – until the baby is stable and breathing on its own.

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