



## Activities and Milestones 2020

December 2020



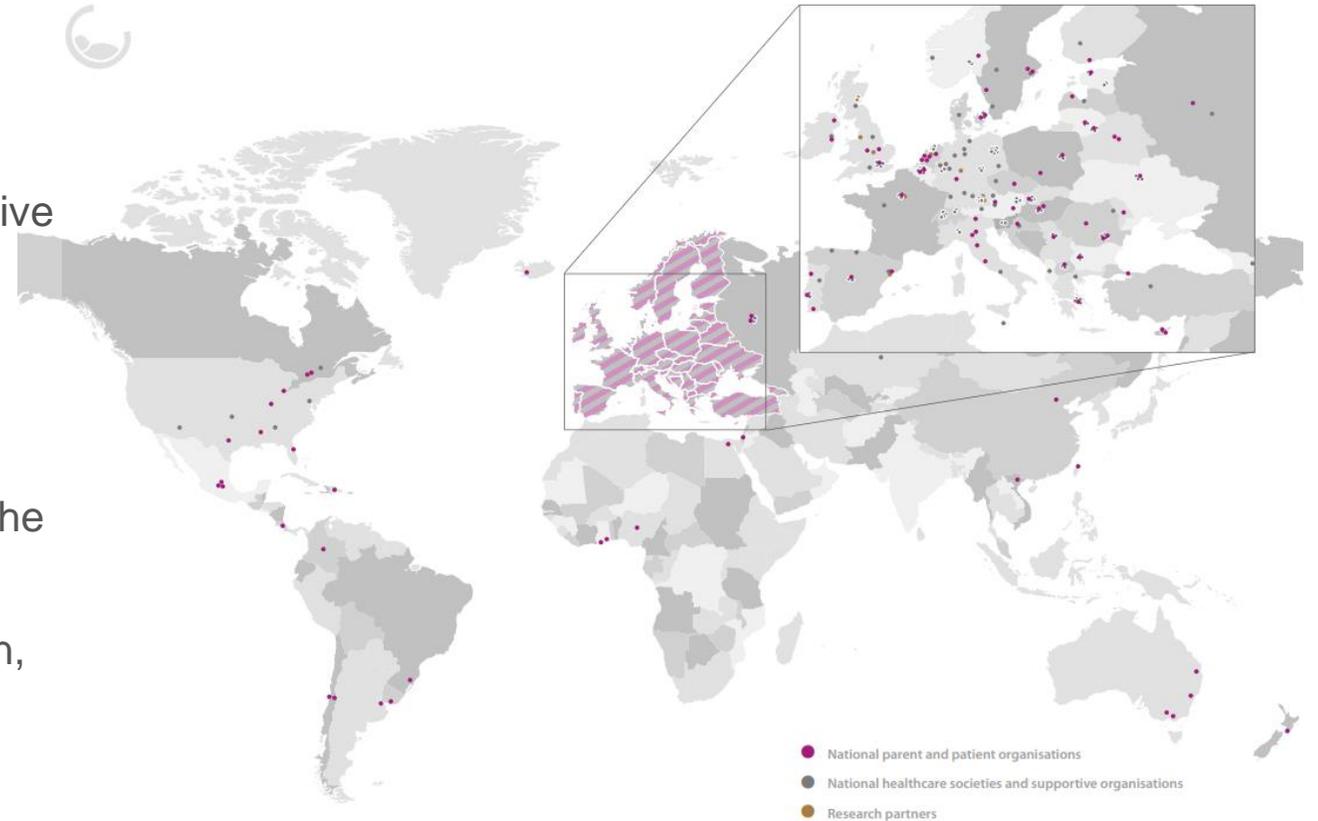
## Overview

1. EFCNI – A strong partnership with different stakeholders
2. European Standards of Care for Newborn Health
3. ICHOM project
4. Research projects
5. Roundtable, expert meetings and position papers and policy work
6. Publications and information material
7. EFCNI Academy
8. GLANCE
9. Communication and Campaigning
10. Conferences and Congresses

# EFCNI – A strong partnership with different stakeholders

## Establishing a powerful network

- > 100 parent & patient organisations worldwide
- > 190 (inter)national healthcare societies and supportive organisations
- > 10 research partners
- > 60 countries
- Supranational organisation (e.g. WHO, Unicef, Save the Children)
- European institutions (e.g. EU parliament, commission, European Medicines Agency)
- G7 preparation meeting



➔ New parent organisations from Kazakhstan, Tansania, Costa Rica, South Africa, Russia and Sudan in our network (to name a few)



# Supporting partners (as of December 2020)

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Platinum partner:  GE Healthcare

Premium partner:     

Silver partner:   

Bronze partner: 

Project partner:     

Other:



# Empowering parents - key drivers of today: The EFCNI Parent Organisations Summit

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- About 70 representatives from > 30 countries
- Annual meeting for:
  - Training in communication, fundraising, advocacy and understanding research and selected health topics
  - Sharing expertise and best practice examples
  - Knowledge increase: Presentations by stakeholders and healthcare professionals
  - Developing common campaigns and projects, e.g. World Prematurity Day, European Standards of Care for Newborn Health, GLANCE – Global Alliance for Newborn Care



Parent  
Organisations  
Summit  
January 2020

# Empowering parents – key drivers of today: EFCNI training workshops throughout the year

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- Selected participants according to workshop level and topic
- Small groups, interactive learning, high-quality
- Second Level IV workshop for the European Standards of Care for Newborn Health in February 2020
- Due to COVID-19 pandemic no further workshops were planned for 2020 as well as for the first half year of 2021.
- Since March 2020: regular update calls exclusively for our parent community on a two weeks basis with focus on questions and activities regarding COVID-19
- Digital webinars for parent community. First workshop for new members: „How to build up a national parent organistaion“ with Silke Mader in November 2020.

## Upcoming workshops

- Parent Organisations Summit postponed to July 2021: digital solution under review
- Digital workshops for parent community on various topics



Level IV workshop for the European Standards of Care for Newborn Health in February 2020



# Empowering the patient community during a pandemic

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- Realising that the parent community were facing many fears and had many questions at the beginning of the pandemic, EFCNI and GLANCE initiated regular parent calls on a two weeks basis to:
  - Provide scientific facts on COVID-19 and the impact on pregnant women and preterm born children
  - Empower the parent community in a difficult time and provide mutual support
  - Provide argumentation based on scientific resources for infant and family centred developmental care and zero separation of parents and child even in times of a pandemic
  - Exchange on projects and celebration of successes
  - Motivate für joint campaigns (participation in campaigns initiated by EFCNI increased significantly)
- Parent calls will be continued on a regular basis in 2021



# Milestones in improving maternal and newborn health

2008  
Declaration of Rome



Catalogue of  
10 demands for  
preterm infants

2010  
EU Benchmarking Report



Key finding:  
Different practices,  
lack of standards

State of the art

2011 / 2012  
European White Paper  
& Call to Action



Background,  
challenges,  
recommendations

Need for change

2013 - 2019  
European Standards of Care  
for Newborn Health



Standards to  
increase  
quality of care

Establishment  
of reference

2019 and beyond  
Rollout, implementation



Learn and share for better care

Bringing theory  
into practice

National  
implementation



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european standards of  
care for newborn health

EFCUNI european foundation for  
the care of newborn infants



## Overview of the European standards of care for newborn health



## Thanks to our supporting industry partners in 2020

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abbvie



Nestlé  
NutritionInstitute

Dräger was a project partner from 2013 to 2015

Shire was a project partner from 2014 to 2018

Philips Avent was a project partner from 2014 to 2019

Philips was a project partner from 2018 to 2019

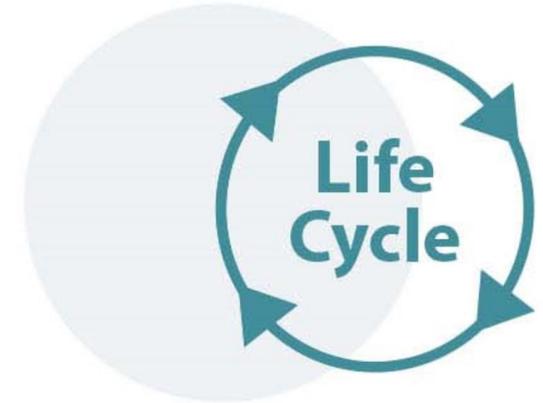
Baxter was a project partner from 2017 to 2019



# Lifecycle of the standards

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- 3, 5, and 10 years lifecycle



- About 20 standards
- Open consultation phase was planned but was finally skipped because of the actual pandemic situation
- Authors revise the standards
- Editing
- Voting of the new standards
- Information to supporting organisations
  
- Launch at the jENS congress 2021 in Athens



## New standards under development

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Topics and authors of new standards:

- **Cord Management at the delivery of preterm infants.** First author Heike Rabe; topic expert group Birth & transfer.
- **Cord Management at the delivery of term infants.** First author Ola Andersson; topic expert group Birth & transfer.
- **Standards for the diagnosis and management of Necrotising Enterocolitis (NEC).** First author Minesh Khashu; topic expert group Medical care & clinical practice
- **Quality indicators.** First author James Webbe; topic expert group Patient safety & hygiene practice
- **Error management/safety.** First author Jens Schwindt; topic expert group Patient safety & hygiene practice
- **Vaccinations for preterm infants.** First author Christoph Härtel; topic expert group Follow-up & continuing care



Launch of new standards at jENS congress 2021



## Translations of materials in 2020

- Translation of all standards into Italian
- Factsheet preterm birth into German



european standards of  
care for newborn health

**EFGONI**

european foundation for  
the care of newborn infants

# Social media campaign: 11 Months – 11 Topics

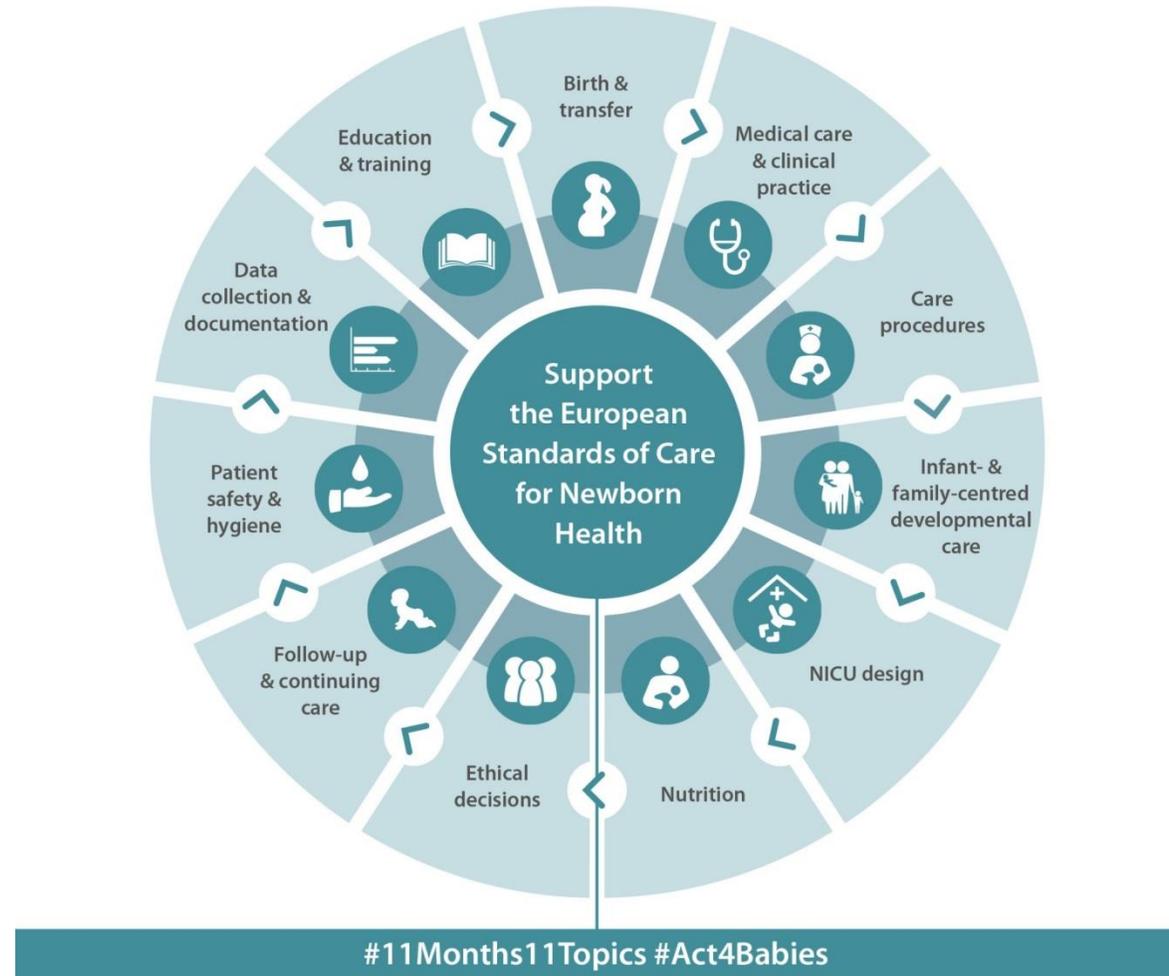
## Aim

- Raise awareness about eleven core topics covered in the project
- Support the dissemination and implementation of the standards

## Realisation

- February to December, every month another standard topic
- Sharing of publications, research news, interviews, guest articles, best practice examples etc. on social media/online communications

Target group: HCPs, policy makers, laypersons



**Patient safety & hygiene practice**

*"Washing my hands before entering the baby's room. It became a habit like brushing my teeth before I go to bed! So simple, so normal!"*

Nathalie de Beuleker, Vlaamse Vereniging voor Ouders van Couveusekinderen - VVOC, Belgium

**Medical care & clinical practice**

**Postnatal support of transition and resuscitation**

Support of postnatal transition to extrauterine life is based on internationally consented guidelines, which are based on scientific evidence, and is performed in an appropriate structured and equipped environment by trained personnel.

**SUPPORT PARENTS IN THEIR ROLE AS PRIMARY CAREGIVERS**

#NewbornHealthReloaded #Act4Babies



# Implementation of the standards: EFCNI's digital roadshow in 2020

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## Digital presentations at

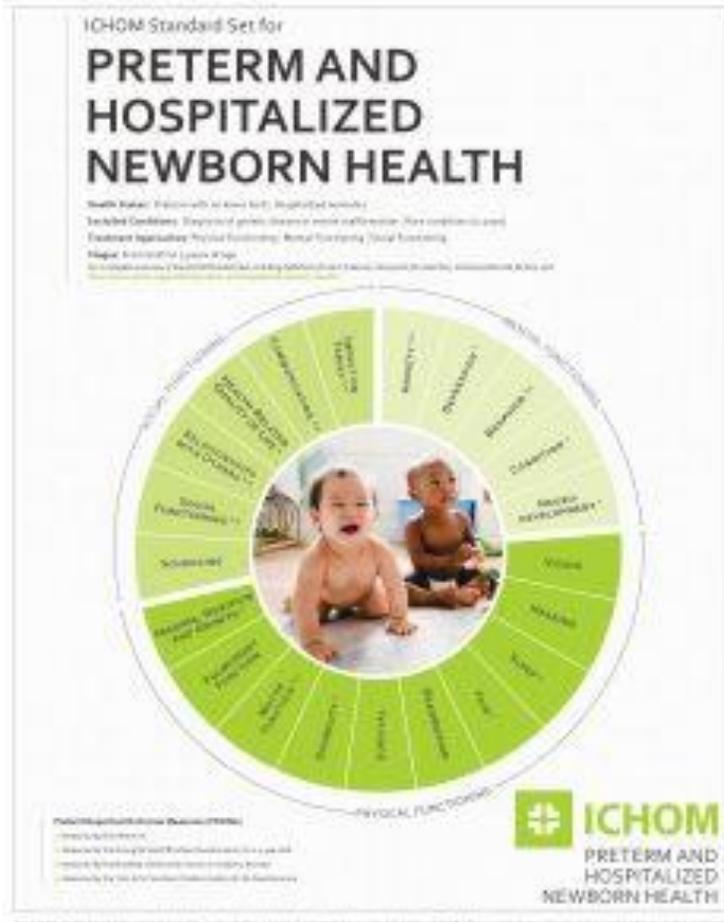
- REaSoN Neonatal Meeting, University of Warwick, Coventry: 30th June 2020
- EAPS congress: participation at 3 sessions: 16th and 19th October (Silke Mader and Luc Zimmermann)
- Health and social aspects of COVID-19 pandemic – a Global Perspective, UENPS and IPOkRATES panel: 29th October 2020
- Virtual SIGNEC 2020 & Neonatal Quality Improvement Conference: 29th October 2020
- GNPI session : 31st October 2020
- World Prematurity Day congress at Nestlé global (internal event): 16th November 2020
- SIN congress: 16th November 2020
- Aswan Conference, Egypt: 19th November 2020
- 10th UENPS congress: 20th November 2020



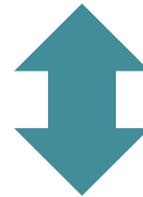
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# ICHOM - Measuring health outcomes for hospitalised newborns are launched



Create a set of **reference standards**.  
Implementation of these standards will help improving the care of preterm/ ill newborn infants



Measuring **health outcome**.  
Defining global outcome standards that really **matter to patients**. Can be used to measure if the implementation of the European standards has improved the health outcome of infants



- Patient-reported outcomes are included to capture symptom burden, functional status and health-related quality of life
- Time points and sources of data collection are clearly defined to ensure comparability of results
- **Health outcomes measurement available in: 2021**



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# Research participation

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2017-2021: **RECAP preterm** – Research on European Children and Adults born Preterm  
(EU Horizon 2020: grant agreement No 733280)



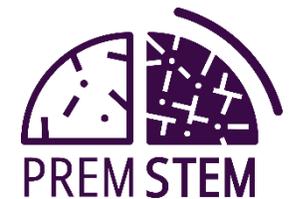
2018-2023: **conect4children** – Collaborative network for European clinical trials for children  
(Innovative Medicines Initiative 2 Joint Undertaking; EU Horizon 2020: grant agreement No 777389. The Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA.)



2020-2023: **TREOCAPA** - Prophylactic treatment of the ductus arteriosus in preterm infants by acetaminophen  
(Study conducted under the conect4children funding frame)



2020-2024: **PREMSTEM** - Brain injury in the premature born infant: stem cell regeneration research network  
(EU Horizon 2020 funding)



# RECAP preterm – Key objectives

- *RECAPpreterm develops a sustainable data sharing platform for research on children and adults born preterm based on national and European cohorts. For this, RECAP preterm Cohort Platform will pool data from 20 population-based cohorts of children and adults born very preterm. Larger sample sizes of combined cohorts and the added value of their geographic and temporal diversity will allow for evaluation of broader questions on care and outcomes. The project was allowed a cost-free prolongation and will end on 31<sup>st</sup> August 2021.*

**EFCNI advises the different Workpackages and mobilises parents to participate in the project's delphi processes for e.g. the development of recommendations for a core dataset for researchers to use when planning and conducting cohort studies into preterm birth. EFCNI supports the new e-cohort HAPP-e set-up under RECAPpreterm, which looks into quality of life of adults born preterm with the help of an annual online questionnaire. EFCNI leads the Workpackage Dissemination, Translation and *Sustainability*, including organisation of a digital Winter/ Summer School in 2021, the explanation of the project to the parent community and general public, the translation of publications into lay language for broader knowledge share, or the development of a policy brief and project brochure.**



# Conect4Children (c4c) – Overview and 2020 milestones

*A large collaborative European network that aims to facilitate the development of new drugs and other therapies for the entire paediatric population. The project is building capacity for the implementation of multinational paediatric clinical trials whilst ensuring the patients and their families needs are met. A novel collaboration between the academic and private sectors.*



→ **EFCNI is involved as a third party: responsible for inputs into PPI and communication tasks across several work packages**

## 2020 milestones

- Leading the creation and development of a c4c newsletter to be sent regularly to members of the c4c PPI database
- Co-developing and presenting EFCNI's experience in PPI at a c4c Patient Organisation training with over 40 organisations throughout Europe
- Participation in regular PPI calls and contributing to c4c monitoring activities of the TREOCAPA study



# TREOCAPA Study – Overview and 2020 milestones

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*TREOCAPA is a Phase II and III European multicentre, double-blind randomised trial being conducted to find out whether the preventive use of paracetamol in preterm infants during the first five days of life to close the ductus arteriosus is safe, effective and may reduce the risk of prematurity associated complications.*

→ **EFCNI is involved as a third party responsible for PPI and communication activities throughout the trial**

## **2020 milestones**

- Preliminary set up of a PAB
- Monthly PPI meetings with the study team
- Draft communication strategy available
- One-page summaries of patient information sheets finalised for both Phase II and Phase III
- Input into a video on the study for general use
- Input into a bi-monthly newsletter for all study sites and national hubs



# PREMSTEM– Overview and 2020 milestones

*PREMSTEM is a pre-clinical study involving international researchers, patient organisations, a pharmaceutical company and an imaging technology company to develop better diagnosis of preterm brain injury (EoP) and a stem cell therapy to repair this damage.*

→ **EFCNI is leader of Work Package 6 “Increase visibility and impact on health and society by developing a dissemination/exploitation strategy”**

## 2020 milestones

- Establishment of a PCAB & 1<sup>st</sup> meeting
- Communication&dissemination strategy finalised and available 7 months ahead of given deadline
- Input into the conception of and set up of a co-creation process
- Presentations at regular ExCom meetings
- Organisation of bi-annual WP6 meetings with all relevant partners
- Regular input into PREMSTEM social media and sharing on EFCNI channels and PREMSTEM web page on EFCNI



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# Previous activities in the field of parenteral nutrition



Agreement on the importance of adhering to the **ESPghan guidelines**



**2018**  
Expert Roundtable  
(international)



**2019**  
Position Paper

Background information and **need to implement guidelines** on national level

Call to action



**2019**  
Expert Roundtable  
(German)

Creation of **German network**

Establishment of **survey** to assess status quo in Germany

Network &  
Status Quo

**2020 +**  
Nationwide survey



Evaluation of situation in Germany and current challenges, **identification of barriers** in practice

Survey

**2021**

**Handbook** with recommendations and practical advice to improve primary care

Handbook

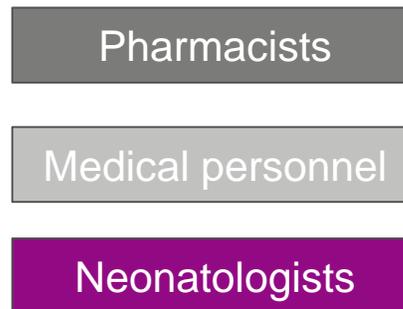
# Survey

## Aim:

1. To identify barriers of implementing ESPGHAN guidelines in clinics and pharmacies
2. To find solutions in order to overcome these barriers and to improve care



## Online-Survey



Distributed via network  
(ADKA & GNPI)  
to health care professionals

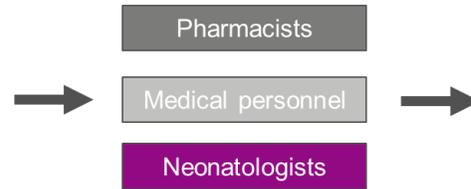
- Launch in March 2020
- 558 contacts (clinics & pharmacies)
- 3 reminders (respecting Covid-19 situation)
- Completion of data collection in September 2020
- 236 completed surveys



# Expert advisory group and meetings



Online-Survey



**Data analysis**  
(September 2020 – actual)

**Meetings with expert advisory group**  
(September 2020 – actual)

## Members of expert advisory group:

Professor N. Haiden (University Vienna)

Professor C. Fusch (GNPI, Clinic Nuremberg)

Dr. B. Piening (Charité Berlin)

Dr. J. Babl (ADKA, Pharmacy LMU Munich)

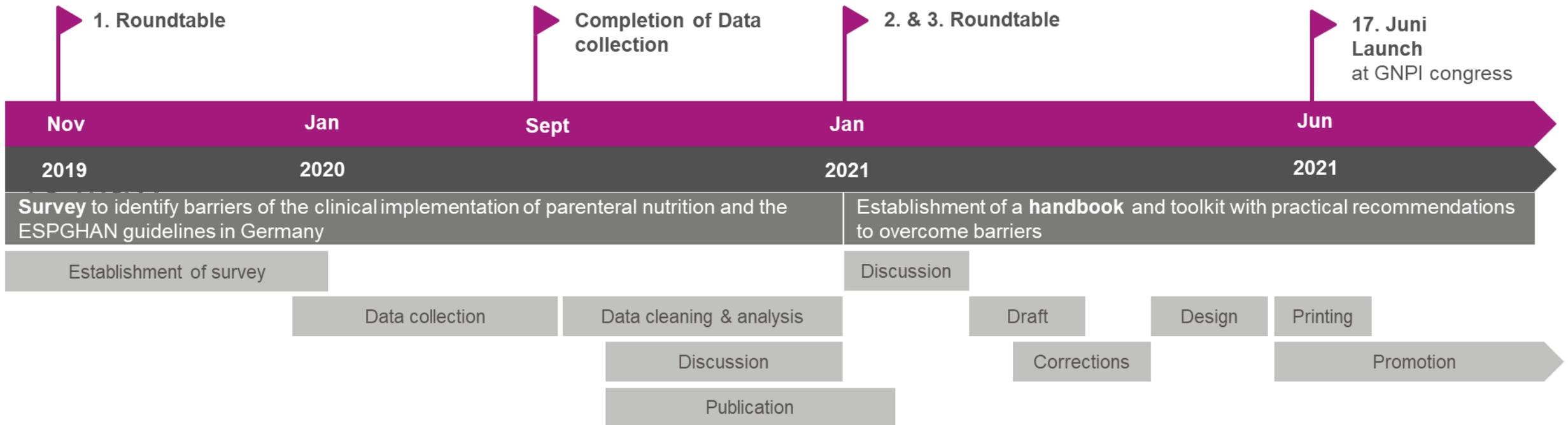
Dr. S. Schubert (ADKA, Pharmacy Mainz)

## Purpose of meetings:

- Discussion of procedures and statistical assumptions
- Discussion of results
- Discussion on barriers
- ‘Transforming’ barriers into practical advice and solutions
- Feedback on manuscript
- Support for roundtables



# Next steps and outlook



# Human Milk Regulation

- Advocating the need for regulation of donor human milk and human milk banking in the European Union
- See: [www.efcni.org/human-milk-regulation](http://www.efcni.org/human-milk-regulation)
- Developed one-pager: “Preterm infant health and human milk”
- Developed policy recommendations: “Making Human Milk Matter – The need for regulation in the European Union”
  - 46 professional healthcare societies and 32 parent organisations support these recommendations
- Commentary in scientific journal in preparation
- Continuing policy work in 2021 (and beyond)
- Cooperation partners: EMBA, ESPR, ESPGHAN, UENPS
- Industry partner: Prolacta



Preterm infant health and human milk  
The need for regulation in the European Union

Human milk helps to reduce complications of preterm birth, e.g.

**Save the date!**  
**Making Human Milk Matter**  
The need for regulation in the European Union  
Policy Recommendations

Hosted by MEP Professor Dr. Angelika Niebler and MEP Radka Maxová  
Digital Workshop: <https://bit.ly/3ozLFUJ>  
Wednesday, 18 November 2020  
2:00-3:30 p.m. (CET)  
Language: English

Preterm birth remains the main predictor of life-long disability.  
Preterm birth remains the main predictor of life-long disability.  
Preterm birth remains the main predictor of life-long disability.

#### Agenda

2:00 p.m.	<b>Welcome and opening remarks</b> MEP Professor Dr. Angelika Niebler & MEP Radka Maxová
2:10 p.m.	<b>Presentations part 1</b> <b>Why human milk should matter to policy makers: key facts</b> Professor Hans van Goudoever, Founder and Director Dutch National Human Milk Bank; Emma Children's Hospital, Amsterdam UMC, The Netherlands
	<b>Human milk donation and banking</b> Radka Maxová, PhD, President Human Milk Bank Foundation, Poland; research, Regional Human Milk Bank, Holy Family Hospital, University of Warsaw, Poland
	<b>EU regulation</b> European Foundation for the Care of Newborn Infants (EFCNI) Directors Board, European Foundation for the Care of Newborn Infants

**Making Human Milk Matter**  
The need for regulation in the European Union  
Policy Recommendations

An initiative of the EFCNI Working Group on Human Milk Regulation.

Collaborating organisations:



# Human Milk Regulation - Digital policy workshop on 18 November 2020

- Digital workshop and launch of our policy recommendations “Making Human Milk Matter – The need for regulation in the European Union”
- Support by the EU Parliament: co-hosted by the Members of Parliament Prof. Dr. Angelika Niebler and Radka Maxova
- High level experts highlighted the need for regulation of donor human milk and milk banks in Europe



**Making Human Milk Matter**  
The need for regulation in the European Union

*Human milk banks fulfill a crucial task in providing donated human milk to vulnerable newborns who cannot be fed with mother's own milk due to various reasons. However, donor human milk and human milk banks are currently not regulated at EU level. A regulatory framework would ensure a minimum standard and equitable access for preterm, sick, and low birthweight infants. It is therefore with great pleasure that I support the policy recommendations developed by the EFCNI Working Group on Human Milk Regulation.*

**Policy Recommendations**

Professor Dr. Angelika Niebler  
Member of the European Parliament



**Making Human Milk Matter**  
The need for regulation in the European Union

**Policy Recommendations**

An initiative of the EFCNI Working Group on Human Milk Regulation. **EFCNI** european foundation for the care of newborn infants

Collaborating organisations: **emba** **ESPGHAN** **European Society for Paediatric Research** **UEMS** Union of European Geriatric & Gerontological Societies



**EFCNI** european foundation for the care of newborn infants



**ESPGHAN**



**UEMS** Union of European Geriatric & Gerontological Societies

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# Communications update: publications

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## EFCNI published the following articles in 2020

- *Tackling bronchopulmonary dysplasia (BPD) to improve preterm health – A call for family-centred care at World Prematurity Day 2020.* **Zimmermann L, Kostenzer J, Mader S.**, Am J Physiol Lung Cell Mol Physiol 319: L867–L870, 2020.
- *Parents’ ratings of post-discharge healthcare for their children born very preterm and their suggestions for improvement: a European cohort study,* Anna-Veera Seppänen, Priscille Sauvegrain, Elizabeth S. Draper, Liis Toome, Rym El Rafei, Stavros Petrou, Henrique Barros, **Luc J. I. Zimmermann**, Marina Cuttini and Jennifer Zeitlin, *Pediatr Res* (2020).  
<https://doi.org/10.1038/s41390-020-01120-y>
- *“Zero separation” keeping babies and parents together,* **Mader S. and Fuegenschuh S.**, *Global Cause UK*, 2020,  
<https://www.globalcause.co.uk/maternal-health/zero-separation-keeping-babies-and-parents-together/> (24.11.2020).
- *Welt-Frühgeborenen-Tag 2020: Unterstützung für Frühgeborene und deren Familien in Zeiten der Pandemie,* **Fuegenschuh S.**, *Kinderkrankenschwester*, 2020
- Interview on the topic *COVID-19 & The NICU: #zeroseparation* published in the Neonatal Network Journal, **Mader S. and Fuegenschuh S** (2020)
- *Creating Room and Opportunities On Wards for Newborns and their families - The CROWN-initiative,* N.R. (Nicole) van Veenendaal, MD, MPH· N.H.M. (Nanon) Labrie, PhD· **Silke Mader**, A.A.M.W. (Anne) van Kempen, MD, PhD, S.R.D. (Sophie) van der Schoor\*, MD, PhD, Professor J.B. (Hans) van Goudoever, MD, PhD (2020)



# Communications update: publications

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## EFCNI was cited in the following articles in 2020

- *World health observances in November 2020: adult and pediatric pneumonia, preterm birth, and chronic obstructive pulmonary disease in focus* 2020, Casado F. and Morty R.E., Am J Physiol Lung Cell Mol Physiol 319: L854–L858, 2020.
- *World Prematurity Day: improving survival and quality of life for millions of babies born preterm around the world*, Lincetto O. and Banerje A., Am J Physiol Lung Cell Mol Physiol 319: L871–L874, 2020
- *World Prematurity Day 2020: “Together for babies born too soon—Caring for the future”*, Gunjak M. and Morty R.E., Am J Physiol Lung Cell Mol Physiol 319: L875–L878, 2020.



# New/updated materials 2020

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## New materials:

- Factsheet „RSV“ (German)
- Factsheet „Retinopathy of Prematurity (ROP)“ in English and German
- Factsheet „Thermoregulation in preterm born babies“ in English
- Bindung und Pflege von Frühgeborenen (English)
- Brochure „Breastmilk for preterm babies“ in English
- Factsheet Preterm Birth in German
- Factsheet Parenteral Nutrition in Hungarian
- Factsheet The first 1000 day in Hungarian

## Updated/revised materials:

- EFCNI corporate brochure
- Position paper „RSV“
- Brochure „Breastmilk for preterm babies“ in German



Factsheets



Position papers & handbooks



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EFCNI  
Academy

*learn and share for better care*

EFCNI european foundation for  
the care of newborn infants



## The EFCNI Academy



# EFCNI Academy - Approach

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- Standardised, high-quality education and training programmes
- Ensuring access to evidenced-based, harmonised (medical) treatment and care for preterm and ill born babies throughout Europe and beyond.
- Target group: healthcare professionals in neonatology (long-term: obstetrics/perinatal)
- Fast, efficient and in high quality for everybody (potentially: several levels)
- Small groups (max 50 participants) ensuring interactive learning and hands on participating. Affordable fee for participants
- Digital solutions in form of webinars during the time of COVID and beyond
- Identifying a pool of high-level trainers (well-known experts with excellent teaching skills) in Europe and beyond
- Using „train the trainer“ and/or „peer-to-peer“ support to scale down into countries
- Co-operation: Internationally renowned universities, Key European Healthcare Societies, Scientific Committee including experts in neonatal/perinatal care, industry partners and publishers can support trainings with grants



# EFCNI Academy: information material for healthcare professionals

- New factsheets targeted for healthcare professionals:
  - The **Retinopathy of Prematurity factsheet** provides information on ROP, prevention, diagnosis, treatment and recommended follow-up routines at a glance. It is available for download in English and German.  
<https://www.efcni.org/activities/efcni-academy/retinopathy-of-prematurity-rop/>
  - The **Thermoregulation in preterm born babies factsheet** provides information on the aspects of regulation of body temperature of newborn care and how temperature control can be achieved through various care practices especially for preterm born babies.  
<https://www.efcni.org/thermoregulation-in-preterm-born-babies/>



## Retinopathy of Prematurity

**What is Retinopathy of Prematurity?**

Retinopathy of prematurity (ROP) is one of the most common avoidable causes of blindness in children.<sup>1</sup> It is estimated that, out of 15 million babies born preterm (born before 37 completed weeks of gestation) every year,<sup>2</sup> about 15 to 20% are affected by ROP.<sup>3</sup>

ROP is a retinal<sup>4</sup> disease that primarily affects very preterm babies born before 31 weeks of gestation.<sup>5</sup> Incidence of ROP has increased in recent years in countries where there is an advancement in neonatal care.<sup>6</sup> In middle- and low-income countries with less advanced neonatal care, ROP also occurs in more mature babies.<sup>7</sup>

During development in the womb, neurons and vessels in the eye grow outwards from the optic nerve head<sup>8</sup> and fully cover the retina by full-term.<sup>9</sup> When a baby is born preterm, the normal development is interrupted. As the retina develops late in pregnancy, this leads to a partly avascular retina. At room air, or in an incubator, the preterm baby is exposed to a much higher oxygen concentration than in the womb. As a consequence, developing vessels in the retina stop growing resulting in peripheral avascular areas. The tissue and the neurons in the avascular retina are subsequently not provided with enough nutrients and oxygen, which over the course of time leads to an increased expression of vascular endothelial growth factor (VEGF), and other factors. Unfortunately, these factors subsequently trigger an abnormal growth of vessels. The vessels grow into the vitreous (the gelatinous mass between the retina and the lens) which can even pull off the retina, referred to as retinal detachment. This ultimately leads to vision loss or blindness in the baby.<sup>9</sup>

**What are the risk factors for developing ROP?**

The more preterm a baby is born, the sooner the growth of vessels into the retina is interrupted and the larger the area that remains without vessels.

These are the risk factors for developing ROP that requires treatment:<sup>10</sup>

- Low gestational age and birth weight
- Postnatal oxygen supplementation
- Anaemia
- Thrombocytopenia
- Infections
- Long-term parenteral nutrition
- A complicated clinical course

**What can you as a healthcare professional do to help prevent a baby from developing ROP needing treatment?**

As described above, mainly very small and sick preterm babies, and babies with an unstable clinical course develop ROP that requires treatment. Certain measures can be taken to help prevent severe ROP stages:<sup>11,12</sup>

- Manage oxygen carefully, avoid hyperoxia through implementation of appropriate alarm levels, education of healthcare professionals, oxygen titration guidelines and sufficient number of skilled attendants
- Minimise rates of infections
- Minimise blood sampling and minimise transfusions
- Provide mother's own milk
- Provide optimised nutrition to improve postnatal growth
- Provide supportive individual developmental care
- Support skin-to-skin care

<sup>1</sup>The retina is the light sensitive layer in the back of the eye that sends visual signals to the brain.  
<sup>2</sup>Optic nerve head is the location where the neurons of the retina exit the eye.

**What is thermoregulation in babies?**

Temperature has been studied as a fundamental physiological parameter.<sup>13</sup> The normal body temperature range for the human body is 36.5°C to 37.5°C. The relative risk of mortality is 10% for newborn babies in order to prevent hypothermia (a low body temperature) and hyperthermia (a high body temperature). Hypothermia is defined by the temperature of less than 36.5°C with 3 different categories:<sup>14</sup>

- Mild hypothermia: 36.0°C to 36.5°C
- Moderate hypothermia: 35.0°C to 36.0°C
- Severe hypothermia: 32.0°C to 35.0°C

For babies born preterm, it is important to maintain a normal body temperature. The relative risk of mortality is 10% for newborn babies in order to prevent hypothermia (a low body temperature) and hyperthermia (a high body temperature). Hypothermia is defined by the temperature of less than 36.5°C with 3 different categories:<sup>14</sup>

**4 out of 10 babies still arrive cold into the NICU!**

**t for preterm born babies?**

Hypothermia is independently associated with a higher risk of mortality, a negative effect on survival, and an increased risk of morbidity.<sup>15</sup> The smaller and more preterm the baby is, the higher the risk of morbidity. Globally, hypothermia upon NICU admission ranges from 26% to 74% in preterm babies.<sup>16</sup>

Every 1°C decrease under 36°C in neonatal temp results in:

- 28% increase in mortality
- 11% increase in morbidity

Temperature can be controlled after birth is one of the major aspects to get right in preterm babies.

**Keeping a baby's temperature within the normal range, is one of the most important things that healthcare professionals can do when a baby is born. It is especially important in the first few hours after birth, particularly for very premature or small babies. Hypothermia is associated with increased mortality and morbidity, and so avoiding it is an essential part of neonatal care.<sup>17</sup>**

son PhD BM BSc FRCPCH  
Neonatologist, Honorary Senior Clinical Lecturer in Neonatal Medicine, Clinical Lead  
Department of Neonatal Medicine, Princess Anne Hospital, Southampton, UK

**EFCNI** European Foundation for the care of newborn infants

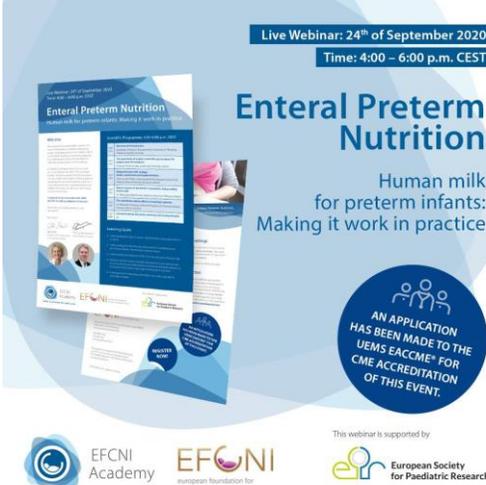
**EFCNI Academy** Learn and share for better care

**EFCNI** European Foundation for the care of newborn infants



# EFCNI Academy: activities in 2020

- Webinar Series on Enteral Preterm Nutrition:
  - Webinar 1: Human Milk for preterm infants: Making it work in practice
  - Webinar 2: Human Milk Oligosaccharides: The magic ingredient
  - Webinar 3: Human Milk for preterm infants: Achieving optimal growth and outcomes
- CME accredited
- Target group: medical specialists and nursing staff working in the field of paediatrics, neonatology or infant nutrition
- ~80 participants each (international audience)
- Recorded videos will be available on website as e-learning (as of March 2021; CME application ongoing)
- Supported by ESPR
- Industry partner: Prolacta



Live Webinar: 24<sup>th</sup> of September 2020  
Time: 4:00 – 6:00 p.m. CEST

**Enteral Preterm Nutrition**

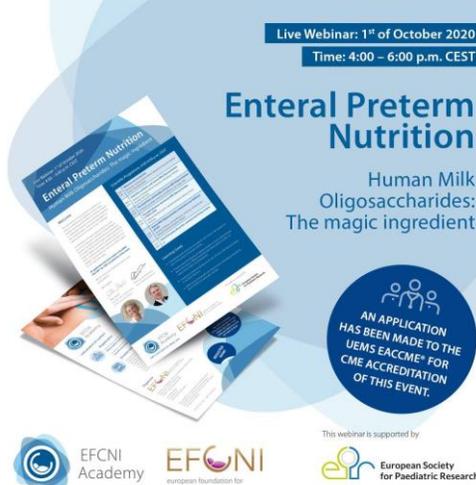
Human milk for preterm infants: Making it work in practice

AN APPLICATION HAS BEEN MADE TO THE UEMS EACCME<sup>®</sup> FOR CME ACCREDITATION OF THIS EVENT.

This webinar is supported by

EFCNI Academy  
European Foundation for the Care of newborn infants

ESPR  
European Society for Paediatric Research



Live Webinar: 1<sup>st</sup> of October 2020  
Time: 4:00 – 6:00 p.m. CEST

**Enteral Preterm Nutrition**

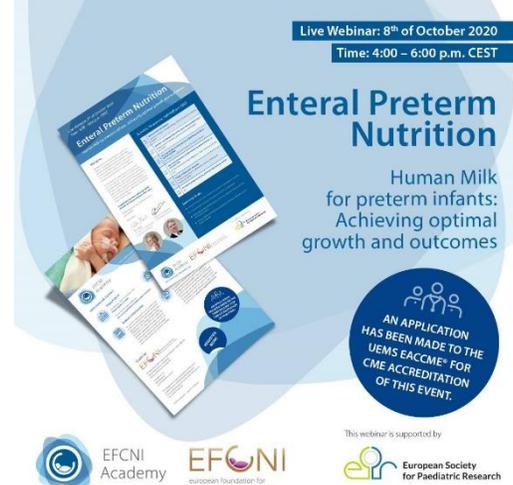
Human Milk Oligosaccharides: The magic ingredient

AN APPLICATION HAS BEEN MADE TO THE UEMS EACCME<sup>®</sup> FOR CME ACCREDITATION OF THIS EVENT.

This webinar is supported by

EFCNI Academy  
European Foundation for the Care of newborn infants

ESPR  
European Society for Paediatric Research



Live Webinar: 8<sup>th</sup> of October 2020  
Time: 4:00 – 6:00 p.m. CEST

**Enteral Preterm Nutrition**

Human Milk for preterm infants: Achieving optimal growth and outcomes

AN APPLICATION HAS BEEN MADE TO THE UEMS EACCME<sup>®</sup> FOR CME ACCREDITATION OF THIS EVENT.

This webinar is supported by

EFCNI Academy  
European Foundation for the Care of newborn infants

ESPR  
European Society for Paediatric Research



# EFCNI Academy: activities in 2020

- Digital webinar in German: „Die ersten 1000 Tage – eine prägende Phase im Leben eines Kindes“
- 4 presentations from experts in the field of infant nutrition and newborn health
- Target group: midwives, nursing staff and physician assistants
- 100 participants
- Webinar was recorded and is available on our website: <https://www.efcni.org/webinar-die-ersten-1000-tage/>
- Industry partner: Nestlé Nutrition Institute

Online Fortbildungsveranstaltung:

7. Oktober 2020, 16 – 18 Uhr

## Die ersten 1000 Tage

– eine prägende Phase im Leben eines Kindes



# „Saving Lives with Paul“ project due to COVID-19 postponed to June 2021

- To establish regular simulation trainings with simulation doll „I trainings to make them sustainable
- First start to train in perinatal centres in Munich
- Later to expand in all perinatal centres in the Greater Munich
- And also to be copied in different regions in Germany
- Involved partners:
  - EFCNI
  - LMU Munich Medical Centre (Prof. Andreas Flemmer)
  - INM (Institute for emergency medicine and management (= provides training for LMU))
  - SIMcharacters (provides „Paul“ simulation doll and initial trainings)

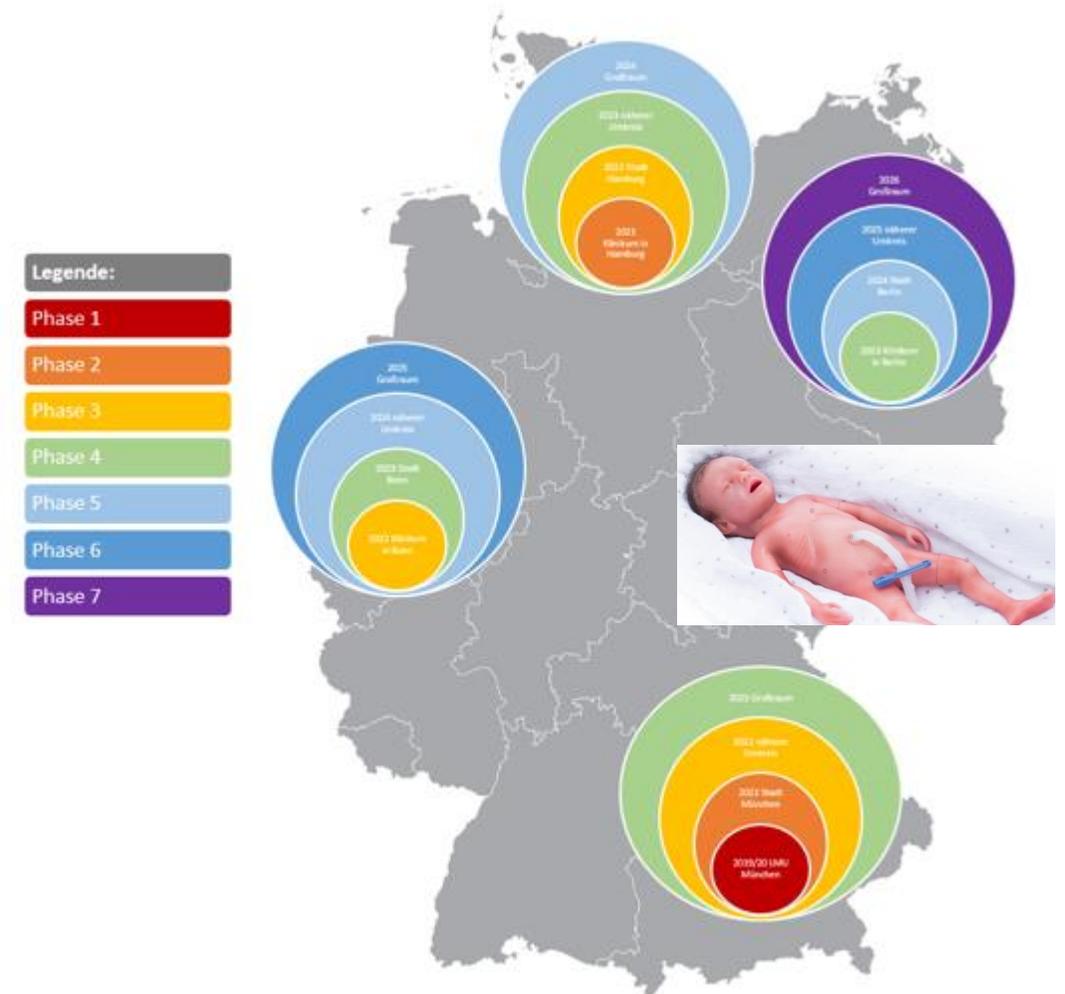


Figure 3: Exemplary representation of the cascading of the training

Source: EFCNI



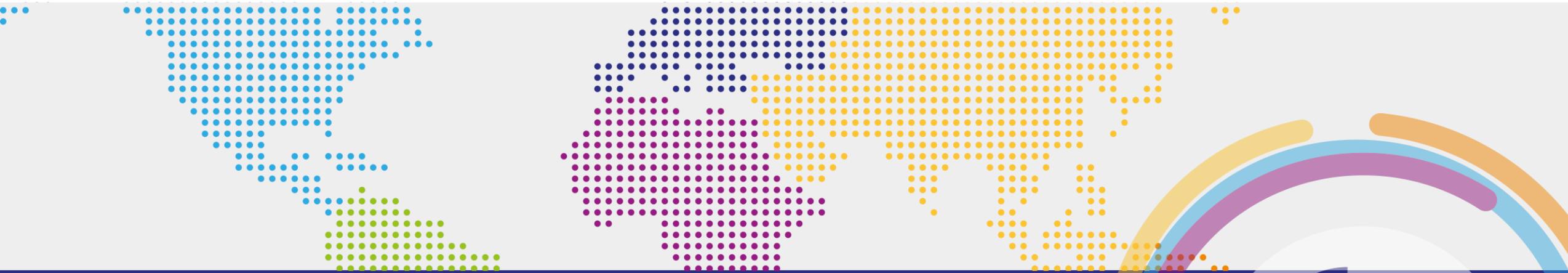
## Overview

1. EFCNI structure, team and network updates
2. European Standards of Care for Newborn Health
3. ICHOM project
4. Research projects
5. Roundtable, expert meetings and position papers and policy work
6. Publications and information material
7. EFCNI Academy
8. GLANCE
9. Communication and Campaigning
10. Conferences and Congresses



global alliance  
for newborn care

EFCUNI  
european foundation for  
the care of newborn infants



## Overview GLocal Alliance for Newborn Care (GLANCE)



# The Global Alliance for Newborn Care (GLANCE)



# COVID-19 FAQ

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- **52 Questions and answers** for the topics Pregnancy, Birth, Breastfeeding, NICU, Discharge and follow-up
- Published online: <https://www.glance-network.org/covid-19/>
- The FAQ was developed in close collaboration with global parent representatives
- Source for the FAQ was information by the WHO, UNICEF, The Lancet and the Royal College of Obstetrics and Gynaecology. Healthcare professionals helped review and finalise the FAQ
- Special thanks for the support and expert knowledge to Professor Christoph Bührer and PD Dr. Dietmar Schlembach

This FAQ is also available in:

[Hungarian](#), [Japanese](#), [Macedonian](#), [Portuguese](#) and [Romanian](#)



Pregnancy



Birth



Breastfeeding



NICU



Discharge and follow-up

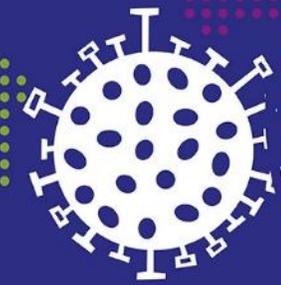


# Coronavirus/Covid-19 Survey

Impact of Coronavirus/ COVID-19 on special/intensive care for newborns – a parents' perspective

Are you a parent of a sick or preterm baby that was born during the COVID-19 pandemic?

**Take part in our global and multilingual survey!**

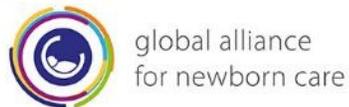


**Title:** Impact of Coronavirus/COVID-19 on special/intensive care for newborns – a parents' perspective

**Aim:** Asking parents of sick and preterm babies who were born during the Coronavirus/COVID-19 pandemic to share their experiences. Answers provide insights to the perceived problems and help identify strengths and weaknesses of the care provision in context of the crisis response.

**Link:** <https://de.surveymonkey.com/r/NewbornCov19>

**Launch:** 27 August 2020, rolled out in 27 languages. Currently under evaluation. First publication expected spring 2021



# Talks on digital conferences and congresses

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- EFCNI has been invited to give presentations about the topic Zero Separation at several organisations and events:
  - WHO
  - COINN
  - British Association of Perinatal Medicine's (BAPM) webinar on prioritising Family-Integrated Care
  - SIAATP – congress (December 2020)
  - National digital neonatal congress in Poland
  - WPD related neonatal conference in Egypt
  - WPD related parent conferences in US and Canada
  - Preterm Births in a COVID19 world: LSHTM-Charité Global Health Lecture Series Event: 17 November 2020
- Parent community is actively sharing the campaign material and including the topic Zero Separation in their talks on congresses, webinars and conferences



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# EFCNI communications: multi-channel approach



# World Prematurity Day (WPD) – 17 November 2020

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- EFCNI is founder of World Prematurity Day and leader of the global planning group
- About 40 global organisations (WHO, Save the Children, UN/Every Woman Every Child, March of Dimes, UNICEF, USAID, World Vision,...) join forces around the yearly motto
- 2020 motto and subthemes allowing broad participation:

## World Prematurity Day 2020

Together for babies born too soon – Caring for the future

- EFCNI as co-administrator of the global WPD Facebook account
- Material available for free at [www.efcni.org/worldprematurityday](http://www.efcni.org/worldprematurityday)
- Material like logo badges available in 37 languages

**Outreach for 2020 to be evaluated by early 2021:**  
Global Coordinating Committee will have their first meeting in Jan/Feb 2021



# World Prematurity Day 2020

## Together for babies born too soon – Caring for the future

- Campaign material available for social media in 23 languages: <https://www.efcni.org/activities/campaigns/wp/>
- Support of more than 170 national and international organisations





# Highlights of World Prematurity Day 2020: Global activities by EFCNI

Twitter Chat: EFCNI was also the host of this year's twitter chat on 16 November with an estimated account reach of 450,129 (as of 20.11.2020)

Silke Mader was invited to speak at the Global Health Lecture of LSHTM-Charité - a lecture focusing on the effects of COVID19 on deliveries and neonatal health worldwide.



**Monday, November 16, 2020**

**Live Twitter Chat 9.00 - 10.00 AM EST**

Join us to share resources and stories while raising awareness



# 5 years celebration of “A Strong Start for Little Heroes”

- A successful cooperation of two competent and reliable partners: Nestlé Nutrition with European Foundation for the Care of Newborn Infants (EFCNI) and other project partners (including national scientific societies and other institutions)
- Hospitals are equipped with free (event)-material to celebrate World Prematurity Day
- In 2020, again more than 170 Neonatal Intensive Care Units (NICUs) in Germany, Austria and Switzerland participated at “A Strong Start for Little Heroes”.
- Content of event-material adapted to COVID-19 situations in hospitals: Information material, decoration, sockline and socks, larger present bags for mothers of premature babies at the NICU – no presents for visitors or event material.
- Digital communication material for clinics available for download: <https://www.efcni.org/activities/campaigns/starker-start-fuer-kleine-helden/>
- 5 years lottery: participants can hand in a short summary of their event with pictures and can win one of 5 kangaroo chairs or 5 kangaroo sweater.



# Act early! Screen early! Pre-eclampsia campaign

Development of campaign material in English to raise awareness through the entire month of May with highlight on World Preeclampsia Day on 22 May with a flashmob initiative

- Poster, also available in several languages
- Flyer (EN/DE)
- Expert/Parent quote cards
- Email Signature Banner
- Facebook/Twitter Banner, Profile Banner,
- Campaign supported by international healthcare societies, parent organisations and partner Thermo Fisher Scientific



Flashmob reaching 44,310 accounts on social media

ThermoFisher  
SCIENTIFIC

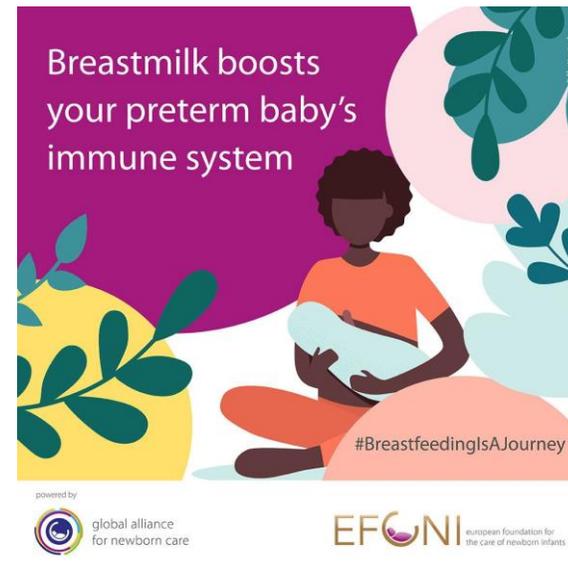
Today is World Pre-eclampsia Day!

We proudly support the Pre-eclampsia Awareness Campaign  
**act early! screen early!**



# Empower Parents – Enable breastfeeding: World Breastfeeding Week 2020

- World Breastfeeding Week is a campaign organised by the World Alliance for Breastfeeding Action (Waba)
- World Breastfeeding Week has been celebrated annually in about 120 countries since 1991
- 2020 EFCNI participated at the campaign with the motto “Support breastfeeding for a healthier planet!”
- Translation of poster into 23 languages
- Development of 3 expert and parent statements as well as 3 statements



# Patient safety: Promoting Optimal Practice in Neonatal Parenteral Nutrition

On World Patients Safety Day, 17 September

EFCNI kicked-off an awareness campaign, promoting safe parenteral nutrition. The launch event of the campaign was a social media photo flashmob supported by national parent organisations, individuals and our corporate partner Baxter.

The campaign continued until the end of October.

The campaign content was based on the Position Paper about Parenteral Nutrition which was launched at the jENS Congress one year earlier.

 **Baxter International Inc.**  
640.137 Follower  
2 Monate • 

+ Folgen

Today is World Patient Safety Day. In line with our mission of saving and sustaining lives, we support efforts by partners like **EFCNI - European Foundation for the Care of Newborn Infants** to increase awareness for safe practices in neonatal parenteral nutrition. [#WorldPatientSafetyDay](#) [#PatientSafety](#)

[Übersetzung anzeigen](#)



**WE SUPPORT**  
optimal practice in neonatal parenteral nutrition



17 September | **World Patient Safety Day**

powered by

 **EFCNI** european foundation for the care of newborn infants

Corporate Partner





# ROP awareness campaign

## The world is bright, save our babies' sight!

ROP is one of the leading causes of childhood blindness –

Provide the right care, at the right time, in the right place!

With the EURETINA congress and the DOG Conference taking place (digitally) on 4-5 and 9-11 October, the ROP awareness campaign was planned around these two events in order to promote the newly developed factsheet.

### Tools:

- Social media posts
- New ROP factsheet in EN and DE

### Timing:

- First post 2 October
- End of campaign 12 October



The world is **bright,**  
save our **babies' sight**

ROP is an eye disease that primarily affects very preterm babies born before 31 weeks of gestation. In the majority of the children, the ROP then disappears without any need for intervention.

Therefore, it is very important to identify those infants where this spontaneous resolution of ROP does not occur and who need treatment.

Walz JM. Acta Ophthalmol. 94, e744-e752 (2016)  
Holmström GE. Arch. Ophthalmol 130, 1418-1424 (2012)

**ROP**  
etinopathy f rematurity

Read more about ROP in our newly developed factsheet

Independently developed and powered by



ROP Corporate Partner



In collaboration with



The world is **bright,**  
save our **babies' sight**

Retinopathy of prematurity (ROP) is one of the most common avoidable causes of blindness in children.

Solebo AL. Arch. Dis. Child 102, 853-867 (2017)

**ROP**  
etinopathy f rematurity

Read more about ROP in our newly developed factsheet

Independently developed and powered by



ROP Corporate Partner



In collaboration with



# Bronchopulmonary dysplasia (BPD) campaign

- Campaign promoting World Lung Day (month of October)



**EFCNI**  
Published by Hootsuite [?] · 27 September ·

Bronchopulmonary dysplasia (BPD) is a chronic respiratory disease that affects children born preterm who undergo prolonged ventilatory assistance. However, treatment with surfactant has been shown to reduce the risk of death and BPD in preterm babies.

Here you find out more about #BPD: <https://www.efcni.org/.../health-conditions-of-preterm-infants>

#WorldLungDay #NewbornHealth #PrematureBaby



#WorldLungDay

**DID YOU KNOW?**

Avoiding invasive ventilation in combination with a less invasive surfactant application (LISA) **decreases bronchopulmonary dysplasia (BPD) of about 25%.**

Aldana-Aguirre JC. Arch DCFNE 102, F17-F23 (2017)



#WorldLungDay

**DID YOU KNOW?**

Preterm infants who develop **bronchopulmonary dysplasia (BPD)** need long-term follow-up as they are at increased risk of decreased pulmonary function and other chronic diseases in their adult life.

Batali E. N. Engl J Med 357:1946-55 (2007); Bhandari A. Semin Perinatol 37, 132-137 (2013); Thébaud B. Nature Rev 5:78 (2019)

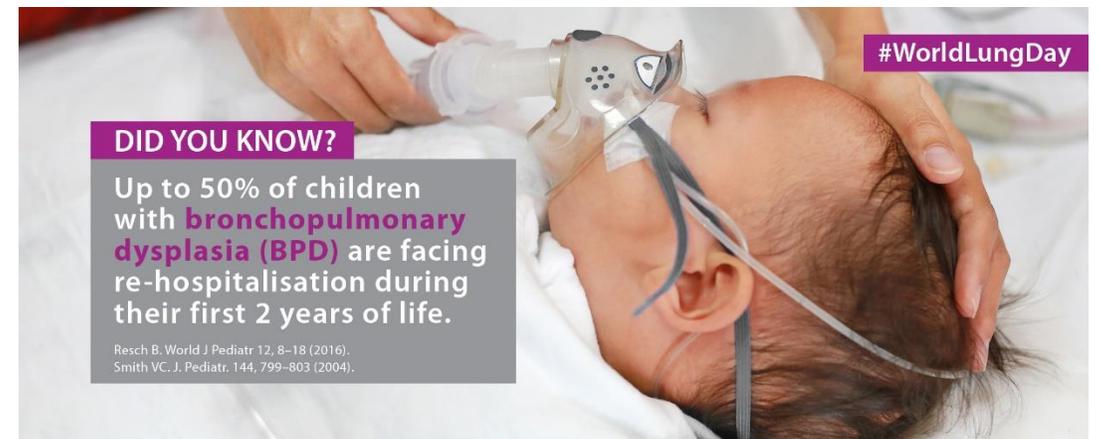


#WorldLungDay

**DID YOU KNOW?**

Avoiding invasive ventilation in combination with a less invasive surfactant application (LISA) **decreases bronchopulmonary dysplasia (BPD) of about 25%.**

Aldana-Aguirre JC. Arch DCFNE 102, F17-F23 (2017)



#WorldLungDay

**DID YOU KNOW?**

Up to 50% of children with **bronchopulmonary dysplasia (BPD)** are facing re-hospitalisation during their first 2 years of life.

Resch B. World J Pediatr 12, 8-18 (2016); Smith VC. J. Pediatr. 144, 799-803 (2004).



# Human Milk Matters – Human Milk Cares – social media campaign

The campaign is a long-term campaign, running until May 2021: Most successful posts of this campaign so far:

Published by HOOTSUITE [?] · 10 August ·

Today we launch our Human Milk Matters – Human Milk Cares campaign! Whether it is mother's own milk or donor milk, human milk is the best nutrition for all babies, and for preterm and sick babies in particular. With this campaign we want to raise awareness for the value of human milk and the important role of donor milk and milk banks.

If you want to know more about the Human Milk Matters – Human Milk Cares campaign, its objectives and supporters, please visit our website: <https://www.efcni.org/activit.../campaigns/human-milk-matters/> and follow the EFCNI social media accounts.

#HumanMilkMatters #HumanMilkCares #HumanMilk #Humanmilkfacts



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Human Milk Corporate Partner  
**Prolacta** BIOSCIENCE Advancing the Science of Human Milk  
in collaboration with  
**UNPS** UNIVERSITY NETWORK FOR PROMOTING THE SCIENCE OF HUMAN MILK

## Campaign Launch

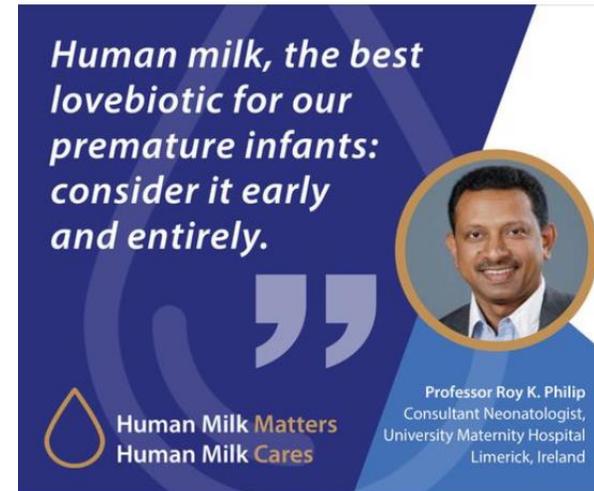
- **Facebook:** 11,876 impressions
- **Instagram:** 323 impressions
- **Twitter:** 1,690 impressions

Published by HOOTSUITE [?] · 11 August ·

Professor Roy Philip knows the benefits of human milk and how it promotes the development of preterm babies. Therefore, his advice to parents and professionals is: "Consider it early and entirely".

Thank you for supporting our campaign Human Milk Matters - Human Milk Cares!

#HumanMilkMatters #HumanMilk #NewbornHealth #NutritionExpert #humanmilkfacts



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Human Milk Corporate Partner  
**Prolacta** BIOSCIENCE Advancing the Science of Human Milk  
in collaboration with  
**UNPS** UNIVERSITY NETWORK FOR PROMOTING THE SCIENCE OF HUMAN MILK

## Expert Quote

- **Facebook:** 4,816 impressions
- **Instagram:** 271 impressions
- **Twitter:** 758 impressions



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## Conferences/ congresses attended by EFCNI in 2020

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- Industry Meeting 2020: 23 January 2020
- Parent Organisations Summit 2020: 24 – 26 January 2020
- 7<sup>th</sup> International Conference on Human Milk Science and Innovation (ICHMSI) Conference in Barcelona: 7- 8 February 2020
- ESCNH workshop level IV: 27 – 29 February 2020
- Impuls - Fortbildung, Beratung und Supervision e.V. in Augsburg, Germany; - Frühchen in der Kita: 2 March 2020

**No congress attendance after 2<sup>nd</sup> of March 2020 – digital participation mostly in form of a presentation by Silke Mader**

- WHO WEBINAR series - Now is the time to transform care for newborns/What the numbers say: 6<sup>th</sup> and 20<sup>th</sup> May 2020
- REaSoN Neonatal Meeting, University of Warwick, Coventry: 30<sup>th</sup> June 2020
- Webinar on “Polyunsaturated fatty acid supply during the first 1000 days – can the controversies be resolved?” was hosted by the Child Health Foundation: 8<sup>th</sup> July 2020
- BAPM Family Integrated Care Webinar: 12<sup>th</sup> August 2020



## Conferences/ congresses attended by EFCNI in 2020

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**No congress attendance after 2<sup>nd</sup> of March 2020 – digital participation mostly in form of a presentation by Silke Mader:**

- 2<sup>nd</sup> COINN Webinar: 23<sup>rd</sup> September 2020
- 2<sup>nd</sup> EMBA Research Meeting on Human Milk Donation and Breastfeeding: 2<sup>nd</sup> October 2020
- EAPS congress: participation at 3 sessions: 16<sup>th</sup> and 19<sup>th</sup> October (Silke Mader and Luc Zimmermann)
- Health and social aspects of COVID-19 pandemic – a Global Perspective, UENPS and IPOkRATES panel: 29<sup>th</sup> October 2020
- Virtual SIGNEC 2020 & Neonatal Quality Improvement Conference: 29<sup>th</sup> October 2020
- GNPI session : 31<sup>st</sup> October 2020
- World Prematurity Day congress at Nestlé global (internal event): 16<sup>th</sup> November 2020
- SIN congress: 16<sup>th</sup> November 2020
- Preterm Births in a COVID19 world: LSHTM-Charité Global Health Lecture Series Event: 17 November 2020
- Canadian Premature Babies Foundation: Premie Power Week: 17<sup>th</sup> November 2020



## Conferences/ congresses attended by EFCNI in 2020

---

**No congress attendance after 2<sup>nd</sup> of March 2020 – digital participation mostly in form of a presentation by Silke Mader:**

- Aswan Conference, Egypt: 19<sup>th</sup> November 2020
- 10<sup>th</sup> UENPS congress: 20<sup>th</sup> November 2020
- Neonatal Emergency Symposium in Poland: 28<sup>th</sup> November 2020
- SIAATP – congress (recorded): December 2020





Thank you very much for your attention!



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