



Milestones and activities Report 2021



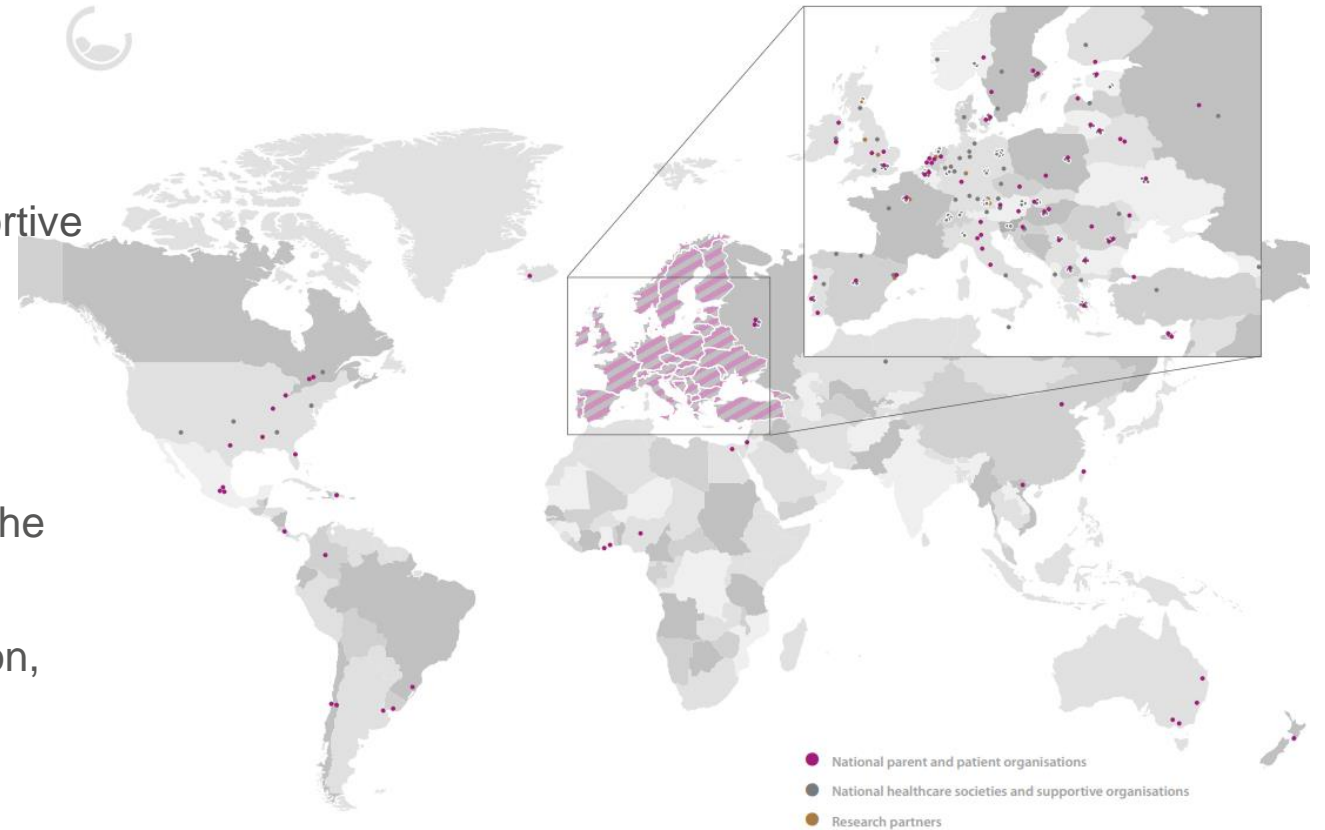
Overview EFCNI

1. Development and outreach
2. World Prematurity Day and Campaigning
3. Congresses and events
4. European Standards of Care for Newborn Health (ESCNH)
5. EFCNI Academy
6. EFCNI research projects
7. Global Alliance for Newborn Care (GLANCE)

EFCNI – 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
- National governmental bodies



Supporting partners

Platinum Partner:



Premium Partners:



Silver Partners:



Project Partners:

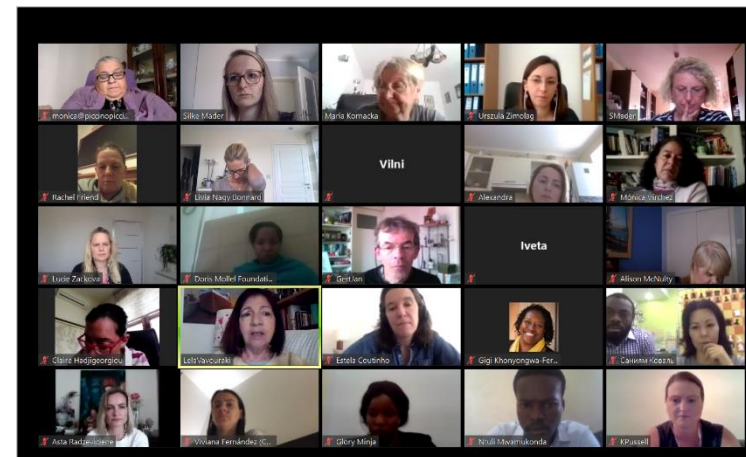


Other:



Empowering our parent community during a pandemic

- Continuation of EFCNI and GLANCE initiated regular parent calls on a 3-4 weeks basis to:
 - Provide scientific facts on COVID-19 and the impact on pregnant women and preterm born children
 - Empower our 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 children even in times of a pandemic
 - Exchange on projects, celebrate successes and motivate for joint campaigns
- EFCNI invited the parent community to two digital workshop with the topic “ how to build up a national parent organisation (January/April 2021)

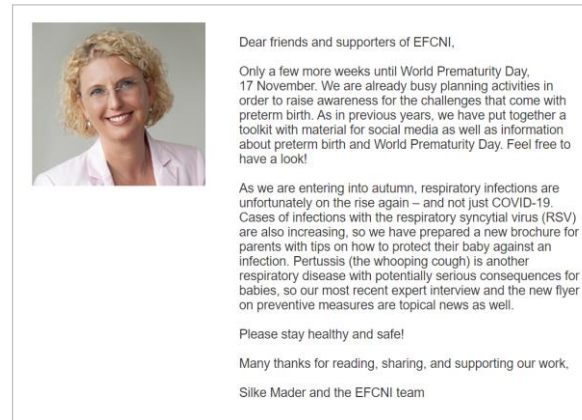


Parent community in one of our Friday Calls, April 2020



The power of the network: The newsletter*

- 12 editions in 2021 (bi-monthly in 2022)
- Distribution via email-marketing tool and via social media and website



*as of April 2022

Communications update: EFCNI scientific output 2021/2022

2021: scientific articles

- Ein Handlungsauftrag am Welt-Frühgeborenen-Tag: „Zero separation. Together for better care!“ Baby- und familienzentrierte entwicklungsfördernde Betreuung in Zeiten der COVID-19-Pandemie. *Kinderkrankenschwester* 2021.
- Zero separation: infant and family-centred developmental care in times of COVID-19. *The Lancet Child and Adolescent Health* 2021.
- RSV: perspectives to strengthen the need for protection in all infants. *Emerg Themes Epidemiol* 2021.
- Neonatal care during the COVID-19 pandemic – a global survey of parents' experiences regarding infant and family-centred developmental care. *EClinicalMedicine* 2021.
- A call for zero separation – restrictive policies and their impact on neonatal care in light of COVID-19. *Infant* 2021.
- Maßnahmen und praktische Tipps zur Verbesserung der parenteralen Ernährung bei Früh- und kranken Neugeborenen. *Kinderkrankenschwester* 2021.
- Parenterale Ernährung bei Früh- und kranken Neugeborenen – Ergebnisse einer Umfrage zu Barrieren in der klinischen Anwendung. *Kinderkrankenschwester* 2021.
- Parenterale Ernährung bei Frühgeborenen. *Frühgeborene* 2021.
- Parenterale Ernährung in deutschen Perinatalzentren. *Monatsschrift Kinderheilkunde* 2021.
- Making human milk matter: the need for EU regulation. *The Lancet Child and Adolescent Health* 2021.



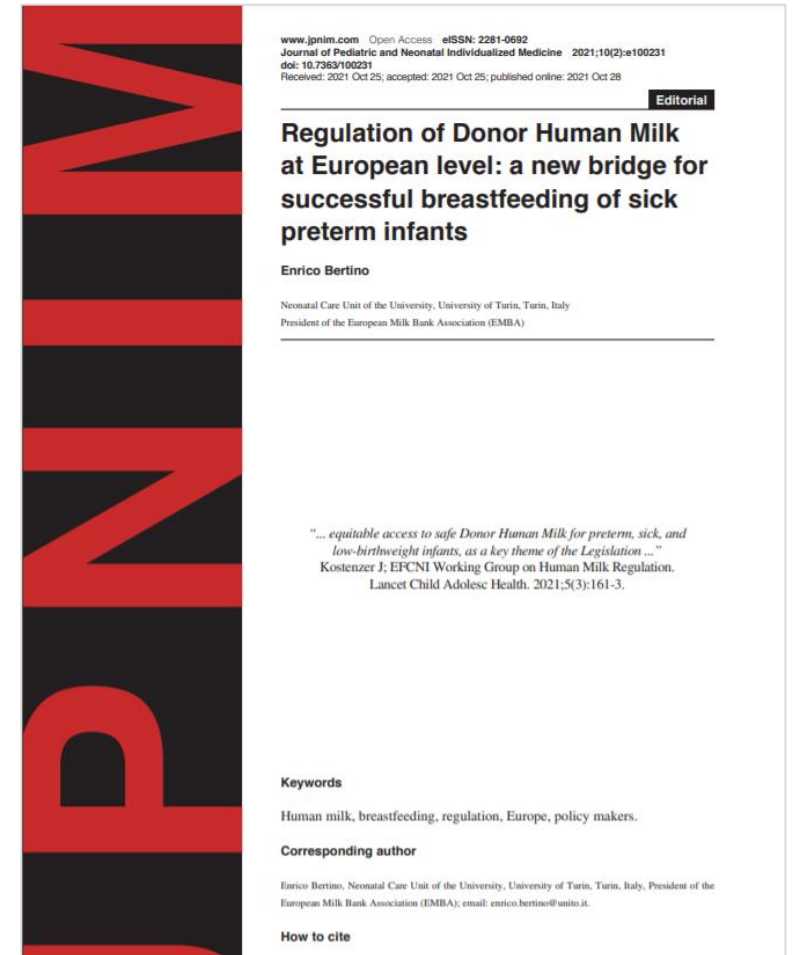
Communications update: EFCNI scientific publications 2021

Published book chapters

Involving Parents in Feeding Their Preterm Infants. **Kolossa S, Mader S, Pfeil J, Zimmermann LJI**. In Nutritional Care of Preterm Infants. Scientific Basis and Practical Guidelines. World Review of Nutrition and Dietetics. 2021, Volume 2. Koletzko B et al. (Eds.)(2021)

EFCNI was cited in the following articles

Regulation of Donor Human Milk at European level: a new bridge for successful breastfeeding of sick preterm infants. Journal of Pediatric and Neonatal Individualized Medicine 2021;10(2):e100231. Bertino E.
<https://doi.org/10.7363/100231>



New/updated materials 2021/2022

New materials

- Toolkit Parenteral Nutrition (DE: Toolkit für die parenterale Ernährung von Früh- und kranken Neugeborenen – Von der Leitlinie in die multidisziplinäre Anwendung)
- Zero separation. Together for better care! Infant and family-centred developmental care in times of COVID-19 – A global survey of parents' experiences. Project Report.
- Parent booklet for parents of all newborns on RSV Are you RSV aware?
- Leitfaden Frühgeburt: Was Sie als werdende Eltern wissen sollten

Updated/revised materials

- Bonding with and caring for a preterm infant (update and translation in English)
- RSV position paper on RSV in preterm infants revised
- RSV factsheet on RSV in preterm infants update (English, German, Hungarian, Greek, Czech)
- Thermoregulation factsheet various translations (French, German, Hungarian, Russian, Spanish)
- Parenteral nutrition factsheet Ukrainian (in progress)
- Breastmilk for preterm babies – more than a meal (updated)



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World Prematurity Day (WPD) – 17 November 2021

- EFCNI is founder of World Prematurity Day and leader of the global planning group
- About 40 global organisations join forces around the yearly motto
- Global World Prematurity Day theme 2021:

Zero Separation

Act now! Keep parents and babies born too soon together.

- Material like logo badges available in 37 languages
- Support of more than 170 national and international organisations
- EFCNI as co-administrator of the global WPD Facebook account
- **Outreach* for 2021 about 40 Million people worldwide.**

*of EFCNI and its global network



World Prematurity Day 2021: Materials – Trello Board

WPD 2021 Öffentlich AB AA CW KR LS +2

General

This column contains general information about World Prematurity Day, preterm birth, and this year's theme "Zero Separation".

- About preterm birth
- About World Prematurity Day
- Message map
- Press Release Template
- EFCNI COVID-19 Report
- Manuscripts

Hashtags

The hashtags in purple are the primary hashtags. Please use those always. The hashtags in white are optional.

- #WorldPrematurityDay2021
- #ZeroSeparation
- #WPD2021
- #COVID19

Social media handles

To tag the network correctly, please use the social media handles below. If you want to add your own social media handles here, please send an email to worldprematurityday@efcni.org!

- AlignMNH
- EDEN Foundation
- EFCNI
- GAPPS (Global Alliance to Prevent Prematurity and Stillbirth)
- GLANCE
- Graham's Foundation
- Healthy Newborn Network
- International Confederation of Midwives (ICM)

Messages for social media / captions

Choose your text(s) and add a graphic of your choice.

- Message: Zero Separation at birth
- Message: Support parents
- Message: Support fathers
- Message: Support breastfeeding

Graphics

Choose your graphic(s) and add a message of your choice.

- Zero Separation
- Graphic #1
- Graphic #2
- Zero Separation

Translated graphics

Choose your graphic(s) and add a message of your choice.

- Arabic
- French
- Portuguese

International events

If you want to add your event here, please send an email to worldprematurityday@efcni.org!

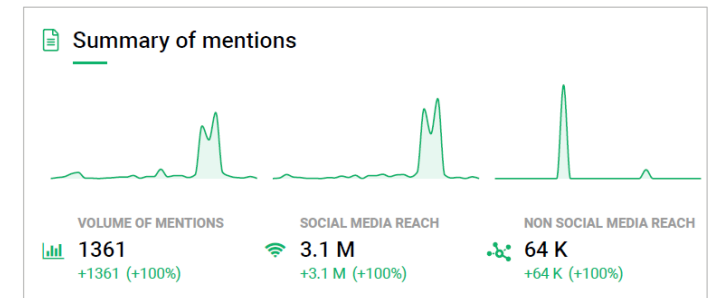
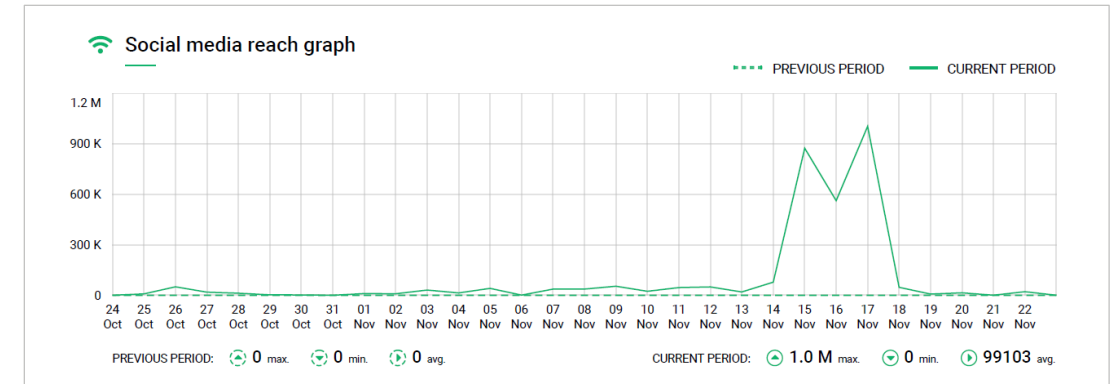
- Zero separation. Together for better care!
- 11 November: EFCNI Webinar on COVID-19 report (Launch event)
- 12 November: 13th WPD Virtual Online Conference (TinyLife, INHA)
- Tuesday, November 16, 2021
- 16 November: Twitter Chat #WPD21Chat

<https://trello.com/b/puHOfqwK/wpd-2021>



World Prematurity Day 2021: Twitter Chat

- Twitter Chat: EFCNI was also the host of this year's twitter chat on 16 November with an estimated account reach of **3.1 million people on social media**



Evaluation period: 24 Oct – 23 Nov 2021
Source: Brand24.com



World Prematurity Day 2021: Activities overview – Trello Board

World Prematurity Day 2021 - events and activities Öffentlich S AL AB KR

General information

- Have your content added
- Zero Separation **Act now!** Keep parents and babies. Keep them close together.
- World Prematurity Day 2021

Activities around the globe

- Australia**
 - World Prematurity Day 2021: Fathers of premature babies are just as busy as Mothers to experience anxiety and Post Natal Depression.
 - 63% of twins, triplets and other multiples are born pre-term
 - In Australia, every hour 6 babies are born premature or critically ill.
 - Miracle babies foundation
- Austria**
- Brazil**

International societies / NGOs

- Global Sepsis Alliance**
 - World Prematurity Day 2021: Zero Separation – Act Now! Keep Parents and Babies Born Too Soon Together
 - Act now!** Keep parents and babies. Keep them close together.
- Global Sepsis Alliance**
- NEST360/Unicef**
- NIDCAP Federation International (NFI)**

Research Partners

- Premstem**
- Premstem**
- Conect4Children (c4c)**
- Conect4Children (c4c)**

Corporate Partners

- AstraZeneca**
- AstraZeneca Germany**
- AstraZeneca African Cluster**

<https://trello.com/b/s0L8jyAK/world-prematurity-day-2021-events-and-activities>



Act early! Screen early! Pre-eclampsia awareness campaign

Campaign material developed in up to 23 languages to raise awareness throughout the entire month of May.

Campaign features:

- Expert Video with Prof. Kypros Nicolaides
- Webinar promotion and presentation
- Social Media Flashmob
- Social Media Banners
- Social Media Posts
- Campaign page



Campaign supported by 11 international healthcare societies, parent organisations and partner



World Breastfeeding Week 2021 #BreastfeedingIsAJourney

Protect and promote breastfeeding in times of the pandemic

- EFCNI launched its own initiative in 2021, separate from the World Alliance for Breastfeeding Action (WABA) to be able to *focus more on the needs of preterm infants and their mothers in regards to breastfeeding*
- Translation of social media graphic into 25 languages
- Development of 1 poster, 1 parent quote card, 1 social media graphic
- Featured article in BabyCare blog <https://www.baby-care.de/das-stillen-foerdern-gerade-waehrend-der-pandemie/>



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German Neonatology and Paediatric Congress (GNPI) 2022 and 2023

- In 2021: participation at over 30 international and national events – digital workshops, conferences and face-to-face meetings.



- 1 workshop organised by EFCNI about how to build up a human milk bank
- EFCNI hosts 3 sessions in collaboration with the German parent organisation



jENS Congress 2021

4th joint Congress of European Neonatal Societies (jENS), EFCNI was co-organiser, chaired 5 sessions and a workshop, had a digital booth and an e-poster on display



Source: MCA Congress Platform

Parallel sessions on:

- Safe and optimal nutrition
- Newborn screening
- Long-term outcome
- Improving quality of neonatal care
- Taking care of infants and families who are in challenging situations

Workshop on:

- Patient safety

Pre-congress course:

- Dealing with parents in critical care decisions

E-Poster on:

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



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european standards of
care for newborn health

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european foundation for
the care of newborn infants

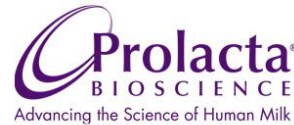


Overview of the European Standards of Care for Newborn Health (ESCNH)



Thanks to our supporting industry partners

Current partners:



AbbVie was a project partner from 2013 to 2020.

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.

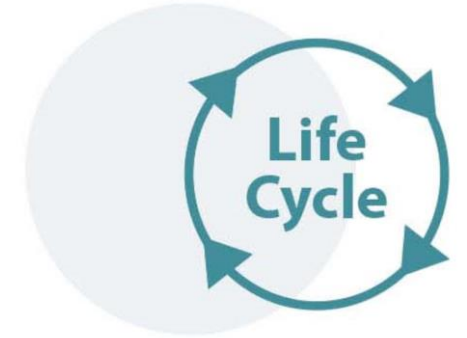
Takeda was a project partner from 2019 to 2020.



Lifecycle of the ESCNH

Status:

- 3 and 5 years lifecycle (10 years included in revision 2023)



- 20 standards are currently under revision
- Open public consultation and targeted expert consultation took place in August until October
 - Information on public consultation and opportunities to participate sent to supporting organisations
- Authors received results of both consultations and most of them have already provided us with an updated version

 Expected launch at the UENPS meeting, September 2022



New standards under development

Topics and status of new standards:

- Cord Management at the delivery of preterm infants: Topic Expert Group Birth & transfer' – status: editing finalised
- Cord Management at the delivery of term infants: Topic Expert Group 'Birth & transfer' – status: editing finalised
- Standards for the diagnosis and management of Necrotising Enterocolitis (NEC): Topic Expert Group 'Medical care & clinical practice' – status: editing finalised
- Quality indicators: Topic Expert Group 'Data collection & documentation' – status: ready for Chair Committee voting
- Error management/safety: Topic Expert Group 'Patient safety & hygiene practice' – status: back with authors
- Immunisation of preterm infants: Topic Expert Group 'Follow-up & continuing care' – status: editing finalised



Expected launch at the UENPS meeting, September 2022



Translations of materials in 2021

Set of standards:

- Ukrainian: translation of topic 'Care Procedures'; topic 'Medical care and clinical practise' in preparation
- Italian: translation of all topics

Information brochure:

- New versions: Romanian, (Portuguese)
- Updated versions: Bulgarian, English, German, Greek and Ukrainian
- Under development: French



european standards of
care for newborn health



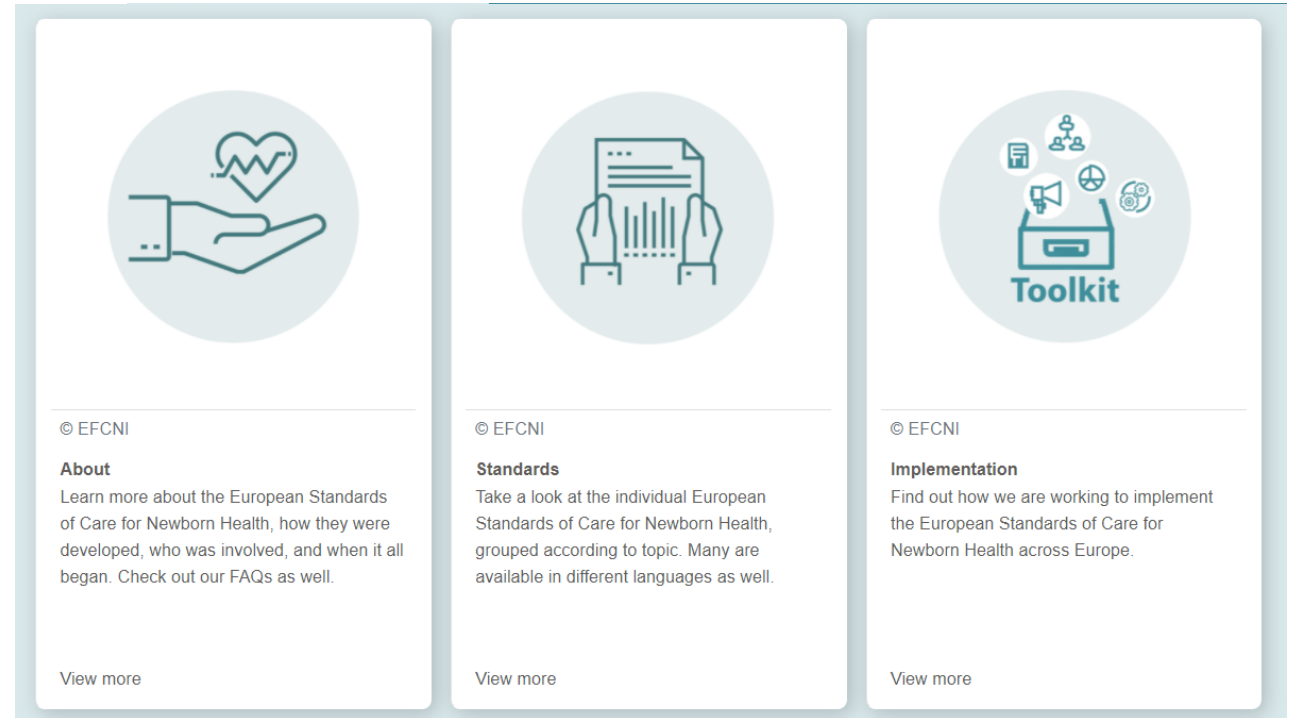
european foundation for
the care of newborn infants



Website relaunch: Newborn-health-standards.org

Improvements:

- Easy sharing of information on different channels
- User friendly handling using tiles
- Optimised user experience
- Updated website content
- Robust content-management-system




Social media campaign: 11 Months – 11 Topics

Aim:

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

New:


- Focus: renewal, implementation, and information
- Promotion of public consultation per standard
- Interviews with experts (Dr Hüning, Dr Paulsson)
- (Re-)Introducing Lighthouse projects (initiative started in 2018)



Follow-up & continuing care

Assessment of visual function

Standardised visual assessment is conducted by age 3.5 to 4 years and repeated by age 5 to 6, at which age additional attention is paid to visual information processing dysfunctions.



Education & training

Evidence-based practice

Every healthcare professional caring for infants and their families delivers care based on the best available evidence, integrated with clinical expertise, available resources and the wishes of the family.



Implementation of the ESCNH: EFCNI's digital roadshow in 2021

(Digital) presentations:

- 47th GNPI digital congress, several sessions, 16 – 19 June 2021
- 4th joint jENS digital congress, several sessions, 14 – 18 September 2021
- Webinar 'Prematurity: Safe starting and future health', session 'European Standards of Care for Newborn Health – the parent perspective' in Cyprus, 6 November 2021
- Romanian neonatal society congress, introduction of the ESCNH and how to implement, Romania, 23 November 2021
- Italian workshop 'The family in the neonatal intensive care unit', session 'Call to action from the European standards of care: taking advantage from the Italian translation' in Rimini, 18 December 2021

Digital presentations for industry partners:

- Prolacta and AstraZeneca briefing

Publication:

- Lindacher V et al.; European Standards of Care for Newborn Health project members. European Standards of Care for Newborn Health-A project protocol. Acta Paediatr. 2021 May;110(5):1433-1438. doi: 10.1111/apa.15712. Epub 2020 Dec 22.



Implementation of the ESCNH: Best practice example - Italy

Key facts:

- Successful cooperation between healthcare society - Italian Society of Neonatology (Società Italiana di Neonatologia = SIN) and parent organisation - Vivere Onlus
- First translation of the entire ESCNH to overcome language barriers
- Duration: 2020 – 2021 (during COVID-19 pandemic)
- Coordination of 30 voluntary medical expert across Italy to support and validate translation and editing process
- Both organisations are recipients of the Congress of joint European Neonatal Societies - jENS Award 2021
- Foundation for national implementation, training and raising awareness across healthcare professionals



Edizione Italiana a cura di:



Implementation of the ESCNH: Best practice example - Italy

Promotion:

- Distribution of the Italian ESCNH (book format) over all NICUs across Italy
- Presentation “*European care standards: the 8 golden points for promoting neonate health*” at the national congress of Italian societies in neonatology on 6 Oct 2021
- Implementation workshop on 18 Dec 2021 in Rimini
- Italian ESCNH are available for download at <https://newborn-health-standards.org/>



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The EFCNI Academy



EFCNI Academy - Approach



Standardised, high-quality education and training programmes for everybody (potentially: several levels)



Target group: healthcare professionals in neonatology (long-term: obstetrics/perinatal).



Small groups (max 50 participants) ensuring interactive learning and hands on participating. Affordable fee for participants. Digital solutions in form of webinars.



Ensuring access to evidenced-based, harmonised (medical) treatment and care for preterm and ill born babies throughout Europe and beyond.



Using „train the trainer“ and/or „peer-to-peer“ support to scale down into countries.



Identifying a pool of high-level trainers (well-known experts with excellent teaching skills) in Europe and beyond.



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.



“Saving Lives with Paul” project

- To establish regular simulation trainings with simulation doll “Paul” and training “Master-trainers” who will conduct trainings to make them sustainable
- First training at LMU Großhadern June 2021
- Second training at LMU centre in March 2022
- Mastertrainer training is ongoing
- Research publication planned 2022/2023
- Involved partners: LMU Munich Medical Centre, Institute for emergency medicine and management in medicine of LMU, SIMcharacters and Vienna University Hospital



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Research participation

2017-2021: **RECAP preterm** – Research on European Children and Adults born Preterm

(EU Horizon 2020: grant agreement No 733280)

Ongoing: collaboration and publication of results: data platform with data from all preterm birth cohorts ready for further use



2018-2023: **conect4children** – Collaborative network for European clinical trials for children

(Innovative Medicines Initiative 2 Joint Undertaking; EU Horizon 2020: grant agreement No 777389.)



2020-2023: **TREOCAPA** - Prophylactic **treatment** of the ductus **arteriosus** in **preterm** infants by **acetaminophen**

(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)



2020-2022: **IFCDC in times of COVID-19** – Infant and family-centred developmental care in times of COVID-19 – A global survey of parents' experiences

(supported with a donation by Novartis Pharma AG)



Research participation

2021-2024: **ResQ Family** – Impact of Respiratory Syncytial Virus hospitalisation on Quality of life of Families – a multi-country study

(Sanofi research grant)



2021-2024: **EndObesity** – Prevention of unhealthy weight gain and obesity during crucial phases throughout the lifespan

(BMF Germany, grant support No 01EA2101)



2021-2025: **PRO-LISA** – Research on European Children and Adults born Preterm

(BMF Germany, grant support No 01KG2024)

2021-2023: **INSPIRE** – International Neonatal Transfusion Point Prevalance

(Dutch blood bank, Sanquin Blood Supply Foundation)



2021-2023: **COUSIN study** – developing a Core OUtcome Set and outcome measures of family-centred care In Neonatal care

(supported by ESPR)



2015-2019: **SHIPS** – Screening to Improve Health in Very Preterm Infants in Europe

(EU Horizon 2020: grant agreement No 633724)

Ongoing: collaboration and publication of results



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global alliance
for newborn care

EFON^{NI} european foundation for
the care of newborn infants

Overview GLocal Alliance for Newborn CarE (GLANCE)



GLANCE at a glance



Global Call to Action for Newborn Care: supported by more than 170 organisations

GLOBAL CALL TO ACTION FOR NEWBORN CARE

Global Call to Action for Newborn Care

GLANCE represents the interests of babies born too soon, too small or too sick and their families. It aims to improve newborn and maternal health worldwide, ensure nurturing care in all settings, and enable every girl, woman and parent to make well-informed choices and decisions during pre-conception, pregnancy and birth as well as during follow up and continuing care after discharge from the hospital.

Therefore, GLANCE calls for action to:



- Girl's and women's reproductive health**
 - Provide age-appropriate, standardised, evidence-based and scientifically accurate, comprehensive sexual education for every adolescent and adult
 - Ensure that every girl and every woman has access to free health information and affordable health services to support her wellbeing, dignity and self-respect with regards to pre-conception, sexuality, pregnancy and parenthood
- Healthy pregnancy**
 - Develop and disseminate knowledge about all topics pertaining to a healthy pregnancy
 - Adopt measures to ensure that all pregnant women can access affordable and high-quality healthcare
- Safe and respectful birth**
 - Provide every woman with a safe environment, and respectful and supportive care during labour and delivery
 - Educate, train and equip healthcare providers to ensure high-quality care
- Nurturing care**
 - Provide every baby born too soon, too small, or too sick with high-quality care in all settings for the best start in life to develop to their full potential
 - Establish a zero-separation policy in hospitals and provide family-friendly facilities
 - Promote continuous training of healthcare providers, and offer parental involvement in all aspects of care
- Parent empowerment**
 - Value, include, educate, and empower parents as key caregivers of their babies at all times
 - Provide access to emotional, psychological, spiritual and financial support to parents
- Follow-up and continuing care after discharge**
 - Provide discharge management, follow up and continuing care to children born too soon, too small or too sick or with related health issues to promote long-term health and quality of life
 - Provide continuing access to medical, financial, educational, emotional, and psychosocial support to these children and their families in home and community settings
- Research and data collection**
 - Identify indicators for developmental and long-term health outcomes, and create assessment tools to allow benchmarking
 - Support research for maternal and newborn health, develop and implement clinical guidelines and protocols to ensure evidence-based care, reduce mortality and morbidity, and improve quality of life
- Framework and Strategies**
 - Develop and establish national and international frameworks for strategies to minimise risks before, during, and after birth

Supported by



The Global Call to Action is available online in 22 languages (more languages will follow):

<https://www.glance-network.org/resources-and-materials/call-to-action-material/>



Separation policies during the COVID-19 pandemic

- Worldwide, neonatal units have adopted separation policies, limiting or prohibiting access of parents to neonatal care units [1,2]
- Separation can result in long-term health and developmental issues in newborns and impact the mental health of parents [1,2]
- The survival benefit of kangaroo-mother-care far outweighs the small risk of death due to the COVID-19 infection [3]
- **Experiences shared by our international parent network showed alarming changes in terms of the involvement of parents in the care of their preterm, sick, or low birthweight babies**



[1] van Veenendaal et al., 2021. Supporting parents as essential care partners in neonatal units during the SARS-CoV-2 pandemic

[2] Rao et al., 2021. Small and sick newborn care during the COVID-19 pandemic: global survey and thematic analysis of healthcare providers' voices and experiences

[3] Minckas et al., 2021. Preterm care during the COVID-19 pandemic: A comparative risk analysis of neonatal deaths averted by kangaroo mother care versus mortality due to SARS-CoV-2 infection

COVID-19 FAQ

- **Regular Update of 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



Pregnancy



Birth



Breastfeeding



NICU



Discharge and follow-up

This FAQ is also available in: [Hungarian](#), [Japanese](#), [Macedonian](#), [Portuguese](#), [Romanian](#), Spanish and [Ukrainian](#)



GLANCE's first campaign: Zero separation. Together for better care!

Zero separation. Together for better care!

Keep preterm and sick babies close to their parents.

First multi-topic, long-term social media campaign, rolled out in 27 languages with a focus infant and family centred developmental care and zero separation.

Support of over 140 national and international organisations.

Continuation of Zero Separation campaign promoting the results of the survey on a longterm perspective.



COVID-19 Report: the parents' perspective on neonatal care in the pandemic

Convincing with data and real parents' experiences to secure and promote a holistic approach to infant and family-centred developmental care.

Zero separation. Together for better care!
Infant and family-centred developmental care in times of COVID-19 – A global survey of parents' experiences

CALL TO ACTION

FOR ZERO SEPARATION AND INFANT AND FAMILY-CENTERED DEVELOPMENTAL CARE (IFCDC)

Based on the findings of this research initiated by the European Foundation for the Care of Newborn Infants (EFCNI), and under the umbrella of the Global Alliance for Newborn Care (GLANCE), we request policy-makers, for public health experts and healthcare professionals to:

- Provide every woman with a safe environment and respectful and supportive care during pregnancy, labour and birth, and allowing support persons to be present during prenatal appointments and birth.
- Prioritise mother's own milk and encourage breastfeeding when possible, emphasising the benefits of adequate infant nutrition for all newborns.
- Provide every baby born too soon, too small, or too sick with high-quality care in all settings for the best start in life.
- Ensure adequate provision of health information and continuous and respectful communication between healthcare professionals and parents.
- Value, include, and empower parents as key caregivers of their newborns at all times.
- Offer and provide access to mental health support to parents and families in need.
- Establish a zero separation and family-inclusive policy in hospitals, ensuring parental presence to enable immediate skin-to-skin and Kangaroo Mother Care, and family-infant bonding.
- Ensure a smooth and holistic application of IFCDC in general and in times of crisis.

 global alliance for newborn care

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

In cooperation with

 **COINN** Council of International Neonatal Nurses

 European Society for Paediatric Research

 **nidecap** FEDERATION INTERNATIONAL voice of the newborn

 **UNPS** united newborn professionals

Zero separation. Together for better care!
Infant and family-centred developmental care in times of COVID-19 – A global survey of parents' experiences

“

It was terrible for my husband not being allowed to see his baby for nearly six weeks. He said he felt totally disconnected from her. I felt the wearing of masks in the unit was inhibiting bonding with my baby. I couldn't kiss her or hold her too close to me as I didn't want her held up against a dirty facemask. Facilities for parents to make a cup of tea and use the toilet were all closed, never felt comfortable in the unit because of this.
Parent from Ireland

”

 global alliance for newborn care

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

In cooperation with

 **COINN** Council of International Neonatal Nurses

 European Society for Paediatric Research

 **nidecap** FEDERATION INTERNATIONAL voice of the newborn

 **UNPS** united newborn professionals

Zero separation. Together for better care!
Infant and family-centred developmental care in times of COVID-19 – A global survey of parents' experiences

“

Immediately after birth, the child was taken to a hospital 130 km away. I did not see the child after birth, no one showed it to me, no one could be with me after the caesarean section. When I was registered and wanted to go to the child, the hospital said it was forbidden to visit. I did not see my daughter for 2 months, only a few photos throughout the period. I saw the child for the first time on the day of discharge. That was a nightmare.
Parent from Poland

”

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“

It should be the right of babies and parents to always be together despite the pandemic, of course with the necessary health checks.
Parent from Mexico

”

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“

I tested COVID positive and had to deliver the baby at 35 weeks. I could neither see my baby nor hold her. It was the worst three weeks of my life as they took my baby to the NICU and I could only see her once she was discharged after three weeks for the first time.
Parent from South Africa

”

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IFCDC in times of COVID-19



Aim: To explore parents' experiences related to the challenges caused by the pandemic regarding neonatal care

Method: Global and multi-lingual online-survey (23 languages)

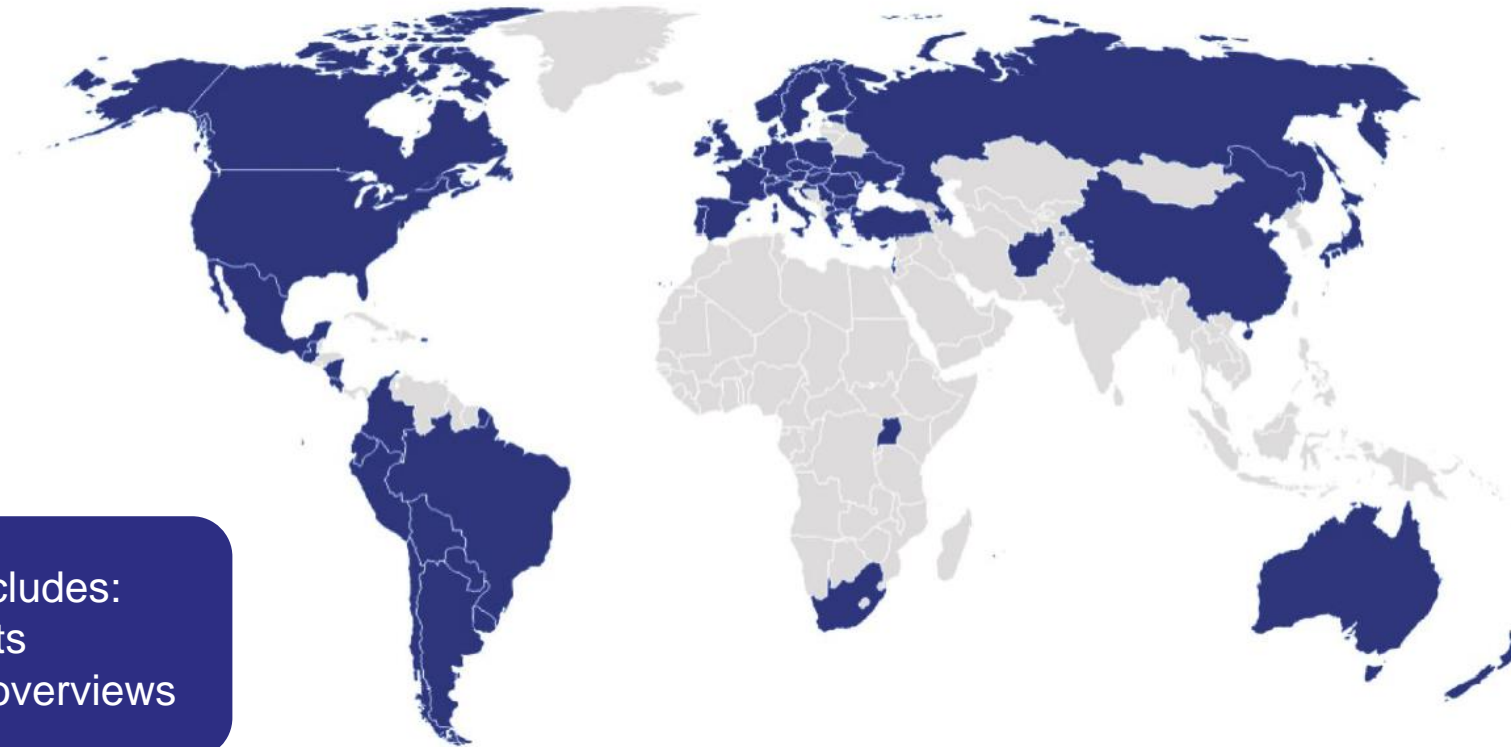
Participants: Parents of infants who were born during the first year of the COVID-19 pandemic and who were receiving special/intensive care

Earmarked donation by Novartis Pharma AG in support of this study

Collaborators: COVID-19 Zero Separation Collaborative Group, including representatives of national parent organisations, and members of:



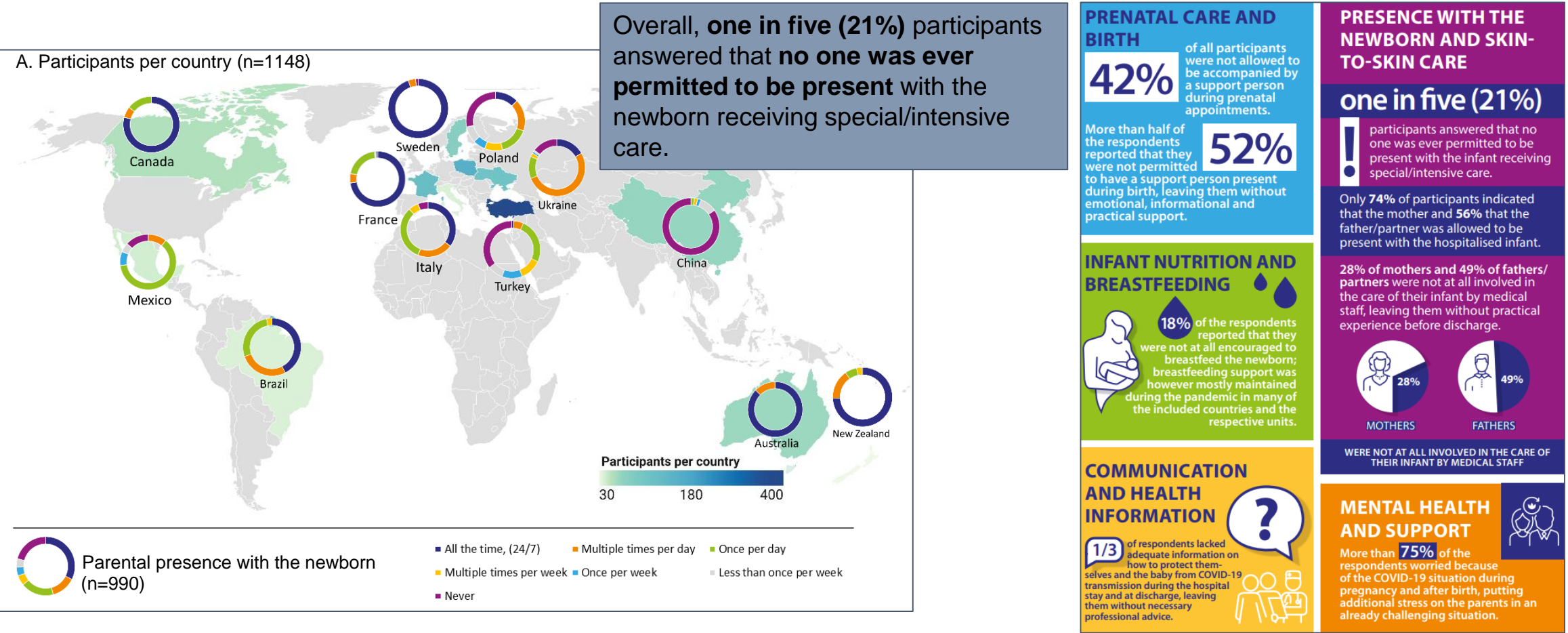
2103 participants from 56 countries



Full report includes:
- global results
- 30 country overviews



Results



Covid-19 Survey – Output 2021/2022

Global findings published in E Clinical Medicine: <https://bit.ly/3iGFmo1>

Commentary published in The Lancet Child and Adolescent Health: <https://bit.ly/3Hus1tx>

Country-specific findings published in BMJ Open: <https://bit.ly/3Ou9fWA>

Full project report, short version, press releases and further information available here: www.glance-network.org/covid-19/survey

Digital launch event: 11 November 2021 (recorded webinar available on website)



Zero separation. Together for better care!

Infant and family-centred developmental care in times of COVID-19 – A global survey of parents' experiences

DIGITAL LAUNCH EVENT

Thursday, 11 November 2021
2:00-3:30 p.m. CET
Language: English

global alliance for newborn care
In cooperation with

EFCONI
European Foundation for the Care of Newborn Infants

COINN
European Society for Paediatric Research

nidrap
Network of Neonatal Intensive Care Units in Europe

UNFS
European Society for Neonatal Intensive Care

Zero separation. Together for better care!

Infant and family-centred developmental care in times of COVID-19 – A global survey of parents' experiences

Project Report available now!

Zero separation. Together for better care!
Infant and family-centred developmental care in times of COVID-19 – A global survey of parents' experiences

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European Society for Neonatal Intensive Care



GLANCE and EFCNI was involved in nurturing care for every newborn

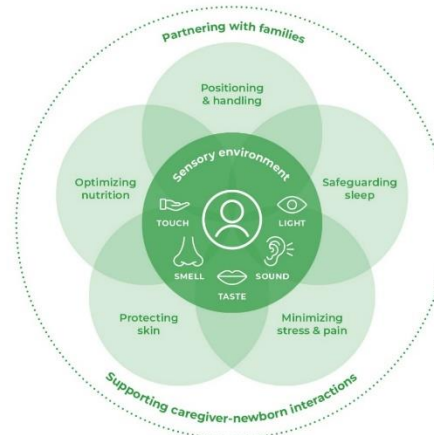


Figure 2. Standards for infant- and family-centred developmental care

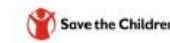


Adapted from: European Foundation for the Care of Newborn Infants (9).

Figure 1. Components of infant- and family-centred developmental care (9)



- Support the development of the brief
- Attend the launch event
- Glance is recommended as valuable source
- ESCNH standards are recommended and included in the brief
- EFCNI is collaborative partner

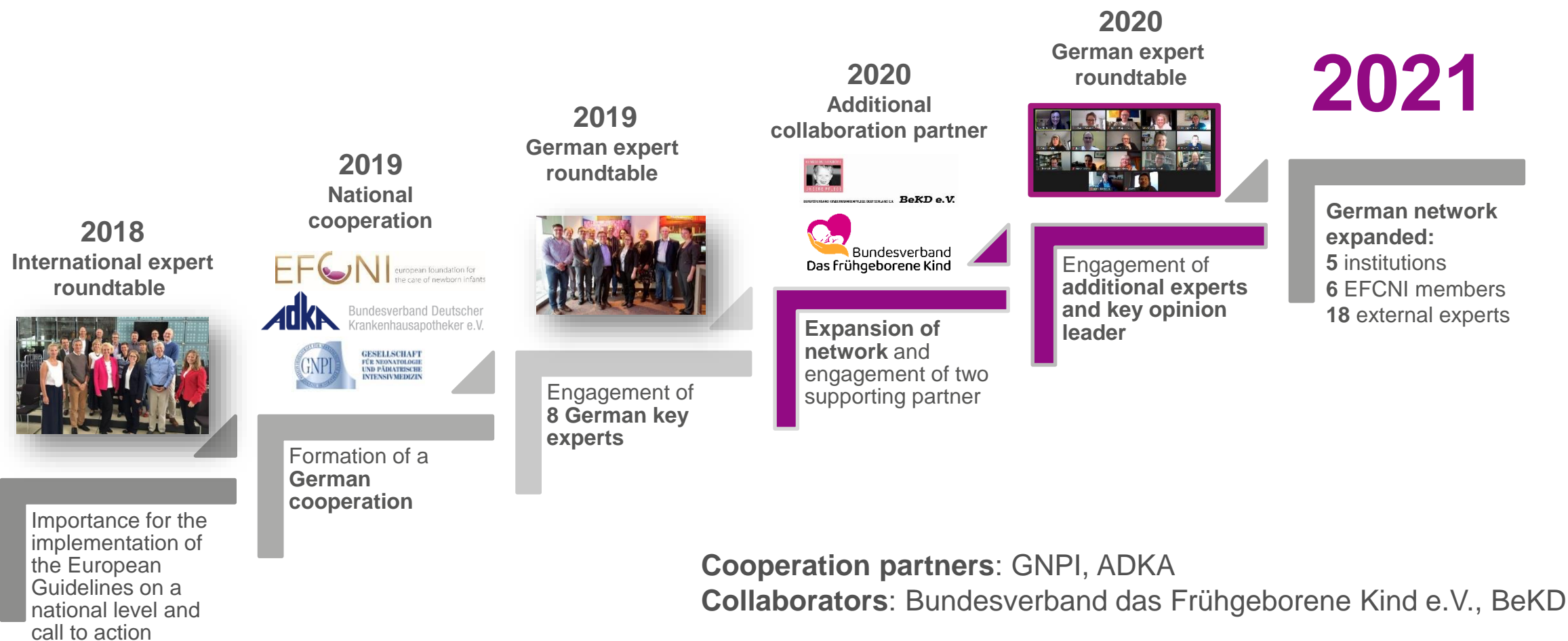


Access the brief on:
<https://nurturing-care.org/nurturing-care-for-every-newborn>

Projects on the topic *Nutrition*

1. Parenteral Nutrition: Barrier Analysis and Toolkit
2. International Program on Preterm Nutrition (IPPN)
3. Workshops on the topic „ The first 1000 days“
4. E-learning series: enteral preterm nutrition
5. Human Milk Matters campaign
6. EU regulation of Human Milk

Expanding a multidisciplinary network on parenteral nutrition in Germany



Achievements in the parenteral nutrition project in 2021

2020
2021

Online survey and digital expert roundtables



- Data collection during the COVID-19 pandemic, nationwide outreach
- Two digital roundtables, discussion of identified barriers and solutions to overcome barriers
- Extension of network: 'Bundesverband das Frühgeborene Kind e.V.' (BVDfK), 'Berufsverband Kinderkrankenpflege Deutschland e.V.' (BeKD)

2021

Scientific publication on implementation barriers in Germany (Barrier Analysis)

'Parenterale Ernährung in deutschen Perinatalzentren – Ergebnisse einer Umfrage zu Barrieren der klinischen Anwendung'



- Published in the [Monatszeitschrift Kinderheilkunde](#) in June 2021
- Open access license purchased



Achievements in the parenteral nutrition project in 2021

2021

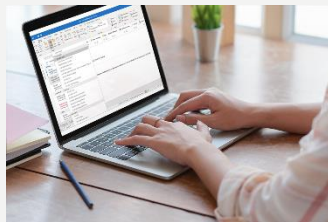
Toolkit

'Toolkit für die parenterale Ernährung von Früh- und kranken Neugeborenen – Von der Leitlinie in die multidisziplinäre Anwendung'



- Basis of advice: European Guidelines on PN and experiences of the expert panel
- Hands-on solutions and practical recommendations to overcome barriers, tools, templates
- Launched at GNPI congress 2021, within EFCNI-GNPI-ADKA collaboration and supported by BVDFK, BeKD,

Scientific publication on elaborated solutions (Toolkit publication)



- Project summary written as Short communication / research letter
- Published in [Zeitschrift für Geburtshilfe & Neonatologie](#) in November 2021

2022

Further activities in 2022 are planned, e.g. a Factsheet



Communication achievements and activities in parenteral nutrition project

Three additional articles to disseminate achievements among the target group, published in

- June edition of the magazine of the BVDfK
- July edition of the **Fachzeitschrift Kinderkrankenschwester**
- August edition of the **Fachzeitschrift Kinderkrankenschwester**
- Promotion on social media, website and monthly newsletter



Ergebnisse einer Umfrage zu Barrieren in der klinischen Anwendung

Eine angemessene Nährstoffzufuhr – vor allem in den ersten 1.000 Lebenstagen – ist für das Wachstum und die gesunde Entwicklung Neugeborener von entscheidender Bedeutung [1-3]. Bei einigen Frühgeborenen und kranken Neugeborenen ist eine ausschließlich orale Ernährung aufgrund der physiologischen Unreife ihres Verdauungstraktes allerdings nicht möglich [4]. Um dennoch eine angemessene Versorgung und ein adäquates Wachstum sicher zu stellen, erhalten diese Neugeborenen über eine Magensonde (enteral) geringe Mengen an Mutter- oder Spenderinnenmilch sowie in manchen Fällen eine parenterale Ernährung. Bei der parenteralen Ernährung werden Nährstofflösungen direkt per Infusion in die Blutbahn injiziert [5]. Die parenterale Ernährung ist zwar für einige Früh- und kranke Neugeborene eine notwendige Therapieform, kann aber unerwünschte Komplikationen nach sich ziehen.

Dr. Julia Hoffmann, Sarah Fügenschuh und Silke Mäder

Evidenzbasierte Empfehlungen

Nationale und internationale Leitlinien liefern evidenzbasierte und praktische Empfehlungen, um die Anwendung der parenteralen Ernährung bei Früh- und kranken Neugeborenen so sicher wie möglich zu gestalten (4,8-9). Trotz dieser Empfehlungen wurden jedoch in der Vergangenheit vermehrt Behandlungsfehler gemeldet [6,10].

Daher hat sich die „European Foundation for the Care of Newborn Infants“ (EFNCNI) gemeinsam mit der „Gesellschaft für Neonatologie und pädiatrische Intensivmedizin“ (GNPI) und dem „Bundesverband deutscher Krankenhauspäthologen e.V.“ (ADKA) zusammengeschlossen, um die Anwendung der europäischen Leitlinien zur parenteralen Ernährung von Früh- und kranken Neugeborenen im deutschsprachigen Raum voranzutreiben. Diese wurden zuletzt im Jahr 2018 von der „European Society for Paediatric Gastroenterology Hepatology and Nutrition“ (ESPGHAN), der „European Society for Clinical Nutrition and Metabolism“ (ESPEN), der „European Society for Paediatric Research“ (ESPR) und der „Chinese Society of Parenteral and Enteral Nutrition“ (CSPEN) aktualisiert. Unterstützt wird diese EFNCNI-ADKA-GN-

1 Als europäische Leitlinie bezeichnet.



Communication achievements – social media activities around the launch

Three social media series

- **Teaser-series in June 2021:** To promote the topic, raise awareness on PN and teaser the launch of the toolkit among German-speaking HCPS
- **Post-launch series in July 2021:** To promote the toolkit and barrier analysis among German-speaking HCPS
- **Pre-jENS social series in September 2021:** To raise awareness and promote on activities among English-speaking HCPs, to promote the EFCNI session on 'Safe and Optimal nutrition' at the jENS 2021 and the talk of Prof. Fusch

Cooperation partners: GNPI, ADKA
Collaborators: Bundesverband das Frühgeborene Kind e.V., BeKD



Scientific dissemination at national and international conferences

- Kick-off talk of Prof. Fusch at the EFCNI Session on 'Safe and Optimal nutrition' at the **GNPI 2021** (80 participants)
- Talk of Prof. Fusch on 'Challenges to ensure optimal and safe parenteral nutrition of VLBW infants' at the EFCNI Session 'Safe and Optimal nutrition' at the **jENS 2021**
- Poster presentation at the congress of the German Society for Perinatal Medicine (**DGPM**) in November 2021
- Poster presentation at **ADKA** annual congress in May 2022
- The topic of safe parenteral nutrition will also be promoted at the **GNPI in May 2022**



Projects on the topic *Nutrition*

1. Parenteral Nutrition: Barrier Analysis and Toolkit
2. International Program on Preterm Nutrition (IPPN)
3. Workshop on the topic “The first 1000 days“
4. E-learning series: enteral preterm nutrition
5. Human Milk Matters campaign
6. EU regulation of Human Milk

Background



The IPPN programme is an educational initiative developed exclusively for Nestlé Enterprises S.A. (NESA) by the EFCNI Academy. It runs for 3 years.



The programme is available for healthcare professionals (HCPs) in all countries worldwide.

Target group: all HCPs engaged with managing preterm infants.



Participants of the programme are recruited and the program is disseminated under Nutrition Institute (NNI) and Wyeth Nutrition Science Center (WNSC) in the markets.



Curriculum and Faculties



Parenteral Nutrition

Professor Nadja Haiden, AT
Katarina Eglin, DE



HMOs and targeted Synbiotics

Professor Lars Bode, US
Mandy Daly, IRL



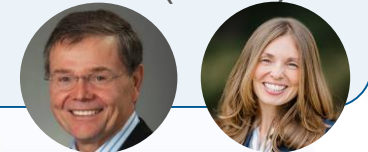
Human Milk for Preterm Infants

Dr Pieter Koorts, AUS
Livia Nagy Bonnard, HU



Modern Concepts in Preterm Necrotising Enterocolitis (NEC)

Professor Josef Neu, US
Jennifer Canvasser, US



Enteral Nutrition and Supplements

Dr Amy Hair, US
Oleksandra Balyasna, UKR

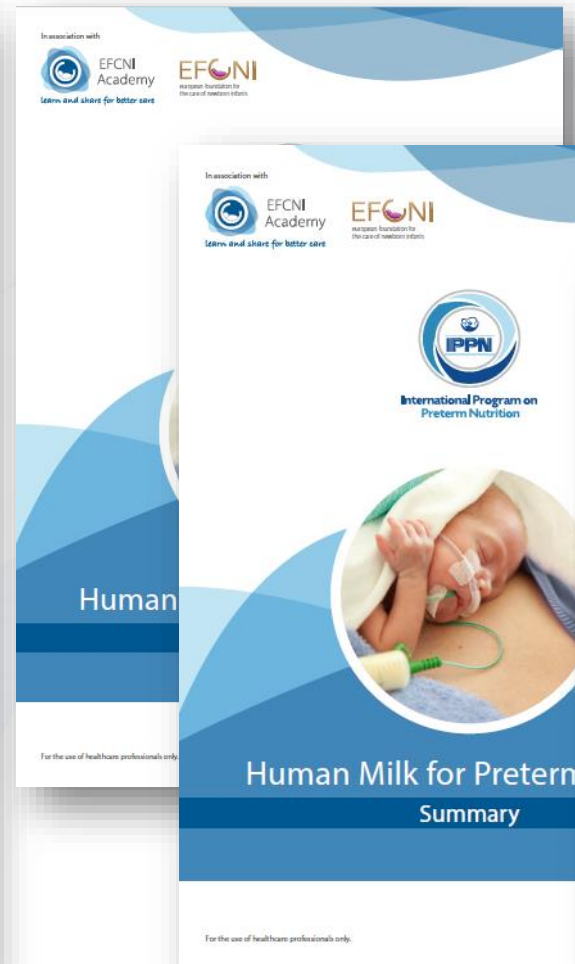


Growth Monitoring in NICU and Post-Discharge

Professor Nick Embleton, UK
Kylie Pussell, AUS



Collateral material



Feedback and Numbers



746

Enrolled HCPs



32

Countries



99%

HCPs have said the
content was 'relevant'
to their clinical
practice



90%

Completion rate



98%

HCPs have given an
average rating for the
**content as 'good
to excellent'**

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EFCNI Academy: Workshop on the topic “The first 1000 days”

- Life event in German: „Die ersten 1000 Tage – eine prägende Phase im Leben eines Kindes“
- 5 presentations from experts in the field of infant nutrition and newborn health
- Target group: midwives, nursing staff and physician assistants
- 30 participants

Fortbildungsveranstaltung:
Mittwoch, 13. Oktober 2021
Courtyard Munich City Center

Die ersten 1000 Tage
– eine prägende Phase im Leben eines Kindes

Wissenschaftliches Programm

Zeit	Thema	Dozent
14:00 - 14:15 Uhr	Eröffnung und Begrüßung	Alle Dozenten
14:15 - 14:30 Uhr	Ernährungsanforderungen und -empfehlungen während der Schwangerschaft und Stillzeit	Dr. Frank Jochims
14:30 - 14:45 Uhr	Die Bedeutung der Ernährung für die Gesundheit des Kindes	Dr. Frank Jochims
14:45 - 15:00 Uhr	Die Bedeutung der Ernährung für die Gesundheit des Kindes	Dr. Frank Jochims
15:00 - 15:15 Uhr	Die Bedeutung der Ernährung für die Gesundheit des Kindes	Dr. Frank Jochims
15:15 - 15:30 Uhr	Die Bedeutung der Ernährung für die Gesundheit des Kindes	Dr. Frank Jochims
15:30 - 15:45 Uhr	Die Bedeutung der Ernährung für die Gesundheit des Kindes	Dr. Frank Jochims
15:45 - 16:00 Uhr	Die Bedeutung der Ernährung für die Gesundheit des Kindes	Dr. Frank Jochims
16:00 - 16:15 Uhr	Die Bedeutung der Ernährung für die Gesundheit des Kindes	Dr. Frank Jochims
16:15 - 16:30 Uhr	Die Bedeutung der Ernährung für die Gesundheit des Kindes	Dr. Frank Jochims
16:30 - 16:45 Uhr	Die Bedeutung der Ernährung für die Gesundheit des Kindes	Dr. Frank Jochims
16:45 - 17:00 Uhr	Die Bedeutung der Ernährung für die Gesundheit des Kindes	Dr. Frank Jochims
17:00 - 17:15 Uhr	Die Bedeutung der Ernährung für die Gesundheit des Kindes	Dr. Frank Jochims
17:15 - 17:30 Uhr	Die Bedeutung der Ernährung für die Gesundheit des Kindes	Dr. Frank Jochims
17:30 - 17:45 Uhr	Die Bedeutung der Ernährung für die Gesundheit des Kindes	Dr. Frank Jochims
17:45 - 18:00 Uhr	Die Bedeutung der Ernährung für die Gesundheit des Kindes	Dr. Frank Jochims

Wissenschaftliche Redatoren

- **Prof. Dr. med. Frank Jochims**: Leiter des Instituts für Neonatologie und Kinderkardiologie, Universitätsklinikum Bonn
- **Dr. med. Maja Richter**: Leiterin des Instituts für Neonatologie und Kinderkardiologie, Universitätsklinikum Bonn
- **Dr. med. Ute Sauer**: Leiterin des Instituts für Neonatologie und Kinderkardiologie, Universitätsklinikum Bonn
- **Dr. med. Ute Sauer**: Leiterin des Instituts für Neonatologie und Kinderkardiologie, Universitätsklinikum Bonn
- **Dr. med. Ute Sauer**: Leiterin des Instituts für Neonatologie und Kinderkardiologie, Universitätsklinikum Bonn

ANMELDEN!

EFCNI Academy

EFCNI european foundation for the care of newborn infants

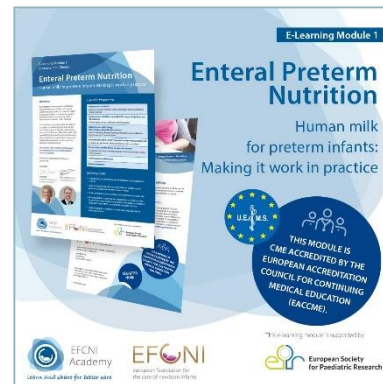


Projects on the topic *Nutrition*

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6. Human Milk Matters campaign
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EFCNI Academy: E-Learning Modules on Enteral Preterm Nutrition

- E-Learning Modules on Enteral Preterm Nutrition: www.efcni.org/activities/efcni-academy/enteral-preterm-nutrition
 - Module 1: Human Milk for preterm infants: Making it work in practice
 - Module 2: Human Milk Oligosaccharides: The magic ingredient
 - Module 3: Human Milk for preterm infants: Achieving optimal growth and outcomes
- CME accredited, January 2021-January 2023
- Target group: medical specialists and nursing staff working in the field of paediatrics, neonatology or infant nutrition
- Supported by ESPR



Projects on the topic *Nutrition*

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Human Milk Matters – Human Milk Cares – social media campaign

With the continued **Human Milk Matters – Human Milk Cares** campaign in 2021/2022, we are raising awareness for the enormous health benefits of human milk for babies born preterm or sick.


Key features of this campaign are:

- Providing facts and further information on human milk, milk banking, highlighting the safety aspect and the need for an EU regulation and EU-wide standardised practices
- Giving insights behind the scenes of milk banks and safe human milk donation
- Experts recommendations and statements
- Experiences of milk donors and former patients/receiving mothers
- Material also included interviews, infographics for social media, see: www.efcni.org/activities/campaigns/human-milk-matters
- Supported by: 



Human Milk Matters – Human Milk Cares – social media campaign

Flashmob 2021 / 2022

- The campaign used a storytelling element and created engagement of a wider public on the occasion of world day of human milk donation, 19 May sharing personal experiences of donors and recipients.
*17.500 impressions
- Supported by: 

2021



One cannot emphasize enough the importance that human milk has in the development of the baby's brain and neurological tissues, especially for premature babies. This is just one of the great advantages of human milk.

Mariza, Portugal

Human Milk Matters
Human Milk Cares

Share this post to help babies in need and support human milk banks.

Independently developed and powered by  EFCUNI
european foundation for the care of newborn infants

supported by  XXS

Human Milk Corporate Partner  Prolacta BIOSCIENCE

In collaboration with  UNPS
Union of European Neonatal & Perinatal Societies



I donated my breast milk in order to give preterm and sick babies a better chance for a healthy start in life.

Julie, USA

Human Milk Matters
Human Milk Cares


Share this post to help babies in need and support human milk banks.

Independently developed and powered by  EFCUNI
european foundation for the care of newborn infants

Human Milk Corporate Partner  Prolacta BIOSCIENCE

In collaboration with  UNPS
Union of European Neonatal & Perinatal Societies

2022




World Day of
Human Milk
Donation,
19 May

Let's share the power of Human Milk

#everydropcounts

Independently developed and powered by  EFCUNI
european foundation for the care of newborn infants

Human Milk Corporate Partner  Prolacta BIOSCIENCE

In collaboration with  UNPS
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Human Milk Regulation in the European Union

- Advocating the need for regulation of donor human milk and human milk banking in the European Union
- See: www.efcni.org/human-milk-regulation
- Developed one-pager “Preterm infant health and human milk”
- 2 successful expert roundtable discussions in June 2020
- Establishment of the EFCNI Working Group on Human Milk Regulation
- Collaborating partners: EMBA, ESPGHAN, ESPR, UENPS
- Development of policy recommendations “Making Human Milk Matter – The need for regulation in the European Union”
- Support by 46 professional healthcare societies and 32 parent organisations
- Digital launch event in November 2020



Human Milk Regulation in the European Union

- Published commentary in The Lancet Child and Adolescent Health
 - Making human milk matter: the need for EU regulation
[https://doi.org/10.1016/S2352-4642\(21\)00021-3](https://doi.org/10.1016/S2352-4642(21)00021-3)
- Continuing policy work in 2021/2022
 - Participation in the open and targeted consultation by the European Commission on the revision of the Blood, Tissues and Cells Directive
 - Participation in policy workshops by the European Commission April-June 2021
 - Further information regarding the revision of the EU legislation: [here](#)

Making human milk matter: the need for EU regulation

One in ten infants is born preterm worldwide, with an average preterm birth incidence of 8-7% in Europe.¹ Together with sick and low-birthweight infants, preterm babies belong to the most vulnerable group of patients and require special care, including nutrition. The mother's own milk is without doubt the preferred choice for infant feeding,² and exclusive breastfeeding during the first 6 months of life is recommended. However, when the mother's own milk is not available, donor milk from a human milk bank is the next best option, because of the undisputed health benefits of human milk.^{3,4} Furthermore, donor milk acts as a bridge to breastfeeding, with positive psychological and emotional effects for both mother and child.^{1,4}

In Europe, an increasing number of human milk banks provide this urgently needed nutrition.⁵ The process of human milk donation is complex, entailing (among other processes) screening and blood testing of donors and processing, preservation, storage, and distribution of donated human milk (appendix p 2). Furthermore, the European Directorate for the Quality of Medicines & HealthCare provides evidence-based recommendations for the establishment and operation of human milk banks.⁶

In view of the unique role and importance of human milk in infant nutrition, it is surprising and problematic that donor human milk (a substance of human origin) and human milk banking are currently unregulated not only at the EU level but also often on a national level.


Legal uncertainty regarding the status and handling of donor human milk provides a disincentive to adopt evidence-based practices about human milk-based nutrition. This uncertainty leads to scant access, concerns about safety, questions about funding and reimbursement, an increased administrative burden, and underutilisation of donor human milk in many neonatal units. These consequences are especially pronounced in countries where human milk bank services are not well established.⁷ The current challenges caused by the COVID-19 pandemic make issues related to human milk banking services even more pressing.⁸

The Human Tissues and Cells Directive (2004/23/EC), which currently does not include donor human milk, was



See Online for appendix

Revision of the EU legislation on blood, tissues and cells

In October 2020, the Commission adopted its Work Programme for 2021. The REFIT Annex (#37 p.15)   to the Work Programme includes the revision of

- Directive 2002/98/EC on safety and quality of human blood and blood components, and
- Directive 2004/23/EC on safety and quality of human tissues and cells and their implementing acts.

This revision comes after an [evaluation](#) of the legislation, published in October 2019, confirming that the legislation had improved safety and quality of blood, tissues and cells used for transfusion, transplantation or medically assisted reproduction. The evaluation also highlighted a number of gaps and short-comings which will be addressed to ensure the framework is up-to-date, fit for purpose and future-proof.

The initiative aims at

- updating the legislation in the direction of a more flexible alignment with scientific and technological developments
- tackling the (re-)emergence of communicable diseases, including lessons learnt from the COVID-19 pandemic
- focusing on the increasing commercialisation and globalisation of the sector
- removing from legislation many technical provisions, which will allow a faster update of standards
- possibly merging the basic acts into a single instrument.

The revision is planned to be adopted in the first quarter of 2022. The legal basis is provided by Article 168(4)(a) of the Treaty on the Functioning of the European Union.

In line with the Commission's [Better Regulation Guidelines](#), the legislative proposal will be preceded by an Impact Assessment, including the following steps.



Projects on the topic *Infectious diseases:*

1. RSV for all infants: Quality of Life; RSV patient booklet, patient videos and campaign, roundtable and position paper
2. RSV for preterm infants: Social media campaign #LittleLungs in multiple languages and translation of RSV factsheet and position paper
3. Awareness campaign: Pertussis vaccination during pregnancy

Status quo: There is currently no adequate information how severe Respiratory Syncytial Virus (RSV) infection leading to hospitalisation of the infant impacts the quality of life of affected families in different countries

Problem:

- RSV as a leading cause of lower respiratory tract infection in infants, globally accounting for more than three million hospital admissions and 60 000 deaths in hospitals for children less than 5 years of age in 2015
- Until today there is no licensed vaccine for RSV, leaving infants vulnerable to infection
- RSV infection is often associated with increased need for intensive care unit admission and mechanical ventilation, long-term complications, and caregiver stress and loss of work productivity
- Higher health care resource utilisation and costs

Aim: Gaining insights into and evidence on the impact on quality of life aspects of caregivers/parents with hospitalised infants (0-2 years) with RSV infection in four European countries

Project countries: Germany, Sweden, Italy, France



ResQ Family Project – current status and timeline

Phase A – From conceptualisation to publication of results in international journal
(Phase A also includes general communication activities to support rollout and awareness)

Study design and conceptualisation

- Literature research
- Set-up **PEG** and **ESAB**
- Development of project identity, digital recruitment toolkit and questionnaire
- **Ethics application** (informed consent sheet and study protocol)

Survey set-up and network strengthening

- **Final questionnaire**
- Project communication (website, etc.) and recruitment strategy management

Data collection



- **Rollout** survey
- Track data collection

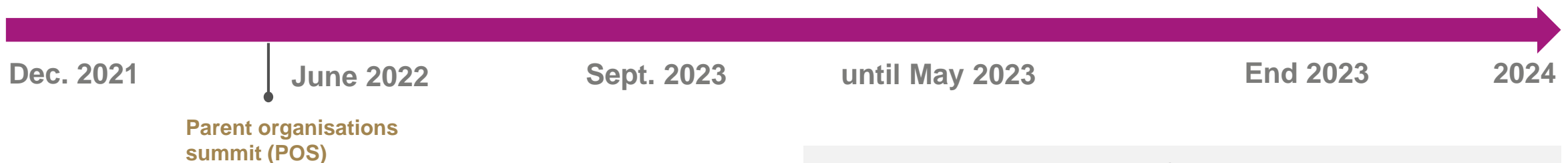
Data analysis and writing

- Data cleaning
- Quantitative data analysis with R
- Qualitative data analysis open question
- First **publication draft(s)**

Publication and follow-up



- **Submission** of manuscript
- Development of one-pager



Phase B – Dissemination of project results – campaigning



#RevealRSV – Social Media Campaign

The “Are you RSV aware” campaign is designed to raise awareness of RSV to protect all infants, especially among expecting and new parents, healthcare providers and caregivers.

The screenshot displays the EFCUNI website with a campaign banner and a sidebar. The banner features the EFCUNI logo, navigation links, and the text "Are you RSV aware? All infants need protection from RSV!" with three hashtags: #RevealRSV, #RSVPrevention, and #AllInfantProtection. The sidebar contains a video player with the title "RSV- Why parents of all infants should be aware of Respiratory Syncytial Virus" and a list of four topics: #REVEAL RSV: WHAT YOU SHOULD KNOW ABOUT RSV, #REVEALRSV: WHAT ARE THE SIGNS & SYMPTOMS OF RSV IN INFANTS?, #RSVPREVENTION: HOW TO PROTECT ALL INFANTS FROM RSV?, and #ALLINFANTPROTECTION: WHAT TO CONSIDER AFTER AN RSV INFECTION.

EFCUNI european foundation for the care of newborn infants

ABOUT US - ACTIVITIES - HEALTH TOPICS - NETWORK - SUPPORTERS - DONATE

Are you RSV aware?

All infants need protection from RSV!

#RevealRSV
#RSVPrevention
#AllInfantProtection

Are you RSV aware? All infants need protection from RSV!

RSV or "Respiratory Syncytial Virus" is a seasonal virus that causes diseases of the respiratory tract. Like the common flu, the virus circulates year-round, but outbreaks occur most often in the colder months, such as autumn, winter and spring. RSV infections are found worldwide. They are the most frequent cause of respiratory infections in all children and, as a result, a major cause of hospital admissions globally. In fact, about 3 million children are hospitalised each year due to RSV, 75% of whom are infants younger than one year.[1]

- + #REVEAL RSV: WHAT YOU SHOULD KNOW ABOUT RSV
- + #REVEALRSV: WHAT ARE THE SIGNS & SYMPTOMS OF RSV IN INFANTS?
- + #RSVPREVENTION: HOW TO PROTECT ALL INFANTS FROM RSV?
- + #ALLINFANTPROTECTION: WHAT TO CONSIDER AFTER AN RSV INFECTION

RSV- Why parents of all infants should be aware of Respiratory Syncytial Virus

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RSV Parent Testimonial Video Series

Video series with parent testimonials

- 4 testimonial videos from parents whose child had an RSV infection
- 4 countries: US, UK, France and Germany
- All videos are subtitled in English language
- Dissemination and communication through EFCNI channels, partner organisations, involved parent testimonials (their network, blogger) and Sanofi



Projects on the topic *Infectious diseases*:

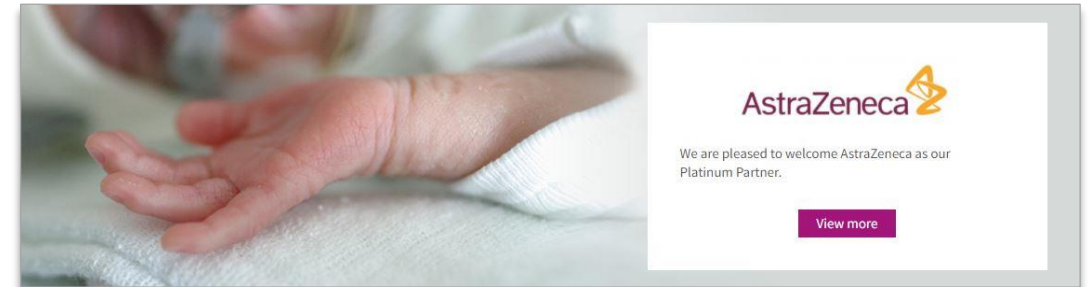
1. RSV for all infants: Quality of Life; RSV patient booklet, patient videos and campaign, roundtable and position paper
2. RSV for preterm infants: Social media campaign #LittleLungs in multiple languages and translation of RSV factsheet and position paper
3. Awareness campaign: Pertussis vaccination during pregnancy

Communication activities on RSV

- Focus topic: RSV in preterm and sick infants

Wide range of activities:

- Translation of RSV factsheet in 6 languages
- Interviews with experts on RSV
- Regular promotion of RSV topic on social media, in research news articles, advertorials and posts in EFCNI newsletter
- Involvement in ESCNH, development of a standard on immunisation
- Networking with parent organisations and other industry partners



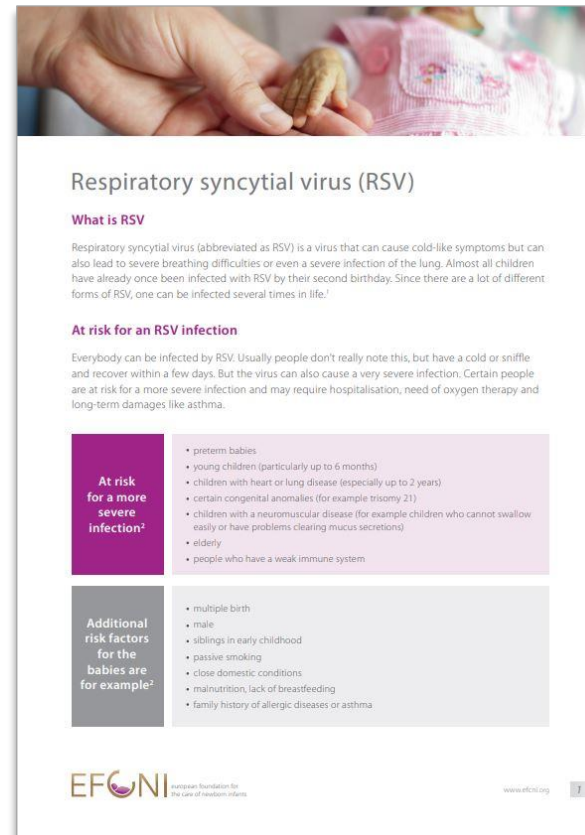
Respiratory Syncytial Virus (RSV)	
Respiratory Syncytial Virus (RSV) (in English)	Download
Respiracní syncytiální virus (RSV) (in Czech)	Download
Das Respiratorische Syncytial-Virus (RSV) (in German)	Download
Αναπνευστικός συγκυτιακός ιός (RSV) (in Greek)	Download
Respiratory syncytial virus (RSV) (in Hungarian)	Download



RSV for preterm infants

With targeted information material, we aim to raise awareness and educate on the topic of RSV in at-risk children:

- **Campaign Page**
- **RSV Factsheet - targeted at lay audience**
- **RSV Position Paper – targeted at HCPs**



#LittleLungs – RSV Social Media Campaign

With the **#LittleLungs** campaign, we raise awareness of the increased risk of RSV infection in infants born preterm or sick.

- Campaign period: 24.11.-3.12.202
- Languages: 7 (EN, FR, DE, HU, IT PT, ES)

Key features of this campaign are:

- Providing facts and further information on the RSV virus, its incidence and distribution
- Signs & Symptoms of RSV infection
- Risks for immature “little lungs” and supportive care measures
- Education on preventative measures to protect infants from contracting RSV



Projects on the topic *Infectious diseases*:

1. RSV for all infants: Quality of Life; RSV patient booklet, patient videos and campaign, roundtable and position paper
2. RSV for preterm infants: Social media campaign #LittleLungs in multiple languages and translation of RSV factsheet and position paper
3. Awareness campaign: Pertussis vaccination during pregnancy

Awareness campaign: Pertussis vaccination during pregnancy

- Campaign slogan: “Schutz schon vor dem ersten Atemzug” – “Protected even before the first breath”
- Objectives of campaign
 - Inform and educate the general public as well as HCPs and parents-to-be, increase knowledge about the dangers of pertussis for babies
 - Raise awareness for vaccination as preventive measure, raise acceptance levels for vaccination
- Target groups:
 - Pregnant women and their families and friends
 - Medical professionals (gynaecologists, paediatricians, midwives, ...)
- Supporters:
 - Supported by seven medical societies and one national parent organisation



Awareness campaign: Pertussis vaccination during pregnancy

- Social media platforms:
Instagram/Facebook for younger community, pregnant women;
Linkedin/Twitter for experts and professionals

Neugeborene verfügen über **keinen eigenen Schutz** gegen Pertussis und können daher besonders leicht erkranken.

Schutz schon vor dem ersten Atemzug:
Eine Impfung während der Schwangerschaft kann Neugeborene vor Pertussis schützen.

powered by **EFCNI** european foundation for the care of newborn infants
mit freundlicher Unterstützung von **gs**

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in Kooperation mit **AG G** **Bund der Geburt** **Deutscher Berufsverband für Kinder- und Jugendärzte e.V.** **DGPGM** **DGPI** **DSM** **Deutscher Stomatologischer Verein e.V.** **Deutscher Zahnärzteverband e.V.** **Deutscher Fachschriften-Verlag e.V.** **Deutscher Fachschriften-Verlag e.V.** **Deutscher Fachschriften-Verlag e.V.**

Eine Impfung während der Schwangerschaft kann Ihr Baby vor Keuchhusten schützen.

mit freundlicher Unterstützung von **gsk**

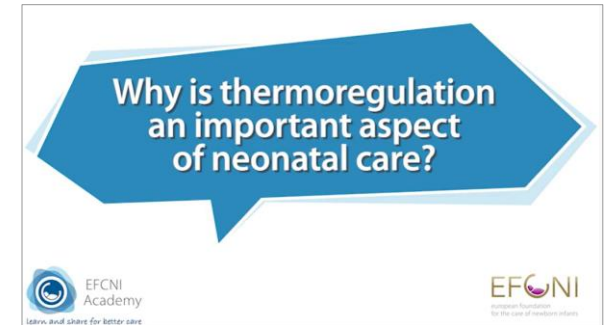


Projects on the topic *Patient safety*:

1. Thermoregulation

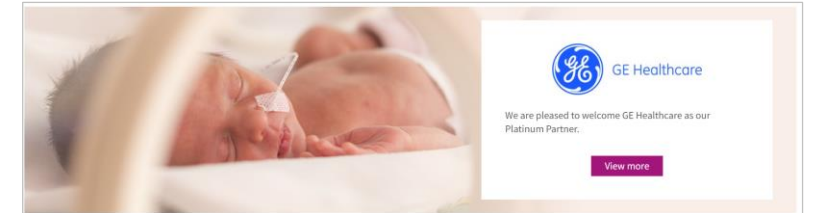
EFCNI Academy: Thermoregulation

- Video interviews with Dr. Mark Johnson, Southampton University Hospital, and neonatal nurse Anna Kalber, published on EFCNI Academy page
- Interview story with Dr. Alok Sharma, Southampton University Hospital, published on EFCNI Academy page
- Factsheet translated, edited, designed and published on the EFCNI Academy page in 5 different languages (HU, FR, ES, RU, DE). Promotion of each translation on EFCNI channels
- Translation and adaptation of factsheet for healthcare professionals in Ghana and Nigeria



Communication activities on Thermoregulation

- Focus topics: thermoregulation, resuscitation, infant falls, home phototherapy
- Wide range of activities:
 - Adapt and translate factsheet on thermoregulation for African settings
 - Interviews with experts on thermoregulation, resuscitation, ...
 - Regular promotion of topics and content on social media and newsletter
 - Involvement in ESCNH, give input on the development of a standard on thermoregulation
 - Networking with parent organisations and industry partners



Thermoregulation in preterm infants

Regulation of body temperature is a basic aspect of newborn care. In preterm born babies, this is particularly important since hypothermia is associated with a greater risk of morbidity and mortality. Temperature control can be achieved through various care practices.

For more information on thermoregulation please download our newly developed **factsheet**. It is available for download in **English, German, Spanish, French, Hungarian, and Russian**.

[Download factsheet \(EN\)](#)

[Download factsheet \(DE\)](#)

[Download factsheet \(HU\)](#)

[Download factsheet \(ES\)](#)

[Download factsheet \(RU\)](#)

[Download factsheet \(FR\)](#)





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