Activities and Milestones of EFCNI

Year: 2019

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Overview

1. EFCNI Network
2. European Standards of Care for Newborn Health
3. Roundtable, expert meetings and position papers
4. EFCNI Academy
5. Communication and Campaigning
6. GLANCE
7. Research projects and publications
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
Empowering parents - key drivers of today: The Parent Organisations Summit in 2019

• In 2019: 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

• Next Meeting: 24 – 26 January 2020 in Freising, Germany
Empowering parents – key drivers of today: EFCNI training workshops throughout the year 2019

• Workshop for parents/patients on
  • "How to organise an expert roundtable" in June 2019
  • First Level IV workshop for the European standards of Care for Newborn Health in November 2019

Upcoming workshops:
• Second Level IV workshop for the European Standards of Care for Newborn Health in February 2020
Milestones in improving maternal and newborn health

- **2008** Declaration of Rome
- **2008** EU Benchmarking Report
- **2011 / 2012** European White Paper & Call to Action
- **2013 - 2019** European Standards of Care for Newborn Health
- **2019 and beyond** Rollout, implementation

**Background, challenges, recommendations**

- Key finding: Different practices, lack of standards
- Standards to increase quality of care
- Need for change

**Establishment of reference**

- State of the art

- **Bringing theory into practice**
- **National implementation**

- **Catalogue of 10 demands for preterm infants**
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Overview of the European Standards of Care for Newborn Health
Thanks to our supporting industry partners

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
Baxter was a project partner from 2017 to 2019
Philips was a project partner from 2018 to 2019
Start of the project in the European Parliament

- Official kick-off on the 7th of April 2014 in the EU parliament in Brussels
- Symbolic signing of the cooperation and participation in the project of politicians, presidents of various societies and parent representatives
Launch of the standards in November 2018

• Bavarian representation in Brussels
• Evening event

• European Parliament
• Afternoon session
Development process of the standards

1. Decision on standard topics by Chair Committee
2. Development of template for the standards by Chair Committee
3. First standard draft written by one or more responsible authors as members of the TEG
4. Editing process regarding grammar and common wording together with Chair teams
5. Peer review process: Feedback from the TEG members and EFCHI
6. In case additional user perspective is needed: Involvement of the Parents' Knowledge Forum and external experts
7. Approval by chairs
8. Review by the authors
9. Final formatting
10. Voting on the standards by the Chair Committee; 80% yes votes needed
11. Chairs voted on every single standard separately

- 36 members
- 220 authors
- Support by >170 organisations
- Launch of the standards and the Call to Action in Brussels and publication on: https://newborn-health-standards.org
- Revision of the standards after a certain life cycle and extension of the standard topics
- Life Cycle
- Implementation
- Support of the standards by healthcare societies, parent/patient organisations, and related Third Parties
Implementing the standards: Supporting healthcare professional societies

Support of 120 international and national healthcare professional societies
Implementing the standards: Supporting parent organisations

Support of 51 parent organisations
Neonatal care – divided into 11 areas
= 11 Topic Expert Groups (TEGs) – 96 standards

→ Aim is to cover the complexity of neonatal care
Implementation of the European Standards of Care for Newborn Health

Decision on standard topics by Chair Committee

Development of template for the standards by Chair Committee

First standard draft written by one or more responsible authors as members of the TEG

Proof of content by the TEG's Chair team

Peer review process: At least one feedback loop with the TEG members and EFONI

In case additional user perspective is needed: Involvement of the Parents' Knowledge Forum and external experts

Review by the authors

Final formatting

Voting on the standards by the Chair Committee; 80% yes votes needed

Revision of the standards after a certain life cycle and extension of the standard topics

Launch of the standards and the Call to Action in Brussels and publication on: https://newborn-health-standards.org

Support of the standards by healthcare societies, parent/patient organizations, and related Third Parties

Now it's time to act!

Implementation
Implementation of the standards: EFCNI's roadshow in 2019

Sessions at
- The German congress of neonatal and paediatric society in Leipzig
- The jENS conference in Maastricht

Presentations at
- Congress of paediatrics in Brussels
- NIDCAP meeting in Brussels
- National conference of neonatology in Kiev
- WHO meeting in Geneva
- BAPM in Newcastle
- 40th UMEMPS Congress in Cagliari, Sardinia
- Conference: Bringing European Standards to Cyprus, Nicosia
- Conference on the standards in Leuven
- Neonatal emergencies symposium in Poznan
- 5th Global Summit in Vilnius
- 23e Journées Francophones de la Recherche Nationale in Paris
Free access to the standards: www.newborn-health-standards.org
Information and educational material for free download in 2019

**Social media graphics**

- Social media graphic “Support parents in their role as primary caregivers”
- Social media graphic “An investment in babies is an investment in the future”
- Social media graphic “Avoid the separation of mother and baby”
- Social media graphic “Working together – give parents and staff the chance to provide the best possible care for newborns”
- Social media graphic “Commit to evidence-based healthcare”

**PowerPoint templates**

We have provided a set of PowerPoint slides with information on the project for you to use. You can of course change the order of slides or delete slides. Please make sure to check back regularly to see if you are using the latest version!

- PowerPoint template “Introduction of the project” – standard format (version: 09/2019)
- PowerPoint template “Introduction of the project” – widescreen format (version: 09/2019)
- PowerPoint template “Presentation of the standards to politicians” – widescreen format (version: 09/2019)

**Factsheet**

Download the factsheet on the European Standards of Care for Newborn Health project

**Information brochure**

English original: Information brochure on the European Standards of Care for Newborn Health project

Translated versions:
- Bulgarian edition: Информационна брошура за Европейски стандарти за първата помощ на новородените
- German edition: Informationsbroschüre über die Europäischen Standards für die Versorgung von Frühgeborenen und kranken Neugeborenen
- Greek edition: Ευρωπαϊκή Πρόταση για τη Νοσηλεία των Νεογέννητων
- Ukrainian edition: Європейські стандарти допомоги для забезпечення здоров’я новонароджених

**Project report**

Download the report on the European Standards of Care for Newborn Health project
Information brochure on the European Standards of Care for Newborn Health in 2019

Translations of the whole standards into Ukrainian and Italian are planned for 2021!
Toolkit – launched at the jENS congress 2019

**Target group:** Parents and healthcare professionals

**Aim:** Support the implementation of the standards

**Content:**

1. Background information
   EFCNI, ESCNH, template, evidence-base, Statements per TEG

2. How to get started?
   Stakeholder mapping, Key negotiation skills, Building up a network, Organising expert meetings

3. Advocacy on EU and national level
   Presentation of politicians/HCPs, Call to Action for Newborn Health in Europe

4. Communication
   Strategy, Plan, Website, Newsletter, Press and media, Social media, Live communication
   Campaigning: 11 Months – 11 Topics, Born with the sign of a genius, Fathers in the NICU, World Prematurity Day

5. Materials
   Factsheet ESCNH/Preterm Birth, Call to Action Material, Information brochure, Project report, Presentation template, Image video, Publications
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
Promotion of the ESCNH: Training of parent representatives

2016
- Level I workshop:
  - Why standards
  - Country specific improvements
  - Challenges

2017
- Level II workshop:
  - Sharing best practice examples
  - Country specific implementations
  - 5-years-plan

2018
- Level III workshop:
  - In-depth knowledge about topics
  - Call-to-Action application
  - Stakeholder mapping & collaboration

2019 and beyond
- Level IV workshop:
  - Learning from each other
  - Presentation training
  - Development of a strategic plan

Outlook: „Tandem workshops“: joint trainings for healthcare experts and parents from one country
Implementation of the standards: activities of parent organisations in 2019

Parents organising own events:

- **Expert roundtable** with ministry of health on Follow-up in Bulgaria
- **Expert roundtable**: Why are standards needed in Estonia?
- **Set of seminars** and **roundtables** in Lithuania
- **Expert roundtable** on assessing the situation of standards on pain in Cyprus
- **Conference** on the standards in the course of WPD in Czech Republic
- **Expert roundtable** with UNICEF and ministry of health to prioritise the topics in Ukraine
- **Conference** with politicians with the aim of accepting the need for standards in Hungary
- **Strategy development** for the implementation of standards in Portugal
- **Presentation** of the standards at every single hospital to inform about the standards (Greece)
- **Establishment of 11 working groups** in Norway
- Presentation of the standards at the **ministry of health** in Slovakia
- **Global summit** on the standards in Lithuania
- **Conference** on the standards for nurses in Belgium

Presentation of the standards in conferences in:

- Cyprus
- Greece
- Ireland
- Czech Republic
- Hungary
- Turkey
- Norway
- Slovakia
Best practice example from XXS, national parent organisation in Portugal

- 16.-17. November 2019 in Coimbra, middle of Portugal
- Conference, focused on the implementation of the standards in collaboration with national healthcare professional societies
- Press release issued shortly before together with the Portuguese Neonatal Society, the National Paediatric Association and the Neonatal Nurses Association
- Participants: paediatricians, obstetricians, nurses, politicians, administrators, parents, psychologists, physicians, journalists
- Presentation of the European Standards of Care for Newborn Health
- Set-up of working groups

**Phase 0**
Disclosure and Presentation in Portugal

**Phase 1**
Creation of Executive Committee ESCNi-PT

**Phase 2**
Creation of Working Groups by Topic – 11 Groups

**Phase 3**
Identification of 3 priority standards for each topic and Actions for Implementation

**Phase 4**
Implementation of the Standards

ESCNiH
Presentation and disclosure of the Project to all Hospital Units and Main Stakeholders

Executive Committee ESCNi-PT
XXS / DGS / SPA / APEP/PT / Other Partners

Topic Groups
Identify heterogeneous groups with specialists for each topic (doctors, nurses, parents, other professionals relevant for the topic)

Identification of Priorities
Each Topic Group identifies 3 priority standards for each topic, relevant stakeholders and actions to execute

Implementation of the Standards
Implementation of the Standards in all units of the country, according to defined implementation plan
Best practice example from XXS, national parent organisation in Portugal

Govern Model of the ESCNH-PT Implementation

- January:
  - 1st MEETING – “KICK OFF” W/ EACH OF THE 11 GROUPS (DOS, DGSS SPN, APEPEN + Stakeholders)

- March:
  - MEETINGS FOR THE IDENTIFICATION OF STAKEHOLDERS

- May:
  - DEFINITION OF IMPLEMENTATION PLAN

- July:
  - MEETINGS W/ STAKEHOLDERS TO SUPPORT IMPLEMENTATION

- August:
  - DEFINITION OF IMPLEMENTATION PLAN

- September:
  - START OF IMPLEMENTATION

- November:
  - IMPLEMENTATION AND FOLLOW-UP
Implementation of the standards: activities of healthcare professionals

- Presentation of the standards at conferences in:
  - Italy
  - Serbia
  - Turkey
  - Spain
  - New Zealand
- Mentioning of the standards in almost every session at the jENS conference
- Citations of the project in several publications
- Linking from professional websites to our standards
- Social media activities
Lifecycle of the standards – an outlook

- 3, 5, and 10 years lifecycle

- Launch 2018
- Revision 2021
- Revision 2023
- Revision 2028

- About 20 standards
- Open consultation phase (May-June 2020!)
- Authors revise the standards
- Editing
- Voting?
- Information to supporting organisations

- Launch at the jENS congress 2021 in Athens
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EFCNI roundtable and position paper on RSV, a process from 2018 to 2019

Expert roundtable in Munich (October 2018)

Professor Angelika Berger
Professor Maria K. Borszewska-Kornacka
Mandy Daly
Professor Egbert Herting
Dr Paolo Manzoni
Associate Professor Fabio Midulla
Professor Christian F. Poets
Professor Charles Christoph Roehr
Professor Elie Saliba
Professor Manuel Sánchez Luna
Dr Renate Swarte
Dr Miklós Szabó
Dr Eleni Vavouraki
Professor Sven Wellmann
Professor Luc Zimmermann

EFCNI (Simone Cramer, Silke Mader,
Dr Johanna Pfeil, Christine Schwaiger)
EFCNI position paper on RSV – supporters

• The position paper is officially supported by 55 national and european medical healthcare professional societies and 36 parent organisations
EFCNI position paper on RSV – media effective launch at the jENS conference 2019

• Official launch of the position paper at the EFCNI lunch symposium
• Distribution of the position paper at the EFCNI booth
• A promotion card for the position paper was distributed into every congress bag
• Social media activities around the launch of the position paper

• Next steps: Update of the position paper and translations into additional languages
EFCNI roundtable and position paper on neonatal parenteral nutrition
A process from 2018 to 2019

Expert roundtable in Munich (July 2018)

Professor Virgilio Carnielli
Professor Magnus Domellöf
Katarina Eglin
Professor Nicholas Embleton
Harald Erdmann
Professor Christoph Fusch
Professor Nadja Haiden
Professor Egbert Herting
Dr Martina Kohl
Professor Berthold Koletzko
Professor Alexandre Lapillonne
Dr Helen Mactier
Dr Sissel Moltu
Livia Nagy-Bonnard
Dr Mattias Paulsson
Dr Miguel Sáenz de Pipaón
Professor Manuel Sánchez Luna
Stephen Tomlin
Professor Hans van Goudoever
EFCNI (Philine Altebäumer, Silke Mader, Dr Johanna Pfeil)
The position paper is officially supported by 80 national and European medical healthcare professional societies and 34 parent organisations.
EFCNI position paper on PN – launch at the JENS conference 2019

- Official launch of the position paper in a session on “Patient safety and hygiene”
- Distribution of the position paper at the EFCNI and Baxter booth
- A promotion card for the position paper was distributed into every congress bag
- Social media activities around the launch of the position paper
EFCNI position paper on PN – Call to Action

• Implement the *Guidelines on Paediatric Parenteral Nutrition of the European Society of Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN), the European Society for Clinical Nutrition and Metabolism (ESPEN), the European Society of Paediatric Research (ESPR), and the Chinese Society of Parenteral and Enteral Nutrition (CSPEN)* into daily practice by translating them to national and hospital level guidelines
• Develop and implement a warning system for the early detection of errors and adaptation of processes
• Develop and implement an evidence-based computerised order entry system according to current guidelines with appropriate interfaces with the compounding units in hospitals adapted to the special needs of neonatal parenteral nutrition
• Increase research into optimal formulations and the long-term outcomes of infants treated with parenteral nutrition
• Develop and implement a benchmarking system to measure and compare the use of parenteral nutrition
• Implement antenatal preparatory conversations with mothers at high risk of having a preterm birth and include information about parenteral nutrition as well as counselling on breast milk expression in these conversations
• Provide accurate and reliable information to parents and families on parenteral nutrition
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EFCNI Academy - Approach

- Corporate design and wording defined. Logo and claim licensed
- 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)
- 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: Pilot project „Set-up of human milk banks“ in 2019

- Pilot project run in „D-A-CH region for 2nd year
  - 2 workshops in Germany in 2019 (Hamburg and Düsseldorf)
  - Target group: nurses, midwives, doctors
  - Presented at GNPI congress in Leipzig, Germany, in May 2019
  - CME accreditation
  - Scientific collaboration with LMU and local collaborations with hospitals/universities
  - Supported by national parent organisation
  - Kick-off for development of worldwide programme
  - Quality assurance through renowned scientific partners, expert trainers and standardisation

- Plans for 2020: new modules on the topic: “the first 1000 days”, TBD: continuation of “set-up of human milk banks”

- The Project ist financially supported by Nestlé Nutrition Institute
The development of the cross-national milk bank project

14 Healthcare societies and organisations from all three German speaking countries are supporting the milk bank project.

Financially supported by Nestlé Nutrition Institute.
EFCNI Academy: jENS congress – September 2019

- 3rd Congress of joint European Neonatal Societies (jENS) in Maastricht 17 to 21 September 2019
- EFCNI function and activities
  - Co-organiser
  - Responsible for 7 sessions 1 pre-congress course and 1 lunch session on RSV
  - Promotion platform of European Standards of Care for Newborn Health
  - EFCNI launches at jENS congress
  - Position paper on RSV incl. social media campaign
  - Position paper on parenteral nutrition
  - Toolkit of European Standards of Care for Newborn Health
„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 start to train in perinatal centres in Munich
• Involved partners:
  • EFCNI
  • LMU Munich Medical Centre (Prof. Andreas Flemmer)
  • INM (Institute for emergency medicine and management in medicine) of LMU (= provides training for LMU)
  • SIMcharacters (provides „Paul“ simulation doll and initial trainings)
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EFCNI communications: multi-channel approach

- Brochures and factsheets
- Campaigns
- Research communication
- Press releases
- Website
- Social media
- Newsletters
World Prematurity Day (WPD) – 17 November 2019

- 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
- 2019 motto and subthemes allowing broad participation:
  - “Born too soon: Providing the right care, at the right time, in the right place”
    - Empower Women to Lead Decision-Making for their Health
    - Ensure High Quality Care for Every Baby Everywhere
    - Provide Nurturing Care for the Best Start in Life
- EFCNI as co-administrator of the global WPD Facebook account
- Material available for free in many languages at www.efcni.org/worldprematurityday
This year's motto poster supported by 170 organisations

Born too Soon:
Providing the right care, at the right time, in the right place.

About 230 illuminations worldwide counted so far
Activities in about 100 countries and on all continents registered so far (as of Nov. 28)
Highlights of World Prematurity Day 2019:
World Prematurity Day 2019: Selection of events
Best practice examples from our industry partners joining WPD

We warmly thank our Corporate Partners for their great commitment to World Prematurity Day.
Campaign “A Strong Start for Little Heroes - 2019

• Successful cooperations with other project partners (including national scientific societies and other institutions)

• Hospitals are equipped with free event-material to celebrate the World Prematurity Day

• Content of event-material: information material, party material e.g. balloons, sockline and socks, presents for visitors as well as a present bag for mothers of premature babies at the NICU

• In 2019, more than 170 Neonatal Intensive Care Units (NICUs) at “A Strong Start for Little Heroes”.

• Lottery: participants can hand in a short summary of their event with pictures and can win a gourmet basket for the entire NICU team donated by Nestlé Nutrition.

• The campaign is financially supported by Nestlé Nutrition
Act early! Screen early! Pre-eclampsia campaign - 2019

Development of campaign material in several languages to raise awareness through the entire month of May with highlight on 22 May:

- Poster
- Flyer
- Email Signature Banner
- Facebook/Twitter Banner, Profile Banner, Supporters Collage
- 8 statements of key experts and affected parents
- 9 video messages with affected women and healthcare professionals
- Campaign is supported by international healthcare societies, parent organisations
- The Campaign is financially supported by ThermoFisher
Pre-eclampsia campaign: visual material in several languages and videos

ACT! Counsel every pregnant woman about pre-eclampsia
SCREEN! Offer pre-eclampsia screening in weeks 11-14 and advise for prevention for high-risk patients

Professor Gian Carlo Di Renzo
Professor and Chair of the Department of Obstetrics and Gynaecology, University of Perugia, Italy, Director of Reproductive and Pelvic Medicine Centre, Founder of the Perugian International and European School of Pelvic and Reproductive Medicine

Hyperensive disorders in pregnancy, and particularly pre-eclampsia, are critical contributors to the loss of mothers and babies. Therefore, we should manage these cases in appropriate settings with expert and trained personnel but mainly we should implement screening tests in early pregnancy to identify the high-risk mothers, in order to apply the new existing preventive tools.
Empower Parents – Enable breastfeeding: World Breastfeeding Week 2019

- 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
- 2019 EFCNI circulated a survey, asking mothers and experts in the field of nutrition for their input in regards to breastfeeding challenges and which kind of support significantly helps to enable breastfeeding. The answers were evaluated and visualised in a campaign poster.
- Translation of poster into 18 languages
- Development of 2 expert statements
Global Handwashing Day – 15 October 2019

„Wash your hands – it’s easy“ campaign

• Raise awareness for better hand hygiene both in hospital settings and at home
• Joint activities in collaboration with the Neven Subotic Foundation
• Several materials available, e.g.:
  • Card game for children (called “Seifetto”, “Seife” = Soap in German)
  • Information flyer on proper handwashing
  • Posters on proper handwashing in five easy steps
  • In development: materials for healthcare professionals
• 2019 focus of the campaign on “Patient safety and hygiene practice”
• Hand hygiene is included in RSV position paper
• Update of flyer content and English translation: target group HCPs
• Distribution of materials at jENS congress (pre-launch) and promotion on Global Handwashing Day
• Campaign website www.efcni.org/washyourhands
ROP awareness campaign - 2019

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!

Tools:
- EFCNI Video: https://www.youtube.com/watch?v=BaJjRt-xYTk&feature=youtu.be
- Facebook / Twitter banner
- E-Mail signature banner
- Social Media Campaign Posts
- Statements of healthcare professionals and parents
- Infographic on ROP
- Interview with Lukas and Silke Mader via Novartis Communication Channels

Timing:
- Teaser for ROP campaign on World Sight Day 2019 (10th of October)
- Start: World Prematurity Day
- End: Around Christmas time, maybe continuation until beginning of next year

- The campaign is financially supported by Novartis
ROP awareness campaign - materials

E-Mail signature banner

Facebook profile title

Social media post

Expert statement

Video
ROP awareness campaign – collaborating partners and supporting parent organisations

Collaborating partners (healthcare professional societies)

Supporting parent organisations
The power of the network: Newsletter

- 4 editions 2019
- 5000 readers
- Distribution online and via social media

Source: EFCNI
New/updated materials 2019

New materials:
• Toolkit „Shaping the future. Combining forces to improve newborn health“
• Position paper „Parenteral Nutrition“
• Position paper „RSV“
• Position paper „Camera systems in the NICU“ (French)
• Factsheet „Preterm birth“
• Factsheet „Pre-eclampsia“ (Hebrew)
• Factsheet „Why the first 1000 days in life matter“ (German)
• Factsheet „RSV“ (Czech)
• Brochure „GLANCE“
• Booklet Standards of Care

Updated/revised materials:
• Factsheet „Parenteral Nutrition“ (English) (2nd edition)
• Brochure „A healthy pregnancy“ (German)
• Factsheet „European Standards of Care for Newborn Health project“
• EFCNI corporate brochure
• Factsheet „Breastfeeding a preterm infant“
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<tr>
<th>Date</th>
<th>Location</th>
<th>Event Description</th>
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<tr>
<td>22 - 23 Feb.</td>
<td>Gießen, Germany</td>
<td>Gießener Neonatologie Symposium</td>
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<td>15 - 16 March</td>
<td>Berlin, Germany</td>
<td>&quot;Philips Symposium&quot;</td>
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<td>20 March</td>
<td>Augsburg, Germany</td>
<td>Preschool Teacher, training</td>
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<td>20 - 21 March</td>
<td>Brussels, Belgium</td>
<td>Belgian Society of Pediatrics</td>
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<td>26 March</td>
<td>Frankfurt, Germany</td>
<td>Bundesverband der Pharmazeutischen Industrie (BPI)</td>
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<td>29 March</td>
<td>Berlin, Germany</td>
<td>International Workshop on Prenatal Screening</td>
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<td>3 - 4 April</td>
<td>London, United Kingdom</td>
<td>Global Forum</td>
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<td>4 April</td>
<td>London, United Kingdom</td>
<td>WFPNM Congress</td>
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<td>8 April</td>
<td>Linz, Austria</td>
<td>B.F.G Konferenz</td>
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<td>9 - 12 April</td>
<td>Geneva, Switzerland</td>
<td>WHO Meeting Human Rights in newborn care</td>
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<tr>
<td>26 April</td>
<td>Salzburg, Austria</td>
<td>ÖANKK Treffen 2019</td>
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## Conferences/ congresses attended by EFCNI in 2019

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<tr>
<td>22-May</td>
<td>Brussels, Belgium</td>
<td>NIDCAP Conference</td>
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<td>23-25 May</td>
<td>Leipzig, Germany</td>
<td>GNPI Congress</td>
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<td>23-24 May</td>
<td>Kiev, Ukraine</td>
<td>Conference on Standardisation</td>
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<td>25 May</td>
<td>Munich, Germany</td>
<td>Stiftung Kindergesundheit</td>
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<td>5-8 June</td>
<td>Glasgow, Scotland</td>
<td>ESPGHAN Congress</td>
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<tr>
<td>7-8 June</td>
<td>Neuwied, Germany</td>
<td>Schwerpunktkongress Geburtshilfe &quot;Sanft und sicher&quot;</td>
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<tr>
<td>17 July</td>
<td>Munich, Germany</td>
<td>EUPATI conference Germany: Patient Involvement in Research</td>
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<tr>
<td>9. August</td>
<td>Tokio, Japan</td>
<td>Introduction to University Hospital</td>
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<tr>
<td>5-7 September</td>
<td>Romania</td>
<td>Conference on Standardisation</td>
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<tr>
<td>13 September</td>
<td>Newcastle UK</td>
<td>BAPM conference</td>
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<tr>
<td>17-21 September</td>
<td>Maastricht The Netherlands</td>
<td>jENS Congress</td>
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<tr>
<td>26-29. September</td>
<td>Berlin, Germany</td>
<td>DOG Congress (Deutsche Ophtalmologische Gesellschaft)</td>
</tr>
</tbody>
</table>
### Conferences/congresses attended by EFCNI in 2019

<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 October</td>
<td>Turin, Italy</td>
<td>EMBA Conference</td>
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<tr>
<td>16 October</td>
<td>New York, USA</td>
<td>Every Newborn Action Plan</td>
</tr>
<tr>
<td>24-26 October</td>
<td>Cagliari, Italy</td>
<td>UMPMUS Congress</td>
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<tr>
<td>1-3 November</td>
<td>Nicosia, Cyprus</td>
<td>Prematurity Conference</td>
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<tr>
<td>8 November</td>
<td>Prague, Czech Republic</td>
<td>Conference on Standards</td>
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<tr>
<td>14 November</td>
<td>Rotterdam, NL</td>
<td>NIDCAP/Erasmus Hospital</td>
</tr>
<tr>
<td>18 November</td>
<td>Leuven, Belgium</td>
<td>Conference on Standards</td>
</tr>
<tr>
<td>12 December</td>
<td>Paris, France</td>
<td>Journées Francophone de la Recherche Néonatale</td>
</tr>
</tbody>
</table>
Overview

1. Brief overview on EFCNI
2. European Standards of Care for Newborn Health
3. Roundtable, expert meetings and position papers
4. EFCNI Academy
5. Communication and Campaigning
6. GLANCE
7. Research projects and publications
Overview GLobal Alliance for Newborn CarE (GLANCE)
GLANCE at a glance

Vision:
Every baby receives the best start in life. Worldwide.

Mission

Topics

Activities

- Reducing mortality and morbidity
- Decreasing the burden of afflicted families
- Collaborating with multiple stakeholders
- Addressing disparities in care and policies
- Developing counter-initiatives and policies

Girls’ and women’s health
Pregnancy and birth
Newborn treatment and care
Follow-up and continuing care

Advocacy
Campaigning
Research
Education
Networking
GLANCE: First steps taken

- Initiated and coordinated by EFCNI
- Registered: 2018
- EFCNI presented GLANCE at the Every Newborn Action Plan (ENAP)-meeting in New York, spring 2019
- GLANCE Founding Committee meeting: Summer 2019 deciding on structure, organisation and first common project
- Launch of new GLANCE website and the Global Call to Action for Newborn Care on 17 November 2019
- Development of the first GLANCE brochure
- Election of GLANCE Committee; term of office 5 years: January 2020 – December 2025

www.glance-network.org
Website since 17 November 2019: www.glance-network.org

Domain name:
www.glance-network.org

You can find GLANCE on all respective social media platforms:

@GlanceNetwork
@GLANCE_Network
@glance_network
via sub-page of EFCNI
Global Call to Action for Newborn Care: supported by more than 170 organisations

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/
GLANCE Chair Committee

- Election of first Chair Committee of GLANCE in December 2019
- 20 renowned experts in the field of maternal and newborn health from 15 countries.
- Interdisciplinary, geographically diverse team with expertise in
  - Neonatology
  - Gynaecology/Obstetrics
  - Paediatric Nursing
  - Parental and patient representation
  - Ethical decision making
  - Global Non Governmental Organisations

- Outlook: First GLANCE Chair Committee meeting in June 2020 in Freising, Germany
Become supporter of GLANCE

• Funded through donations and other incoming grants.
• If you want to know about your possibilities to join this global movement, please contact: info@glance-network.org or contact us directly:

Silke Mader (silke.mader@glance-network.org) or Aurelia Abenstein (aurelia.abenstein@glance-network.org)
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Research participation

2015-2019: **SHIPS** – Screening to Improve Health in Very Preterm Infants in Europe  
(EU Horizon 2020: grant agreement No 633724);

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: grant agreement to be signed)
• Poster presentation at jENS „Real World Data - Hidden Treasure for Neonatal Research? European Parents' Opinion Survey“ Silvia Kolossa, Nicole Thiele, Johanna M. Walz, Mark A. Turner

• Poster presentation at DOG „Prevention, detection, documentation, and treatment of retinopathy of prematurity (ROP) – a newly developed European standard“ Walz JM, Hellström A, Hellström-Westas L, Zimmermann L, Buonocore, G, Mader S, Thiele N, Hård AL, Stahl A on behalf of the European Foundation for the Care of Newborn Infants (EFCNI), Munich, Germany

• Oral speech at DOG: „Frühgeborenenretinopathie aus Sicht betroffener Eltern“ Walz JM on behalf of the European Foundation for the Care of Newborn Infants (EFCNI), Munich, Germany

• Workshop at 23 Journées Francophones de Recherche en Néonatologie: „Transport néonatal. Enquête sur expériences parentales en Europe“ Nicole Thiele


EFCNI – Publications in 2019


Eckstein J, Mader S, Pfeil J, Schwaiger C on behalf of the European Foundation for the Care of Newborn Infants (EFCNI) (2019). Die European Foundation for the Care of Newborn Infants (EFCNI) stellt sich vor. Kinderkrankenschwester 38. Jg. Nr. 11

Eckstein J, Schwaiger S, Walz JM, Mader M on behalf of the European Foundation for the Care of Newborn Infants (EFCNI) (2019). Neue Qualitätsstandards verbessern Entwicklungschancen bei Frühgeborenen und kranken Neugeborenen. Kinder- und Jugendmedizin
Thank you very much for your attention!