

**From local to global – building up a
voice on maternal and newborn health
worldwide**

Silke Mader
Co-Founder and chairwoman GFCNI

Content

- From a private destiny expanding to a Global Movement: Improving maternal and newborn health across the world
- RSV projects and activities:
 - ResQ Family: Research project on Quality of Life of parents who had an infant hospitalised because of RSV infection
 - Are you RSV aware Campaign: Raising awareness
 - Information and education of public, parents and healthcare professionals
 - Policy and advocacy training for patient representatives

That's not what we have expected...



Our life didn't stop after the NICU stay - we had to learn to live with our destiny!



Babies born preterm do not only have a tough time during the first days or months of life. Preterm birth may affect us and our families for a lifetime.



Lukas Mader, 28 years old
born with 515 g at 25 weeks of gestation



Start small – think big, how everything has started

- Kick-off press conference in Berlin in 2008
- Publication on the financial burden of parents of preterm infants throughout the first 5 years of life.
- Experts and founder present data on a conference in Berlin
- First Parent Organization Meeting in Rome and foundation of World Prematurity Day as well as the EFCNI Declaration of Rome



Global Patient and Parent Organization Summit



10 years World Prematurity Day and the world becomes purple



European Standards of Care for Newborn Health - In a nutshell

Aim:

- Development of standards for the key topics in neonatal health in the context of an interdisciplinary European project

Focus:

- Preterm and ill newborn infants

Method:

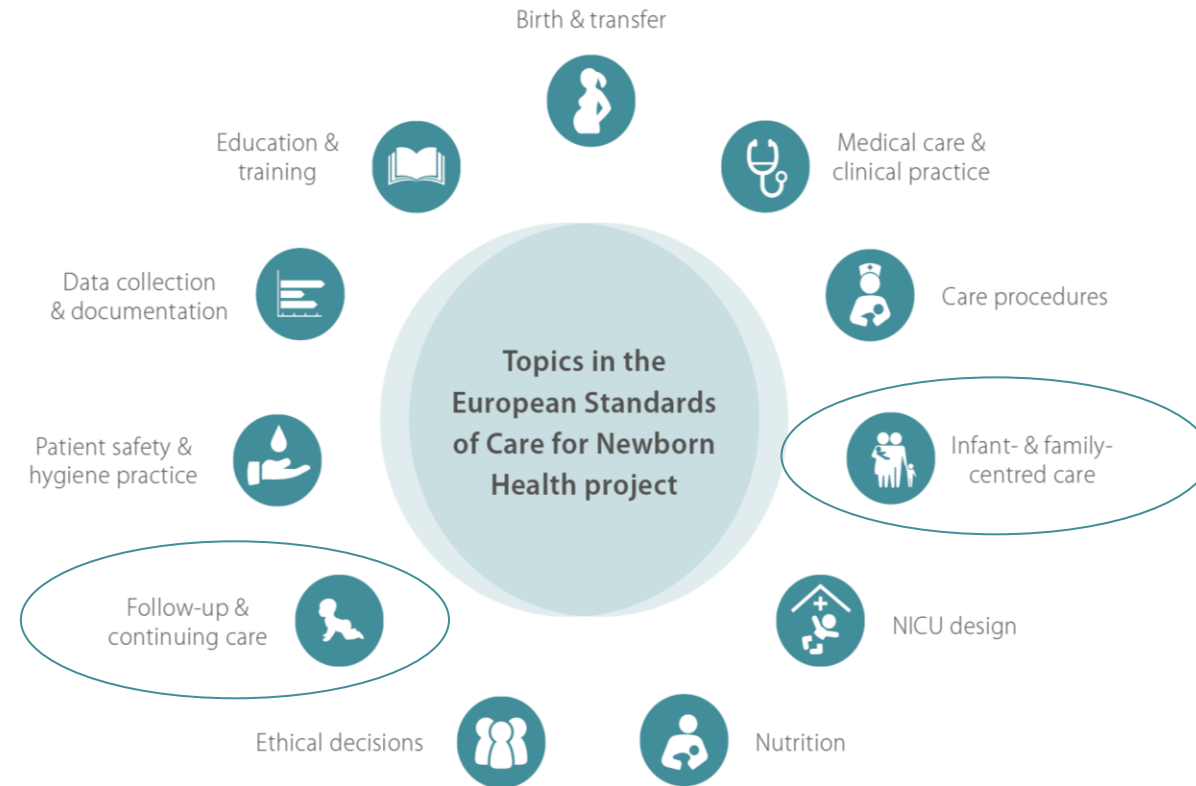
- Work in topic-specific expert groups; about 220 high-level experts of different professions, parent representatives and selected industry specialists from more than 30 countries
- Endorsed by over 170 professional associations and parent organisations worldwide

Development period:

- 2013 – 2018

Ongoing activities:

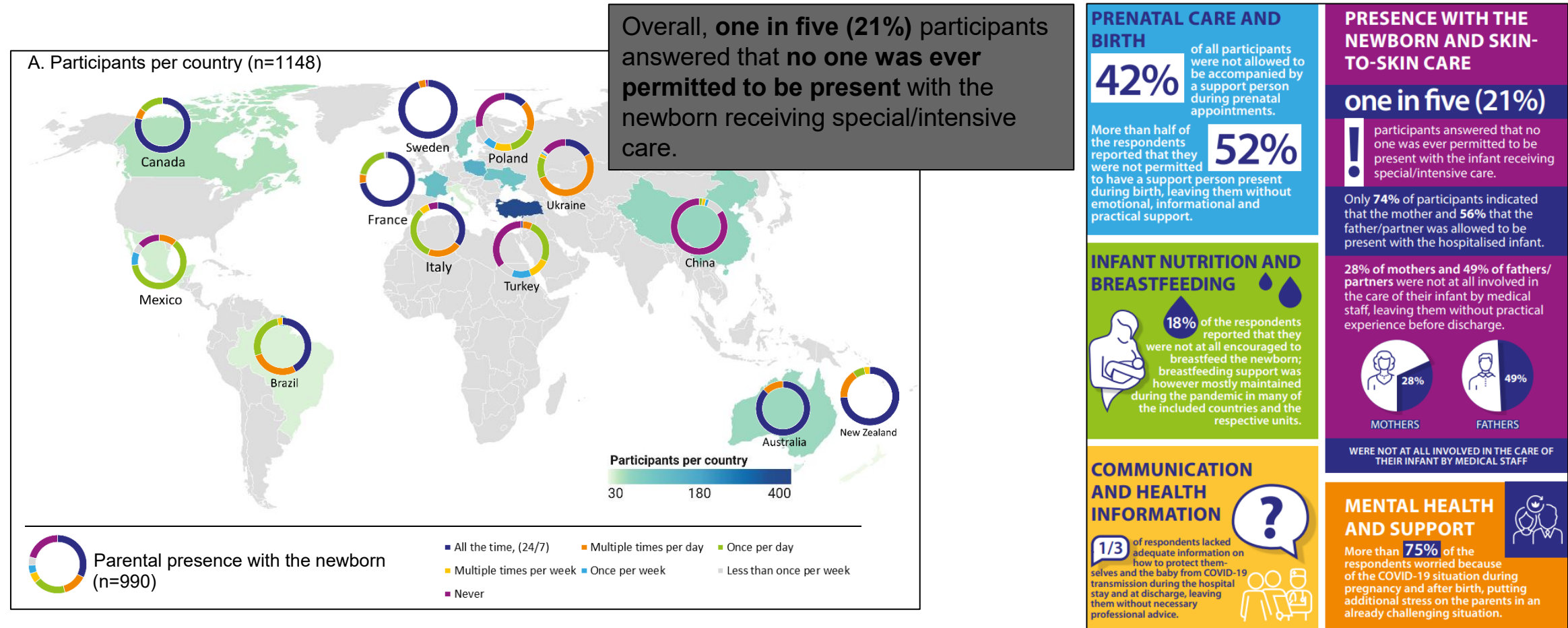
- Regular revisions and extensions
- National implementation



<https://newborn-health-standards.org/>



Results of first global parent survey during Covid-19 pandemic



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)

The screenshot displays the front page of a research article in E Clinical Medicine. The title is "Neonatal care during the COVID-19 pandemic - a global survey of parents' experiences regarding infant and family-centred developmental care". The authors listed are Johanna Kosterer, Julia Hoffmann, Charlotte von Rosenstiel-Puhler, Ailing Walsh, Luc J. Zimmerman, Silke Maier, and the COVID-19 Zero Separation Collaborative Group. The abstract states: "The COVID-19 pandemic revolutionized patient and family-centred care. This study explored parents' experiences regarding the impact of COVID-19 on their infants' care and family-centred developmental care during the pandemic." The page also includes a "Comment" section and "Open access" information, indicating it is available on BMJ Open.

The poster for the digital launch event features a blue background with a rainbow arc. The main text reads "Zero separation. Together for better care!" followed by "Infant and family-centred developmental care in times of COVID-19 – A global survey of parents' experiences". It announces a "DIGITAL LAUNCH EVENT" on Thursday, 11 November 2021, from 2:00-3:30 p.m. CET in English. The poster includes logos for the Global Alliance for Newborn Care, EFCONI (European Foundation for the Care of Neonatal Infants), COINN, European Society for Paediatric Research, nidcap, and LENFS.

This poster is similar to the one above but includes an image of the project report titled "Zero separation. Together for better care!". It features the same title and subtitle, but the event details are replaced by "Project Report available now!". The logos for the collaborating organizations remain the same.



EFCNIs involvement in WHO activities

- **WHO recommendations for care of the preterm or low-birth weight infants** launched 15th November 2022
- **Born too soon report:** launch in May at the International Maternal and Newborn Health conference in Cape Town
- Stage KMC documents (KMC Global Position Paper on *Kangaroo mother care: A transformative innovation in health care* and **Implementation strategy** for scale-up adaptable to different country contexts as well as **Lancet comment**):
- Focus World Prematurity Day 2023 again on Kangaroo Mother Care



WHO published in November 2022 the new recommendations

New strong recommendations

| | | | |
|--|--|---------|--------|
| A.1a Any KMC | Kangaroo mother care (KMC) is recommended as routine care for all preterm or low-birth-weight infants. KMC can be initiated in the health-care facility or at home and should be given for 8–24 hours per day (as many hours as possible). <i>(Strong recommendation, high-certainty evidence)</i> | Updated | Strong |
| A.1b Immediate KMC | Kangaroo mother care (KMC) for preterm or low-birth-weight infants should be started as soon as possible after birth. <i>(Strong recommendation, high-certainty evidence)</i> | New | Strong |
| B.4 Methylxanthines for treatment of apnoea | Caffeine is recommended for the treatment of apnoea in preterm infants. <i>(Strong recommendation, moderate-certainty evidence)</i> | New | Strong |
| B.5 Methylxanthines for extubation | Caffeine is recommended for the extubation of preterm infants born before 34 weeks' gestation. <i>(Strong recommendation, moderate-certainty evidence)</i> | New | Strong |
| C.1 Family involvement | Family involvement in the routine care of preterm or low-birth-weight infants in health-care facilities is recommended. <i>(Strong recommendation, low- to moderate-certainty evidence)</i> | New | Strong |
| C.3 Home visits | Home visits by trained health workers are recommended to support families to care for their preterm or low-birth-weight infant. <i>(Strong recommendation, moderate-certainty evidence)</i> | New | Strong |



Further policy and advocacy work on international level including WHO

- Attending stakeholder meeting on improving implementation strategy between regulatory bodies of the SoHo regulation on **donor human milk and human milk banking** in the European Union in October in Brussels.
- GFCNI is invited as **patient representative and advisor to join the guideline process** and to contribute to the elaboration of European-wide standards in the collection, screening, processing and storing of human donor milk.
- **2 The Lancet publications** as outcome of the **WHO working groups** in the field of maternal and newborn health on development of a Core Outcome Set for maternal and perinatal health for a potential next epidemic and pandemic situation and the new KMC guide.
- New project **“The Lancet Series on IFCDC”**. Equal partner together with WHO and London School of Hygiene and Tropical Medicine.

THE LANCET
Child & Adolescent Health

LANCET CAH SERIES ON
**Family Centered Care
for Vulnerable Newborns**

Key Goals:

- 1** Make it understood
- 2** Make it important
- 3** Make it sustainable

Person- and family-centered care are promoted by many agencies and groups as “the gold standard in neonatology”, but still major implementation and knowledge gaps exist. These gaps not only affect newborn mortality and morbidity, but also result in long term negative developmental outcomes for future generations and have an impact on families’ well-being and mental health. This is particularly relevant in times of mortality transition. Importantly, these gaps highlight suboptimal attention to the legitimate needs and human rights of newborns and their families. Because progress on newborn health and rights is stagnating in many countries, action is urgently needed.

This Lancet CAH series has been conceived to fill existing gaps and provide novel content available to researchers and policy makers, contributing to drive implementation of newborn- and family-centered care worldwide and in promoting newborn and family rights across the continuum of care and in different settings.

41 Members from 20 countries
in the 6 WHO Regions wide
International Advisory Group

For Contact at JENS:

Prof Marzia Lazzarini,
WHO CC, LSHTM

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Silke Mader,
GFCNI

WHO Collaborating Center for
Maternal And Child Health
Trieste Italy

LONDON
SCHOOL OF
HYGIENE
& TROPICAL
MEDICINE

GFCNI global foundation
for the care of
newborn infants



GFCNI Launch Campaign: "Connecting the World for Newborn Health"



SEARCH

Neonatal care: overview | Pregnancy and birth | **NICU experience** | Going home and growing up | Parent support

[Preparing to go home](#)

[Transitioning from the neonatal unit to home](#)

[Premie care at home](#)

[Follow-up care after the neonatal unit](#)

[Premie development](#)

[When can your baby go home?](#)

[Getting organised: what to expect](#)

[Checklist: Premie care and supplies](#)

[Preparing siblings: a new baby](#)

“ Make sure you always have enough oxygen at home. Plan ahead for weekends and public holidays and check your prescription so you can always order it on time. ”

Prof. Nicholas Embleton
Professor of Neonatal Medicine,
Newcastle University, United Kingdom

Voice

Types of Incubators

Incubators come in different designs to help with temperature regulation:

- Closed-box incubators: These have hand holes on the side to maintain heat and humidity, preventing excessive moisture loss from your baby's delicate skin.
- Open-top incubators: These feature overhead heaters and/ or heated mattresses.

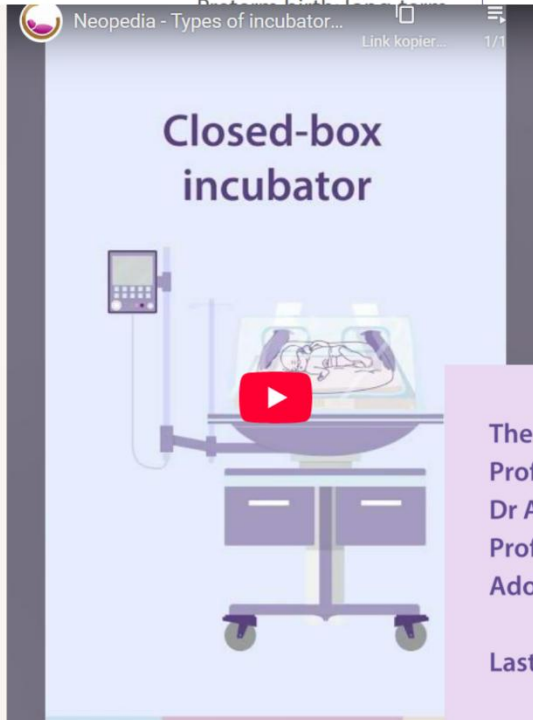
Temperature inside the incubator is managed in two ways:

- Manual controls: Adjusted by healthcare staff.
- Automatic sensors: These monitor your baby's skin temperature. If the sensor dislodges or malfunctions, an alarm alerts the nursing staff to check and adjust the incubator temperature.

Skin-to-skin or Kangaroo Mother Care should ideally begin within the first day – when possible, the first hour – of a baby's life and continue regularly thereafter. This practice not only aids in temperature regulation but also fosters a close connection and attentive care. However, it is important to acknowledge that many extremely preterm babies may struggle to maintain a stable temperature in skin-to-skin care due to their immature ability to regulate heat.

When the body temperature becomes too low, which can be harmful for babies.

While preventing hypothermia is a primary concern, it is equally essential to avoid hyperthermia (body temperature >38.0°C (100.4°F)). This can inadvertently occur



The information on this page was reviewed by Professor Nicholas Embleton, Professor of Neonatal Medicine, Dr Angela Gregoraci, Neonatal Paediatrician and NIDCAP Professional, and Dr Kai König, Specialist in Paediatrics and Adolescent Medicine, Neonatology.

Last updated in May 2025.



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- RSV projects and activities:
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Status quo: Information is scarce on how severe Respiratory Syncytial Virus (RSV) infection leading to hospitalisation of children impacts the quality of life of affected families in different countries

Problem:

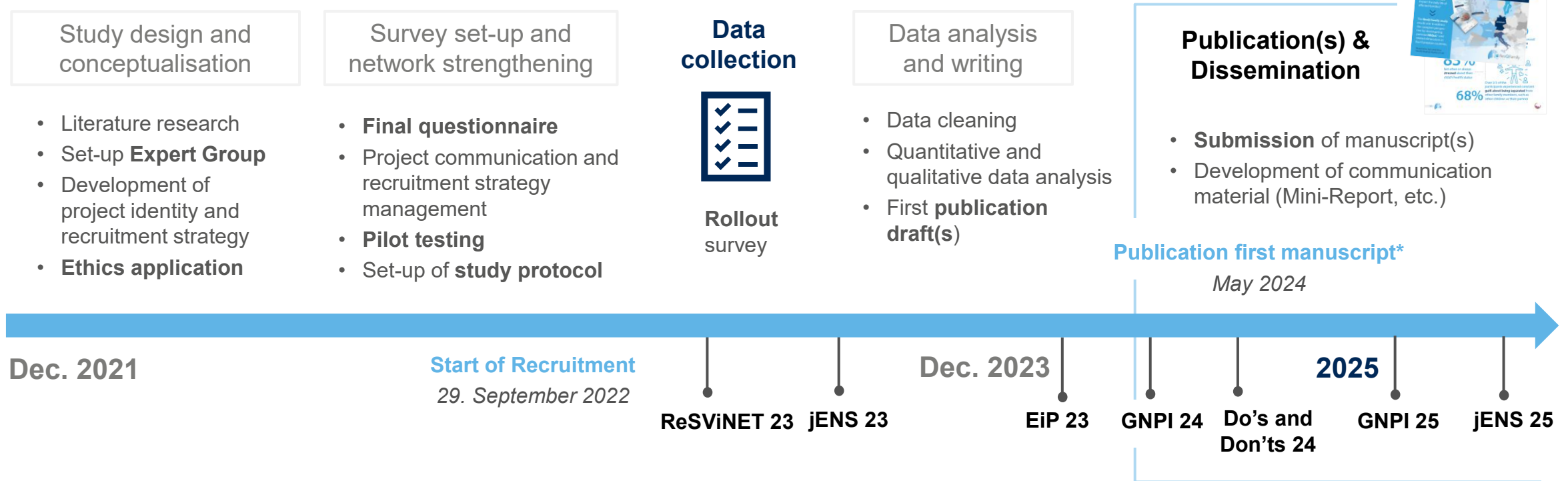
- Globally, on an annual scale, 33 million children under 5 years of age are diagnosed with RSV-associated acute lower respiratory tract infection (LRTI) resulting in more than three million hospital admissions each year
- Besides acute and directly visible effects of the disease (e.g. cough), RSV might also manifest in long-term physical complications (e.g. wheezing) and include psychosocial challenges for the entire family

Aim of the ResQ Family study: Gaining insights into and evidence on the impact on quality of life aspects of caregivers/parents of children (<24 months) hospitalised for RSV in four European countries and raising awareness among relevant stakeholders



ResQ Family Project: Important Milestones

Phase A – From conceptualisation to publication of results in an international journal



*Trautmannsberger I, Bösl S, Tischer C, Kostenzer J, Mader S, Zimmermann LJI, The ResQ Family Study Group. ResQ Family: Respiratory Syncytial Virus (RSV) Infection in Infants and Quality of Life of Families-Study Protocol of a Multi-Country Family Cohort Study. Int J Environ Res Public Health. 2023 May 23;20(11):5917. doi: [10.3390/ijerph20115917](https://doi.org/10.3390/ijerph20115917). PMID: 37297526; PMCID: PMC10252710.

Phase B – Dissemination of project results – campaigning



Health literacy and disease awareness

- More than 1/5 (22%) of all participants have not been aware of the disease and its possible complications/consequences for the child
- Almost half of all participants (49%) were not aware of the consequences of the child's RSV infection and hospitalisation for the whole family

Communication, health information and (mental) health support

- More than 71% of the respondents did not receive any information or did not feel adequately informed about mental health support
- 40% of the participants did not receive any information or did not feel adequately informed about how to protect the child (and their family) from a reinfection



France and Sweden showing significantly higher levels of disease awareness

Germany offering the fewest support structures



ResQ Family Project – Key discussion points

Particularly during the acute phase of a severe RSV infection, the quality of life of affected families is impaired.

Higher impact but more disease awareness in parents of preterm born infants

Despite the high educational level of the study population, knowledge about RSV was still scarce

Possible underestimation of RSV's emotional consequences by HCP leading to a lack of mental health support during hospitalisation

RSV-related hospitalisations in infants impose **a significant and diverse burden on the entire family with profound consequences for both personal and professional aspects of life.** (Standardised) holistic strategies that tackle both direct and structural obstacles to effective disease management are needed.



ResQ Family Project – (outlook) communication & dissemination

Phase A – From conceptualisation to publication of results in international journal



Phase B – Dissemination of project results – campaigning



- Regular target group-specific social media posts and distribution of printout materials to promote participation
- **May 2024:** First manuscript accepted
- Second manuscript currently in review

- Project Report & postcards
- (Country-specific) quote cards
- Research News
- Short motion video

- One-Pager
- Press Release (GER & IT)
- Thought Leadership Article
- Expert interviews

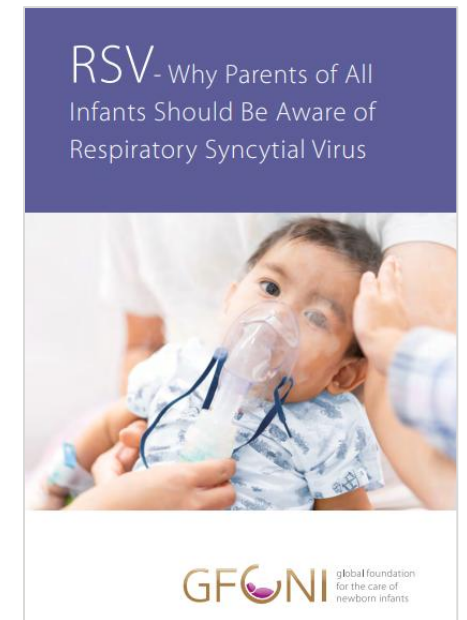


„Are you RSV aware?“ Campaigning for an all infant approach

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

All materials are translated and available in 5 campaign languages to help reach and educate more people about RSV in their mother tongue: English, French, German, Italian and Spanish. Available for download in 5 languages.

2024 campaigning with med-fluencer
2025 with patient representatives



GFCNI Academy: Factsheet on Respiratory Syncytial Virus (RSV)

- **Target group:** Healthcare professionals
- **Content:** Definition, prevalence, symptoms, risk factors, transmission, diagnosis, treatment, prevention, developments in research, communication with carers
- **Experts involved:**
 - Prof. Louis Bont, Chairman of the ReSViNET Foundation
 - Dr Elena Bozzola, IRCCS Bambino Gesù Children Hospital, Rome, Italy
 - Prof. Tobias Tenenbaum, Sana Klinikum Lichtenberg, Germany



What is RSV?
Respiratory Syncytial Virus (RSV) is a virus that may cause a wide range of diseases, ranging from mild upper respiratory illness to life-threatening lower respiratory tract infections (LRTI). Children and adults may be infected repeatedly by RSV.

How prevalent and severe is RSV?
It is estimated that 12.8 million RSV LRTI episodes, 2.2 million RSV-associated hospitalizations and 68,300 RSV attributable deaths occurred in infants in the first year of life in 2018. Most deaths occur in low and middle-income countries. Generally, it is not possible to predict which infants get seriously ill from RSV.

Usually, an RSV infection results in mild, cold-like symptoms. However, it is also a **main cause of hospital admissions** in infants and children.*

What are the symptoms of an RSV infection?*

| Mild course | Severe course | |
|---|---|--|
| Common cold with: <ul style="list-style-type: none"> • Cough • Fever • Rhinorrhea • Wheezing • Decreased appetite • Irritability • Decreased activity | Bronchiolitis with: <ul style="list-style-type: none"> • Cough • Fever • Wheezing • Croup • Subcostal retractions • Respiratory distress | Pneumonia with: <ul style="list-style-type: none"> • Apnoea • Nasal Flaring • Cyanosis • Hypoxemia • Dehydration |

Can usually be managed by a general practitioner or at home. Hospitalization is mostly necessary.

Potential long-term complications**


- Recurrent wheezing/ asthma
- Reduced lung functions/ increased airway reactivity
- RSV-related respiratory morbidity
- Decreased quality of life

EFCNI Academy logo and EFCNI logo are at the bottom.



RSV in preterm and high risk infants

- **# Little Lungs** awareness campaign
- **RSV Factsheet** - targeted at lay audience
8 languages: CZ,EN,ES,DE,GR,HR,IT,NL

Respiratory syncytial virus (RSV)

What is RSV

Respiratory syncytial virus (abbreviated as RSV) is a virus that can cause cold-like symptoms but can also lead to severe breathing difficulties or even a severe infection of the lung. Almost all children have already once been infected with RSV by their second birthday. Since there are a lot of different forms of RSV, one can be infected several times in life!

At risk for an RSV infection

Everybody can be infected by RSV. Usually people don't really note this, but have a cold or sniffle and recover within a few days. But the virus can also cause a very severe infection. Certain people are at risk for a more severe infection and may require hospitalisation, need of oxygen therapy and long-term damages like asthma.

| | |
|---|--|
| <p>At risk for a more severe infection*</p> | <ul style="list-style-type: none"> • preterm babies • young children (particularly up to 6 months) • children with heart or lung disease (especially up to 2 years) • certain congenital anomalies (for example trisomy 21) • children with a neurological disease (for example children who cannot walk or only to have problems (losing) vocal production) • elderly • people who have a weak immune system |
| <p>Additional risk factors for the babies are for example*</p> | <ul style="list-style-type: none"> • multiple birth • male • siblings in early childhood • passive smoking • close kinship conditions • non-smokers, lack of breastfeeding • family history of allergic diseases or asthma |

EFONNI European Foundation for the Care of Newborn Infants

Position paper

Respiratory syncytial virus (RSV) in preterm and ill infants



EFONNI European Foundation for the Care of Newborn Infants



Policy and advocacy training for patient representatives - on the example of RSV

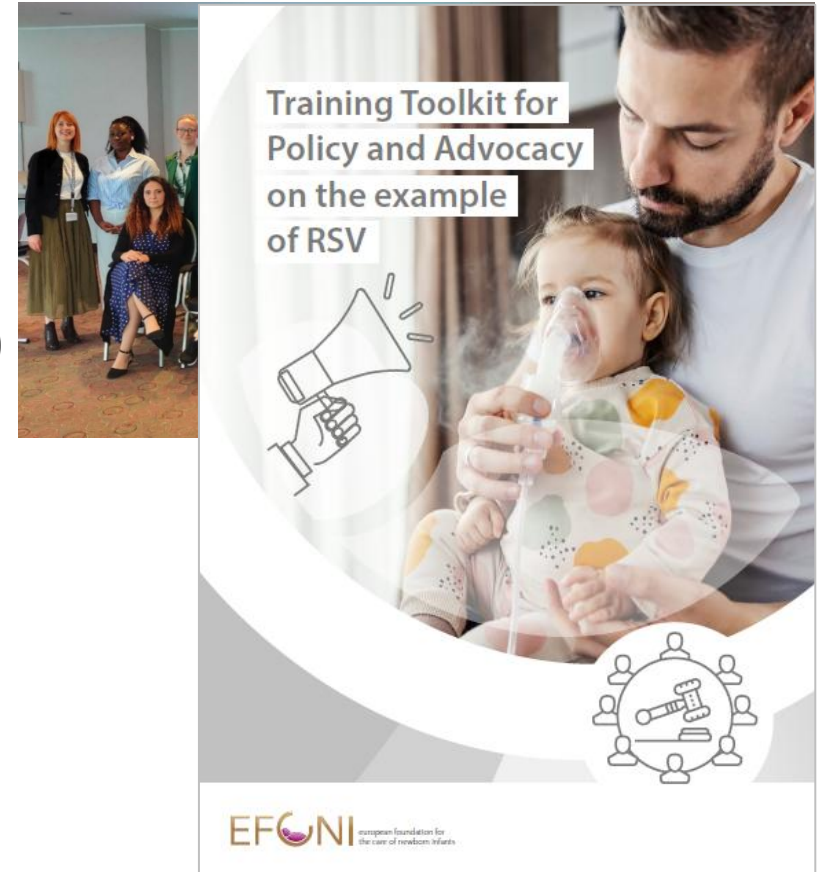
Timing: September 2023/24, October 2025/26 in Munich

Target group: Patient representatives from GFCNI international maternal & newborn health patient network

Aims:

- Equip participants with advocacy tools to engage local/national policymakers
- Guide on using evidence-based data, stakeholder mapping & sustainable strategies (e.g. roundtables, position papers, campaigns)
- Share best practice examples from experienced peers
- Exchange on RSV advocacy efforts and progress after 2023/24 workshop
- Apply the RSV toolkit for practical, country-level action

Results: Participants developed individual advocacy roadmaps

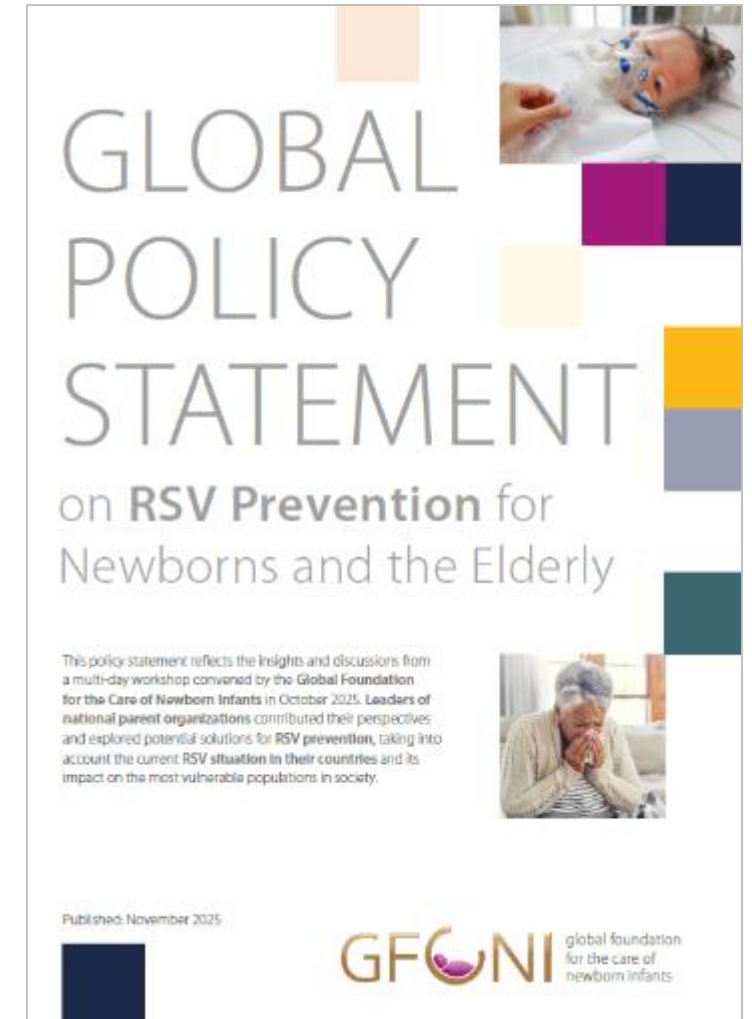


Outcome of 3rd RSV Policy Workshop: Global Policy Statement on RSV Prevention

Insights from country discussions on RSV prevention and disease burden as well as shared commitment to protect vulnerable groups from RSV sparked the creation of a **Global Policy Statement**.

Includes 7 key demands:

- A call for a global united movement
- Clear, understandable public guidance
- Standardized vaccination and other immunization protocols
- Agreement on a global RSV Awareness Day or Week
- Ensure equity and access
- Surveillance, testing and case registration



Coming together is
a beginning;
keeping together is
progress; working
together is success.

Henry Ford



Thank you very much for your attention!