

POSITION PAPER

# Continuous and Uninterrupted Family Presence in the NICU

# Acknowledgments

## NICU Parent Authors

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### *NICU Parent Network*

Jennifer Degl, M.S.Ed

Lead Author, NPN President-Elect; Founder of Speaking for Moms & Babies, Inc.

Leelee Smith Klein, M.S.Ed

Lead Author, NPN Board of Directors; President Emeritus of The Tiny Miracles Foundation

Gigi Khonyongwa-Fernandez, BSc, MSc, ACC, TICC

Co-Author, NPN President; Founder and Principal Coach of Families Blossoming, LLC. & GKF Coaching and Consulting

Kristy Love

Co-Author, NPN Past President; Executive Director of National Perinatal Association

Stephanie Vaughan, MPS

Co-Author; Former Co-founder and President of The Morgan Leary Vaughan Fund

Keira Sorrells, BSFCS, TIP

Co-Author, NPN Founder and Executive Director

## Collaborative Organizations, Co-Authors

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### *Family-Centered Care Taskforce*

Malathi Balasundaram, MD

Kerri Z. Machut, MD

Nicole Nyberg, NNP

### *National Association of Neonatal Therapists*

Christy Gliniak, PhD, OTR/L, CNT, CPXP, NTMTC

Sue Ludwig, OTR/L, CNT

Chrysty Sturdivant, OTR, CN

### *NIDCAP Federation International*

Deborah Buehler, PhD

Dorothy Vittner, PhD, RN, FAAN

### *National Network of NICU Psychologists*

Tiffany Gladdis, PsyD

### *National Perinatal Association*

Patti Bridges, MSW, LCSW

## Introduction

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Neonatal Intensive Care Units (NICUs) are vital in providing critical care to babies requiring specialized medical care due to various health conditions. Amidst the delicate balance of embedding medical intervention within nurturance, recognizing the profound impact of a parent's\* presence and active participation in caring for their babies is imperative.

*\*For this paper, the authors are adopting the American Association of University Women's DEI Toolkit definition of the word parent, which states: "In very basic terms, parental status is whether or not a person has a child or children. This includes being a biological parent, step-parent, adoptive parent, guardian, foster parent, [primary caregiver] or custodian of a minor". We will, therefore, use the term parent and all variations of the word throughout this paper to represent the relationship and status of a baby's primary caregiver.*

## Position

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We advocate for all NICUs to consider parents as their babies' primary caregivers and essential, equal, and integral members of the care team. From admission through discharge, hospital policies and bedside care should encourage and support continuous and uninterrupted presence and participation.

## Rationale

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The relationship and bond between parent and newborn is unparalleled and essential to a baby's physical, cognitive, and psychosocial development and long-term well-being. Research has consistently demonstrated the numerous benefits of parental and primary caregiver involvement in NICU care, including:

- **Promotion of Healthy Relationships and Bonding:** Parental presence and participation foster emotional engagement, healthy relationships, and improved bonding and attachment, which are crucial for the infant's medical, emotional, cognitive, and psychological development. Reliable, nurturing relationships provide comfort and stability for the infant as well as reassurance, increased confidence and competence for parents, and reduced parental stress and anxiety.

- **Support for Growth and Development:** When parents are present, they foster optimal growth and development of their baby through activities such as skin-to-skin holding, breast/chestfeeding, and developing care plans and caregiving tasks. These interventions promote physiological stability, weight gain, a strengthened immune system, and enhanced neurodevelopmental outcomes for premature and critically ill babies.
- **Support for Parental Education and Empowerment:** Parental integration in caring for their baby allows for hands-on learning under healthcare professionals' guidance. This nurturance and educational process supports and empowers parents to establish their role and to understand how their baby expresses its needs. It is critical to participate in decision-making and develop the necessary skills to care for their baby throughout the hospitalization and after discharge.
- **Support for Parental and Caregiver Mental Health:** Continuous presence can improve the emotional health of the parents, caregivers, and families. Addressing family stress in the NICU has been shown to improve parental interactions and positively impact the baby's health. Uninterrupted presence may also reduce the likelihood of negative feelings and mood disorders that NICU parents often experience as a result of separation from their baby and the baby's hospitalization.
- **Promotion of Family-Centered Care:** Parental presence and participation align with the principles of family-centered care, which recognize the family as an integral healthcare team member. Parental involvement during their baby's hospitalization encourages NICUs to develop rich, collaborative partnerships with families, ultimately enhancing the quality of care. This also improves patient safety, health, and well-being outcomes for infants and their families.



The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) considers parents their infants' key nurturers, advocates, and caregivers as well as collaborators in care decisions.

*Deborah Buehler & Dorothy Vittner*

NIDCAP FEDERATION INTERNATIONAL

## Implementation Recommendations

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- **Hospital Policy Development:** Establish clear policies that prioritize parental or primary caregiver presence, integration, and collaboration, outlining expectations, rights, and responsibilities of both parents and healthcare professionals. Involve family partners (those with lived NICU and/or bereavement experience) in the creation and development of such policies from the beginning of these discussions.
- **Infectious Outbreak Considerations:** Parental access to their babies and prevention of parent restrictions on access to their babies during infectious outbreaks should be considered. As stated in the “Canadian Consensus Practice Recommendations Regarding Physical Parental Presence in the NICUs During Pandemics Caused by Respiratory Pathogens like COVID-19” in *Frontiers in Pediatrics*: Significant evidence points to the positive impact presence of parents in the NICU has on infant and parent outcomes, and outweighs the potential harms or risks associated with being present in the NICU.
- **Flexible Parental and Primary Caregiver Presence Policies:** Implement flexible policies that accommodate parents’ diverse needs and schedules. These accommodations should include unrestricted presence at the bedside both day and night, transportation assistance, and access to housing for families who live far from the hospital. For the safety and privacy of all infants, we understand that parental access may need to be interrupted under certain circumstances at the discretion of the medical team. These instances should be minimized and explicitly communicated to parents upon admission and throughout hospitalization as needed.



While developing the support programs of The Tiny Miracles Foundation, I have spent 20 years advocating for parents in the NICU. Partnering on this position paper for supporting parents as essential caregivers in the NICU is not just about providing care; it’s about recognizing the profound bond between parent and child. When parents are empowered to be actively involved in their infant’s care, they foster trust, promote healing, and create a nurturing environment that is vital for the baby’s development and parental mental health. Their presence is not only a source of love and comfort but also an integral part of the healing process.

*Leelee Klein*

PRESIDENT EMERITUS, THE TINY MIRACLES FOUNDATION

- **Legislative Policy Development:** State and federal legislative bodies should continuously seek committee participation, including parents with lived NICU experiences, in writing and sponsoring legislation that supports all areas of parental and infant health. This includes meeting with local constituents and lobbyists who support improvements in parental and infant health care, paid parental leave, and extended leave for parents of premature and medically fragile babies.
- **Healthcare Education and Training:** Provide healthcare professionals with regular and ongoing education and training on the importance and benefits of individualized, trauma-informed, family-centered care. Training should focus on parental involvement in the NICU, providing psychosocial support, and using trauma-informed communication and interaction to empower parents as caregivers.
- **Physical Environment:** Create infrastructure that supports families throughout their baby's hospitalization. Some examples include, but are not limited to, comfortable seating and sleeping arrangements for parents, privacy curtains, breast/chestfeeding equipment, space for additional family members, and designated spaces with bathrooms with showers and areas for food preparation and/or consumption.
- **Transportation Assistance:** Review and evaluate the parents' ability to get to and from the hospital and provide transportation assistance when possible. Many families face significant challenges in being present at the bedside. Developing partnerships with community-based resources that mitigate transportation barriers will enhance families' ability to be present. Assistance may be in the form of, but not limited to, vouchers for public transportation, free hospital parking, taxi and/or rideshare services.



It was important for the National Perinatal Association to be a writing partner for *Continuous and Uninterrupted Family Presence in the NICU* because we believe that the involvement of families is essential to the well-being of both the infants and their caregivers. By collaborating on this initiative, we aim to advocate for practices that foster stronger family bonds, enhance patient care, and support the emotional needs of families during their most challenging times.

*Kristy Love*

NATIONAL PERINATAL ASSOCIATION

- **Communication and Collaboration:** Prioritize open dialogue, shared decision-making, and regular updates on the baby’s condition and care plan. Encourage parents to be present and active at the bedside while also being mindful that every parent’s journey to confident caregiving is unique. Inclusive, trauma-informed communication and collaboration between healthcare professionals and parents are essential for promoting and optimizing parental involvement, outcomes, and positive experiences. When parents feel genuinely welcomed in the unit and build a trusting relationship with their baby’s care team, confidence in their ability to care for their baby may be positively influenced.
- **Peer-to-Peer Support for Parents:** Establish an in-hospital peer-to-peer support program and/or partnership with a community organization that can assist families and the care team in developing families’ skills and confidence to be integral and active members of the care team. Peer-to-peer support is an evidence-based mental health intervention and is considered a best practice by the Substance Abuse and Mental Health Services Administration. This aligns with the NICU Parent Network’s position paper, “NICU Parent-Led Peer-to-Peer Support Services,” which can be downloaded via the link below: <https://nicuparentnetwork.org/position-paper/>.
- **NICU Psychologist or Mental Health Therapist:** The experience of having a baby in the hospital increases parental stress and feels overwhelming for families. For parents to be best positioned for healthy and positive interactions with their baby, it is helpful to have mental health professionals and support embedded in the NICU team to mitigate, address, and treat parental stressors and mental health concerns.



This position paper is important to me to ensure that families in the NICU have the most ideal experience possible. Many parents in the NICU express not feeling like a parent because of all that is stripped away from them when their child is in the NICU and while we can’t change all of that, it should be our mission to change as much as we can and support parents in having a close, connected, and involved relationship with their infant, especially while in the NICU.

*Tiffany Gladdis, PsyD*

NATIONAL NETWORK OF NEONATAL PSYCHOLOGISTS



Latoya holding her NICU baby, Skylar

**"A NICU mother is a postpartum mother, and as such, we wholeheartedly support initiatives that promote increased, uninterrupted parental presence and dedicated bonding time during this crucial period."**

*Latoya Blueford*

FOUNDER & DIRECTOR OF THE SKYLAR PROJECT



Richard & Keira with their NICU baby, Zoe

**"As NICU parents, we often feel stripped of any natural instincts we may have, we may feel isolated and powerless to help our babies as they fight to live - but we can give them what no one else can - our presence. With our presence, we bring our touch, smell, voice, and emotional closeness that provides the safety, comfort, and nurturance we as humans are wired for. We crave and need closeness and connection to heal and alleviate our suffering. Every baby deserves nothing less than the continuous and uninterrupted presence of their parents in the NICU."**

*Keira Sorrells*

FOUNDER & EXECUTIVE DIRECTOR OF NPN



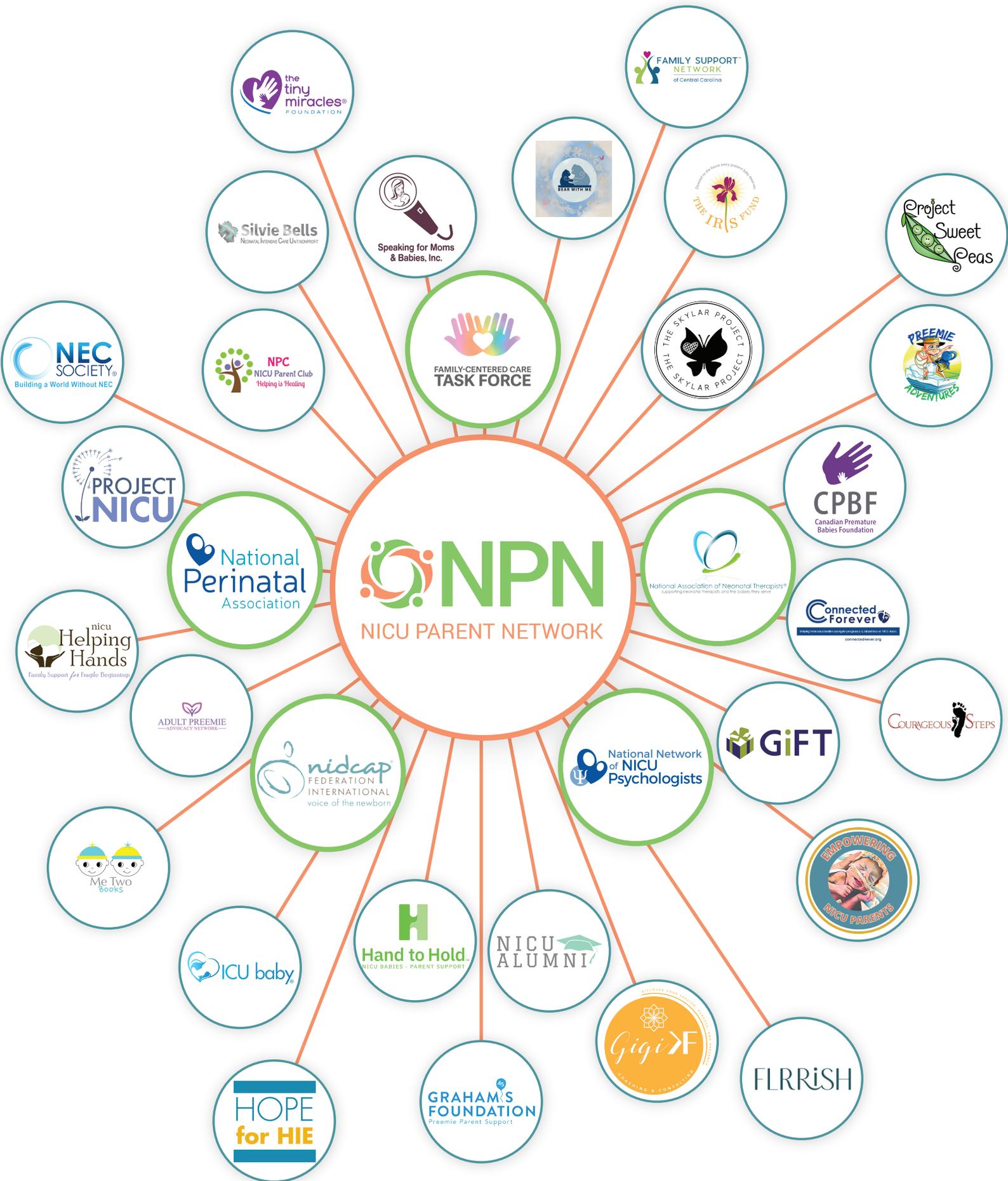
Jennifer holding her NICU baby, Joy

**"There is no better feeling than holding your baby for the first time. For NICU parents, this moment may not happen for days or weeks after a baby's birth, and when this much anticipated moment arrives, it may not feel natural, but instead clouded by tubes, wires and unnatural sounds. Parents should try their best to relax and enjoy this moment nonetheless, because it is an important milestone - one that adds to the bonding process. Uninterrupted parental presence in the NICU allows for more beneficial moments like these for families and babies."**

*Jennifer Degl*

FOUNDER OF SPEAKING FOR MOMS & BABIES, INC.

# SUPPORTING ORGANIZATIONS



## Supporting Research

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