



2018 Media Fact Sheet

Organization Name: Hand to Hold, www.handtohold.org

Founded: September 2010, Austin, Texas

Status: 501 (c) 3 nonprofit organization

Executive Director: Kelli Kelley

Co-Founders: Dave Alter and Kelli Kelley

About:

Hand to Hold is a community-based, national support program that helps families before, during, and after NICU stays and infant loss by providing powerful resources for the whole family, and most importantly, one-on-one mentoring from someone who has been there.

Its resources include in-hospital programs, articles and blogs, an award-winning audio support series for NICU families, social networks, and trained peer mentors. All were designed to meet the emotional, physical, and social needs of the whole NICU family - including siblings and grandparents.

Hand to Hold focuses its support, resources, and programs around four central strengths:

- Peer Support - From Trained, Supervised NICU Graduate Parents;
- Psychosocial and Emotional Support - Crucial for Improved Outcomes;
- Whole Family Care - Including Siblings and Grandparents; and,
- NICU and Beyond - Antepartum through Childhood.

About Preterm Births and Medically Fragile Babies:

One study showed that 14.4% of births in the U.S. are referred to the Neonatal Intensive Care Unit for advanced careⁱ. That's more than a half a million births in the U.S. each yearⁱⁱ. By far the most common reason for a NICU referral is for prematurity, defined as a birth before 37 weeks gestation. Prematurity is the leading cause of newborn death, re-hospitalization and can result in lifelong disabilitiesⁱⁱⁱ. While most major hospital systems are investing in women's services and neonatal care to meet the complex needs of babies who spend time in the NICU, community-based programs for parents before, during and after the Neonatal Intensive Care Unit or in the event of a loss are not widely available across the nation.

Parents of preterm infants and babies born with special health care needs often struggle with depression, anxiety and post-traumatic stress disorder. When parents face these issues alone, the prolonged stress can have a profound impact on the entire family unit, often resulting in depression, separation, divorce and child abuse.

Clients Served: All members in a family affected by a child's NICU stay, a preterm birth or loss

Client Services Provided:

- **Peer Support** – Helping Hands are NICU graduate parent volunteers who are trained to provide individualized peer-to-peer support to new parents. Helping Hands are individuals who are uniquely familiar with the experience of life in the NICU or a loss.
- **NICU Now Audio Support Series** – a podcast support series for parents that are currently in the NICU. Launched in Feb. 2018, by March 2018 NICU Now had more than 15,000 downloads internationally.
- **NICU Family Forum** (formerly) ***Life After NICU*** - Hand to Hold's interactive peer-support forum that allows NICU families to seek out advice and share inspiration directly with one another.
- **Helpful Articles and Educational Videos** – Everything families want to know about navigating the NICU and the world beyond, with advice and information from medical professionals and experienced parents.
- **Sibling Support** – Resources and programs for the brothers and sisters of NICU babies.
- **NICU Graduate Handbook** – A post-discharge guide for NICU parents, educates parents about their baby's unique developmental and health care needs, giving them the tools and information they need to partner with their therapists and health care providers to ensure best outcomes for all babies.

Hospital Services Provided:

- **Ambassador Program** - Comprehensive in-hospital support for NICU families, designed to enhance and extend a hospital's current family support initiatives, and introduce new program options customized to meet the unique needs of a NICU population. The program can include:
 - **Peer Bedside Rounding** - Recognized by the NPA as a critical part of NICU care.
 - **Sibling Support** - Resources and programs for the brothers and sisters of NICU babies, including a NICU Tour Video available in English and Spanish.
 - **Whole Family Support** - Support Group Curriculum that leads NICU families through a five-week program of important topics. Hand to Hold Ambassadors are trained to facilitate these support groups, alongside NICU staff.
 - **Celebrating Milestones** – Hand to Hold's Milestone Bead Program uses milestone beads to encourage parent participation throughout their baby's NICU stay, and celebrate the child's birth & the milestones of their NICU journey.
 - **Bedside Decorations** - Monthly events and special milestones are celebrated.
 - **Hospital Resources** - Expertly written digital and print resources for in-hospital distribution.
 - **NICU Staff Support** - Continuing Education for NICU Staff.
- **NICU Resource Library** – Available by subscription, Hand to Hold's online library for NICUs is full of printable educational resources that help parents understand and cope with their baby's NICU stay.

Geographical Service area:

Programs are built to serve families nationally. Hand to Hold currently has volunteers across the nation; the organization provides in-hospital support to select hospitals in Austin and Dallas, with services that include bedside rounding, family events, and support groups. Hand to Hold serves families when they need it most and uses the hospital to pilot materials and programs before improving and finalizing them, and then making them available to more NICUs and families across the nation.

Online Resources:

Website – <http://handtohold.org>

Blog – <http://handtohold.org/blog>

Hand to Hold Facebook – <https://www.facebook.com/HANDtoHOLD>

NICU Family Forum Facebook – <https://www.facebook.com/NICUFamilyForum/>

YouTube – <https://www.youtube.com/user/HAND2HOLD1>

Pinterest – <http://www.pinterest.com/HandtoHold>

Twitter – <https://twitter.com/nicuhandtohold>

LinkedIn - <https://www.linkedin.com/company/hand-to-hold/>

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ⁱ March of Dimes and National Perinatal Information Center/Quality Analytic Services. *Special Care Nursery Admissions*. Accessed from https://www.marchofdimes.org/peristats/pdfdocs/nicu_summary_final.pdf

ⁱⁱ Centers for Disease Control. National Center for Health Statistics. In 2012, 3,952,841 babies were born. <http://www.cdc.gov/nchs/fastats/births.htm>.

ⁱⁱⁱ March of Dimes. Prematurity Snapshot. <http://www.marchofdimes.org/mission/prematurity-campaign.aspx> Accessed Jan 20, 2015.