



HAND *to* HOLD

2014 ANNUAL REPORT

Hand to Hold

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Raising a nonprofit

Parenting a baby in the neonatal intensive care unit (NICU) and founding a nonprofit have much in common. Both require a strong faith, sheer determination and a community of support. And just as I marvel at the tremendous obstacles my micro preemie has overcome, I am humbled by the impact Hand to Hold is having in the lives of tens of thousands of NICU and bereaved families across the country.

From a local program piloted in Austin, Texas, to a national peer-to-peer network, thriving online support community and educational resources used across the country, Hand to Hold is transforming the way NICU families access critical information, resources and support during and after a NICU stay or loss of a baby.

Approximately 500,000 babies are admitted to the NICU each year. The emotional, physical, financial and psychological fallout of caring for a sick baby often blindsides families. We now know that this prolonged stress can have a profound impact on the entire family unit, often resulting in depression, PTSD, separation, divorce and child abuse.

We are grateful for our corporate sponsors and individual donors who generously support our mission. Each week, Hand to Hold receives cards, emails, letters and gifts from families who have been touched by our mission. Their stories inspire us to keep working until every NICU parent has a hand to hold so we can ensure best outcomes for all babies and their families.



Kelli D. Kelley
Founder and Executive Director,
Hand to Hold
NICU graduate mom to Jackson
Kelley (24 weeks) and Lauren Kelley
(34 weeks)

Born at 24 weeks gestation, Jackson Kelley weighed 1 lb 8 oz and spent four months in the NICU.

Mission

To provide comprehensive navigation resources and support programs to parents of preemies, babies born with special healthcare needs and those who have experienced a loss due to these or other complications.



“Delivering twins at 23 weeks comes with an emotional roller coaster. Nothing can prepare a family for the loss of a child and grasping on to all hope for over four months in the NICU for the other. However, the blessings that continue to surface from such a struggle outweigh the tough days. Supporting Hand to Hold is a way to honor our daughters while holding the hand of another family walking along their roller coaster and creating awareness/prevention for prematurity.”

– Dave & Allie Alter,
NICU Parents, Co-Founders of Hand to Hold



BOARD OF DIRECTORS

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ON THE COVER: Melissa and Adam Turner of Austin, TX, with their daughter, Sofia Victoriana. Sofia passed away shortly after birth due to complications associated with Trisomy 18.
Photo credit: Nicole McGinnis of East Side Creative

Five-Year Milestones

Research shows that NICU parents are at significant risk for depression for up to two years after their baby's birth. Fortunately, that risk can be mitigated and its negative effects can be minimized when parents receive timely support. Eighty-seven percent of mothers who were matched with a trained peer "buddy" reported less stress, less anxiety and reduced feelings of isolation. They said that talking to another parent validated their feelings and helped them understand and cope with their situation.^{1,2}

1. Miles MS1, Holditch-Davis D, Schwartz TA, Scher M. J Dev Behav Pediatr. Depressive symptoms in mothers of prematurely born infants. School of Nursing, The University of North Carolina at Chapel Hill, Chapel Hill, NC. 2007 Feb;28(1):36-44.
2. Preyde M, Ardal F. Effectiveness of a parent "buddy" program for mothers of very preterm infants in a neonatal intensive care unit. Canadian Medical Association Journal. 2003; 168:969-973.

● Hand to Hold has developed comprehensive navigation resource tools, including the **NICU Resource Library**. Endorsed by the National Perinatal Association, the library offers an extensive list of educational materials that hospitals can co-brand and print on demand to help educate families who have a baby in the neonatal intensive care unit. The library is currently used by 54 hospitals across 19 states and the District of Columbia and is available in English and Spanish. "Our members carefully reviewed all the documents contained in the Resource Library and found them to be clearly written, based on sound principles of best practices in neonatology, and engaging towards parents. In addition, the handouts are in alignment with principles of both Trauma-Informed Care and Family-Centered Care."



- National Perinatal Association



● In 2014, Hand to Hold introduced its **NICU Graduate Handbook** in Central Texas. This post-discharge guide for NICU parents educates them about their baby's unique developmental and healthcare needs, giving them the tools and information they need to partner with their therapists and healthcare providers to ensure best outcomes for all. The NICU Graduate Handbook will be available nationally in 2015.



● Hand to Hold has established a national, award-winning **Helping Hands** network of trained NICU graduate parent volunteers. Each Helping Hand provides individualized peer-to-peer support to new NICU parents.

● **HandtoHold.org** is recognized as a leading online resource for NICU and bereaved families and medical professionals, with access to free online resources. (Welcomed more than 250,000 unique visitors in 2014).

● Our **social media** community, including our Life After NICU Facebook Forum and parent blog PreemieBabies101.com, reached an impressive following of more than 32,000 NICU parents and medical professionals.



The Development of A Special Partnership

Hand to Hold partners with St. David's HealthCare of Central Texas to pilot its parent support programs in two hospitals. Hand to Hold's Family Support Navigators, who are NICU graduate parents and licensed social workers, visit with families at their baby's bedside to provide the social and emotional support needed during a NICU stay. Hand to Hold also provides sibling education hours, special events, weekly chat sessions and family support bags that include educational resources and personal care items to help families navigate their NICU journey. Family Support Navigators also serve on multiple committees and panels for nurse and staff trainings at St. David's. The encouragement from medical professionals and leaders at all levels at St. David's has been invaluable to Hand to Hold's development and expansion.



"With the largest NICU in Central Texas, we at St. David's Medical Center are proud of our partnership with Hand to Hold. In fact, we consider Hand to Hold to be an important part of our NICU team. **The support that Hand to Hold provides the families of our smallest and most vulnerable patients is immeasurable and greatly appreciated.**"

- Donald H. Wilkerson, FACHE
Chief Executive Officer, St. David's Medical Center

Impacting the Care of the NICU Baby and Family



Hand to Hold representatives shared our programs and resources via conference speaking engagements, association memberships and by lending a voice to healthcare guidelines affecting the NICU community. Recently, Kelli Kelley served as the parent liaison and spokesperson for the National Perinatal Association Multidisciplinary Guidelines for the Care of Late-Preterm Infants and on the review committee for the National Association of Neonatal Nurses Discharge Planning Module.

Memberships:

- Family Advocacy Network
- National Association of Perinatal Social Workers
- National Association of Social Workers
- National Perinatal Association – Staff served on the development committee for the NPA's Guidelines for the Psychosocial Support of NICU Parents to develop national standards.
- National Premature Infant Health Coalition
- Premie Parent Alliance – Founding Member/Leadership Team
- Central Texas Perinatal Coalition
- Texas Association for Infant Mental Health
- Healthy Texas Babies Initiative



Speaking Engagements:

- Maternal Newborn Conference at Baptist Hospital for Women – Jackson, Mississippi
- 5th Annual Management of Obstetric Crisis: Developing Practice Strategies to Maximize Maternal & Fetal Outcomes – Austin, Texas
- National Association Perinatal Social Workers Conference – San Antonio, Texas
- Neotech Cares Symposium – Valencia, California
- Denver Health 2014 Maternal Child Conference on Preparing for Discharge: Building a Bridge Between NICU and Home – Denver, Colorado
- Emerging Considerations in Maternal Mental Health Forum – Los Angeles, California

Hand to Hold is dedicated to developing and identifying strategic partnerships with leading health and nutrition companies to help distribute our educational resources to NICUs throughout the country.

Examples of 2014 collaboration includes:

- ✓ **Mead Johnson Nutrition distributing our free print newsletter for NICU families.**
- ✓ **IKARIA including our educational materials in their Parent Education Toolkit.**
- ✓ **The Wellness Network, Your NICU Baby incorporating our Sibling Support educational video and resources.**

“Mrs. Kelley’s delivery is emotive, moving and passionate. The audience is drawn in. She interacts with the audience and guides them as they consider their own roles and interactions with mothers and challenged infants. **Her presentations are both instructive and entertaining.**”

- Bradley P. Fuhrman, MD
Professor and Chair, Department of Pediatrics
Texas Tech University Health Sciences Center
Paul L. Foster School of Medicine
Physician-in-Chief, El Paso Children’s Hospital

Educating and Empowering NICU Families

Parents are a baby's primary caregivers. When that care is complicated or complex, families need extra support. If NICU babies are going to thrive after discharge, they need smart, informed parents who understand their needs and are emotionally and physically capable of caring for a medically fragile child.

Hand to Hold believes that every parent can become a powerful advocate for their baby if they are given the tools and education they need to succeed. We provide timely, reliable, and credible resources that empower parents and the professionals they work with.



Members of Hand to Hold's community can access support and information in a variety of ways. From participating in an online chat with a healthcare or developmental specialist, to requesting a Helping Hand peer mentor or watching an educational video

via our YouTube channel, parents can choose the level of support that is right for them.

Families trust Hand to Hold because we have been where they are and understand the impact of a NICU stay. We are uniquely positioned to provide resources and support to help them navigate their NICU stay and prepare to meet the needs of their medically fragile child after hospital discharge.

NICU Resource Library

Parents are often unprepared for a NICU stay. In the face of enormous stressors, they have to quickly adapt to this new, medically complex environment.



Hand to Hold's NICU Resource Library provides tools for NICUs to assist in the education and support of parents during their stay and in preparation for discharge, which helps parents become active members of their baby's care team.

NICU Graduate Handbook

The NICU journey doesn't end at discharge. The transition home can be stressful and parents often feel alone and unprepared. In 2014, Hand to Hold published its first NICU Graduate Handbook, a post-discharge guide for NICU parents. It includes information about everything from protecting their NICU Graduate from common respiratory viruses, to tips for navigating the healthcare system, to help tracking their baby's developmental milestones.

NICU 101 Facebook Chats

Every month, Hand to Hold invites experts to answer the questions we hear most. Whether families want to know more about feeding their baby, promoting healthy development, or understanding their own special needs as a NICU parent, Hand to Hold's moderated online discussions give them thoughtful and reassuring answers.



Video Library

Hand to Hold's series of educational videos help families who want to know more about an issue affecting their baby or need help explaining their baby's unique needs to family or friends. Our growing library of videos feature healthcare professionals and address topics from RSV and nutrition, to breastfeeding and understanding PTSD after a NICU stay.

Helping Hands Peer Mentors

Families need to know that they are not alone. There are families just like theirs who can guide the way. When parents need personal, individualized support, Hand to Hold can help. Hand to Hold carefully matches trained NICU graduate families with parents in need of peer support. These one-on-one relationships inspire hope and give families the chance to talk to someone who knows what it is like to walk the NICU journey.



"A little over two years ago, my daughter, Ellery, was born two months premature. It was a terrifying experience – so much was out of our control. Hand to Hold provided my family with knowledge and compassion through sibling classes, educational resources and shared experiences with moms just like me. **We are forever grateful – the littlest things make the biggest difference.**"

- Katie, NICU Parent

Helping Hospitals Enhance Family-Centered Care

Hand to Hold knows that the premature birth of a baby, a baby born with special healthcare needs or the loss of a baby affects the lives of all family members. Like parents, siblings need support, encouragement and information. So Hand to Hold has created comprehensive programs and services to support both the parent and those they love.

Sibling Sundaes

In partnership with St. David's Healthcare, Hand to Hold leads monthly education hours for older siblings of NICU babies. Siblings learn about the special people caring for their baby brother or sister, the equipment that is helping their baby grow stronger each day and the important role they will play as a big brother or sister when their baby comes home. Siblings also enjoy crafts, songs and ice cream sundaes!



Siblings learn about their little brother/sister's NICU stay from a licensed nurse at St. David's Medical Center in Austin, TX.



A Hand to Hold staff member leads a craft session for NICU siblings at St. David's Medical Center in Austin, TX.

A NICU Tour for Siblings

Hand to Hold produced a NICU Tour video in English and Spanish specifically for siblings who have a brother or sister in the NICU. This video answers common questions and prepares big brothers or sisters for baby's homecoming. Hand to Hold's tour is led by a NICU graduate who explains what a NICU is, about the care babies receive there, and how siblings can show their love for their sibling even if they can't visit them in the hospital.



Sibling Activity Pages

Hand to Hold has produced a series of Sibling Activity Pages in English and Spanish to not only provide siblings with something fun to do while visiting the NICU but to help educate them about their baby brother or sister's NICU stay.



Special Events

Holidays can be a difficult time during a NICU stay. To help parents commemorate these special occasions, Hand to Hold works with hospitals, volunteers and corporate sponsors to plan and implement special events for Mother's Day and Father's Day and to celebrate the holiday season.



Our newest initiatives include developing a new Support Group Curriculum used by hospitals to help families in small group settings, as well as training Hand to Hold ambassadors who will test-pilot our Ambassador Program. We also plan to launch an online store so hospitals can easily adopt Hand to Hold's curriculum, which focuses on a parent's mental health during and after a NICU journey.



"The surprise of and consequent need for support through a premature birth (or two!) cannot be overstated - nor can the importance of these programs! When our twins made their entrance almost seven weeks early, we as new parents felt confused and overwhelmed. New preemie parents need so much support that often their families and friends cannot completely fill the need - it's scary and stressful during an already emotional time. **Hand to Hold provides resources and reassurance to help ease some of the fear so new parents can focus on supporting and loving their new little ones!**"



- Stephanie, NICU Parent

Inspiring Hope through Awards and Recognition

NICU Grand Prize Giveaway



This online peer-to-peer fundraiser invites families to tell their story, raise funds to benefit NICU and bereaved families, and win prizes. It is a way for families to say “thank you” to their NICU and to raise awareness and crucial funding to expand Hand to Hold’s online education and peer support resources. Our 2014 contest winner was the Regusci family from San Luis Obispo, California, who were able to gift a prize package to their adopted twins’ NICU, which included two Kangaroo Care Gliders and Hand to Hold’s NICU Resource Library, among other valuable resources.

Regusci Family at Sierra Vista Regional Medical Center in San Luis Obispo, CA

For the Love of Babies Awards Breakfast

These awards are given annually to medical professionals who touch the lives of those who struggle with conception, complications during pregnancy, a neonatal intensive care unit stay or loss of a baby. Honorees represent the fields of fertility, obstetrics, neonatology, pediatrics, mental health, and pediatric therapy. A panel of previous winners and NICU parents select the winners. The 2014 Award Winners were:



Dr. Kelly Thorstad, Lone Star Pediatrics (far left), Dr. Christopher Seeker, Austin Area OBGYN (left), Dr. Audelio “Sonny” Rivera, St. David’s Healthcare (right), Nancy Sheppard, LCSW, Seton Healthcare Network (far right)

NICU Heroes Award

The NICU Heroes Award, presented by Mead Johnson Nutrition and Hand to Hold, recognizes NICU professionals for their compassion and dedication to improving outcomes not only for medically fragile babies but the entire family. Winners for 2014 were Neonatal Nurse Practitioner Stephanie Horecky Hall, MSN, APRN, NNP-BC, of Medical University of South Carolina (MUSC) in Charleston, South Carolina; and Neonatologist Stewart Lawrence, MD, of Mountain States Neonatology, an affiliate of Pediatrix Medical Group and who practices at Saint Alphonsus Regional Medical Center in Boise, Idaho.



Stephanie Horecky Hall, MSN, APRN, NNP-BC



Stewart Lawrence, MD

Preemie Power Photo & Essay Contest

An international signature campaign during Prematurity Awareness Month (November) Preemie Power is an inspirational contest that raises awareness about preterm birth and helps parents reframe the challenges their NICU baby has faced. Their stories provide hope to thousands of new NICU families. Over the past five years, participant families represented 50 states in the U.S. and abroad, including countries as far away as Mexico, Israel and Ireland, and garnered tens of thousands of online votes. Our Overall Preemie Power Winner in 2014 was Asher ‘Lil Warrior’ Norvell, born at 26 weeks weighing 1 lb 14 oz, who



spent 125 days in the NICU and 21 days in the PICU.



Special Thanks to our 2014 Supporters

Hand to Hold would like to thank the more than 750 individuals, corporations and foundations that gave in 2014 to further our mission, and to ensure that no parent has to experience the NICU alone.

Hand to Hold's Sustaining Circle of Love was established to recognize dedicated annual donors who are passionate about advancing the mission of Hand to Hold. The goal of the Sustaining Circle is to underwrite Hand to Hold's award-winning Helping Hand peer mentor program and online education series as well as innovative new programs each year.

Founder's Circle Members

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 Michael Alter
 Meredith & Jim Bagan
 Barbara & William Balliette
 Kay & Thomas Bonner
 Dr. David Breed
 Denise & Jerry Conway
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Sustaining Circle of Love Members

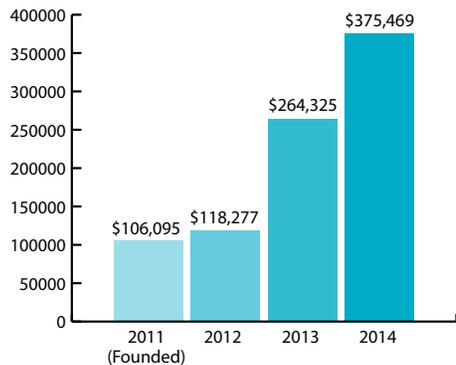
Dr. David Breed
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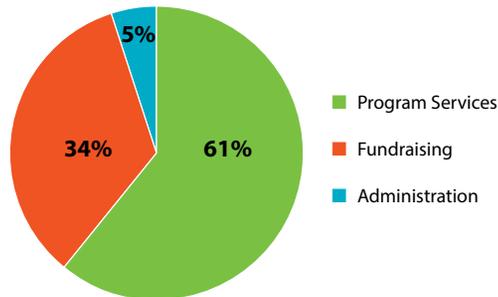
"We give to Hand to Hold because the birth of a child should be the most beautiful, happiest time of a couple's life. For it to be anything less becomes the most terrifying experience imaginable. Although we haven't had a baby in the NICU, we support Hand to Hold to help the thousands of families who have suffered through their own personal story. **We want to ensure that every family with a baby in the NICU receives top-of-the-line support services.** Thank you, Hand to Hold, for meeting these critical needs."

- Megan & Michael Helmbrecht

Hand to Hold Revenue 2011-2014



Hand to Hold Expenses by Category 2014



In November, Hand to Hold introduced a **Baby Shower fundraiser**. In its first year, the event **SOLD OUT** before the invitation was sent, we hosted 300 guests and raised \$100,000+ to benefit NICU and bereaved families.



"I was delighted when Hand to Hold took the leap last year and held their first major fundraiser and was honored to serve as an honorary chair."

- Carla McDonald, Honorary co-chair, 2014 Baby Shower (Austin Woman, January 2015 Issue)

Sponsors & Partners

