



Hand to Hold... NICU BABIES · PARENT SUPPORT

Annual Report 2023

www.HandtoHold.org



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Our Mission



Hand to Hold® provides personalized support before, during and after a NICU stay to help ensure all NICU families thrive.

We believe in the power of early intervention mental health support. Our diverse team of certified mental health peer specialists (called Family Support Specialists) and licensed counselors bring invaluable expertise and empathy to our programs. We are committed to offering comprehensive support through peer support and education, counseling, and support groups, as recommended by the World Health Organization and the American Academy of Pediatrics

Our values of Belonging, Compassion, Equity, Integrity, Boldness, and Growth are the guiding principles behind everything we do.

Hand to Hold experienced tremendous growth in 2023. Thanks to contributors like you, we provided **72,150** sessions of support for NICU and bereaved parents (a 12% increase over 2022); hosted the first citywide celebration for NICU graduates, their families, and the professionals who cared for them; hired our first counseling program manager to scale our counseling program; and expanded our virtual team of certified mental health peer specialists to continue to break down access barriers to mental health support, such as cost, language, transportation, and child care. Your unwavering support has been pivotal in our expansion, and we are deeply grateful.

Looking Forward:

We have a bold target to support 40% of NICU parents by the end of 2026.

Hope Has Been Raised

Dear Supporter,

As a NICU parent of two preterm babies, I sought meaning from my own trauma. I wanted to ensure other parents had the support I so desperately needed throughout our NICU journey and the difficult years that followed. Out of empathy and determination, I birthed a third child in the form of a nonprofit that I affectionately call "Hope." Hope started in 2009 as a volunteer-led program to support Austin-area NICU parents, growing quickly into a nonprofit that now serves as a lifeline for thousands of families as the nation's largest provider of free, bilingual early intervention mental health support for NICU and bereaved parents. Leading Hand to Hold, like parenting, has its challenges, but the joy lies in watching it grow and flourish in ways I could not have dreamt of all those years ago.

In January, I officially announced my intention to retire at the end of 2025 and Katrina Moline's promotion to Executive Director. Katrina most recently served as Hand to Hold's chief operations and finance officer. She joined Hand to Hold in 2018 with two decades of experience managing small business operations and leading teams in the corporate sector. She has also served as a volunteer in Hand to Hold's peer mentor program for more than ten years, mentoring other mothers through their own traumatic NICU experiences.

Together, Katrina and I are working to ensure our leadership team is equipped, not only to continue the incredible work we are doing today, but also to continue to innovate to meet the needs of Gen Z and Gen Alpha. While the mental health challenges these new parents will face will be similar to today's



parents, the way they want to access and receive support continues to evolve – and we want to ensure Hand to Hold is ready to be a trusted resource for them and all generations to come.

Thank you for standing with "Hope" as we continue to provide community and healing to NICU and bereaved families across the nation.

Warm regards,

Kelli Kelley

Founder & CEO, Hand to Hold

Looking Ahead: Growth Strategy & Innovation



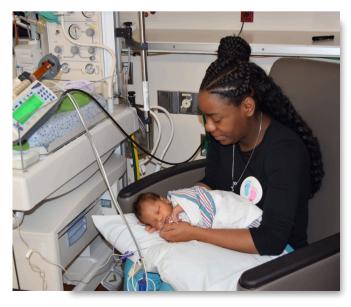
In 2024, our goal is to provide 100,000 sessions of free, culturally congruent mental health support for NICU and bereaved parents.

Did you know? We were the first organization to:

- Require our Family Support Specialists to be certified mental health peer specialists
- Host a conference focused on the mental health of NICU parents
- Create a podcast for NICU nurses accredited for continuing education
- · Create a podcast for NICU parents
- Establish virtual support groups for NICU families during the COVID-19 pandemic
- Launch the only app providing direct access to mental health support for NICU parents

Despite the fact that 1 in 7 babies born in the US spends time in the NICU, only about 10% of NICU parents receive support for the mental health challenges that often accompany a NICU stay. This highlights a significant gap in awareness regarding early intervention mental health support. However, we see this as an opportunity for growth and positive change.

Guided by our strategic plan, we are working to increase our network of hospital partners, expand our virtual support programs, and further optimize our staff capacity. We are constantly innovating to find new, costeffective programs, such as piloting our firstever virtual hospital support model at The Woodlands in Houston (in 2024) and expanding our in-hospital support in 2024 at Texas Children's Hospital in Houston. By embracing creative solutions and pushing the boundaries of traditional approaches to mental healthcare delivery, we are driving positive change and empowering families and healthcare providers with the resources needed to navigate the complexities of the NICU journey with resilience and strength.



Supporting NICU Families: Impact and Outreach

The traumatic experience of the NICU disrupts bonding and increases a parent's risk of perinatal mood and anxiety disorders (PMADs). It can also impair parent-child interactions, which can have a devastating impact on a child's cognitive, social, emotional, and self-regulatory abilities. Early intervention support and resources for parents is critical in mitigating the long-term challenges of PMADs that ultimately impact a parent's ability to bond with and care for their child.

Through Hand to Hold's programs, NICU and bereaved parents have improved mental health, bond with their babies, and become confident and resilient caregivers – improving the baby's long-term physical, emotional, and developmental outcomes.



39,420
educational support sessions by means of our conference, podcasts and webinars



10,192 in-hospital support sessions for parents in our partner hospitals



2,354
counseling and peer support
sessions provided to parents
virtually



20,184 online community support sessions



hospitals referred their parents to Hand to Hold for support



volunteers donated **1,286** hours to Hand to Hold in 2023

Remy's NICU Story

Remy was born at 24 weeks and 5 days, weighing only 1 lb 13 ounces. He was immediately put on a ventilator and given a feeding tube. PICC line, and other IVs. We weren't able to hold our son for the first two weeks of his life. I remember feeling completely helpless; like I could not even comfort or bond with my baby. Those were the most agonizing weeks of my life.



After being in shock for a few days, it was recommended that we go to a meeting with Hand to Hold, a support group that held meetings in the NICU at our hospital. Following the first meeting, we went weekly and formed relationships with the Family Support Specialists and other NICU parents.

Remy remained in the NICU for 135 days. Hand to Hold provided constant support helping us through each week. Now that he is home, we treasure the small mementos: the Hand to Hold necklace & beads, the NICU books we wrote in every single day to track his progress, and the little scent cloths we used to bond with him.

These are so precious to us, and we would not have them without Hand to Hold. Now, we can look back in those books and see exactly how far our little warrior has come.

We also went to couples counseling through Hand to Hold. Being in the NICU is hard on even the strongest relationships. This helped us talk about what we were feeling and focus on supporting. Because we were able to support each other and talk through the difficult feelings, we were able to support our son better. The most powerful symbol of our success story is that now we have the privilege of dealing with the "normal" stresses of having a newborn at home with us, and it fills us with joy every single day.



Proven benefits of peer support include improved mental health of the parent, improved problem-solving capabilities, greater engagement by parents in their child's care, and increased preparedness when caring for a medically fragile baby at home.

"This was not at all the beautiful entry into this world that I had imagined for my son, or the birth experience I had dreamed of... Hand to Hold provided us hope with community, guidance, and someone to listen to us."

– Amanda A., mom to Remy



In-Hospital Support

Our team of bilingual Family Support Specialists is embedded into hospital NICUs, serving as an integrated part of the NICU care team, working in tandem with the medical, social work, and pastoral care staff to reach parents experiencing trauma. Specialists visit with parents at their baby's bedside, lead weekly support groups and special events, provide regular education for parents and medical staff, and facilitate our Milestone Bead program.

1-on-1 Bedside Support & Weekly Support Groups

We provide personalized support to help parents learn to bond with their medically fragile baby and navigate their NICU journey.

Antepartum Support

Our team offers one-on-one support to at-risk moms on bedrest whose newborns may be treated in the NICU. We provide curated self-care kits, virtual support groups for high-risk pregnancies, and selfcare items, such as lotions and coloring books.

Educational & Awareness Programming

We facilitate annual educational and awareness programs for both staff and families to encourage bonding. These events highlight the benefits of breast milk, skin-to-skin contact ("kangaroo care") and reading, and how these can help families create stronger bonds with their baby.

Educating NICU Professionals

We educate professionals through our annual NICU Mental Health Conference, as well as our accredited podcast and NICU parent perspectives webinars, helping them to gain understanding and learn effective methods to better support NICU families.





2023 Highlights:

Provided 9,835 in-person parent support sessions in five Texas hospitals

Looking forward:

In 2024, we will embark on a new hospital partnership, expanding into Houston, Texas. We are now providing in-person family support at Texas Children's Hospital, the largest level IV NICU in the state of Texas.

Current Hospital Partners:

- · St. David's Medical Center
- St. David's Women's Center of Texas
- Dell Children's Ascension Seton
- Dell Children's Medical Center
- Texas Children's Hospital of Houston, TX -NEW in 2024!

In-Hospital Support



Sibling Support Bags

We provide bilingual sibling support bags to families in hospitals to encourage sibling bonding. Each bag includes a special craft, a sibling necklace with our unique Sibling Bead, an activity book aimed at helping children understand and cope with their family's emotions during this challenging period, a "tip" card for families about managing care for both siblings and the baby in the NICU, and a list of recommended books.

NICU Milestone Bead Program

Our NICU Milestone Bead Program is more than jewelry; it's a tangible way for parents to celebrate key milestones with their NICU babies, fostering bonding and guiding them through the journey.

"This necklace became my talisman. It reminded me how far we had come and allowed me to feel connected when I couldn't be at the hospital."

– Kheira A., NICU mom





Virtual Support Groups Provide Community

Our team of Virtual Family Support Specialists facilitate virtual support groups, provided at no cost to NICU parents before, during and after their NICU stay. Groups are available in both English and Spanish. Our support groups are intended as a safe space for NICU and bereaved parents to discuss how to navigate life with the complication of a NICU stay or loss.



2023 Highlights:

- · Revamped our virtual support group schedule to accommodate more parents
- Introduced a group for military NICU families
- Hired our first Virtual Program Manager to lead a dedicated team of Virtual Family Support Specialists

Looking Forward:

In 2024, we will provide 720 virtual support group sessions. We are also piloting a cutting-edge hospital model for virtual support at The Woodlands NICU in Houston, Texas. This innovative initiative represents a paradigm shift in the delivery of NICU support services, offering families unprecedented access to resources, guidance, and community virtually.

We host groups for:

- NICU Moms currently in the NICU
- NICU Moms graduated from the NICU
- NICU Parents (current and graduate)
- · Cafecito con Familias NICU (Spanishspeaking families)
- Black NICU Parents
- High-Risk Pregnancy
- Military NICU Families
- Bereaved NICU Parents

"I was so happy and grateful that when I clicked on the link, all of your information was in Spanish. For the first time, I didn't feel forgotten. I've been looking for a NICU support group for a long time (3 years), so when I found your Cafecito con Familias Support Group, I registered immediately. I was so grateful to be seen and supported!"

- NICU Mom



Virtual Programming Removes Barriers to Support

Hand to Hold uses technology and bilingual staff members to remove barriers to mental health support. Our virtual programs ensure all NICU parents have access to free, bilingual, early intervention mental health support, particularly for those facing transportation or geographical constraints.



Peer Mentor Program – We facilitated 188 new parent matches in 33 states and three countries; 40% of matches were for parents of color. New parents are matched with trained peer mentor volunteers (who are also NICU graduate/bereaved parents) with similar birth experiences. Seasoned NICU and bereaved parents are the lifeblood of this program, inspiring hope and offering new parents the chance to ask personal questions and receive support from someone who is uniquely familiar with their experience.

Educational Resources via Digital Library – Our library provides NICU and bereaved parents in the Hand to Hold App access to valuable information pertaining to their NICU stay. From NICU Basics to Getting to Know Your NICU Baby, there are topics for every stage of the NICU journey, including a NICU Glossary, Meet the NICU Team, Bonding with Your NICU Baby, Breastfeeding, and more. The library has recently grown with the addition of a Your NICU Grad category, with important topics like Taking Care of Yourself, Safely Transporting Your Baby, and Sleep.

2023 Highlights:

Modernized our podcast, app and educational resources to resonate with parents of today.

Looking Forward:

We will continue to innovate to remove common barriers NICU parents face when trying to access mental health support – this includes financial, health equity, racial bias, language, cultural stigma, transportation and childcare.



Podcasts Celebrate 100th Episode! Relaunched in 2023 with a dedicated host and regularly updated episodes, our two podcasts – NICU Heroes
Podcast for NICU professionals and NICU Babies
Parent Support Podcast for NICU parents – have evolved into more modernized platforms. NICU Heroes also stands as the premier accredited podcast choice for NICU professionals. In 2023, we reached 40,000+ downloads and 100 episodes.

Mobile App Relaunched – After listening to parent feedback, we relaunched the app to make it more responsive and easier to navigate. This is the only app where NICU parents can connect directly to mental health peer support.

Free, Accessible Counseling

Nationwide there is a chronic shortage of trained professionals who specialize in postpartum depression – few are bilingual or people of color. Hand to Hold fills a demand for specialized counseling by offering free, accessible counseling from a team of licensed clinicians trained to address trauma, grief and loss, and PMADs; 100% are women, 67% are women of color, and 30% are bilingual. Using an online platform (Telehealth) and a bilingual, diverse staff, Hand to Hold's counseling program eliminates barriers to mental health care.

Each parent/couple is eligible for up to 12 free 1-hour telehealth counseling sessions (in English or Spanish) to help process their birth experiences and/or grieve the loss of their NICU baby.

We know our program works, as witnessed through our screening tool, survey, and through parent testimonials.

- We use the Edinburgh Postnatal Depression
 Scale screening tool at a parent's initial screening
 and subsequently over an eight-week period to
 identify clients at risk for perinatal depression. The
 higher the score, the higher the likelihood for
 depression and continued assessment for
 diagnosis and appropriate treatment.
- As some clients may not be seeking help for PMADs, we use a counseling survey that measures other factors in healing, such as parentchild bonding and a parent's overall sense of hope.





2023 Highlights:

- Delivered 756 free counseling sessions to NICU and bereaved parents
- · Hired full-time counseling program manager
- Streamlined service delivery by centralizing intake system, reducing response time by 50%, and developed policies for late cancellations, no-shows and client surveys

Looking Forward:

In 2024, we will provide 1,000 free counseling sessions and pilot a new intern program utilizing graduate social work students to help train more mental health professionals who specialize in perinatal mood and anxiety disorders.

70% of parents who received counseling reported decreased postpartum depression after just 8 weeks of sessions.

Staff Spotlight - Natalia Castillo

When Natalia's daughter, Mariana, was unexpectedly born at 34 weeks gestation with a genetic disorder called Central Core Disease, she faced many complications. Mariana had to be resuscitated several times within her first month of life due to her disorder. Mariana's lungs were underdeveloped. She couldn't swallow, she had low muscle tone, and she eventually had a g-tube and tracheostomy placed. Natalia remembers "comparing myself with other parents, trying to find out why this was happening to me. That's when I knew I was going to be a special type of mom." After four-and-a-half months, she was able to come home with Mariana and a lot of medical equipment.

While in the NICU, Natalia signed up for Hand to Hold's Peer Mentor Program and was matched with Christine, a fellow NICU (and bereaved) mother and Programs Manager with Hand to Hold. "Christine gave me the tools to advocate for me and for my daughter, and helped me to navigate the pros and cons of important decisions."

In addition to having a mentor, Natalia attended the Hand to Hold NICU Parent Support Group in the hospital every Friday, listened to Hand to Hold's Podcast, and participated in Hand to Hold's NICU Milestone Bead Program as a way to celebrate her daughter hitting her developmental milestones. "Having all these resources in and out of the NICU helped me feel less alone and more confident in my parenting skills," recalls Natalia.

As a special-needs mom and now a bilingual, certified mental health peer specialist with Hand to Hold, she gets to help other NICU parents by providing this same support so they feel less alone in their NICU journey.







Certified Mental Health Peer Specialists (MHPS) are staff members, not volunteers. They are trained to work in and through traumatic situations. Their MHPS certification is through Via Hope, a leader in Peer Specialist training and curriculum since 2010. Other requirements of the position include:

- 40+ hours of training and orientation
- 250 hours of supervised work experience
- 2-year certification applied through state certification boards
- · Certification maintenance through ongoing education (CEUs) and competency checks

"I needed someone who knows the struggle of having a NICU baby, and both Liz and Natalia ... helped to ground us through our journey. Thank you so much, Hand to Hold, for the support you all have provided"

Bereavement Support

Hand to Hold's Family Support Specialists provide personalized bereavement support for NICU parents who have experienced the loss of their baby in the NICU or after NICU discharge. We also support parents whose baby has been referred to palliative and/or hospice care. Specialists are trained in grief and loss, including understanding trauma-informed care and working with hospital bereavement committees to plan annual memorial services for bereaved families. Our staff has firsthand experience with perinatal loss, receiving antenatal life-limiting diagnoses, and palliative care.

"I had two peer matches. Before the death of my baby and afterwards. Both ladies really helped me a lot to feel less alone. They could comprehend what I needed to relay and listened when I was down. I didn't think anyone could help me within my family as they would trivialize my pain, but Hand to Hold gave me support. In the NICU I would talk to my peer mentors daily and they gave me comfort and helped me navigate through the grief process."

- Tanya, bereaved NICU parent

Looking Forward:

In 2024, we are introducing a bereavement handbook, which will cover topics including: Navigating the Challenges After Loss, Physical Recovery, Grief and Depression, Self Care While Grieving, Your New Identity, Parenting Other Children, and much more.



Through Hand to Hold, bereaved NICU parents can:

- Join our Love and Loss Virtual Support Group
- Join our Love and Loss Facebook Group
- Be matched with a peer mentor with bereavement experience
- · Request free counseling focused on bereavement
- Join our private NICU Love and Loss group within our App
- Wear our Love and Loss necklace in memory of their baby
- Listen to our NICU Love and Loss Podcast miniseries
- Attend our annual NICU Mental Health Conference, featuring specific sessions addressing topics of grief and loss

Annual Events

Hand to Hold hosts both national and local community events year-round to celebrate and honor NICU babies and their caregivers. Events also provide a sense of belonging, and empower families with resilience as they navigate the challenges of the NICU.



(Virtual) NICU Mental Health Conference – In its 3rd year, we hosted the only national conference bringing together NICU professionals and parents to focus on mental health. Throughout the course of two days, 444 individuals across 38 states and 6 countries came together to learn, engage, and discuss critical mental health topics to ensure better outcomes for NICU parents and their medically fragile babies. Topics included health equity, burnout/self-care, trauma-informed care, and grief and loss.



NICU Graduate Reunion, sponsored by St. David's HealthCare - As the largest NICU-graduate celebration in Central Texas, 1,600+ gathered to honor their NICU graduates as they celebrated the impactful milestone of their NICU graduation – the start of their journey outside of the hospital!



Contest winner Rich

NICU Grad Then & Now Photo Contest - Sponsored by Huggies® - We created our first-ever national celebration to honor NICU graduates, while raising funds to ensure our support services remain free to all NICU and bereaved families. The stories submitted inspire us daily and underscore the need to celebrate NICU grads for all they have overcome and accomplished. We had 1,600 NICU grad entries from all 50 states, ages 0-18 years old. Following the event, 75+ grads were featured in our exclusive 2024 NICU Grad calendar.



Parkland Memorial Hospital Team

NICU Hero Award Contest, sponsored by Reckitt/Mead Johnson - Our parent-nominated award recognizes a NICU individual and a NICU team who made a difference in a parent's NICU journey by demonstrating compassionate and expert medical care. 2023 NICU Team Winner: NICU team from Parkland Memorial Hospital in Dallas, TX; NICU 2023 Professional Winner: Chelsea, BSN, RN, CPST.



NICU Champion Sydney Kometani

NICU Champions of Central Texas, sponsored by Texas Children's Hospital – More than 250 Central Texas medical professionals, community leaders, NICU parents, friends and family honored those in our Central Texas community who are making great strides in improving outcomes for NICU families. 2023's honorees were: Todd Boullion, Chief Marketing Officer, Encoura; Sydney Kometani, MD, Pediatrician, Austin's First Steps, Pediatrix Medical Group; Peter B. Untalan, MD, Neonatologist, Pediatrix Medical Group; and Ashley Wilson, Chief Strategy Officer, Ascension Texas Foundations.

2023 Supporters

We are deeply grateful for the support of our contributors, whose generosity and commitment have been instrumental in driving our mission forward. Contributions make it possible for us to provide support and resources at no cost to NICU and bereaved families, in English and Spanish.



\$1,000 - \$4,999

Austin Health Partners

Austin Regional Clinic

Arden Barela

Mark Castle

Michael Cave

Child Neurology Consultants of Austin

Cipione Family Foundation

Efrem Colmenaro

Dignity Memorial

Dayna & Steve Diven Household

ECG Foundation

Toni Egolum

Emler Swim School

Encore Bank

Richard Eppler Charitable Fund

Patty Fougerat

Nancy Gililan

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Tiffany Gladdis

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Michael Hynan Household International Biomedical

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Holly & Pete Jordon Household

The Junior League of Austin

Ryan Kelly

Kristin & Marc Knight Family

Janine Krause

Labcorp

Gloria Li

Lana Macrum-Craig

Maxwell Locke & Ritter

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Viva Pediatrics

Kay Weatherford

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\$5,000 - \$9,999

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Austin Diagnostic Clinic

GE HealthCare

Greentex Windows & Siding

Healthline Media

Kalahari Resorts

S Base Tech

SHI / Ranchscapers

Texas Capital Bank Foundation

The University of Texas LEAD

Walter S. Johnson Foundation

2023 Supporters

\$10,000 - \$14,999

Austin Retina Associates
The Black Emotional and Mental Health
Collective (BEAM)
HEB Tournament of Champions
Prolacta Bioscience
St. David's HealthCare
The Lola Wright Foundation

\$15,000 - \$24,999

Ascension Seton / Dell Children's Ascension
James Avery Artisan Jewelry Forging Hope
Kelli & Michael Kelley
The Harry E. & Eda L. Montandon Charitable Trust
Pediatrix Medical Group of Texas
Primrose Schools

\$25,000 - \$49,999

Mallinckrodt Pharmaceuticals Ronald W. Naito MD Foundation Prolacta Bioscience Foundation Texas Children's Hospital

\$50,000 - \$75,000

Deirdre Imus
The Meadows Foundation

\$300,000 - \$350,000

Kimberly-Clark Huggies
Reckitt/Mead Johnson Nutrition





Thank you to all of our volunteers for your efforts, valued at \$43,068.14!

Donor Highlight - Kay Weatherford

My husband and I had our first pregnancy about 3 years after getting married. We were so excited to be expecting our first baby. Then what was supposed to be an exciting time turned into a nightmare when I had complications that led to the delivery of our son at just 21 weeks gestation. He was born and immediately went to heaven.

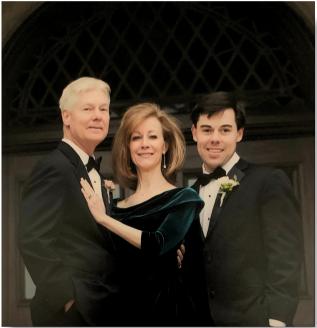
Then in the next year, we had our second pregnancy that resulted in the very premature birth of our son Trent, born at 26 weeks gestation, weighing just 1 pound 15 ounces. We were so scared, and so alone with a very tiny, sick newborn who may or may not survive, and went home without him for a very long time. We had to go back to work and were able to just go through the motions as we continued to grieve what should have been. Both sets of our parents lived far away out of state. We were in the NICU for 6 months before Trent was able to come home.



We were on an emotional roller coaster, as some days Trent progressed, but most days we had news that he had some other health issue or that he had lost weight or backtracked or needed another surgery. He had 9 surgeries in his first year.

The world went on around us. I wanted so badly to have someone to talk to, someone who was walking on the same path.



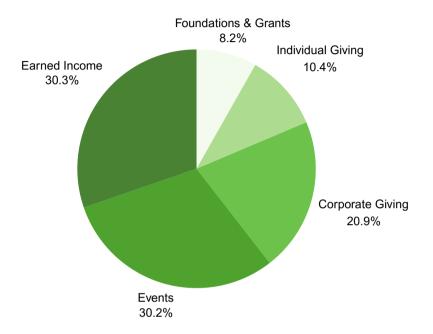


After our experience, I wanted to help parents whose babies had gone to heaven or were in the NICU – after much research, I found Hand to Hold. Since I became a donor and volunteer (peer mentor), they have grown the services they provide to include free counseling, group support, and education, while always looking at how they can do more for families. I would have loved to have had Hand to Hold.

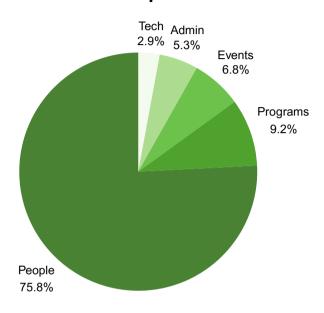
Financial Overview: 2023 Report

We are committed to stewarding your contributions responsibly and dedicated to supporting our growth and sustainability with prudent financial decisions.

2023 Revenue



2023 Expenses



In 2023, Hand to Hold saw a 12% increase year over year in total sessions of support!

\$1.8 million spent equals 72,000+ free sessions of support for NICU and bereaved parents.



Gold Transparency 2024 Candid.



The Best Place for Working Parents® designation for leading the way in our family-friendly work practices and policies for the 2nd year in a row.

2023 National Board of Directors





Board Chair Lydia Contreras, PhD

Associate Professor of Chemical Engineering The University of Texas at Austin

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Licensed Mental Health Professional Austin Independent School District

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