

Fragile Babies. Family Support.

2019 Annual Report



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Our Mission

Hand to Hold 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.

Our Four Cornerstones

Hand to Hold's programs, support and resources are focused on four central strenghts*:



Peer Support from trained, supervised NICU graduate parents



rt Psychological & d, Emotional Support CU crucial for improved ents successful outcomes



Whole Family Care including siblings and grandparents



NICU & Beyond from antepartum through early childhood years

A Year To Celebrate

In August, Hand to Hold welcomed our Austin-area NICU families to our first-ever NICU Family Reunion! We had a fantastic day filled with face painting, raffles and lots of fun. Every parent that came received a special reunion bead to add to their NICU Milestone necklace, a cherished reminder of their NICU journey. More than 65 families showed up to celebrate how far they've come after the NICU, visit with their Hand to Hold Family Support Specialists and connect with other NICU families. All this was made possible by Wag-A-Bag, Aspen Schara Kralich - State Farm Insurance Agent and so many incredible vendors and local in-kind donors. Thank you to Wild Rumpus Photography for capturing this amazing day.













^{*}Essential components in the delivery of Family-Centered and Trauma-Informed Care, as recognized by The Joint Commission and the National Perinatal Association (NPA).



Welcome Letter

2019 marked a year of astounding expansion for Hand to Hold as we grew our services to accommodate our families in many new and exciting ways. We started the year off with a celebration, checking off a long-time goal of mine: the introduction of our support programs in Austin's Ascension Seton Medical Center.

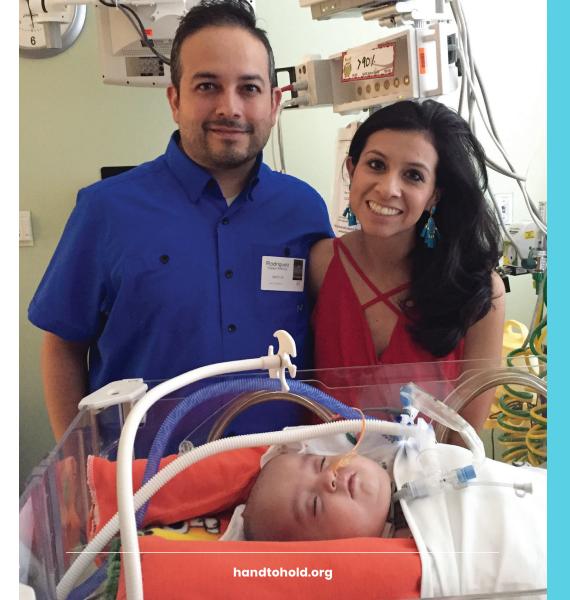
As the year progressed, we introduced many exciting ways to expand our mission and enhance our support for NICU families. We launched two new podcast channels: NICU Dad Discussions and Beyond the NICU. We held our first ever Austin-area NICU family reunion, a fun opportunity for our NICU graduate families to reunite with each other and with their Family Support Specialists. With a grant from the St. David's Foundation, we piloted new in-person counseling services for Austin-area NICU parents, led by our own on-staff counselor.

Finally, we closed out the year by adding yet another hospital to our list of partners: CHRISTUS Trinity Mother Frances in Tyler, Texas, an accomplishment that I hold dear to my heart, as that is the hospital in which I was born.

What an exciting year of growth.
With your continued support, we
can ensure every NICU parent
has a Hand to Hold during and
after a NICU stay.

Thank you to our Board, staff, volunteers, corporate parents and individual donors who make what we do possible. Together we can ensure every NICU and bereaved parent has a Hand to Hold.

Killi Killey



"Hand to Hold has provided me with many wonderful resources. I attended support groups while in the NICU, the beyond the NICU groups, requested a mentor, and got the names of psychiatrists from other moms to help with my PTSD. I feel like I have been able to be there for my 31 have because I have been able to take care of myself!"

-Kailee H

eceived support from a peer mentor

I Could Survive This The Sullivan Family Story

At 1:41 p.m. on April 28, 2018, our beautiful daughter, Grace Lynn, entered the world at 26 weeks gestation, just days after I was diagnosed with severe preeclampsia. I was terrified, feeling like I had no control over anything at all.



When I woke up from the anesthesia, I didn't feel like a mom, but I also didn't feel pregnant anymore. I just felt void. When I was finally able to go visit her in the NICU, I looked into the isolette and saw a tiny little human with whom I felt no connection. I knew that she was my daughter, but I wasn't able to process this journey of parenthood.

My nurses encouraged me to attend the Hand to Hold NICU support group, but I was a little hesitant. A support group sounded like too much for me. But I went. The Hand to Hold Family Support Specialist, Suzy, welcomed me with open arms and listened to my story. She never said, "I understand," because while she had a NICU experience, each experience is so different that you can never completely understand what another person is going through. Leaving the group, I had a new hope that I could survive this because others had.

NICU Support group days quickly became my favorite days. I enjoyed getting to connect with parents who were at different

stages of the journey. I shared what I had learned with the newer parents while learning from the more experienced ones. Suzy and my Hand to Hold family were there to support me through the tough times of finding out my baby had a hole in her heart and hugging me when I experienced my child nearly dying in my arms during an episode of bradycardia. Not only were they supportive through the hard days, they shared in the joy of celebrating the small milestones: holding my baby for the first time, getting to put her in her first outfit, taking her first bath, each progression made with her respiratory status, and finally going home!

It is extremely important to stay connected during a NICU stay and in the days after. I was able to get the emotional support I needed at the NICU support groups, connect with other NICU parents in person and online, and make lifelong friends because of Hand to Hold.





"Hand to hold was there for me when I had my 24 weeker. The emotional support was great but we also made an achievement necklace that we will cherish forever."

-Kaleigh Koeni NICU parent

2019 By the Numbers

NICU Bedside Visits: 3,899

Family members attended a support group: 984

ndividual families served

by our hospital ambassadors: 1,957

Volunteer Highlight

Volunteer hours completed during 2019: 1,530+

Which Included:

19 in-office days, totaling 334 hours

support group lunches provided at 3 Austin hospitals

"We love working with Hand to Hold. It is so emotional seeing the small diapers and tiny onesies. It's nice to be able to come in with my daughter and work on a project that supports NICU families."

-Sunny L



Peer Support:

General Support Requests: 387

Active mentors: 209

Matches made: 166





Launched in June of 2019, NICU Dad Discussions, hosted by The NICU Dad himself, Alex Zavala. A podcast for NICU Dads, by NICU Dads.

Launched in September of 2019, Beyond the NICU. A podcast exploring life after the NICU.



Podcast Numbers

The number of listens/downloads through 2019

NICU Dad Discussions: 637

NICU Heroes: 8,384

NICU Love & Loss: 799

NICU Now: **22,142**

Beyond the NICU: 424





"Hand to Hold was my compass during our 8 week NICU stay. They let me know on day 1 that I was not alone and that there were resources and other families that could help me get through it. The families in our weekly lunches us in our world and knew exactly what we felt and thought, whether it be feedings, eye exams, or just bad days. Hand to Hold is the reason we did not feel alone in a hard, challenging marathon of growing a preemie baby! We are forever grateful!"

achel K.

Peer Connections

Forming relationships in the NICU isn't easy. Families sometimes aren't allowed to speak with one another in the unit, or they want to respect each other's privacy. Sometimes parents don't have the emotional energy to initiate a conversation with a stranger.

Support groups and special events give families the opportunity to socialize outside of those restrictions. They meet other families going through the same thing they are, they get to know one another, and sometimes they even become the closest of friends.

Hillary Sullivan and Vanessa Ibarra delivered their babies on the same day, under many of the same circumstances. Hillary's daughter, Grace Lynn, was born at 26 weeks gestation, after Hillary suffered a bout of severe preeclampsia. Vanessa's son, Liam, was born at 24 weeks after Vanessa spent a month on hospital bed rest due to blood clots and then went into premature labor. The two women spent day after day in the NICU, unaware of each other's presence in the NICU.

It was a Hand to Hold Mother's Day event that brought the two moms together. There they sat down and began exchanging stories, and the two quickly realized that not only were their babies born on the same day, but they were actually NICU neighbors. They became fast friends.

"It was amazing to connect with someone going through the NICU experience at the same time," said Hillary. "Thursdays quickly became my favorite days because I was able to see our amazing Hand to Hold Family Support Specialist, other NICU families and my new friend."

Parents are undoubtedly under increased stress in the NICU. While they may be surrounded by friends and family, these traditional support networks don't always fully comprehend or understand what the parent is going through.

This is where peer support fills in the gaps. Peer support programs in the NICU like Hand to Hold's give parents a safe space to share their fears, get validation on their feelings and receive the confirmation that they are not alone.

"If I hadn't met Hillary, I honestly think I would have been so lost during our NICU stay," said Vanessa. "When I met Hillary, I had someone to vent to, someone to confide in, someone to lean on."

Today the two moms text each other frequently, sharing pictures of their babies and bouncing questions off one another about





milestones and development. Their friendship has been one positive outcome from two terrifying experiences.

"Meeting Vanessa was life-changing," said Hillary. "It was comforting to have someone in the NICU that I knew and could chat with while in this situation."

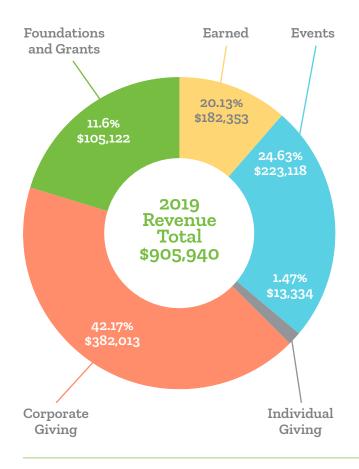
Peer support in the NICU offers parents the connection they desperately need when going through a difficult situation. Vanessa and Hillary both hesitated to reach out to other parents, unsure if the attempt at connection was welcome. But once they came

together, they witnessed first-hand the power of peer support. "Having that friendship and someone to lean on felt like a weight was lifted off my shoulders," said Vanessa.

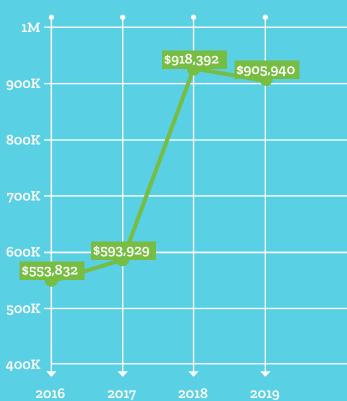
Hillary believes the connections she made in the NICU and in support group helped her heal from the trauma of the NICU. "While I had lost so much (in terms of expectations on pregnancy and delivery and new parenthood), I gained lifelong friends."

handtohold.org handtohold.org

Financials



Year Over Year Growth





"In a time of fear and uncertainty, Hand to Hold became a beacon of hope. It was there where we developed lifelong friendships with people we never would've met otherwise. It was in that meeting room where we learned about what to expect, steps and precautions we should take, and above all we learned patience and trust. Without Hand to Hold I believe we all would've been a little more confused & lost."

-Marta I. NICU Parent

