

Startup nonprofit lending a hand to premature infants, parents

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A new nonprofit backed with seed funding from the foundation of an Austin Ventures co-founder is seeking to help infants and the parents of infants who are starting life early.

Hand to Hold, which is pursuing 501(c)3 status, aims to provide resources, education and counseling related to infants born before reaching full term. Founder Kelli Kelley, who launched Hand to Hold about six months ago, believes there's a need for services geared toward premature babies after they leave the hospital. It's a conclusion she reached after spending several years interviewing parents about the resources available, and doing focus groups to figure out how to better serve them.

Data also suggests that the need for resources related to premature births is great and growing. Premature births have risen over the last 30 years, with one of out eight babies in the U.S. born before 37 weeks — 40 weeks is considered full term. Of the roughly 310 births in Austin each week, 39 are premature, according to Travis County statistics.

Hand to Hold's signature service is a peer-to-peer program, which matches seasoned parents with those needing support. More than 30 families have volunteered to be peer counselors, Kelley said. The nonprofit also offers newsletters, support groups, resource lists and a speakers' series.

Kelley, an experienced marketer and public relations professional, has brought on a development professional, recruited a seasoned board and obtained seed funding from

the Aragona Family Foundation. Joe Aragona is one of the founders of Austin Ventures.

Chris Earthman, executive director of the Aragona Family Foundation, said it invested an undisclosed amount in Hand to Hold because it believed the nonprofit can fill a gap in the local health care system.

"This [premature births] is a huge, growing market that is under served by community-based nonmedical providers," Earthmansaid. "Hand to Hold has identified a compelling niche here in Austin."

Hand to Hold's board includes Dave Alter, an associate at Austin Ventures; Rachel Muir, founder of Girlstart and former executive director of Mothers' Milk Bank at Austin; and Heather Bendle, co-founder of Baby Earth, a baby products retailer.

"We've really set ourselves apart, being such a young organization and having the talent and experience that is on my board," Kelley said.

Although Central Texas has early childhood intervention programs to help with the

developmental needs of premature babies, those programs don't often include direct support for parents. Hand to Hold seeks to distinguish itself, Kelley said, by providing emotional support to parents after the birth or death of a premature baby, as well as ongoing education and resources.

Kelley, who is on the March of Dimes' board, said she's not competing directly with that nonprofit, which provides services in partnership with Seton Family of Hospitals. She believes Hand to Hold's ongoing services after a family leaves a neonatal intensive care unit, or NICU, will complement the March of Dimes' efforts.

"One of the common misconceptions is that once babies go home, they are OK," Kelley said. "They don't understand that a lot of premature babies can't be taken to a grocery store. ... A common cold in a premature baby can lead to rehospitalization and often death."

Research indicates that 76 percent of parents of premature infants report symptoms of post traumatic stress disorder after their babies spend time in NICUs. Peer-to-peer support has shown the ability to reduce that statistic to 36 percent, Kelley said.

"I cannot tell you how stressful a NICU experience is. In many cases, that baby is clinging to life," Kelley said. "These parents are walking back into a war zone every day not knowing what to expect. We want to match you as soon as possible with a peer."

After a baby is discharged from a NICU, parents are often overwhelmed by the stress of caring for a fragile child, as premature babies can suffer lifelong consequences such as cerebral palsy, blindness, mental retardation and asthma. Statistics

EARLY INFANTS DATA

- In Texas, 143 babies are born prematurely each day — 14 percent of all babies born in the state.
- More than 2,200 premature babies are treated in local NICUs each year.
- More than 500,000 babies are born prematurely in the U.S. each year.
- Premature babies often suffer lifelong consequences such as cerebral palsy, blindness, mental retardation and asthma.

Source: Hand to Hold

show such stress on families can contribute to depression, separation, divorce and child abuse.

Kelley said her short-term goals include raising awareness for the need for Hand to Hold and the challenges parents of premature babies face, and developing a diverse funding strategy.

"We want to build awareness and credibility for what we are doing," she said. "We want to continue to build relationships with the medical community so they know what we are and how we can be a resource."

She would also like to identify more families to be volunteers.

"It took me along time to build a strategy and identify the holes and gaps in the system and figure out the business model," Kelley said.

It's a model Earthman and the Aragona foundation sees potential in, similar to what it saw as an early funder of Livestrong, the foundation for cancer patients and families founded by cyclist Lance Armstrong.

"The Hand to Hold opportunity looks and feels very much like cancer survivorship did 10-plus years ago," Earthman said.

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Kelli Kelley
Founder
Hand to Hold

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