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'A Hand to Hold': A mother's journey to provide local support for parents of infants born too soon

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Four Points News

On Aug. 7, 2000, Kelli Kelley was a typical pregnant suburban wife living in the Four Points area of northwest Austin, anxiously making plans for her child's birth. However, after starting labor on Mopac expressway three months earlier than her due date, Kelley and her husband Mike began a life-altering journey with their premature son. At birth, Jackson weighed only one pound, eight ounces. His eyes were fused shut and skin was translucent, and IVs, probes and monitors nearly covered his tiny body. As Kelley tried to focus on the neonatologist's seemingly unending list of possible neurological and physical challenges her helpless infant might face, she found it difficult to bond with such a fragile human life. Miraculously, Jackson fought off the many obstacles which threatened his existence and, after 105 days in the neonatal intensive care unit (NICU), was discharged to his parents.

Ironically, it was at this point in Kelley's story that she felt the most isolated and alone. Jackson, like so many premature infants, left the hospital with a heart monitor, CPR instructions, numerous medications and a list of medical specialists. Furthermore, the Kelleys could not leave home with their newborn son for fear of his contracting infections which could so easily ravage his small body. Additionally, Jackson endured three surgeries by the time he was only 10 months old and the Kelleys' medical bills soared to over \$1 million.

A young mother searches for help

Following the birth of her second premature infant, Lauren, Kelley felt that something must be done to preserve the psychological and physical well-being of families struggling with premature infants and babies. Federal and state agencies existed which provided minimal support with very little funding.

However, Kelley was searching for an organization which

could not only serve as a resource for medical personnel specializing in preemies in her local area but also a direct connection to a listening ear, a mentor, for the issues her family encountered daily.

The need for a local resource for parents of premature infants

"Depression of one or more parents is a likely result in the case of a premature baby since the child is placed in the NICU and the mother separated from the infant at birth," said Kelley.

"Additionally, parents cannot leave the home once the child is released from the hospital for fear of infection, further isolating the family. The *New York Times* likened this situation to the post traumatic stress a soldier at war encounters upon his arrival home: a fighter can function daily in the war zone, but once home adjusting to a different life, problems begin." Kelley felt as though she had "fallen off a cliff blindfolded" as she faced the maze of doctors and specialists treating her son and daughter for their various ongoing special healthcare needs. She

longed for a local connection with other families who had gone through what she was experiencing and could impart what they had learned, through local resources or personal adjustments, to aid her family's well-being.

Kelley soon found out that she was not alone in identifying this void within the Austin community. Inspired by long-time local columnist Andrea Ball's 2007 series, "Tiny Babies, Fragile Families," she began communicating with Ball from home.

"I had a 22-week-old baby boy named Jack who died in 2001," said Ball. "Then I had a regular term baby, a little early. In 2005, I had a 24-week-old boy who was in the hospital for four months. So many people would ask, 'When is he coming home?'"

"When the baby finally came home, everything was just horrible; I felt like a loser, like everything was wrong with me, that I couldn't do this. I didn't feel connected to my baby because I hadn't held him for so long. Somebody had been giving me permission to touch him for four



Courtesy Photo

From left, Andrea Ball, parent of children born prematurely; Kelli Kelley, Canyon Creek resident and founder of "A Hand to Hold;" Laura Warren, executive director of Texas Parent to Parent.

months."

During a moment of despair, Ball recalled seeing a notice soliciting fellowship applications through the Carter Center. Ball applied for the award and proposed constructing a mental health study of the effects of premature babies on families and was awarded funding through the Rosalynn Carter Fellowship for Mental Health Journalism. Her research formulated a unique series for the local Austin newspaper and served as the voice of 30 families. All those Kelley interviewed shared a common thread: they suffered anxiety, depression and guilt which nobody addressed; they had nowhere to turn.

"One day Kelli called me and was crying, angry, upset," Ball said. "She told me that she had read my series and couldn't believe how strongly she identified with the other parents of these babies. She kept saying, 'This is my story, this is my story, this is exactly what happened to me and we have to do something.'"

Kelley discovered the Parent to Parent website, a nonprofit organization headquartered in Austin and part of a national organization which is dedicated, through resources and personal support, to improving the lives of families with special needs children. Once she contacted the Texas Parent to Parent organization in January of this year, things began to move very quickly and A Hand to Hold was created as its pilot program with Kelli Kelley serving in the capacity of program coordinator.

A Hand to Hold is the first nonprofit program of its kind in Texas to provide parents of premature babies resources specific to their special needs. According to the National Center for Health Statistics, in 2006, one in seven babies (13.7 percent of live births) was born preterm (less than 37 completed weeks

gestation) in Texas, an increase of 17 percent over the previous decade.

Kelley's grassroots organization will not only function as a matching program in which a trained volunteer is paired with a specific family for support and information but will also offer Austin families a peer network, parent conferences, local family outings, lecture series and bereavement aid.

"We knew Kelli and had so many parents of children who started life in the NICU or who were premature and then had other issues later," said Texas Parent to Parent founding member Patty Geisinger. "We already were serving those parents but Kelli had such a good vision of what would help them the best through A Hand to Hold. She was very organized and liked what we had to offer in terms of parent support and training. We just saw that it was a perfect fit."

St. David's Medical Center is the title sponsor for Kelley's foundation which is set to begin assisting Travis County parents in the spring of 2010. Additionally, A Hand to Hold officers are anticipating that it will be the recipient of several local community grants in the months to come.

"Vine to Wine"

Earlier this month, Texas Parent to Parent dedicated its Fifth Annual Vine to Wine soiree held at The Bob Bullock Museum to A Hand to Hold. The fund raising reception featured wines selected by Republic National Distributing Company paired with appetizers from Central Market-Westgate. Guests enjoyed silent and live auctions and were treated to the video debut of a song written and performed by Sara Hickman specifically for the event.

For more information on "A Hand to Hold," contact kelli.kelley@txp2p.org, or www.txp2p.org.