



Mended
Little
Hearts

Mended *Little Hearts* is perhaps the one place in the world where the parents and caregivers of children with congenital heart defects, as well as the children themselves, can feel “normal” and accepted. Where else can children who have undergone open-heart surgeries meet other children with “zipper scars”? That does not happen in the typical playground or school yard. Where else can parents reveal their overwhelming anxiety about their child’s future and not have it dismissed with some misdirected platitude? No matter how much they love a family touched by CHD, other people cannot understand what it is like to live with the ongoing upheaval caused by this condition.

That is what Mended *Little Hearts* does — offers profound support at the most crucial time. Mended *Little Hearts* members have a visceral knowledge of fear, of guilt, of worry. And having been lost in that miasma of emotions, they know intuitively how to support new parents going through it.

Mended *Little Hearts* fulfills this function in many ways, most often, perhaps, when a member quietly listens to the grief and sadness of new parents. But Mended *Little Hearts* also reaches out in more obvious ways — care bags, parent matching and group meetings. *Heartbeat* talked to several Mended *Little Hearts* mothers about these efforts, and here is what they said.

HOW MENDED *LITTLE HEARTS* MEETS BIG NEEDS

Support in a Bag

In California

Care bags are filled with practical, mundane items — toiletries and snacks ... and care. It is the care that changes things. Heather Wigginton of Palo Alto, Cal., got one on the day of her son Everett's open-heart surgery, and as she tells it, it changed her life.

"That might sound dramatic," Heather said, "but on that day in a cold, sterile hospital room I felt validated in my grief and felt hopeful for a future with a new family — my heart family."

She and her husband James had had 36 peaceful hours believing everything was fine with their second child. Then the doctor arrived and drew a series of diagrams of the heart, showing them pictures of holes and kinks and abnormalities — coarctation of the aorta, hypoplastic aortic arch, ventricular septal defect and an abnormal mitral valve. Slowly it dawned on Heather that the doctor was talking about Everett's heart. "I was shocked," Heather said. "This is my baby's heart?" I asked innocently. 'You're saying my baby has heart disease?' It took my breath away."

Everett was transferred to another hospital for the surgery, as Heather struggled with the news. Her social worker asked if she would like a "care bag" from a support group. "I thought she was kidding," Heather said. "You mean there are other people out there who have kids with heart disease?" Of course I wanted the bag!"

While eating the snacks, she read the enclosed information. She gave the stuffed heart pillow to Everett's big brother and used the notepad to

take notes during rounds. "But more than anything, I realized that there were people out there who shared my 'normal' and understood my experience."

Since then Heather has given a lot of time to Mended *Little Hearts*. Soon after Everett's birth, she helped charter the Mended *Little Hearts* of Silicon Valley with Andrea Himmelberger, the mother who delivered her care bag. Recently Heather delivered 75 care bags to the Lucille Packard Children's Hospital. "The social workers are bubbling with enthusiasm and support for our group," Heather said. "And knowing that 75 families will feel the hope that a little care bag can bring is so exciting!"

In Illinois

In her 28th week of pregnancy, Angela Latrofa of Chicago learned that her son had coarctation of the aorta. Giancarlo had corrective surgery during his first week of life. That's when a care bag was delivered to her in the surgery waiting room.

After the surgery, she visited the Mended *Little Hearts* of Chicago website and contacted Christine, the coordinator. "I knew that I wanted to get involved with the organization," Angela said. "Christine emailed me back and was so warm. I felt comforted knowing there were other parents that had similar experiences. Our families have shown us tremendous support but the support from other parents whose children had heart defects brought me a lot of comfort. I loved what Mended *Little Hearts* was doing for families like mine."

Angela and her husband Danny started giving back immediately. Instead of giving favors at Giancarlo's baptism, they donated coloring books, crossword puzzles, markers and crayons, and made a monetary donation to Mended *Little Hearts*. "It was fun shopping for the items with my daughter, and I hope the items will bring comfort to children and their families. We are also planning a fundraiser in July, and the



Heather Wigginton delivers Mended *Little Hearts* care bags.



Giancarlo Latrofa



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proceeds will be donated to Mended *Little* Hearts and other CHD-related charities.”

Neither of these families is through with their heart journey, but in some ways their experience has come full circle — and it all started with a care bag!

Parent Matching

No parents discover their newborn has a heart defect and say, “I am ready for this challenge. And I have everything need to meet it. Bring it on!”

Quite the opposite. The news brings parents face to face with their worst fears and most debilitating emotions. Even those who have a sturdy support network of loving family and trusted friends find that network inadequate for the challenge they face. So often all those people can offer are empty promises about a happy future. At that time, what these parents need is someone who has walked this path and knows what lies in front of them. This is not to say that family and friends don’t count; it is just to acknowledge there is profound value in having a guide who has “been there and done that.” That is the purpose behind Mended *Little* Hearts’ Parent Matching Program.

That was certainly the experience Amy and Robert Kijewski had with their daughter Allison Jean in March 2012. Within an hour of her birth, their emotions went from joyful expectation of introducing her to her siblings to utter terror when they were told their baby was born with Ebstein’s Anomaly.

When Allison was diagnosed with EA, Amy searched endlessly for any information. She found numerous sites with medical information but realized that what she was really looking for was support. In her search to connect to others, she found Mended *Little* Hearts and their Parent Matching Program.

She excitedly filled out the simple form that connected her to the Parent Matching Program.

“Within days I received emails from other moms who had children with EA,” she said. “When I got the first email from an EA mom, I felt immediate relief. These parents were able to answer the questions I had and to provide the support my family and I so desperately needed.”

Amy had a strong desire to be connected to parents who had children with the same diagnosis as her daughter, but parents can also be matched by geographical location. Since then, Amy has fulfilled several email requests from Mended *Little* Hearts to reach out to other families looking for the same support that she was looking for when she first found Mended *Little* Hearts.

“Every time I send an email, I know that I am providing support to another family on this CHD journey,” Amy said. “I hope they find the same comfort and reassurance we did. The Parent Matching Program provides CHD families with the means to find the support that will help them to cope with the diagnosis and find hope from other families as they gain knowledge and learn that no one has to walk this journey alone. Communication with others and the support we can give each other can help all of us make it through this journey.”



Allison Jean Kijewski

A Doctor's Thoughts on Mended *Little Hearts*

Heartbeat talked to pediatric congenital cardiologist Mark Townsend of Stroobants Cardiovascular Center in Lynchburg, Va., about his experience with Mended *Little Hearts*.

HB: *What does working with Mended Little Hearts mean to you?*

Townsend: Working with Mended *Little Hearts* gives me the opportunity to move beyond the realm of being a healthcare provider, and into the realm of being connected with the caregivers. It was hard to identify with parents and families who live with congenital heart disease until I made the connection with Mended *Little Hearts*. At an elemental level, all of us work through grief, through tragedy and through heart-wrenching experiences. Being part of the Mended *Little Hearts* family has helped me identify on all of those levels with the families I work with.

HB: *What difference does Mended Little Hearts make with the parents of CHD patients?*

Townsend: To be a parent of a child with a congenital heart defect can be terrifying and traumatizing at the same time. It can be a lonely experience, and not everyone is surrounded with a support system. Mended *Little Hearts* provides such support — there is strength in numbers. Some families tell me that it was the hospital visit that made the difference, whereas other families tell me that making a contact with a family who shares a diagnosis is the best support. I think the strength of Mended *Little Hearts* is that it provides support tailored to the needs of the individual or the family.

HB: *How does Mended Little Hearts contribute to the child's and the family's well-being?*

Townsend: Mended *Little Hearts* serves the spectrum from venting to commiserating. Families band together to help others along the way. Kids see other children with "zipper scars." I see the parents of children with heart defects supporting each other, and thereby supporting each other's children.

HB: *How important is it for CHD parents to talk to other CHD parents?*

Townsend: I have got to say one size does not fit all — some derive support by talking about CHD, but others derive support by minimizing the impact of CHD. Regardless of how the family copes, Mended *Little Hearts* has the ability to help.

HB: *How can Mended Little Hearts groups be most helpful to medical professionals?*

Townsend: The thing that folks in Mended *Little Hearts* have really taught me is the impact that a diagnosis has on a family. I have seen families come together, and others fall apart after a diagnosis. Mended *Little Hearts* has made that journey far more personal for me.



The Ruud family

Meetings ARE Support

At their 20-week ultrasound, Ashley and Jason Ruud found out that their unborn daughter, Breanna, had severe congenital heart defects: tricuspid atresia and transposition of the great arteries. Everything in their world changed at that point. They spent the following months preparing for her arrival on June 7, 2010. The months after she was born were spent fighting for her survival, which has included three open-heart surgeries so far.

"I could feel the loneliness creep in after she was born as I watched the rest of the world carry on while all I could do was hold my daughter's tiny hand," Ashley said. As the days turned into months, she desperately longed to talk to someone who could understand what she was feeling and offer the kind of support she needed.

As soon as they took Breanna home, Ashley started to look for a support group. One month later she was in a meeting of the Central DuPage Hospital Chapter of Mended *Little Hearts*. "Even though every heart warrior has a different diagnosis, the mothers and fathers are all going through the same feelings," Ashley said. "That was what I was looking for. What my friends and family tried to understand, the Mended *Little Hearts* group already knew — and they knew what kind of support I needed."

She felt tremendously excited as she learned about new research, programming, events and advocacy efforts that she could be a part of. She and Jason put together boxes to put at his work place to collect items for care bags. They even received a care bag during an inpatient stay during one of Breanna's surgeries.

"I used to feel lost in this crazy world of CHDs, but now I know I can find my ground and get the support I need with my Mended *Little Hearts* family," she said. In fact, she was so grateful for that group that she became the chapter coordinator to pay forward the support she has received.

"I look forward to leading our group through new endeavors and reaching out to many heart families who need of our support. We've had three new moms join us in just the past three months."