



Mended  
Little  
Hearts



# Helping Families Overcome Fear

by Jon Caswell

**I**magine having the happiest day of your life turn into one of the most frightening – that’s the situation faced by parents of children with congenital heart defects (CHD). Oftentimes their precious children are rushed to another hospital, sometimes in another state, to undergo emergency surgery before the parents even see them. About one percent of all births involve CHD, approximately 40,000 births annually. There are 35 different types of CHD, and often children have more than one defect. Many times multiple surgeries are involved, and heart transplants are not unheard of.

Jodi LeMacks of Richmond, Virginia had just such an experience. Her third child, Joshua, was born without a left ventricle and a pinched aortic valve. The condition is known as Hypoplastic Left Heart Syndrome and had been diagnosed when she was 20 weeks pregnant. As soon as Joshua was born, he was whisked off to surgery. “I did not see him that day,” says Jodi, “and it still haunts me that he might have died without me ever seeing him alive.” Joshua had a second surgery at six months of age and recently had his third surgery, at age 3. “His condition will continue to be life-threatening until they find a way to fix it,” says Jodi. “We have to be very wary of germs, but he is a happy ray of sunshine – the light of my life.

“It is impossible to describe the feelings of a parent faced with this kind of news,” continues Jodi. “At first I felt shock because there’s no history of heart defects in our families. Then I felt angry – why was this happening to our family? The fear and sadness were unbearable, but the most prominent feeling was that of being alone. I didn’t know anyone who had a child with a heart defect, much less one so rare and severe. I called the AHA, but they work mainly with adults. They referred me to Mended Hearts, but again they dealt mainly with adult issues. I felt so alone.”

Having faced this ordeal alone, Jodi was determined that other parents of infants with CHD won’t have to do that. Two years after Joshua’s birth, Jerry Grossman, president of Chapter 28, contacted her about starting Mended *Little* Hearts of Richmond. “For a few

selfish minutes I thought about my hectic life with three sons, but then I told him I would do it. I never wanted another parent to go through what we did. I wanted them to know that someone is out there who truly understands and won't offer annoying platitudes like 'It could be worse.'"

Amanda Eason of Jacksonville, Florida understands Jodi's feelings – her son Jacob, now 9, was born with the same condition as Joshua. He had a heart transplant at six weeks of age. "The psychological effect of seeing your child go through something as drastic as open-heart surgery or a heart transplant is indescribable," says Amanda. "My husband saw his father have a quadruple bypass, but that didn't compare to the emotional impact of seeing his son go through what he did.

"Many times our visits are to very young children, even newborns," Amanda says. "Of course, we aren't there to see them because they don't know the difference. However, the family is suffering greatly. Knowing the loneliness, helplessness and guilt that we went through, we are well suited

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to meet with these families and let them know that they are not alone and that there is hope. I think the most important thing we do is let them know they are not to blame for what has happened to their child."

Because of the special needs of the child with CHD, it is often necessary for a parent to stay home with the child at all times. "Because daycare is often not an option, one parent has to make the decision to leave a job in which they may have years invested," says Amanda. School is always difficult because of germs that can have a dire effect on these children. "And families with more than

one child must carefully balance the focus placed on the medically needy child."

In addition, CHD patients often require rehabilitative therapy such as speech, occupational and physical therapy. And these children also may have special educational needs because of developmental delays. "All of these issues magnify the day-to-day stressors that come with raising any child," says Amanda, who is the co-founder and co-coordinator of MLH of Jacksonville. She is also chair of the national MLH Committee.

"What I've seen is the shock of it," says volunteer Executive Vice President Dale Briggs, whose responsibilities include MLH. "All the attention given the new baby really stresses the family, especially if there are other children. Essentially Mended Little Hearts is there to support parents. I think this is something that many members of Mended Hearts don't understand. As recently as last year members were asking me, 'How do you visit an infant?' Well, it's not for the children, it's for the parents. It's very similar to visiting caregivers. By the time the kids are old enough to understand, they may have already had four or five surgeries.

"For the first time in Mended Hearts' history, we had a program on MLH at this year's convention," Dale continues. "Amanda gave a terrific presentation about how Mended Hearts and Mended Little Hearts can work together."

Like so many needs that MHI aims to meet, this one requires money. Currently, Rita Callens, MH Field Services Director, devotes about 15 percent of her time to MLH. Those hours and this magazine are the main support the national office gives. "I'm trying to get funding for our national office so we can hire someone full time," says Dale. "It was very encouraging to see how excited our members got after they heard Amanda's presentation. Once we have funding, I know we can have a big program because we're getting inquiries from all over the country." ❤️

*Photos (left to right): Jodi and Mark LeMacks with children Joshua (held by mother), Jacob and Nicholas; Amanda Eason with sons Noah and Jacob (center); Jacob Eason with dad Michael*

