



Mended
Little
Hearts

Little Hearts, Big Expense

by Jodi Lemacks,
National Program Coordinator and Heart Mom

This year is an election year and Americans are acutely aware of the national healthcare crisis. Families who have children with heart defects and heart disease are particularly affected. Rodney Masengale from Mended *Little* Hearts (MLH) of St. Petersburg, Florida and father of Olivia, who has a rare congenital heart defect (CHD), sums up what most MLH families experience: “The financial responsibilities of numerous doctor visits, therapy sessions and enormous amounts of medicine add up quickly and contribute to a very strict budget with no room for extras. Our financial standing as a family is now one of instability and constant stress.”



“After refinancing our mortgage for the third time and losing an income, because my wife is now a full-time mom, we are desperately trying to sell our dream home in this pathetic market so we can ‘downsize’ our living expenses and be closer to work. If we don’t find a buyer by the end of this summer, we’ll probably be foreclosed on.”

Many believe that the families hit the hardest are those who don’t pay for health insurance and so can’t afford their child’s medical costs. This is not accurate. The families hit the hardest with out-of-pocket medical costs are “middle-class” families that pay monthly for insurance that was intended to cover their children’s healthcare costs.

It is not uncommon for families that have insurance to have out-of-pocket medical expenses that they will not be able to pay off in their lifetime. So how does this happen? While many facilities can handle adults with heart disease and stroke, far fewer facilities are equipped to handle medical/surgical treatment for children with complex heart defects. This often means that families have to travel outside their city or state to an out-of-network hospital that can care for their child. The family is then forced to make a choice: Saving their child and going into a financial crisis or putting their child in a hospital where there is little to no chance of survival. Of course, if they can, they choose to go where their child has a chance at survival.

Choosing to give our children a chance to live often results in major financial consequences. Families are faced with something called “balance billing.” Balance billing occurs when the doctors charge a certain fee for a service, let’s say \$300 for a dermatologist to look at a dry spot on a child’s cheek, and the insurance company then decides that the “reasonable and customary” charge for this service is \$40. The insurance will pay typically 80 percent (sometimes less) of the reasonable and customary charge (or \$32 in this example). The family in this case is then billed \$268 for this one visit. (This is taken from an actual experience and is not an exaggeration in any way.) When the medical charges are in the hundreds of thousands of dollars, the out-of-pocket costs for a family can easily exceed \$100,000; this is the case for many families. Often these bills start arriving before the family even gets home from the hospital.

Families are forced to figure out how to deal with these out-of-pocket expenses, and the choices are grim. Some declare bankruptcy; some couples are told that they can get a divorce so their child will qualify for Medicaid; some are told that they can put their child up for adoption so medical costs will be covered; others have to sell homes to cover medical costs; and some move to a state with better medical coverage, away from family and friends. Most families pay monthly charges (in addition to ongoing medical costs) to work at paying off the huge medical expenses hanging over their heads. Many dread opening mail or answering the phone because they know that they will be asked for the enormous amount of money they owe for their child’s care.

These medical costs, however, are just one part of the financial picture. Families faced with a child’s hospitalization are forced to make decisions about their employment, and some people are terminated because of missed work. “The emotional stress of having a CHD child is enormous by itself. Dealing with a financial issue like losing an income adds to that stress level exponentially,” Rodney Masengale said. In some cases, fathers or mothers have to go back to work while their child is still in the hospital, while the other parent stays, facing possible loss of employment. One mother in the Richmond, Virginia MLH group was forced to work from the hospital while her child was in intensive care so she wouldn’t lose her clients. When (or if) the child comes home from the hospital, families have to consider childcare options for a child who has many medical needs and should not be exposed to typical childhood germs. This, for many families, means that one parent does not work outside the home, which often causes a significant financial burden. Families work hard to adjust their working situations to care for their child, but it can be very difficult and very expensive for the family.



Len Schendel with wife, Candida and son, Caleb

“I’d gladly give up all my dreams all over again just to see him happy and healthy. And my experience with our chapter of MLH has taught me just how lucky I am to have him.”

Len Schendel of MLH of San Antonio talked about his family’s situation, which unfortunately is not unique to families affected by CHD. “After refinancing our mortgage for the third time and losing an income, because my wife is now a full-time mom, we are desperately trying to sell our dream home in this pathetic market so we can ‘downsize’ our living expenses and be closer to work (gas is killing me). If we don’t find a buyer by the end of this summer, we’ll probably be foreclosed on.”

In addition to the medical bills and loss of employment, another part of the financial picture is the cost to travel to another city or state for a child’s medical care and surgeries. Families have to find housing, food in that location, as well as childcare for other children. Thankfully, many cities have Ronald McDonald houses where families can stay if a room is available. Any extended family that comes to support the family or care for siblings of the heart child can’t stay there, which can mean very high hotel charges. Families also have to buy meals, and hospital food is not inexpensive. The travel to and from the hospital in another city or state can also be very costly. And while the family is away, there are still the costs at home like mortgage, rent, pet care, yard care, utilities, etc. Overall, it quickly gets very expensive to travel to and live in another location and still maintain a home somewhere else.

These financial issues are not exclusive to MLH families, but hit many families nationwide who are affected by CHD and heart disease. Brad Coulter of Saving Little Hearts, another organization that provides support to families who are in the hospital for a child’s surgery or procedure, discussed the financial crisis for our families. “The current healthcare crisis affects us all, but the sicker you are, the harder it is. Some of our children

are very sick. This combination of factors produces an entire segment of society with not only severe physical difficulties to face, but fiscal ones as well.”

As to the answers that might help our families, Coulter said, “I don’t pretend to know the answer to the problem, but I can tell you that my own family struggles to keep up with healthcare costs associated with having a child with a CHD. I work a white-collar job, live a frugal lifestyle, live in a part of the country where the cost of living is low, and even have a child with a relatively ‘minor’ defect, yet healthcare is by far our single largest expense.”

So what do our families hope for? They don’t want to be pitied or to receive handouts, they just want to be able to survive and have a life that is less stressful and allows them to have the things they need to provide a good life for their children. They want to live without huge healthcare bills weighing them down because they chose to give their child a chance at life. But most of all, they want their children to survive and live a “normal” life, and if that means dealing with a financial crisis, they will certainly live with it.

Len Schendel said it perfectly: “Yes, we’re in dire straits financially as a direct result of a CHD. But when I come home at the end of each day and I see my smiling little boy, I suddenly don’t mind that I drive a beat-up old truck that hardly runs, or don’t wear finer clothes, or that I’m not able to take my wife out on a fancy date (okay, that part she doesn’t agree with!), or have cable TV, or any of the material stuff that I dreamed of when I was young. I’d gladly give up all my dreams all over again just to see him happy and healthy. And my experience with our chapter of MLH has taught me just how lucky I am to have him. Since our group started, four of our families have lost their heart child.”