



Mended  
Little  
Hearts



“Reach out and grab anyone willing to help you,” says Valerie Kiger, “even if it doesn’t seem like ‘their job.’ All the research shows helping others is what makes humans happiest, so you’re not imposing, you’re making people happy! Starting is more important than perfecting. You can’t worry that you’re not the best-equipped person to start a support group. Neither was I, but I was the one who was there.”

# Growing, Growing, Growing...

## The MLH Story Continues

by Jon Caswell

**L**ike many of the children at the center of its program, Mended *Little* Hearts is experiencing a growth spurt. In the last few months four new groups have been chartered: Mended *Little* Hearts of Southern Wisconsin, Hearts of Heroes (Rochester, Minn.), Little Hearts Lifeline (Oklahoma City) and Hearts of Hope (Pensacola, Fla.).

Like the other MLH groups – there are now 19 across the country – these new groups were founded on the passion of a few parents. And that passion started with the incredible stress associated with congenital heart disease (CHD), not to mention the fear and loneliness that accompanies multiple surgeries and hospitalizations.

“During my daughter Ashley’s first surgery, I was a nervous wreck,” recalls Sheila Allen, co-founder of the Hearts of Hope in Pensacola. “Sitting in the waiting room and talking to other parents whose children were there for their second, third or even fourth open-heart surgeries gave my husband and me so much hope and encouragement. By the time Ashley had her fourth and final open-heart surgery at age three, I was the parent sitting in the waiting room who was able to give that same hope and encouragement to the first-time heart parent.”

A year after her son Nicholas’s diagnosis and surgery, Amy Basken of Prairie du Sac, Wisconsin, reflected on the events that led up to her starting a MLH group. “The first seven days of his life involved three hospitals, Medflight and open-heart surgery that culminated with an unanticipated discharge home. I am grateful for my happy, healthy two-year-old, with no further intervention expected; however, at the time, I remember feeling so afraid and alone, and remarkably uneducated. I had a child with a disease that I was so totally unaware of, so unsure of the course of action, much less the outcome.”

For Valerie Kiger of Rochester, Minn., the light bulb for a parents' support group went off when she realized she had a special opportunity. "As our son Max's second (and we hope final) open-heart surgery approached, I began to think about ways I could repay all the kindness that had been shown to us during our struggles. A month before that surgery, I had broken my right leg, and I couldn't walk or drive for three months. Besides all the emotions we go through when our children face surgery, I had to deal with the fact I couldn't take care of him the way I wanted to. However, I discovered how truly compassionate people can be, as friends and strangers alike brought us dinners, took care of Max and drove our daughter Fiona to preschool classes and fun outings. I realized that living in the same place that welcomes thousands of patients from around the world each year (Mayo Clinic in Rochester) presented me with a unique opportunity to give back all that had been given our family."

Oklahoma City already had a CHD support group, Little Hearts Lifeline, but "we wanted to reach more people and do more as a group on a more official level," says Teresa Whited, one of the group's co-founders along with Kim Baratz. "When we heard about the work of MLH, we decided to charter into that organization. Our hope is that it helps us bring more awareness to the issue of CHD in Oklahoma and to raise more money for our patients and for finding cures for CHD."

## Getting Organized

Of course, starting a support group takes more than a heart-wrenching event to get it off the ground and keep it going. There must be meetings and getting the support of parents and also the buy-in of hospital officials and pediatric cardiac care specialists.

For Valerie Kiger there were the added hurdles of dealing with a world-renowned clinic. "Mayo Clinic is a wonderful place, but they do have the 'Mayo way' of doing things, and I wanted to make sure from the beginning we would have their support," Kiger says. "I wanted our group to be parent-led, but also high-caliber in order to earn the clinic's respect so the staff would feel comfortable working with us. I spent a year meeting with a Mayo Clinic continuous improvement group before we had a support group meeting — but that assured the clinic's support and gave me access to patient contact information. I also believe having a nationally coordinated effort on behalf of children with CHD is vital. I researched several existing groups, spoke with their representatives, and concluded that MLH seemed best able to meet all my goals."

Amy Basken of Wisconsin also did her homework before affiliating with MLH. "Over the past ten years I have received leadership training



*The Hearts of Heroes MLH group gathers at its booth during the June 2006 AHA HeartWalk in Rochester, Minn.*



*Oklahoma MLH members Seth Baratz, Ethan Cochrane and Tanner Moore celebrate summer.*



*Nicholas Basken of Southern Wisconsin MLH*

**"We are very fortunate to have the strong support of the University of Wisconsin's Children's Hospital," says Amy Basken. "Two staff members from pediatric cardiology are on our board, regularly participating in our meetings. As a result, the pediatric cardiology departments in our community are very supportive."**



Jeff Fague (center) and Linnea Archer (right), parents of Rochester's 2006 HeartWalk honoree Carsen (stroller), cut the ribbon to start the walk.



Governor Brad Henry and the members of Little Hearts Lifeline of Oklahoma commemorate the governor's proclamation of CHD Week in February.



Southern Wisconsin MLH members Scott and Erica Roth with son Owen and Nate Keller (in red shirt)

and had experience with forming a nonprofit organization. I felt with that background, and because Nicholas was healthy, I was in a position to do something. I researched many possibilities for the design of a support organization, and I was impressed with the structure of MLH and the variety of outreach programs it incorporated. Plus, the support of a national organization and opportunities to build off of similar groups was hard to ignore!"

Each group has similar goals — to ease the stress of new CHD families and to raise awareness of CHD in the general public.

Sheila Allen of Pensacola already had an application for MLH when she received a phone call from PaToya Henderson, another mother of a CHD patient and co-founder of Hearts of Hope. "PaToya and I must have spent at least two hours on that first phone call discussing many great ideas," Allen remembers. "I had the application, and she had a list and phone numbers of ten other heart moms in our area. Four days later we had our first support group meeting. We had ten parents join at that first meeting, and three months later we are up to 20 families."

### What They're Trying to Do

Each group has similar goals – to ease the stress of new CHD families and to raise awareness of CHD in the general public. "Once we get established, we would like to give some kind of financial support along with care packages to our local heart families when a child has to go for heart surgery," says Allen. "We want to be able to ease the journey of our heart parents as they face the long road of caring for a child with a congenital heart defect."

When Valerie Kiger visits CHD families, she takes Max with her. "His health is great, and his sunny disposition can

be a great lift for parents who are wondering what their child's future will be," she says. "Generally, we have tried to focus on the three pillars of supporting families: raising awareness of CHD, fundraising for medical research and supporting awareness projects.

"I have also had the opportunity to sit on a patient-family advisory board for the entire Mayo Clinic cardiac department. Through that I have been able to bring a parent's perspective to work aimed at bettering communication and improving Mayo's patient-centered care. They have used our group as a reviewing resource for new material for patients."

### Community Support

"We have had excellent community response," says Teresa Whited of Oklahoma. "We have had great support from the pediatric cardiologist and the cardiothoracic surgeon at the University of Oklahoma's Children's Hospital. Our governor signed the proclamation declaring the week of Valentines as CHD Week. We had a great response at our Valentines Party. We have our own Heart Walk team and have had interest from the media in covering events about CHD."

"We are very fortunate to have the strong support of the University of Wisconsin's Children's Hospital," says Amy Basken. "Two staff members from pediatric cardiology are on our board, regularly participating in our meetings. As a result, the pediatric cardiology departments in our community are very supportive."

Valerie Kiger of Minnesota knows well the work involved in starting a MLH group, but she never doubts whether the work is worth it. "Reach out and grab anyone willing to help you, even if it doesn't seem like 'their job.' All the research shows helping others is what makes humans happiest, so you're not imposing, you're making people happy! Starting is more important than perfecting. You can't worry that you're not the best-equipped person to start a support group. Neither was I, but I was the one who was there." ❤️