



Mended  
Little  
Hearts



# Hope, Help, Healing

by Jodi Lemacks, *National Coordinator, MLH*

“**H**ope, Help and Healing” is the motto for Mended Little Hearts and fully captures what we offer. Many people come to MLH when they feel hopeless, helpless and like the pain is too deep and too great to heal. They have suffered or are suffering. MLH members understand this because they, too, have been there and have felt these feelings. Because we understand these emotions, our groups are uniquely able to provide hope, help and healing to countless families and caregivers throughout the nation who are impacted by congenital heart defects.

Hope, Help and Healing are the foundation of MLH. If you ask most of our MLH leaders why they started their group, they will tell you, as I would, that they didn't want others to be alone when they go through the emotions triggered by having a child with one or more congenital heart defects. They need someone who truly understands and who can tell them they will make it through. Many MLH leaders learned that their child had a heart defect and started looking to connect with others who had been through the same experience. Often there was very little or no support for CHD families, even though it was desperately needed. We knew that there needed to be something to help families like ours, so we started MLH groups to give others hope, help and healing.

+ . . . + *Hope* + . . . +

Hope sees the invisible, feels the intangible and achieves the impossible.

– Charles Caleb Colton

Hope comes first on the list because, as Mary Adair of San Antonio said, “You can’t get to the other two unless you have hope. People without hope cannot receive the help they need, and they cannot heal. Even people who have lost a child, if they have hope, can have a future and can heal.”

“When people see MLH members getting up in the morning, doing okay ... they get a spark of hope, knowing that their whole life is not over.”



Mary Adair of San Antonio

So how does MLH give hope? “When people hear the diagnosis of a heart defect, they are devastated and their world collapses, like someone pulled the rug out from under them,” Mary said. “But when these people see MLH members getting up in the morning, doing okay and even helping others who have children with heart defects, they get a spark of hope, knowing that their whole life is not over. They see that now they will have a new normal, but there is an expectation of a future. MLH members are the incarnation of hope – even those who have buried their child.”

This hope is visible. When members who are pregnant with a child with CHD come to a MLH meeting and see the heart children running around and laughing, they visibly relax. There may still be fear, but there is a spark of hope. That spark is everything. Another example of hope’s visibility comes from Catherine Case Larson, an adult with CHD and an invaluable asset to the MLH fundraising committee. Catherine remembers vividly a gathering of MLH group leaders in San Antonio where she spoke about growing up with CHD. “I remember looking into a mother’s face, and seeing her relief that I was living a normal life after being born 52 years ago with the same diagnosis as her child,” Catherine said. “She was about to cry ... and so was I. I believe the power of seeing others lead a normal life gives an abundance of hope to those parents.”

+ . . . + *help* + . . . +

What we have done for ourselves alone dies with us; what we have done for others and the world remains and is immortal.

– Albert Pike

MLH groups help others in many ways – including through group meetings and gatherings, visiting programs, care packages, creating awareness, and advocacy – and the help we provide is widespread and effective. Because MLH is part of a national organization, the help we can provide is far greater than we could provide as individuals or as isolated groups. “MLH brings together many talented people from all over the nation who make our outreach and the help we give even stronger,” said Susan Vanderpool, National Committee Chair. “Because we are national, we can work on ‘the bigger picture’ with CHD awareness, advocacy, member education, and even support. When our groups connect with one another, our voice is more powerful and more effective, which, in turn, betters our ability to truly help others.”

In MLH, our group meetings and gatherings are at the core of what we do to help others. Many online groups are available to help families dealing with CHD; however, there is nothing as meaningful as the face-to-face support MLH provides at meetings. Not only do families get a chance to share experiences, but they often gain information through our educational programs and even may gain access to some resources that will help them care for their child.

MLH groups also help others through hospital visiting programs that are similar to Mended Hearts’ programs. When parents and caregivers are sitting helplessly beside a hospital bed or crib where their beautiful child lies hooked up to countless tubes and wires, it means a great deal to have someone come visit who has survived this same



Catherine Case Larson

“I believe the power of seeing others lead a normal life gives an abundance of hope to those parents.”



“Because we are national, we can work on ‘the bigger picture’ with CHD awareness, advocacy, member education, and even support. When our groups connect with one another, our voice is more powerful and more effective, which, in turn, betters our ability to truly help others.”

Susan Vanderpool, National Committee Chair with son Max

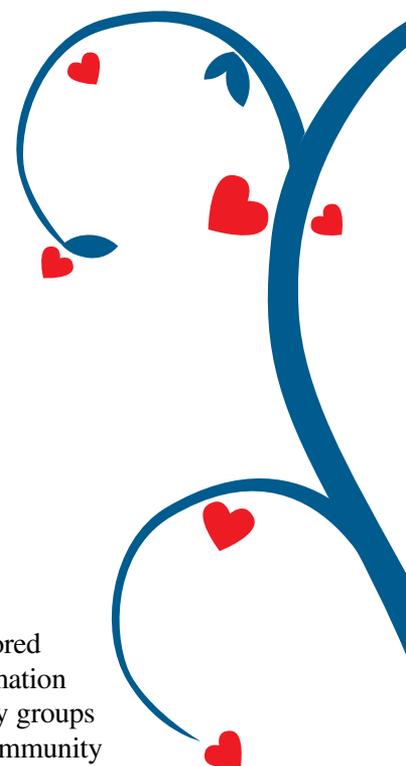
thing. Simply learning that others are out there who have children with heart defects and who are willing to support them helps immeasurably.

Along with visiting, many MLH groups help others by providing care packages to families who have children in the hospital. Often babies (and sometimes older children) born with heart defects are taken via ambulance or helicopter to another city where there is a hospital that can perform surgery or other needed procedures. The parents and caregivers of these children end up away from home with only what they were wearing that day and the contents of their wallet or pocketbook. MLH group members help these families by collecting donations and items to make wonderful care packages. Groups that have no funds for care packages are provided high-quality care packages by Saving Little Hearts ([www.savinglittlehearts.com](http://www.savinglittlehearts.com)).

Creating awareness about CHD helps countless people. Before having a child with CHD, most people have never even heard of congenital heart defects, yet they are the most common birth defect in the United States. One mom, who recently lost her baby to undiagnosed CHD after a happy and uneventful pregnancy, said that she had no idea that about 1 in every 100 babies is born with a heart defect. Most parents feel completely caught off guard when they find out how common heart defects are, and they can’t believe no one told them anything about the possibility. In the popular book *What to Expect When You’re Expecting*, heart defects are barely even mentioned. People believe that diseases like autism, Down’s Syndrome, spina bifida, cystic fibrosis and childhood cancer are far more prevalent, when none are more common than CHD. The result is a severe lack of research funding and a lack of education about CHD. CHD awareness provided by MLH helps in many ways. Lauren Gray, CHD Awareness Committee Co-chair, said, “Every time a member of MLH shares his or her story, whether to another heart patient, parent or someone else, the recipient realizes there is hope for people with CHD

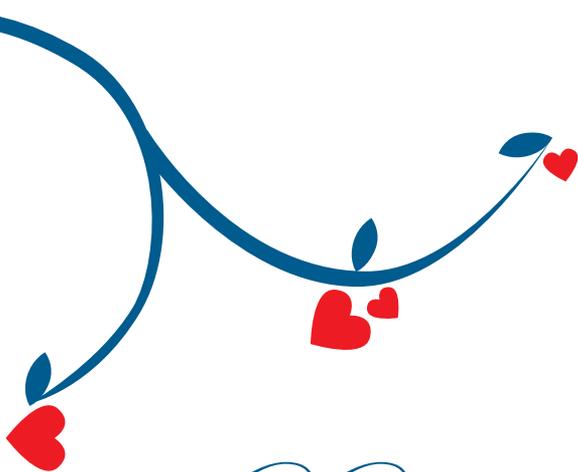
and much they can do to help.” Throughout the year, but especially in February for CHD Awareness Week, MLH groups hold many events sponsored by The Congenital Heart Information Network ([www.tchin.org](http://www.tchin.org)). Many groups participate in health fairs and community events to promote awareness on a local level so people understand how to help.

Finally, through its advocacy efforts, MLH has worked hard to help others by making a difference in the lives of those with CHD. Amy Basken, National Advocacy Chair for MLH and Chair of the National Congenital Heart Coalition, has worked tirelessly to ensure that MLH is involved in supporting legislation that can help all of our families. With Amy’s leadership, MLH has helped to abolish lifetime insurance caps and preexisting-condition limitations for children and young adults with CHD. The Congenital Heart Futures Act has also been introduced in the House and Senate. Amy makes it easy for MLH members to participate in advocacy efforts. “MLH grassroots advocacy is second-to-none in the pediatric CHD world,” Amy said. “Our advocates are clearly providing a voice for the ‘littles heart patients of all,’ and have the potential to help millions of people, whether MLH members or not.



“Every time a member of MLH shares his or her story, ... the recipient realizes there is hope for people with CHD and much they can do to help.”

Lauren Gray, CHD Awareness Committee Co-chair



+ . . . + *healing* + . . . +

Live your life from your heart. Share from your heart. And your story will touch and heal people's souls.

– *Melody Beattie*

When people have hope and get the help they need, they can begin to heal. Evidence indicates that peer-to-peer support groups help people cope with stress and negative emotions and move toward healing. According to the Mayo Clinic, “joining a support group is often a valuable addition to professional treatment. Support groups can help you feel less alone ... and find new coping skills.” Vanessa West, group leader in Tucson, Arizona, said, “When families who have a child with a congenital heart defect get together and talk about emotions, this helps them to heal. Group meetings, where families share experiences, are vital to the healing process.”

“Another way people can heal,” Vanessa said, “is to get involved with MLH and help others. When people help others, they gain some control over an out-of-control experience, and that leads to healing. We recently had a mom join our group who lost her daughter. She has decided to get involved with MLH, and this has helped her to make something good out of a devastating experience.” Healing also takes place when people feel like they belong and they are not alone. “MLH touches so many families who feel that they don’t fit in,” Vanessa said. At a local group function in Pensacola, Florida, one mom – for the first time in nine years – found other families who have children with heart defects. She stated, “As a parent of a heart child, to be able to talk freely, have someone who shares the same fears and also to share in the praise that our heart children are still here for another day, lets me know that I am not alone.” In addition, her nine-year-old

“Our advocates are clearly providing a voice for the ‘littlest heart patients of all,’ and have the potential to help millions of people, whether MLH members or not.”



*Amy and Nicholas Basken*

daughter realized that there were other children like her. The mom said, “It was amazing for my daughter to be around many others who have the same limitations, who all share the same scar, and not to be singled out by her peers because she is different. I couldn’t help but shed tears.” Like so many others MLH has helped, this family now has a community to rely on to help them move towards healing as they continue on their journey with their child.

Len Schendel of San Antonio recently shared with the group leaders some feedback from a woman who lost her nine-day-old CHD child in 2002. This woman saw information about the San Antonio holiday party on the news and e-mailed Len. She said, “I wish I’d had something like this when I was going through it. I was 23 years old. It hurt and was so hard. I have never been complete since then. I never got to heal from it.” Len sent her information about their local group, and she sent another e-mail: “I read a few stories on your website from parents whose kids have/had what my daughter did. I have not heard of anyone else in my area who has had this same disease. It is a well-needed relief to know, after seven years, that someone is out there. You made my heart smile. You will never know the true outreach of hope and help that just a few words brings to someone. It’s a quiet ‘condition’ until you go through it. Having a child born with a special condition is tough.” ❤️

“As a parent of a heart child, to be able to talk freely, have someone who shares the same fears and also to share in the praise that our heart children are still here for another day, lets me know that I am not alone.”



*Vanessa West and daughter Arianna*