



Mended
Little
Hearts

MLH Leadership Training 2012 Another Success

MLH of Winchester, VA, winner of the Group Excellence Award. Left to right: Stephanie Faudree, Sara Northcraft, Megan Setzer and Jenny Myers



The sixth annual MLH leadership training, as part of the Mended Hearts 60th Annual Convention in Dallas, began on Friday afternoon, continued with a full slate of activities all day Saturday, and ended at 1 p.m. on Sunday. MLH had 84 attendees, representing 46 of its then-68 groups, and including 31 first-time training participants.

“Because MLH does not have Regional Directors (RDs) or Assistant Regional Directors (ARDs), as MHI does, it can be very tricky leading 70 groups with just one dedicated staff person. Nor does MLH have cluster meetings where leaders can meet in person and get information throughout the year. Therefore, this training is vitally important to MLH’s growth and development,” said Susan Vanderpool, VP of MLH. “It is the one time group leaders (the leadership training is not open to all MLH members as the MHI convention is) can come together, network, share ideas, learn new information and receive in-person leadership skills training.”

“The goal of the leadership training is to give our leaders the skills they need to go back and lead their groups and help their communities effectively,” she continued. “Our group leaders are mostly moms and dads

of children with congenital heart defects, and caring for their children takes a lot of effort. MLH wants to make it easier for them to give back to their communities by sharing resources, materials and ideas with them so they don’t have to ‘reinvent the wheel.’ Most leaders leave the training feeling revitalized and more ready to support others — the training is one of our ways of supporting them.”

Three attendees shared their thoughts about the training: Holly Studer, mother of 18-month-old Mason and lead coordinator of the Dallas group; Melanie Toth, mother of Luke (age 3) and lead coordinator of the Chicago group; and Lyann Buena Franco, parent of Oliver (age 3) and lead coordinator of the hospital-based Milwaukee group.

This was Holly’s first year at the conference, but Melanie and Lyann’s second. All three of their groups brought additional leaders to the training. In Lyann’s case, the additional person was her husband, Martin. Martin was also a vendor at the Mended Hearts Convention and

sold heart pendants; the Buena Francos generously donated a portion of the proceeds to Mended *Little Hearts*.

Getting away to attend the conference is often a challenge for MLH members, but they feel the training is worth the effort because they know they will bring resources and information back to their groups. The leaders often have to make childcare arrangements for their children, which may take extra effort with a child who has a heart defect. After receiving a



as Holly said, "Huge!" Lyann said she'd phoned, emailed and met other coordinators through social media, but meeting them in person, sharing ideas and having dinner together made her feel like part of a team and was a treat. Lyann also met a woman who is a runner and has the same defect as Oliver. That strongly

reinforced for her that "it's possible for our children to do a lot even with heart defects."

Key Learnings

The breakout session on bereavement by Sara Northcraft, MLH of Winchester, Va., was extremely powerful. As the mother of a heart angel, Sara spoke with authority born of experience. For group leaders, learning how to deal with bereavement is practical



Top: Lyann Buena Franco, mother of Oliver and lead coordinator of the hospital-based Milwaukee group; Left: MLH Coordinators Andrea Himmelberger (left) and Jennifer Kowal; Center: Melanie Toth, mother of Luke and lead coordinator of the Chicago group; Right: Holly Studer, mother of Mason and lead coordinator of the Dallas group.

detailed list of instructions, Lyann's parents agreed to watch Lyann and Martin's three kids, ages 3 to 7 (Oliver, their heart child, is the youngest). Lyann also talked to Oliver's cardiologist about their trip to make sure he was aware of their absence should anything go wrong. In addition, Lyann's emotional commitment to group members made leaving difficult, since some members were faced with tough situations and Lyann wanted to be there to support them, if needed.

All three moms felt that the leadership training was helpful to running their groups and learned new information to take back to their communities.

Meeting People

There is nothing that can replace networking with other leaders in person. The opportunity to network was,



and important. We all wish that children with heart defects wouldn't die but, until answers are discovered, some do. MLH leaders need to be able to support families facing loss.

When a parent loses a heart child, group members may withdraw, feeling sad or vulnerable, not knowing what to say. But bereaved parents, maybe more than anyone, need the support of the MLH community, and allowing them to talk can be enormously therapeutic. According to Sara, often their biggest fear is that their child will be forgotten, so Sara recommended frequently using the child's name when visiting. That validates the child's life and confirms the child's importance.

Later, remembering the child is important. Sara



suggested that MLH members send cards on the child's birthday, on Mother's and Father's Day, and on the Angel-versary (the day of passing). This helps everyone feel, express and accept their grief.

Sara's presence made a vital point. Bereaved parents can also be powerful witnesses for an essential truth: not all children can be "fixed." More research is needed to prevent more deaths.

"Being new, I was lost about what to do," Holly said. "Now I have a bereavement protocol." Lyann, who knows three women who've lost children to a heart defect where one ventricle is missing, also benefited, as did Melanie.

Holly also liked the breakout session titled "What Medical Professionals Want from a CHD Support Group," led by Dr. Josh Koch, the head intensivist in the cardiac ICU at Children's Hospital in Dallas. "Getting a visiting program approved is difficult," Koch said. Hospitals are very concerned about privacy, but also worry that some patients' families may feel pressured to join an organization. Thus, he advised being very transparent in what you do, establishing contact with the right people, remaining neutral and not getting involved in politics. In short, work within a hospital's boundaries; don't try to thwart or work around them. "Doctors and nurses want to be invited and involved," he said.

Another popular session was advice from an adult congenital heart disease survivor on raising a child with CHD. Lyann noted that the speaker, Ruth Phillipi, was "young enough but old enough" to offer wise counsel. Ruth emphasized how heart children don't want to be treated differently. Her advice for parents of teens included not babying them and letting them go to appointments by themselves. Melanie found the information invaluable. "I was able to understand how some things parents do can affect their children negatively, even though unintended, and I will try to avoiding doing those things to my son," she said.

Finally, Melanie and Lyann positively noted the greater integration with Mended Hearts. Lyann says that even though there's no Mended Hearts chapter in Milwaukee, she often meets people whom she refers to Mended



Bob Renault of Chapter 5, Poughkeepsie, N.Y., poses with Susan Vanderpool, VP of MLH.

Hearts chapters or the website and it is good to know more about them. MLH and MHI had two breakout sessions together for the first time this year, one for caregivers and one on finding and recruiting members. Both got very

positive reviews on evaluations, and participants asked for more next year.

Looking Forward to Next Year

When asked if she'd like to attend next year's conference, Holly responded "Absolutely!" The others were equally enthusiastic. And they may all feel increasingly at home. Lyann and Melanie both noted the benefits of being second-year attendees. "This year I knew what to expect," Melanie said. "I could just soak up the information and go to the next meeting. Last year, it was kind of overwhelming."

"You get so much from a conference," Melanie said, "you just leave with the feeling that you can conquer the world. You get so many ideas — new ones you hadn't thought of and better ways to do what you've been doing." Since returning from the convention, her group has gotten in two new hospitals by applying information from the convention. "Now we have almost all the hospitals in Chicagoland," she says, "and certainly all the big ones."

Planning is already underway to make 2013 even better. "We carefully review evaluations and talk to coordinators about what their training needs are so that we can get better and better each year," says Jodi Lemacks, National Program Director. "The training is designed to be helpful to our leaders, our groups, the medical professionals we work with, and to our communities. We were grateful to have so many comments and thoughts given to us after this convention that we can use to develop next year's program. We are also very excited that some of the programs from convention will be made into webinars so those who couldn't attend can receive the training. With so many wonderful leaders, great training programs, and an opportunity to get together and share with each other, the sky is the limit." 

Speaking Up, Speaking Out— Making a Difference Through Advocacy



Amy Basken

Mended *Little Hearts* (MLH) provides peer-to-peer support, visits families with children in the hospital, educates families about caring for a child with congenital heart defects (CHD), creates awareness of CHD, and provides care bags to families. MLH also supports families by advocating on issues that help our children and adults living with CHD. MLH has been fortunate enough to have a national advocacy leader, Amy Basken, who has been instrumental in creating policy and guiding advocacy activities. Currently, Amy is transitioning out of her role as advocacy chair so she can pass the torch to another.

MLH advocacy efforts began about six years ago. Our first goal, to increase CHD-specific funding in the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) was successful, as the Congenital Heart Futures Act became part of the Affordable Care Act and passed into law in 2010. In 2011, the CDC appropriated \$2 million for CHD research and a panel of experts to look at CHD effects across the lifespan.

Mended *Little Hearts* reviews and updates our advocacy goals regularly. We have four major ones:

The first advocacy goal is to increase NIH funding for congenital heart disease research.

The second goal is to work with the CDC to collect information on CHD throughout the entire lifespan. This information is very important and helps give an understanding of the impact of CHD on families and the health care system, and also helps to create informed public policy about CHD.

The third goal is to ensure that every newborn is screened for critical congenital heart defects (CCHD). At present, newborns with undetected heart defects may be sent home, where they can get very sick and die. MLH has been working with patient advocacy partners on this issue.

The fourth advocacy goal is to increase pediatric

pharmaceutical and device research and development.

At present, because it is hard to meet standards for “informed consent,” high development costs, and the small market for the products, there’s little incentive for companies to get products approved for kids.

While it is true that congenital heart defects are the most common birth defect, the many different types of CHD mean the number of children with any specific defect — Tetralogy of Fallot, for example — is relatively small. Because properly testing drugs and products is a lengthy, expensive process, companies often focus on bigger, more profitable markets, so children with CHD often don’t have the products and/or treatment options they need.

Doctors have to use drugs and devices approved for adults and make assumptions as to how they will work in children. This is risky for CHD children because kids aren’t “little big people.” For example, because kids tend to be more active and have a greater chance of bumps and bruises than adults, a device, like a pacemaker, that is put into a child may have to be a little more resistant to this type of activity. Similarly, the side effects of medications may be vastly different in children with growing bodies from the effects in adults.

Thankfully, there are some companies, particularly device companies, that do market products for pediatric use, but far more is needed for CHD kids to have treatment options to help them live longer, healthier lives.

By working with the Food and Drug Administration (FDA) and other patient advocacy organizations, MLH can help ensure that CHD kids have access to the life-saving medications, devices and treatments they need. Our continued success depends on you — families impacted by CHD and the medical professionals who work with us. You can share your story and help us make a difference. To join our advocacy efforts, email us at advocacy@mendedlittlehearts.org or “like” our Mended *Little Hearts* Advocacy Facebook page. ❤️