



Mended
Little
Hearts

MLH at Convention: 4th Annual Coordinators' Training

by Jodi Lemacks, National Program Coordinator

- 1sts for
Mended
Little
Hearts
- 2,826 MLH visits
 - 1,056 care packages
 - new hospital relations panel
 - 6 breakout sessions
 - MLH annual meeting

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ixty-two Mended *Little* Hearts coordinators journeyed to Minneapolis in May for MLH's 4th Annual Leadership Training Conference. This 1½-day conference was preceded by a meeting where the MLH National Committee came together in person to work on strategic planning. Both the training and the meeting were highly successful. MLH received outstanding participant evaluations for the training, with most workshops and speakers receiving well over a 4.5 out of a possible 5 points. The coordinators commented that they left the training feeling energized and motivated and had many good ideas to take back to their local groups. This leadership training for coordinators has proven vital in growing MLH while keeping quality and consistency. Nothing can replace the value of the face-to-face interaction among coordinators, because that is where many good ideas are shared and life-long friendships formed.

The MLH Strategic Planning meeting took place Friday, May 21 and was an open meeting attended by almost all of the Committee members. “The Committee spent four hours cranking out exciting ideas for improving the future of MLH, both on a local level and nationally,” said Susan Vanderpool, MLH National Committee Chair. “We will soon have the information from this meeting compiled and ready for implementation. During 2010 and 2011, we will focus on improving materials available to our coordinators and, of course, on congenital heart defect (CHD) awareness. Through awareness, we not only reach more families that we can help through the most difficult time in their lives, but also have the potential to raise more funds to expand this wonderful and rapidly growing program.”

During our strategic planning session, we took a long look at the MLH program to determine such things as our core values, what is and isn’t working, where our resources are going, the image of MLH in the community, and how we can benefit more CHD families. We were encouraged by the responses, and the process solidified the fact that MLH is a wonderful, growing program with a lot of potential. The most important question we asked was about core values, and we determined that MLH’s core values are: providing hope, help and healing; working with integrity and professionalism; encouraging others; celebrating victories; educating, supporting, being positive and valuing life; being proactive and sensitive; advocating; having compassion and having fun. All MLH’s future goals and objectives will be created with these important values in mind.

The MLH National Committee consists of: National Committee Chair Susan Vanderpool; Advocacy Chair Amy Basken; Awareness Co-Chairs Lauren Gray and Dixie Varns; Visiting Chair Alexia Fussell; National Committee Chair Jodi Lemacks; Pediatric Cardiology/PA liaison Kari Crawford; MH liaison Joe Goldsweig; and Board representative Dale Briggs.

Friday afternoon, after the strategic planning session, all MLH coordinators gathered to meet each other (29 were attending for the first time) and do some team-building exercises. We then were thrilled to head to Medtronic with Mended Hearts. The coordinators all felt that this was very valuable. Many of them got to see replicas of their children’s valves and pacemakers and learn more about them. Group leaders also got to learn more about what every parent of a child with congenital heart defects

(CHD) wants to know—what is on the horizon for our kids. Most of the complex CHDs still cannot be “fixed,” so it is always good to know how technology will help remedy that. Of particular interest to many is Medtronic’s Melody Valve, which is inserted in the cath lab, avoiding open-heart surgery. In terms of the overall experience, one coordinator wrote in her evaluation, “The experience was fantastic. I had the impression they are a company that is emotionally invested in their products and mission.”

On Saturday morning, the MLH coordinators started early for a training day that was packed full of information. The morning started with the MHI Executive Committee (EC) coming to greet the coordinators and welcome them to the convention. The MLH coordinators really enjoy meeting MHI members and were glad to be welcomed by President Raul Fernandes.

There were a few MLH firsts at this convention. One was the first MLH Annual Meeting, which took place after the EC welcome. MLH, like MHI, compiles annual reports so we have data to use to help our organization grow and meet local needs. It also shows what we do as a national organization. It was noted that more than half of the MLH groups that sent in a report have a relationship with local MHI chapters. (Some did not have a chapter in their area.)

Another item of note was our visiting and care package numbers. MLH accredited visitors conducted 2826 visits in 2009 (with 26 groups reporting). This is particularly significant as several of our MLH groups do not have a hospital in their area that does heart surgeries on children. These same groups also gave out 1056 care packages to families with children in the hospital. These care packages are a huge comfort to these families who find themselves in a hospital in another city or state with nothing more than the clothes on their backs and the contents of their purses and wallets. Groups included toiletry items, pens, cameras, snacks, an informational packet, and other items to help families.

Another first was a hospital relations panel. One panel member, pediatric cardiologist Frank Cetta of the Mayo Clinic, graciously talked to MLH on Friday because of a Saturday time commitment. On Saturday the panel consisted of Susan Bonner, cardiac nurse at St. Francis Hospital in Tulsa; Jen Giblin, social worker at Strong Hospital in Rochester, New York; and Alexia Fussell, MLH National Visitor Training Coordinator. The panel answered five previously prepared questions

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about developing relationships with hospitals plus more questions from the coordinators during the panel discussion. Coordinators of new groups and groups without an existing visiting program said they learned about many valuable tools they can use to develop relationships with hospitals.

Yet another first for MLH occurred Saturday afternoon. For the first time, we had breakout sessions where coordinators could choose to attend four out of six different workshops. The workshop topics included: New Group Development; Adults with CHD; Finding CHD Resources; MLH Mentoring Program; Advocacy and Social Media; and Bereavement. This new format was very popular with the coordinators who loved being able to choose what workshops to take and get more detailed information. Also, now that MLH is over five years old, existing groups have different needs than new groups, and this format allowed everyone to meet their needs.

On Saturday night, MLH joined MHI for the Meet & Greet. MLH coordinators commented that they liked having time to mingle with MHI members. Many coordinators were pleased to meet the members from their area in a social environment. The coordinators also enjoyed the relaxed and fun setting. Many of these parents almost never get a night out away from their children, so having time to relax and have fun meant a lot to them. The karaoke was a wonderful addition to the evening, and most of us (even those who can't sing well) thoroughly enjoyed it.

One very meaningful and touching part of the Meet & Greet was the special singing appearance of Donnie Wilson of MLH of Pawtucket, Rhode Island—Helping Hands, Healing Hearts. Donnie is the father of Jacob, who has a heart defect, and he wrote and produced a song called “Superhero Fantasy” for his son.

“I was approaching 40 years old and considering writing

music again,” Donnie said. “I hadn’t performed for at least 10 years. About this time, our son Jacob was diagnosed in utero with a CHD. On the day my wife was giving birth to Jacob, some of the words of a song started coming to me. Then, when we were in the Cardiac Intensive Care Unit at Boston Children’s Hospital, I was lying next to my baby thinking, ‘These people are saving Jacob’s life right before my eyes.’ That made me think of when I was a kid and wanted to put on a superhero cape and save the day. The rest of the words for ‘Superhero Fantasy’ starting coming to me, and I eventually released the song in February 2010.”

Donnie said that singing at the Meet & Greet was very emotional and rewarding. “It was a thrill to be in front of a group that big who had all been through the same thing,” Donny said. “They knew exactly what every single word meant.”

Proceeds from this song have gone to help his local MLH group and to Boston Children’s Hospital for CHD research. MLH used this song for its CHD Awareness Video that is on YouTube at <http://www.youtube.com/watch?v=Vt-WYDP9MmI>.

On Sunday, MLH had two morning sessions, including the coordinators’ accrediting/reaccrediting visiting training conducted by Alexia Fussell. She is a wonderful trainer, and the coordinators found much value in the personal experiences that were shared.

The following evaluation comment was about the overall training and sums up what most people felt about the weekend: “What a great experience. We learned so much information to help us go home and create a much better group! We are really excited about being able to grow our group and organize some of the areas that we previously were struggling with. It was also wonderful to talk and share with other groups and learn from them to work on some areas with our group. It energized us for the future. We feel more focused and ready to roll!” ❤️



Mended Little Hearts leaders Sara Northcraft, Megan Setzer, Jennifer Ross and Kristin Johnson.



Three MLH heart moms – Cheyenne Gibbs, Kirsten Dodds and Danielle Heath.