



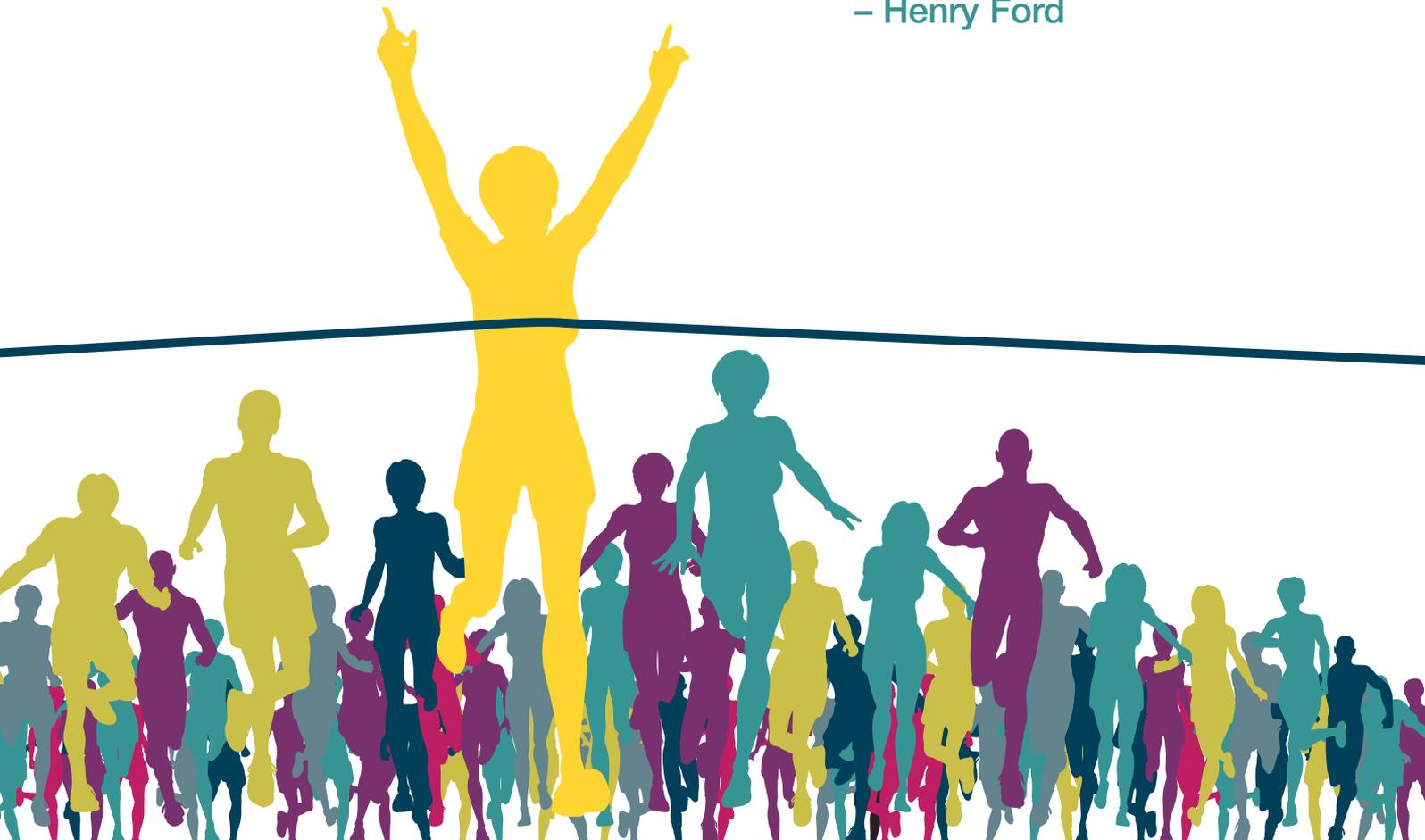
Mended
Little
Hearts

by Jodi Lemacks, National Program Coordinator

Mended *Little* Hearts in Action: Getting Results

“Coming together is a beginning. Keeping together is progress. Working together is success.”

– Henry Ford



The simple fact that Mended *Little Hearts* (MLH) has grown from two groups in 2004 to 57 in the fall of 2010 shows that the program gets results. True to our mission, we have been working with cardiologists, researchers and other congenital heart defect (CHD) organizations to improve the quality of life of CHD patients and their families. On a local level, MLH group leaders work tirelessly to support families, generate awareness, connect families with resources, provide education and advocate for children with CHD. Fulfilling these needs is what makes MLH great. Because MLH works together, we are successful and many communities around the nation benefit from our services.

Picking out MLH groups to highlight in *Heartbeat* is always difficult because so many are doing amazing things. Almost every week MLH groups are recognized in the media and show up on Google Alerts. However, in the last quarter, a few MLH groups have been extremely active in their communities, and some have had a national or regional impact.

CHD Symposium in Madison, Wisconsin

Amy Basken, coordinator of MLH of Southern Wisconsin and National Advocacy Chair, is no stranger to leadership that gets results. This year, in addition to working on a national level with CHD Lobby Day 2010 and many other national advocacy initiatives, Amy hosted a CHD Symposium for parents of children with CHD, along with American Family Children's Hospital in Madison, Wis., Department of Pediatrics.

Amy developed content and secured speakers on a variety of topics, such as prenatal diagnosis of CHD, neurocognitive development, imaging, advocating for your child, educational issues, transitioning into adulthood and guided imagery to help parents relax. As a CHD mother myself, I found these topics extremely helpful.

Attended by 40 participants from nine states, the symposium earned comments such as "This symposium

was chock full of wonderful information, and it was a wonderful opportunity to meet other families affected by CHD" and "Really great practical information I can use in my own life and to inform and aid my group members. Medical information was well-presented for lay people." Carter Ralphe, MD, a pediatric cardiologist at UW, emailed Amy and said, "Thanks for allowing us to host the MLH meeting this year. I was very impressed with the program and the quality of the meeting – the thoroughness of the preparation was impressive. I appreciate getting a different perspective from the parents who came." In fact, because the UW faculty and staff felt this was such a wonderful service to families, UW is considering hosting another CHD Symposium in 2012.

Team MLH of Winchester and Team Aron

MLH of Winchester (Virginia) is a relatively new MLH group – almost a year old – and already they have established excellent leadership that is getting results throughout the nation. Megan Setzer, Sara Northcraft and Jenny Myers work together as a team. Megan said, "We each have our strengths and we allow each other to use them, and that is why we are able to get so much accomplished."

One of this group's major initiatives is Team Aron, created in honor of Sara's son, Aron Matthew Northcraft, who is now, like far too many children with CHD, one of our angels. Aron was born in January 2007 with a severe heart defect that is 100 percent fatal without intervention. Because of this, Aron underwent three open-heart surgeries in his first 2 ½ years. During this time, Sara began to notice how many people did bad things to their bodies – things like smoking and overeating that would negatively affect their heart and overall health. This made Sara angry because these people were abusing their bodies, and Aron, who had done nothing wrong, was struggling to survive. Sara decided that she would become healthier herself, help others become healthier, and work to raise awareness of CHD at the same time – thus Team Aron was formed. The initial plan was to have



LEFT TO RIGHT: (l) Amy Basken, coordinator of MLH, Southern WI and (r) Barb Anderson from the American Family Children's Hospital in Madison, WI; Team Aron participates in a fund-raising race.



FROM LEFT TO RIGHT: Andrea and Brett Baer from MLH Southwestern Pennsylvania delivering care bags; Caylen Ayscue modeling the Southern Belle shirt; Team Aron t-shirts worn for race days; Visiting coordinator Sarah Larson, mother of Lucy, asking a question at the CHD symposium in Madison, WI

four runners, each with one letter of Aron's name on their shirts, run in the Apple Blossom 10K in Winchester, Va. The more the runners talked about it, the more people said they wanted to participate. Then Jenny Myers designed an "official" Team Aron shirt with Aron's adorable face on it.

Shortly after starting on this project, the Northcrafts faced what no family should have to face: Aron passed away. Team Aron took a month off, then Sara decided that she would make something good come out of this devastating experience and started getting the word out on email, Facebook, CarePages, etc. MLH of Winchester became involved. The team anticipated getting about 15 runners and selling about 50 shirts, but more and more people joined. Team Aron sold over 300 shirts and recruited more than 40 runners. "What helped most in creating momentum is that kids aren't supposed to die," Sara said. "Having two dates on the shirt catches attention and generates support."

Team Aron is also creating national awareness, as Mended Hearts member Jim Oldfield is wearing a Team Aron shirt for his next Ironman competition in November 2010. Also, MLH of Winchester and Team Aron will participate in the Apple Blossom event again in 2011 on the last Saturday in April (www.thebloom.com).

MLH of Winchester is also doing many other events to raise awareness of CHD. This past September, they put a team together to participate in a CHD walk to raise money for CHD research and initiatives that will allow our children to live longer, healthier lives. "As soon as I heard about the CHD Walk in the D.C. area, I felt that MLH really needed to be involved, so I started to put together a team to walk in Fairfax on September 12," Megan Setzer said. "We wanted to honor our angels and our heart warriors." Their team had 29 people and raised over \$2,500. Other MLH groups participating were MLH of D.C., Central Virginia and Lynchburg.

MLH of Winchester takes every opportunity to speak about CHD. Recently, members Baer spoke at a small church. Afterwards, a man told them that his son, who was born with CHD 30 years ago, died because the technology wasn't

available to save him. This man was grateful for MLH and what we are doing to prevent more children from dying.

MLH of Southwestern Pennsylvania – Care Bags Because We Care

Andrea Baer, MLH's new national Growth and Development Chairperson, is modest when she talks about her group's accomplishments, but I know how many amazing things this group has done. MLH of Southwestern Pennsylvania is no stranger to the media, with several stories about members' children, CHD and their group's activities in the community. Andrea, like the Winchester coordinators, tries to attend every health fair, parent resource conference, Down Syndrome Association event (more than 50% of children with Down syndrome have heart defects), Heart Walk and speaking event possible. She does this while caring for her CHD and Down syndrome child, Trenton, two other children, and with a baby on the way. She and her husband Brett even made the trip to D.C. for CHD Lobby Day 2010. Andrea told me that she wears her red MLH shirt every day to help create awareness.

Andrea feels her group's biggest impact comes from their care bag program. "Through our care bag program, we can reach so many more families than we could if we were just offering support," Andrea said. "We put together these care bags for families who have children in the hospital so they can have some necessary and comfort items and feel like there are people out there who care and support them."

MLH of Southwestern Pennsylvania started their care-package program by connecting with the volunteer service program at Children's Hospital of Pittsburgh. The group delivers 20 bags to the hospital every two weeks, delivering over 250 (so far) in 2010. The white canvas bags with their logo contain 25 items, including MLH's Family Information Pack (a useful resource for families), MLH wristbands, toiletry items, hand sanitizer, Chapstick, a homemade blanket, a stuffed animal, snacks, a coffee mug with Cup O' Soup, a bottle of water with a flavor packet, and other helpful items. It is not uncommon

for families to end up at big centers like Children's of Pittsburgh with no more than the clothes they have on and the contents of their wallets and pocketbooks. They are very grateful to be able to do things like brush their teeth or take a shower without having to go to a store or purchase expensive items in the gift shop. Also, it is amazing how many parents go for long periods of time without eating because they are afraid to leave their children; the snacks in the bags help ensure they have a little something to eat.

MLH of Mississippi – The Southern Belles

Erin Ayescue is the lead coordinator for MLH of Mississippi, and has a leadership team of seven. Erin's philosophy is "everybody is good at something," so she has put people in leadership roles who can take on certain tasks for the group. Erin said, "Little things add up to big things, but we need to do the big things too. We want to raise awareness and educate our community. We don't want to scare anyone, but hospitals aren't giving out information about CHD to new moms, and everyone of child-bearing age should know about it because awareness equals power. Too many children get very sick before care is given because parents don't know what to look for."

In the Jackson area, MLH of Mississippi works with Blair E. Batson Children's Hospital. They have a new CHD program there, and they will have an expansion completed in eight years that will house the program. The hospital wants MLH involved in the development of the program because they feel that if the families get involved from the beginning, they can serve them better.

When Erin started to list her group's activities, I was surprised that they didn't need a team of 20 to get it all accomplished. They are involved in many fundraising

and awareness projects, such as a televised semi-pro wrestling event on Nov. 13, three health fairs in the next six months, the American Heart Association Heart Walk and a soccer event with a concert hosted by the City of Brandon Soccer League. There's also a one-woman cabaret show performed by a Broadway actress, a Fairy Tale Ball in the fall of 2011 (with the Governor's wife as honorary chair) and a Night of Giving at the local mall where all benefits go to MLH. Still other activities include speaking at school assemblies (at least six schools have already requested speakers), a CHD Week promotion with Mississippi Blood Services, an Art Walk and working with the Jackson Community Coalition (four restaurants give 15% of profits to one charity each month along with giving out brochures, email blasts and other information about the charity). Finally, there are Appreciation Days at the PICU, NICU, cardiac floor of Batson and one pediatric clinic during CHD week where group members will take balloons, art, goodies and a pottery item created by the MLH children.

However, the talk of the town is the group's brightly colored Southern Belle shirts. Southern Belle is a very popular Mississippi company. They do a lot of fundraising and awareness for non-profits. Erin contacted Southern Belle, and they were excited to help create a shirt. "It took five designs to get what we wanted," Erin said. "The shirt is fun, but it also gets the message across. We wanted something the general public would want to buy but that's also linked to our group's shirts. We can't keep them in stock; we've sold 800 so far." Most of the money from the sales went to print a new batch, but those are selling fast.

These are among many examples about how MLH is getting results throughout the nation. As we grow, we're certain to have even more. 

National Exposure

Angee Brock, coordinator of MLH of Mississippi, was interviewed on the TODAY Show in August 2010. She was asked about how raising her two-year-old daughter Riley, who has CHD, changed their lives and how Angee is working to make a difference in the world. Angee entered the TODAY Show's "Everyone Has a Story" contest in January 2010, by submitting an essay and photos. Hers was one of three stories – out of over 5,000 – to be aired. Angee is a single mother of four and is passionate about spreading CHD awareness. This goes to show that one person can make a difference, spreading hope, support and encouragement to others. For more information, visit the MLH blog at <http://mendedlittlehearts.wordpress.com>.

Edwards Lifesciences Corporation

Edwards Lifesciences Corporation is a great example of leadership that gets results. Without Edwards Lifesciences, Mended Little Hearts would not be where it is today. In fall 2006, Mended Hearts received a grant from Edwards (the first ever received for MLH) enabling the organization to hire a much-needed program coordinator to help develop the MLH program and ensure its continuity. In the world, Edwards is also a leader. On September 23, 2010, Edwards announced that they received approval to begin clinical trials in the United States of their next-generation transcatheter valve. This valve, which is placed transfemorally in the cath lab, could keep countless patients from undergoing open-heart surgery.