



MLH Voices – Spreading Awareness and Advocating for CHD Issues

by Jodi Lemacks, *National Coordinator, MLH*

One of the biggest frustrations of parents who have children with congenital heart defects (CHD) is the lack of awareness about them. Many people know about childhood cancer, autism, Downs syndrome and cystic fibrosis, to name a few childhood diseases, but most parents of children with CHD will tell you that until they had their child, they had never heard of heart defects – yet, their lives were changed forever. When most people talk about heart disease, they think about adults and the issues surrounding acquired heart disease – not about children with CHD. More significantly, when people talk about deaths from heart disease, again, children don't come to mind, yet CHD is the leading cause of defect-related deaths for children under one year, and cardiovascular disease is the number two killer of children under 15 years.

CHD is a leading
cause of death
for children
under 1yr.

HELP FUND
CHD
RESEARCH

The unfortunate result of the lack of CHD awareness is a lack of vital funding for CHD research – research that might allow children and adults with CHD to have longer, healthier lives. Most children in MLH groups have more severe heart defects that cannot be completely “fixed,” at least not now. For example, children with single ventricles (missing one of the four chambers of their hearts) either need a heart transplant or typically undergo three open-heart surgeries to reroute the blood so they can survive. A fourth chamber cannot currently be created for them, so if they have had the surgeries, they end up with two-chambered hearts. This is not ideal, and the long-term outlook for these children isn’t good. For other complex defects, children often need repeated surgeries and/or procedures such as valve replacements and angioplasty. So, to parents of MLH children, a lack of awareness is a painful reality; we need new technology from research before it is too late for our children. It is even more painful for those parents who have already lost their children because the lifesaving technology was not there when they needed it.

A scary example of a lack of awareness about CHD in children is the story of Cullen Barnhouse of Bowling Green, Kentucky. When Cullen, who has CHD, was just five months old, he went into respiratory distress. His mom, Lara, says that Cullen was having trouble breathing and went limp in her arms. She tried to resuscitate him but could not. Lara had called 911, and the ambulance arrived fairly quickly, but when it arrived, they didn’t have an oxygen mask small enough for a baby. Then, at the local hospital, the medical professionals were unfamiliar with babies with heart defects and were uncomfortable caring for Cullen. The hospital equipment was also not made for a baby Cullen’s size. Lara and her husband both felt that



LEFT: Cullen Barnhouse having fun playing outside in his car
RIGHT: Lara and Cullen Barnhouse at his second birthday

they had more knowledge about dealing with CHD than the medical staff did. Aside from that experience, Cullen had capillary leaks during his first open-heart surgery. No one knew how to stop them, but they had to be stopped. The doctors decided to try a medication that was typically used for GI bleeds. They did not know how to use it for this condition or the correct dosage for a baby Cullen’s size because research on this drug’s use for capillary leaks was not available. The first dose was given in such a way that it worked too well and raised Cullen’s blood pressure too high, but by the third dose the leaks stopped. Luckily, little Cullen survived and is doing well now, but this lack of awareness could have been fatal. Lara believes that communities need to be more aware of CHD to be prepared if something happens to a child. She also believes that parents need to be more aware of CHD so they understand their children’s special health needs and can be strong advocates for their children.





LEFT: Thumpers MLH CHD Awareness Float; CENTER: (l. to r.) Nancy, Lauren, Glenda, and Donna with Zoey Pollard at Dillard's raising awareness for CHD; RIGHT: Zoey Pollard at the American Heart Association Heart Walk

Venica Pollard, Lara's co-coordinator in Bowling Green MLH, also feels a strong need for CHD awareness, as her daughter Zoey has a severe heart defect. Because of this defect, Zoey needed a cardiac catheterization, but it caused injury to her legs, among other complications. This has caused many problems, and the doctors have no solid answers about what to do to fix it – they are just waiting for her to grow. Zoey, like Cullen, needs the CHD research that would result from awareness. Then the doctors could better treat Zoey and give her a better quality of life.

Community Outreach

Of course, Mended *Little Hearts* – being full of parents of children with CHD, adults with CHD and others who want to make a difference – is doing something about the lack of awareness. MLH groups engage year-round in CHD awareness activities and advocate on issues that impact our children and adults with CHD. Groups are especially active during CHD Awareness Week, February 7-14, sponsored by the Congenital Heart Information Network (www.tchin.org). During CHD Awareness Week 2010, MLH and other CHD families got proclamations signed in 33 states recognizing this important week. This year, MLH has been recognized in the news and media countless times for our awareness efforts and for stories about MLH families and groups. MLH members are diligent in creating the awareness that is needed, so they can better the lives of those living with CHD.

MLH of Bowling Green is one of many good examples of how our groups create awareness in their communities. Lara Barnhouse and Venica Pollard recognize the need for CHD awareness in their area and have worked hard this year to help others become aware of CHD. Their group members participated in several activities to create awareness including media stories and

interviews, community activities with a local mall, and a proclamation-signing event with their mayor. The group members conducted interviews and told their stories, and these were broadcast on local NBC, CBS, ABC and FOX affiliates. They also participated in radio interviews broadcast on two stations. A pediatric cardiologist in Lexington, Kentucky, four hours away, heard one of the interviews and will be coming to Bowling Green to speak with the MLH group so they can care for CHD patients better. Bowling Green MLH also participated in a big awareness event with their local mall. Previously, Venica saw that some of the stores in the mall sold t-shirts to support the fight against breast cancer and thought they might do the same for CHD this year. Lara and Venica, with the help of Lara's aunt, designed a beautiful CHD Awareness t-shirt, and employees of Dillard's, Trademark Home, Master Cuts, and NY & Co. all wore the shirts and sold them. Master Cuts also painted the design on their store windows so everyone walking saw it. Finally, Lara and Venica contacted the mayor of Bowling Green and got her to sign the CHD Awareness Week proclamation with members of the MLH group present. Now, many more people in Bowling Green have information about CHD and its impact on families in their community.

Similarly, Dixie Varns of Thumpers, the MLH group in Sturgis, South Dakota, recognizes a need for awareness in her area and works year-round to promote it. She wants people to understand CHD to make a better life for her son, Tucker, and the other children in her MLH group. For CHD week this year, Thumpers had a big CHD event in conjunction with a blood drive. People came to donate blood, which helps CHD children who need surgery, and they learned about CHD. Many also attended the CHD Awareness Party at the same time. Like most MLH groups, Thumpers doesn't limit awareness events to CHD Awareness Week – they also work to create awareness

throughout the year. This MLH group, with the help of Dixie's husband Terry, has created a CHD Awareness float, complete with light-up hearts. Over the course of the year, the families participate in about six Christmas light parades, six 4th of July parades, and a college homecoming parade to let people in their community know about MLH and CHD. During the Christmas parade this year, the children on the float stayed warm in a little house they put on the float, and the participants handed out hot chocolate. Participating in the parades takes a lot of effort and organization, but Dixie feels it is worth it to raise awareness of CHD. In addition, Thumpers participates in health fairs to spread awareness, and they even hosted one a few years ago, where all of the vendors, such as the regional hospital, Life Flight and a chiropractor, had to relate to the heart in some way. They had about 20 booths. The Black Hills of South Dakota are much more aware about CHD thanks to this MLH group.

Most other MLH groups also do interviews, health fairs, symposiums, proclamation signings, CHD fundraising events, blood drives, speaking engagements, working with schools, partnering with other health organizations, and many other activities. In addition to creating awareness through events, MLH also creates awareness through advocacy and social media.

Advocacy

Advocacy plays an important role in creating awareness, and MLH was able to be a part of history for CHD in the advocacy area by working on disease-specific legislation for CHD. It started in 2009 when MLH worked with four other national CHD organizations on creating CHD legislation called the Congenital Heart Futures Act, which provides for CHD research and data collection. In February 2009, MLH helped to sponsor a CHD Lobby Day that resulted in introducing a CHD bill in the House and Senate. This year that bill has become law, and MLH will again sponsor a CHD Lobby Day, along with the Adult Congenital Heart Association (www.achaheart.org) and the Children's Heart Foundation (www.childrensheartfoundation.org) to ask for funding for that bill and for enhancement of the data collection provisions. The American College of Cardiology (ACC) has also been a big sponsor of the bill and CHD Lobby Day both in 2009 and this year. Not only does this bill help fund CHD research, but it also creates much awareness about CHD within Congress, which hopefully will result in a better understanding of the needs of our CHD children and adults. To create additional awareness with our lawmakers, MLH members spoke at a CHD Awareness Briefing on Capitol Hill this past

February sponsored by the American Heart Association (AHA) and the ACC, and MLH members lobbied with the AHA in April 2009 on healthcare issues, like pre-existing conditions and lifetime insurance caps, both of which impact our children and adults with CHD. MLH also participates in other national advocacy efforts like the Lifetime Caps Coalition, CHD screening initiatives with members of the National Congenital Heart Coalition, and weighs in on laws and studies that impact our families. Many MLH groups advocate on a state level as well. MLH of Southern Wisconsin, for example, has spoken before their state legislature and even spoke to the governor recently about CHD.

Social Media

Another way MLH promotes awareness is through social media. MLH is trying to utilize all of the social media to help people learn about CHD. Both Amy Basken, MLH National Advocacy Chair, and Tanya Sanders of MLH of St. Petersburg, have been instrumental in creating tools and information to share with the public. Tanya feels that social media is important for any organization today and can be a wonderful awareness tool. Tanya posts for MLH on our national Facebook page, which also gets posted on Twitter. Amy also created a blog for MLH (wordpress.mendedlittlehearts.com), and even though it is very new, people are looking at it to find information about MLH and CHD.

Altogether, MLH is still a relatively small program, but we have a big and powerful voice. Being part of a national organization makes a huge difference in creating awareness and advocating for our children. ❤️



(Bottom row l. to r.) Mayor Walker, Cullen Barnhouse, Lara Barnhouse, (2nd row l. to r.) Susan Waggoner, Venica Pollard (3rd row l. to r.) Brandon Greene, Shonda Greene (Top row l. to r.) Amy Patterson with Zoey Pollard and Michelle Alloway attending the Proclamation signing.