

Mended Little Hearts
Leadership Training Session



Sharing and Caring at MLH's Leadership Training

Mended *Little Hearts'* (MLH) Leadership Training, including a national CHD Symposium, was held June 20-22 at the Mended Hearts National Education and Training Conference in Indianapolis, Ind. In keeping with the overall conference theme, the training and symposium featured educational programs and

Pediatric Congenital Heart Association to host a national CHD Symposium as part of the leadership training. This Symposium was open to the public — not just MLH group leaders. Cardiologists and medical professionals came in from around the nation to share their expertise. The leadership training speakers and the Symposium received excellent ratings in the evaluations and the comments were glowing.

Many MLH leaders, both new and old, thoroughly enjoyed the leadership training and CHD Symposium. Valerie King, leader of the MLH group in Winston Salem, N.C., and Steering Committee members stated, "The leadership training in Indianapolis was great this June. There were a lot of high points this year. The training included topics like conflict management and financial education that are so valuable to our leaders."

One of the most important aspects of leadership training for most MLH leaders is the chance to network with other leaders across the country. "Knowing that we aren't alone in this fight is always beneficial to me," said King. "The time we spend with other leaders is enlightening. Being able to share what has worked in our groups and what has not is invaluable." Melanie Toth, leader of MLH of Chicago and also a Steering Committee member added, "For me, the most important takeaway from leadership training is just



Our Mended *Little Hearts* of Chicago group from conference. Heart moms from left to right: Terri Simpson, Melanie Toth, Jen DeBouver and Michelle Williams

workshops designed to Inspire, Inform, and Ignite the MLH Coordinators that were in attendance.

National Program Director Jodi Lemacks stated about this year's program, "We tried things a little differently this year, and it really was a huge success. We joined forces with Children's Heart Foundation and the



Jodi Lemacks, MLH National Program Director

per month, delivering personalized care bags at every visit. Those care bags are supplied thanks to a care bag drive the group conducts during National Heart Month, in which donations for the care bags are received from hotels, dentists' offices, non-profit organizations and the community at large. Karla then gets help filling the care bags at parties she holds in her home for just that purpose.

And that's just the visiting program.

MLH of Phoenix also conducts educational and social meetings on a monthly basis. Program Coordinator Allison Beninghoff organizes these sessions on such topics as estate planning, special education advice and the nutritional needs of CHD children. Dinner and babysitting are provided as part of the program.

The group also connects with local media to get the word out about CHDs and the group's initiatives. Media Coordinator Nikki Granados leads the efforts to gain media exposure for the group, and she was featured in a story on the local NBC affiliate's news program covering CHDs and their impact on local families. The group was also featured in a local magazine, *Raising Arizona Kids*, which raised awareness about CHDs and offered tips to readers on how to get involved.

Raising Awareness, Raising Money

Thanks to the work of Special Events Coordinator Karen Alaniz, Mended *Little* Hearts of Phoenix also holds special events throughout the year — among them, the Winter Heart Family Party and the 2014 CHD Awareness Fair. At the Winter Party, families ate pizza, listened to music, made crafts and got their pictures taken with Santa. The Awareness Fair took place at the local children's hospital, where CHD awareness was front and center through education sessions on feeding issues, developmental struggles, special education and the latest in cardiology. The group plans to hold this event every year.

Part of being so involved in the community is the opportunity to partner with other nonprofit groups, as well as local businesses. Among the ones MLH of Phoenix works with is the Nick and Kelly Children's Heart Foundation, a local nonprofit that helps heart kids enjoy their time at summer heart camp in California. The Nick and Kelly Children's Heart Foundation also holds a cardiac symposium each year at the city's zoo.

A limited budget is a familiar concern to all Mended *Little*



Dr. Aaron Kay speaks to MLH attendees about adult CHD care.

Hearts groups. The Phoenix group relies on the efforts of Fundraising Coordinator Lindsay Gross to generate ideas for raising needed funds throughout the year. During 2014, Lindsay managed to get a Mexican vacation and a car donated for a fundraising raffle, and more ideas

are on the horizon.

Making an Impact

Through all their efforts, MLH of Phoenix now serves more than 200 families across "the Valley of the Sun." For Vanessa Blutrich, the reason for the group's success is straightforward. "I have a wonderful group of heart moms on the board, and we work really well together and want to help other families.



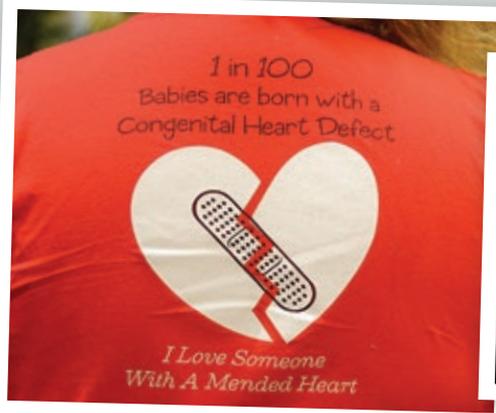
MLH of Phoenix kids rocking!

Because we get along so well, it's very easy to be so active with each other. We want to connect with as many families as possible."

With its tireless commitment to its engaging vision, the group is sure to have an even greater impact in the future. Being honored with the 2014 Group Excellence Award was confirmation that the Mended *Little* Hearts of Phoenix is on the right track for continued success. "It was a great feeling because we had worked so hard the past few months, and it was a great feeling to be recognized for all we had accomplished already," said Vanessa. ❤️



Heart Heroes exhibit at MLH Leadership Conference!



Proud supporter of MLH.



Conference attendees explore the St. Jude Medical booth.

Heartfelt Inspiration

Julie Reves is a true inspiration to many. She is a congenital heart disease survivor who celebrated her 50th birthday by doing what she does so often, helping others.

For her birthday, Julie asked friends and family to make a donation to Mended *Little* Hearts in her honor. She raised money for her local Little Rock, Ark., Mended *Little* Hearts group and for the national organization as well — totaling \$700!

This money will be used towards Bravery Bags for families in the hospital and for educational materials. A heartfelt thanks to Julie!

networking with new and veteran groups on how to improve your group's activities and events. It's always my favorite thing to return home and share what we've learned and try a new fundraiser that worked well for another group. We all learn so much from each other's groups and we leave the conference energized and motivated."

Stucki, Toth and King all agree that events such as this are a good time to meet colleagues from other MLH groups and share information about CHDs and its effect on their lives.

Julie Stucki, who leads MLH of Evansville, IN and was instrumental in planning the program with Lemacks and ensuring its success, understands the importance of leadership training for the volunteer leaders. In order for MLH to support the leaders in the field, it must give them the information and resources they need. "We have so many fantastic and caring group leaders, and many groups care enough to send more than one leader to conference," Stucki said. "Our organization is growing and without all of our volunteers, we would not be who we are."

In talking with other attendees, Stucki, King and Toth heard a lot of good feedback about the leadership training. "We enjoy getting to know each other, and bonding with another Heart Mom or Dad," said Toth. "The roundtable discussions where we can brainstorm and share ideas/successes about our groups are always so helpful and well-received."

She added that the leadership training this year was "beyond

fantastic. Jeff Ton and Dave Stewart from Goodwill Industries gave two powerhouse presentations. "These guys spoke from their hearts and nailed it. I felt very honored that they spoke at our conference," she says.

King said she had a conversation with an Angel Mom (one whose child passed away) at the airport while they were waiting for their flight "about how good it was to meet other Angel parents and come up with a plan on how to celebrate all of the children who pass from CHDs as well."

As for next year's leadership training, Toth says, "I think we are always looking for ways to improve and grow leadership training. You learn what works well and what needs work. I think opening up training again to outsiders with a symposium would be great."

King says she knows her group wants to be at next year's event. "We can't wait until the location and dates are available to start planning," she said. "One other leader and I have gone for four years now — we can't imagine missing the next one!"

Mended *Little* Hearts' CHD Symposium Provides Valuable Information for Parents and Caregivers

Mended *Little* Hearts' National Congenital Heart Defect Symposium was held Saturday, June 21, 2014, as part of the Mended Hearts National Education and Training Conference in Indianapolis, Ind.

In partnership with the Children's Heart Foundation and the Pediatric Congenital Heart Association, the symposium featured speakers renowned in congenital heart defect (CHD) treatment.

"This was the first year for the symposium, and the lineup we had scheduled for that day was dynamite," said Stucki. "All of our speakers did a fantastic job and I had the privilege of this year's MLH conference being in my neck of the woods."

"I think the biggest highlight of leadership training this year was Saturday's CHD (congenital heart defect) Symposium,"

said Toth. “It was a new and fun way to learn about other CHD groups like Sister by Heart, as well as hear heart surgeons speak.”

She says that she and others were “blown away” by the presentations of the doctors during the CHD Symposium. “The passion in those speakers makes us want to work harder to bring that kind of awareness to our local level,” said King.

Stucki was most affected by Dr. John Brown’s presentation on “Treatment Advances & Innovations for Congenital Heart Defects.” “I was privileged to announce this wonderful man. Not only is he an excellent surgeon, but he is my surgeon!” she said. “Mended Little Hearts’ mission is to provide hope; this is the man that has given me my hope. Hearing his presentation not only touched my heart and soul, but touched everyone in that room that day.”

One of the topics, presented by Dr. Nicolas Madsen of Cincinnati Children’s Hospital, was “Exercise and Your CHD Child”. Here, Dr. Madsen discusses the importance of exercise for children with CHD.

Heartbeat: What are the benefits of exercise to people with CHD?

Dr. Nicolas Madsen: The benefits are multiple. People with CHD are exposed to all the unhealthy environmental pressures that everyone faces daily. This includes making unhealthy dietary choices, increasing amounts of time in sedentary activities such as watching TV or sitting at the computer, and a trend toward less time spent in moderate to vigorous physical activity such as hiking, biking, swimming and jogging. As a consequence, there is ever-present risk for the development of obesity, hypertension and diabetes. Importantly, exercise is one of the most well-described tools to prevent the onset of these conditions, and should be promoted as such. People with CHD have additional unique risk factors that may make exercise and the prevention of chronic diseases even more crucial.

Although the evidence to directly support the benefits of exercise and physical activity in the CHD population is less than that found for the general population, I do not think it is a stretch to imagine many examples that highlight the increased risk factors for the CHD population. For example, those individuals who have operations involving their coronary arteries in the newborn period (transposition of the great arteries) probably benefit from regular exercise that helps them maintain a normal blood pressure and optimizes their cholesterol levels. Or those individuals who have ventricles that may show decreased function over time (Tetralogy of Fallot or Fontan) may further benefit from the known benefits of exercise to the heart muscle itself.



Dr. Nicolas Madsen, Cincinnati Children's Hospital

HB: What types of exercise are most beneficial? Does it vary with age?

NM: My first recommendation is to talk to your cardiologist. Exercise comes in many flavors (weight lifting vs. cross-country running) and varying levels of intensity (competitive club soccer vs. biking around the neighborhood). The distinctions between different exercises and the intensity can make a big difference, and needs to be considered within the context of one’s own type of CHD.

However, importantly, almost all persons with CHD can safely perform some type of exercise or physical activity. This is an important point, in my opinion. We know being active is healthy, benefitting not only cardiovascular health but also mental and emotional health. This is why talking to one’s cardiologist about how one can safely remain active is so crucial — it has major benefits to quality of life.

HB: Are there any general guidelines or tips you would recommend?

NM: Talking to your cardiologist is the first step. Next, find out if you have any unique possible contraindications to exercise and physical activity (significant ventricular dysfunction, particular heart rhythm irregularities, significantly elevated pulmonary artery pressures or marked dilation of the aorta). If one does not have any of these less common features, then the guidelines suggest that exercise and physical activity are safe. Remember to advocate for your interest in being active — it will improve your health.

Dr. Brad Marino of Northwestern, who previously conducted a webinar for MLH, spoke at the Symposium about neurodevelopmental issues that CHD children have. Many parents still don’t realize that some kids need to be screened for these issues. Dr. Alistair Phillips spoke about innovations in CHD surgery and treatment, including new techniques that are not as “invasive” as they have been in the past. He brought hearts that were created by a 3D printer for participants to pass around, which were a favorite of many.

Another speaker at the National Congenital Heart Defect Symposium was Dr. Aaron Kay, director of the Adult Congenital Heart Disease Program at Indiana University/Indiana University Health. His presentation was titled, “Empowering Your Child to Transition to Adult CHD Care.” Dr. Kay provided valuable insight about giving your child the tools he or she needs to receive proper care in transitioning to adulthood.

Heartbeat: How difficult is it to make the transition from child to adult CHD care?

Dr. Aaron Kay: It really varies from patient to patient, and depends on how complicated the cardiac birth defect is. The transition is much easier for those who haven't had to have heart surgery, or only one heart surgery, than it is for those who have been admitted many times and required three or even more surgeries during childhood.

HB: What are the most common obstacles faced when making the transition?

AK: One of the hardest parts of making the transition is, honestly, knowing that you will have a competent provider taking care of you when you are an adult. Adult cardiologists generally get very little training in congenital heart disease. There has recently been a push to change this, and in 2015 there will be a board exam that cardiologists with adequate training can take to prove that they are board certified, and thus very competent, in the management of adults with congenital heart disease.

Also, adult facilities are set up for patients who are generally much, much older than your average adolescent patient, and they aren't set up to be as child-friendly, and that can be intimidating for someone who is used to having the availability of very aesthetically pleasing surroundings more common in children's hospitals.

HB: What are some ways to manage the transition?

AK: It really needs to start during adolescence, while the child is still primarily being seen in a pediatric environment. I would encourage parents to empower their children, starting at age 12 or so, to engage with their pediatric cardiologist during office visits and, likewise, ask the pediatric cardiologist to begin directing questions to the child, rather than only to the parents. Of course, every teenager is different, and some are ready for this sooner than others. It is important to be honest and make sure the teenager understands realistic limitations their condition places on them. For example, if they have certain types of disease, they can't lift heavy weights and may want to pursue a career that doesn't involve heavy lifting.

HB: What advice would you offer to people facing this transition?

AK: It is very helpful to have a network of other people in similar situations. Mended *Little* Hearts is a terrific resource. The most important advice I can give is, “don't get lost to

follow up.” Although you may feel well, it is important to stay involved in a source of care that knows you when you are well — that way if you get sick, someone knows what your baseline is, and also knows enough about your condition to treat you adequately.

HB: What resources are available?

AK: There are many websites available to help people with CHD and their parents as they go through the transition. One that I find extremely helpful, especially for those finishing high school or college who suddenly have to relocate for work (and thus have a transition, not from pediatrics to adult life, but from one city to another), is the Adult Congenital Heart Association website, www.achaheart.org, which has a comprehensive directory of every ACHD program in the country. This website not only lists the programs, but also provides details that can give a family a good idea if the program has enough experience to care for them adequately or if they should keep looking, or even consider moving to a different city with better resources.

Other great Symposium speakers were Amy Basken, Pediatric Congenital Heart Association, who inspired us to be “Agents of Change”; Darcie Mille, MLH of Puget Sound, who helped us calm our busy minds; and, Stacey Lihn, Sisters By Heart, who told us about how she used her story to make a difference in the lives of many. ♥

IRUN4 supports Mended *Little* Hearts

IRUN4 is a matching program that matches special needs individuals with runners who dedicate their miles to their “buddy” and raise awareness for their cause.

Andrew Blakley is a Tough Mudder from Dayton, Ohio, who is matched with Trenton Baer, son of Andrea Baer, Vice President of Mended *Little* Hearts. Andrew dedicates all his miles to Trenton and helps to raise awareness for congenital heart defects (CHDs).

He, along with some of his running friends, have recently hosted a fundraiser with a silent auction in order to raise funds for MLH National. Thank you Andrew for running for Trenton, and for Mended *Little* Hearts!

Interested in running for someone? Check out www.whoirun4.com!