



Mended
Little
Hearts

**MLH Coordinators, left to right:
Decia Brown, Toya Henderson, Kari
Crawford, Rene Harrell, Andrea
Himmelberger, Candida Schendel**



MLH Leadership Training

Mended *Little* Hearts (MLH) leaders from around the nation gathered in New Orleans for the Fifth Annual MLH Leadership Training and Networking Weekend. Just over 100 participants from 48 different locations throughout the U.S. attended the training. Again this year, leaders benefitted from thought-provoking presentations and breakout sessions, as well as opportunities to get to know one another face-to-face. The training ran concurrently with the last three days of the Mended Hearts Convention.

Attendees arrived on Friday afternoon for some team-building and socialized that night aboard the *Creole Queen* steamboat, an outing that was well-attended and well-liked. On Saturday, MLH leaders began the leadership training at 7:30 a.m. for a session sponsored by American Medical ID about what Emergency Medical Services providers need to know when responding to an emergency for a child who has a congenital heart defect. East Baton Rouge Parish EMS sent Susan Bailey, an excellent speaker, to begin the training.

Also on Saturday, leaders learned about congenital heart defect research from Heather Brown of Cord Blood Registry, Victoria Pemberton of the National Heart, Lung, and Blood Institute, and Ellen Weiss of the Children's Heart Foundation. The day was long, but attendees felt that they received an abundance of useful information to take back to their local groups.

Many training topics were provided to benefit both new and experienced leaders, including some on leading groups. For example, Mark Levin conducted a session titled "10 Things All Successful Leaders Must Do." He was entertaining and informative, helping leaders understand how to develop their own leadership skills as well as develop others. Many group leaders struggle to find the volunteers they need to effectively run their groups, and this session gave them tips.

MLH also provided "breakout sessions" where leaders could choose which topics most interested them. Amy Verstappen, president and CEO of the Adult Congenital Heart Association and a congenital heart defect survivor, conducted a popular breakout session. She talked to group leaders, mostly parents of children with heart defects, about growing up with heart disease. One point of her talk was to "let kids be kids" and find a balance between keeping your child safe and lapsing into life-limiting over-protectiveness. This is a hard balance for many parents who know their child can become seriously ill in situations that would not harm children without a serious disease. Often and understandably it can be very hard for parents to let go and feel safe after watching their child go through multiple open-heart surgeries and procedures. It's important, however, to help kids feel as "normal" as possible and to learn to set their own limits within reason. Another message Verstappen gives is about talking, in age-appropriate ways, to your child about his or her heart and disease.

Another very popular (and unfortunately necessary) session was on bereavement. This was conducted by social worker Gayden Carpenter of Blair E. Batson Hospital for Children and Sara Northcraft of MLH of Winchester, Va., an amazing mom who lost her son Aron to congenital heart defects. Group leaders often don't know how to include parents who have lost children, and more importantly, how to give them support. Congenital heart defects are still a leading cause of death in children, and parents of heart angels need support that MLH can provide. Sara is very active in MLH of Winchester and promoting awareness about congenital heart defects to make something positive out of a devastating situation.

"She'd lost her child but hadn't lost hope," Len Schendel of MLH of San Antonio, Texas said. "Our chapter has lost a number of children, and her presentation was a strong reminder to continue our relationships with those parents." MLH of San Antonio is one of the MLH groups that have a Mended *Little* Angels subgroup for parents who have lost children to heart defects.

The majority of attendees had never been to a MLH Leadership Training, and there



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was much to see and hear. “We tried to be strategic, so we spread out so we wouldn’t miss anything,” said Len Schendel, who attended with his wife, Candida and another member of their group in San Antonio. Len and Candida are both chapter coordinators and are MLH Leadership Training regulars; they’ve been to all five in-person leadership training programs that Mended *Little Hearts* has conducted, beginning in San Antonio, Texas (their home town) in 2007.

Moms, dads, grandparents and adults with congenital



MLH Coordinators, left to right: Heather Sidle, and Dixie and Terry Varns

heart defects attended the training. Christopher Payton and Len Schendel were two of no more than a half dozen dads who attended. As such, they were heavily outnumbered by the moms. “It would be great if we could get more dads involved,” Len said, “but many must stay home to take care of the kids while their wives attend the training. We’re fortunate that we could send ours to grandma so we both could attend.”

Attendees felt that they both benefitted from and were challenged by the information. “The guest speakers helped me learn to be a better leader,” said Valerie King, lead coordinator of MLH of Winston-Salem’s Tinman Club, “and the breakout sessions helped me learn how to find and recruit resources and other healthcare organizations to help us make things happen.” Candida Schendel felt challenged by the goal of building awareness and doing four events a year. “We need to raise awareness, because many parents hear of many other childhood diseases, like autism and cancer, but never hear of heart defects, the most common birth defect in the U.S., until they have a child who has one.” This can be extremely stressful for parents who are

thrown into a world they know very little about.

Convention attendees consistently noted the benefit of meeting people face-to-face and sharing experiences. For many, that was the highlight of the convention. Often attendees had built relationships with one another over phone or email, but this was the first time they were able to meet in person to share ideas and stories and give one another support. Running a support group can be very hard, but meeting others doing the same thing all over the nation gives attendees a renewed energy and commitment.

“The best thing was connecting with others who faced a similar situation,” said Christopher Payton of Chicago, who attended with his wife Christina Payton. It was his first Mended *Little Hearts* convention and his wife’s second. “Assigned seating took us out of our comfort zone and ensured that we met other people — and within about 30 seconds, we’d be friends because our situations would be so similar.”

Len and Candida Schendel felt the same way. “There’s just a real sense of connection with people across the country who have the same goals.”

Like the Schendels and the Paytons, Valerie King also thought that the best part of the convention was the opportunity to meet, share and learn from others in similar circumstances who live in all parts of the country. “I realized how fortunate I am to have a huge children’s hospital close by,” she said. “A lot of parents end up at medical centers away from their support systems for up to six weeks or longer because their child needs so many tests, and they live too far away to be able to go home. It’s much harder for them.”

Learning about the progress of research studies was another highlight for Valerie. “It was really good to hear updates about studies that we’re involved in,” she said. Research, understandably, is a topic of great interest to many parents of children with congenital heart defects, because medical progress means so much for their children and their families.

Most group leaders left the convention with information to grow their groups and to make a bigger impact in their communities. “I’m a new coordinator to our group and want to raise awareness in our area,” Valerie King said. “Going to the convention has changed how I want our chapter to grow.” Expressing sentiments shared by many, she continued, “I can’t wait to go next year to learn more and get re-energized by my fellow MLH parents and the adult CHD patients whom I now want to be friends with for life.”

“The conventions just keep getting better,” Len said. “Candida and I look forward to going again next year.” ❤️