



Mended
Little
Hearts

Continuing to Grow

by Jon Caswell

Mended *Little* Hearts is growing like a well-tended garden. Last year in San Antonio, 19 group coordinators attended an MLH coordinators meeting the Saturday before the MHI convention; this year in Hartford there were 29. There are now 28 MLH groups, up from 24 last year.

Many of those who attended the San Antonio convention came to Hartford, but there were also many new faces this year. We talked to three coordinators (and heart moms) about their experience at the convention.

Dixie Varns, age 33, is an MLH veteran from Spearfish, S.D. She's the founding coordinator of MLH/Thumpers, affiliated with Chapter 208 in Rapid City. She and her husband Terry, parents of CHD child Tucker, age 10, attended the first coordinators meeting last year and both returned to Hartford this year. Comparing last year to this year, Dixie said, "There were many more coordinators this year, but there were also more husbands there, and they're getting more involved. Of course, with more people, there are more ideas."

Suzanne Hollander-Smith, age 36, is the coordinator for MLH of Loma Linda, California and the mother of heart transplant recipient Alexis, age 5. This was Suzanne's first convention. "It was great to put names with faces. We have a great group of coordinators, and coming together and sharing ideas was really helpful."

Susan Vanderpool, age 42, coordinates MLH of Tulsa and is the mother of Max, age 3, a Tetralogy of Fallot survivor. MLH of Tulsa is affiliated with Chapter 8. This was Susan's first convention too, and she appreciated the treasure trove of ideas on meeting topics, speakers, fundraising and activities for the kids. "I'm excited about becoming involved with Jodi Lemacks in developing the parent matching program," Susan said. "In cities where there are no MLH groups, we're going to connect parents online with established MLH groups, so we can help more families dealing with CHDs. It's an awesome idea, and I hope my past experience as a network administrator and computer software instructor will be helpful."

"I believe parent matching will be very important for MLH," said Jodi Lemacks, MLH National Program Coordinator. "Not only does it put parents in touch with a group, but it allows people to give support online to other parents who have children with the same defect, so they don't feel so alone."



MLH coordinators Susan Vanderpool and Stacey Ebby (from left to right)



MLH coordinators Alicia Hall, Kim Baratz and Kristin Johnson (from left to right)

The 29 coordinators had a full day of presentations and workshops, including a popular workshop called “Leadership and Followership – How follower styles affect your group” led by Lemacks.

“Jodi taught us to be good leaders by being good followers,” Susan Vanderpool said, “and that being a democratic leader works best as a MLH coordinator. We did some great hands-on exercises that really made me think.”

“This organization is amazing,” Suzanne Hollander-Smith said. “I have certainly become more motivated to keep our group going. I am excited to see MLH grow.”

“It’s great to find out what works and doesn’t work,” Dixie said. “It is so nice to sit down with another coordinator and talk face-to-face. I feel refreshed and renewed with lots of great ideas to reach more families.”

The coordinators also appreciated the opportunity to get to know the members of MHI better. “The support MHI gives us is priceless,” said Suzanne. “I really felt the joy MLH brings to MHI members.”

“MHI and MLH are the same and different,” said Dixie Varns. “We’re similar in being scared or worried about an important person in our lives and in wanting to help others. The only real difference is age.”

“This year’s conference was even better than last year’s,” said MLH National Committee Chair Amanda Eason.

“Kathryn Taubert provided great information about what the AHA is doing for children with CHD. And thanks to heart dad Len Schendel of San Antonio, who created a standard Web page, each MLH group can easily have its own Web site. The months ahead will be full of strategic planning and grant writing. We’re really concentrating on building MLH’s reputation as the premier national support organization for families with children born with heart disease. Conferences such as the one in Hartford certainly provide a great opportunity to reach that goal. I know we’re all looking forward to next year’s conference in Orlando to reconnect, not to mention enjoy some family-friendly fun!”❤️



Alexis Smith



Max Vanderpool

Expert Advice

This year the MLH coordinators had two speakers who helped the group leaders understand more about two issues – CHD research and advocacy – that are very important to them.

Dr. Kathryn Taubert’s presentation was titled “Research on Congenital Heart Defects in Children: What Has Been Done and What Can Be Done.” Dr. Taubert, who is Senior Scientist and Special Assistant to the Chief Science Officer at AHA, discussed AHA grants relating to CHD and issues related to grants and funding.

John Ring, M.D., is the director of the Office of Policy Research and Development at AHA. His talk, titled “CHD: Meeting the Challenge of Success,” addressed the scope of the CHD problem as well as access-to-care issues, a new area of advocacy for AHA, and an issue dear to the hearts of everyone in MLH.



Dixie and Tucker Varns