



Mended
Little
Hearts



The Mended Hearts, Inc.



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Mended *Little* Hearts on Board

The integration of Mended *Little* Hearts and Mended Hearts at the governing board level has strengthened both Mended *Little* Hearts and Mended Hearts overall. “It’s important to have both organizations represented at the highest level so that we can work together and help more people,” said Susan Vanderpool, vice president of MLH and a member of the MH Executive Committee. “If we’re going to

function as one organization, everybody needs to know what everybody else is doing and planning,” said Vanderpool, who lives in Tulsa, Okla.

She added: “A lot of the Mended Hearts members really want to be involved with Mended *Little* Hearts. Being represented on the board and executive committee reinforces that we are all one organization.”

As a vital and growing part of the overall organization,

Mended *Little* Hearts is enjoying a greater presence on the governing board of Mended Hearts in recent years.

The 2013 election will be the second time that Mended *Little* Hearts groups will vote on two positions on the Board of Directors: The VP position held by Vanderpool and MLH Board Director, held by Amanda Eason. Neither is seeking re-election, and their terms will end in June after the convention in San Diego.

“Both positions play an essential role in the integration of Mended Hearts and MLH,” said MLH National Program Director Jodi Lemacks. “This communication is crucial to ensuring that the Mended Hearts organization is meeting the needs of all heart patients, from the youngest to the more mature.”

Mended *Little* Hearts works nationally and in communities to support children with congenital heart defects and their families. Services are similar to those offered by Mended Hearts, and include group meetings, accredited hospital visiting, health education and advocacy. MLH also does much work with CHD awareness because so many people still have not heard about the most common birth defect in the U.S.

The board positions were created as a means of recognizing the rapid growth and importance of MLH to the overall organization. MLH has expanded from two groups in 2004 to 71 groups in 28 states and the District of Columbia in 2012.

Here is more information about the vital roles of these two posts:

Vice President of MLH

The VP oversees the Mended *Little* Hearts program and committees. This includes developing and implementing the program’s strategic direction. This individual works directly with Lemacks to maintain program quality and ensure resources for maintaining and growing the program.

As a chief spokesperson for Mended *Little* Hearts, the vice president keeps informed about issues affecting children with CHD and their families, and helps represent MLH’s position on these issues.

Susan has worked tirelessly to grow the program and expand its services and resources. Her son, Max, was born with Tetralogy of Fallot. He is the inspiration for her to give back and help others on a national level.

“Susan recognizes the importance of MLH representation on the Executive Committee,” Lemacks said. “She has been a powerful voice, creating better integration of Mended Hearts and MLH while advocating for our families.”

After five years in various leadership roles, Vanderpool is not running for another term on the board, saying she believes that new ideas and leadership are vital to continued growth.

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MLH Board Director

This position was created by Raul Fernandes, a past president, in 2009. At that time, Mended Hearts Treasurer Dale Briggs graciously assumed this role to give MLH a stronger voice. Dale has been active with the Mended *Little* Hearts group in Fresno, Calif., after working with wife, Sandy Briggs, to get the program started.

In 2011, the MLH Steering Committee voted that this position should be filled by a CHD parent or adult with CHD to better represent the affected community.

The current director, Amanda Eason of Jacksonville, Fla., has worked with Lemacks on field services, leadership training and the mentoring program. The mentoring program is similar to Mended Hearts’ network of assistant regional directors, who help new chapters get started and existing chapters get stronger.

Eason, who is starting nursing school and has decided not to seek re-election, has been an excellent source of ideas for making MLH more effective.

“Amanda is a heart mom who adds a sense of professionalism to the organizations,” Lemacks said. “She has taken us to different levels with her ideas and the way she interacts.”

Jodi is looking forward to working with the individuals who fill these positions to make Mended *Little* Hearts even stronger.

“We have come so far, but there is so much more we can still do,” she said. “We are looking forward to the future.”

Vanderpool agrees, saying, “I’m excited for the new leadership and to see what the new blood is going to do.” ❤️



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Anatomy of a Support Group

By Jodi Lemacks

Well-run support groups leave people feeling empowered, positive, connected to others and to resources, and better able to cope. However, as the national program director of 71 congenital heart defect support groups around the nation, I often hear objections.

More than a few parents and caregivers, medical professionals and others have told me, "Support groups are where people sit around and complain about their child's condition, and I don't want any part of that," or "Support groups are all about the disease. I don't want my child to be faced with his illness each time we go to a meeting or event."

But properly run support groups are greatly beneficial and improve the lives of children and the

whole family.

One very successful support group in the United States, Alcoholics Anonymous, was founded in 1934. (Interesting fact: Mended Hearts is the second-oldest national support organization after AA.) Studies show that alcoholics who are in therapy and also attend AA meetings are far more likely to stop drinking alcohol and maintain that abstinence. CHD support groups, likewise, can complement good medical care and help improve the lives of families.

Many hospitals and medical professionals cite the benefits of support groups for patients, particularly when combined with appropriate medical care. According to the Mayo Clinic, support groups help people:

- Feel less lonely, isolated or judged
- Gain a sense of empowerment and control
- Improve coping skills and sense of adjustment
- Talk openly and honestly about feelings
- Reduce distress, depression or anxiety
- Develop a clearer understanding of what to expect
- Get practical advice or information about treatment options
- Compare notes about resources

Support groups are not about the disease or about complaining about conditions. They are about looking at conditions and saying, “My child may have this condition, but this condition does not have my child and/or my family.”

Any CHD support group can be successful and helpful to families if the leaders:

- Always keep in mind the overall vision for the group: to improve the lives of children and families.
- Create a safe and confidential place for people to share information. Mention confidentiality at the beginning of every meeting.
- Encourage people to share their stories, but don't allow group members to begin a gripe session. Encourage them to say, “My experience with that issue was ...” rather than give advice or criticize a parent or caregiver.
- Never compare hospitals or medical professionals. Each family will have a different experience, and that should be honored.
- Encourage active listening among members, where open-minded people ask questions to gain a better understanding.
- When people offer to help, find out what they love doing and match their talents with the right volunteer opportunity.
- Only commit to what your group can truly accomplish given its available time, resources and talent.

Support groups let people know they are not alone, and that there are ways to get through the sadness, anger and fear and move toward a healthier future. Working together, support groups can accomplish big changes and make the world a better place. ❤️

MLH Webinar Series Answers Questions

Mended *Little* Hearts recently hosted the first two webinars in a new series “Raising My CHD Child: Questions Parents Ask” designed to help answer questions to help families care for their child with congenital heart defects (CHD).

Neurodevelopmental Issues and CHD

Dr. Brad Marino of Cincinnati Children's Hospital and lead author of the American Heart Association's Scientific Statement on the issue, presented “Neurodevelopmental Issues and CHD” Some children with CHD have certain risk factors and are likely to have neurodevelopmental issues that prevent them from performing at the same level as other children their age, according to Marino. They should be evaluated early by a developmental pediatrician or a specialty center that is familiar with these issues, if possible, so that they can work with parents or caregivers and educators to develop a plan to help the child be as successful as possible.

There were more than 230 registrants for the webinar. Comments included, “Outstanding,” “This webinar was like water to a parched soul,” and “I was so relieved I cried. I knew something was different about my child, but no one wanted to acknowledge it. This was excellent information.”

Trans-Catheter Valve Replacement in Children

Dr. Dennis Kim of Children's Healthcare of Atlanta presented on this important issue that many parents have questions about. This webinar was graciously co-hosted by The Society for Cardiovascular Angiography and Interventions on Nov. 12. Again, there was a wealth of information including information about the procedure itself, who is eligible, risks and benefits, and expectations for the future. Comments included, “I found the webinar to be very informative. It was the perfect amount of time and the doctor was a fantastic speaker. I look forward to the next one. Thank you for your work with heart families. It is appreciated more than you realize.”

Both webinars are available for viewing on the Mended *Little* Hearts website (www.mendedlittlehearts.org)