



Mended
Little
Hearts

Joint Efforts, Big Results

by Dixie Varns



The Varns family

“MLH really means a lot to our family. It gives Tucker, my CHD son, other children to relate to so he’s not the only one with a ‘zipper.’”

The relationship between Chapter 208 and our Thumpers Mended *Little* Hearts group is great. We offer each other support way above and beyond just “heart matters.” Both groups meet together the first Saturday of every month. Plus we join our efforts to put together four big MLH/Thumpers meetings each year. Because our MLH group covers a 300-mile radius, a lot of our CHD families can’t make it to the monthly meetings, so we have a great response on our big events. MLH has 35-40 members; Chapter 208 has 45 members.

In January both groups get together for an after-Christmas potluck where we all eat and visit. We all enjoy the opportunity to catch up and see how everyone is doing.

In February, we pull together for an annual get-together of friends and family called “A Day for Hearts: Congenital Heart Defects Awareness Day.” This event features different “projects” set up around the room for the kids to put together or participate in. We have a clown who does games and balloons and face painting, with help from the older siblings and CHD children. We also have a magician that the children look forward to seeing every year. We also have a potluck lunch.

Also in February, both groups volunteer at the AHA’s annual Heart Ball fundraiser. That is also a great place to meet potential members.

In July we have a *huge* potluck picnic at Storybook Island, which is a big (and free) park. At this event, we always seem to be found by the local TV station and they interview some of the families. I think they look for us every year!

In September both groups work together along with the AHA to raise awareness about congestive heart disease and congenital heart defects at the annual Heart Walk in Rapid City.

In 2006, we also paired up for the Pierre Heart Walk in the beginning of October – what a beautiful walk! I am hoping to go every year and get more walkers. After talking to many members, I’m pretty sure that Chapter 208 will join us as well. Also in October next year we are planning a safe Halloween party.

Chapter 208 has helped us raise funds to put together our “Life-Flight bags.” These are supplies for families that have to be flown out to a children’s hospital. Often they have to leave without going home, leaving with nothing more than what is on their backs. Most of our Life-Flight bags have \$100 cash, a Wal-mart gift card, a spiral notebook for journaling, pencils, an informational book about CHD, a quilt made by a member of Chapter 208, a garment for the baby, a receiving blanket, our business card and five postage-paid envelopes.

Both groups come together to build a float that we enter in four area Christmas parades and four more 4th of July parades. We all work together on the float and then ride it together.

Chapter 208 is helping us put together a CPR class for toddlers and infants for our members. Several Chapter 208 members plan to take the class because many of them have grandchildren.

For monthly speakers we alternate between those geared to MH and MLH. It works for both groups because for MLH most of us have parents and grandparents who can use the information. And many of the MH members seem to like the MLH speakers because it helps them know what is going on with the younger members.

MLH really means a lot to our family. It gives Tucker, my CHD son, other children to relate to so he’s not the only one with a “zipper.” It’s also good for Steven, my older son, because he can play and talk with other siblings of CHD families. Chapter 208 is like an extended family, full of grandparents, and I think the boys really look forward to meeting with them. I think it gives my husband Terry a chance to talk. It seems like most people ask the wife all the questions. Our members understand that both parents have feelings about what has happened.

Dixie Varns is vice president of Chapter 208 and coordinator of MLH/Thumpers, “All in the beautiful Black Hills South Dakota!” she says.



Terry and Dixie Varns with sons Steven (left) and Tucker (center)

Recent Developments in Pediatric Cardiology



We recently interviewed Dr. Catherine Webb, chair of the AHA Council on Cardiovascular Disease in the Young. She is professor of pediatrics at Northwestern University and attending cardiologist at Children’s Memorial Hospital in Chicago, Ill.

Heartbeat: What are the salient differences between pediatric and adult cardiology?

Dr. Webb: The biggest difference is that pediatric cardiologists primarily treat children with anatomic malformations of their hearts (holes in the heart, absent parts of the heart, narrowed valves and arteries, etc.) These defects are called congenital heart defects (CHD) because children are born with them. Adult heart disease is primarily acquired over time. Adult cardiologists usually do not deal with heart malformations that their patients are born with. There are some similarities between the patients that adult and pediatric cardiologists treat. Both types of cardiologists treat patients with heart muscle disease (cardiomyopathy) and patients with heart rhythm abnormalities (arrhythmias). Both also treat patients with heart valve disease, but the heart valve disease is congenital in pediatric patients and acquired in adult patients.

Heartbeat: How has pediatric cardiology changed in the past decade?

Major changes in arrhythmia diagnosis and treatment, catheter delivered interventions in the cardiac catheterization laboratory, and major improvements in cardiac surgical techniques have resulted in saving the lives of many children who might have died 20 years ago.

Heartbeat: What educational resources are there available to parents of children with CHD? Where can parents get reliable information?

Pediatric cardiologists often have excellent information in their offices. The AHA Web site is also an excellent source of information (www.AmericanHeart.org). Their articles are written by prominent pediatric cardiologists around the country. The American College of Cardiology also has an excellent site (www.ACC.org). The Adult

Congenital Heart Association is a good resource for adults with congenital heart disease (www.achaheart.org). Other Web sites which can give support to families dealing with CHD are mentioned in the sites noted. Mended *Little Hearts* is an excellent supportive Web site (www.MendedLittleHearts.org).

Heartbeat: What new treatments are available to children with CHD?

Dr. Webb: Many, many new treatments have become available in the past ten years, including arrhythmia diagnosis and ablation. There are also new developments in interventional procedures in the cardiac catheterization laboratory, which avoid the need for open-heart surgery. There are many new surgical techniques that preserve heart function and palliate complex anatomic heart defects.

Heartbeat: What areas of research look promising?

Dr. Webb: We are learning more and more about the genetics of CHD and also about maternal exposures during pregnancy that may increase the baby's risk of having congenital heart disease. By learning more about genes and exposures associated with CHD, we may be able to prevent it or treat it with better outcomes. Additional clinical research on different types of CHD is being done in multi-center studies and registries of patients are being kept. The multi-center studies and registries will enable us to study outcomes of many different types of heart problems.

Heartbeat: What are the resources available to adults living with CHD?

Dr. Webb: First, the Adult Congenital Heart Association. Second, any pediatric or adult cardiologist who has additional expertise in anatomic malformations of the heart. Many medical centers now have adult CHD clinics. These clinics are the best place for adults with CHD to be cared for. Adults with CHD need lifetime cardiac follow up.

Heartbeat: How is the professional community addressing the issue of adults with CHD?

Dr. Webb: There are many ongoing multi-center trials and registries that are funded through the National Heart, Lung and Blood Institute as well as the AHA and other organizations interested in decreasing morbidity and mortality from heart disease. We are particularly interested in reaching all adults currently living with CHD so that we can understand the long-term outcomes of a particular defect and learn how to treat ongoing problems. In the past, many children with CHD did not realize that they would need ongoing cardiac care in adulthood, and they

have been lost to medical follow up. We are trying to deal with this problem by publicizing the need for ongoing care in adulthood and urging adults with CHD to become part of registries and multi-center studies. The best place to learn about these things is through adult CHD programs at major medical centers.

Heartbeat: What is on the horizon that would provide hope for parents with children with CHD?

Dr. Webb: More than 90 percent of children born with CHD today will survive. Some children with minor heart defects will be completely cured by a simple operation or intervention. Other children with more severe heart disease will require serial surgeries or interventions that will result in palliation but not a complete cure for their heart defect. This is why regular, lifetime follow up is important from childhood throughout adulthood for CHD patients.

Heartbeat: What advice would you give to parents of children with CHD?

Dr. Webb: Don't be afraid to ask questions of your pediatric cardiologist. I often tell families to write down their questions, so that we can talk in detail about them at the next clinic visit. Families sometimes forget what some of their concerns are when they are in the doctor's office and remember them when they get home. I also encourage the families to call me on the phone when this happens, so that I can clear up any lingering issues. It is also important for families to follow the advice their doctor gives them: give their child any medicine prescribed; comply with any activity recommendations; be sure to follow up as scheduled with any clinic appointments or tests. Above all, if the stress becomes too great, they should communicate this to their doctor so that we can get appropriate help and support for them.

Heartbeat: How does Mended Little Hearts fit into the treatment puzzle?

Dr. Webb: By providing a network of support for families who have children with congenital heart disease, Mended *Little Hearts* does a tremendous service. Doctors and medical personnel realize what severe stress having a child with significant heart disease places on a family, but we must concentrate on specific medical issues. Having a chance to talk to families who have faced the same problems is very reassuring to families going through this crisis. Although doctors and medical personnel are willing to talk at length with families, somehow it's not the same as talking to someone who has gone through what your family must endure. They offer very important reassurance.