



Mended
Little
Hearts



MLH Leadership
Training attendees

MLH Leadership Training Success Continues

At the 2013 Mended *Little* Hearts Training during the Mended Hearts Convention, Mended *Little* Hearts leaders once again had the opportunity to share group leadership information, learn new information to take back to their communities, and to hear from extraordinary parents of CHD children — people just like themselves. They also benefitted from presentations by prominent doctors in the CHD field.

Highly rated by attendees were presentations by Dr. John Lamberti, pediatric cardiothoracic surgeon, and Dr. Chris Davis, pediatric cardiologist—both from the Rady Children’s Hospital. Dr. Lamberti presented on the past, present and future of CHD interventions and surgery. Dr. Lamberti leads the Rady Children’s Combined Pediatric Cardiac Surgery Program and is an excellent speaker,

putting information into words that non-medical people can understand. He also adds a great sense of humor to his presentation, which made it not only informative, but enjoyable as well.

After narrating the history of CHD surgery, Dr. Lamberti discussed the major advances in CHD treatment. “This was very timely for the leaders of the groups, who need this information to lead their groups in their local communities,” said Jodi Lemacks, National Program Director of Mended *Little* Hearts. “It was a good general overview into how things are changing and developing.”

Another key presentation from the medical point of view came from Dr. Chris Davis. Dr. Davis presented on the changing medical approach to exercise with CHD patients. The changing paradigm for doctors is to

proactively prescribe exercise for their patients, rather than simply limiting what their patients can and should do. “It’s an issue of going from restricting patients from certain types of exercise according to their disease burden, and going toward a new paradigm where we measure the risks of exercise against the benefits, so we can prescribe the right types of exercise according to their disease profile and health profile,” said Dr. Davis.

Dr. Davis suggested that each CHD patient work with his or her doctor to come up with an appropriate exercise plan. “Each patient should have their individualized assessment based on their clinical condition, and the various types of exercise should be weighed against the benefits of exercise,” he said.

Often, parents of children with CHD focus on what their kids can’t do. This approach focuses on what they can (and should) do to keep them as healthy as possible. CHD children are getting acquired cardiovascular disease at the same rate as the rest of the population, so it is important to avoid this and the added strain on the heart.

You can read the new exercise guidelines at <http://circ.ahajournals.org/content/127/21/2147.full?sid=2f33827e-545d-4554-8b5f-611ed4f369d9>.

TV Star Makes Surprise Appearance

CHD survivor Valerie Azlynn (star of the TBS sitcom *Sullivan & Son*) shared her story with the MLH coordinators at convention. She shared her journey from diagnosis and surgery through present day, where she is a wonderfully talented actress. That acting bug is what motivated Valerie to not let her CHD hold her back from pursuing what she loved.

In addition to acting, directing and singing, Valerie is passionate about increasing awareness of CHD. Like many adults with CHD, she did not know any kids “like me” when she was a child and that is one of the reasons she holds MLH near to her heart.

She is especially interested in helping CHD kids cope with their physical scars. Being in the entertainment industry she brings a unique perspective regarding self-esteem and wants to ensure that CHD kids everywhere feel good about themselves despite their scars. She wants them to see that she too is a warrior, she stands with them in their fight and that they too can pursue what they love.

MLH is enormously blessed and incredibly proud that Valerie has agreed to be our National Spokesperson. She is truly an inspiration to us all!



Dr. John Lamberti



Dr. Chris Davis



Actress/singer/dancer Valerie Azlynn surprised MLH attendees with a brief talk! Valerie, an adult CHD survivor, has agreed to be the national MLH spokesperson!



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Mighty Max and His Mom: Striving and Thriving

One of the highlights of the 2013 Mended *Little* Hearts Leadership Training and the Mended Hearts Convention was the presentation of “Mini-Darth Vader’s Mom,” Jennifer Page. Mini-Darth Vader, Max, charmed audiences worldwide in the Volkswagen Super Bowl commercial of 2011. Max is a child actor whose work has incorporated commercials and network TV. What is less obvious about Max is that he, like about 40,000 children born each year, has a CHD.

Jennifer, her husband Buck, and his little brother Ellison (Els) have been on quite a journey with Max throughout his short life.

Everyone in the Page family is an advocate for a variety of causes, including of course congenital heart disease. Jennifer has spoken before Congress and been interviewed on the Today Show, Good Morning America, CNN, and many other national media programs and outlets.

Jennifer graciously found time in her busy schedule to speak with Heartbeat about her family, her powerful story, and her advocacy work on behalf of CHD families everywhere.

HB: What was it like to present your story to the Mended *Little* Hearts attendees at the San Diego convention? What kind of response did you receive?

JP: It was an honor to present my story to a group of people who totally understand the heart journey. Although many people can relate to experiencing difficult times — this group had been through my same experience. The support and love from the

Mended Hearts and Mended *Little* Hearts community was overwhelming. My son Max said, “Mom check it out — a standing ovation! My force worked!”

HB: I have to ask about the mini-Darth Vader role Max performed in the Volkswagen Super Bowl commercial. How did Max get into acting? How did he land this role? Did he enjoy it?



Jennifer Page and her son, Max — better known as “Mini-Darth Vader”

JP: Max is faced with many things he won't be able to do in life because of his heart and pacemaker. Fortunately acting isn't one of them! When he was about 3 we enrolled him a local children's theatre group. His teacher recommended we get an LA agent. We hesitated for a few months, but it was clear that this was one of Max's talents. The VW commercial was a typical audition, about 100 kids. Then he made callback with 16 others and then



landed the role! To date Max has done 14 national commercials, reoccurs on *The Young and the Restless* and reoccurred on *Prime Suspects*. He loves his acting opportunities.

One of the benefits of Max being so well spoken is that he is able to carry his own message. He is interviewed often for television and radio, and appears at many fundraisers. It's such a joy to watch God share His message through Max. Max has lobbied on Capitol Hill two years on behalf of Children's Hospital Association. This past year House Minority Leader Nancy Pelosi let him sit in her chair and bang the gavel. She gave him 30 minutes to talk to her about kids like him. He is a terrific advocate!

HB: How is Max doing today?

JP: Max is thriving. He loves baseball, golf, studies all kinds of sports, is a great student and is super kind. He still sees one of his various doctors about every three months, but so far the prognosis is great.

HB: One of the points you made during your presentation is that the small stuff is the big stuff. Can you explain what you mean by that?

JP: We all expect the days leading up to surgery or a big appointment and then a few days following to be very difficult. But those of us on this journey know that the worry, pressure and stress are life-long. We watch our children daily for signs of energy, appetite, color, etc. The appointments seem endless and one turns into a referral and then another. The bills mount. The insurance papers are overwhelming. You don't simply go to surgery or fix a problem. You enter a new lifestyle. You raise your child in the medical system and all that entails. While we are blessed with modern medicine, it doesn't take away the difficulty of the day-to-day navigation of our child's affliction.

HB: You describe Oct. 25, 2010 as the moment you changed. What changed for you? How important was this change in your life?

JP: On Oct. 25, 2010, I woke up and went into my bathroom. Blue toothpaste had exploded and was all over the mirrors, carpet, bathtub — everywhere! I asked my husband who had done this. He replied, "You don't remember, do you? This was YOU trying to help the boys brush their teeth."

In the shame of that moment I knew I needed to give up alcohol, but I wasn't sure how. Over the years it had gone from a lifestyle to a way to cope with my feelings. The emotions were too painful to walk through and drinking was a way to numb the pain — temporarily. I had tried to cut back, but vacations, holidays, eventually any day ending in "day" got in my way. At the end of my drinking days I was up to about 14 bottles of wine per week.

I joined AA and went to 90 meetings in 90 days. I slowly but surely found my voice through my 2-minute daily shares. I could finally verbalize all of the unspeakable parts of my journey. I could finally lay down the burden of alcohol and be the mom I always intended to be — the one who reads books at night, plays games and is engaged all of hours of the day — not just 10 a.m. to 4 p.m.!

HB: You use the acronym "FORCE" in your presentation, which stands for "Forgive, Outlook, Receive, Commit, and Experience." How can parents use their FORCE to help them in their journey with their CHD children?

JP: I found that I tend to carry around a lot of pain that isn't necessary. I am upset with people who don't even know they hurt my feelings. I am upset with family members I thought should do a better job showing up for me. I realized I needed to forgive people who are just trying to also do their best. People always choose to be where they want to be — not necessarily where I think they should be or want them to be. I also needed to



forgive myself — there is nothing I could have done to change Max being born with Tetralogy of Fallot. I didn't fail him. My mission is to help him fulfill his purpose and live a great life. When I can't eliminate the pain, I can hold him tight and let him know he's not alone.

Robin Roberts (anchor for Good Morning America), who is battling cancer said, "Optimism is like a muscle and you must exercise it. Otherwise it only takes a pinhole of darkness to suck us in." I try to be as upbeat and positive as I can with my messaging and the way I raise Max. But it takes a tremendous effort not to just sit down and have a long cry. It's easier to be cranky than thankful. I work at it every day — some days with more success than others. But a positive outlook is always my goal!

Receiving kindness is uncomfortable for me. In the hospital all these wonderful items showed up like comfy socks, blankets, toothpaste and toys. I wondered where it came from? It came from parents who had been in my shoes before. Having friends bring dinner or help with my other son takes getting used to. I am the ultimate giver and a terrible receiver. I will carpool your kids, make you — well, I won't make you dinner — I will buy it and deliver it! I realized that if I can open myself up and allow the friendship in, everyone feels better and more connected. No one expects me to have it all together and it's OK to let the love in.

Committing to a cause has helped me heal. We support the hospitals we frequent, the boys have charity birthdays each year (over \$60,000 of funds and product raised so far), and we are always supporting a walk or a gala of some kind. Anything involved with pediatric medicine, we offer our time and treasure too. Each time we help, we heal — whether it is lobbying on Capitol Hill or fellowshiping with a family one on one.

Experience is something vital to share. You never know what phrase or story is going to be the piece of comfort that another person will take on their journey. I was uplifted at the Mended Hearts Conference by the number of adult congenital heart defect survivors that shared their story with me. As I am busy raising Max, I look up and realize he WILL be an adult some day. And it looks beautiful! When we share our experience it doesn't have to be long and preachy. Sometimes the person we are helping just needs to know they aren't alone.

HB: Advocacy for CHD research and care giving has become an important part of your public outreach. You've even spoken in Washington, D.C. When did you envision yourself becoming a public advocate for the cause? Are you surprised at how far you've come?

JP: In 2011, I stood in the Cardiac Intensive Care Unit at Children's Hospital Los Angeles with Dr. Sanjay Gupta from CNN. He was doing a piece on Max as Darth Vader and as a heart patient. We stood and looked around and there were 15 babies in there that day. I told him it's up to us to be their voice. They are doing their part — giving all they have to survive. It's up to those of us who are able to do our part and make sure that hospitals and pediatric doctors have what they need to care for all kids.

Summer of 2012, we were the ones in the hospital relying on others to advocate for us. Max had his pulmonary valve replaced and we spent much of the summer in recovery. When you can make a difference — do it!

We feel very blessed to be able to carry the message of children's health care. We will be lifelong advocates!

HB: Max, too, has become a powerful advocate for a variety of causes, as has his little brother Els. What inspired them both to want to give so freely of their time and talent?

JP: We raise them in the spirit of charity. They each choose a charity for their birthdays and use that special day to do good in the world. Last year Els chose Kindness Day. Our family and friends did random acts of kindness and emailed us what they did. Max's last one was Joy Jars — comfort items for children in hospitals battling cancer. This year he is supporting an African orphanage that our dear friends just adopted from.

The boys raise money, walk, and perform at galas — whatever we can do to make an impact. Max donates money from his commercials to various heart causes and Children's Hospital Los Angeles. Charity is simply part of their foundation. And what a beautiful foundation it is!

The Dads' Side

For Rodney Masengale, co-coordinator (along with his wife, Jamie) of the Mended *Little* Hearts of St. Pete group, putting on a first-ever session for MLH dads was a gratifying experience. “Jodi [Lemacks, National Program Director of MLH] originally contacted me asking if I wouldn’t mind doing a session from a dad’s point of view,” said Rodney. “There really is no formula or magic potion to doing this. So I thought, what can I tell other coordinators from other groups about this?”

That’s when he hit upon an idea: Rather than doing a solo presentation himself, why not open up the floor to discussion? So he organized a

panel discussion with Terry Varns of the Black Hills, S.D., group and Len Schendel of the San Antonio group, focusing on the issues CHD dads face. The feedback he got was, in his words, “fantastic.” He said, “The audience participants were very active, had a lot of questions and input.” Glenn Stanton of Dayton, Ohio, added in many helpful comments.

That came as no surprise to Rodney. Jamie and he are parents to a 7-year-old girl, Olivia, who was born with truncus arteriosus, a rare condition in which the pulmonary artery and the aorta are joined and the bottom two heart chambers are not properly divided. The result is oxygen-poor blood getting mixed with oxygen-rich blood, causing severe circulation problems. Olivia had surgery to correct the condition at 6 weeks of age. She will have follow-up surgery in the next few years.

Rodney found that he had plenty of questions and concerns when they learned of Olivia’s condition, when she was two days old. Jamie and he attended the very first meeting of the Mended *Little* Hearts of St. Pete, and they haven’t looked back. “We were a week into the heart world,” Rodney recalled. “We were completely devastated, confused, etc. There was a ton of people there, including news crews. What helped me was that there were a ton of kids there, being kids, running

around, having fun. What was on my mind was, ‘What kind of quality of life is my child going to have?’ And seeing those kids there, laughing, playing, assured me that my child was going to be OK.”

From there, Rodney and Jamie found their own voice as CHD parents. “Since then, we’ve been on the other

side — we’ve been the ones to provide that support, which has been truly uplifting to us. To be able to talk to someone who is new to the heart world, like we were, you can see relief in their demeanor and attitude, that maybe their kid is going to be OK, too.”

So when Rodney got the call to present at the MLH Training Sessions, he didn’t hesitate. What makes CHD dads tick? Rodney and the other attendees learned a lot from the exchange. First topic: Battling stereotypes.

“It’s the male stereotype of the non-emotional, rock of the family who carries all the weight, and so forth. That was my first point,” said Rodney. “When I opened the session with ‘What do CHD dads want from a support group,’ well, we want the same things the moms want. We might process our emotions and thoughts differently sometimes, but that doesn’t mean we don’t need another dad or mom to talk to.”

Another key point that came from the panel discussion: Keeping dads engaged in the group means bringing in some “guy”-type activities. “If you want to keep the dads involved, you might have to do some dad stuff, too,” he said. “Not that we’re allergic to crafts, but you need some “guy” things in there as well to keep dads involved in the group. Say, a cookout — you’re the guy, you’re on the grill cooking. You need a mix of activities to keep dads engaged, too.”

Not surprisingly, the sessions were inspiring to him, as well. “It’s great to get feedback from other coordinators of other groups. Every group does things differently,” he said. “You get to hear new ideas that you hadn’t necessarily thought of yet, and you get to share your ideas, too. It’s great motivation to come back to your own town and put into place some of those ideas, and to get more involved in your own town.”



Rodney Masengale, co-coordinator, MLH of St. Pete