



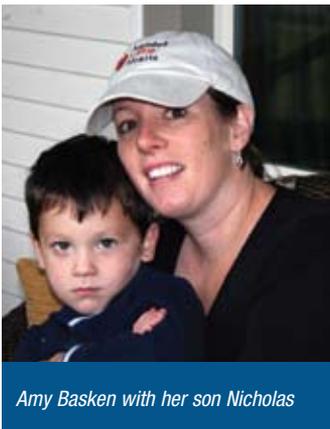
New Leaders in MLH

by Jon Caswell

Mended Little Hearts is making a big difference in the lives of families of children with congenital heart defects (CHD). Of course, this is as it should be because who knows more about living with CHD than those doing it? But passion and experience can only take you so far – if you really want to make a difference, you have to get organized. And that takes leadership, which is something MLH has been blessed with from the beginning. We have chosen five of those leaders to profile here, but they are only the tip of the iceberg. There are many mothers and fathers who are working diligently to make sure no CHD family has to face this frightening ordeal alone and without knowledge.

THE ADVOCATE

Amy Basken, *age 35*
MLH of Southern Wisconsin
Mother of Nicholas, *age 3½*; coarctation of the aorta



Amy Basken with her son Nicholas

Amy started her group soon after Nicholas was born, and soon after that she started lobbying her state legislators. Today she is the MLH representative on the MHI Advocacy Committee and also represents MLH on the National Congenital Heart Coalition, serving on its advocacy subcommittee. She has participated in AHA's Lobby Day in Washington, DC.

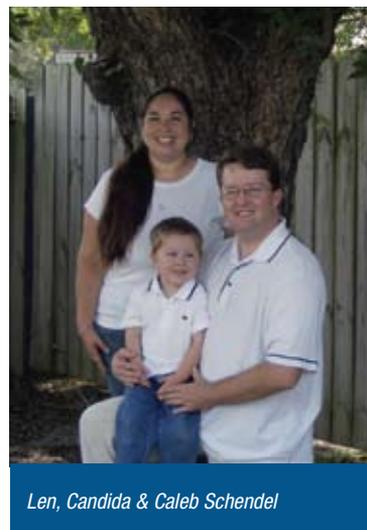
“I have seen success in effective advocacy campaigns in other areas and hope to use advocacy to bring light to CHD. I believe the power of a single voice is amplified

through advocacy. I do it because I can vividly recall our experience with Nicholas: the fear and anxiety resulting from our lack of awareness, education and support; and the sticker shock of his treatment. Since then, I have seen that fear in others and heard the stories of the financial burden. MLH does great things in our communities, but something must be done at a larger level.

“MLH has become part of my extended family. We offer support in ways others cannot. I feel privileged to be part of this.”

THE TECHNOLOGIST

Len Schendel, *age 33*
MLH of San Antonio
Father of Caleb, *age 3*; hypoplastic right-ventricle syndrome



Len, Candida & Caleb Schendel

Len is an instructional technology specialist in a high school near San Antonio. That means he teaches teachers how to implement technology in their classrooms. For MLH, Len is the technology guru who helps local groups have a big web presence without paying a big price. He has created tools that allow amateurs to produce polished websites, and then he hosts them for free.

“My goal is to get more chapters creating bigger, better websites. Most people today turn to the Internet for help or answers, so it's important for MLH to have a large and prominent presence on the web. Since a website is an organization's ambassador to the world, you want one that looks good, is easy to find and is useful.

“When we first learned of Caleb’s condition, we didn’t have and couldn’t find a support group, and I don’t want anyone else to go through that.”

THE LOGISTICIAN

Jaime Olsen, age 32

MLH of Children’s Memorial Hospital (Chicago)

Mother of Tyler, age 2½; severe pulmonary stenosis



The Olsen Family

Jaime’s genius is organizing. In the span of only a few months she has not only started a MLH group, she has put together two satellite groups at suburban hospitals. In addition, she is a member of MLH’s national committee.

Her challenge in Chicago was one of time and distance. “People wanted to be part of our

support group at the hospital, but they couldn’t because it took too long to get there, not to mention the price of gas. I knew it was time to offer support in the suburbs, and I was fortunate to find great co-coordinators, Andrea Sullivan and Jodi Mallett, for the satellite groups.

“It takes a lot of time, but I remember how I felt, always crying, wondering, ‘What did I do to my baby?’ I started looking for a support group and that’s when I found MLH. I promised Tyler that I would never let another parent feel the way I had.”

THE VISITOR

Vanessa West, age 24

MLH of Tucson

Mother of Arianna, age 2; Tetralogy of Fallot and DiGeorge syndrome



Vanessa West with her daughter Arianna

Vanessa has put together a visiting program despite not having a children’s hospital to sponsor her group. Her local hospital does perform pediatric heart surgery, and that’s where she visits.

“When I approached the manager of the pediatric intensive care unit, she was thrilled that we would be providing this service to heart families. I wanted visitors

to be available to families going through those very tough days, plus visiting is a great way for people to get involved in MLH.

“A good visitor has to be positive and compassionate because when you are visiting in ICU, you are dealing with a critical situation, and accredited visitors have to be emotionally ready to handle that. I never want a heart family to go through this alone. Talking to family and friends is not the same as talking to a heart mom or dad who truly understands what you are going through.”

THE ROLE MODEL

Lauren Gray, age 37

MLH of Central Virginia



Lauren Gray today and as a heart child

Lauren did not join MLH because she has a child with CHD. Instead she is one of an increasing number of adults who have survived CHD, in her case Tetralogy of Fallot. Her condition required two surgeries and four

catheterizations before she was 17 years old.

“There are 1 million survivors of CHD, so it’s more important than ever for adults with CHD to be involved with groups like MLH. As a survivor I bring a unique point of view. It’s so important for families and heart children themselves to see an adult who started out like them. I think it brings comfort and light to their experience.

“There are 1 million survivors of CHD, so it’s more important than ever for adults with CHD to be involved with groups like MLH.”

– Lauren Gray

“My parents had no support when they were going through having a sick baby. And as a child, I was the only person I knew who had a heart defect. I think it is important that both parent and child know that there is help and hope. I want to serve as an inspiration that a ‘normal,’ productive life is achievable.” ❤️