



Mended  
**Little**  
Hearts



# CHD Lobby Day

## A Huge Success!

**A**my Basken was blindsided when her third child, Nicholas, was born six years ago with a congenital heart defect – and crushed that she couldn't bring her baby home.

“Instead of going home, we began a week-long journey that included three hospitals, a helicopter ride and heart surgery,” she said. “I felt so alone.”

Fortunately, Nicholas recovered. After life began to return to normal, Amy wanted to offer parents of children with heart defects the support she'd so desperately needed herself. She was drawn by Mended *Little* Hearts' solid national structure and strong leadership, so she started a support group in Madison, Wis.

Since the beginning, her focus has been on helping guide MLH into the federal advocacy world. “It's truly a story of a mom on a mission receiving a crash course in politics, and it has been a wild ride,” she said.



**Above left: Jodi Lemacks (left), Senator Herb Kohl of Wisconsin (center), and Amy Basken (right).**

**Right and above right: Michael Crane, leader of MLH of Toledo, Ohio, lobbies for funding for the Congenital Heart Futures Act (CHFA) with Senator Sherrod Brown and others from his area.**



Mended *Little Hearts*, along with the Children’s Heart Foundation and the Adult Congenital Heart Association (ACHA), recently hosted Congenital Heart Lobby Day 2011: One Day, One Message, One Voice, in Washington D.C.

“This is a terrific example of organizations getting together and making a difference,” said Jodi Lemacks, national program director for Mended *Little Hearts*. “Our lobby day brought together doctors and patients, as well as parents and families who have lost kids to congenital heart disease. It was a very successful event, and the energy was wonderful.”

“We make a great trio,” Jodi said. “The Children’s Heart Foundation focuses on research, ACHA focuses on adults and advocacy, and MLH provides support.”

This is MLH’s third year to participate.

“With a focus on advocating for funding for research

and data collection, MLH invited nine group leaders and experienced advocates to join the team in Washington, D.C.,” Amy said. “We visited 64 members of Congress, sharing our stories and our passion for the fight against congenital heart disease.”

Amy and Jodi know firsthand that those stories can make a powerful difference.

The Congenital Heart Futures Act, the first CHD-specific legislation, was passed into law in March 2010, as an amendment to the Healthcare Reform Act. This happened just 12 months after it was introduced — despite cautions that it could take five to 10 years.

The legislation was drafted by the member organizations with assistance from federal lobby organizations. It calls for Centers for Disease Control and Prevention (CDC) funding to enhance pediatric data collection and develop an adult surveillance system to

study congenital heart disease across the lifespan. It also calls for National Institutes of Health funding for congenital heart disease research.

“This is a remarkable accomplishment – and it’s the result of incredible legislative and advocate support,” Amy said.



But more work is needed to see the Congenital Heart Futures Act implemented. That’s because it hasn’t been funded – \$3

million is needed for the CDC to enhance pediatric and adult surveillance of patients with congenital heart disease.

The CDC is contributing to MLH’s progress, according to Amy, by stepping up to recognize the acute needs of patients with congenital heart disease. In its 2014 priorities, congenital heart disease prevention, early detection and lifelong surveillance are noted.

### **Consortium makes vital heart-health information available**

The CDC has also created the Congenital Heart Public Health Consortium, which is making a difference by educating the public about heart disease. MLH and other leading heart-related organizations and federal agencies are working together to address public health issues like data collection, awareness, screening and advocacy. It’s the first time all of these groups have come together, and their knowledge is invaluable, Jodi said.

The consortium, which organized in 2009, has a Web site in the works. It will help inform and involve more people regarding congenital heart disease issues by providing important public health messaging and updates on the group’s initiatives. With seven working committees, members actively work on public health issues related to CHD.

“It astounds me every time I’m part of it,” Jodi said. “We’ve been waiting forever for someone to take CHD seriously, and this group is really getting things done.”

## **Congenital Heart Lobby Day 2011: One Day, One Message, One Voice, in Washington, D.C.**

Our voices are being heard! Mended *Little* Hearts invited advocates whose legislators were on the budget subcommittee making decisions about health care issues to participate in Congenital Heart Lobby Day. As a team, they visited and shared their passionate stories with 64 members of Congress. These group leaders and experienced advocates joined the team:

### **Sean Pietras – Connecticut**

After losing his son to congenital heart disease, Sean was inspired to make a difference in his memory. He is starting an MLH group in Connecticut, and he joined the team in Washington, D.C. to share how research and better data may have saved his son.

### **Julie Ostiguy – Rhode Island**

Julie is an experienced Lobby Day advocate who also shares a powerful story of loss. Active in her MLH group, she advocates to save the lives of other children.

### **Michael Crane – Ohio**

Michael’s son was born with an undiagnosed congenital heart defect, requiring Michael and his son to fly by airplane to another hospital for treatment. Michael vividly recalls the agony this disruption caused and seeks to help others who may be going through similar situations.

### **Natasha Durham – Alabama**

Natasha knows too well the life of a mother of a child with congenital heart disease. Leaving her baby in someone else’s care for the first time, she joined us in Washington, D.C., to share her story of hope. She hopes that continued research and data collection lead to a better understanding for the future of her child.

### **Mary Adair – Texas**

Mary is an experienced MLH leader, having worked with the San Antonio group since its inception. She inspired the group through her words at the Lobby Day welcome reception before taking the Texas legislators by storm.

### **Leah Helms – Mississippi**

MLH understands the needs of parents who have lost children to CHD. Leah is working to spread awareness about the need for more research.