

Congenital Heart Defect Advocacy Day 2013 — **Another HUGE Success**



Virginia advocates with Senator Tim Kaine.

On March 19, 2013, Mended *Little Hearts* members set out once again in Washington D.C., with our partners from the Adult Congenital Heart Association and American College of Cardiology (ACC) to talk to Congress members about congenital heart defect (CHD) research, data collection and a CHD Caucus. CHDs are the most common birth defects in the United States, affecting about 40,000 babies each year, yet research is severely underfunded, and necessary data about this population is not available. More than 100 advocates from 26 states came to help educate Congress so that people living with CHD can live longer and be healthier.

To prepare advocates for their day on the Hill, the Adult Congenital Heart Association conducted a mandatory training session Monday afternoon. Dr. Jim Fasules, Senior Vice President of Advocacy for the American College of Cardiology, gave advocacy tips and an update on issues advocates face when trying to get funding for bills.

On Monday evening, the American College of Cardiology (ACC) graciously hosted a reception for the advocates at Heart House. Speakers were Dr. Gerard Martin of Children's National Medical Center and the ACPC Section of ACC, Andrea Himmelberger of Mended *Little Hearts*, and Amy Verstappen, President and CEO of

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the Adult Congenital Heart Association. Andrea spoke about how empowering it is to tell your story to legislators and to feel like you are truly making a difference. She also shared some of her story about her son, Drew, who was diagnosed with CHD after birth — a huge shock to their family.

Mended *Little* Hearts would like the National Institutes of Health (NIH) to direct more funding to CHD research so that children with CHD not only survive into adulthood, but have a normal lifespan. Currently, CHD is the leading cause of



Andrea Himmelberger tells her story.

birth defect-related deaths for children under one year, and it causes premature death and severe illness in children of all ages and adults. Twice as many children die from CHD than from all forms of childhood cancer combined, yet CHD gets about 1/5 of the research funding. NIH currently funds the

Pediatric Heart Network, and we would like for them to be able to expand that program. (For more information, see CHD Resources on the MLH website.)

MLH would also like the Centers for Disease Control and Prevention (CDC) to do more studies on the CHD population to help determine what problems are occurring with CHD children and adults. Hopefully, this will allow us to prevent the problems with early intervention, rather than trying to fix a problem that has already happened and is causing serious illness. The CDC has made CHD a priority, and MLH wants to support the work they are doing and allow them to expand it.

Stay tuned as we continue advocating in Washington, D.C., and at home for issues that affect those living with CHD. Join our Advocacy Facebook page to learn more. ❤️

more smiles, *less trials*



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Hearts

A program of The Mended Hearts, Inc.

1 in 110 children will be born with a heart defect this year.
It is a lifelong journey and Mended *Little* Hearts
can help you navigate your way.

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