

**Adult
Congenital
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Association**

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Testimony of

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Before the

Committee on Energy and Commerce; Subcommittee on Health

on

“Examining Legislation to Improve Public Health”

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DISCLAIMER: The following testimony outlines my personal position and should not be attributed to my employer, the Substance Abuse and Mental Health Services Administration.

This testimony was prepared on my personal time without using any of my employer's resources.

Chairman Pitts, Ranking Member Green and distinguished members of the Subcommittee. My name is Brian Altman and I am a 41 year old living with congenital heart disease (CHD). In addition to being an adult with CHD, I am a former member of the Board of Directors and Public Policy Chair of the Adult Congenital Heart Association (ACHA). I appreciate the opportunity to provide testimony on behalf of ACHA whose mission is to improve and extend the lives of the millions born with heart defects through education, advocacy and promoting research.

My Story

I was born in 1975 with transposition of the greater arteries and a ventricular septal defect. To my parents, that was a diagnosis that brought tears to their eyes and at the time likely meant death for me at a very early age. In the short term, the diagnosis meant that I was a blue baby who needed to be rushed out of state for care. We lived in Tulsa, Oklahoma which at the time did not have highly skilled pediatric cardiologists. So, at two weeks old I was taken to Texas Children's Hospital where I received care until approximately 2003. During those years, I was very fortunate compared to many I know with CHD.

First, I had loving parents with private health insurance. Second, I "only" had three surgeries, "only" one of which was an open heart surgery. Third, by all accounts my open heart surgery, performed by the world renowned Dr. Denton Cooley, was a success and I was "fixed." Finally, at 28 years old as my pediatric cardiologist ensured that I was not lost to care and handed me over to a new type of provider, an adult congenital heart specialist. For the last 13 years, I have been fortunate to continue to receive specialty care at Children's National Medical Center and Boston Children's Hospital.

However, through ACHA and my doctors I know I was not “fixed” for life, my birth defect is a chronic illness and most individuals with my condition born in the 1970s are no longer alive. There are also many things which are unknown to me. First, because of a lack of research and surveillance about lifelong outcomes for adults with CHD until the Congenital Heart Futures Act passed in 2010, no doctor, researcher or epidemiologist can tell me the average lifespan of a person with my birth defects. Similarly, no one knows what types of other conditions are most prevalent among adults living with a “mustard procedure,” the type of open heart surgery I had. So, years later when I developed generalized anxiety disorder, atrial tachycardia, and a leak in my tricuspid valve, these conditions were not ones that were easily predicable, despite CHD being the most common birth defect in America. As a result, I have been on costly medications and had a second open heart surgery last year.

For me, my CHD means I try to live each day to the fullest. I’ve studied hard, engaged in a career that advances public health policy and built a family I love with all my being. But it also means I have no idea if I will be alive to see my daughter graduate from high school or college, if I will get to walk her down the aisle when she gets married, or if I will get to hold hands with my husband in a nursing home.

ACHA

ACHA has been a life changing organization for me and so many other adults with CHD. From its founding, it has been dedicated to supporting individuals and families living with congenital heart disease and advancing the care and treatment available to our community. ACHA provides resources I did not even realize I needed such as a travel directory of Adult Congenital Heart specialty programs. I carry this with me wherever I go so if something

happens while away on work travel or vacation, I can be taken to specialists who know my conditions and the reason my EKG and heart look and sound the way they do. ACHA listens not just to patients or providers, but ensures that we are all working together to foster the best research, provide the best care and support each other through surgeries, rehabilitation and unfortunately too often death. ACHA thinks strategically about the next steps forward in care provision, patient support and advocacy. With this in mind, the ACHA provides webinars aimed at providers and patients and hosts a conference with tracks for both, but key sessions that bring the providers and patients together. ACHA formed the Heart to Heart Ambassadors program to help patients and families have a peer support network. And, ACHA is on the forefront of ensuring high quality care by recently launching an accreditation program. This program is crucial for advancing and standardizing the quality of care for ACHD. Every person with CHD needs access to specialized care regardless of where they live. Finally, ACHA has lead the way in advocacy for adults with CHD.

Congenital Heart Futures Act

Because of what I have lived through and the many amazing doctors, nurses, individuals living with CHD, those I have known and lost and their families, I dedicated many hours to ensuring passage of the Congenital Heart Futures Act. The law ensures that the federal government dedicates research, surveillance and awareness to CHD not just as a birth defect, but as a chronic disease that thankfully individuals live with into their forties, fifties and beyond. Even as I fought for passage six years ago, on every visit to offices such as yours I noted the bill and the vital programs it authorized were not for me. Rather, the law and hopefully reauthorization of the law will ensure that those younger than I will know and understand what

steps they and their health care providers can take to ensure they not just live as long as possible, but to thrive in their life.

I am thankful for the efforts the Centers for Disease Control and Prevention and the National Institutes for Health have taken so far and know so much more can be learned and so many more individuals can be reached. I am appreciative of the funding that Congress has provided for the programs authorized by the law and know the funding is vital to keep the research going and the registries up to date.

Conclusion

I appreciate the key members of Congress who have supported the Congenital Heart Futures Act including Representative Bilirakis, Representative Schiff and in the Senate the CHD's tireless champion, Senator Richard Durbin. Thank you for holding this legislative hearing on the Congenital Heart Futures Reauthorization Act. On behalf of ACHA and its members, I look forward to passage of this important bill so that we will have the science, surveillance, outreach and education to help individuals with CHD live and thrive.