

**Statement for the Record**

**In support of**

**H.R. 3952**

**“The Congenital Heart Futures Reauthorization Act of 2015”**

**Submitted to the Subcommittee on Health  
House Committee on Energy and Commerce**

**Submitted by:**

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**Ann & Robert H. Lurie Children’s Hospital of Chicago, IL**

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On behalf of the Ann & Robert H. Lurie Children's Hospital of Chicago, the millions of people with congenital heart disease, or CHD, the health professionals who care for them, and the Pediatric Congenital Heart Association, Children's Heart Foundation, American Heart Association and Adult Congenital Heart Association that represent them, I want to offer my strong support for H.R. 3952, the Congenital Heart Futures Reauthorization Act of 2015.

I wish to thank Representative Bilirakis and Representative Schiff for their steadfast leadership as sponsors of this bipartisan effort to build upon existing programs which track the epidemiology, raise the awareness of and promote lifelong research on the most common birth defect. Thank you, also, to the dozens of congressional cosponsors committed to this goal. I also want to express my appreciation to Chairman Pitts and Ranking Member Green for holding this hearing, providing the opportunity to move this important bill toward enactment.

Lurie Children's, the 6<sup>th</sup> ranked Children's Hospital nationally by US News and World Report, is the largest provider of pediatric specialty care in Illinois, as well as serving children from all fifty states and 46 countries. The Heart Center at Lurie Children's provides the highest quality care for patients with the most complex and serious heart conditions. As the region's largest children's heart center, we care for more patients with cardiac conditions than any other hospital in the state of Illinois, treating more than 10,000 patients with congenital and acquired heart disease each year. Lurie Children's also provides more pediatric Medicaid services than any other hospital in the State of

Illinois. On average, 55 to 60% of the beds in our hospital hold a child that is insured by Medicaid.

As a practicing pediatric cardiac intensivist, epidemiologist, and outcomes researcher for more than 20 years, I have borne witness to the catastrophic results of CHD on affected children and their families. As the national Chair for the American Heart Association Council for Cardiovascular Disease in the Young, Chair for the Pediatric Congenital Heart Association Medical Advisory Board and the Chair for the 36 institution Cardiac Neurodevelopmental Outcome Collaborative, I can attest that CHD has a lifelong impact. However, critical information about the epidemiology of CHD, the effectiveness of treatments, and lifelong outcomes is seriously lacking, at best, and non-existent in specific areas such as secondary sequelae of CHD.

Over the last several decades, advances in surgical techniques, intensive care, imaging, and medical therapies have dramatically lowered mortality rates for children with the most complex CHD and increased the life expectancy of adults with CHD. Survival is now expected, with long-term survival rates (>20 years) estimated at 80% in the current era. In the absence of US data, which the Congenital Heart Futures Reauthorization Act will address, extrapolation of Canadian data suggests that there are currently more than 1.3 million adults with CHD in the US. This prevalence is expected to increase 5% annually, resulting in a burgeoning population of CHD survivors who need life-long specialized cardiac care. Although the growing population of individuals with CHD is a testament to important innovations in CHD care, the reality is that

complex CHD and its treatments may result in important complications including persistent valvular or heart muscle issues that may require further surgery, catheter-based intervention, or heart transplantation, abnormal heart rhythms that may require the placement of a pacemaker, and important kidney, liver, and neurodevelopmental problems. In short, the interventions children with CHD receive are not cures, underscoring the need for children and adults with CHD to have lifelong care by expert providers to avoid health complications later in life.

One of the biggest issues we face is transitioning care for individuals with CHD from pediatric to specialized adult cardiovascular care. As the Director of the Cardiovascular Bridge Programs at Lurie Children's and Northwestern Memorial Hospital, I see first-hand, each day, the lack of infrastructure, systems, providers and payors required to care for the ever increasing adult congenital heart disease population. Adding to this challenge are those patients who no longer seek care believing their childhood intervention has "cured" them, or that they are well enough to no longer need specialized cardiac care. Estimates suggest less than 25% of adults with CHD are receiving appropriate subspecialty care. This population of patients who are lost to follow-up care present a critical public health issue, which will be addressed by this important legislation.

The incidence and prevalence of heart failure in the CHD survivor population is dramatically increasing with a dearth of well-tested and approved heart failure medications, mechanical ventricular assist devices, devices specifically sized and tested

for use in the cardiac catheterization laboratory, and organs for heart transplantation. In addition, congenital heart survivors can face debilitating, ongoing neurodevelopmental issues. Cardiac surgery and perioperative treatments in the infant put the developing brain at tremendous risk for injury and long-term neurodevelopmental complications. Survivors often suffer injury to the brain due to chronic or intermittent low oxygen levels, decreased brain blood flow, and/or reperfusion injury related to the abnormalities of their circulatory systems and the medical and surgical therapies they have received. These brain injuries result in worse neurodevelopmental, psychosocial, and physical functioning, and can significantly negatively impact the individual's quality of life.

In fact, recent studies have shown that individuals with complex CHD have an increased risk for neurodevelopmental impairment across a broad range of domains, including intelligence, school achievement, language, visual processing, memory, attention, executive functioning (organization, planning, and task-management), and fine and gross motor skills. In addition, a disproportionate number of these patients have significant behavioral or emotional problems, including ADHD, anxiety, depression, and post-traumatic stress symptomatology. Many school-age survivors of infant cardiac surgery require remedial services including tutoring, special education, and physical, occupational, and speech therapy. Up to 1/3 of complex CHD survivors will require some form of special education or learning supports. As adults, individuals with CHD are less likely to be employed and reach economic self-sufficiency than the general population.

People born with CHD require lifelong, costly, specialized cardiac care, and face an ongoing risk of permanent disability and premature death. As a result, healthcare utilization among the CHD population is disproportionately higher than the general population. It is estimated that compared to medical costs of care for their peers, the medical costs for individuals with CHD are 10 to 20 times as great. Inpatient care costs (not including costs of physician care) for patients < 21 years old with CHD alone totaled more than \$5.6 billion in 2009, representing 15 percent of hospitalization costs for all patients in this age range. Around half of all dollars spent on pediatric CHD related inpatient stays is paid by Medicaid.

Hospital admissions for adults with CHD roughly doubled between 1998 and 2005. Nearly 20% of these admissions were for cardiac surgery or catheter-based intervention. Healthcare utilization and costs continue to rise, due to hospital admissions, cardiac and non-cardiac surgery, and emergency room visits. For example, with improved longevity to childbearing age, the number of high risk annual births in women with CHD is increasing. Childbearing women with CHD are fourteen times as likely to experience cardiovascular complications during pregnancy and are eighteen times as likely to die from such complications as are women without CHD. They also have longer hospital stays and incur higher hospital charges.

With disproportionate medical costs and, it is critical for us to understand the life-course of those living with CHD, their health care utilization and potential cost reduction strategies.

Before us, we have a reasonable and meaningful solution. To improve care and reduce costs, it is essential that Congress enacts legislation supporting improved understanding of CHD across the lifespan. The Congenital Heart Futures Reauthorization Act of 2015 (CHFRA) calls for improved public health research and surveillance that will help us better understand and improve long-term outcomes for the more than 40,000 babies born with CHD each year.

Previous Congressional investment for CHD activities supported by the Centers for Disease Control and Prevention's (CDC's) National Center on Birth Defects and Developmental Disabilities (NCBDDD) has funded the development of innovative surveillance strategies among children, adolescents and adults with CHD. This has led to the standardization of research methods and an increased understanding of the public health burden of this condition. Since the enactment of the Congenital Heart Futures Act in 2010, Congress has appropriated nearly \$15 million to NCBDDD for these activities. Continued federal investment is necessary to provide rigorous epidemiological and longitudinal public health surveillance and public health research on individuals across the lifespan to better understand CHD at every age, improve outcomes and reduce costs.

The Congenital Heart Futures Reauthorization Act of 2015 (CHFRA) continues and builds upon these important activities.

**The reauthorization bill assesses the current bio-medical research needs and projects related to CHD across the lifespan.** It directs the National Institutes of Health (NIH) to provide a report on its current research into CHD. This will provide a better understanding of the state of bio-medical research to improve understanding of causes and drive innovative and effective treatments for CHD and related disease processes.

**The Congenital Heart Futures Reauthorization Act fills a critical gap and expands public health research on CHD.** The legislation directs the CDC to plan, develop and implement a representative cohort study to help describe basic U.S. demographics of the disease, assess healthcare utilization, and develop evidence-based practices and guidelines for CHD care. Once this data is collected, we will no longer have to rely on statistics from Canada to describe the burden of CHD in the United States.

**The Congenital Heart Futures Reauthorization Act raises awareness about the specialized cardiac care needs of those with CHD across the lifespan.** The bill directs the CDC to establish and implement an awareness, outreach and education campaign aimed at ensuring that those with CHD receive appropriate care across the lifespan. With this critical educational campaign, individuals with CHD and their families will better understand their life-long healthcare needs and the necessity of receiving appropriate lifelong specialized cardiac care.



Congenital heart disease is common, costly and a critical public health issue. On behalf of Ann & Robert H. Lurie Children's Hospital of Chicago, the Pediatric Congenital Heart Association, the Children's Heart Foundation, the American Heart Association, and the Adult Congenital Heart Association, I want to thank the many members of Congress who join me in support of H.R. 3952, the Congenital Heart Futures Reauthorization Act 2015. It is essential that Congress pass this legislation, to provide improved care, outcomes and quality of life for the millions of individuals with CHD.

Thank you for your time and consideration.

## **Summary of Written Testimony for Dr. Bradley Marino:**

Congenital heart disease (CHD) is the most common birth defect, for which there is no cure. Advances in early detection and intervention are resulting in increased survival. However, individuals born with CHD require lifelong, costly, specialized cardiac care, and face an ongoing risk of permanent disability and premature death.

With disproportionate medical costs and nearly half of all dollars spent on inpatient stays paid by Medicaid, we must take measures to understand the life-course of CHD, health care utilization and cost management opportunities.

Before us, we have a reasonable and meaningful solution. This legislation will support improved understanding of CHD across the lifespan, which will improve care and reduce costs.

The Congenital Heart Futures Act Reauthorization builds upon previous Federal investment to:

1. Assess current bio-medical research needs and projects related to CHD across the lifespan at the NIH;
2. Authorize rigorous epidemiological and longitudinal surveillance of people with CHD throughout the lifespan at the CDC;
3. Lead an education and awareness campaign to raise attention to the public health burden of CHD across the lifespan.

CHD is common, costly and a critical public health issue. It is essential that Congress pass H.R. 3952, the Congenital Heart Futures Reauthorization Act 2015, to provide improved care, outcomes and quality of life for the millions of individuals with CHD.