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**Congress of the United States**  
**House of Representatives**  
Washington, DC 20515

**Statement for the Record Prepared by Congressman Andy Barr (KY-06)**  
**Submitted to the House Committee on Energy and Commerce**  
**Subcommittee on Health**

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Thank you, Chairwoman Eshoo, Ranking Member Guthrie, and Members of the Health Subcommittee of the Committee on Energy and Commerce for holding this hearing on Enhancing Public Health: Legislation to Protect Children and Families. I appreciate the opportunity to submit this statement for the record today.

Since coming to Congress, I have long been a supporter of legislation that supports scientific research to improve health and save lives. However, these efforts became much more personal to me when I tragically lost my beloved wife Carol to sudden cardiac arrest on June 16, 2020. She was only 39 years old.

Carol's greatest legacy was our two beautiful daughters, Eleanor (age 10) and Mary Clay (age 8). She was the best wife, mother, daughter, sister, and friend anyone could ever have. Carol was also my rock and helper, my best friend and supporter in all that I did, both professionally and personally. So, the void she leaves behind is enormous and painful.

The medical examiner and Carol's doctors told us that her fatal heart attack was likely brought on by a ventricular arrhythmia. At a young age, Carol had been diagnosed with an underlying condition called mitral valve prolapse (MVP), or floppy valve syndrome—a typically benign condition that results in sudden cardiac death (SCD) in only .2% of cases. The American Heart Association reports that isolated MVP and SCD predominantly affects young females with redundant bileaflet prolapse, with cardiac arrest usually occurring as a result of ventricular arrhythmias.

According to the National Heart, Lung, and Blood Institute (NHLBI), heart valve disease occurs if one or more of your heart valves do not work well. Many people in the United States have heart valve defects or disease but do not have symptoms. For some, the condition remains the same throughout their lives and does not cause significant or life-threatening problems. Unfortunately, over 25,000 people die each year in the United States from heart valve disease, primarily due to underdiagnosis and undertreatment of the condition.

The specific condition that Carol was diagnosed with, MVP, is a common heart valve disease that has an estimated 2.4% prevalence in the general population. Though most cases are thought to be benign, reported complications such as severe mitral regurgitation can result in SCD. Medical research has found an association between MVP and SCD. Predictors of this outcome, however, are not readily available, underlying mechanisms are poorly understood, and indicators

of high-risk individuals are lacking. Despite several studies, there is not sufficient data to generate prescriptive guidelines for care of patients with valvular heart disease, including MVP.

That is why, inspired by the extraordinary life of my wife Carol, I introduced H.R. 1193, the Cardiovascular Advances in Research and Opportunities Legacy Act (CAROL Act). I worked closely with Dr. Gary Gibbons and his team at the NHLBI in addition to other experts and specialists to ensure our efforts would be fruitful and properly respond to the needs to complete this vitally necessary research.

The CAROL Act will address the gaps in understanding about what risk factors make valvular heart disease a potentially life-threatening condition. More specifically, the bill will authorize a grant program, administered by the NHLBI, to support research on valvular heart disease, including MVP. In particular, the research will advance technological imaging and precision medicine to generate data on individuals with valvular heart disease, identify a cohort of individuals who are at high risk of sudden cardiac death, and develop prediction models for high-risk patients, enabling interventions and treatment plans to help keep these patients healthy throughout their lives.

Additionally, the legislation will convene a working group of subject matter experts to identify research needs and opportunities to develop prescriptive guidelines for treatment of patients with MVP.

It will also instruct the Centers for Disease Control and Prevention (CDC) to increase public awareness regarding symptoms of valvular heart disease and effective strategies for preventing sudden cardiac death.

Though there is some ongoing research at the NHLBI on valvular heart disease, and specifically MVP, this legislation and the \$20 MIL figure go to the expansiveness of the research needed to examine the risk factors associated with valvular heart disease and sudden cardiac death and develop prediction models and guidelines for high-risk patients.

The CAROL Act has garnered the bipartisan support of 167 Members of Congress including many on this Committee. Additionally, companion legislation was introduced in the Senate by Minority Leader Mitch McConnell and Senator Kyrsten Sinema. Finally, the CAROL Act has the support of over 20 medical groups including the American Heart Association, the American College of Cardiologists, and WomenHeart.

The CAROL Act invests in critical research to identify patients at high risk of bad outcomes from valvular heart disease. I am so grateful to so many of my colleagues on both sides of the aisle for their support in this legislative effort to help other families avoid the tragedy that has so profoundly impacted mine.

Sincerely,



Andy Barr  
Member of Congress