Dear Chair Murray and Ranking Member Burr,

We are writing to express our support for the Cardiovascular Advances in Research and Opportunities Legacy (CAROL) Act (HR 1193/ S 1133). As organizations that represent and advocate for patients living with heart disease, we urge the passage of this legislation that will advance our understanding and promote awareness of heart valve disease, a condition that kills approximately 25,000 people each year. The CAROL Act will also help increase the chances of survival for more than 350,000 Americans who experience an out-of-hospital cardiac arrest, like Congressman Andy Barr’s wife, Carol Barr, who tragically lost her life in 2020 at the age of 39 due to sudden cardiac arrest.

The CAROL Act authorizes funding for the National Heart, Lung, and Blood Institute (NHLBI) to conduct life-saving research on heart valve disease and to convene a workshop on a degenerative heart valve condition called Mitral Valve Prolapse (MVP). This investment will help address gaps in our understanding of heart valve disease, including what causes sudden cardiac death in a small number of people, predominantly women, due to MVP. Patients with Mitral Valve Prolapse are at least three times more likely than the general population to experience a sudden cardiac arrest, with an estimated 26,000 individuals in the United States living in jeopardy. Thus, identifying risk reduction strategies for those with MVP is imperative.

The CAROL Act also invests in education efforts to broaden awareness of the risk factors and symptoms of heart valve disease and in efforts to increase screening, detection, and diagnosis of heart valve disease. Many people living with heart valve disease, particularly women, are never diagnosed or they are diagnosed later in the course of the disease, leading to missed opportunities for treatment. It is important for both the public and clinicians to be aware of patients’ risk for valve disease, to recognize the symptoms, and to have an accurate and timely diagnosis. Earlier detection and diagnosis can lead to earlier treatment before the onset of worsening symptoms.

Finally, the CAROL Act includes a vital provision that would help prevent the tragic loss of life caused by sudden cardiac arrest by authorizing resources to expand nationwide the Cardiac Arrest Registry to Enhance Survival (CARES). Out-of-hospital cardiac arrest registry data collection is critical to improving patient care and survival rates. It allows communities and public health organizations to monitor the quality of care, compare patient populations, measure interventions and outcomes, and ascertain whether resuscitation is provided according to evidence-based guidelines. Without uniform and reliable data collection in every state, communities cannot ascertain the effectiveness of their sudden cardiac arrest response systems, nor can they assess the impact of interventions designed to improve survival rates.
Thank you for recognizing the impact of heart valve disease on millions of people across the country and for your leadership in advancing solutions that will improve heart health and increase the chances of survival for victims of sudden cardiac arrest. We look forward to working with you to pass this legislation.

Sincerely,

American Heart Association
American College of Cardiology
WomenHeart: The National Coalition for Women with Heart Disease

Cc: Minority Leader Mitch McConnell
    Senator Kyrsten Sinema
    Representative Andy Barr