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Subcommittee on Health**

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Chairman Guthrie, Ranking Member Eshoo, and Members of the Health Subcommittee of the Committee on Energy and Commerce, thank you for the opportunity to testify today on behalf of the American Heart Association and its more than 40 million volunteers and supporters. My name is Gordon F. Tomaselli, M.D. I am the Marilyn and Stanley M. Katz Dean, Emeritus and a Professor of Medicine at Albert Einstein College of Medicine. I am also an Adjunct Professor of Medicine at Johns Hopkins Medical School where I was a faculty member for 29 years and served as the Chief of the Division of Cardiology and co-Director of the Heart and Vascular Institute for 12 years. As an expert in the fields of sudden cardiac death and arrhythmias, my research focuses on ion channel structure, function and remodeling. My lab has been continuously funded by the National Institutes of Health (NIH) for more than 30 years. I hold several patents on methods to improve heart function and prevent arrhythmias, including an implantable device for the delivery of cell-derived biomolecules.

I am the former President of the American Heart Association (2011-2012), where I served as the chief volunteer scientific and medical officer, responsible for the oversight of all medical, scientific, and public health matters, and those related to public policy. As a volunteer with the American Heart Association for more than 30 years, I have been proud to advance the organization's mission to be a relentless force for a world of longer, healthier lives.

Although my interest in cardiovascular disease and science was codified early in my medical training, a personal connection to heart disease galvanized my career track. At the age of 49, my mother who was suffering from dilated cardiomyopathy experienced a cardiac arrest, fortunately she was resuscitated but continued to suffer from life-limiting heart failure. She underwent cardiac transplantation which allowed her to enjoy nearly two decades of a full life.

Now celebrating our 100<sup>th</sup> year, the American Heart Association is the largest nonprofit funding source for cardiovascular and cerebrovascular disease research, next to the federal government. We have funded 14 Nobel Prize winners and several important medical breakthroughs, including techniques and standards for cardiopulmonary resuscitation (CPR), the first artificial heart valve, implantable pacemakers, cholesterol inhibitors, microsurgery, and drug-coated stents. The American Heart Association is also the largest and most experienced provider of CPR training—training millions of individuals, first-responders, and health care workers worldwide each year through a vast network of more than 3,500 Authorized Training Centers and more than 400,000 instructors.

Today I am pleased to testify about the ways in which the bills under your consideration, namely the **Cardiomyopathy Health Education, Awareness, Research, and Training in the Schools Act of 2023 or HEARTS Act (H.R. 6829)** and the **Congenital Heart Futures Reauthorization Act of 2024 (H.R. 7189)**, would improve the safety of students at school and improve the health of those afflicted with congenital heart disease.

The American Heart Association thanks Ranking Member Frank Pallone, Jr. for his work to champion The HEARTS Act, which will help improve the safety of our schools and ensure that students, faculty, and staff are prepared to respond quickly and effectively to a sudden cardiac arrest (SCA) in classrooms and on school playing fields. This legislation requires the

Secretary of Health and Human Services (HHS) to coordinate with the Centers for Disease Control and Prevention (CDC), patient groups, and health professional organizations to develop educational materials and resources on cardiomyopathy, a leading cause of disability and sudden cardiac death among young people,<sup>1</sup> and distribute them to school districts across the country. It also calls for guidelines regarding the placement of AEDs in schools and childcare centers, and the establishment of CERPs, as well as information on CPR training.

In addition to the HEARTS Act, the American Heart Association strongly urges Congress to pass the bipartisan Access to AEDs Act, which would authorize critical resources needed to implement many of these lifesaving policies. Together, these policies would increase CPR and AED training and availability of AEDs on elementary and secondary school campuses and support the development of CERPs that establish specific steps to reduce death from cardiac arrest in school settings.

Annually, more than 350,000 individuals in the United States experience an Out of Hospital Cardiac Arrest (OHCA), with only 1 in 10 surviving this life-threatening event.<sup>2</sup> More than 23,000 such events happen to children under the age of 18 every year,<sup>3</sup> making these preventable tragedies the leading cause of death for high school athletes. Many times, these students may not know they have an underlying heart condition. In younger children, SCA is more often from a secondary (noncardiac) origin, such as respiratory difficulties. In older children and adolescents, SCA is more often from underlying (congenital) conditions, including

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<sup>1</sup> Gajewski, Kelly K; Saul, J Philip1,. Sudden cardiac death in children and adolescents (excluding Sudden Infant Death Syndrome). *Annals of Pediatric Cardiology* 3(2):p 107-112, Jul–Dec 2010.

[https://journals.lww.com/aopc/fulltext/2010/03020/sudden\\_cardiac\\_death\\_in\\_children\\_and\\_adolescents.2.aspx](https://journals.lww.com/aopc/fulltext/2010/03020/sudden_cardiac_death_in_children_and_adolescents.2.aspx)

<sup>2</sup> Heart Disease and Stroke Statistics—2023 Update: A Report From the American Heart Association  
<https://www.ahajournals.org/doi/10.1161/CIR.0000000000001123>

<sup>3</sup> Okubo M, Chan HK, Callaway CW, Mann NC, Wang HE. Characteristics of paediatric out-of-hospital cardiac arrest in the United States. *Resuscitation*. 2020 Aug;153:227-233 <https://pubmed.ncbi.nlm.nih.gov/32348794/>

hypertrophic cardiomyopathy, coronary artery abnormalities and others.<sup>4</sup> As advances in the care of children with congenital heart disease (CHD) has improved, there are more adults living with and who remain at increased risk for SCA.<sup>5</sup> Although SCA can occur at any time or any location, vigorous exercise often acts as a trigger for lethal arrhythmias, making SCA more common during athletic practices and games.<sup>6</sup>

Sudden cardiac arrest is the unexpected loss of heart function, breathing, and consciousness and is commonly the result of an electrical disturbance in the heart. Early access to 9-1-1 and early CPR are the first two links in the chain of survival for OHCA. For every minute without CPR, chances of survival drop by 10 percent.<sup>7</sup> The average arrival time of Emergency Medical Services (EMS) personnel to an emergency scene is seven minutes,<sup>8</sup> which leaves very little time to successfully resuscitate a cardiac arrest victim. That is why it is critical that bystanders who witness a sudden cardiac arrest are prepared to be the true first responder on the scene.

Lay responders play a crucial role in achieving high survival rates, and more AEDs and CPR training for these individuals are needed to provide this life-saving treatment. In cardiac arrest emergencies where bystanders used AEDs before emergency medical services arrived, patients were more than two and a half times as likely to survive their cardiac arrest and had

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<sup>4</sup> Mozaffarian, D., Benjamin, E. J., Go, A. S., Arnett, D. K., Blaha, M. J., Cushman, M., Turner, M. B. (2015) Heart disease and stroke statistics—2016 update: A report from the American Heart Association. *Circulation*, 133, e268-e278.

<sup>5</sup> Ventricular Arrhythmias in Adults With Congenital Heart Disease, Part I: JACC State-of-the-Art Review, F. Bessiere, et al. *J Am Coll Cardiol* 2023 Vol. 82 Issue 11 Pages 1108-1120 Accession Number: 37673512 DOI: 10.1016/j.jacc.2023.06.034

<sup>6</sup> Hazinski, M. F., Markenson, D., Neish, S., Gerardi, M., Hootman, J., Nichol, G., Smith, S. (2004). AHA scientific statement: Response to cardiac arrest and selected life-threatening medical emergencies. The medical emergency response plan for schools: A statement for healthcare providers, policymakers, school administrators, and community leaders. Published simultaneously in *Circulation*, 109, 278-291; *Pediatrics*, 113, 155-168; *Annals of Emergency Medicine*, 43, 83-99.

<sup>7</sup> Link, M., Atkins, D., Passman, R., Halperin, H., Samson, R., White, R., Kerber, R. (2010). Part 6: Electrical therapies. Automated external defibrillators, defibrillation, cardioversion, and pacing: 2010 American Heart Association guidelines for cardiopulmonary resuscitation and emergency cardiovascular care. *Circulation*, 122(Suppl. 3), S706–S719.

<sup>8</sup> Mell HK, Mumma SN, Hiestand B, Carr BG, Holland T, Stopyra J. Emergency Medical Services Response Times in Rural, Suburban, and Urban Areas. *JAMA Surg*. 2017 Oct 1;152(10):983-984

better functional outcomes than those who did not receive bystander defibrillation.<sup>9</sup>

Unfortunately, currently 90 percent of people who experience cardiac arrest outside of a hospital die, in part because they do not receive CPR more than half of the time.<sup>10</sup>

Despite AEDs being proven as life-saving devices in cardiac emergencies, currently, only 20 states require AEDs to be placed in schools.<sup>11</sup> Even fewer states have programs to help schools purchase these devices. The HEARTS Act together with the Access to AEDs Act would address the discrepancy, ultimately increasing the number of individuals capable of using AEDs in critical situations. Final legislation should include a federal HHS grant program to support CPR and AED training of students, staff, and sports volunteers. It should also support the purchase of AEDs, related equipment, and the development of CERPs, which can help reduce death from cardiac arrest in school settings.

Young people aren't the only age group who benefit from AEDs and CPR training. Sudden cardiac arrest is the leading cause of death for adults over 40—including many teachers, administrators, coaches, and school visitors. Thankfully, properly trained public bystanders and school personnel can make a difference in the crucial minutes between the time when the victim collapses and when emergency medical services arrive.

Ideally, all school staff should be trained in first-aid, CPR and AED use. It is considered sufficient if trained responders, including staff and, in some cases, students, are able to bring emergency equipment to any area of the campus within 90 seconds of a suspected SCA. CERPs

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<sup>9</sup> Pollack RA, Brown SP, Rea T, et al. Impact of bystander automated external defibrillator use on survival and functional outcomes in shockable observed public cardiac arrests. *Circulation*. 2018 May 15;137(20):2104-13.

<sup>10</sup> Association of Bystander and First-Responder Efforts and Outcomes According to Sex: Results From the North Carolina Heart Rescue Statewide Quality Improvement Initiative, 15 Sep 2018, *Journal of the American Heart Association*. 2018;7:e009873

<sup>11</sup> Sudden Cardiac Foundation, CPR and AED Laws, 2022 Review <https://www.sca-aware.org/about-sudden-cardiac-arrest/cpr-and-aed-laws#:~:text=addressing%20AED%20placement-,Schools,Columbia%20require%20AEDs%20in%20schools>.

increase survival rates by more than 50% by empowering trained lay-responder teams to take swift action.<sup>12</sup> Drills are an essential part of effective CERP implementation and enhance emergency preparedness in the event of an SCA. It is also important to work directly with local emergency service providers to integrate the CERP into the community's EMS responder protocols. By implementing comprehensive response plans, we can ensure a coordinated and practiced approach that saves lives. A free American Heart Association CERP toolkit can be accessed at [www.heart.org/cerp](http://www.heart.org/cerp)

CPR education is also crucial in increasing the pool of individuals capable of delivering life-saving interventions. As of 2023, forty states and Washington, DC require CPR training as part of their high school curriculum.<sup>13</sup> Still, there are 10 states that do not require such training. As the sudden cardiac arrest of NFL star Damar Hamlin on national television demonstrated, with proper training, preparation, and resources sudden cardiac arrest victims have a high probability of survival. In fact, if defibrillation is administered within 3–5 minutes of collapse, it can produce survival rates as high as 50%–70%.<sup>14</sup> Unfortunately, in too many circumstances, individuals do not receive the urgent lifesaving help they need because we are woefully underprepared as a nation.

Last month in an American Heart Association Scientific Statement, our Emergency Cardiovascular Care Committee outlined an ambitious goal of doubling the survival from cardiac arrest by 2030.<sup>15</sup> This February, as we observe Heart Month, the American Heart Association is

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<sup>12</sup> American Heart Association. Cardiac Emergency Response Planning for Schools. A Policy Statement. 2016 <https://cpr.heart.org/en/training-programs/nation-of-heartsavers/cardiac-emergency-response-plan>

<sup>13</sup> American Heart Association, CPR in Schools Legislation Map <https://cpr.heart.org/en/training-programs/community-programs/cpr-in-schools/cpr-in-schools-legislation-map>

<sup>14</sup> Travers, A. H., Perkins, G. D., Berg, R. A., Castren, M., Considine, J., Escalante, R., Vaillancourt, C. (2015). Part 3: Adult basic life support and automated external defibrillation. 2015 International Consensus on Cardiopulmonary Resuscitation and Emergency Cardiovascular Care Science With Treatment Recommendations. *Resuscitation*, 95, e43-e70

<sup>15</sup> The American Heart Association Emergency Cardiovascular Care 2030 Impact Goals and Call to Action to Improve Cardiac Arrest Outcomes: A Scientific Statement From the American Heart Association <https://www.ahajournals.org/doi/10.1161/CIR.0000000000001196>

working to turn a nation of bystanders into a Nation of Lifesavers, so that everyone, everywhere is prepared and empowered to become a vital link in the chain of survival and provide CPR and use an AED in response to a cardiac emergency. Congress can support us in these efforts by enacting the HEARTS Act and the Access to AEDs Act to strengthen our schools and communities and provide the necessary resources and support. We hope you will also join the Nation of Lifesavers now by learning CPR yourselves and by encouraging your constituents to do the same. Visit <https://www.heart.org/en/nation-of-lifesavers> to learn more.

The American Heart Association is also pleased to support the Congenital Heart Futures Reauthorization Act of 2024, and we thank Congressman Gus Bilirakis for sponsoring this bill. It is a crucial piece of bipartisan legislation that addresses the pressing need for continued funding and research into congenital heart disease (CHD). This legislation builds upon the initial Congenital Heart Futures Act of 2010, a pioneering effort to allocate resources specifically for CHD research and data collection. The original act facilitated expanded infrastructure at the Centers for Disease Control and Prevention (CDC) and increased research efforts at the NIH, mainly through the Pediatric Heart Network (PHN), aimed at improving the care and understanding of CHD across all ages.

Despite its rarity, the economic burden of CHD is disproportionately high. According to a report released today, the average annual cost of complex congenital heart disease (cCHD) reaches nearly \$50,000 per patient, with more than 45 percent of this financial burden being shouldered solely by patients and their families.<sup>16</sup> Moreover, the average lifetime financial burden for cCHD patients amounts to a staggering \$2.2 million per individual and tragically, the consequences extend to profound human costs, with patients losing an average of 31 years of life

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<sup>16</sup> The Cost of Complex Congenital Heart Disease in the US, Diane Pickles and Kirstie Keller, PhD, 2024.

due to cCHD.<sup>17</sup> As noted previously, many of these deaths are the result of SCA may be prevented by CERPs and access to AEDs.

The urgency for comprehensive action is evident, with 1 in 100 newborns being born with CHD and approximately 25 percent of them requiring interventions in their first year of life, the need for comprehensive research, surveillance, and awareness programs is paramount. Additionally, the lifelong nature of CHD, coupled with the fact that fewer than 10 percent of adults with CHD are receiving recommended care, highlights the necessity for sustained efforts in getting and providing CHD resources.<sup>18</sup> Furthermore, in 2013, adults with CHD had 3–4 times higher rates of Emergency Room visits, hospitalizations, and Intensive Care Unit (ICU) stays, which underscores the importance of preventive measures and the need for improved care protocols.<sup>19</sup>

The Congenital Heart Futures Reauthorization Act of 2024 emphasizes vital aspects crucial for advancing CHD research and awareness in three ways. First, the bill calls for assessing current research needs and projects related to CHD at the NIH, aiming to enhance our understanding of biomedical research in this field. Secondly, the bill directs the CDC to further develop its public health research and surveillance programs, which will aid in understanding healthcare utilization, demographics, and the development of evidence-based practices and guidelines for CHD. Improvement in such aspects, such as screening and surgeries for children born with heart defects, has currently saved thousands of lives and, with new and updated protocols, can increase survival rates even more. Lastly, the bill underscores the importance of raising awareness of CHD throughout individuals' lifespans.

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<sup>17</sup> Ibid

<sup>18</sup> Conquering CHD, Facts and Statistics <https://www.conqueringchd.org/learn/facts-statistics/>

<sup>19</sup> Congenital Heart Defects Frequently Asked Questions, Congenital Heart Public Health Consortium, 2019 [https://www.conqueringchd.org/wp-content/uploads/2020/04/CHD\\_factsheet.pdf](https://www.conqueringchd.org/wp-content/uploads/2020/04/CHD_factsheet.pdf)



There is a clear sense of urgency for implementing the Congenital Heart Futures Reauthorization Act of 2024, considering the statistics associated with CHD and how this act can address it. Overall, the bill represents an effort to tackle CHD comprehensively and improve the quality of life and care for individuals affected by this condition. I thank you for the opportunity to offer my perspective today, and for your continued leadership to improve cardiovascular health and wellness for all. I look forward to your questions.