

Proponent Testimony Template:

Chair Cutrona, Vice Chair Gross, Ranking Member Somani, and members of the Health Provider Services Committee, my name is Rachelle Cook and I want to thank you for allowing me to testify as a proponent of House Bill (HB) 47.

I have a rare disease called CPVT, which is a genetic heart arrhythmia caused by adrenaline. It causes sudden cardiac arrest, and, if untreated, has a 50% mortality rate before age 30. While it is rare, it's not as rare as you may think. It's estimated to occur in approximately 1 in 10,000 people. For perspective, if Ohio Stadium is at maximum capacity, there's probably about 10 CPVT patients there, whether they are diagnosed or not.

For a moment, I'd like to talk about Damar Hamlin.

Every time an athlete collapses during a game, our CPVT Patient Facebook groups almost instantaneously flood with posts asking do you think it was CPVT. Statistically, it's likely not. CPVT is rare, but Sudden Cardiac Arrest is not.

Sudden Cardiac Arrest (SCA) is a life-threatening emergency that is a leading cause of death of children and adults in the US and the number one non-traumatic cause of death in NCAA athletes, representing 75% of fatalities during sports and exercise. For over 30 years, 75-100 seemingly healthy athletes from little league, junior high, varsity and collegiate athletics have died per year due to SCA. The number of athletes who have survived is currently unknown. Overall, between 300,000 and 450,000 Americans die from sudden cardiac arrest every year. Almost 80% of those deaths occurred in the community or in their homes. The American Heart Association has called it "a public health crisis".

This time was different though. We still got those asking if he was "one of us," but mostly, we got posts talking about the mental health toll of witnessing SCA. Truthfully, it's hard to see for us who have had SCAs, and witnessed, or even performed CPR on a friend or family member. It's hard for me personally. It's hard to see someone go through potentially the worst day of their life, especially when it looks a whole lot like yours.

You see, about 10 years ago I was Damar Damlin. I collapsed in a boat while rowing and my teammates saw me, unconscious, with my arms dragging through the water. Thankfully, for all of us, I regained consciousness on my own, but because my event was unwitnessed (I was behind everybody), we have no idea how long I was unconscious. My mom actually took a picture of my boat coming down the racecourse without me, not realizing it was me who was missing until later.

The probability of survival from SCA can be as high as 89% when there is properly administered CPR and use of an AED, like with Damar Hamlin. However, probability of survival drops by up to 10% per minute of delay in treatment. In fact, most deaths from SCA are directly attributable to a delay in treatment. It's recommended an AED be within 2 minutes. Damar Hamlin's survival and recovery is not a miracle. It is the direct result of the College and NFL's dedication

to cardiac safety, where an AED is present at all games and practices, and trained professionals have practices for this exact reason. We can have more survival and better recovery.

I am lucky to be on treatment, however my treatment is not designed for CPVT, and there is always the possibility it may become ineffective at any time. Because Ohio law does not require AEDs to be placed in schools or sports and recreation locations across the state of Ohio, I actually have my own defibrillator that I take with me, and all my friends and family are trained on how to use it. Having an AED in these locations accompanied with the proper training can serve as the difference between life and death when it comes to Sudden Cardiac Arrest. These AEDs also need to be accessible to people in an emergency, not locked in an office. This is bipartisan, commonsense legislation that is absolutely necessary to protect the health and safety of our children and our communities. This bill will save lives and I would encourage you all to be a part of that by voting yes on HB 47. I'm actually not here to advocate for me, I'm here to advocate for my future community members who haven't been diagnosed yet.

Thank you for your consideration,

Rachelle Cook