

The Honorable Senator Kate Lieber Chair Senate Committee on Rules 900 Court St. NE, S-223 Salem, Oregon 97301

The Honorable Senator Tim Knopp Vice-Chair Senate Committee on Rules 900 Court St. NE, S-323 Salem, Oregon 97301

Dear Senator Lieber and Senator Knopp,

As the Founder and CEO of the Hypertrophic Cardiomyopathy Association (HCMA), I would like to take this opportunity to express my sincere thanks for your consideration of HB 4104, a Resolution to be heard today designating "Hypertrophic Cardiomyopathy Awareness Day" as the fourth Wednesday in February each year. I am sorry I could not testify in person as I recently tested positive for COVID and, because I am a heart transplant recipient, it is necessary I take every precaution, including adequate rest, to protect myself and my donor heart.

Hypertrophic Cardiomyopathy (HCM) is the most common heritable heart disease and can affect anyone regardless of age, gender, race, or ethnicity.

HCM causes the heart muscles to thicken and obstruct blood flow, which can lead to symptoms like chest pain, shortness of breath, and fatigue, as well as higher risk of blood clots, stroke, and, in rare cases, cardiac arrest. 1 in 250 people in the general population are estimated to have HCM, with many never receiving a diagnosis. In the state of Oregon this equates to potentially over 21,000 constituents. For more information about the prevalence of HCM in the state of Oregon, please click <u>HERE</u>.

Knowing the signs and symptoms of HCM and one's family history is the first step in receiving an accurate diagnosis.

Many disparities and gaps in care exist for Black patients and female patients diagnosed with HCM. Black patients have greater HCM incidence, younger diagnoses, worse symptoms, and

higher rates of symptomatic heart failure. Despite this, Black patients are underrepresented in HCM studies and referred to subspecialty care and genetic testing less often than white patients.

Women diagnosed with HCM are often older, have more symptoms, and are at higher risk of heart failure compared to men. With later diagnoses and more severe symptoms, female patients may have less HCM treatment options.

Young athletes also face increased risks associated with HCM, as it is the most common cause of cardiac death in young people and competitive athletes in North America. These athletes could be completely asymptomatic prior to a severe cardiac event occurring on or off the field. Awareness and screening for HCM can help Oregon athletes, as well as their families, better understand their risk profile and seek potentially life-saving treatment when necessary.

Designating the fourth Wednesday in February of each year as "Hypertrophic Cardiomyopathy Awareness Day" will help raise public awareness and acknowledge the critical importance of HCM to improve cardiovascular health in Oregon.

Thank you for your kind consideration.

Lisa Salberg Founder and CEO Hypertrophic Cardiomyopathy Association