

Ronnie D. Peterson

September 12, 2023

To: Michigan House Committee on Transportation, Mobility, and Infrastructure – Chair Nate Shannon; Majority Vice Chair Sharon MacDonell; and Minority Vice Chair Pat Outman

Re: Testimony Submitted in Support of House Bill 4308 (2023), Sponsored by Representative Amos O’Neal, House District 94

Good morning, Chairperson Shannon, Vice Chairs, and members of the Committee. I am former House Member Ronnie Peterson from House District 54, Ypsilanti, and it’s good to be back in the House. Even though I’ve only been gone a few months, I miss working with my former colleagues who sit on this committee and friends in the House of Representatives.

I’m truly grateful for the opportunity to testify on behalf of Rep. O’Neal’s House Bill 4308, the Sickle Cell Disease License Plate Fundraising Bill. As some of you may know, I care a lot about people suffering from sickle cell disease, and I’m on a personal mission to reduce the horrible effects of this dreaded condition whenever possible. I showed my commitment while serving as a member of the House when I successfully led the passage of House Bill 5920 (2020), the Sickle Cell Disease License Plate Bill, which was signed into law by Governor Whitmer on December 31, 2020. The bill passed in the House with 103 votes and later in the Senate with 37 votes.

Unfortunately, we passed the legislation at the outset of the COVID-19 pandemic and found it difficult to complete all the administrative requirements and due diligence to fully implement the bill. We did not submit the necessary fees to the Michigan Secretary of State Office because our fundraising efforts were hampered by the constraints posed by the COVID-19 disruption and lockdown. I am happy to report that the Sickle Cell Disease Association of America, Michigan Chapter (SCDAA, MI) is now in a position to satisfy all the requirements of the Secretary of State and can move forward as soon as the bill is enrolled and signed by the governor.

Ronnie D. Peterson

Dr. Wanda Whitten-Shurney MD, CEO and Medical Director of SCDA, MI, could not be with us today to testify because she is speaking at an important Sickle Cell Disease Education Summit in California. She is the expert, and I can't begin to speak on her behalf regarding the terrible effects sickle cell disease has on individuals who inherit the disease from their parents. However, I think it is important that I share a few data points about this terrible disease, the effects it has on patients, and how the SCDA, MI, provides critical services to treat and support sickle cell "warriors" and their families.

The Michigan Department of Health and Human Services considers sickle cell disease a public health priority in its "Public Health Plan to Address Sickle Cell Disease Across the Lifespan. "Sickle cell disease is an inherited red blood disorder affecting 100,000 people in the United States, and over 4,000 individuals in our state are affected by sickle cell disease, predominately African Americans and Hispanics. Red blood cells are round and move through the blood vessels, carrying oxygen to all parts of the body. In someone with sickle cell disease, red blood cells become hard, sticky, and C-shaped, similar to a farmer's sickle. These cells do not move easily through the blood vessels, leading to blocked blood flow. Blocked blood flow can cause terrible pain, damage organs, create life-threatening conditions, and lead to early death. On average, the lifespan of sickle cell disease patients is 30 years shorter than the general population."

Until recently, and for the previous 20 years, there was only one disease-changing medication available to sickle cell patients because pharmaceutical companies had few incentives to pursue better drugs. This problem is improving because several major companies are introducing exciting new drugs and innovative treatment therapies.

Currently, many medical care providers don't understand the full effects of the pain experienced by sickle cell disease patients. When some patients seek care in hospital emergency rooms, they are often not believed to be in severe pain and are accused of being individuals seeking painkillers because of drug addiction. Yet the effects of sickle cell disease on patients are unpredictable and involve intolerable pain when patients suffer a "pain crisis." There are not enough trained medical providers who are adequately skilled and willing to care for adult sickle cell patients in Michigan. As a result, there is a high death rate among sickle cell patients when

Ronnie D. Peterson

they transition to adult care. In addition, the opioid crisis in this country has made access to proper pain medication extremely difficult for sickle cell disease patients who really need it.

The 501(c)3 nonprofit Sickle Cell Disease Center of America, Michigan Chapter, is the only organization in our state working full-time to improve the quality of life, health, and services for individuals living with sickle cell disease and their families. The funds raised by the Sickle Cell Charitable License Plate will be used to ensure that all sickle cell disease patients have access to comprehensive medical treatment from qualified medical providers. The SCDA, MI, will expand investments in wraparound services that provide greater access to community resources and clinical services.

The SCDA-MI has been contracted by the state of Michigan to supply services to sickle cell patients and has been in operation for over 50 years. The association provides educational programming, outreach, advocacy, and care management services. These services may include connecting patients to jobs, medical services, and help with basic needs. The association's ultimate goal is to give hope for a brighter future to those who would not otherwise have one.

Currently, the SCDA-MI receives limited government funding and relies heavily on public and corporate donations. As a former member of the House, I fully understand the challenges in making good choices about which organizations are most worthy of support when there are so many requests and too few options available. In the SCDA-MI, I see an organization that has succeeded in filling a vital need in the community for more than 50 years by generating mostly its own funds and resources. The Sickle Cell Charitable License Plate Bill offers the association the opportunity to continue earning its own way through a program that allows raising additional funds through the organization's own efforts to promote and market the plate to supporters and potential donors. I hope the committee agrees and moves this critically important Bill to the House for passage. Thank you for your time and consideration.