## WRITTEN TESTIMONY ON SENATE BILL 1188

## Testimony offered on behalf of: Sickle Cell Coalition of Maryland in support of SENATE BILL 1188

March 31, 2022

RE: Services to Treat and Educate Marylanders with Sickle Cell Disease

Dear Senate Finance Committee Chair;

On behalf of the southern Maryland sickle cell population, their families, and the Sickle Cell Coalition of Maryland, we respectfully ask the members of the Maryland State Assembly to vote favorably on bill SB 1188. If bill SB 1188 passes it would mean SCD warriors such as myself would be afforded the necessary services and resources to live a healthy life. The narrative of the SCD Warrior is often one of despair and silence, nationally and in our great state of Maryland. However, the approval of Bill SB 1188 could begin a change in the narrative; we can begin to chip away at the stigmatization that constantly remains loud and unabated in the community.

Maryland sickle cell warriors like myself have access to little or no hematologists in our home counties. The resources available to support treatment of care inpatient and outpatient, are often limited to scarce. In addition to the minimum assistance available for SCD warriors, social health determinants are aggravated. It is very unfortunate because the sickle cell disease population in Maryland is one of the highest SCD populations in the nation with few resources compared to other states.

Sickle cell disease is a debilitating blood disorder that devastates the body and places a massive financial burden on the state coffers and patients' wallets. A favorable vote for bill SB 1188 would help lessen the financial burden on the state approving preventive protocols to be implemented for the betterment of young SCD warriors. For example, a simple Transcranial Doppler (TCD) scan, when done yearly, can identify children who are at risk for stroke. When a child with SCD suffers a stroke, it can cost the system \$80,000 a year; the requirement for this scan could 1. save a life and 2. save money.

Furthermore, the education of the Maryland population on the dangers of SCD through community health fairs and a Sickle Cell Awareness Month, would help to

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begin to educate the population on SCD where the knowledge barrier is great. Currently, Marylanders have little to no access to relatable information on the disease and the trait. I believe our state can help warn the population through community education on the dangers of inheriting such a disease. I write to ask for you to vote favorably to change the reality of misinformation that runs rampant through our communities.

We are in the age of the CRISPR Cure for SCD and the creation of the first two sickle cell medications, SCD since the year 1910, sickle cell awareness is finally entering the mainstream and I believe our time is now! Your favorable vote for SB 1188 will help affirm sickle cell warriors, the community, and newly formed organizations like the Sickle Cell Coalition of Maryland in the fight to combat health disparities and change the needle and narrative for SCD warriors in our beautiful state.

We respectfully urge a favorable report.

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