



MARYLAND CITIZENS' HEALTH INITIATIVE

2600 ST. PAUL STREET BALTIMORE, MD 21218

P: (410)235-9000

F: (410)235-8963

WWW.HEALTHCAREFORALL.COM

**Testimony of Maryland Citizens' Health Initiative on
Senate Bill 859 – Public Health – Sickle Cell Disease Registry – Establishment
Position: *Support*
March 16, 2022**

Madam Chair and Members of the Senate Finance Committee;

The Maryland Citizens' Health Initiative (MCHI) writes to express our support of **Senate Bill (SB) 859**. SB 859 would establish a much-needed registry for individuals living with sickle cell disease in Maryland, providing comprehensive state-wide data on concentrated areas of need, while maintaining confidentiality for individuals. We thank Senator Watson for introducing this important legislation which can help inform future public health decisions in the state, and we urge a favorable report.

Despite being the most commonly inherited blood disorder in our country, there is very little available data on the populations impacted by sickle cell disease. While newborn screening for the disease is required in Maryland, a large data gap for adult populations still remains. This data is critical for the appropriate allocation of resources to improve community interventions, research, and education campaigns. Simply put, better data means better health outcomes, and Maryland should strive to have a comprehensive understanding of the populations living with sickle cell disease, the areas of high-concentrated need within the state, and the current distribution of resources and providers. Without this, Marylanders living with sickle cell disease will continue to face a shortage of qualified treatment providers, long commutes to care, limited access to modifying treatments, and increased hospitalization rates. Furthermore, this is an issue of racial justice. The vast majority of the 100,000 Americans living with the disease are Black, and they face significantly less access to care than those with other genetic disorders, such as cystic fibrosis, which predominately impacts white populations¹. Much of this is due to a lack of comprehensive care centers for adults with the disease, but it is further compounded by a long history of systemic racism in our nation, which has resulted in people of color being less likely to have private health coverage, more limited disposable resources to afford treatment, as well as poorer health outcomes when interacting with the medical system. Maryland can and must act to help remedy this issue and advance racial equity, and SB 859 would implement important health infrastructure to do just that.

Thanks to the leadership of this Committee, the Maryland General Assembly passed the Maryland Health Equity Resource Act in the 2021 legislative session. This program provides significant new funding to allow local communities throughout the state to address health disparities and to improve health outcomes in ways that best fit the needs of their population and area. To date, nine grantees have been awarded funding through the Pathways to Health Equity program as part of this act, including one proposal to address disparities in access to comprehensive care for sickle cell disease in Prince George's County. The establishment of a state registry would further illuminate areas in need of increased provider access and community supports for those living with sickle cell disease.

We thank this Committee for their ongoing leadership to ensure all Marylanders have access to quality, affordable health care and again urge a favorable report on SB 859.

¹ [https://www.cdc.gov/ncbddd/sicklecell/data.html#:~:text=SCD%20occurs%20among%20about%201,sickle%20cell%20trait%20\(SCT\).](https://www.cdc.gov/ncbddd/sicklecell/data.html#:~:text=SCD%20occurs%20among%20about%201,sickle%20cell%20trait%20(SCT).)