

**MCHI\_FAV\_SB859.pdf**

Uploaded by: Catherine Kirk Robins

Position: FAV



MARYLAND CITIZENS' HEALTH INITIATIVE

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**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 populations<sup>1</sup>. 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.

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<sup>1</sup> [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).)

# **SB859\_PGCoGov\_Carrington\_FAV**

Uploaded by: Darrell Carrington

Position: FAV



# THE PRINCE GEORGE'S COUNTY GOVERNMENT

(301) 952-3700 County Council

## POSITION STATEMENT

### **SB 859**

Senator Watson  
(FIN Committee)

Public Health – Sickle Cell Disease Registry - Establishment

### POSITION:

### SUPPORT

**SB 859** – Public Health – Sickle Cell Disease Registry - Establishment – This bill requires the Maryland Department of Health (MDH) to establish a registry of individuals diagnosed with sickle cell disease (SCD). The purpose of the registry is to serve as a single repository of accurate, complete records to aid in promoting the siting of hematologist offices and health care facilities that provide “Infusion Therapy” in areas of the State with high populations of individuals with SCD. The registry must include any other information regarding individuals diagnosed with SCD necessary and appropriate. A health care provider who serves individuals with SCD must provide specified information, such as data from the designated health information exchange in the state, census-tract level data and information collected from vital records. To the extent authorized by law, MDH must periodically publish information identifying areas with high populations of individuals with SCD, which may include information published in a map.

The Prince George’s County Council recognizes the following estimates as reported by the U.S. Centers for Disease Control (CDC):

- SCD affects approximately 100,000 Americans.
- SCD occurs among about 1 out of every 365 Black or African-American births.
- SCD occurs among about 1 out of every 16,230 Hispanic-American births.
- About 1 in 13 Black of African-American babies are born with the sickle cell trait.

The Council has concerns regarding the security of personal, confidential, and sensitive medical records in light of the reported cyberattacks at the MDH. It is imperative that MDH protect the privacy of medical records and adherence to the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

For the foregoing reasons, the Prince George’s County Council **SUPPORTS SB 859** and respectfully requests your favorable consideration of its position.

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Prepared by: Carrington & Associates, LLC  
On behalf of the Prince George’s County Council

**County Administration Building – Upper Marlboro, Maryland 20772**

# **SB\_859\_Maryland Sickle Cell Disease Association\_FA**

Uploaded by: Derek Robertson

Position: FAV

**Testimony of Derek Robertson, MBA, JD, CHC**  
**President, The Maryland Sickle Cell Disease Association**  
**Before the Senate Finance Committee**  
**Maryland Senate**  
**March 16, 2022**

**Senate Bill 859 - Public Health - Sickle Cell Disease Registry - Establishment**

Good afternoon, my name is Derek Robertson. I am the President and co-founder, along with my wife Shantá, of the Maryland Sickle Cell Disease Association (MSCDA) based in Columbia, MD. My wife and I have three sons, two of whom have Sickle Cell Disease (SCD).

Chairperson Kelley thank you for the opportunity to talk with your committee today about sickle cell disease. Senator Watson, thank you for sponsoring this Bill. MSCDA is in favor of Senate Bill 859 because it is an important first step in ensuring appropriate care reaches persons in Maryland who are living with this devastating disorder.

According to a 2010 study, there are approximately 4,000 people in Maryland living with SCD.<sup>1</sup> This bill will have a direct impact on these 4,000 individuals, their families and their providers.

As many, if not all, of you are aware, SCD is an inherited blood disorder where some of the patient's red blood cells are shaped like a sickle instead of being donut shaped. Red blood cells carry life sustaining oxygen to all of organs and must flow smoothly through our blood system. With SCD, the red blood cells that are sickled shaped are sticky and don't carry oxygen effectively. The stickiness of the cells cause the cells to clump together and block the flow of blood. This "clumping" known as a vaso-occlusive crisis is the cause for extreme pain that characterizes SCD. As bad as it is, the excruciating pain faced by SCD patients is not the only complication of SCD. "Sickling" of red blood cells takes place in every organ leading to the breaking down of organs such as the eyes, kidneys and joint damage.

The need for a Bill such as this was identified Maryland Statewide Steering Committee on Services for Adults with Sickle Cell Disease in their report to the legislature almost fifteen years ago in 2008. In that report, the Committee recommended significant improvements in the quality of life for adults living with SCD, "along with significant savings for the state of Maryland" could be achieved by, "develop(ing) a statewide patient registry to facilitate continuity of care across health care systems and providers".

This Bill is needed for the following reasons:

- There is no accurate count of the number of patients with SCD living in MD. As a result, we do not have comprehensive data on patient outcomes or where patients receive care;
- Newborn screening only captures babies born in Maryland and its data skews to youth, while hospitalization data skews to those who are more ill;

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<sup>1</sup> Hassell, *Am J Prev Med* 2010;38(4S):S512–S521. Table 3, Using CDC Data corrected for early mortality in HbSS.

- To drive effective public health policy for SCD and understand where people with SCD live and receive care, the state needs a dedicated surveillance program;
- With an effective registry and surveillance program healthcare providers can understand how people interact with the healthcare system and can help identify people with SCD who may be receiving the majority of their care in the emergency department and are unaffiliated with high quality sickle expert care;
- An effective registry and surveillance program provides needed information that will allow researchers and public health professionals to know where to target activities and programs;
- Most importantly, the Bill will result in focused efforts to provide expert care to this vulnerable, underserved population which will lead to improvement in health care outcomes, including better access to new treatments or cures.
- Improved access to care has also been demonstrated to decrease costs of care.

SB 859 can address these needs immediately and move Maryland in the direction of having a comprehensive approach to the delivery of healthcare services to person living with sickle cell disease. It is for these reasons MSCDA is in favor of Senate Bill 859.

Thank you, Chairperson Kelley, for allowing my testimony, and thank you Sen. Watson for sponsoring this Bill.

If you have any questions, I can be reached at 240-447-8728 or at [mscdainfo@verizon.net](mailto:mscdainfo@verizon.net).

# **Public Health – Sickle Cell Disease Registry – Est**

Uploaded by: Laura Stewart

Position: FAV



Written Testimony Submitted for the Record to the  
Maryland Senate  
Finance Committee  
For the Hearing on  
Public Health – Sickle Cell Disease Registry – Establishment (SB 859)  
March 16, 2022

**SUPPORT**

Free State PTA represents over 40,000 volunteer members and families in over 500 public schools. Free State PTA is comprised of families, students, teachers, administrators, and business as well as community leaders devoted to the educational success of children and family engagement in Maryland. As the state's premier and largest child advocacy organization, Free State PTA is a powerful voice for all children, a relevant resource for families, schools and communities and a strong advocate for public education.

**Free State PTA submits this testimony enthusiastically in support of Senate Bill 859 – Public Health – Sickle Cell Disease Registry – Establishment.** This bill that requires the Maryland Department of Health to establish and maintain a registry of individuals diagnosed with the sickle cell disease for use as a single repository of accurate, complete records to aid in areas with statistically high populations of individuals with sickle cell disease. Information regarding the registry is not confidential if individuals participating in the registry: (1) are informed of the scope of information to be released and the purpose of the release, and (2) consents to the release.

According to the Center for Disease Control (CDC) a [public health registry](#) is an integral part of improving population and public health. Federal regulations were purposefully general in describing public health registries to provide flexibility and avoid excluding registries.

- Public health registries could include, but are not limited to birth defects registries, chronic disease registries, and traumatic injury registries etc.
- In addition, public health registries operated by patient safety and quality improvement organizations that enable knowledge generation or process improvement regarding the diagnosis, therapy, and prevention of conditions that affect a population could be considered.
- The public health registries cannot be duplicative of any of the other registries included in other public health measures in the promoting interoperability programs.

In fact, the National Institutes of Health provides a [listing of health registries](#) for a multitude of illnesses and unfortunately, while the list is not exhaustive, the sickle-cell disease isn't listed. With Maryland having a registry for those diagnosed with sickle-cell, it makes this painful disease a priority for addressing.

For years now, the PTA supports guidelines that highlight the need to address the health care concerns of children who have the sickle-cell disease. Having a registry developed to target resources in areas that have significant concentrations of populations identified as having the sickle-cell disease will help schools and community leaders provide resources better.

Senate Bill 859 is in direct alignment of the Free State PTA's support for parent, family and community education that includes research and awareness of issues that affect children's health and welfare. With the passage of such a bill, it will help our Association continue our advocacy for health and safety campaigns to properly identify, treat, and resolve youth and/or their families having the sickle-cell disease.

It is for these reasons that Free State PTA urges you to support SB 859.

Testimony is presented on the behalf of

*Marla Posey-Moss*

Marla Posey-Moss, President

Free State Parent Teacher Association

[president.fsptamd@gmail.com](mailto:president.fsptamd@gmail.com)

# **SB 859 Senator Watson FAV.pdf**

Uploaded by: Ron Watson

Position: FAV

RON WATSON, PH.D  
*Legislative District 23*  
Prince George's County

Judicial Proceedings Committee



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## *The Senate of Maryland*

ANNAPOLIS, MARYLAND 21401

March 16, 2022

**To Chair Kelley, Vice-Chair Feldman, and the members of the Finance Committee:**

Thank you for the opportunity to present this legislation before you today.

Dr. Sophie Lanzkron is the Director of the Adult Sickle Cell Clinic at John Hopkins and Co-Chair of the Maryland Statewide Steering Committee on Services to Adults with Sickle Cell Disease. In December 2008, the committee issued its report advising the public and its officials of the situation in Maryland: Expanding Comprehensive Services for Adults with Sickle Cell Disease. After the report was issued, the Committee went dormant until it was reactivated in 2019. However, Dr. Lanzkron, would be quick to tell you there is no funding for the committee to support any needed sickle cell outreach programs to expand the services to those suffering the devastating effects of Sickle Cell Disease or inform the public through testing and counseling upon a Sickle Cell Disease or inform the public through testing and counseling upon a Sickle Cell Trait positive test.

There are few trained hematologists in Maryland who are well versed in the treatment of SCD and NONE in Harford and Cecil counties or the rural counties of the Eastern Shore. The Eastern Shore has more than double the population of SCD patients than Harford and Cecil combined. Despite the overwhelming numbers of individuals with a positive Sickle Cell Trait test in those areas, SCD patients are forced to travel to Baltimore, Delaware, Washington DC, and Virginia for expert health care. A sickle cell registry would provide the demographic information needed to identify where SCD health care providers and facilities are needed.

SCD is the root cause of many catastrophic illnesses. Chronic Organ Damage with related complications may go unreported. SCD can affect the brain, eyes, heart, lungs, liver, gallbladder, spleen, kidneys, and bones. This is not an exhaustive list. Currently, we have fellow Marylanders with Sickle Cell Disease who are suffering without access to the knowledge and health care needed to treat their condition. A sickle cell registry would help to determine where the needs are greatest and what needs are currently unmet due to inadequate healthcare facilities. **For these reasons, I respectfully urge a favorable vote for SB 859.**

Sincerely,

A handwritten signature in blue ink that reads "Ron L. Watson".

Senator Ron Watson

**Lanzkron SB 859-HB 117 3-15-2022.AC.pdf**

Uploaded by: Sophie Lanzkron

Position: FAV

## SB 859 Public Health – Sickle Cell Disease Registry – Establishment

Dr. Sophie Lanzkron

### Support

I am Dr. Sophie Lanzkron, I am a practicing hematologist at the Johns Hopkins School of Medicine where I am the Director of the Sickle Cell Center for Adults. The views expressed here are my own and do not necessarily reflect the policies or positions of Johns Hopkins University/Johns Hopkins Health System. I treat adults with sickle cell disease (SCD), which is characterized by episodes of excruciating pain, known as vaso-occlusive crises and I support SB 859. Over time, adults with SCD suffer from organ damage that leads to significant morbidity and mortality. Average life expectancy for those with sickle cell disease still remains 25-30 years less than the general population.

People with SCD have been historically underserved by the medical establishment. Sickle cell disease is complex medically and many of the people with the disease are also impacted by social determinants of health that multiply the daily struggle with the disease. Due to disabilities caused by the disease, only 40% of people with SCD are employed and 50% report incomes of less than \$20,000 a year. Fifty percent of people with SCD are insured through Medicaid and it is estimated that the costs of acute care alone is \$1.5 million/100 patients/yr.

I care for about 550 adults with the disease and as the only comprehensive sickle cell program in the state I see new patients, often with very complicated, poorly managed disease. Their disease is poorly managed because they have not had access to high-quality sickle cell expert care. Poor outcomes that are preventable happen to people living with SCD in Maryland because there is a lack of access to high quality care and poor provider knowledge about the disease. **Maryland has been identified as one of the states with an inadequate number of comprehensive clinics for the number of people estimated to be living with SCD in the state.**

SB 859/HB 1176 is a good first step toward improving care for people with SCD in the state and could facilitate improved outcomes for this underserved population. There is currently no accurate count of the number of people with SCD living in Maryland. As a result, we do not have comprehensive data on patient outcomes or where patients receive care. The development of a SCD registry and surveillance system would be beneficial in several ways:

1. With an effective registry and surveillance program healthcare providers can understand how people interact with the healthcare system and can help identify people with SCD who may be receiving the majority of their care in the emergency department and are unaffiliated with high quality sickle expert care.
2. An effective registry and surveillance program would provide needed information that will allow researchers and public health professionals to know where to target activities and programs;
3. Most importantly, the bill will result in focused efforts to provide expert care to this vulnerable, underserved population which will lead to improvement in health care

outcomes, including better access to new treatments or cures. Improved access to care has also been demonstrated to decrease costs of care.

In summary SB 859/HB 1176 creates the first key step that could result in a true change in how care is provided to people with SCD in Maryland. Identifying where the need is for establishing additional high-quality comprehensive sickle programs will offer the foundation to build infrastructure that improves outcomes; and with improved outcomes there will be better quality of life for those who live with this disease. I urge a favorable report on SB 859/HB 1176.

# **SB0859\_FWA\_MedChi\_PH - Sickle Cell Disease Registr**

Uploaded by: Pam Kasemeyer

Position: FWA



# MedChi

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*The Maryland State Medical Society*

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TO: The Honorable Delores G. Kelley, Chair  
Members, Senate Finance Committee  
The Honorable Ron Watson

FROM: Pamela Metz Kasemeyer  
J. Steven Wise  
Danna L. Kauffman  
Christine K. Krone

DATE: March 16, 2022

RE: **SUPPORT WITH AMENDMENT** – Senate Bill 859 – *Public Health – Sickle Cell Disease Registry*  
– *Establishment*

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The Maryland State Medical Society (MedChi), the largest physician organization in Maryland, **supports with amendment** Senate Bill 859.

Senate Bill 859 establishes a registry of individuals diagnosed with sickle cell disease (SCD). The registry would serve as a single repository of information to aid in identifying and addressing access to care challenges related to the treatment of SCD in areas of the State with high populations of individuals with SCD. Health care practitioners who serve individuals with SCD would be required to provide information to the registry with protections to preserve the confidentiality of the information provided.

MedChi recognizes the ongoing challenges in addressing the health care needs of individuals with sickle cell disease, including access to care in areas where there is a shortage of practitioners who provide the specific health care services required. To enhance the registry's effectiveness in attaining its objectives, MedChi would recommend the bill be amended to include a provision that the registry be integrated with CRISP, Maryland's designated Health Information Exchange. Integrating the registry with CRISP would provide a means to share health information among doctors' offices, hospitals, laboratories, radiology centers, and other health care practitioners and organizations. With its amendment noted, MedChi supports passage of Senate Bill 859.

**For more information call:**

Pamela Metz Kasemeyer  
J. Steven Wise  
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Christine K. Krone  
410-244-7000

**SB859\_SCDRegistry\_KennedyKrieger\_LOI.pdf**

Uploaded by: Emily Arneson

Position: INFO



Kennedy Krieger Institute

**Bradley L. Schlaggar, MD, PhD**  
President and CEO  
Zanvyl Krieger Faculty Endowed Chair

*A comprehensive resource  
for children with disabilities*

March 16, 2022

The Honorable Delores G. Kelley  
Chair, Senate Finance Committee  
3 East Miller Senate Office Building  
Annapolis, MD 21401

**Re: Letter of Information on Senate Bill 859 - Public Health - Sickle Cell Disease Registry - Establishment**

Dear Chair Kelley:

Kennedy Krieger Institute applauds Senator Watson for his sponsorship of Senate Bill 859 and for advocating for individuals with sickle cell disease.

At Kennedy Krieger Institute, we have a Sickle Cell Neurodevelopmental Clinic. This clinic provides neurological, developmental, neuropsychological, and behavioral psychology services in a comprehensive, multi-disciplinary outpatient clinic.

This legislation would allow identification of communities that have statistically high populations of individuals with sickle cell disease. This information would facilitate Maryland's ability to implement needed improvements in regional services for these patients and significantly broaden knowledge of extant local resources in these areas. The clear objective is to empower people to access specialty healthcare services.

While Kennedy Krieger agrees with the excellent intentions of this proposed legislation, we have concern for the privacy of the individuals living with sickle cell disease. Given the critical obligation to protect the privacy of registrants, we recommend that the General Assembly outlines specifically how the Department of Health will utilize and protect the data collected.

Additionally, to effectively disseminate information to high-risk communities, Kennedy Krieger recommends that the Department engage with people living with sickle cell disease, with sickle cell disease community organization leaders, and with clinical providers all to ensure successful communication campaigns and engender trust with this vulnerable population.

We deeply appreciate the efforts of the Committee.

Respectfully,

Bradley L. Schlaggar, MD, PhD  
President and CEO  
Kennedy Krieger Institute

Eboni Lance, MD, PhD  
Medical Director, Sickle Cell Neurodevelopmental Clinic  
Kennedy Krieger Institute