

**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*

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