



THE MARYLAND HOUSE OF DELEGATES
ANNAPOLIS, MARYLAND 21401

TESTIMONY OF DELEGATE GABRIEL ACEVERO

HB 1079 -Sickle Cell Trait Screening, Treatment, Education, and Public Awareness (Journey's Law)

February 26, 2020

Good afternoon Madam Chair, Vice Chair and members of the Health and Government Operations Committee.

The Sickle Cell Trait Screening, Treatment, Education, and Public Awareness, also known as “Journey’s Law,” is named for Journey Butler, a beautiful young woman who died in July 2016 at the age of 13 from renal medullary carcinoma (RMC), a rare cancer associated with inheriting the sickle cell gene from one parent.

According to the Centers for Disease Control, as many as 1 in 10 Black babies are born with sickle cell trait (SCT). In fact, in the United States, the sickle cell trait is found primarily in people of African ancestry. However, many other people, especially those coming from the Mediterranean, Middle East and some parts of India have SCT.

To be clear, SCT is the carrier trait for sickle cell disease, not the disease itself. When both parents carry the trait, their children have a 50 percent chance of inheriting SCT, and a 25 percent chance of inheriting the actual sickle cell disease. While SCT is not Sickle Cell Disease, as alluded to above, having the trait means that a person has inherited the sickle cell gene from one of their parents. People with SCT usually do not have any of the symptoms of sickle cell disease (SCD), require no special treatment, and generally live normal lives. However, as Journey’s tragic experience reveals, the gene is associated with increased risk for other diseases such as RMC, another distinct cancer named “VCL-ALK renal cell carcinoma” (VCL-ALK RCC), blood in the urine, complications with trauma to the eye, spleen tissue death at high altitudes, and false positives on A1C type 2 diabetes tests.

Moreover, SCT has been linked to an increased risk of death among student athletes. In a recent review of non-traumatic sports deaths in high school and college athletes, researchers determined that among the top four killers of student athletes is a condition known as **acute rhabdomyolysis (AR) tied to SCT**. AR kills more young athletes than the more commonly known condition of asthma, yet it is the least understood of the top four conditions. As a result, the National Athletic Trainers’ Association recommends confirming sickle cell trait status as part of all athletes’ pre-participation physical examinations to address the preventable deaths stemming from AR.

In Maryland, all newborn babies are screened for sickle cell disease, and if a baby is identified SCD, the state ensures that he or she gets the appropriate comprehensive follow-up care. Though screening is done at birth,

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many Marylanders, particularly our most vulnerable student athletes, have no idea about their sickle-trait status, exposing them to unnecessary risk of preventable death.

To this end, when implemented, Journey's Law would require the Maryland Department of Health, in conjunction with local health departments and the Statewide Steering Committee on Services for Adults with Sickle Cell Disease ("Steering Committee") to develop a public awareness campaign addressing the importance of (1) an individual *knowing* the individual's sickle cell trait status; (2) an individual *receiving screening* for the sickle cell trait; and (3) an individual who carries the sickle cell trait *receiving the appropriate counseling*. Moreover, the bill would empower the Steering Committee by requiring it to work in conjunction with members of the medical community in developing and implementing a comprehensive education and treatment program.

Journey's Law supports the idea that knowledge of sickle cell trait status can be a gateway to education, and can lead to the implementation of simple precautions that may prevent complications stemming from SCT.

Simply put, this bill will save lives, and I urge the Committee to grant a favorable report for this bill.