HOUSE BILL 1414

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By: **Delegates A. Washington and Healey**
Introduced and read first time: February 9, 2018
Assigned to: Health and Government Operations

A BILL ENTITLED

AN ACT concerning

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

FOR the purpose of requiring the Statewide Steering Committee on Services for Adults with Sickle–Cell Disease, to work in conjunction with members of the medical community in leading a certain comprehensive education and treatment program for which the Steering Committee is required to seek grant funding; calling on the Maryland Department of Health, in conjunction with local health departments and the Steering Committee, to develop a certain public awareness campaign; and generally relating to screening, treatment, education, and public awareness for individuals with the sickle–cell trait.

BY repealing and reenacting, with amendments,
Article – Health – General
Section 18–506
Annotated Code of Maryland
(2015 Replacement Volume and 2017 Supplement)

Preamble

WHEREAS, Sickle–cell disease is the most common inherited blood disorder in the United States, affecting approximately 100,000 Americans; and

WHEREAS, More than 3,000,000 people in the United States have the sickle–cell trait, and many who do are unaware of their status; and

WHEREAS, In 2010, the total number of babies born with the sickle–cell trait was estimated to have exceeded 60,000, and the total United States incidence estimate was 15.5 cases per 1,000 births; and

WHEREAS, African Americans, with a rate of 1 in 12 carrying the sickle–cell trait,

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EXPLANATION: **CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.**
[Brackets**]** indicate matter deleted from existing law.

and Hispanic Americans, with a rate of 1 in 100 carrying the sickle–cell trait, are most at risk for carrying the sickle–cell trait; and

WHEREAS, The trait has been found in individuals of African, Asian, European, and Middle Eastern origin; and

WHEREAS, Individuals who have the sickle–cell trait have a 1–in–2 chance of passing on the abnormal sickle–cell gene to future offspring and, if their spouses also have the trait, a 1–in–4 chance of having children with sickle–cell disease; and

WHEREAS, Individuals with the sickle–cell trait have the same life expectancy as the general population, but are at risk for certain conditions, including blood in the urine, kidney cancer, complications with trauma to the eye, spleen tissue death at high altitudes, and false positives on A1C type 2 diabetes tests; and

WHEREAS, According to a 2007 study in the American Journal of Medical Genetics, despite a universal requirement of screening for the sickle–cell trait in every state, most states lack a protocol for disseminating the results, and parents are notified only 37% of the time; and

WHEREAS, The limited research regarding the communication of sickle–cell trait test results to parents demonstrates that there is a high prevalence of misleading information being communicated to new parents; and

WHEREAS, No studies have examined whether information on sickle–cell trait test results is being accurately communicated to an individual, whether by a family member or health care provider, prior to the individual becoming a parent;

WHEREAS, The General Assembly recognizes the importance of ensuring that Marylanders can make informed health decisions when they are aware of their sickle–cell trait status;

WHEREAS, The General Assembly recognizes the ongoing challenges in addressing health outcomes among people with the sickle–cell trait and sickle–cell disease; and

WHEREAS, The General Assembly commits to ensuring support for research that expands our understanding of sickle–cell trait, its implications, and the associated health risks; now, therefore, be it

SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF MARYLAND, That the Laws of Maryland read as follows:

Article – Health – General

18–506.

(a) In this section, "Steering Committee" means the Statewide Steering

Committee on Services for Adults with Sickle Cell Disease.

(b) There is a Statewide Steering Committee on Services for Adults with Sickle Cell Disease.

(c) The Steering Committee shall include representatives from:

(1) Local and national groups that advocate for individuals with sickle cell disease;

(2) Interest and support groups for individuals with sickle cell disease;

(3) The Genetic Alliance;

(4) Faith–based organizations;

(5) Community and consumer groups;

(6) Academic and private clinical settings with knowledge and experience caring for adults with sickle cell disease;

(7) Area hospitals caring for individuals with sickle cell disease; and

(8) Pediatric clinics that care for children with sickle cell disease.

(d) The Steering Committee shall:

(1) Establish institution and community partnerships;

(2) Establish a statewide network of stakeholders who care for individuals with sickle cell disease;

(3) Educate individuals with sickle cell disease, the public, and health care providers about the State options for care of sickle cell disease; and

(4) Seek grant funding to:

(i) Develop and establish a case management system for adults with sickle cell disease;

(ii) Establish an adult sickle cell disease day infusion center;

(iii) Develop, implement, and**, WORKING IN CONJUNCTION WITH MEMBERS OF THE MEDICAL COMMUNITY,** lead a State comprehensive education and treatment program for adults with sickle cell disease; and

(iv) Develop and implement a health care provider awareness and education campaign to increase provider awareness of health disparities, community dynamics, cultural practice, behavioral and psychosocial issues, and the use of standardized treatment and emergency room protocols.

(E) THE DEPARTMENT, IN COLLABORATION WITH THE STEERING COMMITTEE AND LOCAL HEALTH PLANNING AGENCIES, SHALL DEVELOP A PUBLIC AWARENESS CAMPAIGN ON 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 COUNSELING.

SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect October 1, 2018.