

The Florida Senate
BILL ANALYSIS AND FISCAL IMPACT STATEMENT

(This document is based on the provisions contained in the legislation as of the latest date listed below.)

Prepared By: The Professional Staff of the Committee on Health Policy

BILL: SB 1408

INTRODUCER: Senator Davis

SUBJECT: Sickle Cell Program

DATE: April 2, 2023

REVISED: _____

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	Stovall	Brown	HP	Pre-meeting
2.			AHS	
3.			FP	

I. Summary:

SB 1408 establishes a grant program within the Department of Health (department) for the prevention, care, and treatment of sickle cell disease (SCD) and for community-based educational programs concerning the prevention, care, and treatment of the disease. The act is named the “Sickle Cell Prevention, Care, and Treatment Act.”

The department must develop application criteria and standards of eligibility for funds under the grant program. The bill directs that priority for grant awards be given to established SCD community-based applicants throughout the state. Further priority must be given to ensuring the establishment of SCD centers in underserved areas with a higher population of SCD patients.

The department is also tasked with developing and maintaining a voluntary SCD registry for persons diagnosed with SCD and conducting a study to determine the prevalence, impact, and needs of patients diagnosed with SCD and the sickle cell trait in this state.

The bill provides an effective date of July 1, 2023.

II. Present Situation:

Sickle Cell Disease and Sickle Cell Trait

Sickle cell disease is a group of inherited red blood cell disorders. Red blood cells contain hemoglobin, a protein that carries oxygen. Healthy red blood cells are round, and they move through small blood vessels to carry oxygen to all parts of the body. In someone who has SCD, the hemoglobin is abnormal, which causes the red blood cells to become hard and sticky and look like a C-shaped farm tool called a sickle. The sickle cells die early, which causes a constant shortage of red blood cells. Also, when they travel through small blood vessels, they get stuck

and clog the blood flow. This can cause pain and other serious health complications such as infection, acute chest syndrome, and stroke.¹

The exact number of people living with SCD in the U.S. is unknown. The U.S. Centers for Disease Control and Prevention (CDC) estimates:²

- SCD affects approximately 100,000 Americans.
- SCD occurs among about one out of every 365 Black or African-American births.
- SCD occurs among about one out of every 16,300 Hispanic-American births.
- Roughly 7.7 percent of Black or African-American babies are born with sickle cell trait (SCT).

There are several types of SCD. The specific type a person has depends on the genes they inherited from their parents. People with SCD inherit genes that contain instructions, or code, for abnormal hemoglobin. The most common types of SCD include:³

- HbSS. People who have this form of SCD inherit two genes, one from each parent, that code for hemoglobin “S.” Hemoglobin S is an abnormal form of hemoglobin that causes the red cells to become rigid, and sickle shaped. This is commonly called sickle cell anemia and is usually the most severe form of the disease.
- HbSC. People who have this form of SCD inherit a hemoglobin “S” gene from one parent and a gene for a different type of abnormal hemoglobin called “C” from the other parent. This is usually a milder form of SCD.
- HbS beta thalassemia. People who have this form of SCD inherit a hemoglobin “S” gene from one parent and a gene for beta thalassemia, another type of hemoglobin abnormality, from the other parent. There are two types of beta thalassemia: “zero” (HbS beta⁰) and “plus” (HbS beta⁺). Those with HbS beta⁰-thalassemia usually have a severe form of SCD. People with HbS beta⁺-thalassemia tend to have a milder form of SCD.

There also are a few rare types of SCD, such as HbSD, HbSE, and HbSO. People who have these forms of SCD inherit one hemoglobin “S” gene and one gene that codes for another abnormal type of hemoglobin (“D”, “E”, or “O”). The severity of these rarer types of SCD varies.

SCD is diagnosed with a simple blood test. In children born in the U.S., it most often is found at birth during routine newborn screening tests at the hospital. In addition, SCD can be diagnosed while the baby is in the womb. Because children with SCD are at an increased risk of infection and other health problems, early diagnosis and treatment are important.

People with SCD may start to have signs of the disease during the first year of life, usually around five months of age. Symptoms and complications of SCD are different for each person and can range from mild to severe.

¹ Centers for Disease Control and Prevention, Sickle Cell Disease available at: <https://www.cdc.gov/ncbddd/sicklecell/facts.html#:~:text=In%20someone%20who%20has%20SCD,shortage%20of%20red%20blood%20cells>. (last visited March 29, 2023)

² Centers for Disease Control and Prevention, Data and Statistics on Sickle Cell Disease, available at: <https://www.cdc.gov/ncbddd/sicklecell/data.html> (last visited March 29, 2023).

³ *Id.*

Management of SCD is focused on preventing and treating pain episodes, anemia, and other complications. Prevention strategies include lifestyle behaviors as well as medical screening and interventions to prevent SCD complications. Lifestyle behaviors might include drinking plenty of water and avoiding getting too hot or cold, high altitudes, or extreme exertion. Vaccines can prevent against harmful infections. Other intervention strategies might include prevention of severe anemia through blood transfusions which has its own set of complications such as iron overload that can cause life-threatening damage to the liver, heart, and other organs.

SCD is a disease that worsens over time. Currently the Food and Drug Administration (FDA) has approved four treatments. However, the only therapy approved by the FDA that may be able to cure SCD is a bone marrow or stem cell transplant, which can be very risky.⁴

Sickle cell trait (SCT) presents itself in people who inherit one sickle cell gene and one normal gene. People with SCT usually do not have any symptoms of SCD, although in rare cases they might experience complications of SCD. A person with SCT can pass the trait on to their children. SCT is diagnosed with a blood test.⁵

The Sickle Cell Program in Florida

The Sickle Cell Program is found in s. 381.815, F.S. Under this section, the department is required, to the extent that resources are available, to provide education to Floridians about SCD, work cooperatively with not-for-profit centers to provide community-based education, patient teaching and counseling, and to encourage diagnostic screening,. The program, through the department, is authorized to make grants or enter into contract with not-for-profit centers.

The Office of Minority Health and Health Equity within the department is responsible for developing and promoting the statewide implementation of policies, programs, and practices that increase health equity in this state, including, but not limited to, increased access to, and quality of health care services for, racial and ethnic minority populations. As a part of this responsibility, the department administers the Closing the Gap grant program found in s. 381.7353, F.S. A Closing the Gap grant proposal must address one or more of 12 priority areas. One of those areas is decreasing racial and ethnic disparities in morbidity and mortality rates relating to SCD.

Closing the Gap grants are awarded on a match basis with one dollar in local matching funds required for each three dollars in grant payment from the state. Exceptions are based on population in which case in-kind contributions may be used to offset some or all of the required match and grant awards to Front Porch Florida Communities are exempt from providing a match.⁶

The amount of a grant award is based on the merits of the application. Awards are made on an annual basis and may be renewed upon application and approval by the department, subject to the achievement of quality standards, objectives, and outcomes and to the availability of funds.

⁴ Center for Disease Control and Prevention, <https://www.cdc.gov/ncbddd/sicklecell/facts.html> (last visited March 29, 2023).

⁵ Centers for Disease Control and Prevention, Sickle Cell Trait available at: <https://www.cdc.gov/ncbddd/sicklecell/traits.html> (last visited March 29, 2023)

⁶ See s. 381.7356(2), F.S.

The Closing the Gap grant program is subject to a specific appropriation provided in the General Appropriations Act.⁷

The 2022-2023 General Appropriations Act provided \$238,860 to the Sickle Cell Disease Association of Florida, Inc. – Sickle Cell Outreach⁸ and \$3 million to the Foundation for Sickle Cell Disease Research.⁹

III. Effect of Proposed Changes:

The act is named the “Sickle Cell Prevention, Care, and Treatment Act.”

The bill amends s. 381.815, F.S., to establish a grant program to be administered by the department for the prevention, care, and treatment of SCD and for community-based educational programs concerning the disease. All grant funds must be used for these purposes. The educational programs must include an outreach program that provides for the dissemination of information relating to the prevention, care, and treatment of SCD.

The department is directed to develop application criteria and standards of eligibility for groups or organizations. Established SCD community-based applicants must be given priority. Further priority must be given to ensuring the establishment of SCD centers in underserved areas with a higher population of SCD patients.

The department is also tasked with developing and maintaining a voluntary SCD registry for persons diagnosed with SCD, and to conduct a study to determine the prevalence, impact and needs of patients diagnosed with SCD or the sickle cell trait in this state.

The department is provided with rulemaking authority to implement these provisions. The preamble for this statute instructs the department to accomplish these tasks to the extent that resources are available.

The bill provides an effective date of July 1, 2023.

IV. Constitutional Issues:

A. Municipality/County Mandates Restrictions:

None.

B. Public Records/Open Meetings Issues:

None.

C. Trust Funds Restrictions:

None.

⁷ See s. 381.7356(6) and (7), F.S.

⁸ See HB 5001(2022) General Appropriations Act at line 524.

⁹ See HB 5001(2022) General Appropriations Act at line 476.

D. State Tax or Fee Increases:

None.

E. Other Constitutional Issues:

None.

V. Fiscal Impact Statement:**A. Tax/Fee Issues:**

None.

B. Private Sector Impact:

None.

C. Government Sector Impact:

The department has not provided an estimate of SB 1408's fiscal impact, but the bill is likely to result in some amount of costs associated with administering the SCD grant program, developing the voluntary registry, and conducting the study.

VI. Technical Deficiencies:

None.

VII. Related Issues:

None.

VIII. Statutes Affected:

This bill substantially amends section 381.815 of the Florida Statutes:

IX. Additional Information:**A. Committee Substitute – Statement of Changes:**

(Summarizing differences between the Committee Substitute and the prior version of the bill.)

None.

B. Amendments:

None.