

THE FLORIDA SENATE
2023 SUMMARY OF LEGISLATION PASSED
Committee on Health Policy

CS/CS/SB 1352 — Sick Cell Disease Medications, Treatment, and Screening

by Fiscal Policy Committee; Appropriations Committee on Health and Human Services; and Senators Rouson and Davis

The bill focuses on newborn and infant (newborn) screenings for a sickle cell hemoglobin variant, establishing a voluntary registry for screening results, educating persons about sickle cell hemoglobin variants and available resources, on-going research on sickle cell disease (SCD), and improving outcomes for persons diagnosed with SCD.

The bill creates s. 383.147, F.S., to require that if a newborn's screening reveals a sickle cell hemoglobin variant, the screening provider must submit the results to the Department of Health (DOH) for inclusion in a registry for persons carrying a sickle cell hemoglobin variant and notify the newborn's primary care physician. A primary care physician so notified must provide information about the availability and benefits of genetic counseling to the newborn's parent or guardian.

The bill requires the DOH to contract with a community-based SCD medical treatment and research center (center) to establish and maintain the registry. The DOH must establish a system to ensure that the center notifies the parent or guardian of a child included in the registry that a follow-up consultation with a physician is recommended, and the bill requires such notice to be provided to the parent or guardian at least once during the child's early adolescence and once during late adolescence.

A parent or guardian may request to have his or her child removed from the registry by submitting a form to be created under DOH rule, and the DOH must make every reasonable effort to notify persons in the registry who have attained 18 years of age that they may be removed from the registry by submitting a similar form, also to be created under DOH rule. The DOH must also provide information to such persons regarding available educational services, genetic counseling, and other beneficial resources.

The bill creates s. 409.91235, F.S., to require that, biennially, the Agency for Health Care Administration (AHCA), in consultation with the Florida Medical Schools Quality Network and a dedicated SCD medical treatment and research center that maintains a sickle cell patient database and tracks SCD outcome measures, must review specified data and report to the Governor, Legislature, the DOH Office of Minority Health and Health Equity, and the Rare Disease Advisory Council whether the Florida Medicaid program's medications, treatments, and services for Medicaid recipients with SCD are adequate to meet their needs or whether additions should be sought to improve outcomes.

The bill appropriates to DOH, for the 2023-2024 fiscal year, \$1,060,804 in recurring general revenue and \$21,355 in nonrecurring general revenue, and five full-time equivalent positions, for the purpose of the DOH implementing its duties under the bill.

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The bill also appropriates to the AHCA, for the 2023-2024 fiscal year, \$250,000 in nonrecurring general revenue for the purpose of the AHCA implementing its duties under the bill.

If approved by the Governor, or allowed to become law without the Governor's signature, these provisions take effect July 1, 2023.

Vote: Senate 40-0; House 116-0