

1 A bill to be entitled
2 An act relating to sickle cell disease; creating s.
3 381.814; creating the Sickle Cell Disease Research and
4 Treatment Grant Program within the department for a
5 specified purpose; specifying the types of projects
6 that are eligible for grant funding; amending s.
7 383.147, F.S.; revising sickle cell disease and sickle
8 cell trait screening requirements; requiring screening
9 providers to notify a newborn's parent or guardian,
10 rather than the newborn's primary care physician, of
11 certain information; authorizing certain persons other
12 than newborns who have been identified as having
13 sickle cell disease or carrying a sickle cell trait to
14 choose to be included in the registry; providing an
15 effective date.

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17 Be It Enacted by the Legislature of the State of Florida:

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19 Section 1. Section 381.814, Florida Statutes, is created
20 to read:

21 381.814 Sickle Cell Disease Research and Treatment Grant
22 Program.-- The Sickle Cell Disease Research and Treatment Grant
23 Program is created within the Department of Health.

24 (1) Definitions.- As used in this section:

25 (a) "Center of Excellence" means a health care facility
26 dedicated to the treatment of patients with sickle cell disease
27 and provides evidence-based, comprehensive, patient-centered
28 coordinated care.

29 (b) "Department" means the department of health.

30 (c) "Health care practitioner" has the same meaning as
31 provided in s. 456.001(4).

32 (d) "Program" means the Sickle Cell Disease Research and
33 Treatment Grant Program.

34 (e) "Sickle cell disease" means the group of hereditary
35 blood disorders caused by an abnormal type of hemoglobin
36 resulting in malformed red blood cells with impaired function.
37 For the purposes of this section, sickle cell disease includes
38 both symptomatic manifestations of sickle cell disease and
39 asymptomatic sickle cell trait.

40 (2) The purpose of the program is to fund projects that
41 improve the quality and accessibility of health care available
42 for persons living with sickle cell disease in this state, as
43 well as advance the collection and analysis of comprehensive
44 data to support research of sickle cell disease. The long-term
45 goals of the program are to:

46 (a) Improve the health outcomes and quality of life for
47 Floridians with sickle cell disease.

48 (b) Expand access to high-quality, specialized care for
49 sickle cell disease.

50 (c) Improve awareness and understanding among health care
51 practitioners of current best practices for the treatment and
52 management of sickle cell disease.

53 (3) Funds appropriated to the program shall be awarded by
54 the Office of Minority Health and Health Equity, within the
55 department, to community-based sickle cell disease medical
56 treatment and research centers operating in Florida.

57 (4) The Office of Minority Health and Health Equity shall
58 award grants under the program to community-based sickle cell
59 disease medical treatment and research centers to fund projects
60 specific to sickle cell disease in the following project areas.

61 (a) Sickle cell disease workforce development and
62 education. Such projects include, but are not limited to,
63 facility-based education programs, continuing education
64 curriculum development, and outreach and education activities
65 with the local health care practitioner community. Workforce
66 development and education projects must be based on current
67 evidence-based clinical practice guidelines for sickle cell
68 disease.

69 (b) Sickle Cell Disease Treatment Centers of Excellence.
70 Such projects include, but are not limited to, operational
71 support for existing centers of excellence, facility enhancement
72 of existing centers of excellence, and the establishment of new
73 centers of excellence.

74 (5) The department shall:

75 (a) Publicize the availability of funds and establish an
76 application process for submitting a grant proposal, and
77 initiate a call for applications no later than July 15, 2024.

78 (b) Develop uniform data reporting requirements for the
79 purpose of evaluating the performance of the grant recipients
80 and demonstrating improved health outcomes.

81 (c) Develop a monitoring process to evaluate progress
82 toward meeting grant objectives.

83 (6) The department shall submit an annual report to the
84 Governor, the President of the Senate, the Speaker of the House
85 of Representatives, and the State Surgeon General by March 1 of
86 each year, and publish the report on the department's website.
87 The report shall include the status and progress for each
88 project supported by the program during the previous calendar
89 year. The report shall include, at a minimum, recommendations
90 for improving the program and the following components for each
91 project supported by the program:

92 (a) A summary of the project and the project outcomes or
93 expected project outcomes.

94 (b) The status of the project, including whether it has
95 concluded or the estimated date of completion.

96 (c) The amount of the grant awarded and the estimated or
97 actual cost of the project.

98 (d) The source and amount of any federal, state, or local
 99 government grants or donations or private grants or donations
 100 funding the project.

101 (e) A list of all entities involved in the project.

102 (7) The department may adopt rules as necessary to
 103 implement the provisions of this section.

104 (8) The recipient of a grant awarded under the program may
 105 not use more than 5 percent of grant funds for administrative
 106 expenses. Notwithstanding s. 216.301 and pursuant to s. 216.351,
 107 the balance of any appropriation from the General Revenue Fund
 108 for the program which is not disbursed but which is obligated
 109 pursuant to contract or committed to be expended by June 30 of
 110 the fiscal year in which the funds are appropriated may be
 111 carried forward for up to 5 years after the effective date of
 112 the original appropriation.

113 Section 2. Section 383.147, Florida Statutes, is amended
 114 to read:

115 383.147 ~~Newborn and infant screenings for Sickle cell~~
 116 disease and sickle cell trait hemoglobin variants; registry.-

117 (1) ~~If a screening provider detects that a newborn or an~~
 118 ~~infant,~~ as those terms are defined in s. 383.145(2), is
 119 identified as having sickle cell disease or sickle cell trait
 120 through the newborn screening program as described in s. 383.14,
 121 the department carrying a sickle cell hemoglobin variant, it
 122 must:

123 (a) Notify the parent or guardian of the newborn and
 124 provide information regarding the availability and benefits of
 125 genetic counseling ~~primary care physician of the newborn or~~
 126 ~~infant and~~

127 (b) Submit the results of such screening ~~to the Department~~
 128 ~~of Health~~ for inclusion in the sickle cell registry established
 129 under paragraph (2)(a). ~~The primary care physician must provide~~
 130 ~~to the parent or guardian of the newborn or infant information~~
 131 ~~regarding the availability and benefits of genetic counseling.~~

132 (2)(a) The Department of Health shall contract with a
 133 community-based sickle cell disease medical treatment and
 134 research center to establish and maintain a registry for
 135 individuals ~~newborns and infants~~ who are identified as carrying
 136 a sickle cell disease or sickle cell trait ~~hemoglobin variant~~.
 137 The sickle cell registry must track sickle cell disease outcome
 138 measures, except as provided in paragraph (1)(b). A parent or
 139 guardian of a newborn or an infant in the registry may request
 140 to have his or her child removed from the registry by submitting
 141 a form prescribed by the department by rule.

142 (b) In addition to newborns identified and included in the
 143 registry under subsection (1), other persons living in this
 144 state who have been identified with sickle cell disease or
 145 sickle cell trait may choose to be included in the registry by
 146 providing the department with notification as prescribed by
 147 rule.

148 (c)~~(b)~~ The Department of Health shall also establish a
149 system to ensure that the community-based sickle cell disease
150 medical treatment and research center notifies the parent or
151 guardian of a child who has been included in the registry that a
152 follow-up consultation with a physician is recommended. Such
153 notice must be provided to the parent or guardian of such child
154 at least once during early adolescence and once during late
155 adolescence. The department shall make every reasonable effort
156 to notify persons included in the registry who are 18 years of
157 age that they may request to be removed from the registry by
158 submitting a form prescribed by the department by rule. The
159 department shall also provide to such persons information
160 regarding available educational services, genetic counseling,
161 and other beneficial resources.

162 (3) The Department of Health shall adopt rules to
163 implement this section.

164 Section 3. This act shall take effect upon becoming law.