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2024 Legislature

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

20
 21 Be It Enacted by the Legislature of the State of Florida:

22
 23 Section 1. Section 381.814, Florida Statutes, is created
 24 to read:
 25 381.814 Sickle Cell Disease Research and Treatment Grant

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26 Program.—The Sickle Cell Disease Research and Treatment Grant
 27 Program is created within the Department of Health.

28 (1) As used in this section, the term:

29 (a) "Center of excellence" means a health care facility
 30 dedicated to the treatment of patients with sickle cell disease
 31 which provides evidence-based, comprehensive, patient-centered
 32 coordinated care.

33 (b) "Department" means the Department of Health.

34 (c) "Health care practitioner" has the same meaning as
 35 provided in s. 456.001.

36 (d) "Program" means the Sickle Cell Disease Research and
 37 Treatment Grant Program.

38 (e) "Sickle cell disease" means the group of hereditary
 39 blood disorders caused by an abnormal type of hemoglobin
 40 resulting in malformed red blood cells with impaired function.
 41 The term includes both symptomatic manifestations of sickle cell
 42 disease and asymptomatic sickle cell trait.

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

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

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

53 (c) Improve awareness and understanding among health care
 54 practitioners of current best practices for the treatment and
 55 management of sickle cell disease.

56 (3) Funds appropriated to the program shall be awarded by
 57 the Office of Minority Health and Health Equity, within the
 58 department, to community-based sickle cell disease medical
 59 treatment and research centers operating in this state.

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

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

72 (b) Sickle Cell Disease Treatment Centers of Excellence.—
 73 Such projects shall include, but need not be limited to,
 74 operational support for existing centers of excellence, facility

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75 enhancement of existing centers of excellence, and the
 76 establishment of new centers of excellence.

77 (5) The department shall:

78 (a) By July 15, 2024, publicize the availability of funds,
 79 establish an application process for submitting a grant
 80 proposal, and initiate a call for applications.

81 (b) Develop uniform data reporting requirements for the
 82 purpose of evaluating the performance of the grant recipients
 83 and demonstrating improved health outcomes.

84 (c) Develop a monitoring process to evaluate progress
 85 towards meeting grant objectives.

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

95 (a) A summary of the project and the project outcomes or
 96 expected project outcomes.

97 (b) The status of the project, including whether it is
 98 completed or the estimated date of completion.

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

101 (d) The source and amount of any federal, state, or local
 102 government grants or donations or private grants or donations
 103 funding the project.

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

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

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

116 Section 2. Section 383.147, Florida Statutes, is amended
 117 to read:

118 383.147 ~~Newborn and infant screenings for Sickle cell~~
 119 disease and sickle cell trait hemoglobin variants; registry.-

120 (1) If a screening provider detects that a newborn or an
 121 infant, as those terms are defined in s. 383.145(2), is
 122 identified as having sickle cell disease or sickle cell trait
 123 through the newborn screening program as described in s. 383.14,

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124 the department ~~carrying a sickle cell hemoglobin variant, it~~
 125 ~~must:~~

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

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

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

145 (b) In addition to newborns identified and included in the
 146 registry under subsection (1), other persons living in this
 147 state who have been identified with sickle cell disease or
 148 sickle cell trait may choose to be included in the registry by

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149 providing the department with notification as prescribed by
150 rule.

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

165 (3) The Department of Health shall adopt rules to
166 implement this section.

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