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1
2 An act relating to sickle cell disease medications,
3 treatment, and screening; creating s. 383.147, F.S.;
4 requiring newborn and infant screening providers to
5 notify primary care physicians of newborns and infants
6 of certain screening results and to submit the results
7 to the Department of Health for a specified purpose;
8 requiring such physicians to provide certain
9 information to parents and guardians of such newborns
10 or infants; requiring the department to contract with
11 a certain center to establish and maintain a sickle
12 cell registry; providing a requirement for the
13 registry; authorizing parents and guardians of
14 children in the registry to request to have them
15 removed from the registry; providing duties of the
16 department and the center; providing requirements for
17 certain notification that the center must provide to
18 parents and guardians; requiring the department to
19 adopt rules; creating s. 409.91235, F.S.; requiring
20 the Agency for Health Care Administration, in
21 consultation with certain entities, to review sickle
22 cell disease medications, treatments, and services for
23 Medicaid recipients and develop a written report, post
24 the report on its website, and submit a copy of the
25 report to the Governor, the Legislature, and certain
26 entities by a specified date and every 2 years
27 thereafter; providing requirements for the report;
28 providing appropriations and authorizing positions;
29 providing an effective date.

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

Section 1. Section 383.147, Florida Statutes, is created to read:

383.147 Newborn and infant screenings for sickle cell hemoglobin variants; registry.—

(1) If a screening provider detects that a newborn or an infant, as those terms are defined in s. 383.145(2), is carrying a sickle cell hemoglobin variant, it must notify the primary care physician of the newborn or infant and submit the results of such screening to the Department of Health for inclusion in the sickle cell registry established under paragraph (2)(a). The primary care physician must provide to the parent or guardian of the newborn or infant information regarding the availability and benefits of genetic counseling.

(2)(a) The Department of Health shall contract with a community-based sickle cell disease medical treatment and research center to establish and maintain a registry for newborns and infants who are identified as carrying a sickle cell hemoglobin variant. The sickle cell registry must track sickle cell disease outcome measures. A parent or guardian of a newborn or an infant in the registry may request to have his or her child removed from the registry by submitting a form prescribed by the department by rule.

(b) The Department of Health shall also establish a system to ensure that the community-based sickle cell disease medical treatment and research center notifies the parent or guardian of a child who has been included in the registry that a follow-up

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59 consultation with a physician is recommended. Such notice must
60 be provided to the parent or guardian of such child at least
61 once during early adolescence and once during late adolescence.
62 The department shall make every reasonable effort to notify
63 persons included in the registry who are 18 years of age that
64 they may request to be removed from the registry by submitting a
65 form prescribed by the department by rule. The department shall
66 also provide to such persons information regarding available
67 educational services, genetic counseling, and other beneficial
68 resources.

69 (3) The Department of Health shall adopt rules to implement
70 this section.

71 Section 2. Section 409.91235, Florida Statutes, is created
72 to read:

73 409.91235 Agency review and report on medications,
74 treatments, and services for sickle cell disease.—

75 (1) The Agency for Health Care Administration, in
76 consultation with the Florida Medical Schools Quality Network
77 and a dedicated sickle cell disease medical treatment and
78 research center that maintains a sickle cell patient database
79 and tracks sickle cell disease outcome measures, shall, every 2
80 years:

81 (a) Conduct a review to determine whether the available
82 covered medications, treatments, and services for sickle cell
83 disease are adequate to meet the needs of Medicaid recipients
84 diagnosed with such disease and whether the agency should seek
85 to add additional medications, treatments, or services to
86 improve outcomes.

87 (b)1. Develop a written report that details the review

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88 findings.

89 2. Beginning November 1, 2024, and by November 1 of every
90 other year thereafter, post the report on the agency's website.

91 3. Submit a copy of the report to the Governor, the
92 President of the Senate, the Speaker of the House of
93 Representatives, the Department of Health's Office of Minority
94 Health and Health Equity, and the Rare Disease Advisory Council.

95 (2)(a) The report developed under subsection (1) must be
96 based on the data collected from the prior 2 years and must
97 include any recommendations for improvements in the delivery of
98 and access to medications, treatments, or services for Medicaid
99 recipients diagnosed with sickle cell disease.

100 (b) The report must provide detailed information on
101 Medicaid recipients diagnosed with sickle cell disease,
102 including:

103 1. The total number of Medicaid recipients diagnosed with
104 sickle cell disease.

105 2. The age and population demographics of the Medicaid
106 recipients diagnosed with sickle cell disease.

107 3. The health care utilization patterns and total
108 expenditures, both pharmaceutical and medical, for services
109 provided by Medicaid for all Medicaid recipients diagnosed with
110 sickle cell disease.

111 4. The number of Medicaid recipients diagnosed with sickle
112 cell disease within the general sickle cell patient population
113 who have experienced two or more emergency room visits or two or
114 more hospital inpatient admissions in a 12-month period,
115 including length of stay, and the expenditures, both
116 pharmaceutical and medical, for those Medicaid recipients.

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117 5. The number of clinical treatment programs available for
118 the care of Medicaid recipients diagnosed with sickle cell
119 disease which are specifically designed or certified to provide
120 health care coordination and health care access for individuals
121 diagnosed with sickle cell disease and the number of those
122 clinical treatment programs, per region, with which managed care
123 plans have contracted.

124 6. An assessment of the agency's existing payment
125 methodologies for approved treatments or medications for the
126 treatment of sickle cell disease in the inpatient setting and
127 whether such payment methodologies result in barriers to access.
128 If barriers to access are identified, the report must include an
129 assessment of whether such methodologies may be modified or
130 improved through the adoption of new or additional policies.

131 Section 3. For the 2023-2024 fiscal year, the sums of
132 \$1,060,804 in recurring funds and \$21,355 in nonrecurring funds
133 from the General Revenue Fund are appropriated to the Department
134 of Health, and five full-time equivalent positions with
135 associated salary rate of 254,408 are authorized, for the
136 purpose of implementing this act.

137 Section 4. For the 2023-2024 fiscal year, the sum of
138 \$250,000 in nonrecurring funds from the General Revenue Fund is
139 appropriated to the Agency for Health Care Administration for
140 the purpose of implementing this act.

141 Section 5. This act shall take effect July 1, 2023.