

Amendment No.

COMMITTEE/SUBCOMMITTEE ACTION

ADOPTED	<u>      </u>	(Y/N)
ADOPTED AS AMENDED	<u>      </u>	(Y/N)
ADOPTED W/O OBJECTION	<u>      </u>	(Y/N)
FAILED TO ADOPT	<u>      </u>	(Y/N)
WITHDRAWN	<u>      </u>	(Y/N)
OTHER	<u>      </u>	

1 Committee/Subcommittee hearing bill: Healthcare Regulation  
 2 Subcommittee

3 Representative Skidmore offered the following:

4

5 **Amendment (with title amendment)**

6 Between lines 17 and 18, insert:

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

9 383.147 Newborn and infant screenings for sickle cell  
 10 hemoglobin variants; registry.-

11 (1) If a screening provider detects that a newborn or  
 12 infant, as those terms are defined in s. 383.145(2), is carrying  
 13 a sickle cell hemoglobin variant, it must notify the primary  
 14 care physician of the newborn or infant and submit the results  
 15 of such screening to the Department of Health for inclusion in  
 16 the sickle cell registry established under paragraph (2) (a). The

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17 primary care physician must provide to the parent or guardian of  
18 the newborn or infant information regarding the availability and  
19 benefits of genetic counseling.

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

29 (b) The Department of Health shall also establish a system  
30 to ensure that the community-based sickle cell disease medical  
31 treatment and research center notifies the parent or guardian of  
32 a child who has been included in the registry that a followup  
33 consultation with a physician is recommended. Such notice must  
34 be provided to the parent or guardian of such child at least  
35 once during early adolescence and once during late adolescence.  
36 The department shall make every reasonable effort to notify  
37 persons who are 18 years of age and who have been included in  
38 the registry that they may request to be removed from the  
39 registry by submitting a form prescribed by the department by  
40 rule. The department shall also provide to such persons

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41 information regarding available educational services, genetic  
42 counseling, and other beneficial resources.

43 (3) The Department of Health shall adopt rules to  
44 implement this section.

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47 **T I T L E A M E N D M E N T**

48 Remove lines 2-4 and insert:

49 An act relating to sickle cell disease medications, treatment,  
50 and screening; creating s. 383.147, F.S.; requiring certain  
51 health care providers to notify primary care physicians of  
52 newborns and infants of certain screening results relating to  
53 sickle cell hemoglobin variants and to submit such results to  
54 the Department of Health for a specified purpose; requiring such  
55 physicians to provide certain information to certain parents and  
56 guardians; requiring the department to contract with a specified  
57 center to establish and maintain a sickle cell registry;  
58 providing the purpose of the registry; authorizing certain  
59 parents and guardians to request to have their children removed  
60 from the registry; providing duties of the department and the  
61 center; providing requirements for certain notification;  
62 requiring the department to adopt rules; creating s. 409.91235,  
63 F.S.;