

House Bill 1054 (COMMITTEE SUBSTITUTE)

By: Representatives Cooper of the 43rd, Silcox of the 52nd, and Martin of the 49th

A BILL TO BE ENTITLED
AN ACT

1 To amend Chapter 12 of Title 31 of the Official Code of Georgia Annotated, relating to
2 control of hazardous conditions, preventable diseases, and metabolic disorders, so as to
3 revise provisions relating to newborn screening for various disorders; to create the Newborn
4 Screening and Genetics Advisory Committee to review and make recommendations to the
5 department when a new disorder is added to the federal Recommended Uniform Screening
6 Panel; to provide for requests for appropriations to cover new disorders; to provide for
7 related matters; to repeal conflicting laws; and for other purposes.

8 BE IT ENACTED BY THE GENERAL ASSEMBLY OF GEORGIA:

9 style="text-align:center">**SECTION 1.**

10 Chapter 12 of Title 31 of the Official Code of Georgia Annotated, relating to control of
11 hazardous conditions, preventable diseases, and metabolic disorders, is amended by revising
12 Code Section 31-12-6, relating to a system for prevention of serious illness, severe physical
13 or developmental disability, and death resulting from inherited metabolic and genetic
14 disorders, as follows:

15 "31-12-6.

16 (a) The department shall promulgate rules and regulations creating a newborn screening
17 system for the prevention of serious illness, severe physical or developmental disability,
18 and death caused by ~~genetic conditions, such as phenylketonuria, galactosemia,~~
19 ~~homocystinuria, maple syrup urine disease, hypothyroidism, congenital adrenal~~
20 ~~hyperplasia, Krabbe disease, and such other~~ inherited metabolic and genetic disorders as
21 identified by the department. The department shall be authorized to consider
22 recommendations from the Newborn Screening and Genetics Advisory Committee
23 established pursuant to subsection (i) of this Code section, to include disorders which are
24 added to the federal Recommended Uniform Screening Panel and may be identified in the
25 future to result in serious illness, severe physical or developmental disability, and death if
26 undiagnosed and untreated. ~~The system shall have five components: screening newborns~~

27 ~~for the disorders; retrieving potentially affected screenees back into the health care system;~~
28 ~~accomplishing specific diagnoses; initiating and continuing therapy; and assessing the~~
29 ~~program.~~

30 (a.1) The department shall provide for newborn screening for Krabbe disease, conducted
31 separately at the option of the parent or parents. Any fees for the screening for Krabbe
32 disease pursuant to this subsection shall be paid directly by the parents to the laboratory.
33 Notwithstanding subsection (g) of this Code section, screening for Krabbe disease may be
34 conducted by a laboratory located outside of this state, if approved by the board. In the
35 event that Krabbe disease is included in the newborn screening system by the department
36 pursuant to this Code section, the cost of such screening for Krabbe disease may be funded
37 by the department in its discretion.

38 (b) The entire process for screening, retrieval, and diagnosis must occur within time
39 frames established by the department pursuant to rules and regulations, and the system
40 shall be structured to meet this critical need.

41 (c) The department shall be responsible for the screening of all newborns for the disorders
42 enumerated by the department and in a manner determined by the department pursuant to
43 rules and regulations and shall be responsible for assessment of the program; ~~provided;~~
44 ~~however, that screening for Krabbe disease shall be conducted separately at the option of~~
45 ~~the parent or parents. When any new disorder is approved by the department after~~
46 ~~recommendation by the Newborn Screening and Genetics Advisory Committee established~~
47 ~~pursuant to subsection (i) of this Code section, the department shall submit a budget request~~
48 ~~to the Office of Planning and Budget prior to the General Assembly's next legislative~~
49 ~~session seeking appropriations to cover the new disorder added to the newborn screening~~
50 ~~system. The department shall begin screening newborns for any such new disorder no later~~
51 ~~than 18 months after such appropriation becomes effective.~~

52 (d) The department shall, to the extent state or federal funds are available for such
53 purposes, including but not limited to funds provided under Title V of the Social Security
54 Act, the Maternal and Child Health Services Block Grant, provide for retrieving potentially
55 affected screenees back into the health care system; accomplishing specific diagnoses;,
56 initiating and continuing therapy; and assessing the program.

57 (e) The department shall utilize appropriate existing resources whenever possible and shall
58 cause the coordination and cooperation of agencies and organizations having resources
59 necessary for the creation of an effective system.

60 (f) The department shall be authorized to establish and periodically adjust, by rule and
61 regulation, fees associated with the screening, retrieval, and diagnosis conducted pursuant
62 to this Code section to help defray or meet the costs incurred by the department; ~~provided;~~
63 ~~however, that the fees for screening for Krabbe disease shall be paid directly by the parents~~

64 ~~to the laboratory.~~ In no event shall the fees exceed such costs, both direct and indirect, in
65 providing such screenings and related services, provided that no services shall be denied
66 on the basis of inability to pay. All fees paid thereunder shall be paid into the general fund
67 of the State of Georgia.

68 (g) The department shall allow any laboratory licensed in Georgia and authorized to
69 perform screening ~~testing~~ of newborn infants in any state using normal pediatric reference
70 ranges to conduct the analysis required pursuant to this Code section; provided, however,
71 that the screening ~~for Krabbe disease~~ may be conducted by a laboratory located outside of
72 Georgia if approved by the board. The testing performed by such laboratory must include
73 testing for newborn diseases as required by law or regulation, ~~except for Krabbe disease~~
74 as otherwise provided by the department, and shall provide test results and reports
75 consistent with law and with policies, procedures, and regulations of the department.

76 ~~(h) No later than January 1, 2007, the Georgia Department of Audits and Accounts shall~~
77 ~~conduct an assessment evaluating the efficiency and effectiveness of the newborn~~
78 ~~screenings conducted by the Georgia Public Health Laboratory pursuant to this Code~~
79 ~~section. If it is determined that private laboratories can provide testing at a lower cost than~~
80 ~~the Georgia Public Health Laboratory, the department shall issue a request for proposals~~
81 ~~to qualified vendors including any private laboratory licensed in Georgia as established in~~
82 ~~subsection (g) of this Code section. The Georgia Public Health Laboratory shall be eligible~~
83 ~~to respond to such request for proposals.~~

84 ~~(i)(h)~~ The requirements of this Code section with regard to screening, retrieval, and
85 diagnosis shall not apply to any infant whose parents object in writing thereto on the
86 grounds that such tests and treatment conflict with their religious tenets and practices.

87 (i) There is established the Newborn Screening and Genetics Advisory Committee. The
88 advisory committee shall consist of not less than 11 nor more than 21 members to be
89 appointed by the commissioner. Each member of the advisory committee shall serve a
90 three-year term and until the appointment of his or her successor. Any member may be
91 reappointed by the commissioner. The advisory committee shall meet at least two times
92 per year or upon the call of the chairperson. The advisory committee shall consider and
93 make recommendations to the commissioner related to the inclusion of screening for any
94 disorder added to the federal Recommended Uniform Screening Panel (RUSP), within one
95 year of such addition. As part of such recommendations, the advisory committee shall
96 advise the commissioner on the estimated cost to the department for screening for such
97 disorder. The advisory committee shall be authorized to establish ad hoc subcommittees
98 and to advise the commissioner on procedures for collection and transmission of specimens
99 and the recording of diagnostic results."

100

SECTION 2.

101 All laws and parts of laws in conflict with this Act are repealed.