

The Senate Committee on Health and Human Services offered the following substitute to HB 567:

A BILL TO BE ENTITLED
AN ACT

1 To amend Title 31 of the Official Code of Georgia Annotated, relating to health, so as to
2 provide for the health of mothers and infants in childbirth; to require health care providers,
3 health care facilities, and pharmacies to provide access to the Maternal Mortality Review
4 Committee to records within 30 days of request; to revise provisions relating to newborn
5 screening for various disorders; to create the Newborn Screening and Genetics Advisory
6 Committee to review and make recommendations to the department when a new disorder is
7 added to the federal Recommended Uniform Screening Panel; to provide for requests for
8 appropriations to cover new disorders; to provide for related matters; to repeal conflicting
9 laws; and for other purposes.

10 BE IT ENACTED BY THE GENERAL ASSEMBLY OF GEORGIA:

11 **SECTION 1.**

12 Title 31 of the Official Code of Georgia Annotated, relating to health, is amended in Code
13 Section 31-2A-16, relating to the establishment of the Maternal Mortality Review
14 Committee, by revising subsection (d) as follows:

15 "(d)(1) Health care providers licensed pursuant to Title 43, health care facilities licensed
16 pursuant to Chapter 7 of Title 31, and pharmacies licensed pursuant to Chapter 4 of

Title 26 shall provide reasonable access to the committee to all relevant medical records associated with a case under review by the committee within 30 days of receiving a request for such records.

(2) A health care provider, health care facility, or pharmacy providing access to medical records pursuant to this Code section shall not be held liable for civil damages or be subject to any criminal or disciplinary action for good faith efforts in providing such records."

SECTION 2.

Said title is further amended by revising Code Section 31-12-6, relating to a system for prevention of serious illness, severe physical or developmental disability, and death resulting from inherited metabolic and genetic disorders, as follows:

"31-12-6.

(a) The department shall promulgate rules and regulations creating a newborn screening system for the prevention of serious illness, severe physical or developmental disability, and death caused by ~~genetic conditions, such as phenylketonuria, galactosemia, homocystinuria, maple syrup urine disease, hypothyroidism, congenital adrenal hyperplasia, Krabbe disease, and such other~~ inherited metabolic and genetic disorders as identified by the department. The department shall be authorized to consider recommendations from the Newborn Screening and Genetics Advisory Committee established pursuant to subsection (i) of this Code section, to include disorders which are added to the federal Recommended Uniform Screening Panel and may be identified in the future to result in serious illness, severe physical or developmental disability, and death if undiagnosed and untreated. ~~The system shall have five components: screening newborns for the disorders; retrieving potentially affected screenees back into the health care system; accomplishing specific diagnoses; initiating and continuing therapy; and assessing the program.~~

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

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

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

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

(f) The department shall be authorized to establish and periodically adjust, by rule and regulation, fees associated with the screening, retrieval, and diagnosis conducted pursuant to this Code section to help defray or meet the costs incurred by the department; ~~provided, however, that the fees for screening for Krabbe disease shall be paid directly by the parents to the laboratory.~~ In no event shall the fees exceed such costs, both direct and indirect, in

70 providing such screenings and related services, provided that no services shall be denied
71 on the basis of inability to pay. All fees paid thereunder shall be paid into the general fund
72 of the State of Georgia.

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

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

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

92 (i) There is established the Newborn Screening and Genetics Advisory Committee. The
93 advisory committee shall consist of not less than 11 nor more than 21 members to be
94 appointed by the commissioner. Each member of the advisory committee shall serve a
95 three-year term and until the appointment of his or her successor. Any member may be
96 reappointed by the commissioner. The advisory committee shall meet at least two times

97 per year or upon the call of the chairperson. The advisory committee shall consider and
98 make recommendations to the commissioner related to the inclusion of screening for any
99 disorder added to the federal Recommended Uniform Screening Panel (RUSP), within one
100 year of such addition. As part of such recommendations, the advisory committee shall
101 advise the commissioner on the estimated cost to the department for screening for such
102 disorder. The advisory committee shall be authorized to establish ad hoc subcommittees
103 and to advise the commissioner on procedures for collection and transmission of specimens
104 and the recording of diagnostic results."

105 **SECTION 3.**

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