

House Bill 241

By: Representatives Hawkins of the 27th, Dubnik of the 29th, Jones of the 47th, Hatchett of the 150th, Powell of the 32nd, and others

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, so as to add Krabbe disease to the list of metabolic and
3 genetic conditions for which newborn screening may be conducted pursuant to the
4 Department of Public Health; to provide for the screening at the option of the parent or
5 parents; to provide for payment of fees directly to the laboratory; to provide for a short title;
6 to provide for related matters; to repeal conflicting laws; and for other purposes.

7 BE IT ENACTED BY THE GENERAL ASSEMBLY OF GEORGIA:

8 **SECTION 1.**

9 This Act shall be known and may be cited as "Cove's Law."

10 **SECTION 2.**

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

15 "31-12-6.

16 (a) The department shall promulgate rules and regulations creating a system for the
17 prevention of serious illness, severe physical or developmental disability, and death caused
18 by genetic conditions, such as phenylketonuria, galactosemia, homocystinuria, maple syrup
19 urine disease, hypothyroidism, congenital adrenal hyperplasia, Krabbe disease, and such
20 other inherited metabolic and genetic disorders as may be identified in the future to result
21 in serious illness, severe physical or developmental disability, and death if undiagnosed and
22 untreated. The system shall have five components: screening newborns for the disorders;
23 retrieving potentially affected screenees back into the health care system; accomplishing
24 specific diagnoses; initiating and continuing therapy; and assessing the program.

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

28 (c) The department shall be responsible for the screening of all newborns for the disorders
29 enumerated and in a manner determined by the department pursuant to rules and
30 regulations and shall be responsible for assessment of the program; provided, however, that
31 screening for Krabbe disease shall be conducted separately at the option of the parent or
32 parents.

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

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

41 (f) The department shall be authorized to establish and periodically adjust, by rule and
42 regulation, fees associated with the screening, retrieval, and diagnosis conducted pursuant
43 to this Code section to help defray or meet the costs incurred by the department; provided,
44 however, that the fees for screening for Krabbe disease shall be paid directly by the parents
45 to the laboratory. In no event shall the fees exceed such costs, both direct and indirect, in
46 providing such screenings and related services, provided that no services shall be denied
47 on the basis of inability to pay. All fees paid thereunder shall be paid into the general fund
48 of the State of Georgia.

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

57 (h) No later than January 1, 2007, the Georgia Department of Audits and Accounts shall
58 conduct an assessment evaluating the efficiency and effectiveness of the newborn
59 screenings conducted by the Georgia Public Health Laboratory pursuant to this Code
60 section. If it is determined that private laboratories can provide testing at a lower cost than
61 the Georgia Public Health Laboratory, the department shall issue a request for proposals

62 to qualified vendors including any private laboratory licensed in Georgia as established in
63 subsection (g) of this Code section. The Georgia Public Health Laboratory shall be eligible
64 to respond to such request for proposals.

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

68 **SECTION 3.**

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