

GENERAL ASSEMBLY OF NORTH CAROLINA  
SESSION 2013

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SENATE DRS35203-MGfa-57 (02/12)

Short Title: Newborn Screening For Krabbe Disease. (Public)

Sponsors: Senator Randleman (Primary Sponsor).

Referred to:

A BILL TO BE ENTITLED

AN ACT TO REQUIRE THE COMMISSION FOR PUBLIC HEALTH TO ADOPT RULES REQUIRING SCREENING FOR KRABBE DISEASE UNDER THE NEWBORN SCREENING PROGRAM ADMINISTERED BY THE DEPARTMENT OF HEALTH AND HUMAN SERVICES; TO INCREASE THE LABORATORY FEE FOR NEWBORN SCREENING TESTS PERFORMED BY THE STATE LABORATORY OF PUBLIC HEALTH TO ACCOMMODATE THE COST OF THIS NEW SCREENING REQUIREMENT; TO REQUIRE HEALTH BENEFIT PLANS TO COVER TESTING FOR KRABBE DISEASE; AND TO APPROPRIATE FUNDS TO THE DEPARTMENT OF HEALTH AND HUMAN SERVICES TO IMPLEMENT THIS NEW SCREENING REQUIREMENT.

Whereas, Krabbe disease, a type of leukodystrophy, is a rare and often fatal degenerative disorder that affects the myelin sheath of the nervous system; and

Whereas, the estimated incidence of Krabbe disease is 1 in 100,000 births; and

Whereas, Krabbe disease generally presents during the first six months of life; and

Whereas, early onset Krabbe disease is characterized by changing muscle tone from floppy to rigid (also known as decerebrate posturing), hearing loss that leads to deafness, failure to thrive, feeding difficulties, irritability, sensitivity to loud noises, severe seizures that may begin at an early age, unexplained fevers, vision loss that leads to blindness, and vomiting; and

Whereas, newborn screening for Krabbe disease provides the earliest window for population-based diagnosis and treatment; and

Whereas, currently, the only available treatment for Krabbe disease involves umbilical cord blood transplantation of the newborn; and

Whereas, umbilical cord blood transplantation has been shown to stabilize or halt the progression of Krabbe disease as long as the transplantation occurs prior to the onset of overt symptoms; Now, therefore,

The General Assembly of North Carolina enacts:

**SECTION 1.** The Commission for Public Health shall amend the rules implementing the Newborn Screening Program adopted pursuant to G.S. 130A-125(b) to require screening for Krabbe disease in a manner that is generally acceptable to the scientific community and consistent with applicable State and federal law.

**SECTION 2.** G.S. 130A-125(c) reads as rewritten:

"(c) A fee of ~~nineteen dollars (\$19.00)~~ twenty-one dollars and twelve cents (\$21.12) applies to a laboratory test performed by the State Laboratory of Public Health pursuant to this



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1 section. The fee for a laboratory test is a departmental receipt of the Department and shall be  
2 used to offset the cost of the Newborn Screening Program."

3 **SECTION 3.** Article 3 of Chapter 58 of the General Statutes is amended by adding  
4 a new section to read:

5 "**§ 58-3-261. Insurance coverage for Krabbe disease screening mandated.**

6 (a) As used in this section, the terms "health benefit plan" and "insurer" have the  
7 meanings applied under G.S. 58-3-167.

8 (b) Each health benefit plan shall provide coverage for Krabbe disease screening. The  
9 same deductibles, coinsurance, reimbursement methodologies, and other limitations and  
10 administrative procedures as apply to similar services covered under the health benefit plan  
11 shall apply to such screening coverage."

12 **SECTION 4.** There is appropriated from the General Fund to the Department of  
13 Health and Human Services, Division of Public Health, the sum of six hundred ninety-four  
14 thousand dollars (\$694,000) for the 2013-2014 fiscal year. These funds shall be used to cover  
15 the cost of scientific equipment and laboratory information management system programming  
16 necessary to implement the newborn screening requirement for Krabbe disease in accordance  
17 with Section 1 of this act.

18 **SECTION 5.** Section 3 of this act becomes effective on the date that rules adopted  
19 by the Commission for Public Health pursuant to Section 1 of this act become effective and  
20 applies to health benefit plans entered into, amended, or renewed on or after that date. Sections  
21 2 and 4 of this act become effective July 1, 2013. The remainder of this act is effective when it  
22 becomes law.