

FIRST REGULAR SESSION  
SENATE COMMITTEE SUBSTITUTE FOR  
**HOUSE BILL NO. 716**  
95TH GENERAL ASSEMBLY

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Reported from the Committee on Health, Mental Health, Seniors and Families, April 30, 2009, with recommendation that the Senate Committee Substitute do pass.

TERRY L. SPIELER, Secretary.

1522S.03C

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**AN ACT**

To amend chapter 191, RSMo, by adding thereto three new sections relating to newborn screenings.

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*Be it enacted by the General Assembly of the State of Missouri, as follows:*

Section A. Chapter 191, RSMo, is amended by adding thereto three new sections, to be known as sections 191.333, 191.1127, and 191.1130 to read as follows:

**191.333. 1. This section shall be known and may be cited as the "Brady Alan Cunningham Newborn Screening Act".**

**2. By July 1, 2012, the department of health and senior services shall expand the newborn screening requirements in section 191.331 to include the following lysosomal storage diseases: Krabbe disease, Pompe disease, Gaucher disease, Niemann-Pick disease, and Fabry disease. The department may by rule screen for additional lysosomal storage disorders when the following occurs:**

**(1) The registration of the necessary reagents with the federal Food and Drug Administration;**

**(2) The availability of the necessary reagents from the Centers for Disease Control and Prevention;**

**(3) The availability of quality assurance testing methodology for such processes; and**

**(4) The acquisition and installment by the department of equipment necessary to implement the expanded screening tests.**

**3. The department may promulgate rules to implement the provisions of this section. Any rule or portion of a rule, as that term is defined in section 536.010, RSMo, that is created under the authority delegated in this section shall become effective only if it complies with**

21 and is subject to all of the provisions of chapter 536, RSMo, and, if  
22 applicable, section 536.028, RSMo. This section and chapter 536, RSMo,  
23 are nonseverable and if any of the powers vested with the general  
24 assembly pursuant to chapter 536, RSMo, to review, to delay the  
25 effective date, or to disapprove and annul a rule are subsequently held  
26 unconstitutional, then the grant of rulemaking authority and any rule  
27 proposed or adopted after August 28, 2009, shall be invalid and void.

28 4. The department may increase the fee authorized in subsection  
29 6 of section 191.331 to cover the additional cost of the expanded  
30 newborn screening test required in this section.

191.1127. The MO HealthNet program and the health care for  
2 uninsured children program under sections 208.631 to 208.659, RSMo,  
3 in consultation with statewide organizations focused on premature  
4 infant health care, shall:

5 (1) Examine and improve hospital discharge and follow-up care  
6 procedures for premature infants born earlier than thirty-seven weeks  
7 gestational age to ensure standardized and coordinated processes are  
8 followed as premature infants leave the hospital from either a well-  
9 baby nursery, step down or transitional nursery, or neonatal intensive  
10 care unit and transition to follow-up care by a health care provider in  
11 the community;

12 (2) Urge hospitals serving infants eligible for medical assistance  
13 under the MO HealthNet and health care for uninsured children  
14 programs to report to the state the causes and incidence of all re-  
15 hospitalizations of infants born premature at earlier than thirty-seven  
16 weeks gestational age within their first six months of life; and

17 (3) Use guidance from the Centers for Medicare and Medicaid  
18 Services' Neonatal Outcomes Improvement Project to implement  
19 programs to improve newborn outcomes, reduce newborn health costs,  
20 and establish ongoing quality improvement for newborns.

191.1130. 1. The department of health and senior services shall,  
2 by December 31, 2009, prepare written educational publications  
3 containing information about the possible complications, proper care  
4 and support associated with newborn infants who are born premature  
5 at earlier than thirty-seven weeks gestational age. The written  
6 information, at a minimum, shall include the following:

7 (1) The unique health issues affecting infants born premature,

8 such as:

- 9 (a) Increased risk of developmental problems;
- 10 (b) Nutritional challenges;
- 11 (c) Infection;
- 12 (d) Chronic lung disease (bronchopulmonary dysplasia);
- 13 (e) Vision and hearing impairment;
- 14 (d) Breathing problems;
- 15 (f) Fine motor skills;
- 16 (g) Feeding;
- 17 (h) Maintaining body temperature;
- 18 (i) Jaundice;
- 19 (j) Hyperactivity;
- 20 (k) Infant mortality as well as long-term complications  
21 associated with growth and nutrition;
- 22 (l) Respiratory; and
- 23 (m) Reading, writing, mathematics, and speaking;
- 24 (2) The proper care needs of premature infants, developmental  
25 screenings and monitoring and health care services available to  
26 premature infants through the MO HealthNet program and other public  
27 or private health programs;
- 28 (3) Methods, vaccines, and other preventative measures to  
29 protect premature infants from infectious diseases, including viral  
30 respiratory infections;
- 31 (4) The emotional and financial burdens and other challenges  
32 that parents and family members of premature infants experience and  
33 information about community resources available to support them.
- 34 2. The publications shall be written in clear language to educate  
35 parents of premature infants across a variety of socioeconomic  
36 statuses. The department may consult with community organizations  
37 that focus on premature infants or pediatric health care. The  
38 department shall update the publications every two years.
- 39 3. The department shall distribute these publications to  
40 children's health providers, maternal care providers, hospitals, public  
41 health departments, and medical organizations and encourage those  
42 organizations to provide the publications to parents or guardians of  
43 premature infants.

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