

FIRST REGULAR SESSION
[TRULY AGREED TO AND FINALLY PASSED]
SENATE COMMITTEE SUBSTITUTE FOR

HOUSE BILL NO. 716

95TH GENERAL ASSEMBLY

1522S.03T

2009

AN ACT

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

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
2 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
2 Cunningham Newborn Screening Act".**

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

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

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

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

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

EXPLANATION — Matter enclosed in bold-faced brackets [thus] in the above bill is not enacted and is intended to be omitted from the law. Matter in **bold-face** type in the above bill is proposed language.

16 **3. The department may promulgate rules to implement the provisions of this**
17 **section. Any rule or portion of a rule, as that term is defined in section 536.010, RSMo,**
18 **that is created under the authority delegated in this section shall become effective only if**
19 **it complies with and is subject to all of the provisions of chapter 536, RSMo, and, if**
20 **applicable, section 536.028, RSMo. This section and chapter 536, RSMo, are nonseverable**
21 **and if any of the powers vested with the general assembly pursuant to chapter 536, RSMo,**
22 **to review, to delay the effective date, or to disapprove and annul a rule are subsequently**
23 **held unconstitutional, then the grant of rulemaking authority and any rule proposed or**
24 **adopted after August 28, 2009, shall be invalid and void.**

25 **4. The department may increase the fee authorized in subsection 6 of section**
26 **191.331 to cover the additional cost of the expanded newborn screening test required in**
27 **this section.**

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

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

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

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

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

6 **(1) The unique health issues affecting infants born premature, such as:**

7 **(a) Increased risk of developmental problems;**

8 **(b) Nutritional challenges;**

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

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