

FIRST REGULAR SESSION
SENATE COMMITTEE SUBSTITUTE FOR
HOUSE COMMITTEE SUBSTITUTE FOR
HOUSE BILL NO. 66
99TH GENERAL ASSEMBLY

Reported from the Committee on Seniors, Families and Children, March 30, 2017, with recommendation that the Senate Committee Substitute do pass.

ADRIANE D. CROUSE, Secretary.

0277S.03C

AN ACT

To repeal sections 191.331 and 191.332, RSMo, and to enact in lieu thereof two new sections relating to newborn screening requirements.

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

Section A. Sections 191.331 and 191.332, RSMo, are repealed and two new
2 sections enacted in lieu thereof, to be known as sections 191.331 and 191.332, to
3 read as follows:

191.331. 1. Every infant who is born in this state shall be tested for
2 phenylketonuria and such other metabolic or genetic diseases as are prescribed
3 by the department. The test used by the department shall be dictated by
4 accepted medical practice and such tests shall be of the types approved by the
5 department. All newborn screening tests required by the department shall be
6 performed by the department of health and senior services laboratories. The
7 attending physician, certified nurse midwife, public health facility, ambulatory
8 surgical center or hospital shall assure that appropriate specimens are collected
9 and submitted to the department of health and senior services laboratories
10 **within twenty-four hours of collection. The laboratories shall process**
11 **the specimens within twenty-four hours of receipt.**

12 2. All physicians, certified nurse midwives, public health nurses and
13 administrators of ambulatory surgical centers or hospitals shall report to the
14 department all diagnosed cases of phenylketonuria and other metabolic or genetic
15 diseases as designated by the department. The department shall prescribe and
16 furnish all necessary reporting forms.

17 3. The department shall develop and institute educational programs
18 concerning phenylketonuria and other metabolic and genetic diseases and assist

19 parents, physicians, hospitals and public health nurses in the management and
20 basic treatment of these diseases.

21 4. The provisions of this section shall not apply if the parents of such
22 child object to the tests or examinations provided in this section on the grounds
23 that such tests or examinations conflict with their religious tenets and practices.

24 5. As provided in subsection 4 of this section, the parents of any child who
25 fail to have such test or examination administered after notice of the requirement
26 for such test or examination shall be required to document in writing such
27 refusal. All physicians, certified nurse midwives, public health nurses and
28 administrators of ambulatory surgical centers or hospitals shall provide to the
29 parents or guardians a written packet of educational information developed and
30 supplied by the department of health and senior services describing the type of
31 specimen, how it is obtained, the nature of diseases being screened, and the
32 consequences of treatment and nontreatment. The attending physician, certified
33 nurse midwife, public health facility, ambulatory surgical center or hospital shall
34 obtain the written refusal and make such refusal part of the medical record of the
35 infant.

36 6. Notwithstanding the provisions of section 192.015 to the contrary, the
37 department may, by rule, annually determine and impose a reasonable fee for
38 each newborn screening test made in any of its laboratories. The department
39 may collect the fee from any entity or individual described in subsection 1 of this
40 section in a form and manner established by the department. Such fee shall be
41 considered as a cost payable to such entity by a health care third-party payer,
42 including, but not limited to, a health insurer operating pursuant to chapter 376,
43 a domestic health services corporation or health maintenance organization
44 operating pursuant to chapter 354, and a governmental or entitlement program
45 operating pursuant to state law. Such fee shall not be considered as part of the
46 internal laboratory costs of the persons and entities described in subsection 1 of
47 this section by such health care third-party payers. No individual shall be denied
48 screening because of inability to pay. Such fees shall be deposited in a separate
49 account in the public health services fund created in section 192.900, and funds
50 in such account shall be used for the support of the newborn screening program
51 and activities related to the screening, diagnosis, and treatment, including special
52 dietary products, of persons with metabolic and genetic diseases; and follow-up
53 activities that ensure that diagnostic evaluation, treatment and management is
54 available and accessible once an at-risk family is identified through initial

55 screening; and for no other purpose. These programs may include education in
56 these areas and the development of new programs related to these diseases.

57 7. Subject to appropriations provided for formula for the treatment of
58 inherited diseases of amino acids and organic acids, the department shall provide
59 such formula to persons with inherited diseases of amino acids and organic acids
60 subject to the conditions described in this subsection. State assistance pursuant
61 to this subsection shall be available to an applicant only after the applicant has
62 shown that the applicant has exhausted all benefits from third-party payers,
63 including, but not limited to, health insurers, domestic health services
64 corporations, health maintenance organizations, Medicare, Medicaid and other
65 government assistance programs.

66 8. Assistance under subsection 7 of this section shall be provided to the
67 following:

68 (1) Applicants ages birth to five years old meeting the qualifications under
69 subsection 7 of this section;

70 (2) Applicants between the ages of six to eighteen meeting the
71 qualifications under subsection 7 of this section and whose family income is below
72 three hundred percent of the federal poverty level;

73 (3) Applicants between the ages of six to eighteen meeting the
74 qualifications under subsection 7 of this section and whose family income is at
75 three hundred percent of the federal poverty level or above. For these applicants,
76 the department shall establish a sliding scale of fees and monthly premiums to
77 be paid in order to receive assistance under subsection 7 of this section; and

78 (4) Applicants age nineteen and above meeting the qualifications under
79 subsection 7 of this section and who are eligible under an income-based means
80 test established by the department to determine eligibility for the assistance
81 under subsection 7 of this section.

82 9. The department shall have authority over the use, retention, and
83 disposal of biological specimens and all related information collected in
84 connection with newborn screening tests conducted under subsection 1 of this
85 section. The use of such specimens and related information shall only be made
86 for public health purposes and shall comply with all applicable provisions of
87 federal law. The department may charge a reasonable fee for the use of such
88 specimens for public health research and preparing and supplying specimens for
89 research proposals approved by the department.

191.332. 1. By January 1, 2002, the department of health and senior

2 services shall, subject to appropriations, expand the newborn screening
3 requirements in section 191.331 to include potentially treatable or manageable
4 disorders, which may include but are not limited to cystic fibrosis, galactosemia,
5 biotinidase deficiency, congenital adrenal hyperplasia, maple syrup urine disease
6 (MSUD) and other amino acid disorders, glucose-6-phosphate dehydrogenase
7 deficiency (G-6-PD), MCAD and other fatty acid oxidation disorders,
8 methylmalonic acidemia, propionic acidemia, isovaleric acidemia and glutaric
9 acidemia Type I.

10 2. By January 1, 2017, the department of health and senior services shall,
11 subject to appropriations, expand the newborn screening requirements in section
12 191.331 to include severe combined immunodeficiency (SCID), also known as
13 bubble boy disease. The department may increase the fee authorized under
14 subsection 6 of section 191.331 to cover any additional costs of the expanded
15 newborn screening requirements under this subsection.

16 3. **By January 1, 2019, the department of health and senior**
17 **services shall, subject to appropriations, expand the newborn screening**
18 **requirements in section 191.331 to include spinal muscular atrophy**
19 **(SMA) and Hunter syndrome (MPS II). The department may increase**
20 **the fee authorized under subsection 6 of section 191.331 to cover any**
21 **additional costs of the expanded newborn screening requirements**
22 **under this subsection. To help fund initial costs incurred by the state,**
23 **the department shall apply for available newborn screening grant**
24 **funding specific to screening for spinal muscular atrophy and Hunter**
25 **syndrome. The department shall have discretion in accepting the terms**
26 **of such grants.**

27 4. The department of health and senior services may promulgate rules to
28 implement the provisions of this section. No rule or portion of a rule promulgated
29 pursuant to the authority of this section shall become effective unless it has been
30 promulgated pursuant to chapter 536.

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