

FIRST REGULAR SESSION

HOUSE BILL NO. 203

94TH GENERAL ASSEMBLY

INTRODUCED BY REPRESENTATIVES DEEKEN (Sponsor), DUSENBERG, MCGHEE, HARRIS (110), FISHER, BRUNS, DAUS AND MOORE (Co-sponsors).

Pre-filed December 28, 2006 and copies ordered printed.

D. ADAM CRUMBLISS, Chief Clerk

0958L.011

AN ACT

To repeal section 191.331, RSMo, and to enact in lieu thereof one new section relating to the metabolic distribution formula program.

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

Section A. Section 191.331, RSMo, is repealed and one new section enacted in lieu thereof, to be known as section 191.331, to read as follows:

191.331. 1. Every infant who is born in this state shall be tested for phenylketonuria and such other metabolic or genetic diseases as are prescribed by the department. The test used by the department shall be dictated by accepted medical practice and such tests shall be of the types approved by the department. All newborn screening tests required by the department shall be performed by the department of health and senior services laboratories. The attending physician, certified nurse midwife, public health facility, ambulatory surgical center or hospital shall assure that appropriate specimens are collected and submitted to the department of health and senior services laboratories.

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

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.

13 3. The department shall develop and institute educational programs concerning
14 phenylketonuria and other metabolic and genetic diseases and assist parents, physicians, hospitals
15 and public health nurses in the management and basic treatment of these diseases.

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

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

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

47 7. Subject to appropriations provided for formula for the treatment of inherited diseases
48 of amino acids and organic acids, the department shall provide such formula to persons with

49 inherited diseases of amino acids and organic acids subject to the conditions described in this
50 subsection. State assistance pursuant to this subsection shall be available to an applicant only
51 after the applicant has shown that the applicant has exhausted all benefits from third party payers,
52 including, but not limited to, health insurers, domestic health services corporations, health
53 maintenance organizations, Medicare, Medicaid and other government assistance programs. The
54 department shall establish an income-based means test to be used to determine eligibility for the
55 formula made available pursuant to this section **for applicants over the age of nineteen. Such**
56 **assistance under this section shall be provided to applicants between the ages of six to**
57 **eighteen whose family income is less than three hundred percent of the federal poverty**
58 **level.**

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