

SECOND REGULAR SESSION

# HOUSE BILL NO. 1694

## 91ST GENERAL ASSEMBLY

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INTRODUCED BY REPRESENTATIVES SELBY, SHOEMYER (9) AND KREIDER (Co-sponsors).

Read 1<sup>st</sup> time January 29, 2002, and 1000 copies ordered printed.

TED WEDEL, Chief Clerk

3420L.011

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### AN ACT

To repeal sections 191.331 and 376.1219, RSMo, and to enact in lieu thereof two new sections relating to metabolic and genetic diseases.

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

Section A. Sections 191.331 and 376.1219, RSMo, are repealed and two new sections  
2 enacted in lieu thereof, to be known as sections 191.331 and 376.1219, to read as follows:

- 191.331. 1. Every infant who is born in this state shall be tested for phenylketonuria,  
2 **primary hypothyroidism, biotinidase deficiency, galactosemia, hemoglobinopathies,**  
3 **medium-chain acyl co-a dehydrogenase (MCAD) deficiency, maple syrup urine disease**  
4 **(MSUD),** and such other metabolic or genetic diseases as are prescribed by the department. The  
5 [test] **tests** used by the department shall be dictated by accepted medical practice and such tests  
6 shall be of the types approved by the department. All newborn screening tests required by the  
7 department shall be performed by the department of health laboratories. The attending physician,  
8 certified nurse midwife, public health facility, ambulatory surgical center or hospital shall assure  
9 that appropriate specimens are collected and submitted to the department of health laboratories.
- 10 2. All physicians, certified nurse midwives, public health nurses and administrators of  
11 ambulatory surgical centers or hospitals shall report to the department all diagnosed cases of  
12 phenylketonuria, **primary hypothyroidism, biotinidase deficiency, galactosemia,**  
13 **hemoglobinopathies, medium-chain acyl co-a dehydrogenase (MCAD) deficiency, maple**  
14 **syrup urine disease (MSUD),** and other metabolic or genetic diseases as designated by the  
15 department. The department shall prescribe and furnish all necessary reporting forms.
- 16 3. The department shall develop and institute educational programs concerning

**EXPLANATION — Matter enclosed in bold faced brackets [thus] in this bill is not enacted and is intended to be omitted in the law.**

17 phenylketonuria, **primary hypothyroidism, biotinidase deficiency, galactosemia,**  
18 **hemoglobinopathies, medium-chain acyl co-a dehydrogenase (MCAD) deficiency, maple**  
19 **syrup urine disease (MSUD),** and other metabolic and genetic diseases and assist parents,  
20 physicians, hospitals and public health nurses in the management and basic treatment of these  
21 diseases.

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

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

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

52 7. Subject to appropriations [provided for formula for the treatment of inherited diseases

53 of amino acids and organic acids], the department shall provide [such formula to persons with  
54 inherited diseases of amino acids and organic acids] **food supplements and treatment services**  
55 **to persons suffering from the metabolic diseases set forth in this section** subject to the  
56 conditions described in this subsection. State assistance pursuant to this subsection shall be  
57 available to an applicant only after the applicant has shown that the applicant has exhausted all  
58 benefits from third party payers, including, but not limited to, health insurers, domestic health  
59 services corporations, health maintenance organizations, Medicare, Medicaid and other  
60 government assistance programs. The department shall establish an income-based means test  
61 to be used to determine eligibility for the [formula] **food supplements and treatment services**  
62 made available pursuant to this section.

63 **8. To defray or help defray the costs of any food supplements or treatment services**  
64 **provided pursuant to this section, the department may prescribe and assess a fee for the**  
65 **food supplements based on a sliding scale. The maximum prescribed fee for food**  
66 **supplements shall be no more than the actual cost of providing such supplements. No fees**  
67 **may be charged for formula, and up to two thousand dollars of pharmaceutically**  
68 **manufactured food supplements shall be available to an individual without fees each year.**

376.1219. 1. [Each policy issued by an entity offering individual and group health  
2 insurance which provides coverage on an expense-incurred basis, individual and group health  
3 service or indemnity type contracts issued by a nonprofit corporation, individual and group  
4 service contracts issued by a health maintenance organization, all self-insured group health  
5 arrangements to the extent not preempted by federal law, and all health care plans provided by  
6 managed health care delivery entities of any type or description,] **Each health carrier that**  
7 **offers or issues health benefit plans** that are delivered, issued for delivery, continued or  
8 renewed in this state on or after September 1, [1997] **2002**, shall provide coverage for formula,  
9 **pharmaceutically manufactured food supplements and treatment services** recommended by  
10 a physician for the treatment of a patient with phenylketonuria [or any inherited disease of amino  
11 and organic acids], **primary hypothyroidism, biotinidase deficiency, galactosemia,**  
12 **hemoglobinopathies, medium-chain acyl co-a dehydrogenase (MCAD) deficiency, maple**  
13 **syrup urine disease (MSUD), and other metabolic and genetic diseases.**

14 **2. For purposes of this section, "health carrier" and "health benefit plan" shall**  
15 **have the same meaning as defined in section 376.1350.**

16 **3.** The health care service required by this section shall not be subject to any greater  
17 deductible or co-payment than other similar health care services provided by the policy, contract  
18 or plan.

19 **[3.] 4.** This section shall not apply to a supplemental insurance policy, including a life  
20 care contract, accident-only policy, specified disease policy, hospital policy providing a fixed

- 21 daily benefit only, Medicare supplement policy, long-term care policy, or any other supplemental
- 22 policy as determined by the director of the department of insurance.