

SECOND REGULAR SESSION

HOUSE BILL NO. 1870

91ST GENERAL ASSEMBLY

INTRODUCED BY REPRESENTATIVE BARRY.

Read 1st time February 11, 2002, and 1000 copies ordered printed.

TED WEDEL, Chief Clerk

4523L.011

AN ACT

To repeal sections 191.323 and 191.331, RSMo, and to enact in lieu thereof three new sections relating to newborn screening data.

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

Section A. Sections 191.323 and 191.331, RSMo, are repealed and three new sections
2 enacted in lieu thereof, to be known as sections 191.323, 191.324 and 191.331, to read as
3 follows:

191.323. The department [may] **shall**:

2 (1) Develop and implement programs of professional education for physicians, medical
3 students, nurses, scientists, technicians and therapists regarding the causes, methods of treatment,
4 prevention and cure of genetic diseases;

5 (2) Develop and implement public educational programs regarding genetic diseases and
6 birth defects and programs available for genetic diagnosis, treatment and counseling;

7 (3) Conduct or support scientific research concerning the causes, mortality, methods of
8 treatment, prevention and cure of genetic diseases which are considered to be of major
9 importance to the problems of genetic disease and birth defects in Missouri, in cooperation with
10 other public and private agencies, except as provided in section 188.037, RSMo;

11 (4) Maintain a central registry, **as defined by the department**, to collect and store data
12 **on genetic diseases and birth defects to assure genetic services and appropriate follow-up**
13 **are provided, and** to facilitate the compiling of statistical information on the causes, treatment,
14 prevention and cure of genetic diseases. [Identifying information shall remain confidential
15 pursuant to the provisions of section 191.315.] Information [will] **shall** be reported to the

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

16 [Missouri board of health] **department** and other health care [agencies so that it may be used for
17 the prevention and treatment of] **providers to screen, treat, and provide services for persons**
18 **with** genetic diseases and birth defects **and to prevent such conditions. Any person who acts**
19 **in good faith in complying with this section by reporting the newborn test results and**
20 **required information to the department shall not be civilly or criminally liable for**
21 **furnishing the information required by the department;**

22 (5) Support genetic trainees annually for the pursuit of training in institutions in the state;

23 (6) Support new program development and specialized services which are not otherwise
24 available and are considered by the department to be of major importance to the public health
25 of Missouri.

191.324. Except as otherwise provided for in this section, the information contained
2 **in the central registry shall be confidential pursuant to section 191.317 and shall be**
3 **divulged or made public in a manner that discloses the identity of an individual. The**
4 **department may disclose and exchange such information as is necessary to assure screening**
5 **and to provide follow-up services for children tested or identified with birth defects, or**
6 **metabolic or genetic conditions to the following persons without a parent's or guardian's**
7 **written release:**

8 (1) **Employees of public agencies, departments, and political subdivisions who need**
9 **to know such information to carry out their official duties;**

10 (2) **Health care professionals or their agents and tertiary genetic centers who**
11 **provide the health care, or genetic diagnostic or counseling services for the child or family.**

12
13 **If a person discloses such information for any other purposes, the person is guilty of an**
14 **unauthorized release of confidential information and shall be civilly liable for damages.**

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

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

13 **good faith in complying with this section by reporting the newborn test follow-up results**
14 **to the department shall not be civilly or criminally liable for furnishing the information**
15 **required by the department.**

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

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

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

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

49 include education in these areas and the development of new programs related to these diseases.
50 7. Subject to appropriations provided for formula for the treatment of inherited diseases
51 of amino acids and organic acids, the department shall provide such formula to persons with
52 inherited diseases of amino acids and organic acids subject to the conditions described in this
53 subsection. State assistance pursuant to this subsection shall be available to an applicant only
54 after the applicant has shown that the applicant has exhausted all benefits from third party payers,
55 including, but not limited to, health insurers, domestic health services corporations, health
56 maintenance organizations, Medicare, Medicaid and other government assistance programs. The
57 department shall establish an income-based means test to be used to determine eligibility for the
58 formula made available pursuant to this section.