FIRST REGULAR SESSION

SENATE BILL NO. 493

92ND GENERAL ASSEMBLY

INTRODUCED BY SENATOR KENNEDY.

Read 1st time February 13, 2003, and 1,000 copies ordered printed.

TERRY L. SPIELER, Secretary.

1590S.01I

AN ACT

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

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Section A. Sections 191.323 and 191.331, RSMo, are repealed and three new sections enacted in lieu thereof, to be known as sections 191.323, 191.324, and 191.331, to read as follows:

191.323. **1.** The department may:

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

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

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

(4) Maintain a central registry**, as defined by the department,** to collect and store data **on genetic diseases and birth defects to assure genetic services and any post-treatment services are provided and** to facilitate the compiling of statistical information on the causes,

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

treatment, prevention and cure of genetic diseases. [Identifying information shall remain confidential pursuant to the provisions of section 191.315.] Information [will] **shall** be reported to the [Missouri board of health] **department** and other health care [agencies so that it may be used for the prevention and treatment of genetic diseases and birth defects] **providers to screen, treat and provide services for persons with genetic diseases and birth defects and to prevent such conditions**;

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

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

2. Any person who acts in good faith in complying with the provisions of subdivision (4) of subsection 1 of this section by reporting newborn test results or other required information to the department shall not be civilly or criminally liable for furnishing such information to the department.

191.324. Except as provided in this section, the information contained in the central registry shall be confidential and shall not be divulged or made public in a manner that discloses the identity of an individual pursuant to section 191.317. The department may disclose and exchange such information as is necessary to assure screening and to provide follow-up services for children tested or identified with birth defects, metabolic, or genetic conditions to the following persons without a parent's or guardian's written release:

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

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

If any person discloses such information for any other purposes, such person is guilty of an unauthorized release of confidential information and the person who discloses is liable for civil damages.

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 **of the department**. 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. **Any person who acts in good faith in complying with the provisions of this section by reporting newborn test results to the department shall not be civilly or criminally liable for furnishing such information to the department.**

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

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

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

6. Notwithstanding the provisions of section 192.015, RSMo, to the contrary, the department may, by rule, annually determine and impose a reasonable fee for each newborn screening test made in any of its laboratories. The department may collect the fee from any entity or individual described in subsection 1 of this section in a form and manner established by the department. Such fee shall be considered as a cost payable to such entity by a health care third party payer, including, but not limited to, a health insurer operating pursuant to chapter 376, RSMo, a domestic health services corporation or health maintenance organization operating pursuant to chapter 354, RSMo, and a governmental or entitlement program operating pursuant to state law. Such fee shall not be considered as part of the internal laboratory costs of the persons and entities described in subsection 1 of this section by such health care third party payers. No individual shall be denied screening because of inability to pay. Such fees shall be deposited in a separate account in the public health services fund created in section 192.900, RSMo, and funds in such account shall be used for the support of the newborn

screening program and activities related to the screening, diagnosis, and treatment, including special dietary products, of persons with metabolic and genetic diseases; and follow-up activities that ensure that diagnostic evaluation, treatment and management is available and accessible once an at-risk family is identified through initial screening; and for no other purpose. These programs may include education in these areas and the development of new programs related to these diseases.

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

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