

HOUSE BILL NO. 995

101ST GENERAL ASSEMBLY

INTRODUCED BY REPRESENTATIVE TAYLOR (139).

1553H.011

DANA RADEMAN MILLER, Chief Clerk

AN ACT

To repeal sections 191.317 and 375.1309, RSMo, and to enact in lieu thereof three new sections relating to medical confidentiality, with penalty provisions and an emergency clause.

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

Section A. Sections 191.317 and 375.1309, RSMo, are repealed and three new sections enacted in lieu thereof, to be known as sections 191.241, 191.317, and 375.1309, to read as follows:

191.241. 1. For purposes of this section, the term "laboratory" means any department of health and senior services laboratory or any other public or private laboratory.

2. Any biological specimen collected or received by a laboratory shall not be released for purposes of anonymous scientific study unless the individual from whom the specimen was obtained consents to such release.

3. At the time of collection of a biological specimen, the individual from whom the biological specimen was obtained may direct the laboratory that is collecting or receiving the specimen to:

(1) Return a biological specimen that remains after testing has been performed;

(2) Destroy a biological specimen in a scientifically acceptable manner after testing has been performed; or

(3) Store a biological specimen but not release the biological specimen for anonymous scientific study.

4. At the time of collection of a biological specimen, the individual from whom the specimen was obtained shall be informed of his or her right to give any direction to the

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.

17 **laboratory under subsection 3 of this section. Except as provided in subsection 5 of this**
18 **section, the laboratory shall not release the biological specimen for anonymous scientific**
19 **study unless the individual from whom the specimen was obtained consented to such**
20 **release at the time of collection.**

21 **5. For any biological specimen in the possession of a laboratory before the effective**
22 **date of this section for which consent to release the specimen for anonymous scientific**
23 **study was not obtained at the time of collection, the laboratory may release the specimen**
24 **for anonymous scientific study if it contacts the individual from whom the specimen was**
25 **obtained and obtains his or her consent to the release.**

26 **6. At the time a laboratory releases any specimen for anonymous scientific study,**
27 **the laboratory shall inform the individual from whom consent was obtained of the fact of**
28 **the release.**

29 **7. A biological specimen released for anonymous scientific study under this section**
30 **shall not contain information that may be used to determine the identity of the donor.**

31 **8. The provisions of this section shall not apply to biological specimens subject to**
32 **the requirements of section 375.1309 or biological specimens obtained in accordance with**
33 **section 191.331 that are subject to the requirements of section 191.317.**

191.317. 1. All testing results and personal information obtained from any individual,
2 or from specimens from any individual, shall be held confidential and be considered a
3 confidential medical record, except for such information as the individual, parent or guardian
4 consents to be released; but the individual must first be fully informed of the scope of the
5 information ~~[requests]~~ **requested** to be released, of the risks, benefits and purposes for such
6 release, and of the identity of those to whom the information will be released. Statistical data
7 compiled without reference to the identity of any individual shall not be declared confidential.
8 Notwithstanding any other provision of law to the contrary, the department may release the
9 results of newborn screening tests to a child's health care professional.

10 **2. (1) The specimen shall be retained for five years after initial submission to the**
11 **department. After five years, the specimen shall be destroyed. ~~[Unless otherwise directed under~~**
12 **~~this section,~~ A biological specimen may be released for purposes of anonymous scientific study**
13 **if the parent or legal guardian of the child from whom the specimen was obtained consents**
14 **to such release.**

15 **(2) At the time of collection, the parent or legal guardian of the child from whom a**
16 **biological specimen was obtained may direct the department to:**

17 **~~(1)~~ (a) Return a biological specimen that remains after all screening tests have been**
18 **performed;**

19 ~~[(2)]~~ (b) Destroy a biological specimen in a scientifically acceptable manner after all
20 screening tests required under section 191.331 or rule promulgated thereunder have been
21 performed; or

22 ~~[(3)]~~ (c) Store a biological specimen but not release the biological specimen for
23 anonymous scientific study.

24 **(3) At the time of collection, the parent or legal guardian of the child from whom**
25 **a biological specimen was obtained shall be informed of his or her right to give any**
26 **direction to the department under subdivision (2) of this subsection. Except as provided**
27 **in subdivision (4) of this subsection, the department shall not release the biological**
28 **specimen for anonymous scientific study unless the parent or legal guardian consented to**
29 **such release at the time of collection.**

30 **(4) For any biological specimen in the possession of the department before the**
31 **effective date of this section for which consent to release the specimen for anonymous**
32 **scientific study was not obtained at the time of collection, the department may release the**
33 **specimen for anonymous scientific study if it contacts the parent or legal guardian and**
34 **obtains his or her consent to the release.**

35 **(5) At the time the department releases any specimen for anonymous scientific**
36 **study, the department shall inform the parent or legal guardian from whom consent was**
37 **obtained of the fact of the release.**

38 3. A biological specimen released for anonymous study under this section shall not
39 contain information that may be used to determine the identity of the donor.

375.1309. 1. Any person who, in the ordinary course of business, practice of a
2 profession or rendering of a service, creates, stores, receives or furnishes genetic information,
3 as such term is defined in subdivision (3) of section 375.1300, **or any biological specimen that**
4 **may be used to conduct a genetic test, as defined in section 375.1300,** shall hold such
5 information as confidential medical records and shall not **release such biological specimen for**
6 **any purpose, including for anonymous scientific study, or** disclose such genetic information
7 except pursuant to written authorization of the person to whom such information pertains **or**
8 **from whom such biological specimen was obtained** or to that person's authorized
9 representative. The requirements of this section shall not apply to:

10 (1) Statistical data compiled without reference to the identity of an individual;

11 (2) ~~[Health research conducted in accordance with the provisions of the federal common~~
12 ~~rule protecting the rights and welfare of research participants (45 CFR 46 and 21 CFR 50 and~~
13 ~~56), or to health research using medical archives or databases in which the identity of individuals~~
14 ~~is protected from disclosure by coding or encryption, or by removing all identities]~~ **Any law**

15 **enforcement agency collecting or holding evidence for the investigation or prosecution of**
16 **an alleged or actual criminal offense;**

17 (3) The release of such information **or specimen** pursuant to legal or regulatory process;

18 or

19 (4) The release of such information **or specimen** for body identification.

20 2. If ~~[the director determines that]~~ a person has engaged, is engaging in, or has taken a
21 substantial step toward engaging in an act, practice or course of business constituting a violation
22 of this section or a rule adopted or order issued pursuant thereto, or that a person has materially
23 aided or is materially aiding an act, practice, omission, or course of business constituting a
24 violation of this section or a rule adopted or order issued pursuant thereto, the director may issue
25 such administrative orders as authorized under section 374.046. A violation of any of these
26 sections is a ~~[level two violation under section 374.049]~~ **class A felony**.

27 3. If ~~[the director believes that]~~ a person has engaged, is engaging in, or has taken a
28 substantial step toward engaging in an act, practice or course of business constituting a violation
29 of this section or a rule adopted or order issued pursuant thereto, or that a person has materially
30 aided or is materially aiding an act, practice, omission, or course of business constituting a
31 violation of this section or a rule adopted or order issued pursuant thereto, the director may
32 maintain a civil action for relief authorized under section 374.048. A violation of any of these
33 sections is a level two violation under section 374.049.

Section B. Because immediate action is necessary to protect the privacy rights of the
2 residents of this state during the ongoing COVID-19 pandemic, section A of this act is deemed
3 necessary for the immediate preservation of the public health, welfare, peace, and safety, and is
4 hereby declared to be an emergency act within the meaning of the constitution, and section A of
5 this act shall be in full force and effect upon its passage and approval.

✓