

HOUSE AMENDMENT NO. ____
TO
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Offered By

AMEND House Amendment No. ____ to House Committee Substitute for Senate Substitute for Senate Bill No. 580, Page 1, Line 1, by inserting after the number "580," the following:

"Page 24, Section 191.255, Line 5, by inserting after said section and line the following:

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

2. The specimen shall be ~~[retained for five years after initial submission to the department. After five years, the specimen shall be]~~ destroyed immediately after the specific tests authorized at the time of collection are completed. ~~[Unless otherwise directed under this section, a biological specimen may be released for purposes of anonymous scientific study. At the time of collection, the parent or legal guardian of the child from whom a biological specimen was obtained may direct the department to:~~

——— (1) Return a biological specimen that remains after all screening tests have been performed;

——— (2) Destroy a biological specimen in a scientifically acceptable manner after all screening tests required under section 191.331 or rule promulgated thereunder have been performed; or

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

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

Further amend said bill, Page 68, Section 338.200, Line 41, by inserting after said section and line the following:

"375.1309. 1. Any person who, in the ordinary course of business, practice of a profession or rendering of a service, creates, stores, receives or furnishes genetic information, as such term is defined in subdivision (3) of section 375.1300, or any biologic specimen that may be used to

Action Taken _____ Date _____

1 conduct a genetic test, as defined in 375.1300, shall hold such information as confidential medical
 2 records and shall not disclose such genetic information except pursuant to written authorization of
 3 the person to whom such information pertains or to that person's authorized representative. The
 4 requirements of this section shall not apply to:

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

6 (2) ~~[Health research conducted in accordance with the provisions of the federal common~~
 7 ~~rule protecting the rights and welfare of research participants (45 CFR 46 and 21 CFR 50 and 56), or~~
 8 ~~to health research using medical archives or databases in which the identity of individuals is~~
 9 ~~protected from disclosure by coding or encryption, or by removing all identities]~~ Any law
 10 enforcement agency collecting or holding evidence for the investigation or prosecution of an alleged
 11 or actual crime;

12 (3) The release of such information pursuant to legal or regulatory process; or

13 (4) The release of such information for body identification.

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

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

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 29 Further amend said bill,"; and

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 31 Further amend said amendment and page, Line 24, by inserting after all of said line the following:

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 33 "Further amend said bill and page, Section C, Line 2, by inserting after said section and line the
 34 following:

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 36 "Section D. Because immediate action is necessary to protect the rights of citizens, the
 37 enactment of section 1 of this act is deemed necessary for the immediate preservation of the public
 38 health, welfare, peace, and safety, and is hereby declared to be an emergency act within the meaning
 39 of the constitution, and the enactment of section 1 of this act shall be in full force and effect upon its
 40 passage and approval."; and"; and

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 42 Further amend said bill by amending the title, enacting clause, and intersectional references
 43 accordingly.

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 45 THIS AMENDS 3142H06.18H