

HOUSE AMENDMENT NO. _____
TO
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Offered By

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

3
4 "Page 24, Section 191.255, Line 5, by inserting after said section and line the following:

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

15 2. The specimen shall be [~~retained for five years after initial submission to the department.~~
16 ~~After five years, the specimen shall be~~] destroyed immediately after the specific tests authorized at
17 the time of collection are completed[~~Unless~~] ; except that, [otherwise directed under this section,] a
18 biological specimen may be retained and released for purposes of anonymous scientific study with
19 the affirmative consent of the individual, parent or guardian. At the time of collection, the parent or
20 legal guardian of the child from whom a biological specimen was obtained may direct the
21 department to:

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

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

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

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

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30 Further amend said bill,"; and

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32 Further amend said amendment Page 1, Line 3 by inserting after all of said line the following:

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34 "Further amend said bill, Page 59, Section 334.150, Line 8, by inserting after the word "state" the

Action Taken _____ Date _____

1 words ", if he or she complies with the provisions of chapter 188,"; and

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

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6 "375.1309. 1. Any person who, in the ordinary course of business, practice of a profession
7 or rendering of a service, creates, stores, receives or furnishes genetic information, as such term is
8 defined in subdivision (3) of section 375.1300, or any biologic specimen that may be used to
9 conduct a genetic test, as defined in 375.1300, shall hold such information as confidential medical
10 records and shall not disclose such genetic information except pursuant to written authorization of
11 the person to whom such information pertains or to that person's authorized representative. The
12 requirements of this section shall not apply to:

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

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

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

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

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

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

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37 Further amend said bill Page 73, Section C, Line 2, by inserting after said section and line the
38 following:

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

45
46 Further amend said bill by amending the title, enacting clause, and intersectional references
47 accordingly.

48 THIS AMENDS 3142H06.12H