

By the Committee on Health Regulation

588-00656-11

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1 A bill to be entitled

2 An act relating to a review under the Open Government
3 Sunset Review Act; amending s. 381.8531, F.S.;
4 providing that personal identifying information
5 pertaining to a donor to the central repository for
6 brain tumor biopsies or the brain tumor registry of
7 the Florida Center for Brain Tumor Research is
8 confidential and exempt from public-records
9 requirements; providing an exception under certain
10 conditions for information disclosed to a person
11 engaged in bona fide research; providing for future
12 legislative review and repeal of the exemption under
13 the Open Government Sunset Review Act; providing a
14 finding of public necessity; providing an effective
15 date.

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17 Be It Enacted by the Legislature of the State of Florida:

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19 Section 1. Section 381.8531, Florida Statutes, is amended
20 to read:

21 381.8531 Florida Center for Brain Tumor Research; public
22 records exemption.—

23 (1) The following information held by the Florida Center
24 for Brain Tumor Research before, on, or after July 1, 2011, is
25 confidential and exempt from s. 119.07(1) and s. 24, Art. I of
26 the State Constitution:

27 (a) Any personal identifying information pertaining to a
28 donor to the central repository for brain tumor biopsies or the
29 brain tumor registry. An individual's medical record.

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30 (b) Any information received from an individual from
31 another state or nation or the Federal Government which that is
32 otherwise confidential or exempt pursuant to the laws of that
33 state or nation or pursuant to federal law.

34 (2) Such information may be disclosed to a person engaged
35 in bona fide research if that person agrees to:

36 (a) Submit to the Florida Center for Brain Tumor Research a
37 research plan that has been approved by an institutional review
38 board and that specifies the exact nature of the information
39 requested, the intended use of the information, and the reason
40 that the research could not practicably be conducted without the
41 information;

42 (b) Sign a confidentiality agreement with the Florida
43 Center for Brain Tumor Research;

44 (c) Maintain the confidentiality of the personal
45 identifying information or otherwise confidential or exempt
46 information; and

47 (d) To the extent permitted by law and after the research
48 has concluded, destroy any confidential records or information
49 obtained.

50 (3) (2) This section is subject to the Open Government
51 Sunset Review Act in accordance with s. 119.15 and shall stand
52 repealed on October 2, 2016 2011, unless reviewed and saved from
53 repeal through reenactment by the Legislature.

54 Section 2. The Legislature finds that it is a public
55 necessity that personal identifying information pertaining to a
56 donor to the central repository for brain tumor biopsies or the
57 brain tumor registry of the Florida Center for Brain Tumor
58 Research pursuant to s. 381.853, Florida Statutes, be made

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59 confidential and exempt from public-records requirements. Brain
60 tumors are a leading cause of death, and there is a significant
61 need to discover cures and develop treatment modalities for
62 brain tumors, which can be facilitated by a registry and
63 repository of specimens from persons diagnosed with brain
64 tumors. The disclosure of such information could hinder the
65 availability of specimens for research. Matters of personal
66 health are traditionally private and confidential concerns
67 between the patient and the health care provider. The private
68 and confidential nature of personal health matters pervades both
69 the public and private health care sectors. For these reasons,
70 the donor's expectation of and right to privacy in all matters
71 regarding his or her personal health necessitates this
72 exemption. The Legislature further finds that it is a public
73 necessity to protect a patient's medical diagnosis and
74 information because the release of such information could be
75 defamatory to the patient or could cause unwarranted damage to
76 the name or reputation of the patient.

77 Section 3. This act shall take effect July 1, 2011.