

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.; providing
 4 that personal identifying information of a donor to the
 5 central repository for brain tumor biopsies or the brain
 6 tumor registry of the Florida Center for Brain Tumor
 7 Research is confidential and exempt from public records
 8 requirements; providing for retroactive application of the
 9 exemption; providing an exception to the exemption for a
 10 person engaged in bona fide research provided certain
 11 conditions are met; providing for future legislative
 12 review and repeal of the exemption under the Open
 13 Government Sunset Review Act; providing a statement of
 14 public necessity; providing an effective date.

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

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

20 381.8531 Florida Center for Brain Tumor Research; public
 21 records exemption.—

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

26 (a) Personal identifying information of a donor to the
 27 central repository for brain tumor biopsies or the brain tumor
 28 registry. ~~An individual's medical record.~~

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

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

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

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

43 (c) Maintain the confidentiality of the information
44 received; and

45 (d) To the extent permitted by law and after the research
46 has concluded, destroy any confidential information obtained.

47 (3)-(2) This section is subject to the Open Government
48 Sunset Review Act in accordance with s. 119.15 and shall stand
49 repealed on October 2, 2016 ~~2011~~, unless reviewed and saved from
50 repeal through reenactment by the Legislature.

51 Section 2. The Legislature finds that it is a public
52 necessity that personal identifying information pertaining to a
53 donor to the central repository for brain tumor biopsies or the
54 brain tumor registry of the Florida Center for Brain Tumor
55 Research pursuant to s. 381.8531, Florida Statutes, be made
56 confidential and exempt from public records requirements. Brain

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57 tumors are a leading cause of death, and there is a significant
58 need to discover cures and develop treatment modalities for
59 brain tumors, which can be facilitated by a registry and
60 repository of specimens from persons diagnosed with brain
61 tumors. The disclosure of such information could hinder the
62 availability of specimens for research. Matters of personal
63 health are traditionally private and confidential concerns
64 between the patient and the health care provider. The private
65 and confidential nature of personal health matters pervades both
66 the public and private health care sectors. For these reasons,
67 the donor's expectation of and right to privacy in all matters
68 regarding his or her personal health necessitates this
69 exemption.

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