

BILL

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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.; 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 public record exemption; providing an exception to the
 10 exemption for a person engaged in bona fide research
 11 provided certain conditions are met; providing for future
 12 legislative review and repeal of the exemption under the
 13 Open Government Sunset Review Act; providing a statement
 14 of public necessity; providing an effective date.

15
 16 Be It Enacted by the Legislature of the State of Florida:

17
 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 (2) This section is subject to the Open Government Sunset
 48 Review Act in accordance with s. 119.15 and shall stand repealed
 49 on October 2, 2016 ~~2011~~, unless reviewed and saved from repeal
 50 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. 381.853, 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.