CHAPTER 2011-203

House Bill No. 7079

An act relating to a review under the Open Government Sunset Review Act; amending s. 381.8531, F.S.; providing that personal identifying information of a donor to the central repository for brain tumor biopsies or the brain tumor registry of the Florida Center for Brain Tumor Research is confidential and exempt from public records requirements; providing for retroactive application of the exemption; providing an exception to the exemption for a person engaged in bona fide research provided certain conditions are met; providing for future legislative review and repeal of the exemption under the Open Government Sunset Review Act; providing a statement of public necessity; providing an effective date.

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

- Section 1. Section 381.8531, Florida Statutes, is amended to read:
- 381.8531 Florida Center for Brain Tumor Research; public records exemption.—
- (1) The following information held by the Florida Center for Brain Tumor Research <u>before</u>, <u>on</u>, <u>or after July 1</u>, <u>2011</u>, is confidential and exempt from s. 119.07(1) and s. 24, Art. I of the State Constitution:
- (a) Personal identifying information of a donor to the central repository for brain tumor biopsies or the brain tumor registry. An individual's medical record.
- (b) Any information received from an individual from another state or nation or the Federal Government that is otherwise confidential or exempt pursuant to the laws of that state or nation or pursuant to federal law.
- (2) Such information may be disclosed to a person engaged in bona fide research if that person agrees to:
- (a) Submit to the Florida Center for Brain Tumor Research a research plan that has been approved by an institutional review board and that specifies the exact nature of the information requested, the intended use of the information, and the reason that the research could not practicably be conducted without the information;
- (b) Sign a confidentiality agreement with the Florida Center for Brain Tumor Research;
 - (c) Maintain the confidentiality of the information received; and
- (d) To the extent permitted by law and after the research has concluded, destroy any confidential information obtained.

(3)(2) This section is subject to the Open Government Sunset Review Act in accordance with s. 119.15 and shall stand repealed on October 2, 2016 2011, unless reviewed and saved from repeal through reenactment by the Legislature.

Section 2. The Legislature finds that it is a public necessity that personal identifying information pertaining to a donor to the central repository for brain tumor biopsies or the brain tumor registry of the Florida Center for Brain Tumor Research pursuant to s. 381.8531, Florida Statutes, be made confidential and exempt from public records requirements. Brain tumors are a leading cause of death, and there is a significant need to discover cures and develop treatment modalities for brain tumors, which can be facilitated by a registry and repository of specimens from persons diagnosed with brain tumors. The disclosure of such information could hinder the availability of specimens for research. Matters of personal health are traditionally private and confidential concerns between the patient and the health care provider. The private and confidential nature of personal health matters pervades both the public and private health care sectors. For these reasons, the donor's expectation of and right to privacy in all matters regarding his or her personal health necessitates this exemption.

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

Approved by the Governor June 21, 2011.

Filed in Office Secretary of State June 21, 2011.