

HOUSE OF REPRESENTATIVES STAFF ANALYSIS

BILL #: PCB GVOPS 16-03 OGSR Florida Center for Brain Tumor Research

SPONSOR(S): Government Operations Subcommittee

TIED BILLS: **IDEN./SIM. BILLS:** SB 7024

REFERENCE	ACTION	ANALYST	STAFF DIRECTOR or BUDGET/POLICY CHIEF
Orig. Comm.: Government Operations Subcommittee		Toliver	Williamson

SUMMARY ANALYSIS

The Open Government Sunset Review Act requires the Legislature to review each public record and each public meeting exemption five years after enactment. If the Legislature does not reenact the exemption, it automatically repeals on October 2nd of the fifth year after enactment.

The Florida Center for Brain Tumor Research (center) is established within the Evelyn F. and William L. McKnight Brain Institute of the University of Florida. The goal of the center is to find cures for brain tumors and its purpose is to:

- Foster collaboration with brain cancer research organizations and institutions;
- Provide a central repository for brain tumor biopsies;
- Improve and monitor brain tumor biomedical research programs;
- Facilitate funding opportunities; and
- Foster improved technology transfer of brain tumor research findings into clinical trials and widespread public use.

Current law provides a public record exemption for the following information held by the center before, on, or after July 1, 2011:

- Personal identifying information of a donor to the central repository for brain tumor biopsies or the brain tumor registry; and
- 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.

The bill reenacts the public record exemption, which will repeal on October 2, 2016, if this bill does not become law.

The bill does not appear to have a fiscal impact on state or local governments.

FULL ANALYSIS

I. SUBSTANTIVE ANALYSIS

A. EFFECT OF PROPOSED CHANGES:

Background

Open Government Sunset Review Act

The Open Government Sunset Review Act (Act)¹ sets forth a legislative review process for newly created or substantially amended public record or public meeting exemptions. It requires an automatic repeal of the exemption on October 2nd of the fifth year after creation or substantial amendment, unless the Legislature reenacts the exemption.²

The Act provides that a public record or public meeting exemption may be created or maintained only if it serves an identifiable public purpose. In addition, it may be no broader than is necessary to meet one of the following purposes:

- Allows the state or its political subdivisions to effectively and efficiently administer a governmental program, which administration would be significantly impaired without the exemption.
- Protects sensitive personal information that, if released, would be defamatory or would jeopardize an individual's safety; however, only the identity of an individual may be exempted under this provision.
- Protects trade or business secrets.³

If, and only if, in reenacting an exemption that will repeal and the exemption is expanded (essentially creating a new exemption), then a public necessity statement and a two-thirds vote for passage are required.⁴ If the exemption is reenacted with grammatical or stylistic changes that do not expand the exemption, if the exemption is narrowed, or if an exception to the exemption is created⁵ then a public necessity statement and a two-thirds vote for passage are not required.

Florida Center for Brain Tumor Research

The Florida Center for Brain Tumor Research (center) is established within the Evelyn F. and William L. McKnight Brain Institute of the University of Florida.⁶ The goal of the center is to find cures for brain tumors⁷ and its purpose is to:

- Foster collaboration with brain cancer research organizations and other institutions;
- Provide a central repository for brain tumor biopsies from individuals throughout the state;
- Improve and monitor brain tumor biomedical research programs within the state;
- Facilitate funding opportunities; and
- Foster improved technology transfer of brain tumor research findings into clinical trials and widespread public use.⁸

Current law requires the center to be funded through private, state, and federal sources.⁹ According to the center, 100 percent of its funding is provided by the state when funds are appropriated, and an additional 20 percent above its working budget is provided by Accelerate Brain Cancer Cure, which is a

¹ Section 119.15, F.S.

² Section 119.15(3), F.S.

³ Section 119.15(6)(b), F.S.

⁴ Section 24(c), Art. I, FLA. CONST.

⁵ An example of an exception to a public record exemption would be allowing another agency access to confidential and exempt records.

⁶ Section 381.853(3), F.S.

⁷ Section 381.853(3)(b), F.S.

⁸ Section 381.853(3)(a), F.S.

⁹ Section 381.853(3)(g), F.S.

private foundation.¹⁰ However, during years when funding is not provided, the University of Florida Department of Neurosurgery provides funding.¹¹

Current law establishes a scientific advisory council (council) within the center.¹² The council, which must meet at least annually,¹³ consists of members from the University of Florida, Scripps Research Institute Florida, University of Miami, Mayo Clinic in Jacksonville, Cleveland Clinic Florida, H. Lee Moffitt Cancer Center and Research Institute, University of Florida Health Cancer Center at Orlando Health, and a neurosurgeon in private practice.¹⁴

Public Record Exemption under Review

In 2006, the Legislature created a public record exemption for the following information held by the center:

- An individual's medical record; and
- 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.¹⁵

Pursuant to the Open Government Sunset Review Act, the public record exemption was scheduled to repeal on October 2, 2011; however, the Legislature reenacted the exemption with changes. In 2011, the public record exemption for medical records was replaced with a public record exemption for personal identifying information of a donor to the central repository for brain tumor biopsies or the brain tumor registry.¹⁶ The public record exemption was also made retroactive.¹⁷

As such, the following information is currently confidential and exempt¹⁸ from public record requirements:

- Personal identifying information of a donor to the central repository for brain tumor biopsies or the brain tumor registry.
- 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.¹⁹

The confidential and exempt information may be disclosed to a person engaged in bona fide research if that person agrees to:

- Submit a research plan to the center that has been approved by an institutional review board. The plan must specify the exact nature of the information requested, the intended use of the requested information, and the reason the research could not practicably be conducted without the information;
- Sign a confidentiality agreement with the center;
- Maintain the confidentiality of the information received; and

¹⁰ Open Government Sunset Review of s. 381.8531, F.S., relating to the Florida Center for Brain Tumor Research, questionnaire by House and Senate staff, August 12, 2015, at question 1. (hereinafter referred to as OGSR Questionnaire)(on file with the Government Operations Subcommittee).

¹¹ *Id.*

¹² Section 381.853(4), F.S.

¹³ *Id.*

¹⁴ OGSR Questionnaire at question 2.

¹⁵ Chapter 2006-259, L.O.F.; codified as s. 381.8531, F.S.

¹⁶ Chapter 2011-203, L.O.F.

¹⁷ In 2001, the Florida Supreme Court ruled that a public record exemption does not apply retroactively unless the legislation clearly expresses such intent. *Memorial Hospital-West Volusia, Inc. v. News-Journal Corporation*, 729 So.2d 373 (Fla. 2001).

¹⁸ There is a difference between records the Legislature designates exempt from public records requirements and those the Legislature deems confidential and exempt. A record classified as exempt from public disclosure may be disclosed under certain circumstances. See *Williams v. City of Minneola*, 575 So. 2d 683, 687 (Fla. 5th DCA 1991) *review denied*, 589 So. 2d 289 (Fla. 1991). If the Legislature designates a record as confidential and exempt from public disclosure, such record may not be released by the custodian of public records to anyone other than the persons or entities specifically designated in statute. See *WFTV, Inc. v. Sch. Bd. of Seminole Cnty*, 874 So. 2d 48, 53 (Fla. 5th DCA 2004), *review denied*, 892 So. 2d 1015 (Fla. 2004); Op. Att'y Gen. Fla. 85-692 (1985).

¹⁹ Section 381.8531(1), F.S.

- Destroy any confidential information to the extent permitted by law and upon conclusion of the research.²⁰

The 2011 public necessity statement for the public record exemption provides that:

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...For these reasons, the donor's expectation of and right to privacy in all matters regarding his or her personal health necessitates this exemption.²¹

Pursuant to the Open Government Sunset Review Act, the exemption will repeal on October 2, 2016, unless reenacted by the Legislature.²²

During the 2015 interim, subcommittee staff sent the center a questionnaire as part of the Open Government Sunset Review process. The center recommended reenactment of the public record exemption and provided that "[i]f the information is not exempt, the researchers will have to inform potential donors that their data is a public record, thus risking the loss of those potential donors."²³

Effect of the Bill

The bill removes the repeal date, thereby reenacting the public record exemption for the following information held by center before, on, or after July 1, 2011:

- Personal identifying information of a donor to the central repository for brain tumor biopsies or the brain tumor registry; and
- 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.

B. SECTION DIRECTORY:

Section 1 amends s. 381.8531, F.S., to save from repeal the public record exemption for certain information held by the Florida Center for Brain Tumor Research.

Section 2 provides an effective date of October 1, 2016.

II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT

A. FISCAL IMPACT ON STATE GOVERNMENT:

1. Revenues:

None.

2. Expenditures:

None.

B. FISCAL IMPACT ON LOCAL GOVERNMENTS:

²⁰ Section 381.8531(2), F.S.

²¹ Section 2, ch. 2011-203, L.O.F.

²² Section 381.8531(3), F.S.

²³ OGSR questionnaire at question 9.

1. Revenues:

None.

2. Expenditures:

None.

C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:

None.

D. FISCAL COMMENTS:

None.

III. COMMENTS

A. CONSTITUTIONAL ISSUES:

1. Applicability of Municipality/County Mandates Provision:

Not applicable. This bill does not appear to affect county or municipal governments.

2. Other:

None.

B. RULE-MAKING AUTHORITY:

None.

C. DRAFTING ISSUES OR OTHER COMMENTS:

None.

IV. AMENDMENTS/ COMMITTEE SUBSTITUTE CHANGES

Not applicable.