

FINAL BILL ANALYSIS

BILL #: HB 7079

FINAL HOUSE FLOOR ACTION:

113 Y's 1 N's

SPONSOR: Rep. Bileca

GOVERNOR'S ACTION: Approved

COMPANION BILLS: SB 420

SUMMARY ANALYSIS

HB 7079 passed the House on April 28, 2011, and subsequently passed the Senate on April 29, 2011. The bill was approved by the Governor on June 21, 2011, chapter 2011-203, Laws of Florida, and takes effect July 1, 2011.

The bill reenacts the public record exemption for the Florida Center for Brain Tumor Research.

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 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.

Current law provides a public record exemption for the center. Medical records and 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, are confidential and exempt from public records requirements.

The bill reenacts the public record exemption, which will repeal on October 2, 2011, if this bill does not become law. It expands the public record exemption by providing that personal identifying information of a donor to the central repository for brain tumor biopsies or the brain tumor registry is confidential and exempt. This change is considered an expansion of the current exemption because it includes personal identifying information of a donor in all records, not just medical records. The bill also provides for retroactive application of the public record exemption.

The bill authorizes the release of confidential and exempt information to a person engaged in bona fide research provided certain requirements are met.

The bill extends the repeal date from October 2, 2011, to October 2, 2016. It also provides a public necessity statement as required by the State Constitution.

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

This document does not reflect the intent or official position of the bill sponsor or House of Representatives.

I. SUBSTANTIVE INFORMATION

A. EFFECT OF CHANGES:

Background

Open Government Sunset Review Act

The Open Government Sunset Review Act¹ 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.

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.

If, and only if, in reenacting an exemption that will repeal, the exemption is expanded (essentially creating a new exemption), then a public necessity statement and a two-thirds vote for passage are required.² 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 created³ 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.⁴ The goal of the center is to find cures for brain tumors⁵ 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.⁶

¹ Section 119.15, F.S.

² Section 24(c), Art. I of the State Constitution.

³ An example of an exception to a public record exemption would be allowing another agency access to confidential or exempt records.

⁴ Chapter 2006-258, L.O.F.; codified as s. 381.853(4), F.S.

⁵ Section 381.853(4)(b), F.S.

⁶ Section 381.853(4)(a), F.S.

The center is funded through private, state, and federal sources.⁷ According to the center, 10 percent of its funding is provided from private sources and 90 percent is provided from state sources.⁸

Current law establishes a scientific advisory council (council) within the center.⁹ The council must meet at least annually; however, it generally meets twice per year.¹⁰ The Council 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, M.D. Anderson Cancer Center Orlando, and a neurosurgeon in private practice.¹¹

Public Record Exemption under Review

In 2006, the Legislature created a public record exemption for certain information held by the Florida Center for Brain Tumor Research (center).¹² The following information is confidential and exempt¹³ from public records requirements:

- Medical records.¹⁴
- 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 exemption will repeal on October 2, 2011, unless reenacted by the Legislature.

According to the center, it extracts the information it uses from medical records of donors to the central repository for brain tumor biopsies and the brain tumor registry, and from other records such as quality of life surveys. Information the center receives from an individual from another state or nation or the Federal Government also is extracted from medical records.¹⁶

⁷ Section 381.853(4)(g), F.S.; the Legislature initially appropriated \$500,000 for the center and in 2009 and 2010, the Legislature appropriated \$500,000 (*see* chapters 2009-81 and 2010-152, L.O.F.)

⁸ Open Government Sunset Review of s. 381.8531, F.S., relating to the Florida Center for Brain Tumor Research, questionnaire by House staff, September 8, 2010, at question 1. (on file with the Government Operations Subcommittee).

⁹ Section 381.853(5), F.S.

¹⁰ Section 381.853(5), F.S., and Open Government Sunset Review of s. 381.8531, F.S., relating to the Florida Center for Brain Tumor Research, questionnaire by House staff, September 8, 2010, at question 2.b. (on file with the Government Operations Subcommittee).

¹¹ *Id.* at question 2.a.

¹² Chapter 2006-259, L.O.F.; codified as s. 381.8531, F.S.

¹³ There is a difference between records the Legislature designates as exempt from public record requirements and those the Legislature deems confidential and exempt. A record classified as exempt from public disclosure may be disclosed under certain circumstances. (*See WFTV, Inc. v. The School Board of Seminole*, 874 So.2d 48, 53 (Fla. 5th DCA 2004), review denied 892 So.2d 1015 (Fla. 2004); *City of Riviera Beach v. Barfield*, 642 So.2d 1135 (Fla. 4th DCA 1994); *Williams v. City of Minneola*, 575 So.2d 687 (Fla. 5th DCA 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 the statutory exemption. (*See* Attorney General Opinion 85-62, August 1, 1985).

¹⁴ Section 381.8531(1)(a), F.S.

¹⁵ Section 381.8531(1)(b), F.S.

¹⁶ Open Government Sunset Review of s. 381.8531, F.S., relating to the Florida Center for Brain Tumor Research, questionnaire by House staff, September 8, 2010, at question 3.b. and 4.c. (on file with the Government Operations Subcommittee).

The center has requested that the exemption be revised to:

- Reflect its current practice of extracting donor information from medical records or other records, such as quality of life surveys.
- Allow researchers access to the confidential and exempt information since the purpose of the center is to provide tissue samples and clinical data for researchers who are conducting studies to find improved treatments or possible cures for brain tumors.¹⁷

Effect of Proposed Changes

The bill reenacts and expands the public record exemption for the center. It expands the public record exemption by providing that personal identifying information of a donor to the central repository for brain tumor biopsies or the brain tumor registry¹⁸ is confidential and exempt. This change is considered an expansion of the current exemption because it includes personal identifying information of a donor in *all* records, not just medical records. The bill also provides for retroactive application of the public record exemption.

The bill authorizes the release of confidential and exempt information to a person engaged in bona fide research if that person agrees to:

- Submit to the center a research plan that has been approved by an institutional review board¹⁹ and that specifies the exact nature of the information requested, intended use of the information, and reason that the research could not practicably be conducted without the information;
- Sign a confidentiality agreement with the center;
- Maintain the confidentiality of the personal identifying information or the information that is otherwise confidential or exempt pursuant to the laws of another state or nation or the Federal Government; and
- Destroy the confidential information to the extent permitted by law and after the research has concluded.

Because the bill expands the current public record exemption, it extends the repeal date for the exemption from October 2, 2011, to October 2, 2016. It also provides a public necessity statement as required by the State Constitution.²⁰

II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT

A. FISCAL IMPACT ON STATE GOVERNMENT:

1. Revenues:

None.

¹⁷ *Id.* at questions 4.c. and 7.a.

¹⁸ The center maintains a collaborative, statewide registry of banked cancerous and non-cancerous brain tumor specimens matched samples of DNA, plasma, serum and cerebrospinal fluid, clinical and demographic information, and quality-of-life assessments obtained from patients.

¹⁹ An institutional review board is an appropriately constituted group that has been formally designated to review and monitor biomedical research involving human subjects.

²⁰ Section 24(c), Art. I of the State Constitution.

2. Expenditures:

None.

B. FISCAL IMPACT ON LOCAL GOVERNMENTS:

1. Revenues:

None.

2. Expenditures:

None.

C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:

None.

D. FISCAL COMMENTS:

None.