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Committee on Education

Senator Evelyn J. Lynn, Chair

OPEN GOVERNMENT SUNSET REVIEW OF S. 1004.445 (9), F.S., JOHNNIE B. BYRD, SR., ALZHEIMER'S CENTER

SUMMARY

Patient, client, and donor personal information; information that is proprietary in nature, such as trade secrets and patents; and information that is already confidential and exempt under existing law and is provided to or maintained by the Johnnie B. Byrd, Sr., Alzheimer's Center and Research Institute ("Center") is exempt from the state's open government requirements. This public records exemption, codified in s. 1004.445, F.S., expires on October 2, 2006, unless the Legislature saves it from repeal after reviewing it under the Open Government Sunset Review Act.

Evaluating the public records exemption against the criteria prescribed in the act, this report finds that the exemption protects information of a confidential nature relating to personal identification of clients and donors or potential donors, medical and health records of individuals, proprietary business records, and information that is made confidential and exempt by state law, another state's or nation's law (when provided by a person from that state or nation), or federal law. Regarding the exemption for personal identification information of clients, this information is of a sensitive, personal nature, release of which could damage the reputation of the individuals. Additionally, without the exemption for donor or potential donor identification, fund-raising efforts of the Center could be greatly impaired, thereby impacting its ability to continue the program. Similarly, the flow of information-sharing may be diminished without the exemption, regarding information that already has a "confidential and exempt" status under existing law. Finally, without the exemption for information relating to manufacturing methods, trade secrets and related types of proprietary business information and transactions, other entities could potentially secure an unfair business advantage over the Center, harming its ability to compete successfully in the marketplace.

The public records exemption could be more narrowly drawn, however, to capture only that information in medical and health records that consists of personally identifiable information. Therefore, this report recommends that the Legislature retain but also revise and narrow the exemption.

BACKGROUND

Public Records Law

Florida has a long history of providing public access to the records of governmental and other public entities. The Legislature enacted its first law affording access to public records in 1909. In 1992, Floridians adopted an amendment to the state constitution that raised the statutory right of access to public records to a constitutional level. Article I, s. 24 (a) of the State Constitution provides that:

Every person has the right to inspect or copy any public record made or received in connection with the official business of any public body, officer, or employee of the state, or persons acting on their behalf, except with respect to records exempted pursuant to this section or specifically made confidential by this Constitution. This section specifically includes the legislative, executive, and judicial branches of government and each agency or department created thereunder; counties, municipalities, and districts; and each constitutional officer, board, and commission, or entity created pursuant to law or this Constitution.

The Public Records Law¹ also specifies conditions under which the public must have access to

¹ Chapter 119, F.S.

governmental records. Section 119.011 (11), F.S., defines the term “public records” to include:

All documents, papers, letters, maps, books, tapes, photographs, films, sound recordings, data processing software, or other material, regardless of the physical form, characteristics, or means of transmission, made or received pursuant to law or ordinance or in connection with the transaction of official business by any agency.

The Florida Supreme Court has interpreted this definition of public records to include all materials made or received by an agency in connection with official business which are used “to perpetuate, communicate, or formalize knowledge.”² Unless the Legislature makes these materials exempt, they are open for public inspection, regardless of whether they are in final form.³

Under Article I, s. 24 (c) of the State Constitution, the Legislature may provide for the exemption of records from the open government requirements provided: (1) the law creating the exemption states with specificity the public necessity justifying the exemption; and (2) the exemption is no broader than necessary to accomplish the stated purpose of the law.

Open Government Sunset Review Act

The Open Government Sunset Review Act of 1995, s. 119.15, F.S., establishes a review and repeal process for public records exemptions. In the fifth year after enactment of a new exemption or the substantial amendment of an existing exemption, the exemption is repealed on October 2, unless the Legislature reenacts the exemption. An “exemption is substantially amended if the amendment expands the scope of the exemption to include more records or information or to include meetings as well as records. An exemption is not substantially amended if the amendment narrows the scope of the exemption.”⁴

Under s. 119.15 (2), F.S., an exemption may be maintained only if it meets one of the following:

- (a) The exempted record or meeting is of a sensitive, personal nature concerning individuals;
- (b) The exemption is necessary for the effective and efficient administration of a governmental program; or
- (c) The exemption affects confidential information concerning an entity.

Section 119.15 (4) (a), F.S., requires, as part of the review process, the consideration of the following questions:

1. What specific records or meetings are affected by the exemption?
2. Whom does the exemption uniquely affect, as opposed to the general public?
3. What is the identifiable public purpose or goal of the exemption?
4. Can the information contained in the records or discussed in the meeting be readily obtained by alternative means? If so, how?

An exemption may be maintained only if it serves an identifiable public purpose, and it may be no broader than necessary to meet that purpose. An identifiable public purpose is served if the exemption meets one of the following purposes and the Legislature finds that the purpose is sufficiently compelling to override the strong policy of open government and cannot be accomplished without the exemption:

- The exemption allows “the state or its political subdivisions to effectively and efficiently administer a governmental program, which administration would be significantly impaired without the exemption.”
- The exemption protects “information of a sensitive personal nature concerning individuals, the release of which information would be defamatory to such individuals or cause unwarranted damage to the good name or reputation of such individuals or would jeopardize the safety of such individuals.”
- The exemption protects “information of a confidential nature concerning entities, including, but not limited to, a formula, pattern, device, combination of devices, or compilation of information which is used to protect or further a business advantage over those who do not know or use it, the disclosure

² *Shevin v. Byron, Harless, Schaffer, Reid, and Assocs., Inc.*, 379 So.2d 633, 640 (Fla. 1980).

³ *See Wait v. Florida Power & Light Co.*, 372 So.2d 420 (Fla. 1979).

⁴ s. 119.15 (3) (b), F.S.

of which information would injure the affected entity in the marketplace.”⁵

Johnnie B. Byrd, Sr., Alzheimer’s Center and Research Institute

The Legislature created the Alzheimer’s Center and Research Institute at the University of South Florida in 2002, and subsequently renamed it the Johnnie B. Byrd, Sr., Alzheimer’s Center and Research Institute (“Center”) in 2004.⁶

The Legislature established the Center as a not-for-profit corporation, considered to be an instrumentality of the state other than as a state agency.⁷ The Center is authorized to create both not-for-profit, and for-profit subsidiaries, upon approval of the State Board of Education.⁸ The State Board of Education is charged with various other duties associated with the Center, such as participating in the drafting of the agreement with the Center, entering into an agreement with the University of South Florida for the housing of the Center in campus facilities, and approving the articles of incorporation for the Center and its subsidiaries.⁹ Should the agreement between the Center and the State Board of Education terminate for any reason, the State Board of Education assumes full governance and facility operation of the Center.¹⁰

The chair or a designee of the State Board of Education holds a seat on the Center’s Board of Directors.¹¹ The board of directors is required to establish a council of scientific advisers to the chief executive officer, to include researchers, physicians, and scientists.¹² Additionally, the chief executive officer of the Center is required to create programs that implement the mission of the Center in the areas of Alzheimer’s research, education, treatment, prevention, and early detection.¹³

According to the Center, its mission is to “collaborate with researchers throughout the State of Florida and the wider global research community to develop treatment

to cure and prevent this disease [Alzheimer’s].”¹⁴ In January 2004, the Center awarded more than \$1.8 million in grants to 16 doctors associated with various research and educational institutions around the state.¹⁵ The Center collaborates with other entities throughout the state, including the University of South Florida Memory Digestive Clinic (Tampa), the University of Florida Memory Disorder Clinic (Gainesville), the Wien Center (Miami), the Mayo Clinic Jacksonville Memory Disorder Clinic (Jacksonville), the Lee Memorial Health System Memory Disorder Clinic (Ft. Myers), and the Tenet at St. Mary’s Medical Center (West Palm Beach).¹⁶

Also in 2002, the Legislature enacted a public records exemption for certain information received and maintained by the Center.¹⁷ The public records exemption for the Center provides that the following information is confidential and exempt:

- Personal identification information of clients of the Center which is maintained by the institute, the University of South Florida, the State Board of Education, or others who provide services through contract with the Center;
- Any patient medical or health record created or received by the Center;
- Materials that relate to manufacturing or production processes, potential or actual trade secrets, potentially patentable material, or proprietary information received, generated, or discovered during research by or through the Center and ensuing business transactions;
- Identification information of a donor or prospective donor who prefers anonymity;
- Any information received by the Center in the performance of its duties which is otherwise confidential and exempt by law; and

⁵ s. 119.15 (4) (b), F.S.

⁶ Chapters 2002-387 and 2002-389, L.O.F, and Chapter 2004-2, L.O.F.

⁷ s. 1004.445 (2) (a) and (8), F.S.

⁸ s. 1004.445 (2) (a), F.S.

⁹ s. 1004.445 (2) (a) and (3), F.S.

¹⁰ s. 1004.445 (5), F.S.

¹¹ s. 1004.445 (2) (b), F.S.

¹² s. 1004.445 (7), F.S.

¹³ s. 1004.445 (6) (a), F.S.

¹⁴ See generally the Center’s website at:

www.byrdinstitute.org/htm_pages_OLD/about_intro.htm

¹⁵ *Id.* at

www.byrdinstitute.org/htm_pages_OLD/research_intro.htm

¹⁶ *Id.* at

www.byrdinstitute.org/htm_pages_OLD/about_collaborators.htm

¹⁷ Chapter 2002-396, L.O.F.

- Any information received by the Center from a person from another state, nation, or the Federal Government which is made confidential or exempt by the laws of that state, nation, or under Federal law.¹⁸

Any governmental entity, however, that demonstrates a need to access information that is otherwise exempt from disclosure is permitted to access this information but is required to keep the information confidential and exempt.¹⁹

In its statement of public necessity, the Legislature found that it is a public necessity to make the following information confidential and exempt:

- Personal, medical, or health information about clients or patients, as access would otherwise constitute an unjustified invasion of a client's or patient's right to privacy, and the misuse of this information could harm the client's or patient's health, safety, or welfare;
- Manufacture of production methods information, actual or potential trade secrets, business transactions, and proprietary information, as disclosure would hinder the effective operation of the Center and potentially create an unfair competitive advantage for those receiving the information;
- Donor or potential donor identification information, in instances where anonymity is preferred, as the ability of the Center to solicit donations would otherwise be impeded, causing a chilling effect on donation flow; and
- Information shared with the institute by entities who are not subject to this state's laws and for whom the information is confidential and exempt, as otherwise others would be discouraged from sharing information with the Center, which would impede the efficacy of the Center.²⁰

This public records exemption is subject to the Open Government Sunset Review Act of 1995, and is repealed on October 2, 2006, unless reviewed and reenacted by the Legislature before that date. The purpose of this report is to evaluate, under the Open Government Sunset Review Act, this public records exemption for specific information provided to, and maintained by the Center.

¹⁸ s. 1004.445 (9) (a) through (f), F.S.

¹⁹ s. 1004.445 (9), F.S.

²⁰ Chapter 2002-396, L.O.F.

METHODOLOGY

Senate staff surveyed the Johnnie B. Byrd, Sr., Alzheimer's Center and Research Institute in conjunction with staff from the Florida House of Representatives. Staff additionally requested input from the First Amendment Foundation of Florida.²¹

FINDINGS

Sunset Review Questions

The Open Government Sunset Review Act prescribes questions to be considered by the Legislature in deciding whether to save a public records exemption from its scheduled repeal.²²

What Specific Records Does The Exemption Affect?

This public records exemption makes confidential and exempt donor or potential donor, and client personal identification information.

The public records exemption additionally makes confidential and exempt patient medical or health records. The Center distinguishes between a medical record and a health record as follows:

Specifically, a medical record comprises official documentation created by a health care provider that relates to: past, present, or future physical or mental health, conditions, statements, or actions of an individual; the provision of health care to an individual; and past, present, or future payment for the provision of health care to an individual. On the other hand, a health record is not an official record of a healthcare provider and is usually controlled, managed, or documented by a patient, client, or other third-party who is not a healthcare provider.²³

²¹ The First Amendment Foundation is a non-profit organization whose stated purpose is to "protect and advance the public's constitutional right to open government by providing education and training, legal aid and information services." See the First Amendment Foundation's website at: www.floridafaf.org

²² s. 115.14 (4) (a), F.S.

²³ Questionnaire Response from L. David de la Parte and Kelly A. Zarzycki, Legal Counsel, Johnnie B. Byrd Sr., Alzheimer's Center and Research Institute, Inc. (July 28, 2005).

Regarding business information, this exemption makes confidential and exempt materials relating to methods of manufacture or production, potential and actual trade secrets, patentable material, and proprietary information.²⁴

Additionally, the exemption extends to information that is made confidential and exempt by other laws, including the laws of this state, other states, countries, or the Federal Government.

Whom Does The Exemption Uniquely Affect?

The public records exemption under review has the potential to uniquely affect patients of the Center, and their families, and clients who are associated with the Center, through the Center itself, the University of South Florida, or the State Board of Education.

The public records exemption also has the potential to uniquely affect donors and potential donors who otherwise may be reluctant to donate to the Center if anonymity is not ensured, thereby also affecting the Center.

The public records exemption directly affects the ability of employees of the Center to pursue daily business activity unencumbered, knowing that any and all information relating to production methods, proprietary information, trade secrets, and patents is not generally accessible by the public.

Additionally, this public records exemption may encourage employees of related entities in-state to work with the Center and share information, research, and trade secrets, as they will know that the information will not be discoverable.

Similarly, this public records exemption may encourage information-sharing between entities from other states, federal agencies, and nations.

²⁴ A trade secret is defined in s. 688.002 (4) (a) and (b), F.S. as information, such as a formula, pattern, compilation, program, device, method, technique, or process that both derives independent economic value, actual or potential, from not being generally known to, and not being readily ascertainable by proper means by, other persons who can obtain economic value from its disclosure or use; and is the subject of efforts that are reasonable under the circumstances to maintain its secrecy.

What Is The Exemption's Public Purpose Or Goal?

In the statement of public necessity accompanying the creation of the public records exemption, the Legislature identified the following grounds as justification for the public records exemption:

- Access to sensitive personal, medical, or health information - disclosure would constitute an unwarranted invasion of the client's or patient's right to privacy and the inappropriate use of the information is potentially harmful to the health, safety, or welfare of the client or patient;
- Information related to methods of manufacture or production, potential trade secrets, potential patentable material, actual trade secrets, business transactions, or proprietary information - disclosure would hinder the effective and efficient operation of the Center and give those accessing the information an unfair competitive advantage;
- Information about donors or prospective donors - disclosure would have a chilling effect on the Center's attempts to solicit donations; and
- Information shared with the Center by those outside the state - disclosure would discourage others from providing useful information to the Center and impair the effective and efficient operation of the Center.²⁵

Is The Information Otherwise Readily Obtainable?

In its response to the survey, the Center indicated that the information cannot be readily obtained from another source.

However, information that has a similar status, such as patient records received by other health care providers, may be accessible in certain circumstances. By way of example, Chapter 456, F.S., provides regulations relating to the health profession. Section 456.057, F.S., addresses the ownership and control of patient records. Various provisions authorize limited disclosure of patient records to specific parties under particular circumstances, including to the actual patient or the patient's legal representative, to a party in a civil or criminal action subsequent to issuance of a subpoena, to statistical and scientific researchers, provided that patient identity is protected, and to the Department of

²⁵ Chapter 2002-396, Section 2, L.O.F.

Health.²⁶ A public records exemption in the statute provides:

All patient records obtained by the department and any other documents maintained by the department which identify the patient by name are confidential and exempt from s. 119.07 (1), F.S., and shall be used solely for the purpose of the department and the appropriate regulatory board in its investigation, prosecution, and appeal of disciplinary proceedings. The records shall not be made available to the public as part of the record of investigation for a prosecution in disciplinary proceedings made available to the public by the department or the appropriate board.²⁷

Therefore, only that patient record information which actually identifies an individual patient is given a “confidential and exempt” status.

Additional Criteria

In 2005, the Legislature adopted two new criteria that apply in the review process of a public records exemption.²⁸ The 2005 legislation does not take effect until October 1, 2005. The additional criteria to be considered are:

- Is the record or meeting protected by another exemption?
- Are there multiple exemptions for the same type of record or meeting that it would be appropriate to merge?²⁹

Is The Record Protected By Another Exemption?

While specific pieces of information may be protected by public records exemptions,³⁰ it does not appear that the general categories of information included in the Center’s exemption are currently addressed by other exemptions.

Are There Multiple Exemptions For The Same Type of Record That It Would Be Appropriate To Merge?

Some of the exemptions are similar to others already established in law, such as those provided to the Florida Institute for Human and Machine Cognition, Inc., for trade secrets, patentable material, and other proprietary information; any information received by a person from out-of-state which receives a confidential or exempt status elsewhere or otherwise made confidential or exempt in-state; and identifying information of a donor or a potential donor.³¹

Additionally, the exemption provided to the H. Lee Moffitt Cancer Center and Research Institute includes proprietary confidential business information; trade secrets such as information relating to methods of manufacture or production, potential trade secrets, and potentially patentable materials; donor or potential donor identification; or any information received by an agency in-state or out-of-state that currently has an exempt or confidential status.³²

Although some of the exemptions are similar, if not identical in wording, to those provided to the Center, they may differ in application as the entities themselves are unique. Therefore, it does not appear that it would be appropriate to merge the exemptions.

Maintenance Of The Exemption

Under the Open Government Sunset Review Act, a public records exemption may be maintained only if it serves an identifiable public purpose, and an exemption may be no broader than necessary to meet that purpose.³³ A satisfactory public purpose includes the following:

- Allowing for effective and efficient administration of a governmental program;
- Protecting sensitive personal information about individuals; or
- Protecting confidential information about entities.

Additionally, the Legislature must find that purpose is “sufficiently compelling” to take priority over the

²⁶ s. 456.057 (4), (5) (a) and (7) (a), F.S.

²⁷ s. 456.057 (8) (a), F.S.

²⁸ Chapter 2005-251, L.O.F.

²⁹ *Id.*

³⁰ *See, i.e.*, s. 119.0721, F.S., which provides an exemption for social security numbers.

³¹ s. 1004.4472 (1), F.S.

³² s. 1004.43 (8) (b), F.S.; However, much of the public records exemption provided to the H. Lee Moffitt Cancer Center and Research Institute predates the public records provision in the Constitution.

³³ s. 119.15 (4) (b), F.S.

state's policy tradition of open government. (See discussion of the Open Government Sunset Review Act in the Background section, above).

Public Purpose Analysis

The Center indicates the following:

- Without the exemption, the Center would not be able to effectively and efficiently accomplish its mission of providing research, education, treatment, prevention, and early detection of Alzheimer's disease;
- The unique and competitive nature of the health care industry and research community and the need to effectively and efficiently compete with private health care providers and researchers who are not subject to the public records law is key to fulfilling the Center's mission;
- Without the exemption, a conflict could result between federal patient protection laws, such as the Health Insurance Portability and Accountability Act (HIPAA) and the public records law; and
- Without the exemption providing for donor privacy, donation flow may be adversely affected.

However, regarding the exemption for patient medical and health records, the HIPAA protects only the use and disclosure of that information from patient records which is considered personally identifiable information.³⁴ Under the federal law, "All 'individually identifiable health information,'³⁵ including information in written, electronic, or spoken form

³⁴ Shannon S. Venable, *A Call to Action: Georgia Must Adopt New Standard of Care, Licensure, Reimbursement, and Privacy Laws for Telemedicine*, 54 Emory L.J. 1183, 1213 (2005).

³⁵ See 42 U.S.C.A. s. 1320d (6), which defines individually identifiable health information as "any information, including demographic information collected from an individual, that—(A) is created or received by a health care provider, health plan, employer, or health care clearinghouse; and (B) relates to the past, present, or future physical or mental health or condition of an individual, the provision of health care to an individual, or the past, present, or future payment for the provisions of health care to an individual, and—(i) identifies the individual; or (ii) with respect to which there is a reasonable basis to believe that the information can be used to identify the individual."

between healthcare providers, is protected."³⁶ Therefore, HIPAA does not preempt the release of the entire patient record, only those portions which can be used to personally identify an individual patient. Additionally, HIPAA expressly authorizes the use of protected health information as is required by law.³⁷ This would include state public records laws.

Although the release of information in patient records beyond that which is personally identifiable is not preempted by HIPAA, it may still be an appropriate subject for an exemption if it satisfies an identifiable public purpose. The most appropriate public purpose is that which protects personal sensitive information, the release of which would be defamatory to specific individuals or cause unwarranted damage to the good name or reputation of those individuals.

Currently, the entire medical and health record is included in the exemption. Regarding the provision in the state's public records law that identifies the goal of prevention from harm as an acceptable public purpose, the focus is on the release of the specific information contained in a record or document, rather than the record or document itself. Personal identifying information can be redacted from a medical or health record, leaving the rest of the record subject to disclosure. Narrowing the exemption to identifying information contained in a patient's record eliminates the need for an exemption preserving the entire record, while at the same time still protects an individual's privacy interests. Consistent with the state's policy of open government, it appears that such a balance is warranted.

Exempt v. Confidential Status of Information

Public records law recognizes a distinction between records that are made exempt and records that are made confidential. If a record is made exempt only, an agency is not prohibited from disclosing the document in all circumstances.³⁸ If the Legislature makes certain information confidential and exempt, however, such information may not be released to anyone other than to the persons or entities designated in statute.³⁹ The public records exemption under review applies a "confidential and exempt" status to information relating to client and donor personal information;

³⁶ Venable, *supra* note at 25.

³⁷ See 45 CFR 164.512(a)(1)

³⁸ See *Williams v. City of Minneola*, 575 So.2d 289 (Fla. 1991).

³⁹ See Inf. Op. to Chiaro, January 24, 1997.

patient medical or health records; proprietary and business information, including trade secrets; data received by the Center that is already confidential and exempt by law; and received from an out-of-state entity and which is already confidential and exempt by that state's laws, federal law, or the laws of another nation. Further, the public records exemption grants any governmental entity that demonstrates a need to access confidential and exempt information to perform its duties and responsibilities access to the information.⁴⁰

The public records exemption is not permanent in all cases, however. Rather, the Center indicates that an exemption expires when the information loses its economic value, including when a patent related to the information expires, when the information is published, or when the information becomes obsolete.

Coverage of the Exemption

The public records exemption currently protects identifying information, patient medical and health records, proprietary information, and information that already have a "confidential and exempt" status by law. It appears that these types of information are generally appropriate subjects for exemption, in that:

- Personal identifying information about clients and donors and patient medical and health records are of a sensitive, personal nature concerning individuals;⁴¹
- Business information that is proprietary in nature, such as trade secrets, if disclosed, could harm the Center's competitive abilities in the marketplace;⁴² and
- Extending the "confidential and exempt" status to information that already is confidential and exempt under law, including those of other states and countries allows this governmental entity to effectively and efficiently administer its program.⁴³

It is unclear, however, that providing an exemption for medical and health records in their entirety is consistent with the broad public records law of our state. Under state public records law, an exemption may be maintained only if it serves an identifiable public purpose, and it may be no broader than necessary to meet that purpose. Further, the public records law

specifically requires that if an exemption is sought on these grounds, the exemption is limited to information which directly identifies those individuals.⁴⁴ In reviewing the public necessity statement accompanying the exemption, the justification for protection against release of patient information is to prevent an unwarranted invasion of a client's or patient's right to privacy, which could potentially harm the patient's health, safety, or welfare. Consequently, public records law requires that this information be restricted to personally identifying information. Modifying the exemption for medical and health records to include only personally identifiable information complies with both public records law requirements and fulfills the purpose of protection from harm as indicated in the public necessity statement.

Therefore, it is recommended that the exemption for medical and health records should be revised to limit the exemption to personally identifiable information from those records, consistent with the exemption provided for donors, potential donors, and clients.

RECOMMENDATIONS

Staff recommends retaining the public records exemption in s. 1004.445, F.S., for:

- Personal identifying information of clients, donors, or potential donors;
- Materials or information that can be considered proprietary in nature, such as trade secrets and business transactions; and
- Any information that is received by the institute which is already made confidential and exempt by law.

However, the Legislature may wish to consider modifying the exemption for all medical or health records relating to patients that are created or received by the Center to include only personally identifiable information contained in medical or health records that are held by the Center in the exemption. Therefore, it is recommended that the public records exemption be reenacted, but also revised and narrowed.

⁴⁰ s. 1004.445 (9), F.S.

⁴¹ s. 119.15 (6) (b) 2., F.S.

⁴² s. 119.15 (6) (b) 3., F.S.

⁴³ s. 119.15 (6) (b) 1., F.S.

⁴⁴ s. 119.15 (4) (b) 2., F.S.