

FLORIDA HOUSE OF REPRESENTATIVES

BILL ANALYSIS

This bill analysis was prepared by nonpartisan committee staff and does not constitute an official statement of legislative intent.

BILL #: [CS/HB 1445](#)

TITLE: Pub. Rec./Parkinson's Disease Registry

SPONSOR(S): Busatta

COMPANION BILL: [SB 1686](#) (Calatayud)

LINKED BILLS: [HB 1443](#) Busatta

RELATED BILLS: [SB 1686](#) (Calatayud)

Committee References

[Health Professions & Programs](#)

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[Government Operations](#)



[Health & Human Services](#)

SUMMARY

Effect of the Bill:

CS/HB 1445 creates a public record exemption for patient identifying information held in the Parkinson's disease registry established in HB 1443. HB 1445 is linked to HB 1443. The bill authorizes patient identifying information to be disclosed to the Parkinson's Disease Research Board (Board) and, under certain circumstances, a private entity the Board has contracted with to establish and maintain the registry.

The bill makes the public record exemption subject to the Open Government Sunset Review Act and states that the exemption shall be repealed on October 2, 2031, unless reenacted by the Legislature.

Fiscal or Economic Impact:

None

Extraordinary Vote Required for Passage:

The bill requires a two-thirds vote of the members present and voting in both houses of the Legislature for final passage.

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ANALYSIS

EFFECT OF THE BILL:

The bill creates a [public record](#) exemption for patient identifying information held in the [Parkinson's disease registry](#) established in HB 1443. Under the bill, such information may be disclosed to the [Parkinson's Disease Research Board](#) (Board) and to a private entity the Board has contracted with to establish and maintain the registry if the entity agrees to:

- Submit a research plan to the Board specifying the exact nature and intended use of the requested information;
- Maintain the confidentiality of the records or information containing personal identifying information;
- Destroy and confidential records or information obtained after research has concluded; and
- Not contact any patient, directly or indirectly, for any purpose. (Section [1](#))

The bill specifies that the public record exemption is subject to the Open Government Sunset Review Act and will stand repealed on October 2, 2031, unless saved from repeal by reenactment by the Legislature. (Section [1](#)).

The bill provides a public necessity statement for the public record exemption, as required by the State Constitution. The public necessity statement states that information held in the Parkinson's disease registry that identifies a patient should remain confidential. If such information is made publicly available, it could be used to

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invade the personal privacy of the patient, hinder the effective and efficient administration of the registry, or be used to solicit or harass an individual identified in the registry. (Section 2)

The effective date of the bill is the same date that HB 1443 or similar legislation takes effect, if such legislation is adopted in the same legislative session or extension thereof and becomes law.

[Article 1, s. 24\(c\)](#) of the Florida Constitution requires a two-thirds vote of the members present and voting for final passage of a newly created public record exemption. The bill creates a public record exemption; thus, it requires a two-thirds vote for final passage.

RELEVANT INFORMATION

SUBJECT OVERVIEW:

[Public Records](#)

The Florida Constitution sets forth the state's public policy regarding access to government records. Every person is guaranteed a right to inspect or copy any public record of the legislative, executive, and judicial branches of government.¹ The Legislature, however, may provide by general law an exemption² from public record requirements provided that the exemption passes by a two-thirds vote of each chamber, states with specificity the public necessity justifying the exemption, and is no broader than necessary to meet its public purpose.³

Current law addresses the public policy regarding access to government records, guaranteeing every person a right to inspect and copy any state, county, or municipal record, unless the record is exempt.⁴ Furthermore, the Open Government Sunset Review Act provides that a public record exemption may be created, revised, or maintained only if it serves an identifiable public purpose and the "Legislature finds that the purpose is sufficiently compelling to override the strong public policy of open government and cannot be accomplished without the exemption."⁵ An identifiable public purpose is served if the exemption meets one of the following purposes:⁶

- Allow the state or its political subdivisions to effectively and efficiently administer a governmental program, which administration would be significantly impaired without the exemption;
- Protect 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; or
- Protect trade or business secrets.

Pursuant to the Open Government Sunset Review Act,⁷ a new public record or meeting exemption or substantial amendment of an existing exemption is repealed on October 2nd of the fifth year following enactment, unless the Legislature reenacts the exemption.⁸

¹ [Art. I, s. 24\(a\), FLA. CONST.](#)

² A public record exemption means a provision of general law which provides that a specified record or meeting, or portion thereof, is not subject to the access requirements of [s. 119.07\(1\), F.S.](#), [s. 286.011, F.S.](#), or [s. 24, Art. I](#) of the Florida Constitution. See [s. 119.011\(8\), F.S.](#) There is a difference between records the Legislature designates exempt from public record requirements and those the Legislature designates confidential and exempt. A record classified as exempt from public disclosure may be disclosed under certain circumstances. See *WFTV, Inc. v. Sch. Bd. of Seminole*, 874 So.2d 48, 53 (Fla. 5th DCA 2004), *review denied*, 892 So.2d 1015 (Fla. 2004); *State v. Wooten*, 260 So. 3d 1060, 1070 (Fla. 4th DCA 2018); *City of Riviera Beach v. Barfield*, 642 So.2d 1135 (Fla. 4th DCA 1994); *Williams v. City of Minneola*, 575 So.2d 683, 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 statute. See Op. Att'y Gen. Fla. 04- 09 (2004).

³ [Art. I, s. 24\(c\), FLA. CONST.](#)

⁴ See [s. 119.01, F.S.](#)

⁵ [S. 119.15\(6\)\(b\), F.S.](#)

⁶ [S. 119.15\(6\)\(b\), F.S.](#)

⁷ [S. 119.15, F.S.](#)

⁸ [S. 119.15\(3\), F.S.](#)

Parkinson's Disease

Parkinson's disease is a progressive neurological disorder that impacts an individual's nervous system and causes unintended and slow movements, such as tremors, stiffness, and difficulty with balance.⁹ Individuals with Parkinson's disease may have trouble walking, talking, and completing day-to-day tasks.

The exact cause of Parkinson's disease is unknown.¹⁰ However, some studies have shown that Parkinson's disease is partially caused by damaged or dead neurons within the *substantia nigra*, which is an area of the brain that controls movement.¹¹ The neurons in this area produce dopamine that send signals to parts of the body to complete movements. However, neurons reduce their dopamine production when they become damaged or die, resulting in limited movement control. Neurons may become damaged from buildup of protein particles, called Lewy Bodies, that are not properly disposed of within brain cells.

Some studies have also indicated that Parkinson's disease may be genetic. About 10 to 15 percent of Parkinson's disease is caused by genetics.¹² Seven genes are linked to causing or increasing the risk of being diagnosed with Parkinson's disease.¹³ However, additional genes and environmental factors largely impact whether a genetic code leads to a diagnosis. Genetic testing is a recent development in Parkinson's disease research, and research on genetic origins is underdeveloped.

There is no cure for Parkinson's disease;¹⁴ however, treatments and therapies can relieve some symptoms.¹⁵ Most treatments focus on restoring dopamine in the brain through prescription medicines.¹⁶ Individuals who cannot manage their symptoms through medication may seek relief through deep brain stimulation.¹⁷ Deep brain stimulation requires surgical implants in a patient's brain and chest to stimulate affected parts of the brain with electrodes.

Approximately one million Americans are affected by Parkinson's disease, with an estimated 90,000 new diagnoses each year.¹⁸ Florida has the highest percentage of state population with Parkinson's disease in the United States, with the disease impacting about 79,990 Floridians.¹⁹ The primary risk factor is age, with Parkinson's disease risk increasing around ages 65-years and older.²⁰ About 21 percent of Floridian's population is 65-years or older, the second highest in the U.S.²¹

⁹ National Institute of Neurological Disorders and Stroke, *Parkinson's Disease* (Mar. 5, 2025), available at <https://www.ninds.nih.gov/health-information/disorders/parkinsons-disease> (last visited Jan. 24, 2026).

¹⁰ National Institute on Aging, *Parkinson's Disease: Causes, Symptoms, and Treatments* (April 14, 2022), available at <https://www.nia.nih.gov/health/parkinsons-disease/parkinsons-disease-causes-symptoms-and-treatments> (last visited Jan. 24, 2026).

¹¹ *Id.*

¹² Parkinson's Foundation, *Statistics*, available at <https://www.parkinson.org/understanding-parkinsons/statistics> (last visited Jan. 24, 2026).

¹³ National Human Genome Research Institute, *About Parkinson's Disease*, available at [About Parkinson's Disease](https://www.genome.gov/about-parkinsons-disease) (last visited Jan. 24, 2026).

¹⁴ *Supra* note 2.

¹⁵ *Id.*

¹⁶ Roger A. Barker and Thomas B Stoker, *Recent developments in the treatment of Parkinson's Disease* (Jul. 31, 2020), available at <https://pmc.ncbi.nlm.nih.gov/articles/PMC7400683/> (last visited Jan. 24, 2026).

¹⁷ *Supra* note 2.

¹⁸ *Supra* note 5.

¹⁹ Parkinson's Association of Southwest Florida, *Florida Parkinson Rate*, available at <https://parkinsonassociationswfl.org/parkinson-disease-in-florida.html> (last visited Jan. 24, 2026).

²⁰ *Supra* note 5.

²¹ Population Reference Bureau, *States Ranked by Percent of Population* (2020), available at <https://www.prb.org/resources/which-us-states-are-the-oldest/> (last visited Jan. 24, 2026).

Parkinson's Disease Registry

A disease registry is a centralized database for the collection of information of specific diseases.²² Such information is collected from a patient and clinical perspective and can inform every stage of the therapy development process.²³

There is no national Parkinson's Disease registry, but several states have created state specific registries.²⁴

Florida does not currently operate a Parkinson's Disease registry. However, HB 1443, linked to this bill, requires the Parkinson's Research Board (Board) within the University of South Florida (USF) to contract with a private entity to establish and maintain a statewide Parkinson's disease registry using a nationally recognized platform. The bill also requires, by January 1, 2027, allopathic and osteopathic physicians who diagnose or treat a patient with Parkinson's disease must regularly report nationally recognized Parkinson's disease performance measures to the registry.

Consortium for Parkinson's Disease Research

In 2025, the legislature created the Consortium for Parkinson's Disease Research (Consortium) within the University of South Florida (USF) comprised of public and private universities, and academic medical centers.²⁵ The purpose of the Consortium is to conduct and disseminate research on the causes, mechanisms, and potential treatments for Parkinson's Disease as well as the prevalence of Parkinson's Disease in first responders.²⁶

Parkinson's Disease Research Board

The Parkinson's Disease Research Board manages the Consortium's operations. Each year, the Board must adopt a Parkinson's disease research plan. The Board may adopt the Consortium's recommendation or create its own plan, provided it describes how the Consortium's research will contribute to knowledge of Parkinson's disease's causes, mechanisms, and treatments and the prevalence of Parkinson's disease in first responders.²⁷

The Board consists of members representing participating universities or academic medical centers. Each president of the participating universities or academic medical centers appoints a member. Board members must have experience in scientific fields, such as neurology, psychology, nutrition, and genetics. Members serve a four-year term and may be reappointed.²⁸

Board members are prohibited from being compensated for their role. However, reimbursement for travel expenses, provided the costs are authorized, necessarily incurred, and follow the rates of per diem requirements in [s. 112.061, F.S.](#) is permitted.²⁹

The board may create, amend, and repeal a charter to govern itself. The Board must select a chair from among its members who will serve a two-year term. All of the Board's actions require a majority vote of present members.

²² National Institutes of Health, *Disease Registries*, available at <https://www.nihlibrary.nih.gov/resources/subject-guides/health-data-resources/disease-registries> (last visited Jan. 24, 2026).

²³ National Institutes of Health National Center for Advancing Translational Sciences, *Toolkit for Patient-Focused Therapy Development – Patient Registries*, available at <https://toolkit.ncats.nih.gov/module/discovery/starting-a-patient-registry-natural-history-study-database/patient-registries/> (last visited Jan. 24, 2026).

²⁴ American Parkinson Disease Association, *How many people have Parkinson's disease?*, available at <https://www.apdaparkinson.org/article/parkinsons-disease-registries/> (last visited Jan. 24, 2026). Fourteen states currently have Parkinson's disease registries (California, Connecticut, Delaware, Maryland, Missouri, Nebraska, New York, Nevada, Ohio, South Carolina, Utah, Virginia, Washington, and West Virginia).

²⁵ Ch. 2025-188, L.O.F.

²⁶ Section [1004.4352, F.S.](#)

²⁷ *Id.*

²⁸ *Id.*

²⁹ *Id.*

The Board must meet at least semiannually, and four members constitute a quorum.³⁰ As of January, 2026, a Board has not been appointed and USF is in the process of identifying the individuals that will serve on the Board.³¹

The Board must submit an annual report to the Governor, President of the Senate, and the Speaker of the House by October 15 of each year describing the Consortium's current research projects and findings, community outreach initiatives, and future research programs.³² USF issued the first report on October 15, 2025, which detailed the Consortium's mission purpose is to prioritize high-impact areas of Parkinson's disease research and disseminate the findings to improve the lives and outcomes of patients and families affected by Parkinson's disease. The report also provided potential priority research projects, including the investigation of ways to reduce hazard exposure for certain high-risk populations, such as first responders, addressing tremors, and further research into pathological processes. The report also provided a prospective Board structure and potential appointees which includes, in addition to a Parkinson's disease patient or family member of a patient, a representative from:³³

- The USF Morsani College of Medicine who shall serve as the initial chair;
- The University of Miami's Miller School of Medicine;
- The University of Florida's College of Medicine;
- The Michael J. Fox Foundation for Parkinson's Research; and
- The Parkinson's Foundation.

RECENT LEGISLATION:

YEAR	BILL #/SUBJECT	HOUSE/SENATE SPONSOR(S)	OTHER INFORMATION
2025	CS/CS/HB 1545 - Parkinson's Disease	Busatta/ Calatayud	Approved by Governor.
2025	HB 1547 - Pub. Rec./Parkinson's Disease Research Program Registry	Busatta/ Calatayud	Died in House.

BILL HISTORY

COMMITTEE REFERENCE	ACTION	DATE	STAFF DIRECTOR/ POLICY CHIEF	ANALYSIS PREPARED BY
Health Professions & Programs Subcommittee	18 Y, 0 N, As CS	1/29/2026	McElroy	Augustine
THE CHANGES ADOPTED BY THE COMMITTEE:	<ul style="list-style-type: none"> • Provided a public necessity statement for the public records exemption; and • Provided for the repeal of the public record exemption on October 2, 2031, unless saved from repeal. 			
Government Operations Subcommittee				
Health & Human Services Committee				

³⁰ *Id.*

³¹ Correspondence from Lauren Hartmann, Assistant Vice President of Government Relations, University of South Florida, HB 1443 Parkinson's Disease Registry, dated Jan. 27, 2026, on file with the Health Professions and Programs Subcommittee.

³² *Id.*

³³ University of South Florida, *HB 1545 Parkinson's Research (October 15, 2025)*, on file with the Health Professions and Programs Subcommittee.

THIS BILL ANALYSIS HAS BEEN UPDATED TO INCORPORATE ALL OF THE CHANGES DESCRIBED ABOVE.
