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/CS/HB 1545 COMPANION BILL: CS/CS/SB 1800 (Calatayud)

TITLE: Parkinson's Disease Research Funding LINKED BILLS: <u>HB 1547</u> (Busatta)

SPONSOR(S): Busatta RELATED BILLS: None

Committee References

Health Professions & Programs
17 Y, 0 N, As CS

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Health Care Budget 13 Y, 0 N, As CS

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Health & Human Services 21 Y. 0 N

SUMMARY

Effect of the Bill:

The bill creates the Consortium for Parkinson's Disease Research within the University of South Florida (USF) to conduct research on the causes, mechanisms, and potential treatment for Parkinson's disease and the prevalence of Parkinson's disease in first responders. The bill also establishes the Parkinson's Disease Research Board to manage the Consortium.

Fiscal or Economic Impact:

The bill has a significant negative fiscal impact on USF, but implementation is contingent upon the appropriation of funds.

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ANALYSIS

EFFECT OF THE BILL:

Parkinson's Disease Research

Florida law does not provide funding or guidelines for <u>Parkinson's disease</u> research. Current law only provides that the Department of Health and the Florida Public Health Institute, Inc., must include Parkinson's disease during its monthly public health awareness campaigns on preventing, detecting, treating, and curing diseases at least once within a two-year period.¹

Consortium for Parkinson's Disease Research

The bill creates the Consortium for Parkinson's Disease Research (Consortium). The Consortium is established within the University of South Florida and is comprised of public and private universities, and <u>academic medical centers</u>. The bill provides that the universities and academic medical centers within the Consortium <u>research Parkinson's disease's</u> causes, mechanisms, and treatments and the prevalence of Parkinson's disease in first responders. (Section 1).

The bill establishes a director of the Consortium, who is appointed by the Parkinson's Disease Research Board (Board), to administer the Consortium. The director must:

- Prepare a research plan that describes how the Consortium's research will contribute to knowledge of Parkinson's disease's causes, mechanisms, and treatments and prevalence in first responders, and submit it to the Board;
- Identify the Consortium's priority research projects;

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¹ S. 381.981, F.S.

- Recruit public and private universities and academic medical centers researching Parkinson's disease to participate in the Consortium;
- Propose the Consortium's budget;
- Apply for research grants;
- Encourage collaboration between scientists, researchers, and other appropriate personnel within the Consortium's charter; and
- Perform any other duties determined by the Board. (Section 1).

Parkinson's Disease Research Board

The bill creates the Parkinson's Disease Research Board to manage 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. (Section 1).

The bill requires the Board to 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. (Section 1).

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. The Board must meet at least semiannually, and four members constitute a quorum. (Section 1).

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. The bill requires members to have experience in scientific fields, such as neurology, psychology, nutrition, and genetics. Members serve a four-year term and may be reappointed. (Section 1).

Members may not receive compensation for their role. However, they may be reimbursed for travel expenses by the Consortium or the Board, provided the costs are authorized, necessarily incurred, and follow the rates of per diem requirements in <u>s. 112.061</u>, <u>F.S.</u>.² (Section <u>1</u>).

The bill provides an effective date of July 1, 2025. (Section $\underline{2}$).

FISCAL OR ECONOMIC IMPACT:

STATE GOVERNMENT:

The bill has a significant negative fiscal impact on USF, but implementation is contingent upon the appropriation of funds. The House proposed General Appropriations Act for Fiscal Year 2024-2025 does not include an appropriation to fund the bill.

RELEVANT INFORMATION

SUBJECT OVERVIEW:

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.³ Individuals with Parkinson's disease may have trouble walking, talking, and completing day-to-day tasks.

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² S. 112.061, F.S.

³ 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 Mar. 19, 2025).

The exact cause of Parkinson's disease is unknown.⁴ 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.⁵ 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. Seven genes are linked to causing or increasing the risk of being diagnosed with Parkinson's disease. 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.⁸ However, treatments and therapies can relieve some symptoms.⁹ Most treatments focus on restoring dopamine in the brain through prescription medicines.¹⁰ Individuals who cannot manage their symptoms through medication may seek relief through deep brain stimulation.¹¹ 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. Florida has the highest percentage of state population with Parkinson's disease in the United States, with the disease impacting about 79,990 Floridians. The primary risk factor is age, with Parkinson's disease risk increasing around ages 65-years and older. About 21 percent of Floridian's population is 65-years or older, the second highest in the U.S.

Current Status of Parkinson's Disease Research

An <u>academic medical center</u> typically refers to a collaborative health center between an allopathic or osteopathic medical school and a hospital owned or affiliated with the medical school. Academic medical centers have a combined focus on patient care, medical education, and research. Academic medical centers in Florida include, but are not limited to, Tampa General Hospital, Mayo Clinic, and University of Miami Health System's UHealth.

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⁴ 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 Mar. 19, 2025).

⁵ Supra note 3.

⁶ Parkinson's Foundation, *Statistics*, https://www.parkinson.org/understanding-parkinsons/statistics (last visited Mar. 20, 2025)

⁷ National Human Genome Research Institute, *About Parkinson's Disease*. Available at <u>About Parkinson's Disease</u> (last visited Mar. 19, 2025).

⁸ Supra note 4.

⁹ *Id*.

¹⁰ 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 Mar. 19, 2025).

¹¹ Supra note 4.

¹² Supra note 6.

¹³ Parkinson's Association of Southwest Florida, *Florida Parkinson Rate*, Available at https://parkinsonassociationswfl.org/parkinson-disease-in-florida.html (last visited Mar. 24, 2025).

¹⁴ Supra note 6.

¹⁵ 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 Mar. 20, 2025).

¹⁶ Institute of Medicine Committee on the Roles of Academic Health Centers in the 21st Century, *Academic Health Centers: Leading Change in the 21st Century* (2004), https://www.ncbi.nlm.nih.gov/books/NBK221676/.

¹⁷ Tampa General Hospital, *Tampa General Hospital: The Region's Only Academic Heath System*. Available at https://www.tgh.org/about-tgh/academic-health-system (last visited Apr. 11, 2025); Mayo Clinic College of Medicine and Science, *Florida*. Available at https://college.mayo.edu/campus-and-community/florida/ (last visited Apr. 11, 2025); University of Miami, *UHealth*. Available at https://welcome.miami.edu/uhealth/index.html (last visited Apr. 11, 2025).

The Parkinson's Foundation designates the U.S.' top medical centers with specialized teams focused on Parkinson's disease clinical research and care as "Centers of Excellence." Florida is home to three Parkinson's disease Centers of Excellence, including the University of South Florida Parkinson's Disease & Movement Disorders Center, the University of Florida Movement Disorders and Neurorestoration Program, and the University of Miami Miller School of Medicine. Omparatively, California is home to five Centers of Excellence, New York is home to four, and Texas is home to one.

The University of South Florida Parkinson's Disease & Movement Disorders Center is the only center in Florida primarily focused on Parkinson's disease research and treatment. The center currently offers multiple clinical trials to improve symptoms of early untreated Parkinson's disease, test innovative treatments, and study the disease's causes and progression.²¹

The University of Florida Movement Disorders and Neurorestoration Program operates within UF Health's Norman Fixel Institute for Neurological Diseases and studies a variety of neurological disorders, including amyotrophic later sclerosis (ALS), dementia, Alzheimer's disease, and Parkinson's disease.²² Currently, the Program offers only two clinical trials for Parkinson's disease research.²³ The Program's Parkinson's disease research focuses on cognitive behavior and emotion, speech production, breathing and swallowing dysfunction, and development of deep brain stimulation.²⁴

The University of Miami Miller School of Medicine does not have a program specifically designated for researching Parkinson's disease. However, the Miller School of Medicine's John P. Hussman Institute for Human Genomics researches Parkinson's disease's genetic causes, along with other genetic disorders such as Autism and Alzheimer's disease. The Institute does not study Parkinson's disease beyond its genetic causes. The Miller School of Medicine also partners with the American Parkinson Disease Association's (APDA) to host the APDA's Information and Referral Center. The Center operates a telephone helpline, provides resources on symptoms and therapies, and connects patients with physicians and specialists.

There is no indication that the three Florida Parkinson's disease research centers and programs collaborate with one another, share data, or form a consortium.

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¹⁸ Parkinson's Foundation, *Centers of Excellence*. Available at https://www.parkinson.org/living-with-parkinsons/finding-care/global-care-network (last visited Mar. 24, 2025).

¹⁹ Parkinson's Foundation, *Florida Chapter*. Available at https://www.parkinson.org/florida/florida-chapter#florida-chapter (last visited Mar. 24, 2025).

²⁰ Supra note 18.

²¹ USF Health, Parkinson's Disease & Movement Disorders Center, *Overview*. Available at https://health.usf.edu/care/neurology/services-specialties/parkinsons (last visited Mar. 24, 2025).

²² UF Health, Norman Fixel Institute for Neurological Diseases, Movement Disorders & Neurorestoration Program, *About*. Available at https://movementdisorders.ufhealth.org/about/ (last visited Mar. 24, 2025); UF Health, Norman Fixel Institute for Neurological Diseases, Movement Disorders & Neurorestoration Program, *Clinical Trials*. Available at https://fixel.ufhealth.org/research-2/clinical-trials-2/ (last visited Mar. 24, 2025).

²³ UF Health, *Parkinson Disease Clinical Trials*. Available at https://ufhealth.org/conditions-and-treatments/parkinson-disease/clinical-trials (last visited Mar. 24, 2025).

²⁴ UF Health, Norman Fixel Institute for Neurological Diseases, Movement Disorders & Neurorestoration Program, *Clinical Research*. Available at https://movementdisorders.ufhealth.org/research/clinical-research/ (last visited Mar. 24, 2025).

²⁵ University of Miami Miller School of Medicine, John P. Hussman Institute for Human Genomics, *Parkinson Disease*. Available at https://med.miami.edu/centers-and-institutes/hihg/research-programs/parkinson-disease (last visited Mar. 24, 2025).

²⁶ University of Miami Miller School of Medicine, *New Center Expands Services to Parkinson's Disease Community, Targeting Underserved Spanish-Speaking Population* (April 28, 2021). https://med.miami.edu/new-center-expands-services-to-parkinsons-disease-community-targeting-underserved-spanish-speaking-population/#:~:text=The%20Miller%20School%20is%20a%20Parkinson%E2%80%99s%20Foundation%20Center,treatme">https://news.med.miami.edu/new-center-expands-services-to-parkinsons-disease-community-targeting-underserved-spanish-speaking-population/#:~:text=The%20Miller%20School%20is%20a%20Parkinson%E2%80%99s%20Foundation%20Center,treatme">https://med.miami.edu/new-center-expands-services-to-parkinson%20Center,treatme

nts%20and%20research%20while%20providing%20the%20best%20care (last visited Mar. 24, 2025).

27 American Parkinson's Disease Association, ADPA's Grassroots Network: ADPA Information & Referral Centers (Mar. 21, 2021).

²⁷ American Parkinson's Disease Association, *ADPA's Grassroots Network: ADPA Information & Referral Centers* (Mar. 21, 2021) Available at https://www.apdaparkinson.org/article/our-network-of-information-and-referral-centers/ (last visited Mar. 24, 2025).

BILL HISTORY

			STAFF DIRECTOR/	ANALYSIS
COMMITTEE REFERENCE	ACTION	DATE	POLICY CHIEF	PREPARED BY
Health Professions & Programs	17 Y, 0 N, As CS	3/27/2025	McElroy	Cook
Subcommittee				
THE CHANGES ADOPTED BY THE				
COMMITTEE:				
Health Care Budget Subcommittee	13 Y, 0 N, As CS	4/9/2025	Clark	Day
THE CHANGES ADOPTED BY THE	Removes appropriations from the bill.			
COMMITTEE:	 Adds academic medical centers to list of eligible members of the 			
	Consortium for Parkinson's Disease Research.			
Health & Human Services	21 Y, 0 N	4/15/2025	Calamas	Cook
<u>Committee</u>				

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