# FLORIDA HOUSE OF REPRESENTATIVES FINAL 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

FINAL HOUSE FLOOR ACTION: 112 Y's 0 N's GOVERNOR'S ACTION: Approved

# **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 and the Florida Institute of Parkinson's Disease within USF as a statewide resource for Parkinson's disease research and clinical care.

# Fiscal or Economic Impact:

The bill has a significant, negative fiscal impact on USF. See Fiscal or Economic Impact Section.

JUMP TO <u>SUMMARY</u> <u>ANALYSIS</u> <u>RELEVANT INFORMATION</u> <u>BILL HISTORY</u>

# **ANALYSIS**

#### **EFFECT OF THE BILL:**

#### **Consortium for Parkinson's Disease Research**

The bill creates the Consortium for <u>Parkinson's Disease</u> Research (Consortium) within the University of South Florida (USF) 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 research Parkinson's disease's causes, mechanisms, and treatments and the prevalence of Parkinson's disease in first responders. (Section <u>1</u>).

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;
- 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

STORAGE NAME: h1545z

**DATE**: 6/26/2025

Parkinson's disease's causes, mechanisms, and treatments and the prevalence of Parkinson's disease in first responders. (Section  $\underline{1}$ ).

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).

The bill prohibits members from being compensated for their role. However, the bill authorizes reimbursement for travel expenses, 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>.¹ (Section 1).

The bill authorizes the board to 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 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).

#### Florida Institute for Parkinson's Disease

The bill creates the Florida Institute for Parkinson's Disease within USF as a statewide resource for Parkinson's disease research and clinical care. The bill requires the Institute to focus on finding a cure for Parkinson's disease and improving patient quality of life and health outcomes through research, clinical care, education, and advocacy. (Section 2).

The bill was approved by the Governor on June 25, 2025, ch. 2025-188, L.O.F., and will become effective on July 1, 2025. (Section 3).

## FISCAL OR ECONOMIC IMPACT:

### STATE GOVERNMENT:

The bill has a significant, negative fiscal impact on USF. The General Appropriations Act for FY 2025-2026 appropriates \$8,000,000 in nonrecurring General Revenue to USF for this purpose.<sup>2</sup>

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

TUMP TO SUMMARY ANALYSIS RELEVANT INFORMATION BILL HISTORY

2

<sup>&</sup>lt;sup>1</sup> S. 112.061, F.S.

<sup>&</sup>lt;sup>2</sup> Conference Report on SB 2500 (2025) Specific Appropriation 151; *see* Appropriations Committee Chairs, "Bump Issues – Appropriations Conference Committee on Higher Education/Higher Education Senate Offer #1 – Budget Proviso, Back of the Bill", Row # 116n (June 13, 2025)

https://www.flsenate.gov/PublishedContent/Session/2025/Conference/9/ConferenceOffer/AHE%20Senate%20Bump%20Offer%201%20 -%20Budget,%20Proviso,%20Back%20of%20Bill\_1567.pdf (last visited June 26, 2025).

<sup>&</sup>lt;sup>3</sup> National Institute of Neurological Disorders and Stroke, *Parkinson's Disease* (Mar. 5, 2025). Available at <a href="https://www.ninds.nih.gov/health-information/disorders/parkinsons-disease">https://www.ninds.nih.gov/health-information/disorders/parkinsons-disease</a> (last visited May 8, 2025).

The exact cause of Parkinson's disease is unknown.<sup>4</sup> 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.<sup>5</sup> 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.<sup>6</sup> Seven genes are linked to causing or increasing the risk of being diagnosed with Parkinson's disease.<sup>7</sup> 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

The Parkinson's Foundation designates the top academic medical centers<sup>16</sup> in the U.S. with specialized teams focused on Parkinson's disease clinical research and care as "Centers of Excellence."<sup>17</sup> 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.<sup>18</sup> Comparatively, California is home to five Centers of Excellence, New York has four, and Texas has one.<sup>19</sup>

JUMP TO <u>SUMMARY</u> <u>ANALYSIS</u> <u>RELEVANT INFORMATION</u> <u>BILL HISTORY</u>

 $<sup>^4</sup>$  National Institute on Aging, *Parkinson's Disease: Causes, Symptoms, and Treatments* (April 14, 2022). Available at <a href="https://www.nia.nih.gov/health/parkinsons-disease/parkinsons-disease-causes-symptoms-and-treatments">https://www.nia.nih.gov/health/parkinsons-disease/parkinsons-disease-causes-symptoms-and-treatments</a> (last visited May 8, 2025).

<sup>&</sup>lt;sup>5</sup> Supra note 2.

<sup>6</sup> Parkinson's Foundation, Statistics, https://www.parkinson.org/understanding-parkinsons/statistics (last visited May 8, 2025).

<sup>&</sup>lt;sup>7</sup> National Human Genome Research Institute, *About Parkinson's Disease*. Available at <u>About Parkinson's Disease</u> (last visited May 8, 2025) <sup>8</sup> *Supra* note 3.

<sup>&</sup>lt;sup>9</sup> *Id*.

<sup>&</sup>lt;sup>10</sup> Roger A. Barker and Thomas B Stoker, *Recent developments in the treatment of Parkinson's Disease* (Jul. 31, 2020). Available at <a href="https://pmc.ncbi.nlm.nih.gov/articles/PMC7400683/">https://pmc.ncbi.nlm.nih.gov/articles/PMC7400683/</a> (last visited May 8, 2025).

<sup>&</sup>lt;sup>11</sup> Supra note 3.

<sup>&</sup>lt;sup>12</sup> Supra note 5.

<sup>&</sup>lt;sup>13</sup> Parkinson's Association of Southwest Florida, *Florida Parkinson Rate*, Available at <a href="https://parkinsonassociationswfl.org/parkinsonassociationswfl.

<sup>&</sup>lt;sup>14</sup> Supra note 5.

<sup>&</sup>lt;sup>15</sup> Population Reference Bureau, *States Ranked by Percent of Population* (2020). Available at <a href="https://www.prb.org/resources/which-us-states-are-the-oldest/">https://www.prb.org/resources/which-us-states-are-the-oldest/</a> (last visited May 8, 2025).

<sup>&</sup>lt;sup>16</sup> An academic medical center 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. *See,* Institute of Medicine Committee on the Roles of Academic Health Centers in the 21<sup>st</sup> Century, *Academic Health Centers: Leading Change in the 21<sup>st</sup> Century* (2004), <a href="https://www.ncbi.nlm.nih.gov/books/NBK221676/">https://www.ncbi.nlm.nih.gov/books/NBK221676/</a> (last visited May 8, 2025).

<sup>&</sup>lt;sup>17</sup> Parkinson's Foundation, *Centers of Excellence*. Available at <a href="https://www.parkinson.org/living-with-parkinsons/finding-care/global-care-network">https://www.parkinson.org/living-with-parkinsons/finding-care/global-care-network</a> (last visited May 8, 2025).

<sup>&</sup>lt;sup>18</sup> Parkinson's Foundation, *Florida Chapter*. Available at <a href="https://www.parkinson.org/florida/florida-chapter#florida-chapter">https://www.parkinson.org/florida/florida-chapter#florida-chapter</a> (last visited May 8, 2025).

<sup>&</sup>lt;sup>19</sup> Supra note 16.

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.<sup>20</sup>

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. <sup>21</sup> Currently, the Program offers only two clinical trials for Parkinson's disease research. <sup>22</sup> 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. <sup>23</sup>

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 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.

JUMP TO <u>SUMMARY</u> <u>ANALYSIS</u> <u>RELEVANT INFORMATION</u> <u>BILL HISTORY</u>

<sup>&</sup>lt;sup>20</sup> USF Health, Parkinson's Disease & Movement Disorders Center, *Overview*. Available at <a href="https://health.usf.edu/care/neurology/services-specialties/parkinsons">https://health.usf.edu/care/neurology/services-specialties/parkinsons</a> (last visited May 8, 2025).

<sup>&</sup>lt;sup>21</sup> UF Health, Norman Fixel Institute for Neurological Diseases, Movement Disorders & Neurorestoration Program, *About*. Available at <a href="https://movementdisorders.ufhealth.org/about/">https://movementdisorders.ufhealth.org/about/</a> (last visited May 8, 2025); UF Health, Norman Fixel Institute for Neurological Diseases, Movement Disorders & Neurorestoration Program, *Clinical Trials*. Available at <a href="https://fixel.ufhealth.org/research-2/clinical-trials-2/">https://fixel.ufhealth.org/research-2/clinical-trials-2/</a> (last visited May 8, 2025).

<sup>&</sup>lt;sup>22</sup> UF Health, *Parkinson Disease Clinical Trials*. Available at <a href="https://ufhealth.org/conditions-and-treatments/parkinson-disease/clinical-trials">https://ufhealth.org/conditions-and-treatments/parkinson-disease/clinical-trials</a> (last visited May 8, 2025).

<sup>&</sup>lt;sup>23</sup> UF Health, Norman Fixel Institute for Neurological Diseases, Movement Disorders & Neurorestoration Program, *Clinical Research*. Available at <a href="https://movementdisorders.ufhealth.org/research/clinical-research/">https://movementdisorders.ufhealth.org/research/clinical-research/</a> (last visited May 8, 2025).

<sup>&</sup>lt;sup>24</sup> University of Miami Miller School of Medicine, John P. Hussman Institute for Human Genomics, *Parkinson Disease*. Available at <a href="https://med.miami.edu/centers-and-institutes/hihg/research-programs/parkinson-disease">https://med.miami.edu/centers-and-institutes/hihg/research-programs/parkinson-disease</a> (last visited May 8, 2025).

<sup>&</sup>lt;sup>25</sup> University of Miami Miller School of Medicine, *New Center Expands Services to Parkinson's Disease Community, Targeting Underserved Spanish-Speaking Population* (April 28, 2021). <a href="https://news.med.miami.edu/new-center-expands-services-to-parkinsons-disease-community-targeting-underserved-spanish-speaking-">https://news.med.miami.edu/new-center-expands-services-to-parkinsons-disease-community-targeting-underserved-spanish-speaking-</a>

population/#:~:text=The%20Miller%20School%20is%20a%20Parkinson%E2%80%99s%20Foundation%20Center,treatments%20and%2 Oresearch%20while%20providing%20the%20best%20care (last visited May 8, 2025).

<sup>&</sup>lt;sup>26</sup> American Parkinson's Disease Association, *ADPA's Grassroots Network: ADPA Information & Referral Centers* (Mar. 21, 2021). Available at <a href="https://www.apdaparkinson.org/article/our-network-of-information-and-referral-centers/">https://www.apdaparkinson.org/article/our-network-of-information-and-referral-centers/</a> (last visited May 8, 2025).