#### The Florida Senate BILL ANALYSIS AND FISCAL IMPACT STATEMENT (This document is based on the provisions contained in the legislation as of the latest date listed below.) Prepared By: The Professional Staff of the Appropriations Committee on Health and Human Services CS/CS/SB 1800 BILL: Appropriations Committee on Health and Human Services; Health Policy Committee; INTRODUCER: and Senator Calatayud Parkinson's Disease SUBJECT: DATE: April 14, 2025 REVISED: ANALYST STAFF DIRECTOR REFERENCE ACTION 1. Morgan Brown HP Fav/CS Gerbrandt **McKnight** AHS Fav/CS 2. 3. FP

## Please see Section IX. for Additional Information:

COMMITTEE SUBSTITUTE - Substantial Changes

#### I. Summary:

CS/CS/SB 1800 creates s. 1004.4352, F.S., to establish the Parkinson's Disease Research Board (Board), as well as the Consortium for Parkinson's Disease Research (Consortium) within the University of South Florida. The Board is established to direct the operations of the Consortium, and the Consortium exists to conduct rigorous scientific research and disseminate such research.

The bill requires the Board to adopt a plan for Parkinson's disease research annually and to award funds to members of the Consortium to perform research consistent with the plan. The Board must issue a report to the Governor and the Legislature on research projects, research findings, community outreach initiatives, and future plans for the Consortium by October 15 of each year.

The bill is subject to legislative appropriation. If an appropriation is provided funds must be allocated as prescribed in the bill. See Section V., Fiscal Impact Statement.

The bill takes effect July 1, 2025.

#### II. Present Situation:

#### **Parkinson's Disease**

Parkinson's disease is a movement disorder of the nervous system<sup>1</sup> that worsens over time. Although Parkinson's disease cannot be cured, medications may help control and improve symptoms.<sup>2</sup>

Parkinson's disease is very common overall, ranking second among age-related degenerative brain diseases. It is also the most common motor (movement-related) brain disease. Experts estimate that it affects at least 1 percent of people over the age of 60 worldwide.<sup>3</sup>

Parkinson's disease is not fatal, but the symptoms and effects are often contributing factors to death. The average life expectancy for Parkinson's disease in 1967 was a little under 10 years. Since then, the average life expectancy has increased by about 55 percent, rising to more than 14.5 years. That, combined with the fact that Parkinson's diagnosis is much more likely after age 60, means this condition does not often affect the life expectancy by more than a few years.<sup>4</sup>

#### Parkinson's Disease Symptoms & Complications

Parkinson's disease symptoms can be different for everyone. Early symptoms may be mild and may go unnoticed. Symptoms often begin on one side of the body, then affect both sides as the disease progresses. Symptoms are usually worse on one side than the other.<sup>5</sup>

Parkinson's disease symptoms may include:<sup>6</sup>

- Tremors Rhythmic shaking that usually begins in the hands or fingers. Sometimes a tremor begins in the foot or jaw, or an individual may rub their thumb and forefinger back and forth, also known as a pill-rolling tremor. The hand may tremble when at rest or when under stress. Some individuals notice less shaking when doing some sort of task or moving around.
- Bradykinesia (slow movement) Parkinson's disease may slow movement, making simple tasks more difficult. It can be challenging to get out of a chair, shower, or get dressed. The disease may cause less facial expression and make it difficult to blink.
- Rigid muscles Parkinson's disease can cause stiff muscles in any part of the body. Muscles may feel tense and painful, and arm movements may become short and jerky.
- Poor posture and balance Parkinson's disease may cause posture to become stooped, and an individual may experience falls or problems with balance.

<sup>&</sup>lt;sup>1</sup> The nervous system is a network of nerve cells that controls many parts of the body, including movement. *See* Mayo Clinic, *Parkinson's Disease, available at* <u>https://www.mayoclinic.org/diseases-conditions/parkinsons-disease/symptoms-causes/syc-20376055#:~:text=Parkinson's%20disease%20is%20a%20movement,a%20foot%20or%20the%20jaw</u>. (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>2</sup> Mayo Clinic, *Parkinson's Disease, available at* <u>https://www.mayoclinic.org/diseases-conditions/parkinsons-disease/symptoms-causes/syc-</u>

<sup>20376055#:~:</sup>text=Parkinson's%20disease%20is%20a%20movement,a%20foot%20or%20the%20jaw. (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>3</sup> Cleveland Clinic, *Parkinson's Disease, available at* <u>https://my.clevelandclinic.org/health/diseases/8525-parkinsons-disease-an-overview#symptoms-and-causes</u> (last visited Mar. 30, 2025).

 $<sup>\</sup>overline{^{4}}$  Id.

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

<sup>&</sup>lt;sup>6</sup> Id.

- Loss of automatic movements Parkinson's disease may lessen an individual's ability to make certain movements that typically are accomplished without thinking, including blinking, smiling, or swinging arms while walking.
- Speech changes The disease may result in soft or quick speech, slurring, or hesitation prior to speaking. Speech may become flat or monotone, without typical speech patterns.
- Writing changes Trouble writing and writing that appears cramped and small are a sign of the disease.
- Nonmotor symptoms These may include depression; anxiety; constipation; sleep problems, including acting out dreams; the need to urinate often; trouble smelling; problems thinking and with memory; feeling very tired; blood pressure changes; and pain or cramps in muscles and joints.

Individuals with Parkinson's disease may have treatable complications, including:<sup>7</sup>

- Trouble thinking clearly Parkinson's disease can affect memory, language, and reasoning skills. The disease can also lead to dementia or other conditions that affect thinking. These complications usually occur later in the disease's progression, and typically medications have only a modest benefit in managing symptoms.
- Emotional changes and depression Some people feel irritable and concerned early in the course of Parkinson's disease, experiencing depression and anxiety. Medications and other treatments can assist with these changes.
- Trouble swallowing and chewing Late-stage Parkinson's disease affects the muscles in the mouth causing trouble swallowing and chewing, which can lead to a nutrient deficiency. The collection of food or saliva in the mouth can also pose a choking hazard or cause drooling.
- Sleep problems and sleep disorders Individuals with Parkinson's disease may wake often during the night, have nightmares, and fall asleep during the day.
- Rapid eye movement sleep behavior disorder This involves acting out dreams, and medications and other therapies may help improve sleep.

#### Causes of Parkinson's Disease

Parkinson's disease causes a specific area of the brain, the basal ganglia,<sup>8</sup> to deteriorate. As this area deteriorates, the ability to control the areas regulated by this portion of the brain decreases. Researchers have uncovered that Parkinson's disease causes a major shift in brain chemistry.<sup>9</sup>

<sup>&</sup>lt;sup>7</sup> Mayo Clinic, *Parkinson's Disease, available at* <u>https://www.mayoclinic.org/diseases-conditions/parkinsons-disease/symptoms-causes/syc-</u>

<sup>20376055#:~:</sup>text=Parkinson's%20disease%20is%20a%20movement,a%20foot%20or%20the%20jaw. (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>8</sup> The basal ganglia are a cluster of nuclei found deep to the neocortex of the brain. It has a multitude of functions associated with reward and cognition but is primarily involved in motor control. In particular, the basal ganglia are considered to be a gate-keeping mechanism for the initiation of motor movement, effectively choosing which actions to allow and which actions to inhibit. See National Institutes of Health, National Library of Medicine, National Center for Biotechnology Information, *Neuroanatomy, Basal Ganglia, available at* 

https://www.ncbi.nlm.nih.gov/books/NBK537141/#:~:text=The%20basal%20ganglia%20is%20a,primarily%20involved%20i n%20motor%20control. (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>9</sup> Cleveland Clinic, *Parkinson's Disease, available at* <u>https://my.clevelandclinic.org/health/diseases/8525-parkinsons-disease-an-overview#symptoms-and-causes</u> (last visited Mar. 30, 2025).

Under normal circumstances, the brain uses chemicals known as neurotransmitters to control how brain cells (neurons) communicate with each other. With Parkinson's disease, an individual does not have enough dopamine, one of the most important neurotransmitters.<sup>10</sup>

When the brain sends activation signals telling the muscles to move, it fine-tunes the movements using cells that require dopamine. A lack of dopamine causes slowed movements and tremors, symptoms of Parkinson's disease.<sup>11</sup>

As Parkinson's disease progresses, the symptoms expand and intensify. Later stages of the disease often affect brain functions, causing dementia-like symptoms and depression.<sup>12</sup>

The cause of Parkinson's disease is unknown, but several factors seem to play a role, including:<sup>13</sup>

- Genes Specific genetic changes are linked to Parkinson's disease, but these are rare unless many family members have been diagnosed with the disease.
- Environmental factors Exposure to certain toxins or other environmental factors may increase the risk of later Parkinson's disease.

Many changes occur in the brains of individuals with Parkinson's disease. Researchers are studying the changes which include:<sup>14</sup>

- The presence of Lewy bodies Clumps of proteins in the brain, called Lewy bodies, are associated with Parkinson's disease and researchers believe these proteins hold an important clue to the cause of the disease.
- Alpha-synuclein found within Lewy bodies Alpha-synuclein is a protein found in all Lewy bodies. It occurs in a clumped form that cells cannot break down. This is currently an important focus among Parkinson's disease researchers. Alpha-synuclein has been found in the spinal fluid of individuals who later have Parkinson's disease.
- Altered mitochondria Mitochondria are powerhouse compartments inside cells that create most of the body's energy. Changes to mitochondria can cause cell damage and are often observed in the brains of individuals with Parkinson's disease.

### Parkinson's Disease Risk Factors

Risk factors for Parkinson's disease include:15

• Age – The risk of Parkinson's disease increases with age. Usually, it starts around age 50 or older. The average age of onset is around age 70. Parkinson's disease can occur in younger adults, but it is rare. When individuals younger than age 50 are diagnosed with the disease, it is known as early-onset Parkinson's disease.

<sup>&</sup>lt;sup>10</sup> Cleveland Clinic, *Parkinson's Disease, available at* <u>https://my.clevelandclinic.org/health/diseases/8525-parkinsons-disease-an-overview#symptoms-and-causes</u> (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>11</sup> Id. <sup>12</sup> Id.

 <sup>&</sup>lt;sup>13</sup> Mayo Clinic, Parkinson's Disease, available at <u>https://www.mayoclinic.org/diseases-conditions/parkinsons-disease/symptoms-causes/syc-</u>

<sup>20376055#:~:</sup>text=Parkinson's%20disease%20is%20a%20movement,a%20foot%20or%20the%20jaw. (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>14</sup> *Id*.

<sup>&</sup>lt;sup>15</sup> Id.

- Genetics The risk of developing Parkinson's Disease increases if one or more first-degree relatives, such as parents or siblings, have been diagnosed with the disease. However, familial Parkinson's disease is only attributed to about 10 percent of all cases.<sup>16</sup>
- Sex Men are more likely to develop Parkinson's disease than women.
- Exposure to toxins Ongoing exposure to herbicides and pesticides may slightly increase the risk of developing Parkinson's disease.

#### Parkinson's Disease Prevention

Since the cause of Parkinson's disease is unknown, there are no proven ways to prevent it. However, research shows that some factors may help protect against it, including:<sup>17</sup>

- Exercise Aerobic exercise has been linked to a lower risk of Parkinson's disease.
- Caffeine Some studies show a link between drinking caffeinated beverages, such as coffee and green tea, may lower the risk of developing Parkinson's disease.
- Medicines Some medications, such as ibuprofen and statins,<sup>18</sup> have been linked to a lower risk of the disease.

#### Parkinson's Disease Diagnosis and Tests

A biomarker is a biological molecule found in blood, other body fluids, or tissues that are a sign of a normal or abnormal process, or of a condition or disease. A biomarker may be used to see how well the body responds to a treatment for a disease or condition.<sup>19</sup>

Biomarker testing is a method to look for genes, proteins, and other substances (biomarkers or tumor markers) that can provide information about cancer and other conditions. Biomarkers are substances in the body that can give researchers and doctors information about a person's health. For example, high cholesterol is a biomarker of heart disease. Currently, the use of biomarkers is in the beginning stages to help diagnose Parkinson's disease.<sup>20</sup>

Diagnosing Parkinson's disease is mostly a clinical process, meaning it relies heavily on a health care provider examining the symptoms, asking questions, and reviewing medical history. Some diagnostic and lab tests are possible, but these are usually needed to rule out other conditions or certain causes; however, most lab tests are not necessary unless the patient is unresponsive to treatment for Parkinson's disease, which can indicate another condition.<sup>21</sup>

<sup>20</sup> Parkinson's Foundation, *Parkinson's Biomarkers, available at* <u>https://www.parkinson.org/understanding-parkinsons/getting-diagnosed/biomarkers</u> (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>16</sup> Cleveland Clinic, *Parkinson's Disease, available at* <u>https://my.clevelandclinic.org/health/diseases/8525-parkinsons-disease-an-overview#symptoms-and-causes</u> (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>17</sup> Id.

<sup>&</sup>lt;sup>18</sup> Statins are drugs that can lower cholesterol. See Mayo Clinic, Statins: Are these cholesterol-lowering drugs right for you?, available at <u>https://www.mayoclinic.org/diseases-conditions/high-blood-cholesterol/in-depth/statins/art-20045772#:~:text=Statins%20are%20drugs%20that%20can.of%20heart%20disease%20and%20stroke</u>. (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>19</sup> National Institutes of Health, National Cancer Institute, *Biomarker Testing for Cancer Treatment, available at* <u>https://www.cancer.gov/about-cancer/treatment/types/biomarker-testing-cancer-treatment</u> (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>21</sup> Cleveland Clinic, *Parkinson's Disease, available at* <u>https://my.clevelandclinic.org/health/diseases/8525-parkinsons-</u> disease-an-overview#symptoms-and-causes (last visited Mar. 30, 2025).

When health care providers suspect Parkinson's disease or need to rule out other conditions, various imaging and diagnostic tests are possible, including:<sup>22</sup>

- Blood tests;
- Computed tomography (CT) scans;<sup>23</sup>
- Genetic testing;
- Magnetic resonance imaging (MRI);<sup>24</sup> and
- Positron emission tomography (PET) scans.<sup>25</sup>

Researchers have found ways to test for possible indicators of Parkinson's disease. Both of these tests involve the alpha-synuclein protein; however, these tests only serve to provide information that can help a provider in making a diagnosis.<sup>26</sup>

- Spinal tap Looks for misfolded alpha-synuclein proteins in cerebrospinal fluid, which is the fluid that surrounds the brain and spinal cord. This test involves a spinal tap (lumbar puncture), where a health care provider inserts a needle into the spinal canal to collect cerebrospinal fluid for testing.
- Skin biopsy Another possible test involving a biopsy of surface nerve tissue. A biopsy includes collecting a small sample of the skin, including the nerves in the skin. The samples come from a spot on the back and two spots on the leg. Analyzing the samples can help determine if the alpha-synuclein protein has a certain kind of malfunction that could increase the risk of developing Parkinson's disease.

#### Parkinson's Disease Management and Treatment

For now, Parkinson's disease is not curable, but there are multiple ways to manage its symptoms. The treatments can also vary from person to person, depending on the specific symptoms and how well certain treatments work. Medications are the primary way to treat this condition.<sup>27</sup>

<sup>&</sup>lt;sup>22</sup> Cleveland Clinic, *Parkinson's Disease, available at* <u>https://my.clevelandclinic.org/health/diseases/8525-parkinsons-disease-an-overview#symptoms-and-causes</u> (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>23</sup> A CT scan is a type of imaging that uses X-ray techniques to create detailed images of the body. It then uses a computer to create cross-sectional images, also called slices, of the bones, blood vessels, and soft tissues inside the body. CT scan images show more detail than plain X-rays do. *See* Mayo Clinic, *CT Scan, available at* <u>https://www.mayoclinic.org/tests-procedures/ct-scan/about/pac-20393675</u> (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>24</sup> An MRI is a noninvasive medical imaging test that produces detailed images of almost every internal structure in the human body, including the organs, bones, muscles, and blood vessels. MRI scanners create images of the body using a large magnet and radio waves. No ionizing radiation is produced during an MRI exam, unlike X-rays. These images give a physician important information in diagnosing a medical condition and planning a course of treatment. *See* Johns Hopkins Medicine, *Magnetic Resonance Imaging (MRI), available at* <u>https://www.hopkinsmedicine.org/health/treatment-tests-and-therapies/magnetic-resonance-imaging-</u>

<sup>&</sup>lt;u>mri#:~:text=Magnetic%20resonance%20imaging%2C%20or%20MRI,large%20magnet%20and%20radio%20waves</u>. (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>25</sup> A PET scan is an imaging test that can help reveal the metabolic or biochemical function of tissues and organs. The PET scan uses a radioactive drug called a tracer to show both typical and atypical metabolic activity. A PET scan can often detect the atypical metabolism of the tracer in diseases before the disease shows up on other imaging tests, such as a CT and an MRI. *See* Mayo Clinic, *Positron emission tomography scan, available at* <u>https://www.mayoclinic.org/tests-procedures/pet-scan/about/pac-20385078</u> (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>26</sup> Cleveland Clinic, *Parkinson's Disease, available at* <u>https://my.clevelandclinic.org/health/diseases/8525-parkinsons-</u> disease-an-overview#symptoms-and-causes (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>27</sup> Cleveland Clinic, *Parkinson's Disease, available at* <u>https://my.clevelandclinic.org/health/diseases/8525-parkinsons-disease-an-overview#symptoms-and-causes</u> (last visited Mar. 30, 2025).

A secondary treatment option is surgery to implant a device that will deliver a mild electrical current to part of the brain (deep brain stimulation).<sup>28</sup> There are also experimental options, such as stem cell-based treatments, however, availability often varies, and many are not an option for individuals with Parkinson's disease.<sup>29</sup>

Medications that do one or more of the following are used to treat Parkinson's disease:<sup>30</sup>

- Adding dopamine Medications like levodopa<sup>31</sup> can increase the available levels of dopamine in the brain. This medication is almost always effective, and when it does not work, that is usually a sign of some other form of parkinsonism<sup>32</sup> rather than Parkinson's disease. Long-term use of levodopa eventually leads to side effects that make it less effective.
- Simulating dopamine Dopamine agonists are medications that have a dopamine-like effect. Dopamine is a neurotransmitter, causing cells to act in a certain way when a dopamine molecule latches onto them. Dopamine agonists can latch on and cause cells to behave the same way. These are more common in younger patients to delay starting levodopa.
- Dopamine metabolism blockers The body has natural processes to break down neurotransmitters like dopamine. Medications that block the body from breaking down dopamine allow more dopamine to remain available to the brain. These medications are especially useful early on and can also help when combined with levodopa in later stages of Parkinson's disease.
- Levodopa metabolism inhibitors These medications slow down how the body processes levodopa, helping it last longer. These medications may need careful use as they can have toxic effects and damage the liver. They are most often used to help as levodopa becomes less effective.
- Adenosine blockers Medications that block how certain cells use adenosine (a molecule used in various forms throughout the body) can have a supportive effect when used alongside levodopa.

https://www.ncbi.nlm.nih.gov/books/NBK482140/#:~:text=Levodopa%20is%20the%20precursor%20to,symptoms%20appar ent%20in%20Parkinson%20disease. (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>28</sup> In years past, surgery was an option to intentionally damage and scar a part of the brain that was malfunctioning because of Parkinson's disease. Today, that same effect is possible using deep-brain stimulation, which uses an implanted device to deliver a mild electrical current to those same areas. The major advantage is that deep-brain stimulation is reversible, while intentional scarring damage is not. This treatment approach is almost always an option in later stages of Parkinson's disease when levodopa therapy becomes less effective, and in people who have a tremor that does not seem to respond to the usual medications. *See* Cleveland Clinic, *Parkinson's Disease, available at* <a href="https://my.clevelandclinic.org/health/diseases/8525-parkinsons-disease-an-overview#symptoms-and-causes">https://my.clevelandclinic.org/health/diseases/8525-parkinsons-disease-an-overview#symptoms-and-causes</a> (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>29</sup> Stem cell transplants add new dopamine-using neurons into the brain to take over for damaged ones. Neuron-repair treatments try to repair damaged neurons and encourage new neurons to form. Gene therapies and gene-targeted treatments target specific mutations that cause Parkinson's disease. Some also boost the effectiveness of levodopa or other treatments. *See* Cleveland Clinic, *Parkinson's Disease, available at* <u>https://my.clevelandclinic.org/health/diseases/8525-parkinsons-disease-an-overview#symptoms-and-causes</u> (last visited Mar. 30, 2025).

<sup>&</sup>lt;sup>30</sup> Supra note 27.

<sup>&</sup>lt;sup>31</sup> Levodopa is the precursor to dopamine. Most commonly, clinicians use levodopa as a dopamine replacement agent for the treatment of Parkinson's disease. It is most effectively used to control bradykinetic symptoms apparent in Parkinson's disease. Levodopa is typically prescribed to a patient with Parkinson's disease once symptoms become more difficult to control with other anti-parkinsonism drugs. See National Institutes of Health, National Library of Medicine, National Center for Biotechnology Information, *Levodopa (L-Dopa), available at* 

<sup>&</sup>lt;sup>32</sup> "Parkinsonism" is an umbrella term that describes Parkinson's disease and conditions with similar symptoms. It can refer not only to Parkinson's disease but also to other conditions like multiple system atrophy or corticobasal degeneration. *See* Cleveland Clinic, *Parkinson's Disease, available at* <u>https://my.clevelandclinic.org/health/diseases/8525-parkinsons-disease-an-overview#symptoms-and-causes</u> (last visited Mar. 30, 2025).

• Other medications are used to treat specific symptoms of Parkinson's disease.

#### Current Status of Parkinson's Disease Research in Florida

The Parkinson's Foundation designates the nation's top medical centers with specialized teams focused on Parkinson's disease clinical research and care as "Centers of Excellence."<sup>33</sup> Florida is home to three Parkinson's disease Centers of Excellence, including the USF's Parkinson's Disease & Movement Disorders Center,<sup>34</sup> the University of Florida's Movement Disorders and Neurorestoration Program,<sup>35,36,37</sup> and the University of Miami's Miller School of Medicine.<sup>38,39,40,41</sup> Comparatively, California is home to five Centers of Excellence, New York is home to four, and Texas is home to one.<sup>42</sup>

#### III. Effect of Proposed Changes:

**Section 1** creates s. 1004.4352, F.S., to provide that the section may be cited as the "Parkinson's Disease Research Act."

<sup>&</sup>lt;sup>33</sup> Parkinson's Foundation, *Global Care Network, available at* <u>https://www.parkinson.org/living-with-parkinsons/finding-care/global-care-network</u> (last visited Apr. 3, 2025).

<sup>&</sup>lt;sup>34</sup> The USF's 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. *See* USF Health, *Parkinson's Disease & Movement Disorders Center, available at* <u>https://health.usf.edu/care/neurology/services-</u> specialties/parkinsons (last visited Apr. 3, 2025).

<sup>&</sup>lt;sup>35</sup> The University of Florida's (UF's) Movement Disorders and Neurorestoration Program operates within the UF'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. See UFHealth, *About, available at* https://movementdisorders.ufhealth.org/about/ (last visited Apr. 3, 2025).

<sup>&</sup>lt;sup>36</sup> Currently, the Program offers only two clinical trials for Parkinson's disease research. *See* UFHealth, *Clinical trials, available at* <u>https://ufhealth.org/conditions-and-treatments/parkinson-disease/clinical-trials</u> (last visited Apr. 3, 2025).

<sup>&</sup>lt;sup>37</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. *See* UFHealth, *Clinical Research, available at* <u>https://movementdisorders.ufhealth.org/research/clinical-research/</u> (last visited Apr. 3, 2025).

<sup>&</sup>lt;sup>38</sup> The University of Miami's 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. *See* Miller School of Medicine, *Parkinson Disease, available at* <u>https://med.miami.edu/centers-and-institutes/hihg/research-programs/parkinson-disease</u> (last visited Apr. 3, 2025).

<sup>&</sup>lt;sup>39</sup> 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. *See* Miller School of Medicine, *New Center Expands Services to Parkinson's Disease Community, Targeting Underserved Spanish-Speaking Population, available at* <u>https://news.med.miami.edu/new-center-expands-services-to-</u> <u>parkinsons-disease-community-targeting-underserved-spanish-speaking-</u>

population/#:~:text=The%20Miller%20School%20is%20a%20Parkinson%E2%80%99s%20Foundation%20Center,treatment s%20and%20research%20while%20providing%20the%20best%20care (last visited Apr. 3, 2025).

<sup>&</sup>lt;sup>40</sup> The Center operates a telephone helpline, provides resources on symptoms and therapies, and connects patients with physicians and specialists. *See* American Parkinson Disease Association, *APDA's Grassroots Network: APDA Information & Referral Centers, available at* <u>https://www.apdaparkinson.org/article/our-network-of-information-and-referral-centers/</u> (last visited Apr. 3, 2025).

<sup>&</sup>lt;sup>41</sup> Parkinson's Foundation, *Florida Chapter, available at* <u>https://www.parkinson.org/florida/florida-chapter#florida-chapter</u> (last visited Apr. 3, 2025).

<sup>&</sup>lt;sup>42</sup> Parkinson's Foundation, *Global Care Network, available at* <u>https://www.parkinson.org/living-with-parkinsons/finding-care/global-care-network</u> (last visited Apr. 3, 2025).

The bill establishes the following legislative findings:

- Parkinson's disease is a progressive neurological disorder affecting approximately one million Americans, with an estimated 90,000 new diagnoses each year.
- Currently, there is no cure for Parkinson's disease, and innovative research is essential to advance therapies, improve patient outcomes, and alleviate the burden of the disease.

The bill defines the following terms:

- "Board" to mean the Parkinson's Disease Research Board.
- "Consortium" to mean the Consortium for Parkinson's Disease Research.

The bill establishes the Consortium for Parkinson's Disease Research (Consortium), which consists of public and private universities and academic medical centers, within the University of South Florida (USF). The purpose of the Consortium is to conduct rigorous scientific research and disseminate such research.

The bill establishes the Parkinson's Disease Research Board (Board) to direct the operations of the Consortium. The Board must be composed of members representing each participating university or academic medical center and appointed by the president or chief executive officer of each participating university or academic medical center. Board members must have experience in a variety of scientific fields, including, but not limited to, neurology, psychology, nutrition, and genetics. Members must be appointed to four-year terms and may be reappointed to serve additional terms. The chair must be elected by the Board from among its members to serve a two-year term. The Board must meet at least semi-annually at the call of the chair or, in his or her absence or incapacity, the vice chair. Four members constitute a quorum. A majority vote of the members present is required for all actions of the Board. The Board may prescribe, amend, and repeal a charter governing the way it conducts its business. Board members must serve without compensation, but are entitled to receive reimbursement for travel expenses by the Consortium or the organization he or she represents in accordance with s. 112.061, F.S.

The bill requires the Consortium to be administered by a director, who must be appointed by and serve at the pleasure of the Board. Subject to the approval of the Board, the director must:

- Propose a budget for the Consortium.
- Foster the collaboration of scientists, researchers, and other appropriate personnel in accordance with the Consortium's charter.
- Engage individuals in public and private university and academic medical center programs relevant to the Consortium's work to participate in the Consortium.
- Identify and prioritize the research to be conducted by the Consortium.
- Prepare a plan for Parkinson's disease research for submission to the Board.
- Apply for grants to obtain funding for research conducted by the Consortium.
- Perform other duties as determined by the Board.

The bill requires the Board to annually adopt a plan for Parkinson's disease research. The plan must organize a program of research that contributes to the body of scientific knowledge on the causes, mechanisms, and potential treatments for Parkinson's disease and the prevalence of Parkinson's disease in first responders. The Board must award funds to members of the Consortium to perform research consistent with the plan.

The bill requires that the Board issue a report to the Governor, the President of the Senate, and the Speaker of the House of Representatives on research projects, research findings, community outreach initiatives, and future plans for the Consortium by October 15 of each year.

**Section 2** requires the following allocation of funds, subject to appropriation from the General Appropriations Act:

- 67 percent of funds appropriated are directed to the USF for Parkinson's disease research including, but not limited to, identifying the genetic origin of the disease and developing therapeutic interventions to slow or stop the progression of the disease.
- 33 percent of funds appropriated are directed to the USF for the Consortium for Parkinson's Disease Research.

The bill takes effect July 1, 2025.

### IV. Constitutional Issues:

A. Municipality/County Mandates Restrictions:

None.

B. Public Records/Open Meetings Issues:

None.

C. Trust Funds Restrictions:

None.

D. State Tax or Fee Increases:

None.

E. Other Constitutional Issues:

None.

#### V. Fiscal Impact Statement:

A. Tax/Fee Issues:

None.

B. Private Sector Impact:

None.

#### C. Government Sector Impact:

The bill is subject to legislative appropriation. If an appropriation is provided funds must be allocated as prescribed in the bill:

- 67 percent of funds appropriated are directed to the University of South Florida (USF) for Parkinson's disease research including, but not limited to, identifying the genetic origin of the disease and developing therapeutic interventions to slow or stop the progression of the disease.
- 33 percent of funds appropriated are directed to the USF for the Consortium for Parkinson's Disease Research.

#### VI. Technical Deficiencies:

None.

#### VII. Related Issues:

The bill does not speak to how the public or private universities, or academic medical centers are chosen to participate in the Consortium. The bill is silent as to the term of service for the director of the Consortium. The term "academic medical center" is not defined in current law.

#### VIII. Statutes Affected:

This bill creates section 1004.4352 of the Florida Statutes.

The bill creates undesignated sections of the Florida law.

#### IX. Additional Information:

A. Committee Substitute – Statement of Substantial Changes: (Summarizing differences between the Committee Substitute and the prior version of the bill.)

# CS/CS by Appropriations Committee on Health and Human Services on April 10, 2025:

The committee substitute revises the makeup of the Florida Consortium for Parkinson's Disease Research to include academic medical centers, in addition to public and private universities and revises the makeup of the Parkinson's Disease Research Board to include appointees from academic medical centers.

#### CS by Health Policy on April 1, 2025:

The committee substitute:

- Deletes the underlying bill's Parkinson's Disease Research Program established within the Florida Department of Health.
- Creates the Parkinson's Disease Research Act within the Education Code instead of public health statutes.
- Establishes a Consortium for Parkinson's Disease Research within the University of South Florida (USF) and establishes a Parkinson's Disease Research Board (Board) to direct the operations of the Consortium.

- Requires the Board to annually adopt a plan for Parkinson's disease research and to submit a report to the Governor and the Legislature.
- Removes the underlying bill's appropriation of funds and provides that, subject to appropriations, specific percentages of funds be used for certain purposes.
- B. Amendments:

None.

This Senate Bill Analysis does not reflect the intent or official position of the bill's introducer or the Florida Senate.