

# JAX HOPE INC

## First Coast Parkinson's Newsletter

Fall 2024



**Bill Wilson**

**JAXHOPEINC's 2nd Annual Bill Wilson Golf Tournament** "Beating Parkinson's One Swing at a Time" will be held at South Hampton Golf Course on Friday, November 15. Go to our website [JAXHOPEINC.ORG](http://JAXHOPEINC.ORG) to register or call (904) 801-5535. We thank everyone who has already signed up to make this happen. Following golf and for non-golfers, please join us for dinner with speaker Philip W. Tipton, MD, Senior Associate Consultant and Assistant Professor of Neurology, Dept. of Neurology, Mayo Clinic Florida.



## Board Members

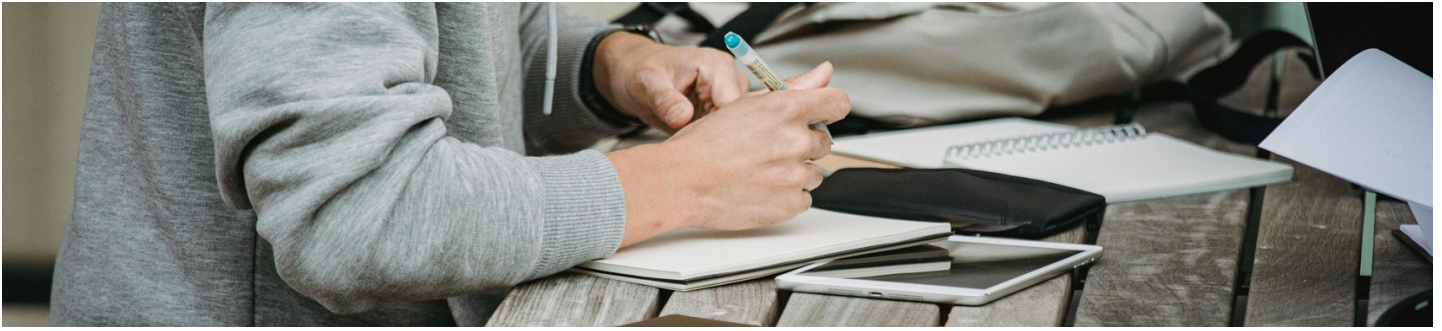
**Terry Hermiston, Ph.D - Board Chairman, Gregg Hummer - President, Sharon Swander -Treasurer, Alaine Keebaugh, Ph.D. - Director of Grants, Marilyn Wilson - Newsletter Editor, Philip W. Tipton, M.D.**

Welcome to **JAX HOPE, INC**, a 501c3 local non-profit dedicated to providing information and to improve the lives of People with Parkinson's.

## What's Inside?

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## President's Message



I am very pleased and thankful to report the beginning of 2 new JAX HOPE Parkinson's Support Groups within the Jacksonville area (details found with Support Group Listings):

**Mandarin Support Group - Katheryn Donaldson, Leader  
&  
WESTSIDE Jacksonville Support Group - Kathy Lowery, Leader**

They are very much needed. I attended a Parkinson's Foundation event a couple years ago, and learned at that time, there were 1 million people in the US estimated to be living with Parkinson's and expected to increase to 1.2 million by 2030.\*. The estimated 25,000 Jacksonville Parkinson's population in 2022 would also be rising.

Along with those growing numbers, JAX HOPE's Mission and Vision of giving hope to People with Parkinson's must expand to include more Support Services within the Jacksonville area. This is where we could use your help. We would like to work with a volunteer or more to begin a Support Group in your area. A few unserved areas might be: Arlington, Mayport, Ortega, San Marco, Northside... or the one you live in. Please help us to connect with these individuals to make their lives better. Contact me for more information by emailing: [community@jaxhopeinc.org](mailto:community@jaxhopeinc.org) or calling (904)801-5535.

With optimism and gratitude,

Gregg Hummer  
President, JAX HOPE INC

\* According to the Parkinson's Prevalence Project supported by the Parkinson's Foundation, the Michael J. Fox Foundation, and the Institute for Clinical Evaluative Science

# New Jax Hope Web Site, with Community Forums

The Jax Hope web site has been refreshed to be easier to read, navigate, and find information. It also includes new features such as the Jax Hope Online Community, which provides a place for the Parkinson's community of north Florida and beyond to have online conversations. Many of you have probably already used online forums, including Reddit, Discord, Quora, and the Parkinson's Foundation (<https://www.parkinson.org/resources-support/helpline/online-pd-community>).

First, the site was redesigned with clarity and read-ability in mind, with fonts, colors, and graphic elements that are large, bold, and attractive, whether you're viewing it on your desktop, tablet, or phone. Information was re-structured in the menus to be more intuitively followed, by following headings like "who we are", "what we do", and "who we serve." This is similar to the way that the Michael J. Fox Foundation is organized, a site that we anticipate you are all familiar with.

The Jax Hope Community is an online meeting space where people can talk about just about anything relating to Parkinson's. It does require a specific free membership sign-up that you can find at the top or bottom of any page on the Jax Hope site ([jaxhopeinc.org](http://jaxhopeinc.org)), or go directly to the community page at <https://www.jaxhopeinc.org/forum-community>. Once you're signed up, feel free to post anything that you might want to share or converse about with the greater Jacksonville Parkinson's community. Examples include queries about support groups, medical providers, medication, places to exercise, caregiving, etc.

The screenshot displays the Jax Hope Online Community website. At the top, there is a navigation bar with a search bar on the left, the Jax Hope logo in the center (featuring a sun icon), and a 'Community' button on the right. Below the navigation bar, there are several menu items: 'Who We Are >', 'What We Do >', 'Who We Serve >', 'Parkinson's Resources >', and 'Get Involved! >'. A secondary navigation bar includes 'All Posts' and 'My Posts' tabs, a search bar, and a settings icon. The main content area features a large banner image of people on a beach with their arms raised, overlaid with the text 'Jax Hope Online Community' and 'Welcome! Have a look around and join the discussions.' Below the banner, there is a list of forum posts. The posts are sorted by 'Recent Activity' and include a 'More Actions' dropdown and a 'Create New Post' button. The list of posts includes:

Post Title	Author	Replies	Views	Comments	Time
Things that I wish I knew when I got a diagnosis	Pete Rishel	0	0	2	1d
Recommend your medical professional or resource on this thread	Pete Rishel	0	0	2	1d
Joining our support group	Carol Rishel	0	0	8	5d
Introduce yourself	Pete Rishel	1	0	10	Oct 11
I have Parkinson's	gregghummer	1	0	3	Oct 10
Welcome to the Jax Hope Community!	Pete Rishel	0	0	8	Aug 28
Forum rules	Pete Rishel	0	0	5	Aug 28

# Medical Research



## “The New and Improved Levodopa”

By: Philip W. Tipton, M.D.  
Assistant Professor of Neurology  
Mayo Clinic Florida

In Parkinson disease, a specific population of brain cells within the substantial nigra pars compact (SNpc) die. A major role of these brain cells is to make a chemical called levodopa, which is converted into an important neurotransmitter called dopamine. When the cells of the SNpc begin to die, dopamine levels decrease and when dopamine is low our movements become slower and scaled down. These slow, small, stiff movements are described by clinicians as parkinsonism, i.e., bradykinesia and rigidity.

Currently, we do not have a way to halt or reverse the neurodegeneration within the SNpc in Parkinson disease. The most effective way to address the problem of low dopamine is by supplementing with levodopa, which alleviates parkinsonian motor symptoms of stiffness, slowness, tremor. While levodopa always works, patients with Parkinson disease will eventually notice that the effect of levodopa doses becomes shorter. Subsequently, some patients may find it necessary to take the medication as often as every 2-3 hours, which can be very disruptive to a person’s life. This faster wearing off of levodopa, i.e., shorter duration of effect, is caused by continued loss of cells within the SNpc resulting in further reduction of the brain’s own production of dopamine.



Clinicians have several tools to help patients who have to take many doses of levodopa throughout the day. These include adjunct medications along with levodopa, long-acting formulations of levodopa, and even continuous infusions of levodopa. Each of these options may help certain patients in certain conditions but lengthening the dose response remains a major challenge for patients with Parkinson disease.

In August of 2023, the phase 3 clinical trial called RISE-PD randomized 506 research participants with Parkinson disease to receive immediate release carbidopa-levodopa (IR C/L) or a long-acting formulation of carbidopa-levodopa called IPX203.<sup>1</sup> IR C/L was dosed 5 times per day while IPX203 was dosed at 3 times per day. After 20 weeks, those receiving IPX203 experienced 1.55 hours of increased on-time without troublesome dyskinesia per dose. Nausea and anxiety were more common for those receiving IPX203.

In August of 2024, the United States Food and Drug Administration approved IPX203 and in September of 2024 Amneal Pharmaceuticals Inc., commercially launched the medication now known as Crexont. This medication marks a significant step forward in the management of parkinsonian symptoms and will likely benefit many patients. Like all new Parkinson disease medications, Crexont is substantially more expensive than IR C/L so patients will need to work with their physicians to determine if the benefit is worth the cost.

I often speak with people who are disheartened that after all these years we are still using levodopa. To this, I would say yes and after all these years we are still using screwdrivers because they work. Screwdriver technology has improved to make certain tasks easier, but it is still a screwdriver. Similarly, our formulations of levodopa are getting better and better but at the end of the day it is still levodopa because levodopa works.

## REFERENCES

1. Hauser RA, Espay AJ, Ellenbogen AL, et al. IPX203 vs Immediate-Release Carbidopa-Levodopa for the Treatment of Motor Fluctuations in Parkinson Disease. *JAMA Neurol.* 2023;80(10):1062-1069.

## Support Groups



### **WESTSIDE Jacksonville Support Group**

Leader: Kathy Lowery Phone: 904:699-5134

Email: [klowery4561@live.com](mailto:klowery4561@live.com)

Meets 3rd Saturday of the month at 10 am

Normandy Park Baptist Church, 7050 Normandy Blvd. Jacksonville, FL 32205

Starting exercise Group November 5, continuing every Tuesday, 2-3 pm

### **Mandarin Support Group**

Leader: Katheryn Donaldson. Phone: 904-710-1449

Email: [serving4\\_him@yahoo.com](mailto:serving4_him@yahoo.com)

Meets 2nd Sunday of the month 2-4 pm

Church of Eleven 22 4911 Losco Road, Jacksonville, FL 32257

### **Jacksonville Beaches Support Group (Local)**

Leader: Carol Rishel Phone: 904-704-4142

Email: [csrishel@gmail.com](mailto:csrishel@gmail.com)

Meets Thursdays (except holidays) at 11 am to 12:00 pm

Palms Presbyterian Church 3410 3<sup>rd</sup> St. S., Jacksonville Beach, FL 32250\_

In person or on Zoom. Call Carol for ZOOM detail

### **UF Health Parkinson's Support Group (Local)**

Leader: Mimi Keith Phone: 904-244-9816

Meets 3<sup>rd</sup> Wednesday of the month at 11:30 am

Call Mimi for location

### **Nocatee Parkinson's Support Group (Local)**

Leader: Pam Brunell Phone: 904-819-3234

Meets 1<sup>st</sup> Wednesday of the month at 3 pm  
Center at Flagler Health+ Village at Nocatee, 351 Town Plaza Ave., Suite 205, Ponte Vedra

**Orange Park Programs (Sacred Heart Catholic Church, 7190 US HWY 17, Fleming Island, FL 32003)**

**Support Group\***

Leader: Gregg Hummer [gummer57@yahoo.com](mailto:gummer57@yahoo.com)\*

Meets 2<sup>nd</sup> Saturday of the month

Facebook: [facebook.com/parkinsonssupportgroupoffororangeparkfl](https://www.facebook.com/parkinsonssupportgroupoffororangeparkfl)

**Orange Park and Clay County Exercise Group**

Leaders: Tom Dorsky, [tomdorsky@hotmail.com](mailto:tomdorsky@hotmail.com) & Gregg Hummer\*

Meets Monday and Thursday at 9:30 am

\*Classes designed for people with Parkinson's and other movement disorders, everyone is welcome and all classes free

**Orange Park Caregivers Group**

Leader: Mike Day, Email: [mdayreston@aol.com](mailto:mdayreston@aol.com):

Meets 3<sup>rd</sup> Saturday of the month

**St. Augustine\***

Leader: Melalnie Lomaglio Phone: (904) 501-8779

Email: [Melanie.neuroPT@gmail.com](mailto:Melanie.neuroPT@gmail.com)

ReBloom Center offers free therapist led opportunities: exercise, voice training, a caregivers group, education and social support.

Location: Parkinson's & Neurologic Health Center at STARS Rehab. at 1711 Lakeside Ave. Suite #5, St Augustine, FL, 32084

**Flagler/Palm Coast Parkinson's Support Group\***

Leader: Renee Shoner Phone: 386-503-2239

Email: [Reneeshoner@gmail.com](mailto:Reneeshoner@gmail.com)

Meets 3<sup>rd</sup> Wednesdays at 3 pm

Palm Coast Community Center, 305 Palm Coast Pkwy NE, Palm Coast FL 32137

**Glynn County, Ga. Parkinson's Support Group\***

Leader: Mike McKinney Email: [mikemckin43@gmail.com](mailto:mikemckin43@gmail.com)

First Thursday of each month

Location: Thorpe Bldg at St. Simons United Methodist Church at 624 Ocean Blvd, St. Simons Island, GA

**\*Support groups with exercise programs**

## **Exercise Programs**



### **Rock Steady Boxing for People with Parkinson's**

Phone: [\(904\) 500-5425](tel:9045005425)

Classes: Tuesday 10:30am – 11:30am, Friday 9:30 – 10:30am & 10:30 --11:30am

Jax Muay Thai 14255 Beach Blvd, Jacksonville, FL 32250

### **Brooks Rehab Parkinson's Wellness Program**

with **YMCA of Florida's First Coast**

Phone: 904-345-6812

Classes: 9am – 12pm Monday, Wednesday and Friday

Brooks Family YMCA 10423 Centurion Parkway, N, Jacksonville 32256

A Brooks Rehab therapist evaluation is required to begin the program.

[www.Brooksrehab.org/program](http://www.Brooksrehab.org/program).

### **Neptune Beach Senior Activity Center\***

Phone: (904) 749-0068

Chair Yoga Classes: Monday 1PM-1:45PM

2004 Forest Ave, Neptune Beach, FL

<https://www.nbfl.gov/senior-center/pages/activities-classes>

**\*Check senior centers for additional exercise classes and activities**



## Parkinson's Wall of Fame

### Bill Wilson Interviews:

Dr. Philp Tipton interviewed Bill and Marilyn Wilson for his Season 1, Episode 6 *Long Live the Brain Podcast* from February 5, 2020: Bill Wilson, a person with Parkinson's disease (PD), and his wife Marilyn, shared his story from the first signs that something was going on with his health to eventually receiving a diagnosis of PD. Bill and Marilyn also touch on many important points such as the importance of support groups and other great activities like Rock Steady Boxing.



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### Florida Times Union Journalist Charlie Patton interviewed Bill for June 5, 2013 article:

When retired University of North Florida statistics professor Bill Wilson was first diagnosed with Parkinson's disease in the spring of 2006, his initial reaction was to hide his condition. "For the first 3 years, I never told anybody. There's a certain amount of stigma attached." Life with Parkinson's a chronic and progressive disease of the central nervous system, and he noted, is filled with small indignities.

He had trouble getting dressed. He sometimes can't get his wallet out of his pants pocket. Eating can be a problem. "You shouldn't eat anything you don't want on your lap. Parkinson's can make you look kind of silly. You do lose your dignity."

As he learned more about the disease, his attitude changed. He accepted his condition and began seeking more information. **He joined a support group, which made him "aware that people want to know about the disease if they don't want people to know they have it."**

He became a research advocate for the Parkinson's Disease Foundation to "train people about Parkinson's and get people involved in clinical trials."

There has been a surge in the amount of Parkinson's research in the last decade as celebrities such as Michael J. Fox and Muhammad Ali, who have Parkinson's, have



brought more attention to the disease. Fox had a TV show in which he played a former newscaster who retired because of Parkinson's but decided to go back to work.

Despite the increased attention, 80% of clinical trials are delayed at least a month because of lack of participants and 35% of research studies never finish because subjects can't be found, Wilson said. He was involved in two trials, one conducted by the Mayo Clinic and the other by the University of Washington in connection with the Veterans Affairs Department.

Wilson also started a quarterly First Coast Parkinson's Disease Newsletter (*which he continued for 8 years*). During Parkinson's Awareness month, he organized *A Conversation with Experts about Parkinson's Disease* where 7 neurologists and 3 physical therapists gave up their Saturday morning to explore 10 topics with an audience of 100 people with Parkinson's and their caregivers. (awarded Davis Phinney Local Hero Award in 2014).

**Bill estimated that 4,000 people in Northeast Florida have Parkinson's. "But they are not showing up at support groups and not getting the education I think they should."**

Parkinson's, in its early stages, can be difficult to diagnose, because of the wide variety of symptoms that can, but don't always, accompany the disease. Wilson's early symptoms included difficulty walking, "people noticed my gait," and talking, "I couldn't make people hear me." But it took about 6 months and visits to several different specialists before he was diagnosed at Mayo Clinic.

Wilson's mother was diagnosed in the early 1970s. At that time, he was told that Parkinson's was not hereditary. That turned out not to be true. About 6 months after Wilson was diagnosed, his older brother was also diagnosed.

Among the motor symptoms that are associated with Parkinson's are slowness of movement, muscle stiffness, tremors, impaired balance, loss of fine motor control, and shuffling gait. It can also cause sleep disturbances, mood changes, digestive problems, fainting, fatigue, tingling in the hands and feet, sexual or urinary problems, fainting or dizziness, excessive sweating, and forgetfulness.

Modern treatments can be effective at managing the early motor symptoms of the disease, mainly through the use of levodopa and dopamine. Surgery and deep brain stimulation have been used in some cases where drugs are ineffective. Wilson said that besides medication, the thing that helps him the most is exercise. He goes to the gym 5 days a week, working on his upper body, his balance, and his flexibility. He also plays golf regularly.

## **National Parkinson's Organizations**

### **Parkinson's Foundation**

200 SE 1st Street, Ste 800, Miami, FL 33131, USA

Call our Helpline: 1-800-4PD-INFO (473-4636) for resources, referrals and support.

Email: [Helpline@Parkinson.org](mailto:Helpline@Parkinson.org) or [contact@parkinson.org](mailto:contact@parkinson.org)

<https://www.parkinson.org/>

### **Michael J. Fox Foundation for Parkinson's Research**

Grand Central Station P.O. Box 4777 New York, NY 10163

1-212-509-0995

Email: [info@michaeljfox.org](mailto:info@michaeljfox.org)

<https://www.michaeljfox.org/>

### **Davis Phinney Foundation**

357 S McCaslin Blvd, Ste 105 Louisville, CO 80027

1-866-358-0285

Email: [contact@dpf.org](mailto:contact@dpf.org)

<https://davisphinneyfoundation.org/>

### **American Parkinson Disease Association (APDA)**

PO Box 61420 Staten Island, NY 10306

Phone: 1-800-223-2732

Email: [apda@apdaparkinson.org](mailto:apda@apdaparkinson.org)

<https://www.apdaparkinson.org/>

## **Jokes are Important**



***Arnold Palmer: "You can cut strokes off your game....  
By using your eraser!"***

## **Transportation Resources**



All Counties	Travel Training - Regional	(904) 632-5249	Public
Baker	Community Transportation Manager for Baker County	(904) 259-9315	Public
Baker	Baker County Council on Aging	(904) 259-2223	Public
Clay	Community Transportation Coordinator for Clay County	(904) 284-5977	Public
Duval	JTA Connexion Paratransit	(904) 265-6001	Public
Duval	ReadiRide	(904) 679-4555	Public
Duval	Dial-a-Ride	(904) 246-1477	Public
Duval	Jacksonville Transit Authority (JTA)	(904) 630-3100	Public



Duval	Community Transportation Coordinator for Duval County	(904) 265-8939 (904)379-2327	Public
Flagler	Community Transportation Coordinator for Flagler County	(386) 313-4185	Public
Flagler	Flagler County Public Transportation	(386) 313-4100	Public
Nassau	Community Transportation Coordinator for Nassau County	(904) 261-0700	Public
Nassau	NassauTRANSIT	(904) 261-0700	Public
Putnam	Community Transportation Coordinator for Putnam County	(386) 325-9999	Public

## DONATION PAGE

JAX HOPE INC is a 501c3 non-profit organization that serves the Jacksonville Parkinson's Community promoting education, exercise and social activities in the Jacksonville area.

**I would like to donate to JAX HOPE INC:**

\$2,500  
 \$1,000  
 \$500  
 \$100  
 \$50  
 Other \_\_\_\_\_

I'd like to pay by check. Please make check payable to JAX HOPE INC and mail to:

JAX HOPE INC, 5000 Highway US 17 South, Suite 18, #334, Fleming Island, FL 32003

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 American Express  
 Discover

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Card exp. date:
Cardholder Signature:

**Estate Planning:** Please send information about making a bequest or other planned gift.

**Matching Gifts:** My employers matching gift form is enclosed.

**Tribute Gifts:** My gift is given: IN HONOR/MEMORY OF (Full Name):

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