
JAX HOPE INC

First Coast Parkinson's Newsletter

Summer 2024



Gregg Hummer, President of JAX HOPE INC

Board Members

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Michelle Hermiston, M.D, Ph.D., **Dr. 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.

We're excited to introduce a new communication program where you can find answers to your questions just by calling (904)801-5535 or e-mailing community@jaxhopeinc. See page 3.

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President's Message



Dear Friends of JAX HOPE,

I'm Gregg Hummer, and I count myself blessed to serve as President of Jax Hope. Nearly a decade ago, I was diagnosed with Parkinson's, a journey that led me to become deeply involved in our community's Parkinson's support and advocacy efforts. It's been an honor to serve on the Advisory Board of the Parkinson's Foundation and to lead our vibrant Orange Park Parkinson's Support Group, alongside contributing to the Orange Park Parkinson's Exercise Group as an instructor.

Recently, I took on the role of President at Jax Hope Foundation—a role that fills me with gratitude and purpose every day. Supported by my partner Lita, whose unwavering dedication ignites our efforts, we've transformed our local Parkinson's group into a thriving community offering education, exercise, and enjoyable activities.

My passion lies in fostering strong local support networks where individuals with Parkinson's and their loved ones can gather, share experiences, find resources, and most importantly, find hope. Parkinson's may be part of my life, but it certainly does not define it. I am committed to living fully and encouraging others in our community to do the same.

In the spirit of positivity and progress, I'm excited to share that despite challenges, Jax Hope has continued to thrive. Our support groups have expanded, offering a lifeline of support and resources. We've hosted monthly speakers, organized enriching programs, such as our Caregiver's Symposium and annual golf tournament, and recently launched a new community initiative to broaden our reach and impact even further.

I invite you to explore our newsletter and visit JAXHOPEINC.org to learn more about how we're making a difference in Jacksonville. Your support, whether through donations, participation or spreading the word, fuels our mission and brings hope to countless lives affected by Parkinson's.

With optimism and gratitude,
Gregg Hummer
President, JAX HOPE INC

The Jax Hope Community

The Jax Hope community will provide a platform for people with Parkinson's and those who care for them to share their experiences, ask questions, and offer solutions. By encouraging active participation and interaction, the community will help to make the Jax Hope site a hub of involvement for our special community. Typically, with communities, as people interact with professionals and each other on a continual, regular basis, levels of trust and enthusiasm increase, encouraging the growth of a valuable base of knowledge through their contributions to the conversations. In addition, participation on the community can spur more interaction and involvement within the membership, both live and online. The organic content-building activity on the community also helps to attract others who may not be familiar with Jax Hope by bringing them to the site through topical queries in search engines.

You might ask, "there are so many Parkinson's resources out there already, why create another?" Simply put, Jax Hope is dedicated to serving the people of the Jacksonville area with Parkinson's. The diverse perspectives, collective knowledge, warmth and acceptance of the members of our community that includes Parkinson's patients, caregivers, and medical professionals, is immensely valuable, and this online public community makes it available to all. Here's an example of subjects of what our online community might be discussing (image for representation only):

- [Do you play board games, cards, etc?](#)
- [How do you like to spend time with your family?](#)
- [Caregivers, how do you maintain your independence?](#)
- [Do you struggle with anxiety and depression?](#)
- [Do you take your carbidopa/levodopa, daytime only, or around the clock?](#)

[Do you play board games, cards, etc?](#)

Posted on 06/27/2024

Replies: 7

I play gin rummy with my husband and banana grams with my dad who has Alzheimer's.

[Join the Discussion](#)

Medical Research



Congress passed the National Plan to End Parkinson's Act

Congress passed the National Plan to End Parkinson's Act on May 22, 2024, marking a historic milestone in the fight against Parkinson's disease. This groundbreaking legislation, unanimously approved by the U.S. Senate and previously endorsed with strong bipartisan support in the U.S. House of Representatives last December, now awaits President Biden's signature.

For the first time, this bill unites our government in a concerted effort to eradicate Parkinson's disease by advancing critical research, promoting more effective treatments, and implementing comprehensive measures. It represents a significant stride toward ultimately conquering this devastating illness, and we express our heartfelt gratitude to all who contributed to its passage.

Special recognition goes to Senators Shelley Moore Capito (R-WV) and Chris Murphy (D-CT), as well as Representatives Gus Bilirakis (R-FL) and Paul Tonko (D-NY), whose exceptional bipartisan leadership was instrumental in shepherding this bill through Congress. We also extend our appreciation to Senate Majority Leader Chuck Schumer (D-NY), Representative Jennifer Wexton (D-VA), and all supporters who championed this vital legislation.

Diabetes Medication for Parkinson's Disease

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

In recent years, medications for diabetes mellitus have gained tremendous attention for uses outside of treating diabetes. Glucagon-like peptide-1 (GLP-1) receptor agonists may sound foreign, but this class of diabetes medication includes Ozempic® (semaglutide), Wegovy® (semaglutide), and Mounjaro® (tirzepatide), which are now popularized weight-loss medications. While unintended side effects are most often the

focus when starting any new medication, unintended *benefits* may occur and lead to therapeutic breakthroughs. For instance, amantadine was initially approved as an antiviral but is now almost exclusively used to help Parkinson's disease (PD) patients who have levodopa-induced dyskinesias. Propranolol was developed as a blood pressure drug but is now a first line therapy for essential tremor. Such benefits are usually identified by observant clinicians or researchers conducting large clinical trials of medications for other purposes. The latter has generated interest in the GLP-1 receptor agonists as a potential treatment for PD.

GLP-1 receptor agonists are used to treat patients with diabetes by stimulating the release of insulin from the pancreas. Studies of diabetic patients have observed a lower prevalence of PD among those being treated with GLP-1 agonists versus other diabetes medication. This led to directly testing several different GLP-1 receptor agonists as viable PD treatments. Unfortunately, there has been no clear consensus, but a recent study yielded some potentially promising results. In April of 2024, Meissner and colleagues published their results from a phase 2 placebo-controlled clinical trial (LIXIPARK) of a GLP-1 receptor agonist injector pen called lixisenatide.¹ By following 156 research participants with mild early PD for 1 year, they found a slight improvement in motor symptoms compared to worsening in the placebo group (worsening is expected due to the progressive nature of PD). The medication was stopped, and reassessment 2 months later revealed better motor scores in the lixisenatide group.

These results indicate that lixisenatide may slow the rate of disease progression in PD making this the first disease modifying therapy for PD. The prospect of such a breakthrough is exciting but should be tempered until a well-designed and well-executed phase 3 clinical trial can validate this hypothesis. This will take time and resources but may well be worth the wait. However, the wait may not be so long because another GLP-1 receptor agonist called exenatide showed similar results in its own phase 2 clinical trial in 2017 and results of its phase 3 clinical trial are expected in late 2024.²

Clinical trials are the currency of validated scientific discovery. Without the commitment of patients these studies would not be possible. If you or someone you know is interested in participating in clinical trials, then go to clinicaltrials.gov and search for studies of your condition. If you're thinking of pursuing a clinical trial, always discuss it with your doctor first.

References:

1. Meissner WG, Remy P, Giordana C, et al. Trial of Lixisenatide in Early Parkinson's Disease. *N Engl J Med* 2024;390(13):1176-1185.
2. Athauda D, MacLagan K, Skene SS, et al. Exenatide once weekly versus placebo in Parkinson's disease: a randomised, double-blind, placebo-controlled trial. *Lancet* 2017;390(10103):1664-1675.

Support Groups



Jacksonville Beaches Support Group (Local)

Leader: Carol Rishel, Phone: 904-704-4142

Email: csrishel@gmail.com

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

Palms Presbyterian Church 3410 3rd 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 3rd Wednesday of the month at 11:30am

Call Mimi for location

Nocatee Parkinson's Support Group (Local)

Leader: Pam Brunell, Phone: 904-819-3234

Meets 1st 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:

(All meet at Sacred Heart Catholic Church, 7190 US HWY 17, Fleming Island, FL 32003)

Support Group*

Meets 2nd Saturday of the month

Visit our Facebook page

Orange Park and Clay County Exercise Group

Leader: Tom Dorsky, tomdorsky@hotmail.com

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:

Meets 3rd Saturday of the month

St. Augustine*

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

Email: Melanie.neuroPT@gmail.com

ReBloom Center, a nonprofit with programs sponsored by the Parkinson Foundation offers 11 different exercise and voice training classes a week at 4 levels, and also education and social support. The programs are free and led by physical and speech therapists.

Location: Parkinson's & Neurologic Health Center at STARS Rehab.
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

Meets 3rd 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

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:(904)500-5425)

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.

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

At an early newsletter staff meeting, Bill Wilson suggested we put a regular feature in called the Parkinson's Wall of Fame. The idea was to recognize local, everyday people living with Parkinson's who have found within themselves extraordinary strength and creative ideas that help them deal with the disease. We all get inspiration and strength by listening to keynote speakers at symposiums and conventions. But we have inspirational stories right here. You and your friends in your support groups and exercise classes accomplish incredible feats every day as you fight the progression of PD. Your courage is demonstrated simply by showing up.

A Day in The Life of Craig and Mila By Mila Hastings



I will give you a brief insight on Craig's life before he was diagnosed with Parkinson's disease. Craig is a healthy young man who likes to work in the yard and around the house. He created a plot of flowers and plants in our courtyard, added pebbles around it, a garden bench and small fountain. He also painted our whole house inside and out. He installed our irrigation system and our garage door opener by himself.

Craig began showing signs of Parkinson's disease before he was diagnosed in

2005. He showed slowness in his movements and started shuffling his foot. It made me think there was something wrong with him. We thought the foot movement was caused by the injury he incurred from his job as a Hull Tech (HT) in the Navy. Part of his job was welding. He fabricated and repaired all metal structures on the ship using equipment that emitted high heat and toxic fumes.

Then I noticed his right hand had a tremor. He went to his primary care doctor who asked him to walk in the hallway and noticed only one of his arms was swinging. He referred him to a neurologist who confirmed Craig had Parkinson's disease and at 44 years old, was categorized as having "young onset" Parkinson's. Since then, his quality of life changed. It affected his motor skills and speech. Let's take a peek and see what his life is like with Parkinson's disease.

Craig wakes up at 5:45 a.m. every day. Stiffness and rigidity of his muscles keep him from sleeping well. He takes his medication every two hours. He likes to start his day with a cup of coffee and biscotti. After eating his small breakfast, he will take his

medicine at 7:45 am. After he takes his medication, his mind becomes foggy and makes his movements slower. When this happens, he has difficulty getting dressed, eating, exercising and performing his hygiene task. So, what he will do first is to watch his favorite TV show “Miami Vice” and wait until the medication works. When he feels that he can move freely, he knows the medication is working, he will then take a shower. He has to do everything that needs to be done before his next dose at 9:45.

When medication wears off, he will have a freezing episode (inability to move). When this happens, we do visual queue, such as step over my foot, which helps him to start walking. He also has dyskinesia (involuntary movements) after taking his medication. When all this happens, he must give up driving and other things he was doing. I am always behind him to give support.

He has activities lined up every day. On Monday he goes to Speech Therapy. Craig works up a sweat every Tuesday and Friday working out at a Rock Steady Boxing Class for People with Parkinson’s. Exercise is the number one recommendation for people with Parkinson’s. These classes improve Craig’s balance, motor skills, and build up his muscles. In addition, the class is good for his mind and gives him an increasing sense of control over the Parkinson’s symptoms. Wednesdays find Craig in a tai chi/yoga class. On Thursday, we enjoy attending the Beaches Parkinson’s Support group meeting. We can discuss our concerns with others and Carol Rishel always has a Parkinson’s related article for us or, we might have a speaker, or yoga.

During the weekend you might find Craig riding his bike in the neighborhood. He also enjoys attending Parkinson related symposiums and reading books about Parkinson’s and searching for new medical updates.

After several years of having it, controlling the symptoms has become more difficult. It requires more medication. He experiences additional motor fluctuations. His medication begins to wear off 30 minutes before the next dose. The symptoms become more sudden or unpredictable. It is important to understand the disease yourself to be able to understand Craig.

Since there is no cure for Parkinson’s disease yet, Craig takes his condition one day at a time. He is doing his best to combat this disease and not to be conquered by it. He is more in a positive way rather than being negative. He’s hoping that someday they can find a cure that will change the life of people living with Parkinson’s.

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 or 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

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

Davis Phinney Foundation

357 S McCaslin Blvd, Ste 105 Louisville, CO 80027

1-866-358-0285

Email: 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

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

Jokes are Important



"I was recently diagnosed with Parkinson's disease...

I was shaken by the news!"

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

Visit our website here:



2024 Bill Wilson Memorial Golf Tournament

Fighting Parkinson's
One swing at a time

Bill Wilson fought Parkinson's disease for over 20 years. Bill spent his life empowering people with Parkinson's to fight back against the known path of this disease. To help bring resources to their PD community Bill Wilson and Kristin Gray co-founded Jax Hope in 2017. All proceeds from this event will go towards making their vision a reality and bring much needed resources to our community.

15
Nov

The Golf Club at South Hampton,
315 S. Hampton Club Way
St. Augustine, FL 32092
Support@jaxhope.com
904-801-5535

Scan the QR code with your phone camera for more information

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

Card Type: ☐ Visa ☐ Mastercard ☐ American Express ☐ Discover

Name as printed on card:
Card number:
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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Please send notification to:

Name:		
Street:		
City:	State:	Zip Code: