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# **JAX HOPE INC**

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## **First Coast Parkinson's Newsletter**

Spring 2025

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

As we welcome the vibrant season of spring and to recognize April as "**Parkinson's Awareness Month**", we invite you to bloom with us! Our community is buzzing with exciting activities designed to uplift and empower everyone affected by Parkinson's Disease from invigorating boxing clubs that pack a punch to energizing exercise classes that get your heart racing. We are here to support your journey toward better physical well-being! And let us not forget our insightful educational events that equip you with knowledge and advocacy tools! Together, we create a supportive atmosphere where everyone can thrive!

JAXHOPE will be hosting the NEURODIVERGENT SYMPOSIUM FOR PATIENTS & CARE PARTNERS on Saturday, May 3rd. This is the JaxHope's 2nd Annual education seminar. Find detailed information on the following page and register by website, email, or by phone. Seating is limited so register soon and learn the latest advancements for the treatment of Parkinson's.

For other questions about JAXHOPES' programs or ways that you can help, please contact me at [community@jaxhopeinc.org](mailto:community@jaxhopeinc.org) or (904) 801-5535.

**Gregg Hummer**, President

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## **Board Members**

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

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# **JAX HOPE INC NEURODIVERGENT SYMPOSIUM FOR PATIENTS & CARE PARTNERS**

## **THE SPEAKER LINEUP**



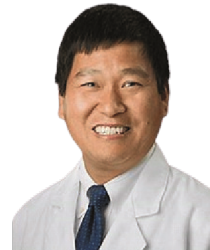
**Syed Asad, MD**

Neurologist  
Universal Neurological Care



**Jesse Cohen, MD**

Neurologist  
University of Florida



**Zhigao Huang, MD**

Neurologist  
Baptist Health



**Michelle Prosje, MD**

Neuropsychologist  
NeuroBehavioral Health, JAX



**Greg Ritscher**

Author  
Parkinson's Disease Ambassador



**Angelo Capobianco**

Physician Assistant  
Universal Neurological Care

## **SPECIAL PARTICIPATION:**

**DAN O'BRIEN - MUSICIAN**

**MELANIE LOMAGLIO - PHYSICAL THERAPIST**

**KATHY LOWERY - WESTSIDE JAX PSG LEADER**

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## **SPONSORS & PARTNERS:**

**Guardian Sponsors:**

**ACADIA, MEDTRONIC, SUPRANUS**

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**Companion Sponsors:**

**AMNEAL, BOSTON SCIENTIFIC**

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**Community Sponsor:**

**HEAL PRECISELY, ABBVIE**

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**Saturday, May 3, 2025**

**9:00 AM - 3:00 PM**

**Sullivan Hall, Sacred Heart Church**

**7190 US-17, Fleming Island, FL**

**[community@jaxhopeinc.org](mailto:community@jaxhopeinc.org)**

**904-801-5535**

**Lunch & snacks will be provided**

**Register now at: [www.jaxhopeinc.org](http://www.jaxhopeinc.org)**



# Parkinson Related Local Neurologists

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## **UF Health Jacksonville Movement Disorders Program**

- Call (904) 383-1022 for all UF locations

*Joseph Legacy, MD*

UF Health Neurology  
580 West 8th Street  
Tower 1, 9th Floor  
Jacksonville, FL 32209

*Jesse Cohen, MD*

UF Health Neurology - North  
15255 Max Leggett Parkway, Ste 6500  
Jacksonville, FL 32218

*Katik Mangipudi, MD*

UF Health Neurology - JTB Kernan  
5191 First Coast Tech Parkway  
Jacksonville, FL 32224

UF Health Neurology - St. Augustine  
300 Health Park Boulevard, Suite 5000  
St. Augustine, FL 32086

### **Mayo Clinic Jacksonville Movement Disorders Program**

Call (904) 893-5340

***Zbigniew K. Wszolek, MD,  
Ryan Utti, MD & Ashley Pena, MD***  
Davis Building  
4500 San Pablo Road S, Jacksonville,  
FL 32224

### **Community Neurologists Specializing in Parkinson's disease**

Call (904) 404-7044

***Syed Asad***  
Universal Neurological Care  
8823 San Jose Blvd., Suite 209  
Jacksonville, FL 32217

### **Baptist Neurology Group**

(904)730-3689

***Zhigao Huang, MD***  
7807 Baymeadows Road East, Suite 401  
Jacksonville, FL 32250

**Note:** There are many more community neurologists in Jacksonville that specialize in Parkinson's disease. If you would like to be added to this list, please send your information to [community@jaxhope.org](mailto:community@jaxhope.org)

# Medical Research

## “Stimulating Information in Parkinson’s Disease”

**By: Philip W. Tipton, M.D.**

Movement Disorders Specialist

University of Tennessee Medical Center

Deep brain stimulation (DBS) was FDA approved to treat tremor associated with Parkinson disease (PD) in 1997 and received approval for advanced PD in 2002. This therapy brought new hope to patients who had run out of therapeutic options. Unlike traditional therapies, DBS involves the surgical placement of a small electrode within a precise location in the brain. The result is reduced tremor, decreased dyskinesias, and/or a more consistent response to levodopa. To say this treatment has been life changing for some would not be an overstatement. In fact, seeing a patient experience near instantaneous tremor resolution from DBS was a major factor in my decision to become a movement disorders specialist. This therapy has been improving patients' quality of life from the moment that it hit the shelf. Since then, the device technology has improved substantially leading to even greater benefits for patients. This article highlights three recent major advancements in DBS technology.

Following the surgical placement of a DBS system, patients periodically return to the clinic for programming of the DBS device to enhance clinical benefits. For years, this has been accomplished by observing the patient's clinical changes as the clinician adjusts electrical stimulation parameters. These clinical changes may include tremor reduction, decreased dyskinesias, emergence of tingling, speech changes, etc. and help clinicians develop an anatomical estimation within their mind's eye. With improved imaging techniques and DBS software capabilities, we can now use a patient's own imaging to visualize their anatomy and DBS electrode placement (See Figure 1). With subsequent software upgrades, we can even model the electrical field generated by stimulation settings and monitor changes in real time as the clinician adjusts a patient's DBS system. This removes the guess work of where an electrode is located and what brain structures are being impacted by electrical stimulation. Figure 1 from a Boston Scientific DBS programmer



*Image courtesy of Boston Scientific*

device and shows the information available to clinicians as they predict which stimulation changes will improve a patient's symptoms.

Another significant advance in DBS technology comes from Medtronic. Their BrainSense feature uses the DBS electrode to detect electrical activity from the brain. This provides clinicians with information about real time brain functioning to guide DBS programming decisions. This ability is possible due to years of study showing that brain activity, measured as local field potentials (LFP), within the beta frequency correlates with parkinsonian symptoms, e.g., rigidity and bradykinesias. BrainSense enables the clinician to locate areas of greatest beta activity and target those areas by adjusting electrical stimulation parameters. Figure 2 shows a beta frequency LFP peak detected by Medtronic's BrainSense. Figure 3 shows a Medtronic DBS programmer where increasing the stimulation current decreases the beta activity. This decrease in beta activity should correlate with an improved parkinsonian symptoms for the patient.

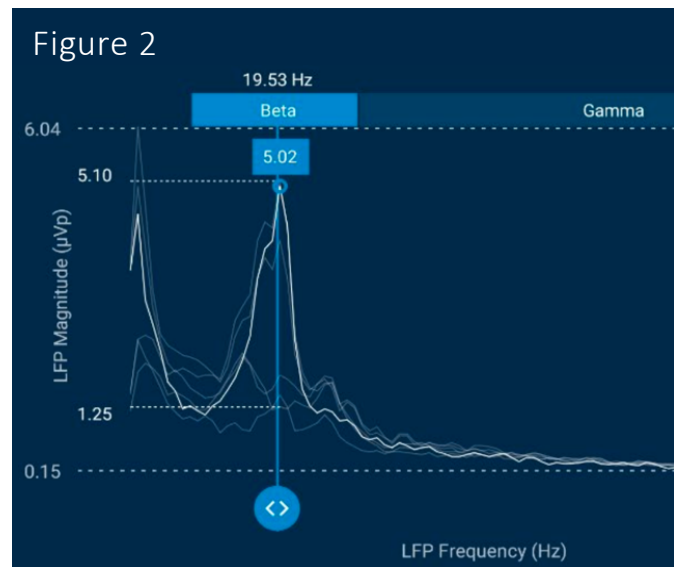


Image courtesy of Medtronic

Figure 3



Image courtesy of Medtronic

The third major advance in DBS therapy is brought to you by Abbott and includes remote programming. DBS programming has historically required the clinician and patient to be in the same location. In 2021, Abbott released the NeuroSphere Virtual Clinic which allows the clinician to connect remotely to a patient's DBS device while engaging in a video call. This effectively eliminates a major travel inconvenience for patients and can be especially beneficial for quick device troubleshooting.

These advances in DBS technology are helpful new tools in the neurologist's toolbox. More recent advances have and will continue to build upon these features to provide individualized treatment that will improve clinical outcomes for patients with PD. See future articles for more details about the latest and greatest in DBS technology.

# Support Groups

**"Once we accept our limits, we go beyond them." - Albert Einstein**

## **Sunrise Senior Living**

*Michelle Cypranowski & Kortney  
Quimby  
904-332-0774*

*jacksonville.DOS2@sunriseseniorcenter  
living.com*

**First Meeting: April 29 at 2 pm**  
*4870 Belfort Road, Jacksonville, FL  
32256*

*serving4\_him@yahoo.com  
2nd Sunday of the month 2-4 pm  
Church of Eleven 22, 4911 Losco Road,  
Jacksonville, FL 32257*

## **Westside Jacksonville Support Group**

*Kathy Lowery  
904:699-5134*

*klowery4561@live.com  
3rd Sat of the month 10-noon  
Normandy Park Baptist Church, 7050  
Normandy Blvd. Jacksonville, FL 32205*

## **Jacksonville Beaches Support Group**

*Carol Rishel  
904-704-4142*

*csrishel@gmail.com  
Thursday's (except holidays) 11-noon  
Palms Presbyterian Church 3410 3<sup>rd</sup>  
St., South, Jacksonville Beach, FL 32250*

## **UF Health Parkinson's Support Group**

*Mimi Keith  
904-244-9816*

*3<sup>rd</sup> Wednesday of the month at 11:30  
am  
Call Mimi for location*

## **Nocatee Parkinson's Support Group**

*Pam Brunell  
904-819-3234*

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

## **Orange Park Programs (7190 US HWY 17, Fleming Island, FL 32003)**

### **Support Group**

*Gregg Hummer  
ghummer57@yahoo.com  
2<sup>nd</sup> Saturday of the month  
Facebook.com/parkinsonssupportgroup  
offororaangeparkfl*

## **JCA Parkinson's Support Group**

*Karen Cataldo  
904-730-2100. ext. 324  
Karen.cataido@jcajax.org  
www: jcajax.org/fitness  
www.facebook.com/roups/jcafitness  
8505 San Jose Blvd., Jacksonville, FL.  
32217*

## **Mandarin Support Group**

*Katheryn Donaldson  
904-710-1449*

## **Orange Park/Clay County Exercise**

*Tom Dorsky, & Gregg  
Hummertomdorsky@hotmail.com  
Monday and Thursday at 9:30 am*



**Orange Park Caregivers Group**

*Mike Day*  
mdayresston@aol.com  
3rd Saturday of the month

Realty Exchange LLC, 300 Palm Coast  
Pkwy, NE Palm Coast FL 32137

**Flagler/Palm Coast Caregivers Group**

*Kathleen Rivera*  
845-222-5208  
Kathleen@jaxmetrosouthcare.com  
Meets: 4th Thursday every other month  
at 5:30 pm

**ReBloom Center**

ReBloom offers free therapist led  
exercises, voice training, caregiver's  
education and social support groups  
*Melanie Lomaglio*  
(904) 501-8779  
Melanie.neuroPT@gmail.com

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***SAVE THE DATE!***



**Sponsorships Available**

Visit [jaxhopegolf.com](http://jaxhopegolf.com)  
for more information!

At The Yards in  
Ponte Vedra Beach, FL



**SCAN ME**

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**FEE**

\$600 per team  
\$150 per person

Registration @ 8am  
Shotgun Start @ 9am

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# Exercise Programs

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***"You don't know how strong you are until being strong is the only choice you have." - Bob Marley***

## **Try Tai Chi on Zoom - Mondays 10-11am**

Tai Chi is a graceful form of exercise often described as meditation in motion. Tai Chi promotes serenity through gentle, flowing movements and when learned correctly and performed regularly, can be a benefit to improve multiple aspects of your health:

- Decrease stress, anxiety and depression and improve mood
- Increase energy, stamina and aerobic capacity
- Improve flexibility, balance and agility as well as muscle strength and definition
- Enhance quality of sleep and the immune system
- Help lower blood pressure and improve joint pain
- Improve symptoms of congestive heart failure

Call Tim Robinson (904) 312-1013. He has over 20 years teaching experience. Students report classes to be enjoyable and challenging, and with Tim always bringing a smile during their practice.

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

Phone: (904) 500-5425

Classes: Tuesdays @ 10:30-11:30am, Friday 9:30-10:30am and 10:30-11:30am  
Jax Muay Thai, 14255 Beach Blvd. Jacksonville, FL 32250

## **Brooks Rehab Parkinson's Wellness Program with YMCA of Florida Coast**

Phone: (904) 345-6812

Classes: 9am - 12pm Monday, Wednesday and Friday  
Brooks: Family YMCA, 10423 Centurian 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 Avenue, Neptune Beach, FL  
<https://www.nbfl.gov/senior-ccenter/pages/activities-classes>

\*Check senior centers for additional exercise classes and activities

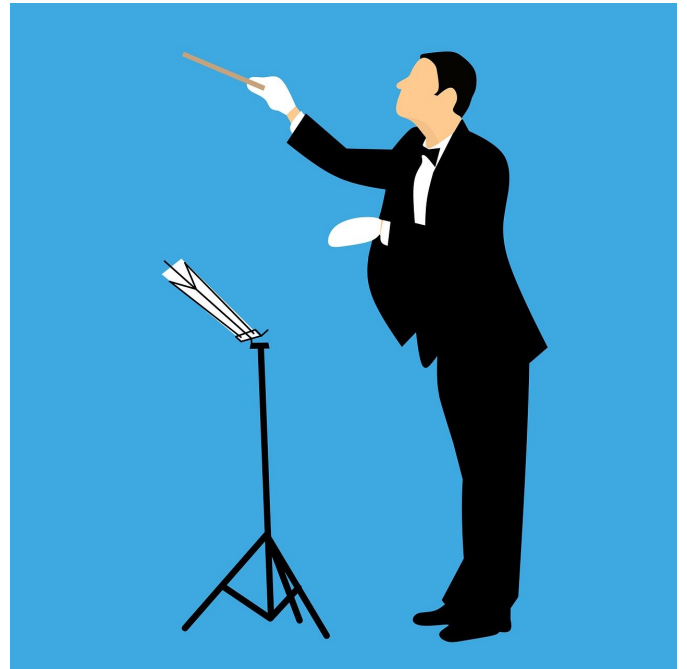


# Parkinson's Wall of Fame

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## **My Story about Parkinson's and a Musician's Life by Jay Landkrohn**

As I step onto the podium, I felt every eye of the audience, every individual upon me; what will I do? How will I perform? How will the musicians respond? Oh, oh, what would I do? With my eyes on the sheet of music then up, to queue the musicians to begin as rehearsed. A motion of the baton, a nod of the head... such is the simple requirements of muscles this day in the life of a Conductor of Music. However, what if there is no order; no discipline of muscle, voluntary or involuntary; hand, voice, breathing, eye movement, no balance or control, if simply sitting still; a pause in the message that is miscommunicated?



This is a daily concert with Parkinson's disease (PD). My days and nights begin with a twitch of a finger. The primary indicator of my change to a new way of life.

It is different for every individual: estimated to be 1 in 5 who are affected by this horrible disease. The symptoms are too many to list; maybe 100, maybe 400 to recognize and treat.

I do my homework; observed People with Parkinsons, go to doctor appointments, participate in trials, and attend Support Groups where practice becomes performance.

By sharing realities; some shake their heads as if to be saying, "Oh Yeah, I remember what my doctor/neurologist, movement disorder specialist said about stumbling, misunderstanding or being misunderstood."

All I can offer is to say, use what applies. There is a lot of wisdom in resources. So, embrace what you like, take lots of notes, and appreciate your caregivers who keep you out of bed and moving.

You are the conductor and performer.

**- Jay Landkrohn**

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**Dr. Philip 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 Marilyn, shared his story from the first signs that something was going on with his health to eventually receiving a diagnosis of PD.

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## Transportation Resources

All Counties	Travel Training - Regional	(904) 632-5249
Baker	Community Transportation Manager for Baker County	(904) 259-9315
Baker	Baker County Council on Aging	(904) 259-2223
Clay	Community Transportation Coordinator for Clay County	(904) 284-5977
Duval	JTA Connexion Paratransit	(904) 265-6001
Duval	ReadiRide	(904) 265-6999
Duval	Dial-a-Ride	(904) 246-1477
Duval	Jacksonville Transit Authority (JTA)	(904) 630-3100
Duval	Community Transportation Coordinator for Duval County	(904) 265-8939 (904) 379-2327
Flagler	Community Transportation Coordinator for Flagler County	(386) 313-4185
Flagler	Flagler County Public Transportation	(386) 313-4100
Nassau	Community Transportation Coordinator for Nassau County	(904) 261-0700
Nassau	NassauTRANSIT	(904) 261-0700
Putnam	Community Transportation Coordinator for Putnam County	(386) 325-9999

## DONATION PAGE

JAX HOPE INC is a 501c3 non-profit organization that serves the local Jacksonville Parkinson's Community. Every dollar raised stays in the area and every donation is appreciated.

### 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:	CVV number:
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 to HONOR or in MEMORY of (Full Name):

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### Please send notification of my Tribute gift to:

Name:		
Street:		
City:	State:	Zip Code:

### Subscribe to Newsletter:

Email:
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### Mailing Address:

Street:		
City:	State:	Zip:

# National Parkinson's Organizations

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## **Parkinson's Foundation**

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

Call our Helpline: 1-800-4PD-INFO (473-4636) <https://www.parkinson.org/>

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

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

Grand Central Station P.O. Box 4777 New York, NY 10163. Phone: 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. Phone: 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/>