#### FOR PEOPLE WITH PARKINSON'S



# **FALL NEWSLETTER** 2025

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#### **BOARD MEMBERS**

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**Gregg Hummer**President

**Sharon Swander** Treasurer

**Alaine Keebaugh, Ph.D.** Director of Grants

Marilyn Wilson Newsletter Editor

Philip W. Tipton, M.D.



# October 15, 2025 @ The Yards Ponte Vedra Beach Registration @ 8am / Shotgun Start @ 9am

Join us for a day of fun, camaraderie, and community! This charity event unites golfers of all skill levels in spirited support for those living with Parkinson's disease.

**Register** to join us on the greens and experience the camaraderie and joy of the day.

**Sponsor** a team, a hole, or the event—your support fuels vital resources for the local Parkinson's community

**Donate!** Your financial support matters. Every gift helps JAX HOPE INC. bring movement, hope, and connection to people living with Parkinson's.

**Swing by the cause**—even if you're not on the green, you're on the team. Join the fun at the Pavilion for free lunch and to learn more about local Parkinson's resources.



To register visit jaxhopegolf.com or call Gregg Hummer (808) 313-0966

See page 8 for more information.

## PARKINSON RELATED LOCAL NEUROLOGISTS

#### UF Health Jacksonville Movement Disorders Program

Call (904) 383-1022 for all UF Locations

Joseph Legacy, M.D. Jesse Cohen, M.D. Katik Mangipudi, M.D.

#### **UF Health Neurology**

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

# **UF Health Neurology North**

15255 Max Leggett Pkwy Suite 6500 Jacksonville, FL 32218

# UF Health Neurology JTB Kernan

5191 First Coast Tech Pkwy Jacksonville, FL 32224

# **UF Health Neurology St. Augustine**

300 Health Park Blvd Suite 5000 St. Augustine, FL 32086

### Mayo Clinic Jacksonville Movement Disorders Program

Call (904) 893-5340

Zbigniew. K Wszolek, M.D. Ryan Utti, M.D. Ashley Pena, M.D. Campbell Dewey, M.D.

#### **Mayo Clinic**

Davis Building 4500 San Pablo Road South Jacksonville, FL 32224

# Community Neurologists Specializing in Parkinson's Disease

Call (904) 404-7044

#### Syed Asad

#### **Universal Neurological Care**

8823 San Jose Boulevard Suite 209 Jacksonville, FL 32217

#### Baptist Neurology Group

Call (904) 730-3689

#### Zhigao Huang, M.D.

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** 

## MEDICAL RESEARCH

# "Infusion Therapies Bring Treatment Precision"

By Philip W. Tipton, M.D.

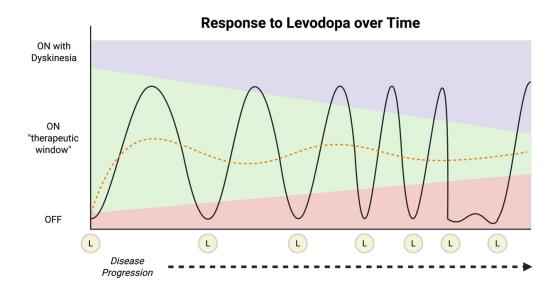
Movement Disorders Specialist and Associate Professor of Medicine, University of Tennessee Graduate School of Medicine

In the Fall 2024 newsletter, I discussed the release of Crexont. This new long-acting formulation of carbidopa/levodopa was shown to increase "ON" time without troublesome dyskinesias by 1.55 hours per dose compared to immediate release carbidopa/levodopa. While this has been a significant addition to our treatment toolbox, there are still many patients who continue to experience short and/or inconsistent benefits from each dose of medication. Clinicians also see many patients for whom they cannot identify a carbidopa/levodopa dose that provides desired reduction of parkinsonian symptoms, e.g., slowness, stiffness, etc., without causing troublesome dyskinesia. We now have two new subcutaneous (under the skin) continuous infusion therapies that better address these challenges.

In October 2024, the U.S. Food and Drug Administration (FDA) approved foscarbidopa/ foslevodopa now marketed under the brand name of Vyalev<sup>TM</sup>. In 2022, a randomized, double-blind, active-controlled, phase 3 clinical trial of 141 participants showed that those receiving 24-hour continuous infusion of Vyalev<sup>TM</sup> showed a significantly greater increase in daily "ON" time without troublesome dyskinesia by 1.75 hours compared to the placebo group.<sup>2</sup> Adverse events led to premature discontinuation of FC/FL in 22% of participants. The most frequent adverse events were infusion site reactions. A 52-week open label extension study showed that patients receiving Vyalev<sup>TM</sup> experienced an average of 3.8 additional hours of "ON" time without dyskinesias per day.<sup>3</sup>

While levodopa is the most effective means to compensate for the dopamine deficit experienced by patients with PD, dopamine agonists have been used since the late 1970s. Apomorphine is a dopamine agonist that was previously marketed as a sublingual film (Kenmobi) or subcutaneous injector pen (Apokyn). In February of 2025, Onapgo<sup>TM</sup> became the first commercially available subcutaneous continuous infusion of a dopamine agonist. Approval of this medication was based on results from TOLEDO study, a multicenter, double-blind, randomized, placebo-controlled phase 3 clinical trial. This study was conducted across 23 European hospitals including 106 patients with PD and motor fluctuations that were not adequately controlled by medical treatment. At the completion of a 12-week study period, participants receiving 16 hour per day Onapgo<sup>TM</sup> experienced 1.89 hours less daily "OFF" time compared to those receiving placebo. A follow-up open label study showed that average daily "ON" time without troublesome dyskinesias was increased by 3.31 hours after 64 weeks of treatment. Most common adverse events were infusion site nodules, somnolence, and nausea.

## MEDICAL RESEARCH CONTINUED



This figure illustrates how the response to oral levodopa (black line) changes as PD progresses. Early in the disease patients experience improvements from levodopa that last many hours. As the disease progresses, the duration of symptom improvements shortens and patients may require additional doses of carbidopa/levodopa, long-acting formulations of carbidopa/levodopa or additional medications to lengthen the levodopa response duration. Vyalev™ and Onapgo™ provide a steady stream of medication (orange dashed line) that provides patients a much tighter, more consistent, and longer lasting reduction of parkinsonian symptoms. In addition to longer lasting symptom improvement, the lack of fluctuating dose levels can benefit patients experiencing troublesome dyskinesia despite best attempts to optimize oral medications. Another benefit is eliminating dose failures, which are more common later in disease progression but can occur earlier especially when levodopa is taken too close to meals. The latter scenario is often unavoidable when patients require more than 4-5 doses of carbidopa/levodopa per day.

While these infusion therapies may help many patients who have exhausted oral medication options, they require more attention and maintenance than oral medications. Parameters such as infusion rate and bolus dose specifications must be programmed and often require adjustments especially when initially switching from oral therapies to infusion therapies. Patients must charge the pump, connect syringes, replace tubing, and insert the cannula into the skin. The risk of infusion site reactions or nodules is a common side effect of these treatments so patients should frequently change the cannula site and clean the skin thoroughly. Despite these precautions, skin site reactions may still occur and both phase 3 clinical trials had a significant number of patients discontinue therapy for this reason. These extra steps can be daunting to some patients. However, by working closely with a knowledgeable and attentive treatment team many patients will achieve a new level of symptom improvement.

## MEDICAL RESEARCH CONTINUED I REFERENCES

#### **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.
- Soileau MJ, Aldred J, Budur K, et al. Safety and efficacy of continuous subcutaneous foslevodopafoscarbidopa in patients with advanced Parkinson's disease: a randomized, double-blind, activecontrolled, phase 3 trial. *Lancet Neurol*. 2022;21:1099-1109.
- Aldred J, Freire-Alvarez E, Amelin AV, et al. Continuous Subcutaneous Foslevodopa/Foscarbidopa in Parkinson's Disease: Safety and Efficacy Results from a 12-month, Single-Arm, Open-Label, Phase 3 Study. Neurol Ther. 2023;12:1937-1958.
- Katzenschlager R, Poewe W, Rascol O, et al. Apomorphine subcutaneous infusion in patients with Parkinson's disease with persistent motor fluctuations (TOLEDO): a multicentre, double-blind, randomized, placebo-controlled trial. *Lancet Neurol*. 2018; 17(9):749-759.
- 5. Katzenschlager R, Poewe W, Rascol, et al. Long-term safety and efficacy of apomorphine infusion in Parkinson's disease patients with persistent motor fluctuations: Results of the open-label phase of the TOLEDO study. *Parkinsonism Relat Disord*. 2021;83:79-85.

Dr. Tipton has received financial compensation from AbbVie, Inc. for consulting.

### **EXERCISE PROGRAMS**

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

Tai Chi on Zoom

(904) 312-1013

**Tim Robinson** 

Classes: Mondays 10-11am

Rock Steady Boxing for People with Parkinson's

(904) 500-5425

**JAX Muay Thai** 

14255 Beach Blvd, Jacksonville, FL 32250

Classes: Tuesdays 10:30-11:30am

Friday 9:30-10:30am and 10:30-11:30am

Brooks Rehab Parkinson's Wellness Program with YMCA of Florida Coast (904) 345-6812 **Brooks: Family YMCA** 

10423 Centurian Parkway, N. Jacksonville, 32256

Classes: Mondays, Wednesdays & Fridays • 9am-12pm

A Brooks Rehab therapist evaluation is required to

begin the program. www.Brooksrehab.org

Neptune Beach Senior Activity Center (904) 749-0068 Chair Yoga Classes @ Neptune Beach Senior Activity Center 1101 5th Street, Neptune Beach, FL 32266

Classes: Monday 1-1:45pm

https://www.nbfl.gov/senior-center

#### SUPPORT GROUPS

**Sunrise Senior Living** 

(904) 332-0774

Michelle Cypranowski & Kortney Quimby

sunriseseniorcenterliving.com

4870 Belfort Road, Jacksonville, FL 32256

Jacksonville Beaches
Support Group

(904) 704-4142

**Carol Rishel** 

csrishel@gmail.com

Thursdays (except holidays) 11am-Noon in person & on Zoom

Palms Presbyterian Church

3410 3rd Street South, Jacksonville Beach, FL 32250

Nocatee Parkinson's Support Group

(704) 728-9484

Pam Brunell

1st Wednesday of the month @ 3pm

**UF Health Building** 

655 W. 8th Street, Jacksonville, FL 32209

JCA Parkinson's Support Group

(904) 730-2100 ext. 324

Karen Cataldo

Karen.cataldo@jcajax.org

https://jcajax.org

https://www.facebook.com/groups/jcafitness

3rd Saturday of every month @ 10am-12pm 8505 San Jose Blvd, Jacksonville, FL 32217

Mandarin/Southside Support Group

(904) 710-1449

Katheryn Donaldson

serving4\_him@yahoo.com

2nd Sunday of the month 2-4pm

Church of Eleven 22

4911 Losco Road, Jacksonville, FL 32257

Mandarin/Southside Parkinson's Caregiver Support Group

(904) 707-8482 Mary Jane Fitzsimons

mjbfitzsimons@gmail.com

(904) 704-6943 Mary Powers

mapowers2013@gmail.com

4th Saturday of every month, 10am-Noon 11480 Pine Street, Jacksonville, FL 32258

Westside Jacksonville Support Group

(904) 710-1449

Katheryn Lowery

klowery4561@live.com

3rd Saturday of the month, 10am-Noon

Normandy Park Baptist Church

7050 Normandy Blvd, Jacksonville, FL 32205

UF Health Parkinson's Support Group (904) 244-9816 Mimi Keith

serving4\_him@yahoo.com

3rd Wednesday of the month, 11:30am

Call Mimi for Location

### ORANGE PARK PROGRAMS

#### All groups meet at 7190 US HWY 17, Fleming Island, FL 32203

**Support Group** 

(808) 313-0966

**Gregg Hummer** 

ghummer57@yahoo.com

2nd Saturday of the month

www.facebook.com/parkinsonssupportgroupoforangeparkfl

Orange Park/

**Clay County Exercise** 

Tom Dorsky & Gregg Hummer tomdorsky@hotmail.com

Monday and Thursday at 9:30am

Orange Park
Caregivers Group

Mike Day

mdayresston@aol.com

3rd Saturday of the month

# FLAGLER COUNTY/PALM COAST PROGRAMS

**Support Group** 

(904) 332-0774

Renee Shoner

Reneeshoner@gmail.com

3rd Wednesdays of the month @ 3pm Palm Coast Community Center

305 Palm Coast Parkway, NE Palm Coast, FL 32127

Caregiver's Group

(845) 222-5208

Kathleen Rivera

Kathleen@jaxmetrosouthcare.com

4th Thursday every other month at 5:30pm

Realty Exchange LLC

300 Palm Coast Parkway, NE Palm Coast, FL 32127

**ReBloom Center** 

(904) 501-8779

Melanie Lomaglio

Melanie.neuroPY@gmail.com

ReBlooom offers free therapist led exercises, voice training, caregiver's education and social support groups.



"Once we accept our limits, we go beyond them"

-Albert Einstein



## October 15, 2025 at The Yards in Ponte Vedra Beach, FL

#### **ENTRY FEES**

FOURSOME	.\$650
INDIVIDUAL	.\$175
Includes golf for one, cart, and lunch	

#### **SPONSORSHIPS**

T:41 a Con a mana w	400 000
Title Sponsor	
Presenting Sponsor	\$15,000
Platinum Sponsor	\$10,000
Golf Cart Sponsor	\$5,000
Gold Sponsor	\$5,000
Golf Ball Sponsor	. \$4,000
Silver Sponsor	\$3,000
Lunch Sponsor	
Beverage Sponsor	
Hole in One Contest Sponsor	\$1,000
Long Drive Sponsor (Men and Women)	\$750
Closest to the Pin Sponsor (Men and Women)	\$750
Foursome	\$650
Pin Flag Sponsorship	\$500
Hole Sponsor	\$200
Individual Golfer	\$175
Cart Path Sponsor	\$100

## Registration 8am



To register, scan the QR code, visit jaxhopegolf.com or call Gregg Hummer (808) 313-0966



## PARKINSON'S WALL OF FAME

# Catherine Salvadore's Journey with Parkinson's

2020 marked a pivotal chapter in my life— I embraced retirement with open arms, joining the vibrant community at the Eagle Harbor golf club and setting sail on Doctor's Lake with my new Boston Whaler eager to explore every nook and cranny. My to-do list was as ambitious as it was exciting, filled with dreams to transform my house into a sanctuary. Over two years, I poured my heart into home improvements—installing gutters to catch the rain, building a sturdy fence, adding a generator for peace of mind, screening in the back porch for evening breezes, and crafting a beautiful dock with all the bells and whistles to bring my dreams of waterfront living to life.

In February 2022, a shadow entered my life—a frozen shoulder that led to a diagnosis I never expected: Parkinson's Disease. Shock and denial tried to hold me back, but I refused to give up. I started researching, joining support groups, and connecting with inspiring people, including Gregg Hummer, who introduced me to the Orange Park Support Group. Through them, I found hope and community.

With each exercise session, I was filled with awe at the resilience of my fellow warriors. Among us were souls of all abilities—some in wheelchairs, others with walkers, and many standing tall on their own. Yet, we all shared a fierce determination to battle this disease together. Now, I proudly join my comrades every Monday and Thursday at 9:30, and we've even expanded our horizons to include invigorating boxing sessions on Sundays at Smiley's Gym in Orange Park.

Playing in the 2024 Jax Hope Golf Tournament was a powerful reminder: exercise and community support are our lifelines. Golf isn't just about the game; it's about coming



Catherine Salvadore takes a swing

together to fight Parkinson's. Every swing contributes to hope—hope for additional resources, improved quality of life, and a future where we can thrive despite the diagnosis.

Participating in events like this shows strength, unity, and resilience. It's a chance to make a difference, not just for ourselves but for others on similar journeys. Let's keep moving, fighting, and supporting each other—because together, we are unstoppable.

Exercise, my friends, is our lifeline. It slows the progression of this condition and keeps our spirits soaring. So, let's keep moving, keep fighting, and embrace the journey ahead with unyielding courage and hope!

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.



To listen scan the QR code or go to <a href="https://podcasts.apple.com/us/podcast/long-live-the-brains/id1492601739?i=1000464680090">https://podcasts.apple.com/us/podcast/long-live-the-brains/id1492601739?i=1000464680090</a>

# TRANSPORTATION RESOURCES



All Counties	Travel Training - Regional	(904) 632-5249
All Courilles	naver naming - Regional	(704) 002-0247
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**

# To donate online go to <a href="https://www.jaxhopeinc.org/jax-hope-donations">https://www.jaxhopeinc.org/jax-hope-donations</a>

**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 do	onate to JAX HOPE IN	C.:			
\$2,500	\$1,000 \$500	\$100	\$50 Other		
l'd like to pay	/ by check. Please mo	ake check po	payable to JAX HOPE INC. and mail to:		
JAX HOPE INC.,	5000 Highway US 17 So	uth, Suite 18,	s, #334, Fleming Island, FL 32003		
Card Type:	Visa Masterco	ırd Am	merican Express Discover		
Name as printed	on card:				
Card number:					
Card Expiration Date:			CVV Number:		
Cardholder Signo	ture:				
Estate Planning: Matching Gifts:			naking a bequest or other planned giff. n is enclosed.		
Tribute Gifts:	My gift is given to HONOR or in MEMORY of (Full Name):				
Please send notif	fication of my Tribute	gift to:			
Name:					
Street:					
-			Zip Code:		
	bscribe to the Newsl				
Email:					
Mailing Address:					
Street:					
City:		State:	Zip Code:		

### NATIONAL PARKINSON'S ORGANIZATIONS

**Parkinson's Foundation** 

200 SE 1st Street, Ste 800, Miami, FL 33131 USA Call our Helpline: 1(800) 4PD-INFO

https://www.parkinson.org/ (473-4636)

Email: Helpline@Parkinson.org or contact@parkinson.org

Michael J. Fox Foundation for Parkinson's Research

Grand Central Station PO 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, Suite 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 1(800) 223-2732

Email: apda@apdaparkinson.org/ https://www.apdaparkinson.org/

FOR PEOPLE WITH PARKINSON'S



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