JAX HOPE INC

First Coast Parkinson's Newsletter

Winter 2025



Thank You for Supporting the 2nd Annual Bill Wilson Golf Tournament – Beating Parkinson's One Swing at a Time.

Because of your generosity, we were able to bring together an amazing group of 87 golfers, 19-hole sponsors, and 8 dinner sponsors, to raise funds and awareness for Parkinson's disease. Your support helped create a memorable day of friendly competition, community spirit, and a shared commitment to making a difference.

A special thank you goes to **Dr. Tipton**, whose dinner presentation was a highlight of the evening. He provided an insightful overview of the latest advancements in Parkinson's treatments, and his dedication to the cause truly resonated with everyone in attendance.

Bill Wilson We couldn't have done it without you. Thank you once again for your support, and we look forward to seeing you at next year's tournament!

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.

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President's Message



As JAX HOPE enters 2025, our goal is to help those in the Parkinson's Community to live a fulfilled life by supporting educational, exercise and social programs. Jax Hope will continue to be a major resource for People with Parkinson's in the Jacksonville area.

JAX HOPE assisted Parkinson's support groups, care partner groups, exercise and boxing programs in 2024. We enhanced our website **JAXHOPEINC.ORG**, published a quarterly newsletter, and created a new Facebook Page "JAX HOPE for people with Parkinson's", to keep the local Parkinson's community informed of activities and medical breakthroughs. On the website there is a Community page, where you can ask questions or just communicate with others.

There is much more to be done to meet JAX HOPE's Mission and Vision, for instance, we are constantly looking to increase the number of Support Groups in Jacksonville. There are unserved areas including the Northside, Mayport, Arlington and maybe your area. JAX HOPE will assist in organizing the details. We are looking for volunteers to assist with this effort and with our educational seminars, fundraising events, support groups, and exercise programs.

Thank you for your support this upcoming year. If you have questions or suggestions, please contact me at community@jaxhopeinc.org or call (904) 801-5535.

We may be challenged but we are not defeated,

Gregg Hummer

President, JAX HOPE INC

Medical Research

Every day, researchers are working hard to identify the mechanisms in the brain that are responsible for Parkinson's disease (PD) and it's symptoms. The Parkinson's Foundation reported their top science news articles of 2024. To read the full articles go to Parkinson.org.

1. A Skin Test Could Detect Parkinson's and Related Diseases

When diagnosing Parkinson's doctors focus on symptoms since there is no single test that can diagnose Parkinson's. This can result in a delay of diagnosis as early symptoms are often hard to distinguish as PD. This study investigated whether a skin test could help diagnose Parkinson's earlier.

In Parkinson's, the protein alpha-synuclein clumps in the brain, which is also referred to as phosphorylated alpha-synuclein (P-SYN). This study found that P-SYN could also be detected in the nerve cells in the skin. The amount of P-SYN in the skin could also be connected with the severity of a person's symptoms.

2. A Protein that Protects Against Brain Cell Degeneration Associated with PD

In Parkinson's, the dysfunction of the mitochondria is one of the causes of the death of neurons in the brains. This study was the first to discover a receptor called GUCY2C, which could lead to a potential new way to fight dopamine loss.

Researchers found that the loss of GUCY2C led to dysfunction of mitochondria and cell loss in the part of the brain affected by PD. GUCY2C was found as a defense to protect dopamine neurons in the brain. This new discovery could lead researchers to explore the possibility of stimulating GUCY2C as a treatment for PD.

3. Non-invasive Focused Ultrasound Helps Alleviate PD Symptoms

Movement symptoms associated with Parkinson's often impact quality of life. A study found that the non-invasive treatment option called a focused ultrasound helps relieve tremors, improve mobility and other movement symptoms related to PD.

In this study, the focused ultrasound treatment targeted the part of the brain that controls movement. Nearly 70% of participants in the treatment group responded successfully to treatment after three months of follow-up.

4. Plastic Waste Contaminants Could Promote Parkinson's

Plastic waste is a rising problem, especially as it breaks down into tiny pieces. This study observed that these tiny pieces may be an environmental risk factor for developing Parkinson's.

Parkinson's is diagnosed when the protein alpha-synuclein starts to accumulate in neurons in the brain. Through various experiments, this study found that polystyrene nanoparticles can interact with alpha-synuclein and promote its clumping formations — meaning plastic waste may be contributing to Parkinson's as an environmental factor.

5. New Study Further Personalizes Deep Brain Stimulation

Deep brain stimulation (DBS) is a surgical therapy used to treat certain aspects of Parkinson's. PD symptoms vary throughout the day, which can make DBS ineffective whether it's too much or too little.

This study used a clinical trial enrolled four participants to test a surgical treatment called adaptive DBS that detects and responds to brain activity to provide individualized and customized stimulation to help with Parkinson's symptoms.

6. New Cell Types Identified in Parkinson's

A hallmark of Parkinson's is the death of brain cells called dopaminergic neurons in a part of the brain called the substantia nigra. For people with Parkinson's, these neurons stop producing dopamine, which helps control the body's movements and moods. However, it's not clear if other types of cells are also affected.

This study identified a new type of neuron associated with Parkinson's. By looking at which genes were turned on and off in hundreds of thousands of different cells in the substantia nigra, the researchers developed an "atlas of gene expression." This research may help us better understand Parkinson's, and possibly help guide the development of new treatments.

7. Screening for Depression Can Improve Parkinson's Care

Even though up to 50% of people with Parkinson's experience some form of depression, when it comes to PD mental health care, symptoms like depression are often overlooked. This study showed that introducing a five-minute questionnaire — the 15-question Geriatric Depression Scale (GDS-15) — to movement disorder clinics can improve the rate of depression screening and follow-up care for people with Parkinson's.

The screening is a helpful way to detect in depression in people with Parkinson's, which can help in finding suitable treatment earlier.

8. New Continuous Pump Medication for PD Completes Trials in Europe

PRODUODOPA (available in Europe), also known as VYALEV, is a new Parkinson's drug delivered continuously via a pump, like insulin pumps used for people with diabetes. Clinical trials show that it can be an effective option for those whose medications are wearing off or who may have dyskinesia.

Support Groups

New Support Group coming soon:

JCA Parkinson's Support Group

Leader: Karen Cataldo 904-730-2100. ext. 324

Email: Karen.cataido@jcajax.org

www: jcajax.org/fitness

www.facebook.come/roups/jcafitness

Meets monthly to support Parkinson's Disease Fighters and their Caregivers

8505 San Jose Blvd., Jacksonville, FL. 32217

Westside Jacksonville Support Group

Leader: Kathy Lowery Phone: 904:699-5134

Email: klowery4561@live.com

Meets 3rd Saturday of the month at 10 am & Exercise Group

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

Meets 2nd Sunday of the month 2-4 pm

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

Jacksonville Beaches Support Group

Leader: Carol Rishel Phone: 904-704-4142

Email: csrishel@gmail.com

Meets Thursdays (except holidays) at 11 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

Leader: Mimi Keith Phone: 904-244-9816 Meets 3rd Wednesday of the month at 11:30 am

Call Mimi for location

Nocatee Parkinson's Support Group

Leader: Pam Brunell Phone: 904-819-3234 Meets 1st Wednesday of the month at 3 pm

Flagler Health+ Village at Nocatee, 351 Town Plaza Ave., Suite 205, Ponte Vedra

Orange Park Programs (Sacred Heart Church, <u>7190 US HWY 17, Fleming Island, FL 32003)</u>

Support Group*

Leader: Gregg Hummer ghummer57@yahoo.com*

Meets 2nd Saturday of the month

Facebook: facebook.com/parkinsonssupportgroupoffororaangeparkfl

Orange Park and Clay County Exercise Group

Leaders: Tom Dorsky, tomdorsky@hotmail.com & Gregg Hummer*

Meets Monday and Thursday at 9:30 am

*Free Classes for people with movement disorders

Orange Park Caregivers Group

Leader: Mike Day, Email: mdayreston@aol.com:

Meets 3rd Saturday of the month

Flagler/Palm Coast Parkinson's Support Group*

Leader: Renee Shoner Phone: 386-503-2239

Email: Reneeshoner@gmail.com Meets 3rd Wednesdays at 3 pm

Location: Palm Coast Community Center, 305 Palm Coast Pkwy NE, Palm Coast FL

32137

St Augustine*

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

Email: Melanie.neuroPT@gmail.com

ReBloom Center offers free therapist led exercise, voice training, caregiver's,

education and social support groups.

Location: Parkinson's & Neurologic Health Center at STARS Rehab at 1711 Lakeside

Ave. Suite #5, St Augustine, FL, 32084

*Support groups with exercise programs

Exercise Programs



Rock Steady Boxing for People with Parkinson's

Phone: (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

Out and Back - Our Australian Experience by Bill and Marilyn Wilson



Our nephew and wife invited us to accompany them on a trip-of-a-lifetime to Australia. We purchase d tickets and began making plans, when Parkinson's intervened. Bill was choking on food and liquid, requiring a swallowing test which showed he was aspirating everything he put in his mouth. The result, swallowing therapy and a feeding tube for all intake of food and drink.

Bill began therapy. Meanwhile, we researched how to transport 100+ pounds of cans to Australia and how to

enable Bill to "eat" on our long flights, etc. Two days before we left, Bill had a follow-up swallowing test and in 6 short weeks, Bill's test results improved from "severe" to "mild/moderate" (swallowing exercises work!). He had permission to "sample" food and drink in Australia. Bill did more than sample, he ate and drank everything. And, of course, we had a "trip of a lifetime!" When we returned, we compared some of our vacation highlights to Parkinson's Disease. And so, the following is our "take back from the outback" with some observations requiring more explanation than others.

We drove a car on the wrong side of the rode (adjusting is normal for people with Parkinson's) to watch the "Parade of Penguins". Penguins emerge from the sea, several at a time and wait for others to join them before marching on (there's strength in joining Parkinson's Support Groups). A penguin's gait is not a unique trait (like a Parkinson's shuffle). Some became exhausted and fell forward, lay down for a bit, then got up and continued (Parkinson's patients have set backs and go forward again). The penguins march until they find their individual burrow in sand dunes and stay there for the day (Parkinson's patient may "stay" at home and avid being among others).

The Sydney Opera House's design was chosen from an illustration, with no structural instruction included (Parkinson's is so individualized, it's often difficult to know how to proceed). The time and money originally allowed to build the structure were greatly underestimated (again, often how to manage Parkinson's is an unknown). After years of construction, a dream of a design was made into a reality (time and effort can make it possible to live well with Parkinson's).

We stayed in centrally located city apartments enabling us to take public transportation or, most often, to walk to our destinations. We "walked about" 4-5 miles a day. At the

end of our trip, both of our physical conditions had improved! In fact, we learned the willingness. to experience the world around us improved both our physical and mental health and we want it to be a sign to others to go out and experience life, as it is not only healthy, it's important!

"No worries, mate" you can go to Australia (or anywhere you desire)!

Repeat from last issue:

Bill Wilson Interview: 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.



*How to use a QR Code: Simply open your phone's camera app, point it at the QR code, and your phone will automatically recognize and display the linked information, it will be a yellow button which you can then select. Which will open the information. For example, the QR code above will direct you to the audio interview with Bill and Marilyn Wilson. You can also use QR codes to access restaurant menus.

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 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: IN HONOR of or in MEMORY of (Full Name):
Please send notification
Name:
Street:
City: State: Zip Code:
Subscribe to Newsletter:
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Street:
City: State: 7in:

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) https://www.parkinson.org/

Email: Helpline@Parkinson.org or 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/
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

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/