



First Coast Parkinson's Disease Newsletter

Fall 2021

Jax Hope Inc Expands it's Mission

Jax Hope Inc was founded with the primary mission to provide Rock Steady Boxing classes to the Jacksonville area. In 2021, Jax Hope Inc expanded its mission to include 3 programs: (1) Let's Get Physical - Mental and Physical Health Program, (2) The Bill Wilson Parkinson's Resource Program, and (3) The Support Group Assistance Program. Jax Hope Inc will be providing this newsletter as part of the Resource Program. We look forward to working with people with Parkinson's, caregivers and families, the medical and research profession, as well as industry partners to bring you new information, expanded resources, more classes and services and the support you need for a better quality of life.

The Bill Wilson Parkinson's Resource Program

Fulfilling Bill's Dream

Bill always wanted to build a center to provide a place to meet, have classes and expand resources provided to people with Parkinson's and their families. This program is based upon this dream.



Request a Resource Packet

Please visit jaxhopeinc.org to request a resource packet. This packet will include information on support groups, classes, transportation, equipment, events, and additional documents from local and national organizations. This packet will be extremely beneficial to individuals who have been newly diagnosed, new to the area or just looking to learn more about living with Parkinson's Disease.

The Future

Jax Hope Inc has plans to unveil a brick and mortar location in the future which will serve as a center with possible satellites for all those living with PD across the First Coast. Stay tuned for exciting details.

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2021 First Coast Parkinson's Run

The 2021 First Coast Parkinson's Run was a blast! It was super successful despite the impacts of the Covid-19 delta variant causing it to be a virtual event. Groups met up across the First Coast region and rallied together to honor their loved one, raise awareness of PD, and support all of those living with Parkinson's. Thanks to all for being incredible! All proceeds from this event go directly to Jax Hope Inc to fund programs local to the First Coast Region.

The next run is scheduled for April 23, 2022 in person at Riverside Park in Jacksonville, FL. Register Now at [FirstCoastParkinsonsRun.com](https://www.FirstCoastParkinsonsRun.com)



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Moving Day JAX 2021

Moving Day is an inspiring and empowering annual fundraising walk event that unites people around the country living with Parkinson's disease (PD), their care partners and loved ones to help beat PD. Moving Day is more than just a walk. It's a celebration of movement – proven to help manage Parkinson's symptoms.

Leading up to the event, participants and teams fundraise to help the Parkinson's Foundation provide everything people with Parkinson's need to live better — from lifesaving resources to delivering quality care to more than 193,500 people living with Parkinson's to improving Parkinson's treatments through research. Thanks to all who came out and supported this great event!



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Support Groups Rock!

Leaders - Jax Hope Inc is Here to Support



Support Groups are often the daily connection for people with Parkinson's to others living with PD. Support groups can be a bunch of friends, workout buddies, and even an ear to listen to your concerns. It is critical support groups are provided the resources and assistance to maintain, grow, and meet the needs of their members. Support group leaders often face challenges such as:

1. support group leader departures
2. meetings during Covid
3. transitioning to a new meeting location
4. meeting topics
5. reaching participants
6. technology/equipment challenges
7. re-establishment post-COVID
8. financial challenges
9. or maybe there is no group at all



Jax Hope inc has established the Support Group Assistance Program with a mission to provide assistance to support groups and their leaders. Please visit [JaxHopeInc.org](https://www.JaxHopeInc.org) for more information or contact Program Lead Alaine Keebaugh at alaine.keebaugh@bsci.com for more information.

Website Update

First Coast PD Website Ending January 2022

The previous website [firstcoastpdinfo.org](https://www.firstcoastpdinfo.org) will no longer be in service as of January 1, 2022. To see all past and present newsletters please check out [jaxhopeinc.org](https://www.jaxhopeinc.org).

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Updates and Events From The Medical Field

Deep Brain Stimulation

Deep brain stimulation (DBS) surgery was first approved in 1997 to treat Parkinson's disease (PD) tremor, then in 2002 for the treatment of advanced Parkinson's symptoms. More recently, in 2016, DBS surgery was approved for the earlier stages of PD — for people who have had PD for at least four years and have motor symptoms not adequately controlled with medication. To learn more about DBS please visit:



<https://www.parkinson.org/Understanding-Parkinsons/Treatment/Surgical-Treatment-Options/Deep-Brain-Stimulation>

CND Life Sciences Creates New Test For....

CND Life Sciences has commercialized the first skin test to detect abnormal synuclein, which is present in patients with Parkinson's, dementia with Lewy bodies, pure autonomic failure, multiple system atrophy and REM sleep behavior disorder. Together these are categorized as "synucleinopathies". Check out further information at: <https://cndlifesciences.com/syn-one-test/>

LSVT Therapy in Jacksonville

Are you a patient with Parkinson's disease (PD) or know someone who is diagnosed with it? Join Beyond Parkinson's for this free webinar on "Fall Prevention and Home Modifications". They will go over common areas (such as bathroom, bedroom, kitchen etc.) and help you identify factors that increase your chances of falling. They will also suggest some no-cost or low-cost modifications to address the issues.

About Beyond Parkinson's: They are partners in PD rehabilitation. Their goal is to help you stay independent in aspects of life that matter the most to you, and prevent falls. Occupational therapist, Divya Desai, has been in the field for over twelve years and has extensive experience treating patients with various neurological disorders (including PD). She is also trained in the LSVT-Big protocol that specifically addresses movement quality in patients with PD.

Details of the webinar:

Date: 11th November 2021

Time: 10.00am- 11.00am

RSVP: info@beyondparkinsons.com

Stay till the end of the webinar for a chance to win a free set of motion sensor lights that can reduce your risk of falling.

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PD Hall of Fame

Tom Dorsky, retired from Texaco petroleum corporation. He currently volunteers his time twice a week as a certified instructor for the Parkinson Exercise Network on Fleming Island. Tom, though with a commanding voice of a corporate executive and a vigorous discipline, has a great deal of compassion and empathy for the people with Parkinson's as well as their caregivers that attend this class on Mondays and Thursdays at 9:30. Though Tom, himself deals with the progressive disease of Parkinson's, leads the class with an affable humor which makes the time very enjoyable for the participants. Often as many as 30 people leave their homes on Mondays and Thursdays to enjoy the socialization which Tom promotes. He along with two other instructors come early to set up chairs at the Sacred Heart Catholic Church on US highway 17 for the last 7 years to help those living with Parkinson's improve their balance, flexibility, and health. They live in a world where exercise is medicine. Trying to stay ahead of this disease is like trying to swim faster than the gator following you. Tom keeps the group informed on what is happening in the Parkinson community, as well as current research. "Many times I have observed Tom being confided in by class members as he responds to their questions, disheartening medical news, and pleas for help." "People who need someone to listen seem to sense an individual who cares about others." "Often he shares with the class about phone calls he received from former members. "He stays in touch with people. That's just an observation I've made. The class is designed so that, no matter what their physical health looks like they, can exercise, move, and be successful. They may sit or stand. Accommodations are made for those that need. The exercises themselves are simple to follow yet everybody feels like they are stretched to their limits. At the end of each class everyone in attendance feel good, and though their muscles ache, they feel like their shoulders and burdens have been lightened. People need to feel they are not alone in handling all that Parkinson's disease throws at them. Tom represents that help.



Tom locking up the church after an exercise class.



Tom demonstrating to the class in sitting position and performing one of the exercises.

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Support Group Spotlight

Each month we will highlight a different support group from around the First Coast region

First Coast Young Onset Alliance

Earlier this month, the First Coast Young Onset Alliance was joined by Dr. Gupta from Mount Sinai to throw the event, Cooking with Sri and B, a hands-on line cooking show simulcast. The FCYOPD Alliance was happy to connect with the Parkinson's community at large to help all Parkinson's warriors fight their best fight and live well with Parkinson's.

Group leader Shannon Parish shared, "My mission and vision for this amazing support group was formed several years ago after my own diagnosis, it is finally coming to fruition with the assistance and umbrella of a care-community. These professionals truly love what they do and love helping our PD warriors."

Thank you Brian Richardson for making this possible. Many thanks to Dr. Gupta and Sri for coming together and supporting the FCYOPD Alliance.



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Events

Jax Hope Inc Key Stakeholders and Volunteers Meeting

November 18th at 7pm via Zoom [Zoom Link Here](#)

Please call Jennifer Otero at 904-874-7083 if you have any questions or concerns.

Christmas Concert Parkinson Voice Project Fundraiser

Sunday, December 5, 2021 at 6:00 p.m.

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

(Church is set back off the road a little and is directly across the street from Sonic and ALDI)

Come enjoy Christmas Songs and Sing-alongs, Information about Speak Out and the nonprofit, Parkinson Voice Project, which developed the Speak Out program and offers it at no charge.

Donations received during event will support the Parkinson's Voice Project.

See below flyer.

Support Group Leaders Coffee Hour

December - specific date to be determined

Parkinson's Foundation Revolution Fundraiser Spinning Event

February 26, 2022 - Details to follow.

First Coast Parkinson's Run

April 23, 2022

Riverside Park, Jacksonville, FL

Register Now at FirstCoastParkinsonsRun.com

DEC
05



CHRISTMAS CONCERT

PARKINSON VOICE FUNDRAISER



Normandy Park Baptist Church
7050 Normandy Blvd. - across from Sonic and Aldi's
6 p.m. - 8 p.m.

Did you know that Parkinson's Disease can steal the voice?
Join us for a fun and festive evening of old and new Christmas carols.
Wear your favorite or your ugly Christmas sweater and bring the kids
in their Christmas jammies. Help us raise money for Parkinson Voice
Project. Enjoy cookies and conversation with us after the concert.

IF YOU HAVE QUESTIONS, CONTACT KLOWERY4561@LIVE.COM


PARKINSON VOICE PROJECT

Holiday Challenge
\$1, 

If we raise \$1,000,000 by December 31st,
we will receive an additional \$500,000!

OUR GOAL IS \$500.00.

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Local Support Groups

First Coast Young Onset Alliance Parkinson's Support Group

Contact: Shannon Parish (young onset PD fighter), separish@comcast.net, 561-715-5717

Zoom: Fridays 11am-12 pm (please email for link). We are a local group of Parkinson's fighters that meet weekly to share our successes. Each weekly group meeting has a specific focus but also plenty of friendly fun activities and banter. Come join us for an uplifting, informative and engaging hour that will lift your spirits and fuel your fight.

Jacksonville Beaches

Contact: Carol Rishel, crishel@gmail.com, 904-247-7876

When: every Thursday

Time: 11-12:00pm

Location: Palms Presbyterian Church, 3rd street and 35th Avenue South, Jacksonville, FL 32250

Zoom Meeting Information: Please, contact Carol for ZOOM meeting details.

Orange Park

Contact: Stan Harris, dsharrisjr@gmail.com, 904-860-2471

When: 3rd Saturday of the month, Time: 2pm

Location: Orange Park Public Library, 2054 Plainfield Ave, Orange Park 32073.

Zoom Meeting Information: Contact Stan for log in information

Orange Park Caregivers Group

Contact: Elaine Balcom, Evesmimi2@gmail.com

Meetings held the first Saturday of each month at 10:00am at the Orange Park library in a meeting room in the reference section of the library. Meetings have resumed in person. Please, contact Elaine for more information.

Mayo Clinic Parkinson's and Related Diseases Support Group

Contact: Dr. Ashley Pena, FLAParkinson@mayo.edu

The group meets on the 1st Wednesday of each month at Mayo Clinic, exact site may vary. All meetings are held virtually until the COVID epidemic is under control. Please, contact Dr. Pena to be put on the mailing list for these meetings and other related information from Mayo Clinic.

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Local Support Groups

St. Augustine

Contact: Melanie Lomaglio, Melanie.neuroPT@gmail.com, to be added to our email list,
or call: 904-501-8779

What we do: FREE Support, Education, Art classes, Meditation classes, Book Club,
Voice and Exercise Classes

Location: STARS Rehab, 4320 A1A South, St. Augustine, FL, 32080

* Programming supported by a grant from the Parkinson's Foundation.

UF Health Jacksonville

Contact: This group is being re-established post-Covid.

Please contact Jennifer Otero 904-874-7083 for the most recent information on this group.

Bridges of Hope

When: 2nd Monday each month @9:30 CST

Location: Brookdale Panama City & Virtual

Time: 9:30 AM CST

Join Zoom Meeting

<https://us02web.zoom.us/j/89510438550?pwd=VXRyYVcvSFFHNlibG5TaU9VNXhhdz09>

Meeting ID: 895 1043 8550 and Passcode: 051708

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Local Sports and Exercise Programs

Yoga UF Health Jacksonville

Contact: Heather Devos, heatherdevos@gmail.com

Yoga class is intended for Parkinson's and other movement disorder patients, but all are welcome. All classes are held virtually on ZOOM. Please, contact Heather for more details. Classes will resume at UF Health when the COVID epidemic is under control.

Rock Steady Boxing Jacksonville DBA Jax Hope Inc.

Contact: Kristen Gray, 904-321-9505, kristen@jaxhopeinc.org

Due to the COVID epidemic all classes are held via ZOOM. Please, contact Kristen or check out their website for more information.

Rock Steady Boxing Fernandina Beach

Contact: Guy Petty 904-310-6678, Mary Anne Waikart 904-310-6678

Advanced Muscle Therapy, 961687 Gateway Blvd. Suite 101A, Fernandina Beach 32034
Please, contact Guy or Mary Anne for current meeting times.

Rock Steady Boxing Orange Park

Contact: Stan Harris, 904-860-2471, dsharris@gmail.com

Please, contact Stan for upcoming class schedule and information.

Rock Steady Boxing San Marco

Contact: Jason Watson, sanmarco@rsbaffiliate.com 904-636-0092 Contact Jason for class times and dates.

Rock Steady Boxing St. Augustine

Contact Melanie Lomaglio, 904-501-8779. email: melanie.neuroPT@gmail.com
Classes are Tues, Thurs, and Fri with 3 different challenge levels.

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Brooks Rehab Parkinson's Wellness Program

904-345-6812, www.brooksrehab.org/programs-and-services/adaptive-wellness

Check out website for schedules of all their activities.

Parkinson's Exercise Network Fleming Island

Contact: Tom Dorsky, tomdorsky@hotmail.com

People of all ages and stages of Parkinson's attend class; caregivers are also invited to attend. All certified trainers have Parkinson's. Classes are free to join. Classes held at Sacred Heart Church, 7190 US Highway 17, Fleming Island, 32003. Monday's and Thursday's at 9:30am. Contact Tom for more information and to be put on their mailing list.

Parkinson's Exercise Network St. Augustine

Contact: Jim Gillespie, 404-374-1412, JamesHoytGillespie@gmail.com

Classes are on ZOOM Monday and Thursday 10:00 to 11:00am, until the COVID epidemic is under control. Please, contact Jim for more information.

Brooks Adaptive Sports Program

Contact: Suzy Blalock, 904-345-7314, adaptivesports@brooksrehab.org

Please, check out their website and sign up to be on their mailing list. There are numerous weekly activities and monthly special events. All activities are free to people with disabilities as well as their family and friends.

Total Healthworks

Contact: Jackie Russell, David Zid, Bennett.gatto@totalhealthworks.com

Join us for class every Wednesday – Brain and Body with Jackie and David at 12:00pm noon EST! Join the class at ZOOM. Meeting ID: 998 9032 2883, Pass code: Health

The Parkinson's Health Center at STARS Rehab

Offering one on one Physical Therapy and Speech Therapy with Parkinson's specific clinicians who exclusively treat people with PD. Also offering free voice and group exercise classes supported by a grant by the Parkinson's Foundation. Classes include Functional Movement Training, Yoga, Singing and Loud Crowd voice training at different challenge levels. Both live online and in-person options are available.

Contact Melanie Lomaglio, 904-501-8779. email: melanie.neuroPT@gmail.com

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National Resources

American Parkinson's Disease Association (APDA)

135 Parkinson Avenue, Staten Island, NY 10305-1425
apda@apdaparkinson.org www.apdaparkinson.org
Tel: 718-981-8001 800-223-2732
Young Onset Center: 800-223-3801

Parkinson Alliance

P.O. Box 308, Kingston, NJ 08528-0308
Tel: 609-688-0870, 800-579-8440

Michael J. Fox Foundation for Parkinson's Research

Grand Central Station, P.O. Box 4777, NYC, NY 10163
www.michaeljfox.org
Tel. 212-509-0995

Parkinson's Foundation

200 SE 1st Street Suite 800, Miami, FL 33131, help@parkinson.org
www.parkinson.org, 800-4PD-INFO

The Parkinson's Institute and Clinical Center

675 Alanor Avenue, Sunnyvale, Ca 94085, Parkinsonsinfo@thepi.org
www.thepi.org, Tel. 800-655-2273

Parkinson's Resource Organization

74-090 El Paseo, Suite 104, Palm Desert, Ca 92260, info@parkinsonsresource.org
www.parkinsonsresource.org Tel: 877-775-4111

Bachman-Strauss Dystonia & Parkinson Foundation

P.O. Box 38016, Albany, NY 12203 info@bsdcpf.org www.dystonia-parkinsons.org

Dementia Family Pathways

Changing the landscape of Dementia and Parkinson's care – One Resource at a Time.
For information and support group times and locations check out their web site!

Dementiafamilypathways.org

Know of a group or organization not listed?

Please, forward info to Jennifer Otero, support@jaxhopeinc.org