

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

Issue 12 Spring 2019

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**Read more about the First Coast Parkinson's Run, p. 4**

# April

## *Parkinson's Awareness Month Local Events*

**Dr. Odinachi Oguh**, M.D. Medical Director of UF Health Jacksonville Parkinson Center, Neuroscience Department, and **Lisa Smith**, CCRP Parkinson's Clinical Research & Program Coordinator UF Health Jacksonville Department of Neurology Research presented the annual Parkinson Symposium at the Aloft Hotel, Deerwood Center on Saturday, April 6, 2019.

Every third Thursday, the Michael J. Fox Foundation has informative webinars. The next webinar is April 18, 2019.

[www.michaeljfox.org/webinars](http://www.michaeljfox.org/webinars).

**Jennifer Otero**, Race Director and co-founder of the First Coast Parkinson Run with UF Health Jacksonville will host the sixth annual run at Riverside Park on April 20, 2019. The 5k run will kick off at 9:00 AM with the 1-mile Fun run beginning at 10:00. Pre-register at [www.firstcoastparkinsonsrun.com](http://www.firstcoastparkinsonsrun.com) (See p. 4)

**Anne S. Martin**, BS Clinic Research Coordinator Neurology – Movement Disorders Mayo Clinic Jacksonville in conjunction with APDA American Disease Association will present the annual Parkinson Symposium in the Cannaday Building, Kinne Auditorium on Saturday, April 27, 2019 from 8:30 AM-1:00 PM. Pre-registration is required. Speakers include Clemens R. Scherzer, M.D., Harvard and Brigham and Women's Hospital, on the topic: The Hunt for Genes that Drive Parkinson's Disease Progression, and Pamela J. McLean, Ph.D., Associate Professor of Neuroscience, Mayo College of Medicine, on the topic: Understanding the Mechanisms Causing Parkinson's Disease.

## **How It All Began** by Jennifer Otero

The First Coast Parkinson's Run is an honor to my mother Lorraine Hollinger. It is the culmination of my family's loss, hope, and strength throughout the last 10 years. It is the only way I know how to memorialize her life and ensure the lessons we learned from her experience with PD may be passed on to others.

The First Coast Parkinson's Run was a dream of mine for years before the start of my friendship and partnership with Co-Founder Dr. Odinachi Oguh. In 2005, I moved my family to Florida in hopes of helping both my mother and father recover physically, mentally, and financially from a series of ailments including what doctors thought was anything but Parkinson's. Never would I have expected that within a year from then, my mother would be diagnosed with Parkinson's (at the age of 56). The diagnosis itself wasn't the hardest part - it was the impact that the additional diagnosis of Lewy Body Dementia took and would continue to take the most from our family.

To lose control of one's body is painful and life-changing, but to lose control of one's mind as well is incomprehensible. To see my amazing mother lose her greatest assets, intelligence and wisdom, was mind boggling. To watch a loved one diminish in mind and body is overwhelming. My mother's decline was rapid, my father had to transition into a primary caregiver, and my sisters and I managed to process, experience, observe, and assist our parents with all that this disease threw at us. As a daughter, it was heart wrenching, and on many days, being numb to the disease was the only way I could keep moving forward. Throughout my life, moving forward meant doing something. Taking action. I do not sit still; I do not leave room or time to think about the "bad", the "loss".

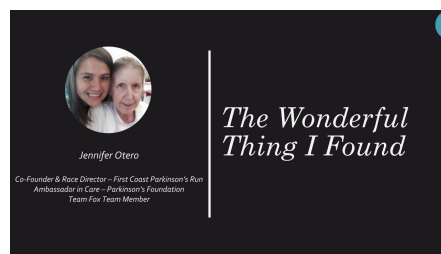
I had been faced with a number of hardships throughout my life, and my solution was always to act, to find a way to make a difference. My mom losing herself was another challenge that was not going to change my way of coping. Parkinson's had already taken my mom, it was not going to take me. In 2012, I was nominated, unbeknownst to me, for the Jacksonville Business Journal Women of Influence award. A peer, a fellow VP of my company, nominated me and through some form of evaluation, the Jacksonville Business Journal agreed with him and chose me as one of the 2012 Women of Influence. When notified of this award, I was overjoyed, very surprised that my peer would recognize me and amazed that I was perceived in such a manner. All I could think was "but I hadn't even figured out how to hold my Parkinson's Run...how could I even be considered influential ...they haven't even seen what I can do". I felt unworthy. During my acceptance speech, I mentioned the fact that I hoped to one day hold a 5K for Parkinson's. My mother was not in attendance as Parkinson's had made

events such as an awards ceremony, virtually impossible to attend.

My mother's condition continued to deteriorate. The disease had a funny way of tricking us. She would plateau and we would adjust to her at that state, and then a sharp decline would occur and nothing would be normal again. The the new normal would again set in and we would be adjusted. The beginning of the final decline went hand in hand with a life changing conversation. I had finally gotten the courage and timing right to approach my mother's new neurologist (Dr. Oguh) regarding her sponsoring or involvement in a possible 5K. The hope was that she would just hear me out, maybe provide some support. So for my mother's next appointment, I chose to arrive early in hopes of speaking with her physician beforehand. The Universe is kind and harsh...and sometimes kind simultaneously. While Dr. Oguh listened to my hope of planning a 5K and she explained that she too had wanted to plan a 5K for Parkinson's, my mother got off on the wrong floor of the hospital, fell and broke her hip, and confirmed she was in one of her steepest declines thus far.

Throughout the next year, Dr. Oguh, Karen Perrin (my mother's nurse and Dr. Oguh's Clinical and Research Coordinator), my family and I created a team, planned a 5K, and in January 2014 held the Inaugural First Coast Parkinson's Run. My mother was pushed by our family in her wheelchair. She was overjoyed and cried through her small bits of clarity. She met so many people who had Parkinson's or affected by Parkinson's. She had always believed she was alone. She finally was not alone. In December 2014, my mother was rushed to the hospital from the nursing facility where she then resided due to her advanced dementia and inability to move. We were told that day she would not live another 2 weeks. 10 days later she passed in hospice as our entire family hugged and cried with her.

My family endured so much. We lost so much. This next phase of our life has been bitter sweet, we have found that there are so many others affected by PD, which breaks our hearts. Yet, we have found that meeting these people, joining in the fight for a CURE, finding resources for people TODAY, and UNIFYing to support patients and caregivers, brings us peace, joy, and therapy, I have found a way to rejoice her and those afflicted with a disease so unknown, so under publicized. I truly believe that the voice for Parkinson's must be louder, must be stronger, must include HOPE.



## **REPORT on 2018 MOVING DAY**

The first annual Moving Day Jacksonville, November 10, 2018, raised \$53,345. 29 teams registered for the event which was held at the University of North Florida's Coxwell Amphitheater. There were various booths showcasing exercise groups around the First Coast (such as Tai Chi, Rock Steady Boxing, Yoga, Parkinson Network Exercise, Dance) and other therapies available in addressing the progressive nature of many of the Parkinson's Disease Symptoms. Way to go First Coast!

Annual Moving Day events can be found in over 52 locations nationwide and have involved more than 100,000 participants, raising over \$17 million. Funds raised through moving Day events support the Parkinson's Foundation mission by funding cutting-edge research aimed at better treatment and care and providing free resources. The Foundation offers thousands of dollars in Community Grants to local applicants that qualify. One of these organizations, Jax Hope, Inc. the local nonprofit that supports one of the Rock Steady Boxing programs on the First Coast, was recently awarded \$10,000 for this purpose. In these ways the Parkinson Foundation delivers expert care to more than 100,000 people living with Parkinson's.

Moving Day Jacksonville 2019, will be at the same venue as last year with the main event happening on November 16th. Let's make this year an even bigger success providing hope and critical funds for people with Parkinson's and their family and friends.



## TRANSPORTATION SOLUTIONS

### For people with Parkinson's in N.E. Florida

Tricare, Medicare and Medicaid may pay for some or all of the costs

(\*Not an exclusive list)

**Elder Affairs** 1-800-963-5337 <http://elderaffairs.state.fl.us/doea/transportation.php>  
[www.findarideflorida.org/](http://www.findarideflorida.org/) Need 48 hour notice

**My Elder Source** 904-391-6600; 888-242-4464; 10688 Old St. Augustine Rd, Jax, FL 32257 [Myeldersource.org](http://Myeldersource.org) If you contact them, they provide you the names and phone numbers of agencies they contract with in your county. Costs vary depending on need and contract carrier involved.

**JTA Connexion** Reservations (904) 265-6999 Cancellations (904) 265-6999  
 Eligibility Center (904) 265-6001 TDD (904) 636-7402  
<https://ecommerce.jtafla.com/pages/ada-riders> 100 N. Myrtle Ave., Jax, FL 32204  
 Daily service including weekends and holidays from 8 a.m. to 5 p.m. They have a van/bus that is fully handicapped accessible and will take you door to door. Cost Varies based on need and distance traveled. Averages between \$1-\$5 per trip.

**Florida Commission for the Transportation Disadvantaged (CTA)** 850-410-5700  
 800-983-2435 (toll free) 605 Suwannee St., Mail Station 49, Tallahassee, FL 32399  
<https://ctd.fdot.gov> Business hours Mon. thru Fri. 8 a.m. to 5 p.m. They are a resource provider which contract with vendors in your area to provide transportation. Cost varies with financial need.

**Dial-a-ride** 904-246-1477 [beachesdialaride.com](http://beachesdialaride.com) <https://www.beachescoa.com/>  
 281 19<sup>th</sup> Ave. South Jax Beach, FL 32250 \$5.00 donation request per trip, but no rider is turned away



**SPEAK OUT!® addresses the motor speech deficits associated with Parkinsonism. The speech therapy program was specifically developed to be practical and efficient in order to comply with insurance limitations, productivity standards, and other administrative constraints. The program is based on the teachings of Daniel R. Boone, PhD, CCC-SLP, a world-renowned speech-language pathologist and voice expert, who recognized in the late 1950s that individuals with Parkinson’s could improve their communication if they spoke with “intent.”**

**SPEAK OUT!® combines speech, voice, and cognitive exercises laid out in a SPEAK OUT!® Workbook. This training course includes instruction on individual therapy, group therapy (The LOUD Crowd®), documentation, marketing, and Parkinson Voice Project’s music program.**

**For information on speech therapist who are trained in the speak out program, check the website <https://www.parkinsonvoiceproject.org>**



## Parkinson Exercise Network

GZSPN® offers the Parkinson's Disease community an opportunity to participate in an exercise class that was designed by a person with Parkinson's Disease for people with Parkinson's Disease. The exercise instructors for this class are taught an exercise philosophy that specifically addresses symptoms often associated with Parkinson's disease. The 75-minute Foundations class for PWP targets these eight critical areas:

1. **Rigidity** – Muscle stiffness & resistance to movement
2. **Hand Dexterity** – Problems with handwriting, fine-motor tasks
3. **Akinesia** – Inability to move spontaneously
4. **Bradykinesia** – Slow movements
5. **Postural Stability** – Impaired posture and coordination
6. **Balance** – Problems with falls, stability
7. **Cognition** – Problems acquiring new knowledge, multi-tasking
8. **Gait** – Problems with shuffling, range of motion

Everyone is welcome at our classes. This includes people using walkers and wheelchairs who are accompanied by a caregiver, friend or relative. See the exercise section of this newsletter find information in the Exercise section of the newsletter about our local Parkinson Network classes held in Fleming Island and in St. Augustine

Website: <http://www.parkinsonsnetwork.org/>

Contact: [303-378-4732 info@parkinsonsnetwork.org](mailto:303-378-4732 info@parkinsonsnetwork.org)



## Exercise and Sport Programs

**Tai Chi UF Health Jacksonville** Contact: Elizabeth Liu at (317) 331-3120 or Lisa Smith (904) 383-1022; 9480 UF Health Towers, Tower 2 on 10th floor, 580 8th St. W., Jacksonville, FL 32209 Class time: Wednesdays at 10 a.m. **NOTE: This class is particularly for Parkinson patients and other movement disorders.**

**Yoga UF Health Jacksonville** Contact: Lisa Smith (904) 383-1022; 9480 UF Health Towers, Tower 2 on 10th floor, 580 8th St. W., Jacksonville, FL 32209 Class time: Tuesdays at 10:30 a.m. **NOTE: This class is particularly for Parkinson patients and other movement disorders.**

**Tai Chi Brooks Family YMCA Jacksonville** (904) 345-6812  
<http://www.brooksrehab.org/programs-and-services/adaptive-wellness> 104 Centurion Parkway, N., Jacksonville, FL 32256

**Rock Steady Boxing Fernandina Beach** Contact: Guy Petty or Mary Anne Waikart at (904) 310-6678 Advanced Muscle Therapy, 961687 Gateway Blvd., Quote 101A, Fernandina, FL 32034 3 weekly sessions MWF 2 p.m.

**Rock Steady Boxing Jacksonville** Contact: Kristen Gray at 904-321-9505, [www.jaxhopeinc.org](http://www.jaxhopeinc.org) Title Boxing, 14286 Beach Blvd. #40, Jacksonville, FL 32250 Tuesdays and Fridays (Boxing) 9:45-10:45, 10:45-11:45, Wednesdays 10:30-11:30 a.m. (alternating-Balance & Flexibility, Dance, Yoga, and Tai Chi)

**Rock Steady Boxing San Marco** Contact: Jason Watson (904) 636-0092, [sanmarco@rsbaffiliate.com](mailto:sanmarco@rsbaffiliate.com) 1780 Emerson Street, Jacksonville, FL 32207 Mondays, Wednesdays, and Fridays 9:30 a.m.

**Brooks Rehab Parkinson's Wellness Program** within the **YMCA of Florida** (904) 345-6812, <https://www.brooksrehab.org/programs-and-services/adaptive-wellness> 10423 Centurion Parkway, N., Jacksonville, FL 32256 and the Dye Clay Family YMCA, 3322 Moody Avenue, Orange Park, FL 32065 Contact for class days and times (including boxing segment)

**Parkinson's Exercise Network Fleming Island** People of all ages and stages of Parkinson's attend classes. There is no charge for the classes. Caregivers welcome. Contact: J.J. Ryan, [jjryan@bellsouth.net](mailto:jjryan@bellsouth.net) and Tom Dorskey, [tomdorskey@hotmail.com](mailto:tomdorskey@hotmail.com) also [parkinsonsnetwork.org](http://parkinsonsnetwork.org) Sacred Heart Church, 7190 US Highway 17, Fleming Island, FL 32003 Mondays and Thursdays 9:30-10:45 a.m

**Parkinson's Exercise Network St. Augustine** Contact: Bill Castelli, [bill.castelli@gmail.com](mailto:bill.castelli@gmail.com) Trinity Episcopal Church, 215 St. George Street, St. Augustine, FL 32084 Mondays and Thursdays 2:30-4:00 p.m.

**Dance for Life** Program provides therapeutic and recreational movement opportunities for people with Parkinson's disease and their caregiver or friend. Contact: Cari Freiburger, (904) 256-7398, [ccoble@JU.edu](mailto:ccoble@JU.edu) Jacksonville University Campus, 2800 University Blvd. N. Phillips Fine Arts Building, Mondays 1:00-2:00 p.m.

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All About Ballroom Exceptional Abilities Dance Program (904)-679-5697  
<https://aabdance.com> [aabdance@yahoo.com](mailto:aabdance@yahoo.com)

778 State Road 13 N St, St John's, FL Tuesdays 5:30 there is a fee, but Scholarships available

#### **Other Programs which include people with Parkinson's:**

**Brooks Adaptive Sports Program** Contact: Alice Krauss, (904) 910-9738 or Suzy Blalock, (904) 345-7314 receive weekly newsletter at [adaptivesports@brooksrehab.org](mailto:adaptivesports@brooksrehab.org) There are numerous weekly activities and monthly special events. All activities free to people with disabilities as well as their family and friends and no prior skills needed. Equipment provided, as are the adaptations and the expert instruction. Additionally, limited bus transportation is provided. You do not have to be a previous or current Brooks Rehab customer.

## Local Parkinson's Support Groups

**UF Health Jacksonville** Contact: Lisa Smith, Clinical Research Coordinator, Dept. of Neurology Research [lisa.smith@jax.ufl.edu](mailto:lisa.smith@jax.ufl.edu) Phone: (904) 244-9480 2nd Wednesday of the month at UF Health Jacksonville (11:30-1:30) Tower 2, 10th Floor Banquet Room 580 West 8th Street, Jacksonville 32209

**Jacksonville Beaches** Contact: Carol Rishel: [csrishel@gmail.com](mailto:csrishel@gmail.com)  
Every Thursday at Palms Presbyterian Church (10:00-12:00) Third Street and 35th Avenue South, Jacksonville Beach 32250

**Orange Park** Contact: Stan Harris: [dsharrisjr@gmail.com](mailto:dsharrisjr@gmail.com) or (904) 860-2471 (cell) 3rd Saturday of each month at 2:00 pm at the First Baptist Church of Orange Park, Room F112 1140 Kingsley Ave, Orange Park 32073

**Orange Park Caregivers Group** Elaine Balcom [evesmimi2@gmail.com](mailto:evesmimi2@gmail.com) - 1st Saturday of the month at 1:00 PM at the First Baptist Church of Orange Park, Room F112 1140 Kingsley Ave, Orange Park 32073.

**Fernandina Beach** Contact: Lee Collins [texasskipper@att.net](mailto:texasskipper@att.net) 3rd Thursday of every month at 7:00 pm in the Nassau County Council on Aging Facility, 1367 South 18th Street, Fernandina Beach, FL 32034

**St. Augustine** Contact: Melanie Lomaglio: [melanie@starsrehab.org](mailto:melanie@starsrehab.org) or (904) 501-8779  
Meets monthly with an alternating schedule of socials and guest speakers. 105 Mariner Health Way, St. Augustine, 32086 or see <https://starsrehab.org/parkinsons-support-group> for event schedule including rehab and wellness classes.

**Mayo Clinic Parkinson's Disease and Related Diseases Support Group** Contact: Anne Martin, [martin.anne@mayo.edu](mailto:martin.anne@mayo.edu) - (904) 953-6523 or (904) 953-7787. 1st Wednesday of the month at Mayo Clinic (12:30-1:30). Exact site may vary at 4500 San Pablo Road, Jacksonville, FL 32224.

## Credits..

This is issue 12 of the newsletter, A subsidiary of The Orange Park Parkinson support group, a 501(c)(3) non-profit. Chairman: Stan Harris. Newsletter staff: Stan Harris [dsharrisjr@gmail.com](mailto:dsharrisjr@gmail.com) , Bill and Marilyn Wilson [billmarilyn@bellsouth.net](mailto:billmarilyn@bellsouth.net) , Marsha Franklin [marsha0652@att.net](mailto:marsha0652@att.net) , Annette Whitten [annetwhitten@gmail.com](mailto:annetwhitten@gmail.com) , Carol Rishel [csrishel@gmail.com](mailto:csrishel@gmail.com) , Lucinda Mosher [lucinda@lucindamosher.com](mailto:lucinda@lucindamosher.com)

Note: Find previous newsletters and additional information on website [firstcoastpdinfo.org](http://firstcoastpdinfo.org).

## Call for articles, topics, and suggestions

Please help make this your newsletter. If you would like to write articles and submit them, suggest topics or any other ideas for improving the newsletter to make it a functional part of your life with Parkinson's, please send these ideas to Stan Harris [dsharrisjr@gmail.com](mailto:dsharrisjr@gmail.com)

We are especially interested in suggestions for the wall of fame, a spotlight for a particular exercise program you have an affinity with, any changes in your particular support groups, and calendar additions for three months out.



