

# *The First Coast Parkinson's Disease Newsletter*

Issue 11

Summer 2018



**Moving Day Jacksonville hosted by the national Parkinson's Foundation will take place at the University of North Florida on Saturday, November 10.**

The Parkinson's Foundation is excited to be hosting the first annual Moving Day Charity Walk in the First Coast! Moving Day is a fun and inspiring event that raises awareness in the fight against Parkinson's disease by highlighting exercise and the role it plays in the management of symptoms.

Moving Day Jacksonville will feature a 1/2 mile and 2 mile walk route as well as a festival area with a unique Movement Pavilion. The Pavilion will have exercise demonstrations adapted for people with Parkinson's — demonstrations include yoga, Tai Chi, dance, Parkinson's Wellness Recovery (PWR!) exercises and boxing. The festival area will also feature educational materials for participants and vendor booths where participants can learn more about local resources.

Moving Day unites families, friends and communities in the fight against Parkinson's disease across the country. Annual Moving Day events can be found in over 40 locations nationwide and cumulatively have involved more than 116,000 participants and raised over \$17 million. Funds raised support the Parkinson's Foundation's mission by delivering expert care to more than 100,000 people living with Parkinson's, funding cutting-edge research aimed at better treatment and care, and providing free resources for people living with Parkinson's.

Join us this Fall on Saturday, November 10th at the University of North Florida Coxwell Amphitheater for an amazing event that provides hope and critical funds for people with Parkinson's and their families and friends. Register as a team or as an individual participant at [www.movingdayjacksonville.org](http://www.movingdayjacksonville.org).

For more information or assistance registering, please contact Celeste Tennant, Community Development Manager at the Parkinson's Foundation (404 397-1014 or [ctennant@parkinson.org](mailto:ctennant@parkinson.org))

## **Free Parkinson's Symposium on Rehabilitative Therapies Saturday, September 15, at the University of North Florida**

Can the benefits of physical therapy, occupational therapy and speech therapy really help you enjoy a higher quality of life while living with Parkinson's disease? The Parkinson's Foundation (PF) is hosting a free educational symposium addressing that very question.

The educational program features local Jacksonville neurologist Zhigao Huang, MD, PhD from Baptist Neurology Group who will speak to "The Role of Therapy" for people with Parkinson's. In addition, the event will include an exercise demonstration and a live Q&A session with a panel of local therapists including a physical therapist, speech language pathologist, neurological music therapist, physical therapist and occupational therapist.

Seating is limited and advanced registration is required. Register at [www.parkinson.org/Jacksonville](http://www.parkinson.org/Jacksonville) Symposium or call Celeste Tennant (404) 397-1014 for more information.

## **Parkinson's Disease Incidence and Prevalence**

The Parkinson's Disease Foundation reports that Parkinson's affects about 4 million people worldwide. The United States estimates 930,000 persons with Parkinson's disease and approximately 60,000 persons are diagnosed each year. Florida currently numbers approximately 64,000 people diagnosed with Parkinson's. The disorder occurs in all races with Caucasians somewhat more prevalent and men develop the disease slightly more often than women.

Parkinson's disease symptoms can appear at any age, even in persons younger than 30 and the risk increases with age. Five to ten percent of Parkinson's patients may experience symptoms before 40. The average age of onset is 60 and Parkinson's affects 1 person in 20 persons over the age of 80.

## **Get Involved in Research**

There are multiple opportunities to get involved in research both locally and abroad. Visiting [www.clinicaltrials.gov](http://www.clinicaltrials.gov) is a great resource for current trials throughout the world. For information on Mayo's local research studies, contact Anne Martin at [martin.Anne@mayo.edu](mailto:martin.Anne@mayo.edu)

### **Investigating the Relationship between Fall Risk and Walking Ability in Individuals with Parkinson's Disease**

Anne Boddy PT, DPT, NCS, Assistant Professor at the University of St. Augustine and currently working towards her PhD from Texas Woman's University is conducting the study. To participate, you must be diagnosed with Parkinson's disease between the 55-85 years old and be able to walk 33 feet without assistance. The study takes place at the University of St. Augustine for Health Sciences. For more information about participating, contact Anne Boddy at (904) 806-3126 or [aboddy@use.edu](mailto:aboddy@use.edu).

### **2018 World Parkinson's Congress - August 19-22**

The directions of the future will be determined at this meeting. The theme is: "Empowering the Next Generation of Clinicians, Scientists and Health Professionals! Focus on education - the most comprehensive educational program in movement disorders delivered by a global faculty.

### **STARS Rehab launch of Pre-Hab Wellness and Recovery Program in St. Augustine**

Small group therapy will be led by Neurological Physical Therapists and Physical Therapy students and will include targeted therapeutic exercises to promote near protection and maximize function. Classes will include aerobic interval training, therapeutic non-contact boxing, agility classes, whole body flexibility and strengthening, body and brain training, and more! Participants will undergo full mobility and balance assessments bi-annually. Grant applications available for those unable to pay for services. For more information contact Melanie Lomaglio at (904) 501-8779, [melanie@starsrehab.org](mailto:melanie@starsrehab.org), or visit our website: <https://starsrehab.org/>.

## **LOUD for LIFE!**

### **Speech Therapy Maintenance**

San Pablo Brooks Clinic announces LOUD for LIFE! Do you remember your LSVT speech therapy sessions? Have you ever wished that you could keep performing vocally at the same level as you did for your therapist? Well now is your chance! If you have had LSVT speech therapy training with a certified speech therapist, you can take part in a weekly group maintenance session that will help you recall what your therapist taught you! This Offer is good even if you were not a patient of the Brooks Clinic when you had your LSVT Therapy! The cost is \$7 per class or \$20 per month. Since this is a maintenance class and not individual speech therapy, insurance cannot be charged. Classes will be on Mondays from 12:45 p.m. to 1:35 p.m. at the Brooks Rehabilitation San Pablo Clinic, 14286 Beach Boulevard, Suite #34, Jacksonville, Florida 32250. You can just show up at the prescribed time, or if you have questions, call 904-345-7511 or email [Cecilia.Brooks@BrooksRehab.org](mailto:Cecilia.Brooks@BrooksRehab.org).

### **Tai Chi for Parkinson's**



Tai Chi is an internal martial art form that uses the mind to control movements of the body. It helps you become aware of your body and the integration of each part with the whole. Visual imagery is used to help in this mind-body connection and to aid in movement and coordination. The slow, deliberate movements of the Tai Chi form can directly address many of the major Parkinson's symptoms. For example:

- Preventing falls and developing flexibility - The constant sinking, turning, and shifting of weight in the Tai Chi form gives a tremendous workout to the legs and lower body. The constant transition from move to move stretches the hip and groin area

strengthening the muscles and joints. Each stance ends with roots sunk deep into the ground, while remaining flexible like a tree in the wind.

- Balance - Proper alignment of the body is obtained by tucking in the chin, raising the back of the neck slightly, relieves the stress on the back muscles, relaxes the shoulders and improves posture and balance.

- Rigidity and freezing - It is not unusual for Parkinson's people to experience rigidity or to suddenly become frozen when walking. Concentrating on flowing like a river in the form produces beautiful even movements that are thrilling to experience.

## 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.

### **Tai Chi Brooks Family YMCA Jacksonville**

(904) 345-6812 <http://www.brooksrehab.org/programs-and-services/adaptive-wellness>  
104 Centrion 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 (404) 229-8217 <http://rsbjax.org>  
Title Boxing, 14286 Beach Blvd. #40, Jacksonville, FL 32250  
Tuesdays and Fridays 9:45-10:45, 10:45-11:45, Wednesdays 10:30-11:30 a.m.

### **Rock Steady Boxing San Marco**

Contact: Jason Watson (904) 636-0092, [sanmarco@rsbaffiliate.com](mailto:sanmarco@rsbaffiliate.com)  
1780 Emerson Street, Jacksonville, FL 32207  
Contact for class days and times

### **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)

### **GZ Sobol Parkinson's 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 Dorsky, [tomdorsky@hotmail.com](mailto:tomdorsky@hotmail.com) also [parkinsonsnetwork.org](http://parkinsonsnetwork.org)

Sacred Heart Church, 7190 US Highway 17, Fleming Island, FL 32003  
Mondays ad Thursdays 9:30-10:45 a.m.

### **GZ Sobol Parkinson's 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.

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

#### **Brooks Adaptive Sports Program**

Contact: Alice Krauss, (904) 910-9738 or Suzy Black, (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 in the Orange Park Public Library (10:00-11:00) 2054 Plainfield Ave., Orange Park

### **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. Scheduled Speakers:

<u>Date</u>	<u>Title</u>	<u>Speaker</u>	<u>Place</u>
9/5/18	Socialization & Emotional Support	Jennifer Ferguson, MS, LMHC	Kinne Aud.
10/3/18	Dementia and Lewy Bodies	Tanis J. Ferman, Ph.D.	Mayo 3-002N
11/7/18	Nutrition and Parkinson's	Lexy DeSchepper, Suria Khurana, Jessica Schilz	Mayo 3-002N
12/5/18	What's New and Why Participate in Research?	Owen Ross, Ph. D.	Mayo 2-002N

## **National Parkinson's Organizations/Resources**

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

Grand Central Station, P.O. Box 4777, New York, NY 10163

<http://www.michaeljfox.org> or <http://www.dystonia-parkinsons.org>

Tel: (212) 509-0995 or (202) 638-4101



**Bachmann-Strauss Dystonia and Parkinson Foundation** hopes to fund research that discovers the links between Parkinson's and dystonia in order to find a cure.

P.O. Box 38016 | Albany, NY 12203 | T: 212—509—0995 x331

<http://www.dystonia-parkinson.org/>

**Parkinson's Foundation\*** undertakes research to find the cause of Parkinson's Disease, provides up to date information, resources, support, and an online community.

201 SE 1st Street, Suite 800, Miami, FL 33137 or

1359 Broadway, Suite 1509, New York, NY 10018

<http://www.parkinson.org> Tel: (212) 923-4700 or (800) 457-6676

### **Parkinson's Resource Organization**

74-090 El Paseo, Suite 104, Palm Desert, CA 92260

<http://www.parkinsonsresource.org> Tel: (760) 773-5628 or (877) 775-4111

### **Davis Phinney Foundation\***

1722 14th Street, Suite 150, Boulder, CO 80302

[info@davisphinneyfoundation.org](mailto:info@davisphinneyfoundation.org) or <http://www.davisphinneyfoundation.org>

Tel: (866) 358-0285 or (303) 733-3340

### **American Parkinson Disease Association (APDA)**

135 Parkinson Avenue, Staten Island, NY 10305-1425

<http://www.apdaparkinson.org> General: (718) 981-8001 or (800) 223-2732

Young Onset Center: (800) 223-3801

**Parkinson Alliance (Parkinson Unity Walk)** Raises funds to promote research.

P.O. Box 308, Kingston, NJ 08528-0308

<http://www.parkinsonalliance.org> Tel: (609) 688-0870 or (800) 579-8440

### **\*Foundations that have merged:**

The **Michael J. Fox Foundation** merged with the **Michael Stern Parkinson's Research Foundation**.

The **Parkinson's Disease Foundation (PDF)** and the **National Parkinson's Foundation** merged to become the **Parkinson's Foundation**.

The **Davis Phinney Foundation** partnered with **Carmichael Training Systems**.

## Other web resources:

- [Driving with Parkinson's Disease](http://www.nhtsa.dot.gov/people/injury/olddrive/Parkinsons)– Answers to frequently asked questions about driving with Parkinson's Disease from the U.S. Department of Transportation [www.nhtsa.dot.gov/people/injury/olddrive/Parkinsons](http://www.nhtsa.dot.gov/people/injury/olddrive/Parkinsons)
- [Lotsa Helping Hands](http://www.lotsahelpinghands.com/)– provides a free service for family caregivers through community members who help with meals, rides, errands, childcare and other activities of daily living. [www.lotsahelpinghands.com/](http://www.lotsahelpinghands.com/)
- [Parkinson's Action Network](http://www.parkinsonsaction.org/)– The unified voice of the Parkinson's community in America that influences public policy and legislative issues concerning people with Parkinson's Disease. [www.parkinsonsaction.org/](http://www.parkinsonsaction.org/)
- [Parkinson's Disease Information at Parkinson's Hope](http://www.parkinsonshope.com/index.html)– Support and information for patients and caregivers including how to arrange your home to best accommodate a person with Parkinson's Disease. [www.parkinsonshope.com/index.html](http://www.parkinsonshope.com/index.html)
- [Parkinson's Disease Research, Education, and Clinical Center \(PADRECC\)](http://www.parkinsons.va.gov/New_Front_Page.asp)– The PADRECCs offer care to all veterans currently enrolled in the VA Healthcare System. This includes veterans who have been previously diagnosed with PD or veterans who have just started to notice Parkinson-like symptoms. [www.parkinsons.va.gov/New\\_Front\\_Page.asp](http://www.parkinsons.va.gov/New_Front_Page.asp)
- [The Parkinson's Institute](http://www.thepi.org/)– Promotes scientific research and an on-site patient clinic. [www.thepi.org/](http://www.thepi.org/)
- [Tardive Dyskinesia Center](http://www.tardivedyskinesia.com/)– Features information and resources about tardive dyskinesia, a movement disorder that mimics Parkinson's disease. [www.tardivedyskinesia.com/](http://www.tardivedyskinesia.com/)
- [Tremor Action Network](http://www.tremoraction.org/)– Working to spread information and create support for people with movement disorders. [www.tremoraction.org/](http://www.tremoraction.org/)
- [We Move](http://wemove.org/)– Resource for movement disorders, and a hub for the latest web activity on movement disorders. [wemove.org/](http://wemove.org/)

## Credits...

This is the 12th issue of the newsletter that we have produced in the past 7 years and we haven't done it alone. Thanks to Ann and Scott Freudenthal, our good friends and computer gurus, who have provided incredible technical support from day one, and continue to do so. And now, we have coerced Stan Harris, who brings years of experience in the Orange Park area as a retired teacher, an organizer and Director of the Orange Park Support Group, to work with us on the content. Together we hope to make the next 7 years as beneficial as possible to the First Coast Parkinson's Community.

Bill and Marilyn Wilson  
[billmarilyn@bellsouth.net](mailto:billmarilyn@bellsouth.net)

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