

The First Coast Parkinson's Disease Newsletter

Issue 9

Summer 2016

We continue to attempt to reach as many First Coast people living with Parkinson's disease (PD) and dealing with its daily effects. This newsletter and website are intended to inform people with PD, their care partners, family and friends, or anyone else interested in PD, about local happenings, support groups and other resources, national happenings, and what's going on in PD research.

We produce a limited number of hard copies of the newsletter, relying on e-mail and the web (firstcoastpdinfo.org) for the majority of the distribution. Advertising is by "word-of-mouth," so please share this newsletter with anyone you think would benefit from the information. Also, if you have suggestions or are interested in helping in any capacity, please let us know.

This issue is all about April being Parkinson's Awareness Month and the related local, state and national activities which can be found in the **Topics** section and the web page **Calendar**. Check the website regularly for updates. This is the time for you to learn more about PD, meet people with similar problems, information about activities conducted locally, and much more. BE ACTIVE

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I. Local Support Groups

UF Health Jacksonville Support Group:

Contact: Karen Perrin,

Karen.Perrin@jax.ufl.edu

Phone: 904-244-9719

2nd Wednesday of the month at UF Health Jacksonville (11:30-1:30)

Tower 2, 10th Floor Banquet Room 580

West 8th Street, Jacksonville

Jacksonville Beaches Support Group:

Contact: Carol Rishel

csrishel@gmail.com

Every Thursday at Palms Presbyterian Church (10:00-12:00)

Third Street and 35th Avenue South, Jacksonville Beach

Orange Park Support Group:

Contact: Stan Harris

dsharris@oneclay.net

3rd Saturday of the month in the Orange Park Branch Library in room A (2:00)

2054 Plainfield Avenue, Orange Park

Caregivers meet 1st Saturday of the month in the same room (10:00 - 12:00)

Note: sponsored by **Life Care Center at Wells Crossing**

Mayo Clinic Parkinson's Disease and Related Diseases Support Group

Contact: Anne Martin

martin.anne@mayo.edu Phone: (904) 953-6523

1st Wednesday of the month at Mayo Clinic (12:30 - 1:30)

Cannaday [Building](#), Room 1107

4500 San Pablo Road, Jacksonville, FL 32224

St. Augustine Parkinson's Disease Support Group

<http://www.usa.edu> Parkinsons

Contact: Melanie Lomaglio: mlomaglio@usa.edu, 904-826-0084, ext. 1270

or Dr. Anne Boddy, 904-826-0084, Ext. 1270

2nd Saturday every other month at University of St. Augustine (2:00)

1 University Blvd., Room 101, St Augustine, FL 32086

Fernandina Beach Parkinson's Support Group

Contacts: Lee Collins texasskipper@att.net

and Linda Raker lindarker@yahoo.com

3rd Thursday of every month (9:30-10:30 a.m.)

Parlor Room of St. Peter's Episcopal Church, Fernandina Beach, FL

For a virtual support group go to My Parkinson's Team at:

www.myparkinsonsteam.com

II. Local Events - Calendar

Monday, **UF Health/Jacksonville University Dance Classes** for people with
Wednesday, Parkinson's and guests offered at JU 1-2 p.m. To be part of the related
Friday research, contact Jill Sonke at 352-733-0880. For more details, see Fall/
Winter 2015 Newsletter within FirstCoastpdinfo.org

Monday, **Brooks Rehab Parkinson's Wellness Program****in partnership with
Wednesday, the **YMCA of Florida's First Coast** meets in 2 hour sessions. An
Friday initial evaluation by a Brooks Rehabilitation therapist is required prior to
beginning the program. For more information, call (904)345-6812 or
visit BrooksRehab.org/program service. Location and Times:

9-12 at Brooks Family YMCA, 10423 Centurion Pkwy N., Jax 32256
1-3:30 at Dye Clay Family YMCA, 3322 Moody Ave., O.P. 32065

Brooks Adaptive Sports and Recreation program activities may
include bowling, shooting billiards, rowing, yoga, water skiing, surfing,
rock wall climbing, skeet shooting, archery, golf, dancing, horseback
riding, cycling and more. Requires physician clearance and physical
therapy evaluation and activities are non-competitive and free. See
on-line schedule: brooks.adaptivesportsandrecreation.com

Monday, **Parkinson's Network** certified instructors, Mike Bleecker and Tom
Thursday Dorsky teach exercise classes for people with Parkinson's (PWP) and
their caregivers in Fleming Island at Sacred Heart Church Activity
Center, Hwy 17, north of Green Cove Springs at the following times:

Monday - 9:30-11 am & 6-7:30 pm; Thursday - 9:30-11 am
(see website at parkinsonsnetwork.org)

Tuesdays **Chair Yoga with Nancy**** is held 3-4 p.m. at Neptune Beach Senior
Activity Center* 2004 Forest Avenue, Neptune Beach. Phone 270-1688
for directions. (See Spring 2013 Newsletter for Nancy's inspiring story.)

*Local communities across the First Coast offer exercise classes and
activities appropriate for people with Parkinson's. Please check your
closest Senior Activity Center for class schedules.

**Nominal fee

April Parkinson's Awareness Month 2016

2 Orange Park Support Group for Caregivers

2 **UFHealth Jacksonville presents a Parkinson's Disease Symposium**, 8 am-12:30 pm at the Radisson Hotel Jacksonville, 4700 Salisbury Road, Jacksonville, FL 32256. To register, call (904)244-9700 or visit ufhealthjax.org/pds. Questions? Call (904)244-9719. Topics and speakers:

Individualized Medicine in Parkinson's Disease, Owen A. Ross, Ph.D. Mayo Clinic

Management and Treatment of Motor Symptoms in Parkinson's Disease, Natalya Shneyder, M.D. Asst. Prof., UF COM Jacksonville

Jacksonville PD Dance for Life Program, Cari Coble, Ph.D. Professor of Dance and Director of Graduate Programs, Jacksonville University College of Fine Arts

Cognition & Parkinson's Disease, Michelle A. Prosje, NeuroBehavioral Specialists, Psy.D

Sleep Challenges and Parkinson's Disease, Mariam Louis, M.D. Assistant Professor, UF COM Jacksonville

Rehabilitative Therapy, Heather Barksdale, PT, DPT, NCS, MSCS and Sarah Mersch, OT, UF Health Jacksonville

From Unable to Unstoppable - A Story In The Making, Jimmy Choi

3 **Jacksonville-wide Pints for Parkinson's event at all Jax Mellow Mushrooms**, fundraiser to support First Coast Parkinson's Run as well as Team Fox. Contact Jen Otero, Race Coordinator at (904)874-7083 or info@firstcoastparkinsonsrun.com for more information.

- 6 Mayo Support Group - **Genetics of Atypical Parkinson's Disease**,
Rosa Rademakers, PhD, Consultant - Research & Professor of Neuroscience,
Mayo College of Medicine
- 7 Beaches Support Group
- 8 St. Augustine Support Group at 1 p.m. - **Social** at STARS rehab, 105
Mariner Health Way, St. Augustine, 32086, just south of the Moultrie
Public on the west side of US 1).
- 13 UF Health Jacksonville
- 14 Beaches Support Group
- 16 Orange Park Support Group - **Dr. Christine Sapienza**, Dean, Brooks
Rehabilitation College of Healthcare Sciences, Jacksonville University
will talk on the topic: *Continued Discussion and Practice of Respiratory
Muscle Strength Training as a Behavioral Treatment in Parkinson's disease.*
- 18 **PD Boxing Classes Begin — Rock Steady Amelia Island** at 2 p.m. (a program
based on training for boxing that has proven to reduce PD symptoms. Google
“Lesley Stahl, boxing” to see how the program helped her husband.). Advanced
Muscle Therapy, 961687 Gateway Boulevard, Fernandina Beach. Nominal fee.
- 21 Beaches Support Group
- 21 Fernandina Support Group
- 23 **First Coast Parkinson's Run:**
Website: firstcoastparkinsonsrn.com and
Facebook page: www.facebook.com/firstcoastparkinsonsrn
- 28 Beaches Support Group
- 30 **Mayo Clinic Event: Life After Parkinson's Diagnosis — Free Event, lunch
provided. Call 953-6096 or email: martin.anne@mayo.edu for reservation
10-2:30 at the Mayo Clinic Cannaday Building, Kinne Auditorium**
- Speakers: John Palfreman, Author (Keynote Speaker)

Hardy Jones, Artist
Doug Vanderlaan, Musician
Research: Owen Ross, Ph.D.

Panel Discussion: Clinicians: Drs. R.J. Uitti and Z.K. Wszolek
Geneticists: Drs. R. Rademakers and O. Ross

May 2016

- 4 Mayo Support Group - **Positivity and Resilience**, Tanis Ferman, PhD, Consultant - Psychology and Associate Professor of Psychology, Mayo College of Medicine
- 5 Beaches Support Group
- 7 Orange Park Support Group for Caregivers
- 7 UF Health Gainesville - **2016 Annual Parkinson's Educational Symposium**
Guest Speaker: **Stanley Fahn**, MD. founder and Emeritus Director of the Center for Parkinson's Disease and Other Movement Disorders at Columbia University.
- 11 UF Health Jacksonville
- 12 Beaches Support Group
- 14 St. Augustine Support Group (tentative date) at 2 p.m. - **Dr. Oguh**, MD, board certified in Neurology and Movement Disorder from UF Health Jacksonville will talk about the **importance of optimizing your medications**. (location: University of St. Augustine)
- 19 Beaches Support Group
- 19 Fernandina Support Group
- 21 Orange Park Support Group at 2 p.m. - **Dr. Zhigao Huang**, Neurologist, Baptist Health, Baptist Neurology Group **will speak and answer questions**
- 26 Beaches Support Group

- 28 **Mayo Event - Dr. Eric Ahlskog, Neurologist, Debunking Ten Myths that May Sabotage Treatment of Parkinson's Disease** 10-11:30 at Mayo Clinic, Cannaday Bldg., Kinne Auditorium.

The Rochester MN Mayo neurologist is a world renowned movement disorder neurologist and author of several books on Parkinson's disease, including: *The New Parkinson's Disease Treatment Book: Partnering with Your Doctor to Get the Most from Your Medications* (2nd Edition).

June 2016

- 1 Mayo Support Group - **A Holistic Approach to Parkinson's Disease, Zhigao Huang, MD, PhD, Neurologist, Baptist Medical Center Jacksonville.**
- 4 Orange Park Support Group for Caregivers
- 17 St. Augustine Support Group at 1 p.m. - **Social** at STARS rehab, 105 Mariner Health Way, St. Augustine, 32086, just south of the Moultrie Publix on the west side of US 1.
- 18 Orange Park Support Group at 2 p.m. - **Sherry Mahoney, Department of Nutrition, Mayo Clinic will speak.**

July 2016

- 2 Orange Park Support Group for Caregivers
- 16 Orange Park Support Group

August 2016

- 6 Orange Park Support Group for Caregivers
- 20 Orange Park Support Group

III. National Parkinson's Organizations

Provided by the National Institute of Health:

American Parkinson Disease Association (APDA)

135 Parkinson Avenue, Staten Island, NY 10305-1425

apda@apdaparkinson.org <http://www.apdaparkinson.org>

Tel: 718-981-8001 800-223-2732 Young Onset Center: 877-223-3801

National Parkinson Foundation (NPF)

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

helpline@parkinson.org <http://www.parkinson.org>

Tel: 800-473-4636

Parkinson Alliance

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

<http://www.parkinsonalliance.org>

Tel: 609-688-0870 800-579-8440

Michael J. Fox Foundation for Parkinson's Research

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

<http://www.michaeljfox.org>

Tel: 212-509-0995

Parkinson's Action Network (PAN)

1025 Vermont Ave., NW, Suite 1120, Washington, DC 20005

info@parkinsonsaction.org <http://www.parkinsonsaction.org>

Tel: 800-850-4726 202-638-4101

Parkinson's Disease Foundation (PDF)

1359 Broadway, Suite 1509, New York, NY 10018

info@pdf.org <http://www.pdf.org>

Tel: 212-923-4700 800-457-6676

The Parkinson's Institute and Clinical Center

675 Almanor Avenue, Sunnyvale, CA 94085

info@thepi.org <http://www.thepi.org>

Tel: 408-734-2800 800-655-2273

[Parkinson's Resource Organization](#),

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

info@parkinsonsresource.org <http://www.parkinsonsresource.org> 

Tel: 760-773-5628 877-775-4111 877-775-4111

[Bachmann-Strauss Dystonia & Parkinson Foundation](#)

P.O. Box 38016, Albany, NY 12203

info@bsdpf.org <http://www.dystonia-parkinsons.org> 

Tel: 212-509-0995

[Davis Phinney Foundation](#)

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

info@davisphinneyfoundation.org <http://www.davisphinneyfoundation.org> 

Tel: 866-358-0285 303-733-3340

IV. Research

Following is a sampling of current Parkinson's research. Find more on the national organization's web pages.

Monitoring Technologies to Assess Parkinson's Disease

From <http://www.viartis.net/parkinsons.disease/news.htm>

Researchers carried out a systematic review to list, compare and classify technological-based devices used to measure motor function in people with Parkinson's Disease into wearable, non-wearable and hybrid devices. A systematic literature search of the PubMed database resulted in the inclusion of 168 studies.

For each device they reviewed the availability, use, reliability, validity, and sensitivity to change. 73 devices were identified. Of these, 22 were wearable, 38 were non-wearable, and 13 were hybrid devices. In accordance with their classification, 9 devices were recommended, 34 were suggested, and 30 devices were classified as listed. Within the wearable devices group, those recommended were: the Mobility Lab sensors from Ambulatory Parkinson's Disease Monitoring (APDM), Physilog, StepWatch 3, TriTrac RT3 Triaxial accelerometer, McRoberts DynaPort, and Axivity (AX3). Within the non-wearable devices group, the Nintendo Wii Balance Board and GAITRite gait analysis system were classified as recommended. Within the hybrid devices group only the Kinesia system was classified as recommended.

Ref: Journal of Neuroengineering and Rehabilitation [2016] 13 (1) : 24 (C.Godinho, J.Domingos, G.Cunha, A.T.Santos, R.M.Fernandes, D.Abreu, N.Gonçalves, H.Matthews, T.Isaacs, J.Duffen, A.Al-Jawad, F.Larsen, A.Serrano, P.Weber, A.Thoms, S.Sollinger, H. Graessner, W.Maetzler, J.J.Ferreira) Complete study: <https://jneuroengrehab.biomedcentral.com/articles/10.1186/s12984-016-0136->

Researchers Identify when Parkinson's Proteins become Toxic to Brain Cells

From the Journal **Science Daily**, March 14, 2016

Researchers have used a non-invasive method of observing how the process leading to Parkinson's disease takes place at the nanoscale, and identified the point in the process at which proteins in the brain become toxic, leading to the death of brain cells.

The results suggest that the same protein can either cause, or protect against, the toxic effects that lead to the death of brain cells, depending on the specific structural form it takes, and that toxic effects take hold when there is an imbalance of the level of protein in its natural form in a cell. The work could help unravel how and why people develop Parkinson's, and aid in the search for potential treatments. The study is published in the journal *Proceedings of the National Academy of Sciences*.

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V. What We Are and What We Do

Parkinson Volunteers initiate 2 new exercise programs

Rock Steady Boxing!

Many of us have heard about it and saw Lesley Stahl interviewing her husband whose Parkinson's symptoms improved after learning to box! Rock Steady started in Indianapolis in 2006, based on boxing training, has proven to reduce PD symptoms. And the program is coming to our area thanks to Amelia Island's residents, **Guy Petty**, who happens to have Parkinson's and **Mary Anne Walkart**. With the help of other locals, Larry Oglivie, Dana Edge, Tifini McGill, Max Hord and Carolyn and Bryan Peeples, these individuals are raising funds to finance Dana, Tifini and Guy to travel to Indianapolis on April 6 to be Rock Steady trainers. Rock Steady Amelia Island will begin its boxing training sessions on April 18 at 2 pm and on subsequent Mondays, Wednesdays and Fridays at Advanced Muscle Therapy, 961687 Gateway Boulevard, Fernandina Beach. Nominal fee. For additional information, contact Guy Petty or Mary Anne Sharer at (904)310-6678.

Parkinson's Network Exercise Program

If you are looking for a way to stay engaged, maintain or improve your lifestyle and are a Person with Parkinson's (PWP) or caregiver, this Program may be for you. Relatively newly diagnosed People with Parkinson's, Mike Bleecker and Tom Dorsky became certified to conduct exercise classes for people with Neurological disorders and their caregivers by the Parkinson's Network.

GZ Sobol's Parkinson's Network was established in 2013 as a non-profit 501(c)(3) public charity. Parkinson's Network exercise classes help PWP using three guiding principles: **Overcome** challenges, **Improve** quality of life, **Restore** functions.

Mike and Tom's free exercise classes for people with Parkinson's (PWP) and their caregivers takes place at Fleming Island at Sacred Heart Church Activity Center, Hwy 17, north of Green Cove Springs at the following times:

Monday - 9:30-11 am & 6-7:30 pm; Thursday - 9:30-11 am

Parkinson's Network exercise classes are enhanced by camaraderie, cognition, voice and FUN! The classes are dramatically changing the lives of participants who regularly attend. In fact, many participants are recommended by their neurologist.

And, Mike and Tom are actively seeking out people to attend classes and become certified to teach classes so the exercise program can expand geographically to cover the greater Jacksonville-St. Augustine area. They believe a class will be starting in St. Augustine, late summer/early fall. For more information, contact Mike Beecher at bleeckerstreet@comcast.net.

VI. What I Learned about Parkinson's by Marti Gili

After a lively discussion about how much there is to learn about Parkinson's Disease, Beaches Support Group Leader Carol Rishel assigned attendees homework, to each write a listing of PD information as they know it. As a result, Marti Gili, whose early signs of Parkinson's showed up 15 years ago, wrote the following listing which would be helpful to all related to PD patients, caregivers, friends and family:

May Affect: smell, balance, speech, tremors, the way you walk, rigidity in muscles, facial expression, constipation, sleep, deprivation, sex, memory, swelling, vision, urinary...

Helpful Ways to get you through P.D.:

Exercise - use it or lose it. Do yoga, biking, weight training, etc. Dance and Boxing help with balance.

Medication - try to take medications same time every day. Habit is key. Take medicine one hour before meals or two hours after so body can absorb.

Clothing - choose clothing that is easy to get on and off.

Home - get rid of scatter rugs and objects you may trip over. Make lighting a priority for those nighttime trips to the bathroom or kitchen. Install grab bars in bath for balance and arrange furniture to grab hold of to prevent falling.

Eat Healthy - to help with constipation. Eat beans (black are best) for fiber, fruits and veggies and drink lots of water.

Read Articles on PD to keep up on new treatments and new discoveries. (See websites under "National Organizations" pages 8 & 9.)

Support System - explain to your family what to expect with the change in your body. Have them go to doctors with you to take notes and ask questions. Ask to watch for new symptoms and to make you aware of them.

Doctor - get a good neurologist who treats PSD. Tell your doctor the whole story, such as anything that's out of the ordinary. Start a symptom diary to take to doctor. Ask questions. Be your own advocate. Stand your ground if you feel your doctor's not listening. Make sure you understand, don't be afraid to ask him to explain again.

Support Group - **Joining a PD Support Group is the BEST THING you could ever do. You're all in the same boat so you can ask and compare. Plus, they give you a lot of HOPE. They are like an extended family.**

If you are interested in being on the e-mailing list for future issues of this newsletter or have any suggestions, please e-mail:

Bill Wilson
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