

# *The First Coast Parkinson's Disease Newsletter*

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Issue 7

Winter/Spring 2015

We will have a web page up within the next two weeks. We're sending this newsletter to you now because, as you probably know, April is Parkinson's Awareness Month and we wanted to announce the many April events. We will send you an e-mail with the url as soon as we have it ready.

We continue to attempt to reach as many First Coast people dealing with Parkinson's Disease (PD) and its effects. This newsletter and soon our website are intended to inform people with PD, their care partners, their 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 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.

Since April is Parkinson's Disease Awareness Month, there is a lot going on. See attached brochure to learn about UF Health at Jacksonville's April 18th Parkinson's Symposium. They will also sponsor the 2nd Annual Parkinson's 5K run/walk on April 25th (see attached flier). This is a good year for you to join in the effort to promote awareness of the disease suffered by an estimated 1 million people in the US. See some suggestions in the **Topics** section.

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## Local Support Groups

### **UF Health at Jacksonville Support Group**

**Contact:** Karen Perrin

[Karen.Perrin@jax.ufl.edu](mailto:Karen.Perrin@jax.ufl.edu) Phone: (904) 244-9719

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

Tower 1, 2nd Floor, Mason Room

580 West 8th Street, Jacksonville, FL 32209

### **Jacksonville Beaches Parkinson's Support Group**

**Contact:** Carol Rishel

[csrishel@gmail.com](mailto:csrishel@gmail.com) Phone: (904) 247-7876

Those with any movement disorders welcome.

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

Third Street and 35th Avenue, Jacksonville Beach

### **Orange Park Support Group**

**Contact:** Stan Harris

[dsharrisjr@gmail.com](mailto:dsharrisjr@gmail.com) Phone: (904) 860-2471

3rd Saturday of each month in the Orange Park Branch Library, room A

(2:00)

Caregivers meet 1st Saturday of month (10:00 - 12:00)

2054 Plainfield Avenue, Orange Park, FL

### **Mayo Clinic Parkinson's Disease and Related Diseases Support Group**

**Contact:** Anne Martin

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

1st Wednesday each month (12:30 - 1:30)

Cannaday Building, Room 1107

4500 San Pablo Road, Jacksonville, FL 32224

### **Jacksonville Southside Support Group**

**Contact:** Dr. Michelle Prosjje

[info@neuropsychfl.com](mailto:info@neuropsychfl.com) Phone: 904-296-8338

2nd Tuesday each month (4:00 - 5:00)

Neuropsychology Consultants of North Florida  
6817 SouthPoint Parkway, Suite 1203, Jacksonville, FL

### **Other Support Groups in Northeast Florida Area**

#### **Gainesville Parkinson's Support Group**

**Contact:** Amanda Eilers

[amanda.eilers@neurology.ufl.edu](mailto:amanda.eilers@neurology.ufl.edu) Phone: (352) 294-5434

3rd Thursday of each month (12:30 - 2:00)

UF Center for Movement Disorders and Neuroregeneration

3450 Hull Road, 4th floor, Gainesville, FL

#### **Flagler Parkinson's Disease Support Group**

**Contact:** Laurel Gaddy to RSVP and questions

[Laurel.gaddy@ahss.org](mailto:Laurel.gaddy@ahss.org) Phone: (386) 586-4420

2nd Wednesday each month

Florida Hospital, Flagler Education Center

60 Memorial Medical Parkway, Palm Coast, FL

#### **St. Augustine Parkinson's Disease Support Group**

**Contact:** Roger Geronimo, PhD

[Tenore2@hotmail.com](mailto:Tenore2@hotmail.com) (904) 386-0605

or Melanie Lomaglio [mlomaglio@usa.edu](mailto:mlomaglio@usa.edu)

every other month (2:00)

University of St. Augustine, 1 University Blvd., Room 101

(Directly behind Flagler Hospital), St. Augustine, FL 32086

#### **Fernandina Beach Parkinson's Support Group**

**Contact:** Lee Collins

[texaskipper@att.net](mailto:texaskipper@att.net)

3rd Thursday each month (7:00 p.m.)

Council on Aging of Nassau County, 1

307 South 18th Street, Fernandina Beach, FL

also: Caregiver's Support Group <http://www.toulastipsforcaregivers.com/>

**Parkinson Association of Greater Daytona Beach**

P.O. Box 4193, Ormond Beach FL 32175

Leave Message: (386) 252-8959

**Contact:** Vince Kinsler, President

Phone: (386) 676-6375

Read more at Jacksonville.com: <http://jacksonville.com/news/metro/>

**Local Activities**

**Parkinson's Awareness Month Activities:**

**See attached fliers - UF Health Jacksonville -- Neuroscience Institute:**

April 18     **Parkinson's Symposium 2015**  
                  Jacksonville Marriott, 4670 Salisbury Road, Jacksonville, FL 32256

April 25     **Parkinson's 5K Run/Walk and 1-mile Fun Run**  
                  Riverside Park, 753 Park Street, Jacksonville, FL 32204

**Mayo Clinic's Support Group Programs (12:30-1:30 p.m.):**

April 1       **Advocacy in Florida: Parkinson's Action Network Update**  
*Gretchen Church and Michael Church, So-State Directors*  
*Parkinson's Action Network*  
Mayo Clinic, Cannaday Bldg. Room 2207

May 6        **Swallow Function with Parkinson's Disease**  
*Christine Sapienza, M.D., Associate Dean, College of Health*  
*Sciences,*  
*Program Director - Speech Language, Jacksonville University*  
Mayo Clinic, Cannaday Bldg. Room 2207

June 3       **Medical Service Dogs Parkinson's Disease**  
*Carol Borden, CVT and Professional Dog Handler/Trainer for*  
*Guardian*  
*Angels Medical Service Dogs, Inc.*  
Mayo Clinic, Cannaday Bldg., Kinne Auditorium

**See attached flyer - Caregiver Coalition of Northeast Florida**

May 16      **Free, Fun & Focused On You** (9:30 a.m. - 3 p.m.)  
*Don't miss this day of celebration and renewal for family caregivers.*  
University of North Florida Herbert University Center

**St. Augustine Support Group Activities:**

April 4      Dr. Chris Hass, Associate Professor of Applied Physiology and  
Kinesiology at the University of Florida, will discuss his research into  
exercise slowing the progression of Parkinson's disease. University  
of St. Augustine, Room 101, 1 University Blvd., St. Augustine, FL. (2  
p.m.)

for              Click on the below link to watch a short promo and the attached flier  
more information. <https://youtu.be/IeeALLjoC7c>

The support group also has an informational web page  
<http://www.usa.edu/Parkinsons> to keep you informed.

Hopefully there will be more to come. We will send out notices as we get  
information. If you know of any, please let us know.

**National Activities**

The following is a sample list of national foundations upcoming events in Florida.

**Sponsored by the National Parkinson's Foundation:**

April 11th - Tampa      Moving Day®, A Walk For Parkinson's, see:  
[www.MovingDayTampaBay.org](http://www.MovingDayTampaBay.org)

April 12th - Naples      Earl Morrall Celebrity Charity Golf Classic,  
Hideout Golf Club 3025 Brantley Blvd.  
Naples, FL 34117

April 18th - Tallahassee      What You and Your Family Should Know: PD 101

Westminster  
FL 32308

The Maguire Center for Lifelong Learning at  
Oaks 4449 Meandering Way, Tallahassee,

**Sponsored by the The Michael J. Fox Foundation - Team Fox:**

April 11th - Winter Haven [Annual Golf for the Cure for Parkinson's Disease](#)

The National Parkinson Foundation and the Parkinson's Disease Foundation websites have event listings for every day in April.

More can be obtained on the home pages of major PD organizations listed below:

- (1) American Parkinson Disease Association (APDA) [www.apdaparkinson.org](http://www.apdaparkinson.org)
- (2) Michael J. Fox Foundation for Parkinson's Research [www.michaeljfox.org](http://www.michaeljfox.org)
- (3) National Parkinson Foundation (NPF) [www.parkinson.org](http://www.parkinson.org)
- (4) Parkinson's Action Network (PAN) [www.parkinsonsaction.org](http://www.parkinsonsaction.org)
- (5) The Parkinson Alliance [www.parkinsonalliance.org](http://www.parkinsonalliance.org)
- (6) Parkinson Disease Foundation (PDF) [www.pdf.org](http://www.pdf.org)

See also National Parkinson Foundation's web page including an interactive "Whatever It Takes to Beat Parkinson's ®" page to learn tips for reaching your Parkinson's-related goals.

### **Research**

Following is a sampling of current significant research. Find more on the national organization's web pages. The following web pages also offer research information on Parkinson's research:

[www.sciencedaily.com/news/health/](http://www.sciencedaily.com/news/health/) (enter Parkinson's in search field)

<http://www.webmd.com> (enter Parkinson's in search field)

[www.viartis.net/parkinsons.disease/news](http://www.viartis.net/parkinsons.disease/news)

Creatine Does Not Slow Parkinson's Disease Progression - see website below:

Jacksonville's Mayo Clinic Parkinson's Disease Unit researches the underlying causes of Parkinson's disease and other movement disorders. Grants from the National Institutes of Health [Morris K. Udall Centers of Excellence for Parkinson's Disease Research](#) as well as foundations, Mayo Clinic research committees and individuals sponsor their work:

<http://www.mayo.edu/research/labs/parkinsons-disease-clinical-genetics/overview>

In case you have not heard, a New Long-Acting Medication for Parkinson's Disease, Rytar, has received FDA approval.

<https://support.pdf.org/page.redir?target=http%3a%2f%2fparkinsons.about.com%2fod%2ftreatmentoptions%2ffl%2fNew-Long-ActingMedicationforParkinsonsDisease.htm&srcid=60758&srctid=1&erid=17520245&trid=e09eb8dd-acdd-4cee-925e-896a823b9768>

The latest article to be announced on **Viartis** can be found at:

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

### Parkinson's Moments

A famous Floridian once sang 'With all of our running and all of our cunning, if we couldn't laugh, we would all go insane'. This section helps us laugh with each other over the absurdities that are Parkinson's. After all, laughter is the best medicine (maybe even better than Sinemet). Received this from a fellow Parkinson...

"As a guy with PD and 64 years old, I thought this was hilarious. Thought you might like this for the PD Newsletter. All The Best, Greg Lloyd"



## What We Are and What We Do

This section highlights some of our own who are dealing with PD in a unique way. These stories serve as guideposts for the rest of us as we try to navigate through the rough waters of this damnable disease. If you or someone you know has a story (and we all do), please send it in for future issues of the First Coast PD Newsletter.

This issue features a remarkable man, Hardy Jones, who used the diagnosis of Parkinson's to change his avocation. Hardy Jones, an artist from St. Augustine, epitomizes the relationship between the onset of PD and the blossoming of the creative side of people with PD. Mr. Jones spent his professional life as a wildlife and conservation [filmmaker](#). He began his career in radio at [WNOE](#) in [New Orleans](#) and has worked for [United Press International](#), The Peruvian Times, and [CBS News](#). He has been a television [documentary](#) producer since 1978 having produced over 75 films for [PBS](#), [Discovery](#), [TBS](#), and [National Geographic](#). His numerous awards include: 2005 Filmmaker of the Year Award from Filmmakers for Conservation, a Lifetime Achievement Award from the [International Wildlife Film Festival](#), the [Genesis Award](#) of the [Humane Society of the United States](#), and the Special Jury Award of the [Explorers Club](#). He also appeared in the [2010 Academy Award](#) winning documentary, [The Cove](#).





In 2000, Jones joined actor and ocean activist Ted Danson and founded a website dedicated to the protection of dolphins and whales with the main emphasis to stop the hunting of dolphins in Japanese fishing villages. The organization, Blue Voice, uses television and the internet to publicize ocean issues.

Currently Blue Voice is researching and exploring the contamination in the marine food chain that is threatening both dolphins and now humans.

Mr. Jones was diagnosed with Parkinson's Disease in 2012. Not much later, he decided to take up painting and currently has a painting in the Parkinson Disease Foundation gallery <http://www.pdf.org/en/gallery/artist/709>. He also has a web page: <http://www.hardyjonesdolphins.com/>. Hardy Jones shares his experience with PD:

### The Hardy Jones Story

I have spent my career filming dolphins and whales in the oceans of the world and producing films for television. Shortly after I was diagnosed with Parkinson's disease in 2012, I took a class in watercolor painting while on a river cruise from Normandy to Paris. Traveling and exploring the great impressionist paintings there, felt like falling in love. I started sketching on my iPad and later made the leap into acrylics. Something happened in my wiring and painting became a profound passion.

Painting has not only helped to calm the tremor in my hand, but has improved my attitude toward life and increased my energy level. My paintings are often based on my photography from places around the world.

### **Special Topics**

This section is dedicated to material submitted by readers or anyone else, and may consist of just about any topic in any form.

Tips for celebrating National Parkinson's Awareness Month gathered from national organizations, publications and past experience:

National Parkinson Foundation

<http://www.parkinson.org/About-Us/Press-Room/Press-Releases/Press-Releases'sArchive/2011/April/Celebrate-Parkinson-s-Awareness-Month>

8 Ways to Raise Awareness for Parkinson's Disease All Year Long  
from *Everyday Health*

<http://www.everydayhealth.com/parkinsons-disease-pictures/ways-to-raise-awareness-for-parkinsons-disease-all-year-long.aspx>

Micheal J. Fox Foundation

<https://www.michaeljfox.org/get-involved/parkinsons-awareness-month.html>

Parkinson's Disease Foundation

[http://www.pdf.org/parkinson\\_awareness](http://www.pdf.org/parkinson_awareness)

These web pages offer suggestions on how an individual or group can raise the awareness of PD. These suggestions may be as simple as participating in activities in your area, or writing a letter to the editor in your local newspaper; or as complicated as organizing your own fund raising activity. If you go to <http://www.pdf.org/>, you will find templates for letters to the editor, etc.

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

Our nephew and his wife invited us to accompany them on a trip-of-a-lifetime to Australia. We purchased 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 with Jodi Morgan, ... from Brooks Rehab and, in our opinion, the most talented, encouraging and enthusiastic therapist possible. Meanwhile, we researched how to transport 100+ liquid food 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. And, off we went. 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 road (adjusting is normal for a Parkinson's people) 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 often have set backs and go forward again). The penguins find their individual burrow in sand dunes and stay there for the day (a Parkinson's patient may "stay" at home and avoid being among others).

The Sydney Opera House's design was chosen from an illustration, no structural instruction included (Parkinson's is so individualized, it's often difficult to know how to proceed). The time and money originally allocated 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 continue to experience life, as it is not only healthy, it’s important!

“No worries mate” you can go to Australia (or anywhere you desire)!

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

Bill Wilson  
[wjw1940@bellsouth.net](mailto:wjw1940@bellsouth.net)