

April is Parkinson's Disease Awareness Month

Three events are occurring on The First Coast and Gainesville
(find individual flyers at end of newsletter)

In Jacksonville

April 13, 2013

There will be Round Table Discussions with researchers from Mayo Clinic, The University of North Florida, and Shands Jacksonville heading tables that allow for small discussion groups from 9:00 a.m. to 12:00 noon.

April 27, 2013

A Parkinson's Disease Fair will be held at Cypress Village from 1:00 p.m. to 4:00 p.m.

In Gainesville

April 20, 2013

The University of Florida Center for Movement Disorders and Neurorestoration will host the 11th Annual Parkinson's Disease Symposium starting at 8 a.m.

The First Coast Parkinson's Disease Newsletter

Issue 2

Winter 2013

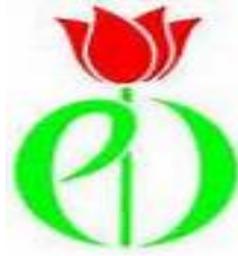
This is the 2nd issue of *The First Coast PD Newsletter*. This newsletter attempts to reach as many of the estimated 4,000 people calling the First Coast area home living with Parkinson's Disease (PD) and dealing with its effects daily. It is intended to inform people with PD, their care partners, their family and friends, or anyone else interested in PD, about local happenings, local support groups and other resources, national happenings, and what's going on in PD research. This newsletter depends solely on local input.

The current plan is to produce a limited number of hard copies of the newsletter, relying on e-mail for the majority of the distribution. Advertising will be by "word-of-mouth" so please share this with anyone you think would benefit and be interested in the material in the newsletter. Our goal is to reach everyone living on the First Coast impacted by PD. If you are interested in serving in any capacity, or have any suggestions please include this information when you sign up for the newsletter (on the last page).

This issue has two additional sections. One helps us laugh with each other over the absurdities that are Parkinson's Disease. After all, laughter is the best medicine (maybe even better than Sinemet). These Parkinson's Moments will come from you the reader and will be published anonymously. So please send them in! The second new section describes who we are and recognizes those among us that are doing different things that make us feel good about ourselves.

The National Parkinson Foundation has released its report on the largest clinical study of Parkinson's Disease ever conducted, called the "Parkinson's Outcomes Project: Report to the Community." The three-year program involved more than 5,500 people from four countries. The study gives a wonderful look at who we are as a population (for example, 37% of Parkinson's patients are female and 63% are male.) More on the report later. The entire report can be seen on NPF's home page, parkinson.org.

Parkinson's Disease was named after British physician James Parkinson, who published a description of the condition, *An Essay on the Shaking Palsy*, in 1817. He was born on April 11th, hence April is named Parkinson Disease Awareness Month.



The tulip was first recognized as a symbol for Parkinson's in 1980. At that time, a Dutch horticulturalist named J.W.S. Van der Wereld decided to honor Dr. James Parkinson, the first person to describe Parkinson's in 1817, by naming a tulip after him. It thus became a symbol for Parkinson's Disease,

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Local Support Groups

UF Movement Disorders Center Affiliated Parkinson's Support Groups Jacksonville, Fl

Contact: Karen Perrin
Karen.Perrin@jax.ufl.edu
Phone: 904-244-9719
Meets 2nd Wednesday of every month at
Shands at Jacksonville
Meeting Time: 11:30 - 1:30

Jacksonville Beaches Support Group

Contact: Carol Rishel
csrishel@gmail.com
Meets every Thursday at
Palms Presbyterian in Jacksonville Beach
Meeting Time: 10:30 - 12:00

Mayo Clinic Parkinson's Disease Education Series

Contact: Audrey Strongosky
Strongosky.Audrey2@mayo.edu
Meets first Wednesday of every month at
Mayo Clinic Cannaday Building
Meeting Time: Temporarily on hold

St. Mary's, Georgia Support Group

Contact: Jack Davis
jackd@tds.net
Meets first Wednesday of every month at
St Mary/Kingsland Hospital
Meeting Time: 2:00PM

Local Activities

April is National Parkinson's Awareness Month. There are a number of activities planned for that month and this issue will be largely devoted to describing what is happening on the First Coast. **Please put the following dates on your April calendar:**

April 13, 2013 There will be Round Table Discussions with researchers from Mayo, UF Shands, UNF, and Shands Jacksonville heading tables that allow for small discussion groups from 9:00 a.m. to 12:00 noon.

April 20, 2013 The University of Florida Center for Movement Disorders and Neurorestoration will host the 11th Annual Parkinson's Disease Symposium starting at 8 a.m.

April 27, 2013. A Parkinson's Disease Fair will be held at Cyprus Village from 1:00 pm to 4:00 pm.

A brochure for each of these events is attached to this newsletter.

National Activities

This newsletter will try to list only those events that appear to have broad appeal. Others can be found on the home pages of major PD organizations. These are:

- (1) American Parkinson Disease Association (APDA)
www.apdaparkinson.org
- (2) Michael J. Fox Foundation for Parkinson's Research
www.michaeljfox.org
- (3) National Parkinson Foundation (NPF)
www.parkinson.org
- (4) Parkinson's Action Network (PAN)
www.parkinsonsaction.org
- (5) The Parkinson Alliance
www.parkinsonalliance.org
- (6) Parkinson Disease Foundation (PDF)
www.pdf.org
- (7) We Move
www.wemove.org
- (8) The Parkinson Alliance
www.parkinsonalliance.org

Some examples of National Activities that may be of interest:

The Parkinson Alliance is sponsoring the 19th Parkinson's Unity Walk (PUW) on April 27

There will be a gentle 1.4 mile walk in Central Park, New York City and informational booths along Margot Zobel Way which will include Ask the Doctor, and representatives from sponsors and major US Parkinson's foundations.

The Parkinson Disease Foundation is sponsoring:

Celebrate Spring (NY) on April 3 at 6:00 p.m. <http://www.pdf.org/celebrate> spring

Celebrate Spring Boston (MA) on April 26 at 9:00 p.m. <http://www/pdf.org/en/event>
calendar/event

There are many events celebrating Parkinson's Awareness month throughout the country. To take advantage of these, simply go to the home pages listed above.

Current Research

APDA reports that the developer of an inexpensive speech test hopes it will speed the diagnosis of Parkinson's. The British mathematician discovered that the disease affects voice just as it does limb movement. He also learned that symptoms can be detected by using computer algorithms to analyze speech patterns. Interestingly, this was published in an engineering journal. The complete paper can be seen at: <http://www.medicalnewstoday.com/articles/247022.php>.

Research of major interest is the **Parkinson's Outcomes Projects Report to the Community** found on the NPF home page. This project attempted to determine what works best in treatment and care of Parkinson's patients. The main findings of this report are:

Negative mood and depression have the greatest impact on health status. At least 40 percent of people with Parkinson's will experience some form of depression, and just as many will experience an anxiety disorder.

Impaired mobility is the second most influential factor on health status. Mobility problems often result in difficulty walking, balance problems and an inability to perform everyday tasks such as feeding and bathing. However, regular exercise — more than 2.5 hours per week — is associated with lower degrees of mobility impairment.

Patients at some centers fare better than similar patients at other centers.

Medication use varies substantially from one neurologist to another.

Centers refer patients differently to allied health professionals. Referral rates to physical, occupational, speech and other therapists vary by as much as 50 percent for similar patients

Parkinson's Moments

As 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 new section gives a few examples:

We were having dinner at a friend's house and of course everybody had gathered in the kitchen. At the time I had bad dyskinesia and my right leg was out of control. On the floor, near the sink was a full recycling bin witch I promptly kicked. Everyone rushed to pick up the mess, set it back straight and I immediately kicked it again. My friend screamed "OK! OK! I'll take it out right now!" We all had a good laugh.

We were meeting friends at a restaurant for diner. I was wearing a brand new pair of white pants for the occasion. I tripped and fell in the parking lot. Everyone, very concerned, wanted to take me to the ER but all I said was: "I wonder if I have any Baking Soda at home. " Why?" they asked.

"To remove the blood stains from my new pants."

They were thinking broken bone and I was thinking "SAVE THE PANTS."

What We Are and What We Do

This new section will highlight some of our own who are dealing with PD in a unique way. Hopefully these highlights will 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), send it in for future issues of the *First Coast PD Newsletter*.

The population “we”. The NPF report obtained a sample of over 5,500 PD patients from four countries by using NPF centers of excellence. The authors assure us that the sample represents the population of all PD patients. They identified the following profile of an “average” PD patient: 2/3 of us are male; average age 67-68; 2/3 between 52-83; 7 percent under the age of 40; 58 percent are in the early stage of the disease; 27 percent in the mild stage and 8 percent in the advanced stage. (The rest were undetermined). On average, we have lived with the disease 7 years with about 6 percent of us having Parkinson's over 20 years. The longest duration in this sample was 48 years.

The individual “we”. This issue highlights a member of the Shands Jacksonville Support Group from Orange Park. As **Alice Grisham** indicates in her own story, she was diagnosed with PD over 17 years ago. Since that time she has been an art and gifted teacher (now retired), an author of children's books, and an artist (a local gallery displayed her watercolors, and theater production companies have used her jewelry and costumes). Her Florida home is filled with her

thimble, doll and Eiffel Tower collections. She loves traveling, especially to Europe, and has traced her family back to European royalty.

She has two sons and five grandchildren—four boys and one girl, and has been married to her husband, Jimmy, for 30 years. Alice is active in the community and presently serves as one of the vice presidents of the Orange Park Woman's Club.



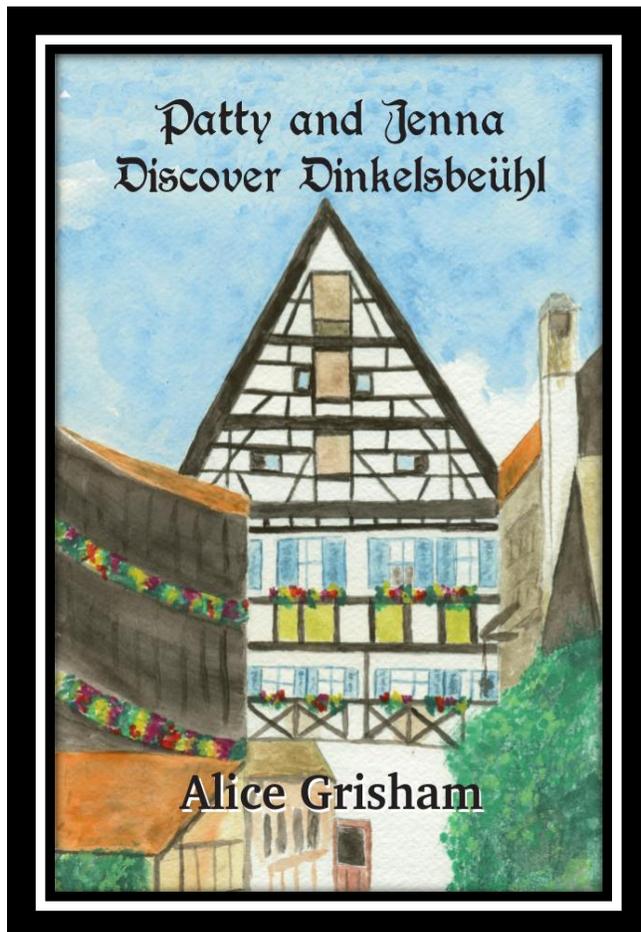
Here is her story

July 23, 1996, a day that is forever etched in my brain, for on that day I found out I had Parkinson's disease. Parkinson's, how could I have that? That was an old people's disease and I wasn't old, I was only 48. It had taken over a year to discover what was wrong. It took going to a neurologist to put it all together. My right side had for some time given me problems. I felt like I was moving in slow motion on that side. I really had to think hard to get my fingers to move. I was also not swinging my right arm when I walked (I later learned that was a typical symptom of PD) and I was dragging my right foot.

After being told I had PD I was given the medicine carbidopa-levodopa. That was like getting my life back in a way. My symptoms were not as pronounced; I could move my right side better. I was still bothered with cramps in my right thigh muscle. I still traveled. I backpacked through Europe twice by myself, once in 2001 and again in 2006; each time for a period of 5 weeks. I also went to Mexico to see the Mayan pyramids (I climbed to the top). That time I went on a cruise with my cousins. I continued to do other activities such as sewing, crafts and paint watercolors. Parkinson's did not affect these as much for I am left-handed.

My condition stayed much on the same level, but as time went on I was developing dyskinesia due to the medicine and it was getting worse. By 2007 the dyskinesia was so bad it forced me to retire from teaching, something I loathed to do

Then on July 23, 2008 exactly 12 years to the day, my life again took a change. This time for the good; I had the DBS surgery done. It has made a tremendous difference. It has turned my life around 180 degrees. I still have some leg cramps, but not like before. I stay active with club work and writing and illustrating books for children. I still travel; the last trip was in 2009 and was like the other trips. Most people who meet me for the first time are shocked to hear I have Parkinson's. They can't believe it. DBS is not for everyone, but I encourage everyone to check into the possibility. It changed my life, it gave me a new lease on life. It might do the same for you.



Register to have the *First Coast Parkinson's Disease Newsletter* e-mailed to you by sending the following information to wjw1940@bellsouth.net:

Name:

Email address:

Age:

Indicate: Parkinson's patient, care partner, family member, health professional, or interested party

Suggestions:

Interested in helping with newsletter



A Conversation with Experts about Parkinson's Disease April 13, 2013

University of North Florida Herbert University Center
9 a.m. to 12 noon (doors open at 8:30 a.m.)

April is National Parkinson's Disease Awareness Month. If you are one of the nearly 4,000 people in the First Coast who live with Parkinson's Disease (PD), a caregiver or a family member, you will want to attend this **free** small group discussion with researchers and health care professionals in a round table format. Six to eight participants will meet with an expert at each table to discuss current findings and trends in PD research and treatment. Participants will change to another table and speak to a different expert after 40 minutes. This will happen 3 times so that each participant will be a part of three different discussions. The meeting will end with a casual lunch for continued conversation between participants and experts.

Pre-registration is required. Sign on to <http://www.parkinsons-roundtable.org> and follow the instructions to register for the roundtable. You will be assigned a table and time for each 40 minute segment of the meeting. Every effort will be made to accommodate your choices:

Table	Table Expert	Topic
1	Owen Ross, Ph.D., Associate professor of Neuroscience, Mayo Clinic	Your DNA and Risk of Parkinson's Disease
2	Zbifnlew K. Wszolek, M.D., Professor of Neurology, Mayo Clinic	Genetics and Parkinson's Disease
3	Odinachi Oguh, M.D. Assistant Professor of neurology, Shands Jacksonville	Managing Parkinson's Disease
4	Zhizago Huang, M.D., Ph.D., Neurologist, Baptist Hospital	Cognitive Impairment of Parkinson's Disease
5	Dawn Saracino, D.P.T. Instructor, University of North Florida	Exercise is Medicine so Don't Miss a Dose
6	Karen Perrin, RM,BSN, Parkinson Coordinator, Shands Jacksonville	Caregiver Resources
7	Alison Buckell, M.S. CCC-SLP, Brooks Rehabilitation Hospital	Why LSVT (Big and LOUD) Therapy Works
8	TBA	Nutrition and Parkinson's Disease
9	TBA	What you should know about Deep Brain Stimulation

Parkinson's Awareness Fair

April 27, 2013

1 – 4 p.m.

Cypress Village
4600 Middleton Park Circle E
Jacksonville, FL

If you or a loved one lives with the challenges of Parkinson's Disease (PD), you will want to participate in this **free** public fair where you will have an opportunity to talk one-on-one with health care providers who specialize in PD. The Parkinson's Awareness fair will start at 1 pm with a welcome by Ty Morgan, CEO of Cypress Village, followed by a presentation by Jay A. Van Gerpen, M.D. entitled "Upcoming Research and Treatments in Parkinson's Disease".

After the presentation, participants will be free to talk on an informal manner with the health care experts in a casual, relaxed setting. The experts will be identified by a name tag which describes their area of expertise. Snacks will be served and a cash bar will be available (drink ticket can be purchased at the registration desk).

In addition to the experts available on the floor, there will be tables with personnel and printed material to answer questions concerning speech, physical and occupational therapy and home health care.

On display will be art work created by people with Parkinson's.

Pre-registration is required because of limited space. You can register by signing on to <http://www.parkinsons-roundtable.org> and follow directions to Parkinson's Awareness Fair.

In Gainesville, Fl

2013 Annual Parkinson's Symposium

UF | Center for Movement Disorders
and Neurorestoration



Saturday April 20th, 2013

Doors open at 8. Program 9am-1pm

Alachua County Senior Recreational Center
5701 NW 34th Street, Gainesville FL

To RSVP, please call or email:
Amanda Eilers (352)294-5434
Amanda.eilers@neurology.ufl.edu