

***The First Coast Parkinson
Disease Newsletter***

Issue 4

Summer 2013

This 4th issue of ***The First Coast PD Newsletter*** brings it to a full year of existence. We continue to attempt to reach as many of the people calling the First Coast area home, living with Parkinson’s Disease (PD) and dealing with its effects daily. The newsletter is 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. This newsletter depends solely on local input. Let us know how we are doing by dropping an e-mail to Bill Wilson at wjw1940@bellsouth.net.

We are producing a limited number of hard copies of the newsletter, relying on e-mail 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 include this information when you sign up for the newsletter (on the last page).

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Local Support Groups

UF Health Jacksonville Support Group:

Contact: Karen Perrin
phone: 904-244-9719
Meets 2nd Wednesday of the month at
UF Health Jacksonville (Shands at Jacksonville)
Tower 1, 2nd Floor, Mason Room
580 West 8th Street
Time: 11:30 - 1:30

Jacksonville Beaches Support Group:

Contact: Carol Rishel
e-mail: csrishel@gmail.com
Meets every Thursday at
Palms Presbyterian Church
Third Street and 35th Avenue
Time: 10:00 - 12:00

Orange Park Support Group:

Contact: Stan Harris
e-mail: dsharris@oneclay.net
Meets 3rd Saturday of the month in a
conference room of the Orange Park Branch Library
2054 Plainfield Avenue
Time: 2:00 p.m.

Parkinson's Disease and Related Diseases Support Group at Mayo Clinic

Contact: Anne Martin
e-mail: martin.anne@mayo.edu
Phone: (904) 953-6523
Meets 1st Wednesday of the month at
Mayo Clinic
Cannaday Building, Room 1107
4500 San Pablo Road
Time: 12:30 – 1:30p.m.
(Note: The November meeting will be in Davis 264W, and the January meeting will be on Jan 8th)

St. Marys, Georgia Support Group

Contact: Dr. Odinachi Oguh

Meets 1st Wednesday of the month at

St. Mary/Kingsland Hospital

Meeting Time: Program on Temporary Hold

St. Augustine Disease Support Group

Contact: Roger Geronimo PhD

(904) 386-0605 and e-mail: Tenore2@hotmail.com

Or Melanie Lomaglio at e-mail: mlomaglio@usa.edu

Meets 2nd Saturday every other month at

University of St. Augustine

1 University Blvd., Room 101

Time: 2:00 p.m.

Gainesville Support Group

Contact: Amanda Eilers

(352) 294-5434 and email: amanda.eilers@neurology.ufl.edu

Meets 3rd Thursday of the month at

UF Center for Movement Disorders and Neuroregeneration

3450 Hull Road, 4th floor

Time: 12:30 – 2:00

Daytona Beach Support Group

Contact: Nancy Dawson

nancy.dawson@halifax.org

Meets 4th Wednesday of the month at the

Bishop Glenn Retirement Center

Time: 2:00 – 3:00

Local Activities

Thanks to the efforts of Anne Martin, the support group at the Mayo Clinic has re-started with an excellent agenda. A listing of speakers and topics follows. For more information, contact Anne at the address in the **Local Support Groups** section.

- October 2, 2013** Depression, Apathy and Stress Management
Dr. Tanis Ferman,
Associate Professor of Psychology, Mayo College of
Medicine
- November 6, 2013** Exercise, Fall Prevention, Physical Therapy
Gleydiane DeOliveira, P.T.
Physical Therapist
- December 4, 2013** Nutrition in Parkinson's Disease
Nutrition Interns
Mayo School of Health Sciences
- January 8, 2014** Double Vision, Glasses, Eyecare
Dr. Christian Guier
Assistant Professor of Ophthalmology, Mayo College of
Medicine
- February 5, 2014** Evaluate Residence, Dressing, Handle Cash
Angelica Gicalone, OTR/L
Registered Occupational Therapist
- March 5, 2014** Medications and Tips on Managing PD Medications
Pharmacy Resident
Mayo School of Health Sciences
- April 2, 2014** Reduced Volume and Pitch Range in Speech - "LOUD"
Therapy
Valerie Donalson, M.A., CCC-SLP
Speech Pathologist
- May 7, 2014** Disturbed Sleep Patterns
Dr. Siong-Chi Lin
Mayo Sleep Disorder Center

January 25, 2014 Mark your calendars for the **Davis Phinney Foundation's Victory Summit[®]** coming to the University of North Florida's Herbert University Center.

The Davis Phinney Foundation was founded in 2004 by Olympic medal-winner and cycling great, Davis Phinney, who was diagnosed with Parkinson's disease in 2000 at the age of 40. The Foundation is a 501(c)(3) public charity supporting programs and research that delivers inspiration, information and tools to enable people living with Parkinson's to take more control in managing their disease. It operates without an endowment and relies on direct support from individuals, foundations and corporations. In 2011, the Davis Phinney Foundation put nearly \$800,000 to work to benefit Parkinson's patients, their families and caregivers throughout the United States.

The Victory Summit® symposia series focuses on the things people living with Parkinson's disease can do today to improve the quality of their lives – from learning about the latest research and treatment options to participating in demonstrations of yoga, speech therapy, exercise programs, and other activities. Featuring nationally recognized researchers, clinicians and physical therapists in movement disorders field, The Victory Summit® symposia delivers up-to-date information and practical tools that people with Parkinson's can use to live well today. More information can be obtained from the web site: www.davisphinneyfoundation.org.

January 26, 2014 UF Health Jacksonville will sponsor a run/walk downtown for Parkinson's research. Watch for further information, including directions to the web page. Let's all get out for this fun activity that will raise much needed funds for Parkinson's research.

Currently -- Last issue we reviewed a book by Dr. Michael Okun entitled *Parkinson's Treatment: 10 Secrets to Happier Life*. Dr. Okun now has an [Audible.com](http://www.audible.com) and iTunes version of the English edition. Audible Audiobook link (free with a 30 day trial membership).

http://www.audible.com/pd/ref=sr_1_13?asin=B00ESPJ73E&qid=1377775638&sr=1-1

December 5, 2013 There will be a free National Parkinson Foundation (NPF) webinar on the *10 Secrets*.

National Activities

This newsletter will try to list national events that appear to have broad appeal. Others can be found on the home pages of major PD organizations which include:

- (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 www.wemove.org
- (7) We Move www.wemove.org (will be discontinued by the end of 2013)

The third World Parkinson Congress will to be held in Montreal from October 1 - 4, 2013. See: <http://www.worldpdcongress.org>

Current Research

Find out what's going on in research by checking the web pages of the national organizations listed in the previous section. The following research project is currently recruiting participants.

Oregon Health and Science University is one of 24 worldwide sites taking part in a \$55 million Parkinson's study sponsored by The Michael J. Fox Foundation.

Researchers are looking at various risk factors in their ongoing quest to develop therapies that could slow or stop the disease progression. They will also explore whether testing for a reduced sense of smell might be combined with other measures to identify people who may be at risk for developing the disease.

During the last three years, the OHSU study has been working to identify biological markers of Parkinson's disease progression. This latest phase will be aimed at finding ways to detect the disease before the motor symptoms of Parkinson's – tremors, slowness of movement and rigidity begin.

Other potential risk factors being studied include rapid eye movement, sleep behavior disorder and a mutation found by genetic testing.

Anyone interested in the research can become one of the 10,000 individuals needed to complete a brief online or paper survey about their sense of smell. People over the age of 60 who do not have Parkinson's disease are needed to participate. Most survey respondents will be sent a scratch-and-sniff smell test and brief questionnaire in the mail to be completed at home. Some individuals may also be asked if they are willing to undergo more extensive testing at OHSU.

Anyone interested in taking part in the study can go to the Parkinson's research web site, call 1-877-525-PPMI (7764), or contact OHSU study coordinators Alicia Portillo and Art Lenahan at 503-494-1382.

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).

This section contains quotes from the book *Parkinson's Humor: Funny Stories about My Life with Parkinson's Disease*, by Beverly Ribaud.

"I asked several of my fellow 'Parkies' to come up with good things about having Parkinson's. *Here are some of these replies. Turns out they have a sense of humor too.* Here are some of their replies and a few of my own:

I don't notice when the batteries die in my electric toothbrush...

I get new dishes every few months...

I get a handicapped-parking permit.

I have a great excuse for not shaving my legs.

I don't need a blender to make a margarita.

I don't get asked to change diapers or feed babies.

I buy Velcro shoes.

I can Shake-N-bake like no body else.

I never get asked to pour the iced tea at dinner."

Special Topics

This section is dedicated to material written or submitted by readers and may consist of about any topic and in any form. This issue's special topic is about PD research and what you can do to help in the search for a cure or to slow down its progression.

The number of people affected by Parkinson's Disease is much larger than thought a mere decade ago. It also is no question that the cure will come through research. Clinical research (often called clinical trials) involve human participants and are a final and crucial step in development of treatments of PD and its symptoms. About 85% of trials are delayed because of lack of participants and 35% never get started.

Obviously research is expensive. So one way to help the process is to donate to those institutes, foundations, laboratories, or centers that are doing the kind of research you feel is the best. Before you give the farm away, check on the status of the organization. The following web pages can provide information on charities:

[Charity Watch](#)

[Association of Fundraising Professionalinicals](#)

[American Institute of Philanthropy](#)

[Wise Giving Alliance](#)

The three national organizations that most actively solicit donations, NPD, PDF and Michael J. Fox Foundation, all have an A rating.

While money is always needed, another significant contribution comes from volunteering to participate in a study. While it would be nice if everybody had the higher motive for participation in clinical studies, there are other valid reasons. A survey of participants yielded the following data:

Access to new treatment	80%
Knowing how it would help the community	84%
Doctors recommendation	90%

Other reasons to participate include:

To learn more about the disease

To enlarge (not substitute) one's medical care team and support circle

To engage and learn from other people with PD

Where people considering participating in clinical studies learned about the studies:

Support group	40%
Persons with PD	27%
Mail	15%
Radio	15%
Internet	11%
Doctor	11%
Family or friend	11%

A clinical study is a vital step in transforming scientific concept into medical reality. In order to develop and bring to market a treatment (often a new drug) there are three steps or phases of experimentation that takes place. These are listed as phase I, II, and III in the following table (furnished by PDF). These phases may not take place at the same location, nor even be conducted by the same researchers. The most important of the three phases is phase III. It is during this phase that the value of the treatment is established as well as its safety. Notice that this phase of the experiment may require 100 or more participants, usually all volunteers.

	Phase I	Phase II	Phase III	Phase IV
Number of Participants	15-30 people	Less than 100 people	Generally, from 100 to thousands of people	Several hundred to several thousand people
Purpose	Evaluates safety, determine the safe dosage and identify side effects.	Determines effectiveness and further evaluates safety.	Confirms effectiveness, monitors side effects, compares the potential treatment to current treatments and collects information on using the treatment safely.	Post-marketing studies to determine more information about a treatment, including risks, benefits and optimal use.

From the definitions given in the table for Phases I and II studies, we can see that these are the “exploratory” phases. These are normally done by researchers using convenient participants (such as college students) prior to recruiting for the important phase III. It makes sense that most people would probably want to volunteer for a phase III study.

The fourth phase listed in the table is for experiments done on treatments already on the market. For example, the University of Florida is conducting a study to see if Azalect reduces the fatigue level in PD patients. Since Azalect has already been approved and is on the market, the study is classified a phase IV study.

The effort in finding a study that fits your needs can be simplified by registering with one or both of two web pages. One is an activity of NIH and found at: clinicaltrials.gov, a searchable data base of publicly and privately supported clinical studies of human participants conducted around the world. Search for PD trials and then search for a trial that fits your needs. The second data base is Foxtrialfinder.org which contains only PD trials. After signing on to this webpage, you can register, answer a few questions and you will be given a list of trials that fit your profile.

When you find a possible clinical study, research it, discuss your involvement with your family, your physician and possibly your support group. Most studies require an Informed Consent document which contains all the procedures being performed

during the study as well as any compensation offered. Read it before signing. In other words, make an informed decision.

What We Are and What We Do

This 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.



This issue highlights Lawrence “Bunky” Johnson, a member of the Shands support group, and a person who does not let a small thing like Parkinson's Disease slow him down. In fact, you can see Bunky and his wife Marie just about any place in town that has something going on. They attend every educational program on Parkinson's and usually also can be found at the Mayo support group meetings. Further, Bunky has volunteered for several research projects in the area.

Of course everybody who knows the couple knows that they are the premier Jacksonville Jaguars football fans. Bunky has been a season ticket holder since the beginning of the franchise, in 1995. The last time he missed a home game was in 2010. This in spite of the fact that to attend the game (because he has problems with crowds), they must drive to the Convention Center, board the handicapped bus which takes him to the disabled entrance at Everbank Field, then the wheelchair attendant takes him to their seats and returns for pickup at the designated time and delivers him to the handicapped bus area. Before physical challenges made it impossible for the couple to drive to Gainesville, as an avid Gator fans, they spent many a Saturday afternoon at the “Swamp”.

As Bunky says in “My story” below, he has two daughters, Jennifer Bailey (son-in-law Lee, and 2 granddaughters, Christina age 14 and Jessica age 9) who lives in Gainesville and is Vice President of the Actuarial Department of Tower Hill Insurance. Another daughter, Katherine Bible, lives in Jacksonville and is a Crime Laboratory Analyst in the Chemistry Section of the Florida Department of Law Enforcement.

The nickname “Bunky” was given to him by his Mother Etta shortly after his birth and was based on Bunky, a comic strip character originated by Billy De Beck in 1926.

My Story

My name is Lawrence “Bunky” Johnson and I was born at St. Vincent’s Hospital in Jacksonville, Florida on December 23, 1931. Being a native of Jacksonville, I have seen many changes throughout the City. I retired from CSX in 1995 after 42 years of service as a railroad conductor. I am proud to have two daughters and two granddaughters.

A friend told me that life was an adventure and you never know what to expect. How true is that! In 2002, I was told by my physician that I had old age tremors. At that time my hands had a slight tremor, and I was not swinging my arms properly. In February 2004, my wife read in the paper that Mayo was encouraging people to give blood samples for a study in Parkinson's Disease. After we arrived, I asked if I could participate. Blood samples were taken, examinations for walking, reflexes, and a family history all were also done. I also remembered that I had an Aunt that had

Parkinson's. At the end of the consultation, Dr. Wszolek looked at me and said you have the beginnings of Parkinson's.

I knew something was wrong but I didn't expect Parkinson's. How could that be? Dr. Wszolek said that medication would not be started at this time and to return in October for another appointment. By that time my condition was worse and the doctor prescribed Carbidopa-Levodopa 25mg/100 twice a day. He told me there was no cure but emphasized exercise, fresh fruit, vegetables and to remain active.

One of my most catastrophic moments was when I was taking a plate of spaghetti to the table and I lost my balance and fell. The spaghetti ended up on the carpet. Needless to say, that was my first and my last time I tried that. Since then I use plastic glasses and Corelle plates for safety.

I remain active attending all home Jaguar games, Jacksonville Symphony Pops concerts, research studies, church activities, and other social functions. And not to forget the doctor visits. I also walk 2 miles a day, travel, and attend the Parkinson's Driving Proficient Test to test my driving ability. In 2008, I went on a bus tour to National Parks out West and in 2010 I went to Waikiki Beach in Honolulu HI. The highlight of the trip was climbing the Diamond Head Crater which is 761 feet high.

In 2010, Dr. Wszolek prescribed Azilect and also adjusted the Cardidopa-Levodopa to 100mg/250. Recently I have had problems with my feet not wanting to move (freezing) and that is when I am prone to falling. When I regain my balance, I have to move fast to keep from falling. Crowds are a problem because I don't have room to maneuver, and tight places in the house also present a problem.

Recently, I bought a TheraCycle to assist me in exercising at home. I cycle 30 minutes in the morning and 30 minutes at night. I also use a U-Step Laser Walker to assist me when I visit friends in the hospital. **My motto is keep on keeping on and continue life's adventure one day at a time. Don't give up, Life is precious and never forget that all cases are different and no two people are alike.**

Required Reading

In this issue we take a look at a 214 -page book by Beverly Ribaudo entitled *Parkinson's Humor: Funny Stories about My Life with Parkinson's Disease*.

There are 101 sections in the book, each one a story or a parody of a well-known song. Besides having a sense of humor, the author has a knack for re-writing the words to songs using PD vocabulary. The stories and songs chronicle the journey through PD of Yuma Bev (as she is known online) from Early Onset PD diagnosis (it took 8 years to make the diagnosis in 2007 when she was 47) through 2012. This journey is familiar to many of us and the book is full of “aha” moments.

Before writing the book, Yuma Bev wrote a blog consisting of funny stories laughing at the predicaments that resulted from PD. At the encouragement of family and friends the blog grew into the book. The author states up front that all profits from the book will go toward research in PD.

Each of the 101 stories elicit a chuckle or two, but more importantly, they also educate the reader on handling the challenges of Parkinson's. For example in the section called “charting a Parkie” she gives an example of using a chart to track progress of symptoms that can then be given to the neurologist at the next visit. In the “My Pike's Peak Adventure” the author discovers that her medications lose their effect at an altitude of about 10,000 feet...Who knew!

Chronologically (generally), the book starts with Halloween and goes through Parkinson's awareness month (April). One of the sections, “Holiday Advice for Friends and Family” consists of things that all Parkies would like to have known as holidays approach. The best is “Please invite me to join you for whatever you have planned. Don't assume that I won't feel well enough to attend but please try to understand why I may say no.”

The book is touted as “humorous”, however, it is more than just a funny look at PD, it is educational and informative and presents the story of a persistent, courageous, intelligent young woman who as stated in the book “...by the end of the day, I can always find something to laugh about.”

The book may be purchased from Amazon.com for around \$8. I recommend it.

Bill Wilson

If you are interested in getting on the e-mail list for future issues of this newsletter, or have any suggestions, e-mail me at wjw1940@bellsouth.net.