

# *The First Coast Parkinson's Disease Newsletter*

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Edition 1

Fall, 2012

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An estimated 4,000 people calling the First Coast area home (over one million nationwide) live with Parkinson's Disease (PD) and deal with its effects daily. This newsletter 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.

This is the first attempt to reach as many people touched by PD in the area as possible, so things will be changing as the newsletter develops. Right now there are several things that need attention. First an advisory board needs to be established. Second, a contact person is needed for each of the support groups in the area. Third, writers and proof readers are needed. 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).

The current plan is to produce a limited number of hard copies of the newsletter, instead relying on e-mail for the majority of the distribution. The only 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.

## **Table of Contents**

- I. Local Activities
- II. National Activities
- III. Current Research
- IV. Special Topics

## **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: 11:30AM-1:30 PM

### **Jacksonville Beaches Support Group**

**Contact:** Carol Rishel  
[csrishel@gmail.com](mailto:csrishel@gmail.com)  
Meets every Thursday at  
Palms Presbyterian in  
Jacksonville Beach  
Meeting Time: 10:30 AM-12:00 Noon

### **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. Marys, Georgia Support Group**

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

## Local Activities

**On December 1<sup>st</sup>, The Mayo Clinic Jacksonville is offering a free Parkinsonism Symposium** for patients, family, caregivers and health care providers from 8:30 to noon. The symposium will take place in the Kinne Auditorium on the Mayo campus. Topics include:

- (1) Management of PD and other Movement Disorders  
Ryan J. Uitti, M.D., Professor of Neurology,  
Mayo Clinic College of Medicine
- (2) Update on Lewy Body Disease  
Neill R. Graff-Radford, M.D., Professor of Neurology  
Mayo Clinic College of Medicine
- (3) Genetics of Parkinsonism's and Memory Loss Owen A. Ross, Ph.D.,  
Assistant Professor of Neuroscience

For questions, or to reserve a seat, call 904-953-6523.

**The Parkinson's Monthly Support Group at Shands Jacksonville** will present “**Ophthalmic Problems and Parkinson's**” by Derrick Pau at its January meeting, and “**Nutrition and Parkinson's**” by Elvira Rivas at its February meeting (see above for meeting dates and times)

**April is Parkinson's Disease Awareness Month. Look for some happenings in the area aimed at bringing awareness of the issues facing PD patients and their care partners.**

## National Activities

**Join PDF for its annual Carnival celebration, which benefits its research programs.** This Brazilian inspired fundraising event will feature DJ Brenda Black, Samba dancing, games of chance, raffle, buffet dinner and premium open bar. January 30, 2013, 6:30pm - 10:30pm at the Slate, 54 West 21st Street, New York, NY Hosted by the Parkinson's Disease Foundation (PDF) and Event Co-Chairs Peter Dorn, Stephanie Goldman-Pittel, Sharon Klein, Amy Sole, Douglas Stern and Jeffrey Zyglar. Tickets are on sale at [www.pdf.org/carnaval](http://www.pdf.org/carnaval).

**National Parkinson Foundation's Quality Improvement Initiative Enrolls 5,000 Parkinson's Patients.** In April of this year the National Parkinson Foundation (NPF) announced that it had enrolled 5,000 people in its Quality Improvement Initiative (QII), the largest study of clinical care and outcomes in PD ever. The goal of the QII is to improve care of people with PD by identifying and implementing best practices in treatments. More on this initiative on the NPF web page – the address is given at the end of this section.

**The 19th Parkinson's Unity Walk** will be held on a Saturday in April 2013, in New York's Central Park. We will receive confirmation from the Parks Department before the end of the year. Please check the Parkinson's Alliance web page below.

Every attempt will be made to list national activities related to PD. However, there are many things going on all over the country so we recommend that you get on the mailing lists of the major PD organizations. These are:

- (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)
- (7) We Move  
[www.wemove.org](http://www.wemove.org)

## Current Research

### **Newly Identified Protein May Help Damaged Dopamine Neurons Recover in Parkinson's Disease**

Read about a new study from the PDF Research Center at Columbia University Medical Center which may potentially provide a new strategy for treating Parkinson's:

[http://www.pdf.org/en/science\\_news/release/pr\\_1348760634](http://www.pdf.org/en/science_news/release/pr_1348760634)

### **Good Night's Sleep May Improve Working Memory Training in Parkinson's Disease - Sep 06 2012**

New research has shown that some people with Parkinson's disease (PD) can improve their working memory with specialized training, but only after a period of deep sleep at night.

The study was published online August 20 in the journal *Brain*.

Working memory is the ability to actively store and manipulate information in the brain.

Everyday tasks that require working memory include planning, problem solving, mental arithmetic and navigation. The mild cognitive impairment that can occur in Parkinson's disease

can affect working memory, leading to difficulty performing everyday activities, such as being able to remember who called just after hanging up the phone. Recent research has shown that people can improve their working memory with specific training tasks. Scientists do not know exactly how it works, but brain imaging studies have shown that training can actually change connections between brain cells (or neurons). The article can be found at:

<http://lib.bioinfo.pl/pmid/journal/Brain>

### **The Causes of Parkinson's Disease Remain in Doubt, but Advances in Treatment Can Ease its Effects**

*Read a column about Parkinson's which includes an interview with Barbara Changizi, M.D., co-director of the Center for Neuromodulation at Mount Sinai:*

<http://www.nydailynews.com/life-style/health/neuromodulation-offers-new-tool-alleviate-parkinson-article-1.1190297#ixzz2AEvmzQ9r>

**A possible vaccine against PD.** AFFiRiS AG: Parkinson's Vaccine - Worldwide First Clinical Study in Vienna, Read more here: <http://www.sacbee.com/2012/06/05/4539144/affiris-ag-parkinsons-vaccine.html#storylink=cpy>

Many recent publications show the value of exercise in improving PD severity, balance, gait, cognition, memory, and depression; and increases neurotrophic factors in animal models

As an indication of this, 3 of 10 most cited studies in the Movement Disorders Journal relate to the effect of exercise for PD. There have been 227 citations in PUB MED since 2010. There are 13/74 studies on [pdxtrials.org](http://pdxtrials.org) involving exercise and PD.

Besides these examples, work is being done in stem cell research, gene therapy using a virus that has been genetically modified, and a host of new drugs in the U.S. and Canada. Information on current and future research can be found on the websites of the national organizations listed in the section above. Web sites such as WebMD, the NIH web page, Mayo Clinic web page and many other agencies and universities offer results of research on PD. Every attempt will be made to list interesting research related to PD in this newsletter, however, there are many things going on all over the world related to PD and it is not possible to put them in a newsletter.

## Special Topics

This section will be dedicated to material written or submitted by readers. It may consist of just about any topic in any form. In this edition the special topic is a brief discussion of the process of research in Parkinson's disease by Bill Wilson of Jacksonville Beach, a Research Advocate for PDF..

About 50 years ago my mother was diagnosed with Parkinson's disease. At that time we were told by her neurologist that there was no cure, there was no way to stop the progression of the disease, and at that time there was very little that could be done to alleviate the symptoms. However, her children (me included) were assured that PD was not hereditary so we did not need to worry. L-dopa (now known as levodopa) had just been approved for public use, but there was no standard of either dosage or method of administration so that very little relief was available for the tremor and stiffness (freezing actually) that my mother experienced. She died of peritonitis in 1976 at the age of 68.

Fast forward to spring of 2006. My neurologist tells me that I have Parkinson's Disease. I was told that there is no cure for PD, there is no way to stop the progression of the disease, but there are many drugs and therapies that help to alleviate the symptoms. Today, carbidopa is used with levodopa to prevent the breakdown (metabolism) of levodopa before it can reach the brain and take effect. This provides a consistent dosage of levodopa to treat the symptoms of PD. Many other drugs have been developed to treat symptoms, and a deep brain stimulation operation is now available for people who no longer benefit from standard medication.

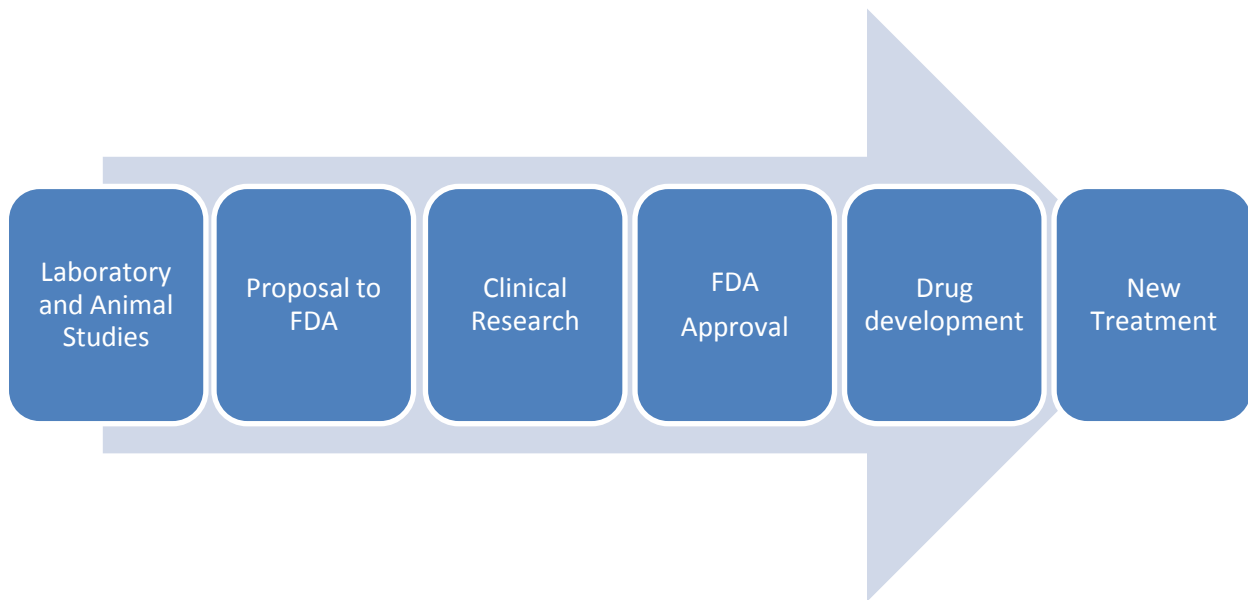
About six months after I discovered that I had PD, my older brother was diagnosed with PD in Houston. So much for no genetic link! Today there are a number of research studies looking at the genetics of PD. Two such studies are still recruiting volunteers who have PD and a member of their immediate family also has it. One is at the Mayo Clinic. Information on the study can be found on the web page Genetic Study of Parkinson's Disease and Parkinsonian Conditions, [www.mayo.edu/fpd](http://www.mayo.edu/fpd). The other is being conducted jointly with the University of Washington and the Veterans Administration. Information can be obtained by contacting the PaGeR (Parkinson's Genetic Research) Study at 206-277-4594. Google also has a project in progress to examine the genetics of PD. Information and registration for the project is free and can be found at [23andme.com](http://23andme.com), It is possible that in the near future we may have therapy targeted for individuals based on their genetic make-up.

All these treatments and many more enhance the quality of living for those of us with PD and are a result of previously conducted research done by medical professionals. By far, the most important advancement in the last 50 years is the increase in communication and availability of information through the internet. Now new and exciting discoveries are available to everyone almost instantaneously.

There has been a surge in the amount of research into Parkinson's disease over the last decade and, thanks to celebrities like Michael J. Fox and Mohammad Ali, this research has a

public image and considerable funding from both private and public agencies. It appears that we may be very close to having a cure for PD - or at least being able to slow the progress of the disease.

However, even if a cure was discovered today it may be as long as 10 years before the cure (whatever form it takes) can be marketed and become part of our regular therapy. For example, the steps for developing and bringing to market a new drug are illustrated in the following graphic (furnished by PDF). It may look as if the Federal Drug Administration (FDA) might be the bottleneck for the progress, but the US FDA has been shown to be faster in handling research proposals than similar agencies in any other country. The real slow down is usually found in the Clinical Research portion of the development.



Clinical research (also called clinical trials) consists of research conducted with people to answer specific scientific questions. It is designed to test the safety and efficacy of new treatments and learn more about the disease. All approved clinical research studies are well planned and monitored to ensure the safety of the participants (occasionally called subjects.) Almost all clinical trials depend on volunteer participants.

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 table below (furnished by PDF). These three 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 type of experiment may require more than 100 participants, usually all volunteers. This is why the clinical research step in bringing a new treatment to market becomes such a bottleneck. According to PDF only about one percent of PD patients participate in clinical studies and 80% of clinical trials are delayed at least a month because of lack of participants. In fact, an estimated 35% of clinical trials do not get even one volunteer participant.

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,

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

How can you become involved in PD research and help speed up the pursuit of a PD cure? First, donations help fund the effort. See the National Activity section for organizations that would put your gift to good use. Second, become a participant in a clinical research study. Find a study that meets your criteria and research it. Opportunities can be found on two major web pages. One is an activity of NIH and found at: [clinicaltrials.gov](http://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. This web site contains a complete glossary of terms used in clinical research. The second data base is [Foxtrialfinder.org](http://Foxtrialfinder.org) which contains only PD trials. After signing on to this webpage, you can register and after answering a few questions, 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.



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WELL, I ALWAYS WANTED TO BE ONE  
OF THE MOVERS AND SHAKERS-- I'VE BEEN  
DIAGNOSED WITH PARKINSON'S

**Register to have the First Coast Parkinson's Disease Newsletter E-mailed to You**

Send the following information to [wjw1940@bellsouth.net](mailto:wjw1940@bellsouth.net):

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Email address:

Age:

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

Suggestions:

interested in helping with newsletter:

Upcoming activities: