

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

---

Issue 6

Spring 2014

---

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 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.

We produce 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 let us know.

April is National Parkinson's Disease Awareness Month. You'll find activities, ideas and suggestions designed to bring Parkinson's awareness from national organizations such as the Parkinson's Disease Foundation, listed in the section **Local Activities**.

**Table of Contents**

- I. Local Support Groups
- II. Local Activities
- III. National Activities
- IV. Current Research
- V. Parkinson's Moments
- VI. What We Are and What We Do
- VII. Required Reading

## **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)

Tower 1, 2nd Floor, Mason Room

580 West 8th Street, Jacksonville

Time: 11:30 - 1:30

### **Jacksonville Beaches Support Group:**

**Contact:** Carol Rishel

e-mail: [csrishel@gmail.com](mailto:csrishel@gmail.com)

Meets every Thursday at Palms Presbyterian Church

Third Street and 35th Avenue South, Jacksonville Beach

Time: 10:00 - 12:00

### **Orange Park Support Group:**

**Contact:** Stan Harris

e-mail: [dsharris@oneclay.net](mailto:dsharris@oneclay.net)

Meets 3rd Saturday of the month in Conference Room A in the Orange Park Branch Library

2054 Plainfield Avenue, Orange Park

Time: 2:00

\*\*Caregivers meet 1st Saturday of the month in the same room from 10:00 - 12:00

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

**Contact:** Anne Martin

e-mail: [martin.anne@mayo.edu](mailto: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, Jacksonville, FL 32224  
Time: 12:00 – 1:30

**Southside Support Group**

**Contact:** Dr. Michelle Prosje  
e-mail:[info@neuropsychfl.com](mailto:info@neuropsychfl.com)  
Phone: (904) 296-8338

Meets 2nd Tuesday of the month starting April 8, 2014  
Neuropsychology Consultants of North Florida  
6817 SouthPoint Parkway, Suite 1203  
Time: 4:00 - 5:00

**St. Mary's Georgia Support Group - Program on Temporary Hold**

**Contact:** Dr. Odinachi Oguh

**St. Augustine Disease Support Group**

Contact: Roger Geronimo PhD  
(904) 386-0605 and e-mail: [Tenore2@hotmail.com](mailto:Tenore2@hotmail.com)  
Or Melanie Lomaglio at e-mail: [mlomaglio@usa.edu](mailto:mlomaglio@usa.edu)  
Meets 2<sup>nd</sup> Saturday every other month at University of St. Augustine  
1 University Blvd., Room 101, St Augustine, FL 32086  
Time: 2:00

**Gainesville Support Group**

**Contact:** Amanda Eilers  
(352) 294-5434 and email: [amanda.eilers@neurology.ufl.edu](mailto:amanda.eilers@neurology.ufl.edu)  
Meets 3<sup>rd</sup> Thursday of the month at UF Center for Movement Disorders and  
Neuroregeneration  
3450 Hull Road, 4th floor, Gainesville, FL

Time: 12:30 – 2:00

### **Daytona Beach Support Group**

**Contact:** Nancy Dawson

[nancy.dawson@halifax.org](mailto:nancy.dawson@halifax.org)

Meets 4<sup>th</sup> Wednesday of the month at the Bishop Glenn Retirement Center

Time: 2:00 – 3:00

### **Local Activities**

Notice the addition of a Southside support group. Further information can be found on the attachment at the end of the newsletter.

**April is Parkinson's Awareness Month** and there are several activities this month bringing attention to PD and its effect on the community:

On **April the 5th**, the University of Florida will host its annual Parkinson's Symposium. Check the flier at the end of the newsletter for information.

On **April 29th**, the Life Care Center in Orange Park is sponsoring a Celebration of Parkinson's at Whiteys Fish Camp. See flier at the end of the newsletter for details.

To raise community awareness of the many faces of Parkinson's, log onto the Parkinson's Disease Foundation's web page and go the "30 Ways to Raise Awareness of Parkinson's". For example, last year we used the Proclamation template when asking the Mayor of Jacksonville to declare April as Parkinson's Awareness Month.

This April would be a good time for you to write a letter to the editor of your local paper (or the Florida Times Union) and to tell your story, explain the consequences of ignoring the symptoms. You might want to use some statistics. For example, it is estimated that over 1 million people suffer from PD. It is often called an old man's disease, however, about 37% of people with PD are women. About 7.5% of PD sufferers are at or below 40. You can find additional statistics in the Parkinson's Outcomes Project on the National Parkinson Foundation web page.

Mayo Program Agenda:

- May 7      Disturbed Sleep Patterns - Dr. Siong-Chi Lin, Mayo Sleep Disorder Ctr.
- June 4      References and Resources - Tiffany Coco, LCSW, Case Manager
- July 2      Dance for Life - Emily Pozek, Artist in Residence UF Health Shands Arts  
Medicine

### **National Activities**

This newsletter will 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](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)

Both the NPF and the PDF websites have calendars listing events for every day in April. In addition, the National Parkinson Foundation web page has an interactive "Whatever It Takes to Beat Parkinson's ®" page to learn tips for reaching your Parkinson's-related goals.

### **Current Research**

#### **Stem Cell Research and Parkinson's Disease**

Parkinson's disease is a common condition that affects more than 2 percent of the population over 65 years of age. The disease is caused by a progressive loss of dopamine -- producing nerve cells. This leads to the classic Parkinson's disease symptoms, including tremors, rigidity, and abnormally decreased mobility.

Parkinson's disease may be the first disease where stem cell transplantation proves successful, for a couple of reasons. The first is that scientists know the specific type of nerve cell needed to relieve the symptoms of the disease. Second, several laboratories have been successful in transplanting stem cells into animals with Parkinson's disease.

### Previous Findings on Parkinson's Disease and Stem Cells

There is a lot of excitement surrounding the use of stem cells to treat Parkinson's disease. Part of this excitement comes from a study that was published in January 2002 in the Proceedings of the National Academy of Sciences.

This study showed that mouse embryonic stem cells transplanted into rats with brain damage resembling Parkinson's disease spontaneously acquired many of the features of dopamine-producing brain cells. These animals also showed a gradual reduction in their Parkinson's disease symptoms, and brain scans revealed evidence that the transplanted cells integrated with the surrounding area and began to produce dopamine.

The findings raise the possibility that embryonic stem cell transplants may one day be useful in Parkinson's disease treatment, as well as treatments for other brain disorders.

Many Parkinson's symptoms result from the loss of neurons that produce dopamine, a nerve-signaling chemical. Previous studies showed that embryonic stem cells can take on the characteristics of dopamine-producing neurons in culture. However, this is the

first study to show that undifferentiated (unspecialized) embryonic stem cells transplanted into the brains of animals with Parkinson's-like diseases can develop into dopamine-producing cells -- with no special pretreatment to control their fate.

International Stem Cell Corporation Announces Positive Interim Data From Primate Study Parkinson's Disease Cell Therapy  
March 5, 2014

CARLSBAD, CA -- (Marketwired) -- 03/04/4 -- International Stem Cell Corporation (OTCQB: ISCO) ([www.internationalstemcell.com](http://www.internationalstemcell.com)), a California-based biotechnology company developing novel stem cell-based therapies and biomedical products, today announced positive data from the first interim analysis of the ongoing IND-enabling pharmacology/toxicology primate study being conducted under the supervision of Professor D. Eugene Redmond Jr. MD, of Yale University Medical School.

"The initial data from this large controlled study is very encouraging," said Professor Redmond. "In Parkinson's disease research non-human primate data are considered the gold standard and are by far the best indicator of likely outcomes in humans." The majority of the animals in this ongoing study have shown significant improvement in Parkinsonism, including a return of many normal behaviors. The study consist of 18 primates divided into three cohorts, a control group and two treatment groups with the treatment groups receiving different doses of human neural stem cells (hPNSC) derived from ISCO's proprietary parthenogenetic stem cell line. This study design uses an extremely well validated and widely published non-human primate model of Parkinson's disease. The symptoms of the disease are induced by the administration of a neurotoxin which selectively destroys the same type of neuron that is affected in the human condition. This results in the monkeys exhibiting all the classic symptoms of PD from akinesia, rigidity gait abnormalities to tremors, freezing and fine motor coordination.

Dr. Ruslan Semechkin, Chief Scientific Officer for the Company commented: "This pharm/tox primate study, together with our rodent tumorigenicity study, is fundamental for ISCO's planned IND submission -- which we believe will be the first

IND in the world using pluripotent stem cell-derived therapeutic cells to treat Parkinson's disease. We anticipate providing further updates on this study in the second and third quarters, to report the final results towards the end of 2014 and to file the IND soon thereafter."

Read more: [International Stem Cell Corporation Announces Positive Interim Data From Primate Study Parkinson's Disease Cell Therapy - FierceBiotech Research](http://www.fiercebiotechresearch.com/press-releases/international-stem-cell-corporation-announces-positive-interim-data-primate#ixzz2xMJEJ0Jh)  
<http://www.fiercebiotechresearch.com/press-releases/international-stem-cell-corporation-announces-positive-interim-data-primate#ixzz2xMJEJ0Jh>

Subscribe at [FierceBiotech Research](#)

### The Michael J. Fox Foundation's view on stem cells to treat Parkinson's disease

Stem cell research has the potential to significantly impact the development of disease-modifying treatments for Parkinson's disease, and considerable progress has been made in creating [dopamine](#)-producing cells from stem cells. The development of new cell models of Parkinson's disease is a particularly promising area of stem cell research, as the current lack of progressive, predictive models of Parkinson's disease remains a major barrier to drug development. Cell models of Parkinson's disease generated from stem cells could help researchers screen drugs more efficiently than in currently available animal models, and study the underlying biological mechanisms associated with Parkinson's disease in cells taken from people living with the disease. However, there are many challenges that need to be overcome before stem cell-based cell replacement therapies for Parkinson's disease are a reality. Work is still needed to generate robust cells, in both quality and quantity, that can also survive and function appropriately in a host brain. Although ES (and now iPS) cells hold great potential, we do not yet know which stem cell type ultimately holds the greatest promise. Thus, researchers require scientific freedom to pursue research on all types — including ES, adult and IPS cells — in order to yield results for patients.

The Michael J. Fox Foundation played an early role in supporting work in stem cell research for Parkinson's disease, including funding the original proof of principle



demonstrating that ES cells could provide a robust source of dopamine [neurons](#). Since that time, significant other funding resources — at both the state and federal levels — have been unleashed to support the whole field, allowing the Foundation to continue to target strategic funding in other critical areas of developing therapies for Parkinson’s disease. The Foundation will continue to monitor Parkinson’s disease specific stem cell developments for opportunities where the Foundation can help in advancing this research.

### **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).

Howard is 95 and lives in a senior citizen home. Every night after dinner, Howard goes to a secluded garden behind the Center to sit and ponder his accomplishments and long life. One evening, Mildred, age 87, wanders into the garden. They begin to chat, and before you know it, several hours have passed. After a short lull in their conversation, Howard turns to Mildred and asks, “Do you know what I miss most of all?” She asks, “What?” and he replies “SEX!!!” Mildred exclaims, “Why you old fart, you couldn’t get it up if I held a gun to your head.” “I know,” Howard says, “but it would be nice if a woman just held it for a while.” “Well, I can oblige”, says Mildred, who gently unzips his trousers, removes his manhood and proceeds to hold it. Afterward, they agree to meet secretly each night in the garden where they would sit and talk and Mildred would hold Howard’s manhood.

Then, one night, Howard didn’t show up at their usual meeting place. Alarmed, Mildred decided to find Howard and make sure that he was O.K. She walked around the senior citizen home where she found him sitting by the pool with another female resident, Ethel, who’s holding Howard’s manhood! Furious Mildred yelled, “You

two-timing creep! What does Ethel have that I don't have?!?" Howard smiled happily and replied, "Parkinson's!"

### **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 features Stan Harris, the organizer and director of the Clay County (Orange Park) support group. After earning his bachelor's degree from Brigham Young University, Stan moved his family to Florida and began teaching in the Clay County school district. In 1999, at the age of 44, he was diagnosed with Parkinson's disease. Within two years, he was laid off at work and entered into a period in which he was the stay-at-home parent. After a short period of time, he decided that he could, in fact, return to the classroom which he did. In the meantime, he worked toward and obtained his MsEd from UNF.



*Stan with one of his students at a school event.*

About 18 months ago, Stan decided that Orange Park needed a PD support group, so he started one. Currently the group is growing steadily, offers activities for caregivers and Tai Chi and exercise opportunities for its members. In recognition of Parkinson's Awareness Month, his group is supporting the Awareness Celebration at Whitey's Fish Camp. Here is his story:

**My Story:** I was happily married in 1985 with 3 beautiful children and a life filled with dreams and aspirations. I had just moved my family from Utah to Jacksonville, Florida to continue my career in education. At this time I noticed a slight tremor in my left hand. My primary care physician said it was too early to tell, but commented that she did not believe it to be Parkinson's.

The next 14 years were filled with normal life events, but in 1999 I began to notice an increase in the tremor along with slowness, rigidity, and balance issues. A referral to a neurologist as well as a second opinion from a movement disorder

specialist confirmed a diagnosis of PD. I was 44 and was oblivious to the changes in my life that this announcement implied. All I knew about PD was that Muhammad Ali's arms and head shook a lot.

My wife at the time began an exhaustive research campaign producing 2 binders full of "Internet information," which began to increase my awareness level. She also visited a local support group and interviewed several doctors in the Jacksonville area. When she found "the one doctor" she made an appointment for me. I dutifully went with her to my appointment and began attending the weekend support group meetings organized by a newly begun NPF Parkinson Center. Although still working, I immediately began taking advantage of lunch time yoga classes offered at the Center, as well.

Within 2 years I had lost my job due to a RIF at work. Upon consultation with my neurologist I took the opportunity to apply for social security disability and was approved. This situation brought an immediate need for my wife to obtain full time employment and left me alone at home to get into trouble. Although I filled some of my time with volunteering efforts, medical appointments, Tai Chi and other exercise classes, support group activities, and house dad duties, I also took the opportunity to increase my obsessive involvement in addictive practices that created extreme havoc in my personal and family life.

During this period of unemployment I underwent several medication adjustments and changes. Although I was unsure how well I could endure the rigor of the school classroom, after 2 ½ years of life on disability I concluded that there was no reason I could not still teach, and I went back to work full time. That was 10 years ago. Though the decade has been troubled by divorce, death of a son, and addiction, I attribute the longevity of my extended career with PD to faith, exercise, support, and a professionally managed comprehensive health treatment plan that has included, among other therapies, bi-lateral DBS.

Perhaps one of the most meaningful tools I have utilized to improve my quality of life with PD is that of reaching out to others. Noticing a lack of support groups in Clay County 1 ½ years ago, I notified as many individuals as I could locate and held an initial PD support group in Orange Park. Thirteen people attended our first meeting! Over the months we have met 52 PD patients and their caregivers. Out of the original group, a separate caregiver support group began. It is facilitated, attended by and meets the needs of the caregivers exclusively. During the month of April, PD awareness month, we are hosting a display at the Orange Park Library and a free introductory Tai Chi class. I am very pleased for the opportunity of reaching out to the PD community through our support group.

### **Required Reading**

*What Your Doctor May Not Tell You About(TM): Parkinson's Disease: A Holistic Program for Optimal Wellness* by Jill Marjama-Lyons, Mary J. Shomon

Stan Harris wrote the following preface and at the same time, a review of the book:

Three years ago, at age 43, I was referred to a neurologist who diagnosed me with Parkinson's disease. With four children, and having recently begun my second career, I suddenly found myself faced with a spiraling decline in my ability to provide for my family. Prior to my diagnosis, I had always been in excellent health and had therefore given little attention to my physical well-being, although I did have a casual interest in a holistic approach to health. With the onset of PD and through the encouragement of my wife I began to learn all I could about complementary medicine, especially as it related to my condition.

It was during this quest for knowledge that I became acquainted with the Parkinson Center at Shands Hospital in Jacksonville, and with Dr. Jill Marjama-Lyons, the Parkinson Center director at that time. My wife made the initial consult visit and came home exclaiming, "They believe in treating the whole person!" From that initial contact, along with attendance at a symposium hosted by the center, I knew that I needed to change doctors--I wanted to see Dr. Marjama-Lyons.

There is no doubt I could have continued with my first neurologist and received competent medical treatment. I hate to think, however, of all that I would have missed out on if I had not become familiar with a team of medical professionals who recognize that quality of life includes more than dopamine in a brain. Those who treat me don't have all the answers, but they are open to all the answers, from wherever they come. Nutrition, exercise, natural supplements, spirituality, various European and Oriental treatments--they all play a part, not to the exclusion of traditional medicine, but incorporated with it. As a Parkinson's patient, the greatest benefit that comes from a holistic approach to my treatment is the support that I feel from a team of people who don't blindly follow the suggestions of political correctness, but rather, who do what is right for me, the patient.

I would encourage other Parkinson's patients to find a doctor whom you trust and who will trust you. Discuss your interest, plans and understanding about holistic therapies. We each need to take an active role in our own treatment, but we also need a professional to manage that treatment. I recommend this book for all who are associated with Parkinson's disease in any way: patient, caregiver, and professional. I recommend it to those Parkinson's disease patients interested in improving their health in general, and to those who are in the business of improving health. Lastly, I recommend it to the skeptic who will take time to read a few of these pages with an open mind.

-----

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)

## PARKINSON'S DISEASE SUPPORT GROUP

**FREE** support group for people living with Parkinson's Disease, including patients, caregivers, and loved ones.

Dr. Michelle Prosjc, a neuropsychologist specializing in PD and other movement disorders, will lead the group. She has extensive experience with PD and was fellowship trained at the UF Center for Movement Disorders and Restoration in Gainesville, FL.

**Day:** 2nd Tuesday of the month (starting April 8, 2014)

**Time:** 4:00-5:00 p.m.

**Location:** Neuropsychology Consultants of North Florida  
6817 South Point Parkway, Suite 1203, JAX, FL 32216

**Contact:** (904) 296-8338 or [info@neuropsychnefl.com](mailto:info@neuropsychnefl.com)



Alachua County  
Senior  
Recreational  
Center  
5701 NW 34th  
Street,  
Gainesville FL  
Doors open at 8.  
Speakers start at 9



To RSVP, please call  
or email:  
Amanda Eilers

(352)294-5434  
Amanda.eilers@  
neurology.ufl.edu

# 2014 ANNUAL PARKINSON'S SYMPOSIUM

---



## SAVE THE DATE

### April 5th, 2014

9:00am -1:00pm

Free educational day open to the public. It is a great way to update your knowledge of the specifics of Parkinson's Disease and meet people who are fighting for a cure.

Check out our website for more details

<http://movementdisorders.ufhealth.org>



Join us to celebrate

# Parkinson's Awareness month!

**Date:**  
April 29

**Time:**  
4 – 7 p.m.



**Location:**

Whiteys Fish Camp,  
2032 County Road 220,  
Orange Park, FL 32003

All proceeds will benefit  
the Clay County Parkinson's  
Support group.

**Join us** for a silent auction and  
live music! Wristbands will be sold  
at the door for \$5 which entitle  
each guest to heavy hors d'oeuvres  
and two alcoholic beverages.

To **RSVP** or for more  
information, please call  
Sara Dewitt at  
(904) 501-9242.

**RSVP by April 22.**

**Sponsored by:**

