

*The First Coast Parkinson's Disease
Newsletter*

Issue 8

Fall/Winter 2015

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 and soon and website are intended to inform people with PD, their care partners, 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 (firstcoastpdinfo.org) 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.

This issue is full of information, and some exciting news. It looks like Jacksonville will have a comprehensive PD Center! Read about what Brooks Rehab is planning under Local Activities. Find a comprehensive list of NIH recommended resources in the National Activities section. Also, check out a newly established PD internet "chat room."

Table of Contents

- I. Local Support Groups
- II. Local Activities
- III. National Activities
- IV. Current Research
- V. Topics
- VI. What We Are and What We Do

Local Support Groups

UF Health Jacksonville Support Group:

Contact: Karen Perrin,

Karen.Perrin@jax.ufl.edu

Phone: 904-244-9719

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

Tower 2, 10th Floor Banquet Room

580 West 8th Street, Jacksonville

Jacksonville Beaches Support Group:

Contact: Carol Rishel

csrishel@gmail.com

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

Third Street and 35th Avenue South, Jacksonville Beach

Orange Park Support Group:

Contact: Stan Harris

dsharris@oneclay.net

3rd Saturday of the month in the Orange Park Branch Library in room A (2:00)

2054 Plainfield Avenue, Orange Park

Caregivers meet 1st Saturday of the month in the same room (10:00 - 12:00)

Mayo Clinic Parkinson's Disease and Related Diseases Support Group

Contact: Anne Martin

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

1st Wednesday of the month at Mayo Clinic (12:30 - 1:30)

Cannaday Building, Room 1107

4500 San Pablo Road, Jacksonville, FL 32224

St. Augustine Parkinson's Disease Support Group

<http://www.usa.edu> Parkinsons

Contact: Melanie Lomaglio: mlomaglio@usa.edu, 904-826-0084, ext. 1270

or Dr. Anne Boddy, 904-826-0084, Ext. 1270

2nd Saturday every other month at University of St. Augustine (2:00)

1 University Blvd., Room 101, St Augustine, FL 32086

Fernandina Beach Parkinson's Support Group

Contacts: Lee Collins texaskipper@att.net

and Linda Raker lindarker@yahoo.com

3rd Thursday of every month (9:30-10:30 a.m.)

Parlor Room of St. Peter's Episcopal Church, Fernandina Beach, FL

For a virtual support group go to My Parkinson's Team at:

www.myparkinsonsteam.com

Local Activities

Brooks Rehabilitation Umbrella Center for Parkinson's

We are excited to announce, Jacksonville will have a comprehensive PD Center!



Thanks to Ceil Brooks, a Speech-Language Pathologist at Brooks Rehab, the project got a huge boost on September 11th when she and her team (in photo) won a Crowdsourcing award given by Brooks Rehab for innovative ideas for new programs. The award furnishes start-up capital for the development of the Center. The team consisted of Ceil, Dawn Saracino, Bill and Marilyn Wilson, and Melissa Godsey, with

supporting roles by, Scottie and Kathy McGregor, Larry and Mary Silas and Joe and Jo Gambert.

The Brooks Rehabilitation Umbrella Center for Parkinson's will focus on three main areas: **Therapeutic programs** such as exercise, yoga, and dancing, offered at convenient times and locations and enhancing Brooks Rehab's current offerings of BIG & LOUD and Parkinson's Wellness; **Education**, including up-to-date lists of health care agencies in the First Coast area, as well as lists of support groups and other resources for increasing the quality of life of people with Parkinson's. The Center will also assist with editing and circulating the First Coast Parkinson's Disease Newsletter and design and support the webpage <http://firstcoastpdinfo.org/>.

The third area of focus will be **Research**. The Center will construct a confidential registry of people with Parkinson's disease. This will be used to alert people with PD of opportunities to participate in clinical trials conducted in this area and monitor the progress of participants during the trial. The Center will also organize professional meetings, symposia, and lectures on topics relating to PD.

Of course this endeavor is in the early planning stages and changes may occur to the original proposal. Much more to come - check the webpage.

PD Dance Social and Classes

UF Health Jacksonville is partnering with the University of Florida Center for Arts in Medicine and the Dance Program at Jacksonville University College of Fine Arts to bring a Dance Social and Dance classes to the Jacksonville Parkinson's community. A number of studies are looking at the benefits of dance for PD through classes conducted by professionally-trained instructors who are also movement experts, and preliminary results reveal it is an enjoyable and creative way to help with balance, cognition, motor skill, depression and improve physical confidence.

The University of Florida Center for Arts in Medicine has offered similar classes since 2009, which has provided a significant component of education for their dance students and a major source of support for their local PD community. They have been engaged in a study on the effects of dance on PD, and will be extending their study to Jacksonville.

The program kicked off Saturday, November 7 at Jacksonville University. There were participants from various support groups in the local area, as well as a number of

dance students and instructors. Both singles and couples enjoyed guided dancing, and kicked up their feet with enthusiasm, while sitting, standing, side-stepping, and every which way they could move, all while enjoying good music and good company. The event ended with tasty refreshments. Dance research will be starting up week of November 16 along with commencement of the dance classes. Whether you may be interested in just dance, research or holding off through the holidays, the door remains open to join for this wonderful means of exercise. If interested, please contact Karen Perrin, RN/BSN, Parkinson Coordinator, UF Health Jacksonville, at (904) 244-9719, or email her at Karen.perrin@jax.ufl.edu.

National Activities

The National Institute of Health provided the following comprehensive list of major PD organizations. This can be a handy information resource to keep on hand.

American Parkinson Disease Association (APDA)

135 Parkinson Avenue

Staten Island, NY 10305-1425

apda@apdaparkinson.org

<http://www.apdaparkinson.org> 

Tel: 718-981-8001 800-223-2732 Young Onset Center: 877-223-3801

National Parkinson Foundation (NPF)

201 SE 1st Street

Suite 800

Miami, FL 33137

helpline@parkinson.org

<http://www.parkinson.org> 

Tel: 800-473-4636

Parkinson Alliance

P.O. Box 308

Kingston, NJ 08528-0308

<http://www.parkinsonalliance.org> 

Tel: 609-688-0870 800-579-8440

Michael J. Fox Foundation for Parkinson's Research

Grand Central Station

P.O. Box 4777

New York, NY 10163

<http://www.michaeljfox.org> 

Tel: 212-509-0995

Parkinson's Action Network (PAN)

1025 Vermont Ave., NW

Suite 1120

Washington, DC 20005

info@parkinsonsaction.org

<http://www.parkinsonsaction.org> 

Tel: 800-850-4726 202-638-4101

Parkinson's Disease Foundation (PDF)

1359 Broadway

Suite 1509

New York, NY 10018

info@pdf.org

<http://www.pdf.org> 

Tel: 212-923-4700 800-457-6676

The Parkinson's Institute and Clinical Center

675 Almanor Avenue

Sunnyvale, CA 94085

info@thepi.org

<http://www.thepi.org> 

Tel: 408-734-2800 800-655-2273

Parkinson's Resource Organization

74-090 El Paseo, Suite 104

Palm Desert, CA 92260

info@parkinsonsresource.org

<http://www.parkinsonsresource.org> 

Tel: 760-773-5628 877-775-4111 877-775-4111

Bachmann-Strauss Dystonia & Parkinson Foundation

P.O. Box 38016

Albany, NY 12203

[**info@bsdpf.org**](mailto:info@bsdpf.org)

[**http://www.dystonia-parkinsons.org**](http://www.dystonia-parkinsons.org) 

Tel: 212-509-0995

Davis Phinney Foundation

1722 14th Street, Suite 150

Boulder, CO 80302

[**info@davisphinneyfoundation.org**](mailto:info@davisphinneyfoundation.org)

[**http://www.davisphinneyfoundation.org**](http://www.davisphinneyfoundation.org) 

Tel: 866-358-0285 303-733-3340

Current Research

From the BUSINESS section of the Washington Post:

Novartis Cancer Drug Shows Promise as Treatment for Parkinson's
by Johannes Koch (Bloomberg)

A Novartis AG drug used for treating leukemia may also work for patients with Parkinson's disease, judging from one small and early clinical test. An early stage trial conducted by the Georgetown University Medical Center found a small dose of the medicine, Tassigna, produced "meaningful clinical improvements" in 10 out of 11 patients, the university said in a statement on Saturday. Unlike standard clinical tests, this one didn't include a control group for comparison. The findings appear significant nonetheless, because there is no cure for Parkinson's disease and participants in the study saw production of the brain chemical dopamine increase so much researchers had to advise them to reduce or stop taking other drugs. Parkinson's, a degenerative condition causing tremor and motor impairment, is associated with dysfunctions in the dopamine system and affects an estimated 10 million people worldwide.

Alan Hoffmann, a retired social science professor diagnosed with Parkinson's disease in 1997 who took part in the trial, said he was now able to "empty the garbage, unload the dishwasher, load the washer and the dryer, set the table, even take responsibility for grilling" after taking the Novartis drug. Previously, he did almost nothing around the house.

Some patients in the study had Lewy body dementia, the second most common type of progressive dementia after Alzheimer’s disease. The study marks the first time a therapy appears to reverse the “cognitive and motor decline in patients with these neuro-degenerative disorders,” Fernando Pagan, a neurology professor who helped oversee the trial at Georgetown University Hospital, said in the statement, “it is critical to conduct larger and more comprehensive studies before determining the drug’s true impact.”

Topics

Advanced Directives

It is especially important families living with PD have an advanced care plan in place.

Advanced care planning is a process of understanding, reflecting on and discussing future medical preferences in the event of a sudden illness or injury, or a chronic or life-limiting illness.

In case you missed both recent talks at the Mayo and the UF Health at Jacksonville support groups, there is a document that simplifies this activity called “Honoring Choices.” This document is intended to supersede the “Five Wishes.” Information can be found at www.honoringchoicesfl.com.

Inspiring Poetry

When poet Robin Morgan was diagnosed with PD five years ago, she turned to poetry to express her feelings. She has a body of work some of which can be experienced on Facebook: <https://www.facebook.com/parkinsonsdiseasefoundation/posts/10153580743894004>

New Doctor in Town

There is a new neuro-ophthalmologist located in Jacksonville. Dr. Hazem Samy’s private practice is Quality Eye Care, located at 13241 Bartram Park Blvd., telephone: 904-374-6890.

Dr. Samy is also the Director of the Neuro-Ophthalmology service at UF Gainesville. Referral is now available for patients with unexplained visual loss, optic neuropathy, double vision, and many other neurological diseases including Parkinson’s.

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. If you or someone you know has a story, please send it in for future issues of the First Coast PD Newsletter.

This issue highlights a remarkable woman, who celebrated her 75th birthday and her retirement at the August meeting of the UF Health Jacksonville Support Group. In spite of being diagnosed 11 years ago and a DBS, she is always cheerful and encouraging. She participates in activities and has a strong family bond (as evidenced in the photo below at last years 5-k run). Her name is Florence LaFur and this is her amazing story in her own words.



L-R: Grandson Noah, son Joel, Florence, friend Lisa and her son, daughter Anne with husband Patrick, grand-daughter Lynsey with Baby Judith-Grace, Joel's wife Teresa and baby's daddy, Shawn.

A long time ago In a country far far away....

A little girl was born and almost became a tiger's breakfast.

It happened in the jungle of South Vietnam, then known as Cochinchina. My father was serving in the french army; his job was to map some of the unexplored and remote regions of the province. As I understand it today, my mother would follow him on these trips and on that particular voyage, brought me, a three-month-old baby. The expedition traveled in wagons pulled by buffaloes (sounds like the Wild Wild West). One morning, a tiger jumped in the middle of the trail, the buffaloes panicked, the wagons turned over, it was a mess! No one could find me, the baby, not a sound or a cry would give a clue as to where I was. Everyone was afraid to think that the tiger might have gotten me! Trying to put everything back in order, they found me sound asleep under an overturned basket. It was my first escape from death.

What was I doing in Vietnam!? Let's get some family background:

My maternal grand-father, Andre JOURDAN, was French, from Tournon (Ardeche), on the Rhone river, where the Cote-du-Rhone wine is produced (yum, yum!). He was bitten by the traveler's bug and decided to go explore the planet. He went to Morocco but didn't like it. So he searched further away for a more exotic French colony. He fell in love with Cochinchina and the Mekong Delta, and established himself there as a rice farmer. His rice plantation was the second biggest in Indochina, now Vietnam. There he married a local girl. They stayed married through thick and thin, war and peace, through the continents, until death did them part. They had ten children. My mother, Josephine, was one of them; she was half French, half Vietnamese.

My father, Robert Louis LE FUR, was French from Brittany (Bretagne), but raised in Paris. He enlisted in the French Army where he was a civil engineer (a cartographer) and was stationed in Vietnam, where he met my mother. As a result, I am 3/4 French, 1/4 Vietnamese.

I was born in Saigon, Cochinchina, because that's where my mother was. I had no choice, ha-ha! The reason I write Cochinchina is because at the time it was a French department and therefore, part of France (like Hawaii is a part of the USA).

After the tiger incident, when my parents went on these expeditions, they would leave me behind. I would then spend a lot of time at the plantation, the “Riziere”. I played with my youngest uncle Michel who was six or seven years my senior. We rolled down mountains of paddy; it was scratchy but fun! There was a plant called sensitive, whole leaves curl up when you touch them, and a lot of Lantanas, whose flowers we pulled and sucked the nectar. Smells and taste good; I still do it when I find Lantanas! Other times I stayed with friends of my parents. I hated it. Some of them were not very nice.

One time, I stayed with people who had children, all older than me. I didn't fit in. At the first opportunity, I ran away. I can still see myself running on the road, by a peanut field. I know it was a peanut field because we had been there with my parents to pick peanuts. Of course I was caught very fast. I was three years old. Spunky little thing, wasn't I?

WW2.

Everything after that was confusing and the time line is not clear. I remember walking to school with other little kids. The nuns were very strict and would knock on our fingers with a wooden ruler if we didn't behave. We shared a house with several other families. Life seemed normal most of the time. When it was raining, we would get a good scrubbing with soap and be sent outside to rinse and play in the rain. For us kids, it was a lot of fun! But every once in a while we would hear the sirens and everybody had to go to the dugout that was hidden under a lean-to and stay until the sirens sounded again to let us know it was safe to get out. Sometimes it happened when dinner was ready and the women would bring the food and we would eat dinner in the dugout while the Japanese planes were flying over, bombing the city. It was exciting; there was a feeling of mystery and a certain tension in the air that made it somewhat thrilling. The grown-ups talked of war, the children played war, but nothing was explained very clearly. One of the men in our little community was taken prisoner. When he came back he was emaciated and we were told that all he had to eat was one bowl of rice a day.

Prisoners of the Japanese

At one point, all the French people were gathered together in one part of the city Tourane, now Da Nang, near the sea. It was like a ghetto. We didn't have many resources. I know for a fact that we had no fresh produce because my mother made

me eat bean sprouts every day so I wouldn't have scurvy. I hated them. Bean sprouts are easy to grow from dry beans, it takes only 3 days.

During our time in the ghetto, the Viet Minh (predecessors of the Viet Cong) decided to riot around our houses. I don't know how the grown-ups heard about it, but preparations were made. Everybody got on the roof, which was flat, and the men pulled furniture on top of the trap door. We, the children, were told to keep very quiet and lay down in our sleeping bags. There was some fear and excitement, but we had fun counting falling stars while the men were on the lookout. I must have fallen asleep because I don't remember getting off the roof.

Anyway, we children had fun playing on the beach across the street and running around, free as birds, or so we thought. The grown-ups certainly didn't feel that way. One of my mother's childhood friends has been abducted by the Japanese and tortured, and returned in small pieces, so I was told later. Can you imagine the fear and anxiety.....mostly when rumors started in the camp about the Japanese taking the men to Japan to work in their arm factories, and liquidating everyone else !!!!!

Fortunately for us, the Americans decided to drop the "bomb" on Hiroshima and Nagasaki, which ended the war. Every time a discussion about the morality of using the "bomb" would start, my mother would close it very fast by saying "I don't care, I wouldn't be here if it wasn't for it".

Why did I deserved to live while millions were lost, I don't know. British ship came ashore to take us to Saigon. One of them got beached and the sailors unloaded it to lighten it. They invited everyone in the ghetto to a huge party; we were given food that had been sorely lacking. One of my most vivid memories is having two apricot halves in a plate and thinking that they looked like eggs sunny side up, but they tasted SO DELICIOUS!!!!!! A long time after that, way in my adulthood, I kept buying canned apricots in syrup, but none of them ever tasted as good as those.

While we were waiting for transport, the British started bombing the part of the city still occupied by the Japanese. Over our heads, we watched from our roof, clapping and cheering, as if it was the most beautiful fireworks!

Back to France.

We stayed in Saigon, waiting to be sent home; back to France for my parents. For me, it was a New World. The carefree days of my childhood were over.

We were declared “victims of war”, having lost everything, and shipped on the MS Pasteur where the accommodations were less than luxurious. No private cabin, we slept in hammocks. The highlight of the trip was sailing the Red Sea, which I discovered is the bluest sea you’ll ever see! It is red only for a few days a year. Going through the Suez Canal was also amazing.

The New World was not to my liking. I discovered snow; I didn’t like it, it was too cold, gray skies, no sun, and heavy clothing. One of the worst winters since 1918, the end of the previous World War. Seems like Someone up in the Sky doesn’t like wars and sends us a reminder of who’s in charge.

The country was in sad shape: no housing, ration tickets, no coal for heating, scarcity of jobs. We had to live with my father’s aunt. I went to school and stayed with an old couple. The wife embroidered monograms for people’s hope chests and taught me how to cross stitch initials on kitchen cloth. She would threaten to lock me in the basement if I messed up. I cried every day that I had to go to her house; I was so scared. To this day I’ll do all kinds of needle work but no cross stitch.

A year or so later, my father got sick and hospitalized; my mother moved into a room under the roof of a building and placed me in an orphanage with the nuns, who accept children displaced by the war.

My father passed away when I was 8 and my mother struggled to raise me. Being poor was no fun. I had only hand me down clothes. I felt so humiliated and inadequate and depressed.

What a difference from the little girl who ran naked under the rain! I remember that period of my life as being all gray.

Vive l’Amerique

Let’s skip a few years: I married and had 2 children, that’s the good part. My husband hated his life and wanted to move, so we came to Jacksonville to visit his sister, who was married to a National Guard pilot. My husband was from Casablanca and I saw the similarities between the two cities and thought it would be perfect for him! But no, he continued searching for a better place and where ever he went, there he was, still unhappy. I decided to stay in Florida and let him find his own Nirvana

I remarried, and 3 months later had a car accident that left my husband a paraplegic. It was a very trying time, and I had to deal with rehabilitation, addiction to drugs, work, and supporting my children, my stepchildren, and my husband.

Thank you children

After the car accident that left their step dad paralyzed, my children, Anne and Joel (11 and 9 years old), were so helpful. I was so caught up in all the things that were going on that I don't think I ever thanked them; so this may be very late, but from the bottom of my heart:

Thank you! Merci de tout mon Coeur!

What I had to learn.

I was self-sufficient and took care of everything and everyone. It was quite overwhelming.

In order to survive, I had to learn a few things: ***It is said that what won't kill you will make you stronger.*** That is true, but you don't have to fight the battle alone. I needed to renew my faith in a Higher Power. I made friends and I need those friends. They showed me new ways of living and thinking. I learned a lot: ***I*** can choose to be happy, Happiness is an inside job, nobody can make you happy but yourself; I can change my life by changing my attitude, not the circumstances; happiness is the journey, not the destination; I don't have to like every situation, but it is imperative that I like myself in it.

When people ask me what I like best, France or USA, my answer is: some things I like better here, some things I like better there. There is good everywhere, I just have to look for it.

Life is terminal, but you don't have to be dead before you die.

Then my kids grew up and went to live their own lives, so I ended up living by myself.

In the fall of 2003 my daughter came for a visit and was shocked to see me shuffling and hunched over like an old lady. She promptly sent me to a doctor. The first GP I

saw did not pay much attention to my situation and, no doubt, thought I was just getting old.

Luckily for me, she went on maternity leave and her replacement saw right away that I might have Parkinson and sent me to a neurologist. After all the tests to eliminate other possibilities, he confirm the diagnostic: I had Parkinson disease. It was March 2004. He was quite surprised by my reaction, I was elated. I was so afraid that I might have ALS or MS or any of those capital letter illnesses! I started treatment and responded well.

My friends ordered all kind of books on PD and its treatments but they never coddled me. We always laugh about my mishaps, like when I kicked over a bucket full of recycling in my friend's kitchen, twice in a row. Laughter is the best medicine! Luckily for me, I was hooked up with a Neurologist who was interested in movement disorders and kept current with different treatments. When I started having severe dyskinesia as a side effect of the Parkinson's medicine, he sent me to a movement disorder specialist.

Luckily for me, Jacksonville has some very good neurology facilities. So here I went into a series of tests to see if I qualified for Deep Brain Stimulation (DBS) surgery, and I did! The surgery worked very well for me. The dyskinesia disappeared for about 5 years. It started again but has not gotten anywhere near what it was 6 years ago.

Luckily for me, Jacksonville has a follow up program and I don't have to go out of town for checkups every 3 to 4 months.

Thank God, I was prepared for March 2004.

In retrospect I can see how every aspect of my life brought me to a point where I would be able to accept my circumstances with serenity and a laughing heart. Because it never affected my hands, I was able to continue working as a hairdresser for 11 years. I was so fortunate because the people at work, co-workers and customers alike, were very supportive; they called me the Dancing hairdresser because of my dyskinesia. A good sense of humor is essential. Don't take yourself so seriously. My friends don't, and I love them for that.

All along, I was led toward the right doctor, who sent me to the right specialist, who sent me to the right surgeon, and brought me to a support team and a chance to meet a lot of my friendly co-patients, benefiting from the camaraderie and shared knowledge.

I talk to many people with PD who deprive themselves of a support group, or never go to a good specialist, and refuse to do anything about it. I suppose it is some form of denial: if I act like I'm not sick, I am not sick, like an ostrich burying its head in the sand.

For me it is better to face reality and accept the things I cannot change (not being as young as I used to be, not having as much stamina, being so slow) and concentrate on what I can still do. Learning to ask for help when I need it, be humble but don't feel humiliated, do what I am able to do even if it takes 5 times longer, be grateful for the support I get from my family, my friends, the medical staff, the community, for the weather, the sunshine, the warm rain....the list can go on and on....

I did organize a big trip to France a couple of years ago with my son, my daughter, their spouses, and my grand-children, to visit family. We are all now planning another family trip to Washington State to visit my step-son and his family.

There is so much that I can still do; I don't think I'll live long enough to do it all. There are a few hundred countries I have not visited yet, I'll have to come back for another tour.

The End and the Beginning by Florence LaFur

Bill Wilson

wjw1940@bellsouth.net