

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

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Issue 5

Fall/Winter 2013/2014

This 5th issue of ***The First Coast PD Newsletter*** brings it to the second 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 as we can. 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, local 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 email to Bill Wilson at [wjw1940@bellsouth.net](mailto: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 let us know.

It's time to take this newsletter to the next level. We need a governing board of some kind (editorial board?) to set policy and a management team who can do what the board decides. If you have any experience in doing either of the above and/or have an interest, send a short summary of your background and include the type of board you envision to the above email.

As always, if you do not want to receive the newsletter and related emails please send me an email and your name will be removed.

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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)

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 – 1:30p.m.

**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 p.m.

### **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**

Orange Park Support Group - Stan Harris and Alice Ho have initiated a monthly caregivers meeting the first Saturday of the month (see above for time and place).

#### Mayo Agenda:

- |            |   |
|------------|---|
| February 5 | Evaluate Residence, Dressing, Handle Cash<br>Angelica Gicalone, OTR/L<br>Registered Occupational Therapist          |
| March 5    | Medications and Tips on Managing PD Medications<br>Pharmacy Resident, Mayo School of Health Sciences                |
| April 2    | Reduced Volume and Pitch Range in Speech - “LOUD”<br>Therapy<br>Valerie Donalson, M.A., CCC-SLP, Speech Pathologist |
| May 7      | Disturbed Sleep Patterns<br>Dr. Siong-Chi Lin, Mayo Sleep Disorder Center   |

UF Health, Jacksonville Partial Agenda:

February 12 Michael J. Foxx Organization representative to talk about their research activities

March 12 Jennifer Barrow, Occupational Therapist, to discuss adaptive equipment for activities of daily living for PD

**January 25 - Davis Phinney Foundation's Victory Summit**

The **Davis Phinney Foundation's Victory Summit**<sup>®</sup> is coming to the University of North Florida's Herbert University Center Mark your calendars. **Please find registration flier attached.**

**January 26 - First Coast Parkinson's Run**

On Sunday, **January 26**, UF Health Jacksonville will sponsor a run/walk at Riverside Park for Parkinson's research. Let's all get out for this fun activity that will raise much needed funds for Parkinson's research. Visit the website [Firstcoastparkinsonsrun.com](http://Firstcoastparkinsonsrun.com) to register, or to sign-up for sponsorship, for a booth, or to volunteer your support. **A flier is attached.**

**April is Parkinson's Disease awareness month...** We should do something this year, recall we did the Conversation with Parkinson's Experts Round Table and the Parkinson's Awareness Fair last year. **Let us know if you have any ideas and/or would like to help with the activities.**

**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](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)

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**

For additional information, check the national organization’s web pages above. Much of the current research being done is listed on the web page of the National Institutes of Health. The National Institute of Neurological Disorders and Stroke (NINDS), part of the National Institutes of Health (NIH), is the leading U.S. funder of research on Parkinson’s disease (PD). The Institute conducts and supports three types of research: *basic*—scientific discoveries in the lab, *clinical*—developing and studying therapeutic approaches to Parkinson’s disease, and *translational*—focused on tools and resources that speed the development of therapeutics into practice. The goals of NINDS-supported research are to better understand and diagnose PD, develop new treatments, and ultimately, prevent PD. NINDS also supports training for the next generation of PD researchers and clinicians, and serves as an important source of information for people with PD and their families.

**The Parkinson’s Disease Biomarkers Programs (PDBP)**, a major NINDS initiative, is aimed at discovering ways to identify individuals at risk for developing PD and to track the progression of the disease. Identifying biomarkers (signs that may indicate risk of a disease and improve diagnosis) will speed the development of novel therapeutics for PD. Six projects are actively recruiting volunteers at sites across the U.S. The NINDS also collaborates with the Michael J. Fox Foundation for

Parkinson's Research (MJFF) on **BioFIND**, a project collecting biological samples and clinical data from healthy volunteers and those with PD. For more information about the PDPB and how you can get involved, please visit the PDBP website at <http://pdbp.ninds.nih.gov/>.

**The NINDS Morris K. Udall Centers of Excellence for Parkinson's Disease Research program**—a central component of NINDS PD research—was established in 1997 to find the fundamental causes of PD and better diagnose and treat people with PD. The NINDS currently funds 10 Udall Centers across the country, where researchers are examining PD disease mechanisms, the genetic contributions to PD, and potential therapeutic targets and treatment strategies. To learn more about the NINDS Udall Centers, see [www.ninds.nih.gov/research/parkinsonsweb/udall\\_centers/index.htm](http://www.ninds.nih.gov/research/parkinsonsweb/udall_centers/index.htm).

**Parkinson's Disease Clinical Studies** offer an opportunity to help researchers find better ways to safely detect, treat, or prevent PD and therefore hope for individuals now and in the future. NINDS conducts clinical studies on Parkinson's disease at the NIH research campus in Bethesda, Maryland, and supports PD studies at medical research centers throughout the United States. But studies can be completed only if people volunteer to participate. By participating in a clinical study, healthy individuals and people living with Parkinson's disease can greatly benefit the lives of those affected by this disorder. Talk with your doctor about clinical studies and help to make the difference in improving the quality of life for all people with Parkinson's disease. For more information about NINDS clinical trials on PD, see <http://clinicaltrials.gov/ct2/results?term=Parkinson%27s+disease+AND+NINDS>. Current studies include genetics and PD, search for PD biomarkers, experimental therapies and other treatment options, diagnostic imaging, brain control and movement disorders, DBS, and exercise and PD.

**Animal models:** These are invaluable tools for scientists studying disease mechanisms to develop new treatments for people with PD. For example, a recently completed study of the drug isradipine—which had been shown in animal models to

have a protective effect on dopaminergic neurons—found a similar neuroprotective effect in humans.

**Cognition and Dementia:** Mild cognitive impairment is common in PD, sometimes in its early stages, and some people develop dementia in the disease's later stages. The NINDS has funded research using neuroimaging to predict which individuals with PD might develop cognitive impairment.

**Deep Brain Stimulation (DBS):** NINDS has been a pioneer in the study and development of DBS, which is now considered a standard treatment option for some people living with PD whose symptoms no longer respond to PD medications. While NIH supported research on brain circuitry was critical to the development of DBS, NINDS research continues to fine-tune the optimal site within the brain to implant the DBS electrode to help even more people with PD regain function.

**Dyskinesia:** Involuntary movement, tremor, and motor response complications become evident as PD progresses. NINDS scientists have studied the safety and effectiveness of drugs in alleviating movement disorders in persons with PD. A current clinical study is evaluating the effectiveness of botulinum toxin in treating a variety of movement disorders, including PD. For more information, see <http://clinicaltrials.gov/ct2/show/NCT00001208?term=dyskinesias&rank=109>.

**Environmental studies:** Risk factors such as repeated occupational exposure to certain pesticides and chemical solvents may influence who develops PD. A NINDS-funded research consortium is hunting for environmental risk factors that increase susceptibility to developing PD before age 50. For example, NINDS-funded researchers analyzed the occupational histories of twins in which one of the pair developed PD. Based on estimates of exposure to six chemicals previously linked to PD, the researchers concluded that two of the common solvents were significantly linked to development of PD. (See [www.ninds.nih.gov/news\\_and\\_events/news\\_articles/solvents\\_PD\\_twins.htm](http://www.ninds.nih.gov/news_and_events/news_articles/solvents_PD_twins.htm))

**Exercise:** Exercise routines are often recommended to help individuals with PD maintain movement and balance necessary for everyday living. A recent NINDS-



funded study evaluated three different forms of exercise—resistance training, stretching, and tai chi—and found that tai chi led to the greatest overall improvements in balance and stability for people with mild to moderate PD. A current trial is studying the effects of two levels of exercise in people who have been recently diagnosed with PD. For more information, see [www.ninds.nih.gov/disorders/clinical\\_trials/NCT01506479.htm](http://www.ninds.nih.gov/disorders/clinical_trials/NCT01506479.htm).

**Genetic studies:** A better understanding of genetic risk factors is playing a critical role in elucidating PD disease mechanisms. A 2011 NINDS workshop led to an analysis of data from PD genome-wide studies around the world, to correlate genetic variants and common traits among people with PD. The workshop contributed to the development of NeuroX, the first DNA chip that can identify genetic changes in persons at risk for a number of late-onset neurodegenerative diseases, including PD. Another NINDS collaborative, the Consortium On Risk for Early-onset Parkinson's Disease (CORE PD), hopes to identify the genetic factors that contribute to the development of early-onset PD. Current clinical studies include: the genetic connection to memory and motor behavior; the search for genes that may increase the risk of PD and related neurodegenerative disorders; and identifying biomarkers for PD. For more information on these studies, see <http://clinicaltrials.gov/ct2/results?term=genetics+AND+Parkinson%27s+disease>.

**Mitochondria:** These cellular energy factories may play a central role in PD. NINDS-funded scientists have found that hundreds of genes involved in mitochondrial function are less active in people with PD. Drugs that target genes involved in mitochondrial function could perhaps slow progression of the disease. Scientists funded by the NINDS and the Michael J. Fox Foundation are measuring the safety and effectiveness of oral doses of the drug pioglitazone on disease progression in individuals with PD. For more information and to participate in the trial, see [www.parkinsontrial.ninds.nih.gov/netpd-fs-zone.htm](http://www.parkinsontrial.ninds.nih.gov/netpd-fs-zone.htm)

**Nerve growth factors:** Growth factors are proteins involved in nervous system formation and are of interest to researchers studying neurodegenerative diseases. One small clinical trial will assess the safety, tolerability, and potential clinical effects of

gene therapy with Glial Derived Neurotrophic Factor (GDNF)—a protein that may help protect dopamine-producing nerve cells. This trial for individuals with advanced PD is based on NINDS-sponsored research showing that an advanced technique for delivery of the GDNF gene into the brain improves the health and function of the dopamine neurons in animal models of PD. For more information, see [www.clinicaltrials.gov/ct2/show/NCT01621581](http://www.clinicaltrials.gov/ct2/show/NCT01621581).

**Stem cells:** Scientists are exploring various types of cells, including stem cells, as opportunities for PD drug discovery. Stem cell technology could be used to define disease mechanisms and the most promising treatments for sporadic PD. To pursue this area of research, NINDS established a PD cell research consortium in 2009 in collaboration with the Michael J. Fox Foundation and the Parkinson's Disease Foundation. For more information, see [www.ninds.nih.gov/news\\_and\\_events/news\\_articles/pressrelease\\_nih\\_stem\\_cells.htm](http://www.ninds.nih.gov/news_and_events/news_articles/pressrelease_nih_stem_cells.htm) or <http://stemcells.nih.gov/>

### **Where can I get more information?**

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

BRAIN

P.O. Box 5801

Bethesda, MD 20824

(800) 352-9424

<http://www.ninds.nih.gov>

**\*\*Please note a local research study opportunity: Volunteers needed** for an NIH sponsored study (7R33DC011131-04) of **swallowing and coughing function** in persons with Parkinson's Disease. Participants will be reimbursed \$50 for a one-time visit. For more information, please contact Flo Singletary, Brooks Clinical Research Center, (904) 345-8973 or [Flo.Singletary@brooksrehab.org](mailto:Flo.Singletary@brooksrehab.org). The study will take place at Brooks Center at 3901 University Boulevard South, Suite 101, Jacksonville, FL 32216.

## **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, alughter is the best medicine (maybe even better than Sinemet).

Submitted by Marijane and Vincent Sipple:

Two elderly ladies were talking: “At our age, I don’t know what would be worse; Parkinson’s or Alzheimer’s” one said. Her wise friend ansered, “Oh, I’d rather have Parkinson’s, definitely Parkinson’s. Better to spill half my wine than to forget where I keep the bottle.

### **Special Topics**

This section is dedicated to material submitted by readers and may consist of just about any topic and in any form.

This issue’s special topic is a history of Parkinson’s Disease put together by Dr. Owen Ross, a professor at the Mayo Clinic Jacksonville:

The clinical syndrome we refer to as Parkinson’s disease (PD) was first described in 1817 by James Parkinson (1755-1824) in his classical publication “An essay on the shaking palsy” (Paralysis Agitans). In his work, Parkinson described the motor signs that define this disorder:

Shaking Palsy (Paralysis Agitans): Involuntary tremulous motion, with lessened muscular power, in parts not in action and even when supported; with a propensity to bend the trunk forwards, and to pass from a walking to a running pace: the senses and intellects being uninjured.”

Interestingly, Parkinson also described nonmotor features of this disorder, e.g. his mentioning of symptoms that would now be attributed to REM sleep behavior disorder (RBD); “*the sleep becomes much disturbed. The tremulous motion of the limbs occurs during sleep, and augment until they awaken the patient, and frequently with much agitation and alarm.*” Finally, in the end stage of the disease Parkinson’s

*description includes fatigue and hallucinations: “..at the last, constant sleepiness, with slight delirium, and other marks of extreme exhaustion, announce the wished-for release.”*

It was the work of the great Martin Charcot (1825 – 1893) to Parkinson’s description. syndrome by adding rigidity coined the term *maladie de*



French neurologist Jean-who brought general attention Charcot further defined the to the motor signs, and he *Parkinson.*

For a long time PD remained effective treatment. In their al. first demonstrated that precursor that crosses the reserpine-induced

a devastating disorder with no 1957 publication, Carlsson et levodopa, a dopamine blood-brain barrier, reverses Parkinsonism in mice and

rabbits and later that dopamine is a neurotransmitter present in the brain. This was followed by the work of Ehringer and Hornykiewicz demonstrating striatal dopamine deficiency in brains of PD patients. Birkmayer and Hornykiewicz built on this work by demonstrating for the first time that levodopa improves Parkinsonism in humans. After some initial controversy, Cotzias and colleagues established the efficacy of dopamine replacement therapy in PD when they reported dramatic improvement in PD patients with oral administration of levodopa in increasing amounts over long periods.

The levodopa revolution is to date the basis of motor symptom treatment in PD. Although a wide range of compounds have been developed since 1960, levodopa remains the single most effective symptomatic treatment for PD. Surgical treatment for PD has been available for decades, but played a minor role until continuous deep brain stimulation (DBS) was introduced in the 1990’s. DBS of the subthalamic nucleus (STN) is now established as a well-documented treatment for carefully selected, particularly young patients, with fluctuating motor symptoms and dyskinesias.

Over the last decades it has become increasingly clear, however, that PD patients suffer from symptoms that go beyond the classical motor features that define the disease. These nonmotor symptoms result in disability, diminish quality of life for patients and contribute substantially to caregiver burden. Most nonmotor symptoms do not respond to levodopa treatment. This insight has increasingly highlighted PD as a multisystem brain disorder and that novel treatment that reaches beyond the nigrostriatal system is needed.

### **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 Andy Ward King, a member of the UF Health Jacksonville support group, and a well known musician and song writer. As a recent newspaper article described him “He’s a musician, and a thinker too, something of a philosopher, and lately he finds that deep insights and simple truths come to him more easily, more intensely. It comes from living with Parkinson’s disease, he figures.”

#### **My Story**

Hello Everybody,

When asked by Bill Wilson to write up my story, I kept coming back to the same thought...my story is pretty much the same as all of our stories. All of us who have PD, all of us who are beautifully sad.

I signed up for the three hour tour, but instead my little boat hit a storm and ran aground on a small desert island, an island from which I can’t leave. I still have three

choices however. Number one - give up and die from exposure and starvation - NOT an option. Number two - moan, groan and complain, making everyone around me, including myself, miserable - also not a pleasant prospect. Number three - make the best of a bad situation and learn how to make lemonade out of the silver-lined clouds God has given me. I have chosen door number three. I can safely say that none of us chose to have PD, but we all have a choice as to how we are going to react to this unforeseen circumstance. This is were the tough get going. Having PD is not for the weak or faint of heart, you either buck up - tough up, or check out, the ultimate final exam.

This disease treats everyone differently. It even plays favorites and who those favorites are can change at any time. So, we must all treat how we deal with it in our own way. **PD cannot define us, we must define it.** In my daily blog "Letters From GroovyLand - My life with Parkinson's the best life I've ever had." I admit my technique for living a full and productive life. It all boils down to this... I must have a reason to get up in the morning - something to look forward to each day. I have found my reason, for me it was simple - I create things, I make something out of nothing. Be it writing a song and recording that song, or writing in my private journal or in my blog which I call "My Public Diary," or taking photographs and messing around with video and putting it all up on YouTube. Knowing that I have something that I need to create keeps me getting out of bed each and every day. It keeps me from option number one. Making something out of nothing, artistic creation is not the only category of activity that can give you purpose, give you a reason. A satisfying job, working with the elderly and infirm, working with children, or any volunteer work can give you purpose. I've found my reason and so can you. I might look sad on the outside but inside I'm beautiful. I'm beautifully sad.

A year ago, I would have laughed in your face if you had told me that. It was sad, and far from beautiful. I couldn't even get out of bed without help, I couldn't even sit in a chair or sit on the floor without a production crew - work with the elderly - heck, I WAS the elderly and infirm. To make an incredibly long story short - I found a good neurologist (not that I didn't have good ones before, they were playing the game well,

just not scoring any points) he changed the paradigm, said that we weren't leaving until we figured it out, and four hours later we had. Within a month, I was doing every thing on my own, including push-ups, tai chi and walking for an hour each day. I'm on the basic Sinemet and Neupro patch treatment, as thousands of others are, it might have seemed like another day at the factory for some. But, to me, I had gotten my life back. It is a year later now and although I am experiencing some side effects and diminished "on" time, it's still been like a miracle.

Except for 3 years in the US Army I've made a living as a musician playing electric and upright bass. It's nice work if you can get it, and even though the industry as a whole doesn't, you can make an honest living at it. I've played everywhere and anywhere from the Grand Ole Opry to Manhattan Jazz clubs - Disney to South Georgia Moose Lodges, Paris to Nashville to LA to NYC back to Jacksonville. That's all behind me, I'm retired. There is no way, even with the Sinemet, I could keep up with a bands traveling schedule. Even a local gig, I'm still a little (pardon) shaky about driving alone after dark, would be very problematic. But I still make music, even more now because I'm not using all my juices making someone else sound good - a bass players job. I've written, produced and played most of the instruments on two CD's, the second will be released in the spring. Maintained a daily blog, which I am turning into a book. Created a web world called GroovyLand. And, as of yesterday, started a improv comedy Theatre and Radio troupe which I co-write, produce and direct. I stay busy.

For me, treatment for the relief from the physical symptoms, i.e. better living through chemistry, plenty of fresh air sunshine and exercise, activities such as dancing, Tai Chi and Yoga, are very important. Also a healthy, nutritious, diet is crucial. However, treatment of the mental aspects also have necessarily become a part of my lifestyle. I try to socialize when I can, even though sometimes I would rather not, an extra bonus for me there is that my wife loves it when we go places together. And when she's happy... I do what ever I can to stave off any mental decline. I read, I try to exercise and challenge my mind, I create. I make things out of nothing. I stay busy. Busy because I've found a reason, a reason to get up in the morning. Thank you for your

time. Remember, there are around 4000 people with PD in the First Coast Area, if we could all get together we could have one heck of a party. I'll even provide the dance music.

I want to thank Bill and Marilyn Wilson for putting together this much needed publication, and you for your support.

I am going to leave you with excerpts from an article they did about me in the Florida Times Union, September 13, 2013, written by Matt Soergels.

Andy Ward King can't sleep much past 3 a.m. these days, so when he awakens he gets up and climbs narrow, winding stairs to the third floor of his 102-year-old house on a quiet street in Riverside. Up there is what his wife Kathleen calls "the pointy room," for its steeply sloped attic walls. He, though, prefers to call it "the tower." For up there he is surrounded by his big stand-up bass and his recording equipment and his assorted musical instruments — guitars, harmonicas, banjos, keyboards, drum kit and more. They have defined his life, given it purpose and joy and even some money to live on. He's a musician, and a thinker too, something of a philosopher, and lately he finds that deep insights and simple truths come to him more easily, more intensely. It comes from living with Parkinson's disease, he figures. That's why, when he gets up in the morning, he heads to the computer keyboard on his father's old desk in the Tower. He goes there to write his blog ([andywardking.wordpress.com](http://andywardking.wordpress.com)), which thoroughly explores GroovyLand. GroovyLand is Andy Ward King's world these days, one of nostalgic recollections, whimsical observations, musical musings and serious statements, delivered lightheartedly, about the meaning of his life. Oh, and there's some stuff about the Parkinson's mixed in there too.

■■■

The tremor in King's hand was there for a while before he got the official diagnosis at age 50. It got really bad a few years ago. He couldn't get anywhere without Kathleen's help; here he was, a stand-up bass player who couldn't stand up. But he's found a happy combination of medication, physical therapy and diet that can stave off



the worst of his Parkinson's. Exercise helps too: He walks around Riverside, lifts light weights and can now do 100 pushups a day, five at a time. When it comes to feeling good, though, all that's nothing compared to having a reason to wake up in the morning. That's what makes life worth living.

King's grandfather, Sidney King, was a Baptist preacher, and while the grandson, now 55, has a rather more flexible kind of faith, he has more than a little of the preacher in him too. He'll tell anyone the word: We all need a reason to wake up in the morning. "If you have a reason to get up, you're golden," he says. For him that reason is



something...

### **Required Reading**

In this issue we look at a book entitled: *A Soft Voice in a Noisy World* by Karl Robb, Published in November 2012. Review by Bob Bohle

It's no fun Parkinson's Disease. One of the hardest aspects of being a "Parkie" is keeping a positive attitude. That's one of the attributes of Karl Robb I appreciated in his book about living with Parkinson's: *A Soft Voice in a Noisy World*. He didn't simply accept the disease, he tried to find the best ways to live with it.

The book is subtitled, 'A Guide to Dealing and Healing with Parkinson's Disease' and it is a good guidebook indeed. His attitude is quite positive, which is even more impressive when you learn that Robb was diagnosed with PD at 23 and that he was aware of his own symptoms six years prior to that. That's awfully young to face having Parkinson's Disease as your constant life companion.

The book is filled with short chapters and divided into five sections: "If doctors had all the answers, medicine wouldn't be called a practice"; "Living with Parkinson's Disease"; "Support groups and relationships"; "Reiki, meditation and other complementary therapies"; and "Raising awareness and effecting change."

The second section includes all sorts of helpful chapters, including one of my favorites, "Ten tips for dealing with Parkinson's Disease." The list is more about your personal approach to life than it is about what shoes to buy or other specific ations. One tip is "Seek inspiration around you. There is courage, strength and beauty all around us..." Another really hit home with me: "Take charge of your life and body. Exercise as best you can." That's always been my personal advice to my fellow PD travelers: get as much exercise as you can.

The Reiki section might strike some people as a little odd, but I thought the author shared some valuable insights by bringing up reiki – a Japanese technique for stress reduction and relaxation that promotes healing – yoga, meditation and other palliative activities. Using his own experience, he explains how he at first relied exclusively on western medications to ease symptoms. But as he opened up to some of the eastern

modalities, he found that they helped him greatly: “I attribute the delay of progression of my PD symptoms to many of these beneficial tools and techniques.” I have found that my own symptoms are significantly worse when I am nervous or anxious, and I have found meditation helpful – and without side effects!

Robb says in chapter 50 (don’t panic – some of the chapters are only a few pages) that he is convinced – as am I – that there are emotional, energetic and psychological components to PD. He says that by altering his thought processes, reducing stress and changing his behavior, he has noticed himself improving over the past few years. And this is without medication changes.

Robb ends the book with a valuable list of helpful web sites, books and organizations. The book is chock full of helpful and realistic tips for living with Parkinson’s. In fact the book ends with a list of insights that Robb has gathered during his experience with PD. Well worth a look. I got it from Amazon.

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If you are interested in getting 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)



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**VICTORY**  
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A Davis Phinney Foundation Event  
for People Living with Parkinson's Disease

**Register**

**Now!**

**Saturday, January**  
**25, 2014**

**Adam W. Herbert University Center at**  
**University of North Florida**

**12000 Alumni Drive,**  
**Jacksonville, FL 32224**

More than 10,000 people around the country living with Parkinson's have been inspired and challenged at The Victory Summit®. Now it's your turn!

Join the Davis Phinney Foundation and our partners the [UF Health Neuroscience Institute – Jacksonville](#), [Mayo Clinic in Florida](#), [Brooks Rehabilitation](#), [Lyerly Baptist](#) and [Baptist Neurology](#) for a moving day of information and inspiration. This one-day event will feature presentations by nationally recognized researchers, clinicians, and physical therapists, providing the latest information and practical tools that people with Parkinson's can use to **live well today**.

Topics will include:

- Parkinson's Research Update: Telemedicine
- The PD You Don't See: Cognitive and Non-Motor Symptoms
- Living Well Today with Parkinson's
- Interactive Exercise Sessions
- Care for the Care Partner
- Fall Prevention
- Is Deep Brain Stimulation (DBS) for Me?

The event is **free of charge** and includes lunch. Learn more about The Victory Summit at [the Davis Phinney Foundation's website](#). Bring your care partner, family and friends. This is day not to be missed!

To register, please call (888) 364-6415 or register online at <http://VictorySummit.kintera.org/Jacksonville>.

***Registration is required. We look forward to seeing you there!***





Presented by:



UF Health Neuroscience Institute – Jacksonville

**Sunday, Jan. 26, 2014**

RIVERSIDE PARK

753 Park Street, Jacksonville, FL 32204

5K RUN/WALK – 9 A.M.

1-MILE FUN RUN – 10 A.M.

POST-RACE CELEBRATION INCLUDES: MOVEMENT TENT,  
HEALTH FAIR, LIVE ENTERTAINMENT AND MORE

[www.FirstCoastParkinsonsRun.com](http://www.FirstCoastParkinsonsRun.com)

**Run to Raise Awareness. Fight the Progression. Cure the Disease.**