



# The PADRECC Post

Department of Veterans Affairs  
2014

THE PHILADELPHIA VA PARKINSON'S DISEASE RESEARCH, EDUCATION & CLINICAL CENTER

## Alternative Therapies for Parkinson's Disease

By: Dr. Alexander Pantelyat, PADRECC Fellow



A number of alternative therapies for Parkinson's disease (PD) have emerged in recent years. They have been reported to benefit a number of PD symptoms and possibly improve patients' quality of life. However, unlike well-known treatments for PD (including medications, deep brain stimulation surgery, physical therapy, and the

Lee Silverman Voice Treatment (LSVT®) program), these have mostly been studied in small groups of patients. Therefore, more studies are needed to clearly show the scope of their benefit. However, several of the selected therapies I describe here hold promise as added and hopefully enjoyable ways of improving your daily functioning and quality of life. **Because all of these treatments need to be done on a regular basis in order for them to keep working, you will be much more likely to benefit from them if you find them fun.** So please read on, pick the type(s) of therapy that sound most fun to you, and get started! Your PADRECC doctor, nurse or social worker can help refer you to local programs.

### Tai Chi

Tai Chi is an ancient Chinese martial art that typically involves the practice of slow, controlled, coordinated upper and lower body movements. A well-designed study published in 2012 showed that 6 months of twice-a-week 1-hour Tai Chi sessions reduced balance problems in patients with mild to moderate PD, with added benefits of improved functional capacity and reduced falls. These benefits were maintained for 3 months after the classes ended, and no serious side effects were observed. A number of Tai Chi classes are taught throughout the Philadelphia area.

### Dance and Music

Music-based movement therapies involve the use of rhythm, music and/or dance for either individual or group treatment. Several studies have shown that these therapies can improve gait speed, stride length, and balance in patients with PD. Several types of partnered dance, Argentine Tango in particular, have been shown to improve balance and walking speed, but not freezing. Dance for PD® ([www.danceforparkinsons.org](http://www.danceforparkinsons.org)) is an international program for patients that began in Brooklyn in 2001, and involves dance movements drawn from tap, ballet, jazz, modern dance and improvisation. The movements can be done seated or standing, and there is a DVD available for home use. There are a number of Dance for PD® groups in the Philadelphia area.

### Yoga

Yoga refers to several types of ancient Indian practices that involve meditation and physical exercises; it has become a popular form of exercise in the general population. Yoga has been thought to improve strength and balance in a few PD patients, but another recent report did not support this claim. Formal clinical trials of yoga in PD are needed to determine the scope of its benefit. Yoga can be an intensive form of exercise, and is not for everyone. Please speak with your PADRECC doctor or nurse before trying it!

### Other Complementary/Alternative Therapies

Recently published studies have found that 26-76% of PD patients use at least one form of complementary/alternative therapy (40% in the United States, 61-76% in Asia), compared to 20 (United Kingdom) -42% (United States) of the general population. In the United States, the most common therapies used are vitamins/herbal supplements, massage therapy, acupuncture, and

relaxation techniques. None of these treatments have been shown to slow down the progression of PD or improve symptoms of PD in clinical trials; they are not recognized by the American Academy of Neurology or the International Movement Disorder Society as proven therapies.

The Alexander technique is a method that teaches people how to stop using high levels of muscular and mental tension during their everyday activities. Twenty four weekly lessons in Alexander technique were shown to improve PD patients' own assessment of their disability at the end of lessons, and when reassessed 6 months later. Compared with PD patients who received no treatment, those receiving Alexander technique lessons were less depressed by the end of the lessons. Alexander technique is currently recommended for PD patients by the National Institute for Health and Clinical Evidence (United Kingdom). Please speak with your PADRECC doctor or nurse before trying any of these therapies!

In sum, these alternative therapies hold promise for patients with PD. They may improve symptoms and quality of life, but not all of them are right for everyone. Please be sure to discuss whether these treatments are right for you with your PADRECC doctor or nurse.

## Local PD Exercise

### Dance For PD Programs

#### Abington YMCA

1073 Old York Rd, Abington, PA

Contact: Wendy Lewis

wlewis@theparkinsoncouncil.org

#### The 954 Dance Movement Collective

954 9th St., Phila, PA

Contact: Keila Cordova 215-627-1157

#### The Rock School West

1510 Paoli Pike, West Chester, PA

Contact: Karen Lynch 610-524-1566

### Yoga Programs

#### Yoga Evolution

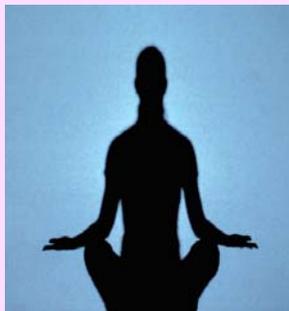
261 Old York Rd, Jenkintown, PA

Contact: Julie Coopersmith 215-885-1800

#### Yoga on the Ridge

493 Domino Lane, Phila, PA

Contact: Theresa Conroy 215-792-6400



### Pilates for Movement

2402 Hirst Terrace, Havertown, PA

Contact: Sheila Hatzell 610-853-1979

### General Exercise Programs

#### Dan Aaron Stay Fit at Arcadia University

450 S. Easton Rd, Glenside, PA

Contact: Janet Readinger 215-572-2144

#### Center City Exercise Group

330 South 9th Street, Phila, PA

Contact: Heather Cianci 215-829-7275

#### Body in Balance

Linwood, NJ

Contact: Ellie Hagan 609-365-8499

### Moss Rehab Maintenance Programs for PD

#### *Moss Rehab Center One*

9880 Bustleton Ave Suite 328, Phila, PA

#### *Moss Rehab at Tabor Road*

1200 W Tabor Rd, Phila, PA

Contact for both locations: 215-827-1650

**Above classes may require a fee, please contact the program of interest to inquire further. Dates and times may change without notice.**

## Research Happenings at PVAMC PADRECC

### Traumatic Brain Injury

Dr. John Duda, PADRECC Director, and his colleagues, Drs. Kacy Cullen and John Wolf, from the Department of Neurosurgery at the University of Pennsylvania, began studies funded by the Rehabilitation Research and Development Service of the Department of Veterans Affairs to develop animal models of Chronic Traumatic Encephalopathy (CTE) that sometimes develops years later in people such as football players and war fighters who have had traumatic brain injuries (TBI). The goal of these studies is to develop models of these changes in the brains of animals so that new treatments and preventive strategies can be tested. It is hoped that these studies will lead to treatments to prevent the development of these neurodegenerative diseases in Veterans and others with TBI.

### Caregivers & Parkinson's Disease

Dr. Jayne Wilkinson, Gretchen Glenn, LCSW, and Eileen Hummel, RN, BSN conducted a study to examine a telephone support group that aims to help empower family caregivers to maintain their health, well-being and capacity to care. The telephone support group consisted of 8 weekly, 90 minute telephone conversations of spouse caregivers of patients with Parkinson's disease. The support group phone calls were facilitated by a masters prepared nurse, a registered nurse and a social worker. It is hoped that this telephone support group will help to develop skills for better coping and handling of caregiving issues, as well as provide inspiration and support to caregivers.

### Telehealth

Dr. Jayne Wilkinson, is conducting a study to evaluate the use of telehealth technology. Telehealth allows a patient to see a clinician by a video connection and the use of telehealth is thought to increase access to healthcare as well as reduce patient travel expenses. Recruitment for the study began in June 2011 and ended in February 2013. Dr. Wilkinson is beginning to analyze the study data and hopes to examine whether the use of telehealth improves accessibility to care offered by PADRECC clinicians and reduces cost and travel difficulties for Parkinson's patients, as well as maintaining customer satisfaction. An abstract was presented at the annual American Academy of Neurology Meeting in April 2014.

### Parkinson's Disease & Blood Pressure Medication

Dr. Shital Shah, PADRECC Movement Disorders Fellow, will be conducting a study to show the effects of a medication that increases blood pressure on symptoms of dizziness in patients with Parkinson's Disease. This study is based on a prior study conducted at the PADRECC by Dr. Amy Hellman who looked

at abnormal control of blood pressure changes in some PD patients. It is hoped that the results of this study will be able to provide additional options for the treatment of disabling dizziness to patients with Parkinson's Disease.

### Parkinson's Disease & Motor Symptoms

Dr. James Morley, Associate Research Director of the PADRECC, continues to study whether movement tests can help identify early signs of PD and make the diagnosis of movement disorders more accurate. Data is being analyzed from patients who performed several movement tests using electronic monitoring devices. This included walking on a mat with sensors and moving their fingers and feet while wearing movement monitors. Through the use of computers and other devices, Dr. Morley and his research team recorded the results of these tests. Updated findings were presented at the annual American Academy of Neurology Meeting in April 2014.

### Medication-Induced Parkinsonism

Drs. James Morley and Alex Pantelyat are conducting a study to understand how Parkinson's-like symptoms caused by medications are related to PD. Symptoms of PD can be mimicked by certain medicines (usually used for schizophrenia and some other psychiatric conditions) that block dopamine—the major brain chemical missing in PD. Not everyone's symptoms improve after the medicines are changed or stopped, so it is possible that the medicines uncover very early PD in some cases. Dr. Morley's team is comparing medication-exposed patients with and without Parkinson's symptoms and following patients with symptoms after the medication is changed or stopped. Their goal is to determine whether clinical features, simple tests (including smell testing) and brain scans looking at dopamine-containing areas can predict which patients are at higher risk of developing PD. The results of this study will also be used to help design future studies.

### NATIONAL RESEARCH LINKS

#### Fox Trial Finder (FTF)

<https://foxtrialfinder.michaeljfox.org/>

#### NIH Clinical Research Trials and You

[www.nih.gov/health/clinicaltrials](http://www.nih.gov/health/clinicaltrials)

#### ClinicalTrials.gov

[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

## Living with PD - Things I've Learned Along the way

By: John P. Creveling



Five years ago when I learned I had Parkinson's disease I recall thinking, "This most definitely is going to have an impact on riding my motorcycle into old age." Three years later without hesitation or second guessing, I sold my motorcycle after having ridden it several thousand miles beyond my previous 75,000 miles I had driven during 25 years of safe riding. Trust me when I say that I had experienced my fair share of dreadful storms, floods, hailstones, bitter cold weather, and even Hurricane Floyd (another story for another time)!

Although I will not be riding my motorcycle into my retirement years, I'm okay with that because I know the decision was the right one for me. Even now as I reflect about those 25 years, a huge smile comes across my face as I recognize how fortunate I have been to have had the chance to engage in an activity that gave me great joy, wonderful experiences, fond memories, and fulfilled some personal dreams. I learned that while there may be activities I may have to "give up" because of PD, I can savor the memories. Inevitably, the time I gain allows me to start new activities that provide joy and meaning.

Several years ago my wife, Christina, gave me a birthday card with this saying on the front: "Dance like no one is watching, love like you've never been hurt, sing like no one is listening, and live like it's heaven on earth." I think that summarizes the spirit of how I approach living with PD and life in general.

If you have PD, or know of someone that does, perhaps we need to be reminded that Parkinson's disease does not define the person. *The dis – ease is not who we are.* We are more than any disease. By recognizing this we empower ourselves to decide how we will respond to the challenges of PD, as well as ways we can manage other more "natural" and predictable changes such as getting older. Like snowflakes, we each respond differently to having PD and the challenges that will occur. But, *how* we respond, may make all the difference in the quality of our lives.

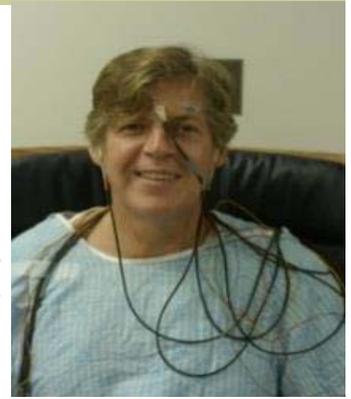
I've learned during these past five years that having PD does not mean we must give our power, who we are, and our very essence away. *We are responsible* for living our best life while we can. For more than 30 years I've embraced the philosophy of *Carpe Diem*, which literally means "seize the day," or being present every day and the choices offered to us. For me, *Carpe Diem* means celebrating life every day.

I believe having PD has had the unexpected benefit of making me a better person. I am more patient with myself and others around me. Because my time is precious, I do not waste it obsessing about things I can't control. I don't spend a whole lot of time looking back, over my shoulder, on the "shoulda, coulda, and wouldas." I'm looking forward – focusing on now. We can't change what has already occurred. But, we *can* actively engage in now, today, and the future.

I, and I am sure you do, too, hope for **a cure for Parkinson's disease**. I truly believe that a cure is possible. I have learned that to be most effective, hope must be combined with action. A cure will not be possible unless increasingly more people in larger numbers get involved. There are many ways people can contribute to research efforts. For example, they can advocate for research, become involved in studies, and present the "human face" of PD. They can encourage friends and family members who do not have PD to participate in research as "controls." Waiting for a cure is not an option. Without the required number of participants studies

require, more than 80% of PD research studies are delayed a month or more. Time is of the essence! The more people that **get involved in research now**, the faster we can begin to finding more effective medicines, treatments, and ultimately a cure.

To summarize what I have learned from PD - **LIVE, LIVE, LIVE!** There will be ups and there will be downs. There will be challenges in our lives at some point for every single one of us – we can be sure of that. However, how we choose to respond, is in our hands. My advice? Live your life every day as best as you can – but become *involved* in living. If you need to make changes, make them and move on. Find ways to rediscover that which gives you joy, love, and laughter.



*“Wired” for Research*



Having PD has reminded me of the gift of today. Carpe Diem!

John Creveling is a photographer, artist, budding poet, and has started to learn to play the guitar so he can sing a love song to his wife.

*“Working on a new Creative Space in our home for Chris and me.”*

## THE COUNSELING SERVICE

at the Pennsylvania Hospital Parkinson’s Disease & Movement Disorder Center

By: Dolly Johnson, LCSW

As we journey through the experience of PD and its varied effects, many physical and mental challenges can cross our path. At the beginning of the journey, there can be a range of feelings, including a sense of betrayal by our body, fears of the future, and even a view of “this can’t be happening to me.” All of these emotions are a natural part of the PD experience. The opportunity to share these feelings can occur with loved ones and friends as well as a trained counselor. The process of discussing symptoms, changes, and fears in a one to one setting with a trained counselor can enable the individual and family to be supported and affirmed along the way.

The Counseling Service at Pennsylvania Hospital’s PD and Movement Disorders Center provides a safe and confidential environment with experienced staff who will listen and care about your specific journey. The service offers ways to help an individual cope with the full range of feelings and concerns. The program offers individual and couple, or care partner, counseling as well as support groups. Learning about emotions and responses through the counseling process can result in becoming “pro-active” rather than “reactive” to the common frustrations of PD. Taking charge of your own journey through the use of available and specialized resources can earn many benefits, most importantly greater awareness and better coping skills. For more information on The Counseling Service at Pennsylvania Hospital’s PD and Movement Disorders Center, please call **215-829-6688**.



**Dr. John Duda**  
**Director**



**Dr. Jayne Wilkinson**  
**Associate Clinical Director**



**Dr. James Morley**  
**Associate Director of Research**

## **The Philadelphia PADRECC Team**

Dr. John Duda, Director

Dr. Jayne Wilkinson, Associate Clinical Director

Dr. James Morley, Associate Director of Research

Dr. Pratap Yagnik, Chief, Neurology Service

Dr. Alexander Pantelyat, 2nd year Fellow

Dr. Shital Shah, 1st year Fellow

Dr. Daniel Weintraub, Geriatric Psychiatrist

Dr. Paul Moberg, Neuropsychologist

Rebecca Martine, MSN, RN, PMHCNS, Nurse  
Coordinator

Heidi Watson, BSN, RN Nurse Coordinator

Eileen Hummel, BSN, RN Nurse Coordinator

Gretchen Glenn, LCSW Social Worker

Stephanie Pawlowski, Research Coordinator

Dawn McHale, Program Specialist

Tonya Belton, Program Support Associate

Yolanda Robinson, Patient Services Assistant

**To learn more about the Philadelphia PADRECC and  
the National PD Consortium, please call:**

**215-823-5934 or 1-888-959-2323**

**or check us out on the Internet at:**

**[www.parkinsons.va.gov](http://www.parkinsons.va.gov)**

## PADRECC Parkinson's Disease Support Group

Group meets the **1st Monday** of each month at **1:30 pm** in the 4th Floor PADRECC Conference Room and at the **VA Fort Dix & Willow Grove Clinics** via video connection. If you are interested in attending the support group at the **VA Ft. Dix or Willow Grove Clinics please contact Gretchen Glenn, 215-823-5934, as space is limited.**

*\*Topics and Speakers are subject to change*

### April 7

Speaker: Katie Herrero, PT Moss Rehab  
Topic: Staying Active with PD & LSVT BIG

### May 5

Speaker: John Creveling and Christine Robertson, PDF Advocate & PADRECC Patient & Support Partner  
Topic: Research Advocacy

### June 2

Speaker: Julia Wood, Occupational Therapist  
Topic: Fatigue Management/Energy Conservation

### July 7

Speaker: Gretchen Glenn, Social Worker  
Topic: VA and Community Resources

### August 4

Speaker: TBA  
Topic: TBA

### September 1 LABOR DAY NO GROUP

### October 6

Speaker: Dr. James Morley, PADRECC Neurologist  
Topic: Research Update

### November 3

Speaker: PADRECC Fellow  
Topic: Motor vs. Non-Motor Symptoms of PD

### December 1

Speaker: Becky Martine, PADRECC Nurse  
Topic: Mind, Mood & Memory

## New PADRECC Resources

### Patient Education Video Series

The PADRECCs in collaboration with the VHA Employee Education System (EES) developed the "My Parkinson's Story" Film Library Video Series. The videos provide information about common concerns related to PD. Each of segments explores a specific issue related to PD from the perspectives of the patient, his or her family and his or her healthcare team. Topics include: DBS, depression, early PD, environmental exposures, falls, genetics, memory and thinking problems, sleep problems, driving, hospitalization, exercise, advanced PD, impulse control disorders, medications, role of the caregiver, and speech and swallowing problems. All videos are available for viewing on the National PADRECC & VA PD Consortium website: **www.parkinson.va.gov** and on You Tube.

### Parkinson's Disease Hospital Kits

According to the National Parkinson's Foundation (NPF), people with PD face greater risks and challenges when hospitalized. The best way to avoid complications while hospitalized is to be prepared. The **PADRECC Parkinson's Disease Hospital Kit** and the **NPF Aware in Care Kit** were developed to help you do this. If you are interested in obtaining a Parkinson's Disease Hospitalization Kit and/or the NPF Aware in Care Kit ask your PADRECC clinician or Social Worker.



## UPCOMING PADRECC EVENTS

### Living Healthy with Parkinson's Disease/ Multiple Sclerosis

This is a collaborative patient education program for people diagnosed with Parkinson's Disease or Multiple Sclerosis. Presentations and demonstrations will be done to highlight the importance of taking care of the mind and body. Please wear comfortable shoes and clothing as you are encouraged to participate in demonstrations. **May 13<sup>th</sup> 9:00a-12:00p** PVAMC RM 7A141. Registration is required. Please contact **Gretchen Glenn at 215-823-5934** for additional information.



## PD Organizations

### American Parkinson Disease Association (APDA)

[www.apdaparkinson.org](http://www.apdaparkinson.org) (800) 223-2732

### National Parkinson Foundation (NPF)

[www.parkinson.org](http://www.parkinson.org) (800) 327-4545

### Parkinson Disease Foundation (PDF)

[www.pdf.org](http://www.pdf.org) (800) 457-6676

### Michael J. Fox Foundation

[www.michaeljfox.org](http://www.michaeljfox.org) 212-509-0995

### Davis Phinney Foundation

[www.davisphinneyfoundation.org](http://www.davisphinneyfoundation.org) (866) 358-0285

## Related Movement Disorder Organizations

### CurePSP

[www.psp.org](http://www.psp.org)

### Lewy Body Dementia Association

[www.lbda.org](http://www.lbda.org)

### Association for Frontotemporal Degeneration

[www.ftd-picks.org](http://www.ftd-picks.org)

### Huntington's Disease Society of America

[www.hdsa.org](http://www.hdsa.org)

### International Essential Tremor Foundation

[www.essentialtremor.org](http://www.essentialtremor.org)

## Veterans Affairs

### National PADRECC & VA PD Consortium

[www.parkinsons.va.gov](http://www.parkinsons.va.gov) 1-888-959-2323

### Agent Orange Website

[www.publichealth.va.gov/exposures/agentorange](http://www.publichealth.va.gov/exposures/agentorange)

### VA Health Care Eligibility

[www.va.gov/healthbenefits](http://www.va.gov/healthbenefits) 1-877-222-8387

### Veterans Benefits Administration

[www.benefits.va.gov/benefits/](http://www.benefits.va.gov/benefits/) 1-800-827-1000

### VA and Department of Defense

[www.ebenefits.va.gov](http://www.ebenefits.va.gov)

### My HealthVet

[www.myhealth.va.gov](http://www.myhealth.va.gov)

### VA Caregiver Support

[www.caregiver.va.gov](http://www.caregiver.va.gov) 1-855-260-3274

### State Veterans Affairs Offices

[www.va.gov/statedva.htm](http://www.va.gov/statedva.htm)

### Veterans Crisis Line

1-800-273-8255 Press 1

## The PADRECC Post

Editors: Gretchen Glenn, LCSW, Becky Martine, MSN, RN PMHCNS & Dawn McHale

### Philadelphia VA Medical Center

PADRECC 127-P

3900 Woodland Ave

Philadelphia, PA 19104

[www.parkinsons.va.gov](http://www.parkinsons.va.gov)

Phone: 215-823-5934 or 1-888-959-2323

Fax: 215-823-4603