



The PADRECC Post

*Department of Veterans Affairs
2018*

**THE PHILADELPHIA PARKINSON'S DISEASE RESEARCH, EDUCATION & CLINICAL CENTER at
THE CORPORAL MICHAEL J. CRESCENZ VAMC**

Staying Connected: An Update on Telehealth at the Philadelphia PADRECC *"Telehealth changes the location where health care services are routinely provided"*

By: Eileen Hummel, MSN, RN-BC



Since 2011, the Philadelphia PADRECC has been using Telehealth to improve veterans' access to specialty care. Telehealth allows providers and patients to interact in real-time through the use of video. Instead of traveling to our clinic in Philadelphia, patients can go to the nearest VA outpatient center or VA medical center for their scheduled PADRECC visits. There is also a Telehealth at home option through the use of a secure internet connection on a personal computer or tablet device.

The Philadelphia PADRECC uses two types of Telehealth: Clinical Video Telehealth and Home Telehealth. For Clinical Video Telehealth, patients go to a more conveniently located VA outpatient center or VA hospital, where they are seen by their Philadelphia PADRECC providers through the use of specialized videoconferencing technology. Home Telehealth allows providers and patients to securely and privately connect using the patient's personal computer or tablet device. The VA may also issue to the patient a tablet device just for Telehealth use. Other requirements for Home Telehealth include an internet connection, webcam plus microphone, and internet browser (Microsoft Internet Explorer or Google Chrome).

We started our Clinical Video Telehealth program with three local VA outpatient centers. The program has expanded greatly to include VA community-based outpatient centers (CBOCs) and VA medical centers (VAMCs) in various areas. Currently, the PADRECC works with the following VA facilities to provide Telehealth accessibility for our patients:

Burlington County CBOC (Marlton, NJ)
Gloucester County CBOC (Sewell, NJ)
Victor J. Saracini CBOC (Horsham, PA)
Wilkes-Barre VAMC (Wilkes-Barre, PA)
Williamsport CBOC (Williamsport, PA)
Coatesville VAMC (Coatesville, PA)
Wilmington VAMC (Wilmington, DE)
Atlantic County CBOC (Northfield, NJ)
Cape May County CBOC (Cape May, NJ)
Cumberland County CBOC (Vineland, NJ)
Kent County CBOC (Dover, DE)

Sussex County CBOC (Georgetown, DE)
Lebanon VAMC (Lebanon, PA)
Camp Hill VA Clinic (Camp Hill, PA)
Lancaster VA Clinic (Lancaster, PA)
York VA Clinic (York, PA)
VA Butler Healthcare (Butler, PA)
Bath VAMC (Bath, NY)
Elmira CBOC (Elmira, NY)
Wellsboro VA Clinic (Wellsboro, PA)
Wellsville VA Outpatient Clinic (Wellsville, NY)
Albany Stratton VAMC (Albany, NY)

Even with the barriers of mobility problems, transportation difficulties, and geographical distance, Telehealth has proven for many patients to be an effective and more convenient way to receive specialty care and stay connected with the Philadelphia PADRECC. However, not all patients are appropriate to participate in Telehealth. Patients should discuss with their PADRECC provider if interested. Also, patients always have the option to do traditional in-person visits instead of Telehealth.

Get Up and Go: The Importance of Exercise for People with Parkinson's Disease

By: Sneha Mantri, PADRECC Fellow



Physical activity and exercise are crucially important for people with Parkinson's disease (PD). Not only does exercise maintain strength and mobility, it helps the brain release neurochemicals like endorphins and dopamine, which slow down disease progression. In fact, a recent study of over 3000 people with PD published by the National Parkinson's Foundation found that those who exercised at least 150 minutes per week had less disability and better quality of life after two years. Here at the Philadelphia PADRECC we are finding similar results in our Veterans with PD—those who are physically active have less disability, fewer non-motor symptoms, and perform better on cognitive testing. But getting started and staying committed to exercise can be challenging for everyone. Here are some frequently asked questions and answers for how to “get up and go.”

I take a walk around the neighborhood every day. Is that enough exercise? What else counts as exercise?

Walking—whether on a treadmill or outdoors—is a great activity. To count as “exercise,” though, you should walk a little faster than a stroll—enough to make you breathe a little faster than usual. Other popular activities among our Veterans with PD include biking, Tai Chi, Rock Steady Boxing, and Dance for PD. But really, almost anything counts—the important thing is to find something that you enjoy.

My mobility is impaired by PD or other problems, and I'm afraid of falling. What sorts of exercises can I do safely?

An evaluation by a physical therapist is an important part of your PD care, and a good PT can help you come up with tailored exercises for your disease stage and ability. If you know how to swim, water aerobics or swimming laps can be helpful as well; the buoyancy of the water is also easier on your joints.

How long do I need to exercise?

That depends on how intense your activity is. The American Heart Association recommends at least 150 minutes per week of moderate activity (e.g. fast-paced walking) – that's just over 20 minutes per day. If you jog, swim, or do other vigorous activities, you can cut down to just 75 minutes per week, or about 10-12 minutes per day. You should also include at least 2 days per week of strength training (e.g. weights) – this is really important for people with PD to maintain muscle strength over the course of the disease.



How do I stay motivated to exercise?

This can be tough for everyone! The two most effective ways to stay committed to an exercise program is to have a schedule and make it social. Sticking to a schedule helps make exercise as much a part of your daily routine as brushing your teeth. The social aspect of an exercise program can't be stressed enough. Whether it's your spouse, your neighbor, or your dance partner, having someone else around can be the difference between watching TV and lacing up your sneakers. New technology like wearables and smartphone apps even allow you to “challenge” your friends, spicing up your routine with some friendly competition.

For more information about local exercise programs for people with PD, reach out to your PADRECC clinician.

Wearable Devices for Parkinson's Disease

By: Michelle Fullard, MD, MSCE, Movement Disorders Specialist



The symptoms of Parkinson's disease vary greatly from person to person, and for an individual, symptoms can change over the course of a day. As Parkinson's disease progresses, patients can develop motor fluctuations in which they alternate between periods of ON time, when Parkinson's medications are improving symptoms of slowness, tremor and stiffness, and periods of OFF time, when the Parkinson's symptoms return. Dyskinesias, or excess movements, can also occur. During clinic visits, examinations are performed that provide a snapshot of a patient's symptoms, but also leave hours of symptoms unmonitored. Wearable devices offer a new approach to tracking Parkinson's symptoms, which is important for treatment management.

Wearable devices are sensors that are worn on the body to collect information about movement. They typically contain an accelerometer, which is used to detect and measure motion, as well as a gyroscope that measures direction. An example of devices that are currently in use include activity trackers, such as Fitbits, which measure the number of steps taken in a day, as well as distance traveled. What makes a device specific for use in Parkinson's disease are the algorithms that are used to process the data and detect Parkinson's symptoms. Several studies are ongoing in the United States and around the world to test different wearable devices for monitoring Parkinson's disease. The goal of many of these studies is to develop an objective way to monitor symptoms over time to give us a better picture of how a person is doing from day to day. This information can help clinicians track the effectiveness of medications and identify time periods of worsening symptoms where medication changes may be beneficial. When coupled with a smartphone application, these devices can also provide a display of symptoms for patients so they can better track their own symptoms. Overall, these devices may help clinicians build a more personalized approach to treating each patient with Parkinson's disease.

My HealthVet

My HealthVet (MHV) is the VA's Personal Health Record. It is designed to give Veterans and their care partners, anywhere, anytime access to VA health care information. To use MHV all you need is a computer with Internet access which can be used at home or through public access like a library, Internet café, or even your local VA Medical Center.

MHV Services

Secure Messaging: allows Veterans to communicate with their medical provider or specialists they see at the VA. It is web-based, encrypted communication between patients and health professionals, similar to email but more secure. This can be used for *non-urgent issues*.

Pharmacy: Veterans can refill VA prescriptions, check VA prescription history, track VA prescriptions, and view their medication list.

Appointments: Veterans can view past, present and future VA appointments and schedule VA appointments when needed.

Track Health: Veterans have access to check labs and test

results, record of their vitals and readings, health history, journals, goals and Healthy Living Assessments.

Health Records: The Blue Button Medical Reports enables Veterans to generate and download or print their entire VA medical record.

Education: VA Providers can email Veterans information on educational programs and opportunities available at the VA and in the community. *PADRECC has been sending monthly educational emails since January 2018!*

Important Facts

- ◆ Secure messaging is **NOT** to be used for emergencies. Always call 911.
- ◆ MHV is easy to use, private and secure
- ◆ **National Help Desk** for website problems is available Monday-Friday 8am-8pm. 1-877-327-0022
- ◆ MHV Coordinator for Philadelphia is Yvette Roberts 215-823-5800x5579
- ◆ MHV Office is located in the Medical Center Library, Room GC126.



Research Happenings at the Philadelphia PADRECC

Balance and Parkinson's Disease

Dr. Delaram Safarpour, former PADRECC Fellow who is now on faculty at Oregon Health Sciences University and Dr. James Morley are studying whether a balance vest, Balance Based Torso Weighting (BBTW), can improve walking and balance in patients who have PD and related conditions. The weighted vest has been shown to improve walking and balance in patients with other neurological conditions, but it is unknown whether the vest could help patients with PD and related conditions. This study completed recruitment of 20 patients and is now undergoing data analysis. It is hoped that the BBTW can potentially be a non-pharmacological approach for improvement of balance and walking in patients with PD and related disorders

Medication-Induced Parkinsonism

Dr. James Morley is conducting studies to understand how Parkinson's-like symptoms caused by medications are related to PD. Symptoms of PD can be mimicked by certain medicines that block dopamine—the major brain chemical missing in PD. Not everyone's symptoms improve after the medicines are switched 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 using questionnaires, physical exam, blood tests and a brain scan in addition to following patients with symptoms after the medication is switched or stopped. Initial analyses published recently demonstrated that more than 20% of patients with drug-induced symptoms actually had underlying PD or a related disorder that was "unmasked" by the dopamine blocking drugs. Loss of the sense of smell (as is seen in most PD patients) was the strongest predictor of an abnormal brain scan. Appearance of PD-like symptoms after treatment with a low dose of antipsychotic medication also predicted an abnormal scan suggesting that dopamine blocking drugs can act like a "stress test" for the brain. Patients with abnormal brain scans suggesting they may have early PD, are being further studied by Dr. Morley to test whether exercise can improve movement symptoms and disease progression on the brain scan.

The Immune System and Parkinson's Disease

Dr. Morley and the PADRECC are collaborating with a local biotech company (Longevity Biotech) on a project recently funded by the Michael J. Fox Foundation to study whether the immune system plays a role in PD. The team will recruit *pairs of patients and their caregivers* to study whether immune cells and other blood markers are different in PD and are associated with disease severity or other PD characteristics. This study will begin recruiting subjects in June 2018.

Bacteria and Parkinson's Disease

Dr. Fullard and Dr. Duda, in collaboration with Dr. Noam Cohen from the Ear Nose and Throat Department, continue to

study how bacteria that colonize our body might contribute to the risk of Parkinson's disease. It has been shown that these bacteria are different in people with Parkinson's disease compared to people without Parkinson's disease. This study is trying to understand if there are genetic reasons why some people have certain types of bacteria in the hopes of developing new therapies in the future. Preliminary results show that participants with Parkinson's disease were more likely to be non-tasters of bitter compounds compared to participants without Parkinson's disease. This confirms prior findings. Once recruitment is complete, we will examine differences in the genetics of the taste receptors and in the bacteria of the nose and gut between those with Parkinson's disease and those without.

Traumatic Brain Injury

Dr. John Duda, PADRECC Director and his colleagues, Drs. Kacy Cullen, Isaac Chen and John Wolf, from the Department of Neurosurgery at the University of Pennsylvania, continue studies funded by the Rehabilitation Research and Development Service of the Department of Veterans Affairs to study the relationship between brain trauma and neurodegeneration. The researchers have published several studies that have shown how the brain reacts to trauma and how that could possibly lead to chronic neurodegenerative disease development. It is hoped that these studies will lead to treatments to prevent the development of these neurodegenerative diseases in Veterans and others who have suffered head injuries.

Neurorestoration in Parkinson's Disease

Dr. John Duda and his colleagues Kacy Cullen, PhD, and Isaac Chen, MD, PhD from the Center for Neurotrauma, Neurodegeneration, and Restoration (CNNR) at the Crescenz VA Medical Center, continue to investigate whether one of the main brain pathways affected in Parkinson's disease, the nigrostriatal pathway, can be generated in a petri dish and transplanted in animal models to reverse the motor symptoms in PD. While studies are early, the success of their efforts to date have led to several publications and special recognition at several different scientific meetings.

Exercise and Parkinson's Disease

Dr. Sneha Mantri, PADRECC Movement Disorders Fellow, and Dr. James Morley continue to study physical activity habits and attitudes about exercise of people with Parkinson's disease (PD). Participants are asked to complete a series of questionnaires to assess exercise and activity habits, attitudes about exercise, sleep, mood, memory, and other symptoms. Interim analysis of the first sixty participants shows that one in five meet American Heart Association recommended physical activity (20-30 minutes of moderate to vigorous activity, 2-3 times per week). Active Veterans score higher on cognitive tests, have fewer PD-related symptoms, and enjoy a better quality of life. By understanding a veteran's physical activity habits, we can better design an exercise program that meets their needs to remain physically active.

Merger of 2 National PD Organizations



The National Parkinson's Disease Foundation (NPF) and The Parkinson's Disease Foundation (PDF) merged in 2016 and is now known as the Parkinson's Foundation (PF). According to their website, the Parkinson's Foundation "makes life better for people with PD by improving care and advancing research toward a cure." For more information on the newly merged foundation please visit their website at: www.parkinson.org

National PD Web-Based Resources

Michael J. Fox Foundation: www.michaeljfox.org

◆ **Fox Feed Blog:** the latest reporting of progress in PD research & issues that matter to you.

◆ **Third Thursday Webinars:** learn about various aspects of living with PD and the Foundations work to speed medical breakthroughs.

Parkinson's Foundation (PF): www.parkinson.org

◆ **PD Expert Briefings:** 1 hour online seminars that offer practical tips and tools. Seminars are broadcasted live and archived for later viewing.

◆ **Educational Publications:** brochures, newsletters, booklets, videos and archived webinars on various PD topics are available for viewing and download on the PF website.

American Parkinson Disease Association:
www.apdaparkinson.org

◆ **Webinar Series:** Up-to-date information on PD & treatment featuring expert speakers from the PD community. Available via the web and telephone and archived for future use.

◆ **Brochures & Pamphlets:** Materials focused on the clinical and psychosocial aspects of PD are available for download on the website.

NATIONAL RESEARCH LINKS

Fox Trial Finder (FTF)

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

Online matching tool that connects volunteers with PD clinical trials.

NIH Clinical Research Trials and You

<https://www.nih.gov/health-information/nih-clinical-research-trials-you>

An online resource to help people learn more about clinical trials, why they matter and how to participate.

ClinicalTrials.gov

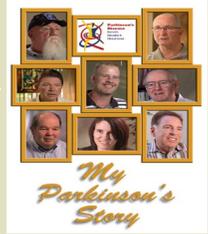
www.clinicaltrials.gov

Is a registry and results database of federally and privately supported clinical studies conducted around the world.

PADRECC Resources

Patient Education Video Series

The PADRECCs developed the "My Parkinson's Story" Film Library Video Series. The videos provide information about common concerns related to PD. Each segment explores a specific issue related to PD from the patient's perspective, his or her family and his or her healthcare team. All videos are available for viewing on the National PADRECC & VA PD Consortium website:



www.parkinsons.va.gov/patients.asp

Patient Education Brochures

Patient Education Brochures were developed to provide patients and families with information on the most common topics concerning Parkinson's disease:

Fall Prevention

Exercise and Physical Activity

Medications

Agent Orange & Toxic Exposures,

Motor and Non-Motor Symptoms of PD

The brochures are available in the Philadelphia PADRECC Clinic or can be downloaded from the National PADRECC & VA PD Consortium website:

www.parkinsons.va.gov/patients.asp



PD "At-Home" Telephone Education & Support Group

The Southwest PADRECC in West Los Angeles sponsors a Telephone Education/Support Conference on the **2nd Tuesday of every month, 1-2 pm Eastern Time**. Participate in the convenience of your home. Simply dial toll-free **1-800-767-1750** and enter code **54321#**.

For more info, contact West LA PADRECC at 1-800-952-4852 or (310) 478-3711 x 48041.

Parkinson's Disease Hospital Kits

In 2011, the Parkinson's Foundation launched the **Aware in Care** campaign to help people with PD get the best care possible while hospitalized, the best way to do this is to be prepared. The PADRECC **Parkinson's Disease Hospital Kit** and the **PF Aware in Care Kit** were developed to help you with this process. If you are interested in obtaining a Hospitalization Kit and/or the Aware in Care Kit ask your PADRECC clinician or social worker.

PADRECC Events

6 Week Selfie-Project at The Philadelphia Museum of Art



This summer the Philadelphia PADRECC is partnering with the **Philadelphia Museum of Art's Accessible Program** to offer a **6 Week Selfie-Project**~a self-portrait workshop for Veterans with PD. Program registration is now closed but please keep an eye out for the **Art Show** displaying the self portraits this fall at the Crescenz VAMC.



Walk to Stamp Out Parkinson's

Last October, several members of the Philadelphia PADRECC Team and their families joined the local Parkinson's community in **The Parkinson's Council's: Walk to Stamp out Parkinson's**. The walk is being held again this year on **October 13th** at the Philadelphia Zoo. Come out and join the Philadelphia PADRECC Team: **Soldier On-Team VA PADRECC**-for a fun day raising awareness and supporting the local PD community. Visit The Parkinson Council website to learn more, www.theparkinsoncouncil.org or contact, Gretchen Glenn at: 215-823-5934.



2018 PADRECC Parkinson's Disease Support Group

Support Groups are held the 1st Monday of the month from 1:30p-2:30p. Location of each group is listed below. Not all groups will be available at the CBOCs this year.

- August 6th** Topic: To be determined

Location: 4th Fl. PADRECC Conference Rm & Burlington and Horsham CBOCs via video
- September 3rd** **Labor Day-No Group**
- October 1st** Topic: Thinking & Memory Problems

Location: 4th Fl. PADRECC Conference Rm & Burlington and Horsham CBOCs via video
- November 5th** Topic: Discussion Group

Location : 4th Fl. PADRECC Conference Rm
- December 3rd** Exercise Group: Dance for PD

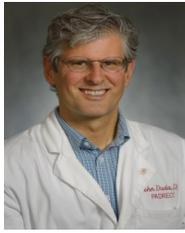
Location : 3rd Fl. Multi Purpose Room

Tai Chi with Marcus at Crescenz VAMC

Balance, strength, flexibility, mobility and stress reduction. Discover what is known as the Supreme Ultimate martial arts as you find balance and harmony, physically and mentally, through the practice of Tai Chi.

Every Monday- 11:30am-1pm
Location: 3rd floor Multipurpose Room
Contact: 215-823-5800 x3756





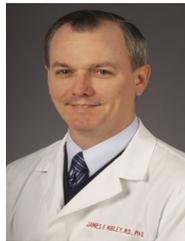
Dr. John Duda

The Philadelphia PADRECC Team

- Dr. John Duda, Director
- Dr. Jayne Wilkinson, PADRECC Associate Clinical Director, Associate Chief of Staff, Clinical Operations
- Dr. James Morley, Associate Director of Research
- Dr. Branch Coslett, Chief, Neurology Service
- Dr. Daniel Weintraub, Geriatric Psychiatrist
- Dr. Rasham Shah, Pharmacist
- Rebecca Martine, MSN, RN, PMHCNS, Nurse Coordinator
- Heidi Watson, BSN, RN, Nurse Coordinator
- Eileen Hummel, MSN, RN, Nurse Coordinator
- Gretchen Glenn, LCSW, Social Worker/Associate Director of Education
- Stephanie Wood, Research Coordinator
- Dawn McHale, Program Specialist
- Tonya Belton, Program Support Associate
- Yolanda Underwood, Patient Services Assistant



Dr. Jayne Wilkinson



Dr. James Morley

To learn more about the Philadelphia PADRECC and the National VA PD Consortium, please call: **215-823-5934 or 1-888-959-2323** or check us out on the Web at: **www.parkinsons.va.gov**

The Philadelphia PADRECC Consortium Network



National VA PD Consortium Centers

The National VA Parkinson's Disease Consortium was established in 2003 as a means to broaden the impact of the Parkinson's Disease Research, Education and Clinical Centers (PADRECCs) and encourage modern Parkinson's disease care across the VA Healthcare System. Together, the PADRECCs and Consortium Centers create a hub and spoke model of care, allowing effective and convenient services to all veterans, regardless of location. Veterans who cannot access services at a PADRECC facility can receive specialized care at the closest Consortium Center in their region.

Northeast Consortium Centers	
<p>Albany, NY Consortium Director: Dr. Donald Higgins Referral Number: 518-626-6373</p>	<p>Jamaica Plain, MA Consortium Director: Dr. Raymond Durso Referral Number: 617-232-9500 x4750</p>
<p>Baltimore, MD Consortium Director: Dr. Paul Fishman Referral Number: 410-605-7000 x7060</p>	<p>Pittsburgh, PA Consortium Director: Dr. Edward Burton Referral Number: 412-688-6185</p>
<p>Bronx, NY Consortium Director: Dr. Ruth Walker Referral Number: 718-584-9000 x5915</p>	<p>Syracuse, NY Consortium Director: Dr. Dragos Mihaila Referral Number: 315-425-3474</p>
<p>Cleveland, OH Consortium Director: Dr. Aasef Shaikh Referral Number: 261-791-3800</p>	<p>West Haven, CT Consortium Director: Dr. Diana Richardson Referral Number: 203-932-5711</p>





PD Organizations

Parkinson's Foundation:

www.parkinsons.org 1-800-473-4636

American Parkinson Disease Association (APDA)

www.apdaparkinson.org 1-800-223-2732

Michael J. Fox Foundation

www.michaeljfox.org (212)509-0995

Davis Phinney Foundation

www.davisphinneyfoundation.org (866) 358-0285

Related Movement Disorder Organizations

CurePSP

www.psp.org

Lewy Body Dementia Association

www.lbda.org

Association for Frontotemporal Degeneration

www.ftd-picks.org

Huntingdon's Disease Society of America

www.hdsa.org

International Essential Tremor Foundation

www.essentialtremor.org

Veterans Affairs

National VA PADRECC & PD Consortium

www.parkinsons.va.gov 1-888-959-2323

Agent Orange Website

www.publichealth.va.gov/exposures/agentorange

VA Health Care Eligibility

www.va.gov/healthbenefits 1-877-222-8387

Veterans Benefits Administration

www.benefits.va.gov/benefits/ 1-800-827-1000

VA and Department of Defense

www.ebenefits.va.gov

My HealthVet

www.myhealth.va.gov

VA Caregiver Support

www.caregiver.va.gov 1-855-260-3274

State Veterans Affairs Offices

www.va.gov/statedva.htm

Veterans Crisis Line

1-800-273-8255 Press 1

With Sincere Thanks

The Philadelphia PADRECC would like to thank those who made charitable donations on behalf of loved ones followed in the PADRECC clinic. The donations are used to support our education initiatives.

The PADRECC Post

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