The PADRECC Post

Department of Veterans Affairs
2022

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

Deep Brain Stimulation: Who, What, When, Where, Why & How?

By: Pavan Vaswani, MD, PhD, Philadelphia PADRECC Attending

There are many treatments we can use for Parkinson's Disease (PD) and Essential Tremor (ET). These include medications, diet, exercise, therapy, and treatments that involve surgery. Deep brain stimulation (DBS) is one of those surgeries.

DBS is not a new or experimental therapy. It was first approved by the FDA in 1997, and there have been over 100,000 patients treated worldwide. The VA was involved in some of the first studies of DBS, and so we have been using DBS at the VA for 20 years.

Who should consider DBS, and when?

Deep brain stimulation is a surgery approved by the FDA to treat ET, PD, and dystonia. It can be used to treat tremor in PD, tremor in ET, and trouble with "on" and "off" episodes in PD. It can also help with dyskinesias: wiggling and fidgeting movements usually related to PD medications. The surgery can be done at any age, though older people do have higher risks of having surgery in general. In young people with PD, it can be helpful to think about DBS early, as some studies have shown that patients do better with surgery and medications.

Why have DBS surgery?

Deep brain stimulation can help many of the symptoms of PD, ET, and dystonia. On average, PD patients will have 3 to 5 more hours per day of good "on" time without dyskinesias after DBS surgery. It usually helps tremor, stiffness, slowness, and dystonia. Walking may also get better. Usually, medications can also be reduced a lot after DBS, though most people will still need to take some medications afterwards.

Some things do not improve or may get worse. Speech, swallowing, and balance usually do not get better, and in some people may get worse. Older people and people with memory or thinking problems before surgery could have more trouble after surgery. Anxiety, depression, and fatigue usually do not improve but also do not worsen, after DBS.

What evaluation happens before surgery?

Before surgery, all patients considering DBS surgery have a detailed evaluation by the DBS team:

1. A **movement disorders neurologist** will see you for a longer visit than usual. For this visit, people with PD will come to the clinic OFF your medications for 12 hours. The doctor will do an exam, ask you to take your medicine in the office, and then do another exam when the medication starts to work. They will also talk to you about the procedure, including some of the risks, benefits, and other options.
2. You will meet a **PADRECC nurse** who will help coordinate visits and answer questions
3. An **MRI of the brain** will be done, if you have not had one in the last few years
4. A **Neuropsychologist** will evaluate your thinking and memory
5. **Physical, Speech, and Occupational therapists** may evaluate your walking, balance, speech, swallowing, and coordination
6. You may see a **Social Worker** to make sure you have the support you need before and after surgery
7. A **Neurosurgeon** will see you to talk about the procedure, risks, benefits, and recovery

After you meet all the DBS team, the team meets to discuss your care. We talk about the risks and benefits, and make sure we can meet your expectations.

Deep Brain Stimulation (continued)

What is the surgery and recovery like?

In DBS surgery, a small hole is made in the skull and a wire is inserted into a particular region in the brain. A battery, which looks like a pacemaker, is also placed under the skin in the upper chest. All of the parts of the system are under the skin. Usually, patients stay in the hospital for 1 or 2 nights for monitoring, and then can go home. You should take it a little easier for a few weeks after surgery. No driving, no swimming, and no heavy lifting are recommended for about 4 weeks.

In the long term, there are only a few restrictions. The most common one is that you should get patted down instead of going through metal detectors.

What happens after surgery?

After surgery, you will work with your movement disorders neurologist over a few months to make full use of the DBS device. The wire in the brain can be stimulated to stop problematic brain signals. Your neurologist will adjust the stimulation to help treat your symptoms. They will also work with you to reduce your medications.

The first visit after surgery to "program" the stimulation should be done in person with your neurologist. Depending on your personal situation, the next visits may be able to be done remotely, using telehealth.

Where can I have DBS evaluation and surgery?

We do the DBS evaluations at the PADRECC in Philadelphia. If you are interested or if your doctor refers you, we can help setup the visits with the DBS team. We are also excited to be doing surgeries at the Philadelphia VA again, soon. Dr. Isaac Chen and Dr. Casey Halpern are the neurosurgeons who will be doing DBS surgeries and are both experienced.

How can I learn more?

DBS is a personal decision that depends on your specific medical situation. It is not a cure and depends on your personal situation. Talk to your movement disorders neurologist at the PADRECC if you are interested in DBS. We also have flyers and information booklets in the PADRECC waiting room. You can also find good information online, on the Parkinson's Foundation website:

https://www.parkinson.org/Understanding-Parkinsons/Treatment/Surgical-Treatment-Options/Deep-Brain-Stimulation.

Parkinson's Foundation

There is also a support group that meets online through University of Pennsylvania, our academic affiliate, for interested patients. To learn more, contact: Suzanne Reichwein at: 215-829-7273 or **sreichwein@pennmedicine.upenn.edu**

Penn Medicine

Biomarkers: how do we find and track Parkinson's disease?

By: George T. Kannarkat, MD, PhD, Philadelphia PADRECC Fellow

Biomarkers are traits related to disease that doctors use to predict, find, and track disease. Symptoms, imaging, or body fluids can be biomarkers. Biomarkers in Parkinson's disease (PD) are hard to find because of its slow, changing course. Biomarker research is active and changes quickly. Below are the types of useful PD biomarkers.

Biomarkers show who is at risk for disease. For example, high blood cholesterol marks people at high risk of heart attack or stroke. People with PD (PwPD) often have symptoms before diagnosis. Of these symptoms, REM-sleep behavior disorder is the strongest risk factor for PD. People with RBD move or talk during dreams. More than half of people with RBD are at risk of PD in their lifetime.

Changes in genes also increase risk for PD. Gene testing can be discussed with your doctor. This testing is useful in people with PD before 50 years old, in people with family members with PD, or in specific ethnic groups. Scientists are finding more risk factors for PD so that we can treat at-risk people before PD starts.

Biomarkers also find people with disease. One example is measuring blood troponin levels during a heart attack. In PD, there are two imaging tests that track dopamine, a brain chemical. These tests separate PwPD from people who have essential tremor or PD due to medications. A new spinal fluid test measures misfolded proteins in PwPD and similar diseases. Scientists are working to find other fluid and imaging tests for PD.

Predictive biomarkers track the course of a disease or treatment response. One example is the breast cancer genes that causes faster spread. PwPD whose first symptom is one-sided tremor have slower disease. Scientists continue to look for reliable body fluid predictive biomarkers.

Treatment response in PwPD is hard to measure without biomarkers. The disease symptoms change over years. Testing new drugs takes a long time and is very expensive. Research continues to find treatment biomarkers to speed up drug testing and creation. As we find more biomarkers, we will be better able to predict, find, and treat PD.

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Research Happenings at the Philadelphia PADRECC

Ongoing Projects

Behavioral or Solifenacin Therapy for Urinary Symptoms in Parkinson's Disease

The Philadelphia PADRECC continues to work with Dr. Camille Vaughn (Atlanta VA) on a study for overactive bladder symptoms in PD. Patients are randomly split into either medication or behavioral treatment (pelvic floor muscle exercises) to see if both are equally effective in controlling frequent urination.

Developing Personalized Medicine Strategies to Increase Physical Activity in Parkinson's Disease Through Digital Health Technology

Under a grant from the Department of Defense's PD program, Dr. Morley's study is looking at new approaches that 1) use "gamification"— applying rules of games like point scoring, achieving silver, gold or platinum levels and competition-- to increase physical activity in PD; 2) identify whether certain PD patients respond differently to gamification than others.; 3) use readily and commercially available (including Fitbits) digital health devices to perform all study activities remotely and enable a "touchless" study where patients don't have to come in person for any studies visits.

Neurorestoration in Parkinson's Disease

Dr. Duda and his colleagues Dr. Kacy Cullen and Isaac Chen from the Center for Neurotrauma Neurodegeneratio, and Restoration (CNNR) at the Crescenz VA Medical Center, continue to study whether one of the main brain pathways affected in PD, the nigrostriatal pathway, can be made in a petri dish and transplanted in animal models to reverse motor symptoms in PD. The team has been successful in placing these pathways into a rat model of PD and are now funded to do the same in pigs, which more closely resemble what would need to be achieved to begin trying in humans. In the last year, another breakthrough was reached when these constructs were derived from human stem cell lines and transplanted successfully, potentially paving the way for these constructs to be made from a patient's own cells.

A Multi-center, Randomized, Active-controlled, Double-blind, Double-dummy, Parallel Group Clinical Trial Investigating the Efficacy, Safety, and Tolerability of Continuous Subcutaneous ND0612 Infusion in Comparison to Oral IR-LD/CD in Subjects with Parkinson's Disease Experiencing Motor Fluctuations (BouNDless)

Sponsor: NeuroDerm Ltd./Syneos Health

The Philadelphia PADRECC is the VA's coordinating site for this new tria of a new under the skin pump for levodopa/carbidopa. Enrollment began and study completion is expected early 2023.

Understanding What is Wrong in Parkinson's Disease Cells

Dr. Duda and his colleagues, Drs. Kacy Cullen, Isaac Chen and Dimple Chouhan have begun making a copy of a complete nigro-striatal system, which includes the nigrostriatal pathway constructs mentioned above as well as cells from the striatum, where the nigrostriatal pathway projects to, on the other end of the construct. They are hoping to use these bioengineered constructs to study how cells in the brain of someone with PD die, and to develop new therapies to stop it. While these studies have just begun, they have already been successful at making the constructs from human-derived stem cells and have begun studies to learn the mechanism involved in cell death. Dr. Duda was awarded Senior Clinician Scientist Investigator Award by the Biomedical Laboratory Research and Development Service of the Department of Veterans Affairs, in part because of a grant he wrote to fund this research.

Upcoming Projects:

Upcoming Projects:

Summer 2022 *Parkinson's Disease Biomarkers in Human Olfactory Cleft Mucus*

(Sponsor: National Institute of Health)

Dr. Morley and his colleague Dr. Noam Cohen (Philadelphia CMVAMC/ Department of ENT) are collaborating with Dr. Hong Wang from the Monell Chemical Senses Center on a project looking to identify PD biomarkers in the nose cavity mucus to aid in the diagnosis and identification of PD.

Research Happenings at the Philadelphia PADRECC

Fall 2022 *Global Parkinson's Genetics Program (GP2)*

(Sponsor: Michael J. Fox Foundation)

The VA PADRECC network is joining the Global Parkinson's Genetics Program (GP2) funded by the MJF Foundation. The five-year program is looking to identify PD genes is >150,000 volunteers around the world to further understand genetic risk factors of Parkinson's Disease. The PADRECC sites will be included as a sub-study (VA-PD) focusing on veterans' genetics and environmental exposures. Additionally, recruitment will focus on including underrepresented minority patients diagnose with Parkinson's disease.

Fall 2022 VA Cooperative Study #2015 – *"Multicenter, Randomized, Double-Blind Comparator Study of Antipsychotics Pimavanserin and Quetiapine for Parkinson's Disease Psychosis (C-SAPP Study)."*

This is a nationwide, multicenter clinical trial comparing two antipsychotic medications (quetiapine and pimavanserin) for the management of PD related psychosis. Drs. Duda and Weintraub will be the national co-PIs and Dr. Morley will be the Philadelphia site PI.

PADRECC Education Resources

The National VA PADRECC website has a wealth of patient education materials and resources

www.parkinsons.va.gov/patients.asp

- **PADRECC Support Groups:** listing of virtual support groups for all 6 PADRECCs
- **Suggested Education Essentials for Veterans with PD:** document that includes useful links to resources that provide information on topics such as: Overview of PD, Exercise, Medications, Nutrition, and Non Profit Organizations
- **Patient Education Video Series- "My Parkinson's Story"** These 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.
- **Patient Education Brochures-**developed to provide patients and families with information on the most common topics concerning PD:
  - **Fall Prevention**
  - **Exercise and Physical Activity**
  - **Agent Orange & Toxic Exposures,**
  - **Motor and Non-Motor Symptoms of PD**

2022 PADRECC Parkinson's Disease Virtual Support Group

The Philadelphia & Richmond (Virginia) PADRECCs joined together to offer a virtual support/education group where you can join from the comfort of your home by computer or phone. Groups are held the 1st Monday of the month from 1p-2p EST. **Contact Gretchen Glenn: 215-823-5800 x203194 to register.**

August 1st	Carergivers—Accepting Help Gretchen Glenn, Philadelphia PADRECC Social Worker
September 5th-Holiday-NO Group	
October 3rd	Tai Chi for PD Deb Damaroo, OT Central Virginia VAMC
November 7th	Psychiatric Issues in PD Dr. Daniel Weintraub, Psychiatrist Philadelphia PADRECC
December 5th	Sleep Hygiene Drs. Elsa Matthews & Leslie Hudgins

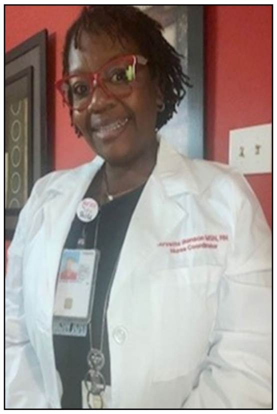
Welcome NEW PADRECC Staff

Dr. Pavan Vaswani—Attending Neurologist

Dr. Vaswani is from Seattle, WA but did much of his training on the east coast and so is excited to now call Philadelphia home. He did his undergraduate training at the University of Washington, and then moved to Baltimore, MD to complete his MD and PhD Degrees at Johns Hopkins University School of Medicine. He then did residency at the BWH-MGH-Harvard Medical School Neurology residency program in Boston, where he served as Chief Resident. He joined the PADRECC and University of Pennsylvania in 2020 as a movement disorders fellow, and is excited to stay on and join the faculty at PADRECC and UPenn starting in July 2022.

Dr. Vaswani will be leading the deep brain stimulation program at the Philadelphia PADRECC. See the article in this issue to learn more about this treatment option we are bringing back to the VA! He hopes to make this treatment more easily available and accessible to our patients with Parkinson disease, essential tremor, and other movement disorders. Outside of the hospital, he enjoys hiking, snorkeling, cooking, traveling, and reading science fiction.

Arvette Benson, MSN, RN—Nurse Coordinator



Arvette joined the Philadelphia PADRECC in October 2021 as a nurse coordinator. She has been serving Veterans in various roles at the VA since 2008. Arvette's career with VA started in health administration services helping veterans enroll in VA healthcare. She then went on to social work service in support of the homeless program HUD-VASH. Prior to joining the PADRECC, Arvette had the pleasure of working with long term care residents at the Community Living Center.

Arvette studied nursing at the Abington Memorial Hospital Dixon School of Nursing. She obtained her Bachelor of Science in Nursing from Penn State University and Master of Science in Nursing Informatics from Western Governors University.

Arvette is a self-proclaimed plantsman with a vast collection of indoor and outdoor plants. When she is not taking care of her plants, she enjoys spending time with family and traveling.

Arvette looks forward to getting to know all the patients and being a member of the interdisciplinary team that provides world-class care in the treatment of PD and movement disorders.

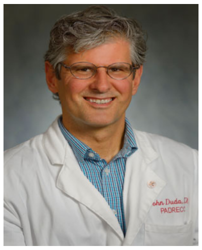
The Myhealth*e*Vet portal is a safe and secure way to reach out to her with any questions or concerns that you have.

Ashley Pfeifer, BSN, RN—Nurse Coordinator

Ashley is a Nurse Coordinator in the PADRECC. She previously worked as an inpatient registered nurse in a private hospital in New Jersey prior to joining the VA in 2021. She attended Saint Francis Medical Center School of Nursing and went on to earn her Bachelor of Science in Nursing from Walden University.

Ashley enjoys cheering her children on at their soccer and lacrosse games on the weekends and vacationing with her family in her free time.

Ashley is honored to be a member of the Philadelphia PADRECC team and serve our Veterans through their healthcare journey. She looks forward to working with the Veterans and the collaborative healthcare team.



Dr. John Duda

Dr. James Morley

Dr. Jayne Wilkinson

The Philadelphia PADRECC Team

Dr. John Duda, Director
Dr. James Morley, Co-Director
Dr. Jayne Wilkinson, Medical Director, National Tele–Neuro
Dr. Allison Willis, Chief, Neurology Service
Dr. Pavan Vaswani-Attending Neurologist
Dr. Daniel Weintraub, Geriatric Psychiatrist
Dr. Rasham Shah, Pharmacist
Eileen Hummel, MSN, CRNP, Nurse Practitioner/Coordinator
Arvette Benson, MSN, RN, Nurse Coordinator
Ashley Pfeifer, BSN, RN, Nurse Coordinator
Gretchen Glenn, LCSW, Social Worker/Assoc. Dir. Education
Stephanie Wood, Research Coordinator
Sreelatha Koganti, Research Assistant
Dawn McHale, Program Specialist
Tonya Belton, Program Support Assistant
Yolanda Underwood, Patient Services Assistant

Parkinson's Foundation: Partnership Update

VHA/PADRECC & Parkinson's Foundation (PF) partnership established in 2020, continues to grow with the goal of improving the health, well-being and quality of life for Veterans living with PD. Check out the PADRECC website for listing of notable resources:

PADRECC-For Veterans & Family

Parkinson's Foundation

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 closet Consortium Center in their region.

Northeast Consortium Centers

Baltimore, MD
Consortium Director:
Dr. George Uhl
Referral Number: 410-605-7000 x7060

Bronx, NY
Consortium Director:
Dr. Ruth Walker
Referral Number: 718-584-9000 x6804

Cleveland, OH
Consortium Director:
Dr. Aasef Shaikh
Referral Number: 261-791-3800

Jamaica Plain, MA
Consortium Director:
Dr. Ornella Dubaz
Referral Number: 617-232-9500 x4750

Pittsburgh, PA
Consortium Director:
Dr. Edward Burton
Referral Number: 412-360-6185

Syracuse, NY
Consortium Director:
Dr. Dragos Mihaila
Referral Number: 315-425-3338

West Haven, CT
Consortium Director:
Dr. Diana Richardson
Referral Number:
203-932-5711 x3118

Northampton, MA
Consortium Director:
Dr. Banu Sundar
Referral Number:
413-584-4040 x6600

NEW Veterans Crisis Line

July 16th, 2022—the Veterans Crisis Line has a new and simpler number-**Dial 988 then Press 1**. The Crisis Line offers free 24/7 confidential support, live connection to a qualified responder and serves Veterans, their families and friends.

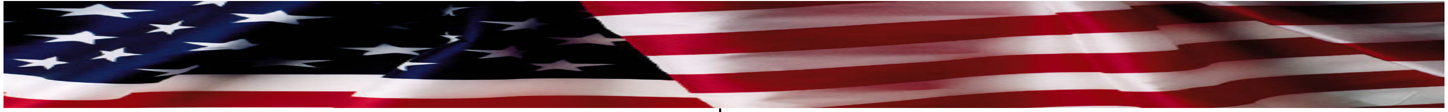
Dial 988 then Press 1, chat live, or text 838255

New number, same support.
Dial 988 then Press 1.

Veterans Crisis Line
DIAL 988 then PRESS 1

My HealtheVet

My Health*e*Vet (MHV) is the VA's Personal Health Record designed to give Veterans and their care partners, anywhere, anytime access to VA health care information. Veterans can schedule appointments online, refill prescriptions, view their health records, and send and receive secure messages with their treatment team. To learn more and register visit: **https://www.myhealth.va.gov**



PD Organizations

Parkinson's Foundation:
www.parkinsons.org 1-800-473-4636

American Parkinson Disease Association (APDA)
https://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

Parkinson & Movement Disorder Alliance
https://www.pmdalliance.org/

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

VA Health Care Eligibility
www.va.gov/health-care/ 1-877-222-8387

Agent Orange Website
www.publichealth.va.gov/exposures/agentorange

Veterans Benefits Administration
www.benefits.va.gov/benefits/ 1-800-827-1000

Filing a VA Disability Claim
https://www.va.gov/disability/how-to-file-claim/

My Health*e*Vet
www.myhealth.va.gov

VA Caregiver Support
www.caregiver.va.gov 1-855-260-3274

State Veterans Affairs Offices
www.va.gov/statedva.htm

The PADRECC Post

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