The VA Parkinson Report

DEPARTMENT OF VETERAN AFFAIRS

A Newsletter from the Parkinson's Disease Research, Education & Clinical Centers and The National VA Parkinson's Disease Consortium

Volume 20 Fall 2023

IN THIS EDITION:

Accessible Care for Cognition, Speech & Swallowing - Parkinson's Disease (ACCSS-PD): Rural Health Quality Improvement Program

By: Vanessa Neal, PhD, CCC-SLP & Nan Musson, MA, CCC-SLP, BC-ANCDS

Increasing access to speech-language pathology care for Veterans with Parkinson's disease

Approximately 40% of persons with Parkinson's disease (PD) have mild cognitive impairment, which is associated with greater risk of developing major neurocognitive disorder (Hely et al., 2008; Saredakis et al., 2019). In addition, nearly 90% of persons with PD will develop symptoms of speech impairment (dysarthria) (Dashtipour et al., 2018) and/or swallowing impairment (dysphagia) (Schindler et al., 2021). Speech-language pathologists (SLPs) are uniquely qualified to treat these impairments; however, Veterans who lack transportation or who live in rural areas may have limited access to SLP services.

To address these barriers, the Audiology and Speech Pathology Program Office initiated the *Accessible Care for Cognition, Speech, and Swallowing – Parkinson's Disease* (ACCSS-PD) program in 2022 with funding support from the VA Office of Rural Health - Rural Health Resource Center (Gainesville, FL). This quality improvement program is designed to (1) improve access to high quality services for rural and homebound Veterans with PD, utilizing virtual modalities (e.g., telehealth, MyHealtheVet, MyVA Images), (2) develop a framework for evidence-based SLP assessment and treatment of PD, and (3) utilize SLP and patient feedback to identify best-practices and strategies for enterprise-wide expansion and sustainment. The SLPs and researchers engaged in the project utilize principles of evidence-based practice, implementation science, and quality improvement models to continually assess and improve the program.

U.S. Department of Veterans Affairs
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Parkinson's Disease Research, Education & Clinical Centers

The ACCSS-PD team and program participants

ACCSS-PD currently includes over 20 SLPs located at 13 VA medical centers across the United States. A total of 15 additional sites joined the program in July 2023. These clinicians are vital to the success of the program and are tasked with implementing the protocol, entering assessment and treatment data into an online database, and providing feedback on the design of the program. The program is overseen by Nan Musson, SLP Discipline Lead with the Rehabilitation and Prosthetics Services Program Office, and managed by Dr. Vanessa Neal, SLP and specialist in cognitive-communication disorders associated with dementia.

Figure 1. Current VA Medical Centers involved in the ACCSS-PD program. These sites include VA Finger Lakes Healthcare System (Bath and Canandaigua, NY), Pittsburgh VA Medical Center (Pittsburgh, PA), Durham VA Medical Center (Durham, NC), Richmond VA Medical Center (Richmond, VA), Carl Vinson VA Medical Center (Dublin, GA), Miami VA Healthcare System (Miami, FL), Nashville VA Medical Center (Nashville, TN), Cincinnati VA Medical Center (Cincinnati, OH), Audie L. Murphy Memorial Veterans' Hospital (San Antonio, TX), Grand Junction VA Medical Center (Grand Junction, CO), Martinez VA Medical Center (Martinez, CA), VA Pacific Islands Healthcare System (Honolulu, HI), and Fargo VA Health Care System (Fargo, ND). (Note: Stars may not represent the exact location of the VA site.)

Since July of 2022, approximately 250 Veterans with PD have been enrolled in the program, with over 30% of those Veterans residing in rural zip codes.

What can Veterans expect when being enrolled in the program?

Enrollment begins with a brief interview about the Veteran's medical history and a conversation about challenges and goals pertaining to cognition, speech, and swallowing. The SLP then conducts a comprehensive assessment including objective clinical measures and patient-reported outcome tools. The initial intake and evaluation may be conducted over telehealth and is typically done in 1 to 2 visits. The SLP may recommend a visit to the medical center if the Veteran needs an instrumental assessment of voice or swallowing (e.g., endoscopic or fluoroscopic exam).

Following the evaluation, the SLP will create a treatment plan tailored to the Veteran's specific needs and preferences. The SLP will also determine if the Veteran would benefit from any assistive technology or devices to support cognition, speech, or swallowing. The Veteran will be offered individual and group treatment sessions and clinicians will provide home exercises and strategies to help with generalization and maintenance of skills. Family and other care partners are also included in treatment to provide education and training on supportive approaches. After completing evaluation and the initial treatment plan, if applicable, Veterans are re-assessed every 6 to 8 months to monitor changes in functioning and determine the need for additional follow-up.

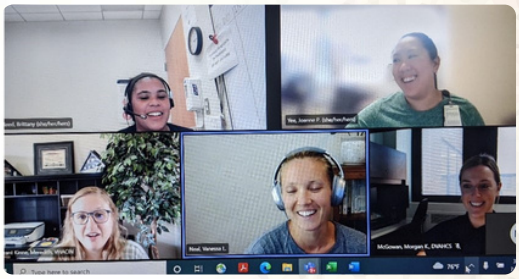

Figure 2. ACCSS-PD team members during weekly office hours. Pictured top left to right: Brittany Reed, Richmond VAMC and Joanne Yee, Madison VAMC. Pictured bottom left to right: Meredith Grant-Kinne, Cincinnati VAMC, Vanessa Neal, Orlando VAMC, and Morgan McGowan (Powers), Durham VAMC.

Figure 3. Veteran receiving telehealth services.

Learn more about ACCSS-PD

For additional information or if you are interested in implementing the ACCSS-PD program at your facility, please contact nan.musson2@va.gov or vanessa.neal@va.gov.

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A NURSE PERSPECTIVE FROM THE WORLD PARKINSON'S CONGRESS

By: Jessica Kaplan, BSN, RN - Southeast PADRECC

The World Parkinson's Congress (WPC) reconvened post-COVID in Barcelona, Spain this July. One of the major international conferences for Parkinson's disease, what makes WPC stand out above the rest is the mélange of both professional health providers and researchers alongside people with Parkinson's disease and their caregivers. It is a phenomenal chance for everyone to collaborate and plot world domination…or in this case, find ways to treat, cure and end PD worldwide.

I had never submitted an abstract before (and did not know the pains of carrying a large cardboard tube all the way to Europe and back) but I was really proud of the interdisciplinary clinic that our PADRECC had created alongside our rehab team and felt compelled to showcase it at WPC (and also show that nurses can develop and implement cool things too!) I was nervous it wouldn't even be accepted and was overcome with emotion when I saw that my abstract was accepted in the top 15th% and invited to the poster tour!

The conference itself was amazing. Each scientific talk was balanced out by real people with PD stepping in to share their experience, wisdom, and even their own research! I heard many exciting talks on subtypes of PD, genetics breakthroughs and the developmental work in PD biomarkers. I learned about the important but often neglected role that a nutritionist can play in managing PD. A very memorable evening was spent enjoying the improv show, Tremors and Triumphs, put together by a group of people with PD who had been meeting only virtually and had come together in-person for the first time. The days I spent in Barcelona were a whirlwind, but it was such an inspiring conference, and one I would encourage people to try and attend if they have an opportunity!

My proudest moment, by far, was when a Veteran from my PADRECC clinic, Bob Pearson, who attended the WPC with his wife, waited around until the very end of the poster tour at the very end of a long day of presentations, to stand up with me at my poster and tell the few that had signed up for this tour how important this clinic had been to him. My heart swelled; his endorsement was better than any graphic or chart! That is what makes WPC such an amazing conference, that you never lose sight of the patients that really matter and that they are there to guide you to their needs. Truly a remarkable experience, I was filled with hope of what we could all accomplish together in the future.

A New Biomarker for Parkinson's Disease

By: Joe Quinn, MD - NW PADRECC

A recent paper from the Parkinson's Progression Markers Initiative (PPMI) and the Michael J. Fox Foundation generated much discussion and many questions from patients about a new biomarker for Parkinson's disease (Siderowf, A. et al, "Assessment of heterogeneity among participants in the Parkinson's Progression Markers Initiative using a-synuclein seed amplification: a cross sectional study", Lancet Neurology 22:407-417, 2023). The biomarker is a cerebrospinal fluid assay (CSF) that is sometimes described as "RT-Quic", which most neurologists associate with a CSF test for Creutzfeld-Jacob Disease (CJD). "RT-Quic" actually refers to a "seed amplification" methodology for amplifying a small signal of aggregated protein, in an iterative process often compared to RT-PCR. The first clinically important application of the methodology was with the prion protein in CJD, as identification of pathologically aggregated prion protein with the RT-Quic method has shown excellent sensitivity and specificity in diagnosing CJD, and has now been in clinical use for many years. The method can theoretically be adapted for any pathologically aggregated protein, and the company "Amprion" has fine-tuned the method to detect aggregated alpha synuclein. Several published reports prior to the recent PPMI/MJF study have shown excellent sensitivity and specificity in diagnosing Parkinson's disease and Lewy body dementia in clinically defined patients. In one of those studies, we contributed banked CSF samples collected from patients who later came to brain autopsy, with systematic confirmation of the presence or absence of Lewy pathology. Amprion performed the assay completely blinded to diagnosis and other clinical information, and found exceptional specificity and good sensitivity in this sample, many of whom were not suspected of having Lewy pathology at the time of CSF collection (Arnold et al, "a-synuclein seed amplification in CSF and brain from patients with different brain distributions of pathological a-synuclein in the context of co-pathology and non-LBD diagnoses" Annals of Neurology, 92: 650-662, 2022).

The MJF/PPMI paper applied Amprion's RT-Quic approach to banked CSF samples from the entire PPMI population and confirmed the diagnostic accuracy of the test while taking the story several steps further. For example, the sensitivity of the CSF assay was reduced in LRRK2-positive PD, consistent with pathologic studies which have shown that a portion of LRRK2 PD patients do not have Lewy pathology. They also found that the sensitivity of the CSF assay was better in PD with hyposmia compared to PD with normal olfaction, suggesting that hyposmia may be a marker for synucleinopathy.

The findings in prodromal and at-risk populations (rather than manifest PD) were even more interesting. The CSF assay was positive in 86% of people with REM behavior disorder or hyposmia, and the CSF assay was more "sensitive" in these groups than DAT scan in detecting pathology in the prodromal period. ("Sensitive" is in quotation marks here since there is no independent confirmation of brain pathology, so this is implied rather than demonstrated.). Rates of positivity in the at-risk groups of asymptomatic LRRK2 and GBA carriers were lower (9% and 7% respectively), but again the CSF assay appeared to be more "sensitive" than DAT scan. The implication of these findings is that the CSF assay may be useful for distinguishing people with early synuclein pathology even before dopaminergic degeneration takes place, so that neuroprotectant strategies can be applied at the earliest possible time.

The Amprion assay is currently commercially available. It is reported as "positive" or "negative" rather than as a quantitative result. Each sample is run in triplicate, and is reported as positive if at least two out of three amplification curves exceed a defined threshold. As of this writing, the test is not covered by Medicare or other insurance carriers, and the cost is approximately $1000. Coverage within the VA system will have to be negotiated locally. The company is currently seeking CMS coverage. Efforts are also under way to see if the test can be performed with biological samples that do not require lumbar puncture. Plasma has limited utility but efforts to develop the test with nasal swabs or skin biopsy are under way.

Physical therapy services delivered via telerehabilitation for Veterans with Parkinson's Disease

By: Aaron E. Embry, PhD, PD, DPT, MSCR – Ralph H. Johnson VAMC

Parkinson's Disease is a chronic progressive neurological disease resulting in a variety of movement related difficulties. It is defined by a loss of dopaminergic neurons in the substantia nigra pars compacta located in the midbrain[1]. The treatment for Parkinson's Disease often centers around management of motor (e.g., tremor, rigidity, bradykinesia, freezing of gait, increased risk of falls) and non-motor (e.g., mood disorders, hallucinations, sleep disturbance) signs and symptoms[2]. Treatment approaches are best delivered as a multi-modal and multi-disciplinary approach which includes physical therapy. Physical therapy evaluation and intervention focuses primarily on the mediation of impact on movement symptoms but can have consequences on non-motor symptoms. Primary outcome measures for physical therapy are primarily focused in the Body Structure and Function, Activity, and Participation domains of the International Classification of Function, Disability, and Health (ICF)[3]. From the evaluation measures, treatment typically focus on improving amplitude and coordination of movement, balance, stretching and flexibility, aerobic exercise, and strength training[4]. Due to the nature of Parkinson's Disease, types of outcome measures, and active treatments, have traditionally been delivered in-person, but the rise of secure, high-quality audio and video platforms and the forced implementation of novel treatment programs due to the COVID-19 pandemic have paved a way for the successful implementation of telerehabilitation programs across the country. United States Veterans make up a large proportion of the overall population of adults living with Parkinson's Disease[5]. Exposure to chemicals like Agent Orange or contaminated water and Traumatic Brain Injury are potentially variables responsible for higher rates of Parkinson's Disease in Veterans when compared to civilians[5]. The VA health care system provides multidisciplinary care that includes physical therapy to Veterans with Parkinson's Disease. Physical therapists are uniquely equipped to deliver care via VA Virtual Care (telerehabilitation platform) to supplement in-person care. As part of routine clinical care, it has been proven effective through a variety of demonstration, feasibility, and clinical integration programs designed to provide access in rural and underserved areas and was fast-tracked into temporary use during the COVID-19 pandemic.

The delivery of high quality and safe telerehabilitation demands additional attention and considerations beyond traditional in-person care. Telerehabilitation care provided to our Veterans should be delivered by clinicians familiar with the Veteran experience, knowledgeable about Parkinson's Disease and secondary complications of motor and non-motor symptoms, the complexities of a home care environment, possess excellent communication and problem-solving skills, and have an understanding and knowledge of the technology hardware and software used. Delivering quality care is highly dependent on the relationship between the provider, system, Veteran, and family/support system. Currently, the American Physical Therapy Association is finalizing a Clinical Practice Guideline (CPG) to guide physical therapy telerehabilitation practice. This CPG contains information specifically related to medical conditions like Parkinson's Disease which can help guide clinicians and scientists in their implementation of telerehabilitation into successful routine practice. Veterans have expressed high levels of satisfaction with their telerehabilitation experience (unpublished data)

that includes individualized exercise based virtual care or routine scheduled check-in video appointments for health maintenance and multidisciplinary follow-up. The addition of virtual care into either established or developing multidisciplinary clinics can improve the quality of care we provide our Veterans with Parkinson's Disease.

Parkinson's Disease is a chronic progressive neurological disorder with impacts felt beyond the nervous system. Engaging our Veterans in meaningful exercise and activity-based interventions in their home reduces the impact of travel into VA Community Based Outpatient Clinics and VA Medical Systems and saves therapist time which allows for more Veteran encounters and closer monitoring of disease progression. Telerehabilitation allows therapists to be 'in the home' to keep a close eye on the home dynamics, family support, and structure/set up for potential intervention and Veteran safety. The implementation of telerehabilitation programs that include physical therapy keep Veterans in their homes, reducing potential Veteran confusion and difficulty accessing care, and provides a conduit for a skilled, licensed medical professional to maintain the dignity and independence of our Veterans.

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4. Osborne JA, Botkin R, Colon-Semenza C, et al. Physical Therapist Management of Parkinson Disease: A Clinical Practice Guideline From the American Physical Therapy Association. Phys Ther. 2022;102(4).
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HOUSTON PADRECC UPDATE

Houston's Parkinson's Disease Research, Education and Clinical Center (PADRECC) housed in the Michael E DeBakey VA Medical Center provides state of the art medical and surgical services to Veterans with Parkinson's disease and related movement disorders who reside in the South Central and Mid-Western United States. The area served by the Houston PADRECC includes all or parts of the following states: Texas, Louisiana, Mississippi, Oklahoma, Arkansas, Alabama, Florida, Kansas, Missouri, Indiana, Illinois, Wisconsin, and Kentucky (Houston PADRECC Consortium).

Consortium Update

In FY 23, we added Dr. Tania Zayas-Torres (Neurologist) at the San Juan VA, Puerto Rico to our consortium members group. A new initiative to provide prolonged virtual clinical case management support to our Consortium members regarding complex movement disorders patients was initiated that benefitted 2 patients. We also updated our Points of Contact and organizational chart of the regional consortium. We enhanced our educational services to include consortium members participation in our virtual educational webinars. In addition, we continued to provide educational materials and conducted our monthly educational meetings with all our consortium sites that include clinical case discussion, and sharing of latest clinical, educational and research related information amongst the site participants.

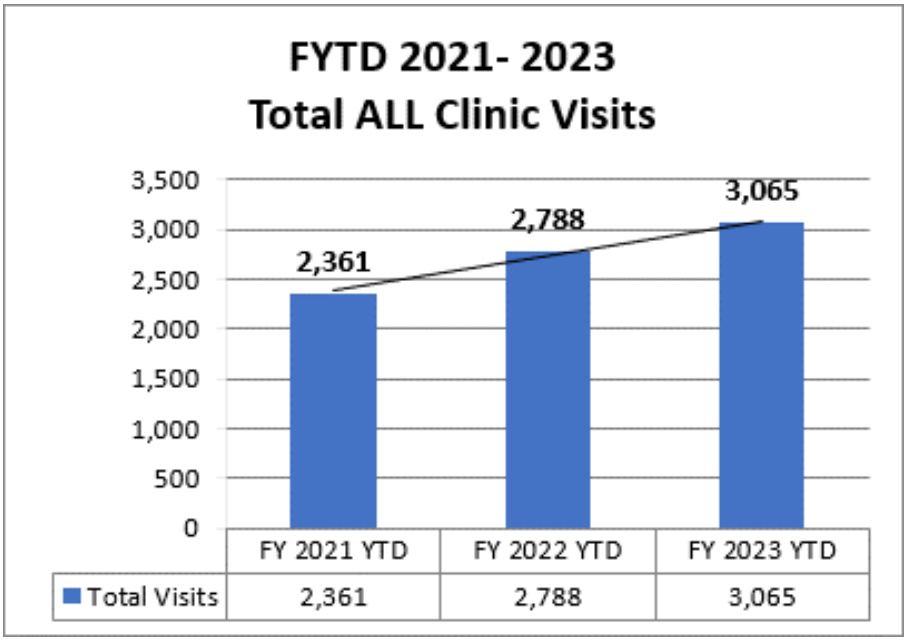
HOUSTON PADRECC UPDATE (continued)

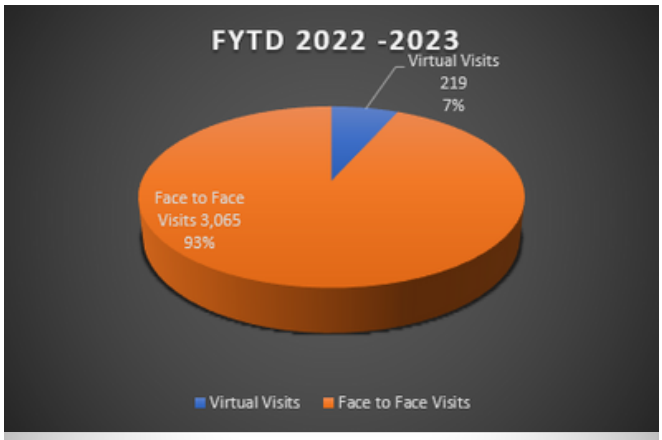
Administrative Update

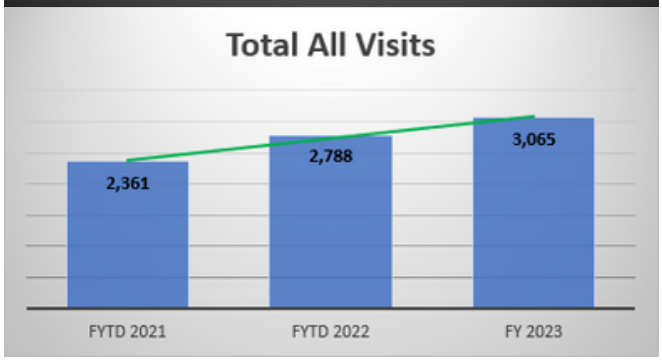
We are extremely delighted to welcome new staff members, Mr. David Padilla, BS, who joined the Houston PADRECC as the Health Research Science Specialist (HRSS) on September 11, 2022. In addition, the Houston PADRECC's administrative team have successfully recruited Ms. Lizamma George, RN, on February 15, 2023, who backfilled the vacant Nurse position (Nurse Educator) vice Ms. Olga Diverse, R.N.

Clinical Update

Houston PADRECC continued its robust clinical services which include a mix of face-to-face and virtual clinical evaluations. Our virtual clinics were successfully expanded and adequately utilized.







Performance Improvement Initiatives started in FY23

- The Houston PADRECC actively integrated Whole Health practices in the care model. The Director received the full WH training and acted as a champion for WH. The remainder of the PADRECC team that included two physicians, two nurses, administrative officer, RHSS and a neuropsychologist were also trained directly by the facility's whole health coordinator. These training sessions were specially arranged, virtually conducted, and included an invitation to all other PADRECCs and consortium site members.

- Dr. Fariha Jamal is developing Houston PADRECC Guidelines for ordering Cala Trio to provide transcutaneous afferent patterned stimulation for improving tremor in Veterans with Essential tremor and Parkinson's disease.

Education Update

Houston PADRECC is actively recruiting for its Movement disorders Fellowship position (VA Post Residency Advanced Fellowship in Parkinson's disease) for FY 24. This would be a fellowship position dedicated to Houston PADRECC at the Michael E. DeBakey with the purpose of training a future Veteran-centric movement disorders specialist to serve within the VA healthcare system.

Houston PADRECC has a broad range of educational programs for the staff, medical and allied health trainees, junior physicians, patients, and caregivers. Our Associate Director of Education position has been vacant since 2018.

We offer:

- Five **Patient-Centered Education Programs** (Support groups, Educational Conferences, Clinic based 1:1 Education, Community Educational Conferences, Educational Newsletters)
- Twelve **Medical Professionals Centered Educational Programs** (Live lecture series, Audio Lecture Series, Journal Club, Clinic based Education, Bedside teaching, Mandatory BCM PGY4 monthly elective rotation, Pharmacy residency elective rotation, PADRECC training rotations for three fellowship programs (Geriatrics, Neuropsychiatry, Geriatric Psychiatry), BCM didactics, Community lectures, Case Conferences, National and Local Educational Teleconferences)

Research Update

We currently have 11 active research projects. Recruitment has resumed in our Circadian Rhythm/ Sleep Study following a period of suspension due to COVID 19 pandemic related precautions.

Funded Research Projects in FY23

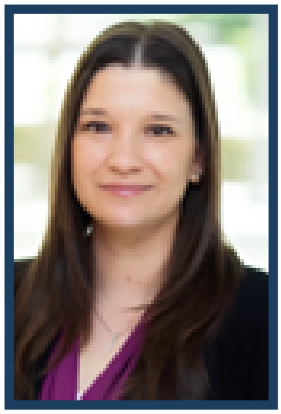
1. Multicenter, randomized, double-blind comparator study of antipsychotics pimavanserin and quetiapine for Parkinson's disease psychosis. Cooperative Studies Program (CSP) 2015. One subject in phase 3 (Site PI: Sarwar)
2. Veterans Parkinson's Disease Genetics Initiative (Vet-PD) ~ now recruiting. (Site PI: Jackson, GR)
3. A Multicenter observational study on the prevalence of loss of benefit after DBS for medication-refractory tremor (MDS-Tremor task force) – 3 subjects have been recruited. (Site PI, Jamal, F)
4. Screening for prodromal markers of alpha-synucleinopathies in post-9/11 Veterans." Center for Alzheimer's and Neurodegenerative Diseases (CAND) Scholars Program. Assessment of post-9/11 Veterans in the ongoing Translational Research Center for TBI and Stress Disorders (TRACTS) cohort for RBD and other prodromal features of alpha-synucleinopathies (PI: Jones, M, Co-I, Sarwar, AI ~ concluded 12/2022

Publications and other research presentations

- Abstracts/posters = 6 (accepted and/or presented)
- Manuscripts = 4 (2 published, 2, under review)

SAN FRANCISCO PADRECC UPDATE

Staffing Updates to San Francisco Team



Dr. Tamara Stiep is a movement disorders neurologist at the University of California, San Francisco (UCSF) and the San Francisco Veterans Affairs Medical Center. Dr. Stiep completed her medical degree at New York Medical College. She completed a residency in adult neurology at Jackson Memorial Hospital at the University of Miami, where she served as chief resident and received an award for compassion in medicine. She completed a fellowship in movement disorders at the University of Florida. Dr. Stiep is experienced in using advanced techniques to treat movement disorders, including deep brain stimulation, well versed in using botulinum toxin (Botox) injections and alternative delivery systems for carbidopa/levodopa (Duopa). Her research interests include learning more about the effects of deep brain stimulation on non-motor symptoms in patients with Parkinson's disease.

Dr. Meredith Bock is a movement disorders neurologist at the University of California, San Francisco (UCSF) and the San Francisco Veterans Affairs Medical Center. She completed her medical degree, neurology residency, movement disorders fellowship, and neuroepidemiology research fellowship at UCSF. She specializes in the clinical evaluation of individuals with Parkinson's disease, dementia with Lewy bodies, and other movement and cognitive disorders. Her research interests include the cognitive, behavioral, and other non-motor symptoms of Parkinson's disease across the full illness course. She is also interested in earlier diagnosis of Parkinson's disease, optimizing quality of life at each stage of illness, and neuropalliative interventions to manage complex symptoms.

Welcome Junior Fellows

We welcome new fellows Victoria Chang from the University of Washington and Diksha Mohanty from the University of Louisville School of Medicine to the San Francisco PADRECC!

Clinic Updates

San Francisco is developing a new multidisciplinary clinic for Advanced PD. Stay tuned for further developments.

Research

Dr. Rafael Zuzuarregui has 3 abstracts that were accepted for the poster presentation at this year's Movement Disorder's Society International Congress in Copenhagen, Denmark. If you are going, please stop by to say hello.

- Hoang P and Zuzuarregui JR. A 78-year-old man with progressive ataxia, palatal tremor, parkinsonism and motor neuron disease.
- Wiltshire A, Mahes A, Wang S and Zuzuarregui JR. Globus pallidus interna deep brain stimulation for Parkinson's Disease: Impact on Restless Legs Syndrome.
- Mahes A, Wiltshire A, Wang S and Zuzuarregui JR. Impact of globus pallidus interna deep brain stimulation on REM sleep behavior disorder in Parkinson's disease.

Clinical Update

Integrative Medicine: Dr. Indira Subramanian, Director of the Southwest PADRECC, has collaborated with the Integrative Medicine group at the VA Greater Los Angeles (VA GLA). Dr. Subramanian is incorporating Integrative Medicine techniques that considers the whole person, to include all aspects of lifestyle. It emphasizes the partnership between provider and patient and meeting the patients where they are especially from a cultural context. She is working on further solidifying the concept of wellness - where patients proactively make lifestyle choices to help them thrive. From a loneliness perspective, Dr. Subramanian is working on identifying screening questions to identify lonely PWP and clarify what social prescribing strategies can help them with their quality of life. She has been hosting a weekly virtual support group since the March 2020 and has been coediting a blog under Parkisonsecrets.com

Healing Touch Therapy (HTT): In May 2023, Patricia Pittman, RN, MBA, Clinical Nurse Coordinator, began training towards Certification in Healing Touch Therapy (HTT), within the VA system. Training involves extensive coursework and documentation of patient care time prior to the completion for certification. HTT is a form of energy medicine / biofield therapy in complementary and integrative health (CIH). The hands are used to maneuver the energetic field patterns based on a patient's presentation. The evidenced based practice focuses on healing according to detailed descriptions of energy anatomy and flow.

Aromatherapy: In September 2023, Patricia Pittman, RN, MBA, Clinical Nurse Coordinator, will receive training, within the VA system, on Aromatherapy for Environmental Enhancement. The training aims to introduce healthcare professionals to the safe use of select essential oils for comfort care. Patricia is receiving Healing Touch Therapy and the Aromatherapy practicum trainings with Veterans, which will include Parkinson's patients, under the direction of Certified HTT practitioners in the Integrative Medicine team at the VA Greater Los Angeles.

Neuro-Pharmacy Program: In collaboration with Sunita Dergalust, Neurology PharmD, specialized pharmacy care was integrated in the PADRECC clinic. Patient records are reviewed to determine if a patient is compliant in refilling Movement Disorders related medications. If compliance is not met, a pharmacy resident will call the patient to review dosing and assess for any barriers or concerns. Pharmacy residents also meet with patients during clinic to provide education and ensure they are taking their medication as prescribed.

Education Update

Living Well with PD Symposium (previously known as PD 101): Patricia Pittman, RN, MBA, Clinical Nurse Coordinator, organizes a yearly 2-hour event held at the medical center. The symposium is for patients and caregivers to provide information about PD and how they can better care for themselves utilizing resources within the VA and outside community. In collaboration with VA staff members and the community, diverse topics related to PD are presented. Some of the topics were mindfulness, yoga, physical therapy, exercise, dancing through Parkinson's, medications, mood, cognition, and psychosis. Patients participated in a range of fun and beneficial activities including yoga, mindfulness, and boxing.

Mindful Movement for Parkinson's: VA GLA PADRECC Movement Disorders clinic, in collaboration with Elika Razmjou, Psy.D., VA GLA Clinical Health Psychologist and Aubrey White, MA CCC-SLP, VA GLA Audiology and Speech department, has a virtual drop-in mindfulness group for Veterans who have been diagnosed with Parkinson's, and are established with the GLA Movement Disorders clinic. The focus will be to practice mindfulness skills for improved concentration, self-regulation, and social engagement. Each session will include education, breathing exercises, a gentle and seated movement practice, and a closing meditation.

Research Update

Parkinson's Environment and Gene (PEG) Study: Dr. Adrienne Keener, is a study physician on this NIH-funded study of over 800 patients and 800 matched controls recruited to date. They have continued to recruit new subjects and controls through a recently funded grant from the NIEHS using the California Registry to identify new subjects. Dr. Keener was the recipient of a pilot grant from the American Parkinson Disease Association to examine PD onset and progression phenotype in Hispanic participants of the PEG study. She conducts the assessments of new and follow-up study subjects and assists in data analysis.

National Consortium Cooperative Studies Program clinical trial, VA CSP#2015, "Multicenter, Randomized, Double-Blind, Placebo-Controlled Comparator Effectiveness Study of Antipsychotics Pimavanserin and Quetiapine for Parkinson's Disease Psychosis: Denise Feil MD, MPH, PADRECC Neuropsychiatrist, is the Site Investigator

PHILADELPHIA PADRECC UPDATE

Clinical Update

Working together to provide optimal care: Collaboration with local and national VA programs

- **Assistive Technology Program:** implemented a referral process with Richmond VA's Assistive Technology Program to evaluate, develop and implement appropriate technology services, strategies, devices and/or practices to improve Veterans' functional challenges.
- **Whole Health Program:** established a consult process for local Veterans to meet with a Whole Health Coach to support their health goals and overall well-being.
- **Palliative Care:** continuing a fruitful relationship with local Palliative Care Team to help PADRECC patients and their families address goals of care and end of life needs .
- **Mindfulness Based Cognitive Therapy for People with Parkinson's Disease:** this VA Office of Rural Health telemedicine program is now being offered to Veterans diagnosed with PD living in the Philadelphia VA PADRECC catchment area. This program has been designed to help Veterans with PD cope with depression, anxiety and the stress and challenges living with PD.
- **Caregiver Support Program (CSP)**: Crescenz VAMC was awarded a CSP special emphasis program supporting a Parkinson's Disease Program Coordinator to address the needs of caregivers of Veterans with PD. The PADRECC has been working closely with CSP to integrate the Program Coordinator into clinical care for patients and caregivers.

DBS is back at the Philadelphia PADRECC!

We are excited to once again offer Deep Brain Stimulation (DBS) surgery at the Philadelphia VAMC for Veterans with PD, ET, dystonia and related disorders. The Philadelphia VA PADRECC was at the forefront of studies of DBS outcomes in the early 2000's. Through the multidisciplinary collaborative efforts of Drs. Casey Halpern and Isaac Chen in neurosurgery, and Dr. Pavan Vaswani, Arvette Benson, Ashley Pfeifer in the PADRECC, Dr. Sol Kalkstein in Neuropsychology, and Andrea Dombroski in OT, Casey Barnett and Kyle Mohan in PT, and Caitlin McKnight in speech pathology, we're thrilled to offer this therapy again after 15 years!

Key Staff Updates

Dr. John Duda
PADRECC
National Director

Dr. Jim Morley
Philadelphia
PADRECC
Director

Dr. Pavan Vaswani
Fellowship Director

Eileen Hummel, NP
Associate Director
of Clinical Care

Dawn McHale
National PADRECC
Administrator

Education Update

Monthly Patient & Caregiver Support Group Program: continues to be held virtually in collaboration with the Richmond PADRECC and is offered year round.

PD 101: This annual webinar was held virtually in April in celebration of PD Awareness Month. The program provided an overview of PD symptoms, treatment and the expert care available through the PADRECCs and Consortium Centers. The webinar was open to all Veterans, caregivers and anyone interested in learning more about PD.

Community Outreach: Clinical staff continued outreach efforts presenting at several virtual support groups and attended 4 local community health fairs including the Michael J Fox Parkinson's IQ + You fair.

DIVERSITY PD: The Philadelphia PADRECC is proud to be a partner of this unique multi-institutional initiative centered around relationship building with key community partners to create a foundation for reaching and providing high-quality care and education to people with PD from underserved communities. This summer our PADRECC participated in the "Living Well" internship sponsored by the Davis Phinney Foundation, that included clinical observations for 2 full-time undergraduate/graduate students with interest in PD and who identified as Black/African American.

Fellowship Program: The Philadelphia PADRECC receives two fellowship slots each year shared with the University of Pennsylvania. Clinical observations are provided for Geriatric and Pain Medicine fellows, psychology post docs and neurology residents.

Case Conferences: The Philadelphia PADRECC continues to host monthly video case conferences for providers throughout the VA.

Research Update

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

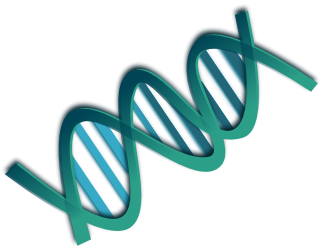
This is a nationwide, multicenter clinical trial comparing two antipsychotic medications (quetiapine and pimavanserin) for the management of PD related psychosis. Drs. Duda and Weintraub are the national co-PIs and Dr. Morley is the Philadelphia site PI.

Parkinson's Disease Biomarkers in Human Olfactory Cleft Mucus

Dr. Morley, Dr. Noam Cohen (CMCVAMC/ Department of Otolaryngology) and Dr. Hong Wang from (Monell Chemical Senses Center) are collaborating on this NIH-funded project seeking to identify PD biomarkers in nasal cavity mucus to aid in the diagnosis and prognosis of PD.

Vet-PD: The Veterans Parkinson's Disease Genetics Initiative

The VA PADRECC network has joined this sub-study of the Global Parkinson's Genetics Program (GP2) funded by the Michael J. Fox 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 Vet-PD sub-study is focused on recruitment of underrepresented minority Veterans that have not traditionally been included in PD genetic research.



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

Grant from the Department of Defense's PD program. Dr. Morley is investigating new approaches that 1) use "gamification"— applying rules of games like point scoring —to increase physical activity in PD; 2) identify whether certain PD patients respond differently to gamification interventions; 3) use readily and commercially available digital health technologies to perform all study activities remotely and enable a "touchless" study.

Understanding What is Wrong in Parkinson's Disease Cells

Dr. Duda and his colleagues, Drs. Kacy Cullen, Isaac Chen and Dimple Chouhan have begun generating a replica 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 novel therapies to stop that process.

Neurorestoration in Parkinson's Disease

Dr. Duda and his colleagues Drs. Kacy Cullen and Isaac Chen from the Center for Neurotrauma Neurodegeneration, and Restoration (CNNR) at the Philadelphia VAMC, continue to investigate whether the nigrostriatal pathway can be generated in a petri dish and transplanted in animal models to reverse motor symptoms in PD. This work has been funded by many organizations, including the VA, the Michael J. Fox Foundation and Innervace, Inc. The team has been successful in implanting these bioengineered pathways into a rat model 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 rat model, the constructs survive well, integrate into the brain structures and generate dopamine. In the last year, another breakthrough was achieved when these constructs were derived from human stem cell lines and transplanted successfully, potentially paving the way for these constructs to be generated from a patient's own cells.

SOUTHEAST/RICHMOND PADRECC UPDATE

Clinical Update

In June 2023 the SE PADRECC marked one year since starting their interdisciplinary clinic. This 3 hour in-person or telehealth appointment provides the Veteran access to physical therapy, occupational therapy, speech therapy, assistive technology, nursing, social work, chaplain, and vision rehab. After completing this evaluation, the team meets and devises a treatment plan for the Veteran and follow-up for this clinic is yearly. Over one-hundred Veterans have been seen in this clinic in it's first year. This person-centered, preventative-care approach to movement disorder treatment has been received well from Veterans, caregivers, and clinic providers.

Education Updates

In Fall 2022, SE PADRECC partnered with Greater Richmond YMCA and local foundation POP, to put on an event **"Finding you Team"**. This event was held at Hunting Hawk Golf Course and involved a panel of rehab providers (physical therapy, occupation therapy and speech therapy) discussing ways to involve rehab providers in treatment for Parkinson's disease. A new hire to Virginia Commonwealth University, Dr. Miller-Patterson, gave an introduction and Dr. Lehosit moderated the rehab panel.

In April 2023, SE PADRECC partnered with local organization SwimRVA and Greater Richmond YMCA to put on a **Senior Wellness Fair** with a PD expo. Over 30 local and national vendors were present, 13 of which were PD-related. There were live exercise classes and a keynote by Virginia Commonwealth University gerontologist, Dr. Welleford MSG, PhD, AGHEF.

Also in April 2023, the PADRECC hosted a **Technology and Innovation Fair** in the multipurpose room at the Richmond VAMC. Our interdisciplinary team services (physical therapy, occupational therapy, speech therapy, recreation therapy, music therapy, Vision rehab, social work, and more) brought various technology and equipment available to Veterans with movement disorders. This hands-on fair provided an opportunity for our patients to test out devices and many left with consults for follow-up or equipment orders (see picture)

Recreational Therapy Collaboration

We have also started partnering with our local recreation therapy group to offer some programming for our PADRECC patients. We have held a virtual informational meeting, had a baseball game night at the Diamond to see a Richmond Flying Squirrels game, and we are doing a park picnic on September 8th. We look forward to planning more group outings and activities!

SOUTHEAST/RICHMOND PADRECC UPDATE

Support Groups: This year two additional support groups were created by SE PADRECC. The **Early Onset Support Group** was created to meet the needs and lifestyles of Veterans living with early onset PD. Many of the Veterans in this group are still navigating work and young children. Another group was started to support the **Caregivers of Veterans with Movement Disorders**. Both groups are held monthly and virtually.

Staff/Training Updates

This year we welcomed **Emily Hall, LCSW**, Social Worker to our PADRECC family. Emily completed her Bachelor of Arts Degree in Psychology and Sociology at Gettysburg College. She completed her Master of Social Work Degree at Virginia Commonwealth University. She completed clinical internships at the Psychiatric Institute of Washington: The Center, The Mill House with Community Brain Injury Services, and the Inpatient Polytrauma Rehabilitation Center at the Richmond VAMC. She has experience in Emergency Room & Medical Social Work Case Management, Rehabilitation, Brain Injury, Mental-Health Skill Building, Intensive In-Home Services, Parent Coaching, and Psychiatric Trauma Treatment for Inpatient and Partial-Hospitalization Day Programs. Emily has been employed at the Central Virginia VA HCS since August 2018, previously serving as Clinical Social Worker in the Polytrauma Inpatient Rehabilitation Center working with veterans and active-duty service members. Additionally, she serves on Richmond VAMC's Social Work Professional Practice Council, Social Work Education Committee, and Social Work Morale Committee. Emily is a Board-Certified LCSW Supervisor and MSW Clinical Field Instructor.

We have also hired **Rachel Sinclair** as our PADRECC Health Science Specialist Research Coordinator. **Christina Kausek** as the PADRECC PSA and two MSAs dedicated to the PADRECC program (**Cari Kowalsky and Fatima Smith**). We are currently in the process of recruiting and hiring an additional movement disorder neurologist.

Research Updates

The SE PADRECC is working to expand our research program.Current projects include **VetPD**, the **Veterans Parkinson's Disease Genetics Initiative and CSP 2015, Pimavanserin vs Quetiapine for Treatment of Parkinson's Psychosis**. Recently we closed **BOSS-PD**, which aims to establish non-inferiority of pelvic floor muscle exercise-based behavioral therapy vs a drug therapy for urinary incontinence in Parkinson's Disease. There are also projects in development such as MAV-PD, **Methylphenidate for Apathy in Veterans with Parkinson's Disease**, and a feasibility study for the use of a wearable exoskeleton device to assist with mobility for Parkinson's Disease.

Minneapolis VA Healthcare System

Rehabilitation Updates – Bringing Life to Your Years

At the Minneapolis VA PADRECC Consortium site, management of Parkinson's Disease (PD) is shared between Neurology and Rehabilitation Medicine. Veterans are referred to the neuro rehab clinic from their neurologist or other Rehabilitation and Extended Care (REC) provider. Rehabilitation Medicine performs a comprehensive assessment focused on daily function and works together with the neurologist to manage the Veteran's care through a multi-disciplinary, holistic approach. Veterans are followed lifelong, including regular referrals and follow-ups to neuro-based therapies (PT/OT/SLP/Rec Therapy/Psychology). Early referral to Rehab Medicine and subsequent PD therapies engages Veterans early in the disease process. To maximize the Veteran's quality of life, a variety of specialized, PD rehab programs are offered, including:

- **Outpatient LSVT BIG® Hybrid Program** – An evidenced-based, intensive therapy program with PT/OT over 6 weeks. Emphasizes intensity and amplitude of movements specifically for people with PD. 3 sessions/week are virtual and 1 session per week is face to face.
- **Outpatient Speak Out! ® Voice Program** – Intensive voice therapy for people with Parkinson's disease, offered virtual, face to face, or a combination approach, including 2-3 sessions/week for 3-4 weeks.
- **Inpatient/Residential Living Large Program** – 5-week, residential rehab program for people with Parkinson's including intensive voice and movement therapies (LSVT BIG®, Speak Out! ® / LSVT LOUD®), in addition to a full range of interdisciplinary therapies throughout their stay.
- **Virtual Wellness/Exercise and Voice groups** – A robust offering of PD specific virtual wellness/exercise groups (10/week) and voice groups (4/week) to keep our Veterans with PD active and living their best lives.
- **Recreation therapy** – Veterans with PD can participate in weekly community golf outings, adaptive bike rides and kayaking, fly fishing, walking programs, and much more, along with individual sessions for recreation/leisure assessments and exploration of familiar or new interests.
- **Community Outings** - Nearly 20 Veterans, along with family members and staff participated in the 3rd annual community outing to Parkinson's Awareness Day at Target Field. Veterans were able to participate in a pre-game walk on the field and enjoyed a Twins shut out against the Boston Red Sox, including 3 home runs!

Minneapolis VA Healthcare System

Deep Brain Stimulation (DBS) Center Updates

The Minneapolis VA is proud to offer an in-house DBS program, including multi-disciplinary work-up, surgical implantation, and post-operative programming. Our first DBS implantation occurred in November 2021. To date, the Minneapolis VA has performed 20 DBS implantations, despite a 6 month pause in surgeries in 2022. The Minneapolis VA takes referrals from all VISN 23 sites.

Support Group Updates

Parkinson's Disease Veteran Support Group – Occurs via Webex once per month and is open to all Veterans and care partners. Groups are facilitated by members of the Parkinson's Disease and Movement Disorders team and include a PD specific discussion topic and psychosocial support.

Parkinson's Disease Caregiver Support Group – A support group specific for caregivers of Veterans with Parkinson's Disease. There are 4 cohorts per year of 8 sessions (including educational topics specific to PD + support), with the option to continue in the monthly, ongoing support group after completing the initial cohort. Topics include Parkinson's 101; apathy/depression; occupational therapy (including adaptive equipment, in-home modifications, and HISA grant, driving, cognition); physical therapy (including functional mobility, falls prevention, gait and transfers, and importance of exercise); self-care strategies for the caregiver; and sleep tips and resources for both the Veteran and caregiver.

PATIENT RESOURCES

PADRECC Support Group Offerings

Philadelphia & Richmond VA PADRECC
Meetings: 1st Monday of the Month @ 1pm-2pm EST
Location: Virtual
Contact: Gretchen Glenn, email for link information

San Francisco PADRECC
Meetings: 3rd Tuesday of the Month @ 4pm to 5:30 pm PT
Location: Virtual
Contact: Annie Li Wong, GNP, MSN, RN,
email or call for video links: 415 379 5530

Houston PADRECC
Meetings: 1st Thursday of the @ 12:30pm - 1:30pm CT
Location: Virtual via Microsoft Teams- Meeting link
Contact: Sally J. Samuel, RN (713) 794-8410

West Los Angeles PADRECC
VA Greater Los Angeles PADRECC
Meetings: 2nd Tuesday of the Month @ 10am – 11am PT
Location: Virtual
Contact: Patricia V. Pittman 310-478-3711 x48001

VA Long Beach Health Care System
Meetings: every other Friday @ 1pm – 2:30pm PT
Location: Virtual via VA Video Connect (VVC)
Contact: Megan Gomez, PhD: 562-706-0740

Northwest PADRECC-Portland
Meetings: 2nd Friday of the month @ 10am-11:30pm PT
Location: VA Portland Health Care System (presently held virtually)
Contact: call to register-- 503-220-8262 x58594

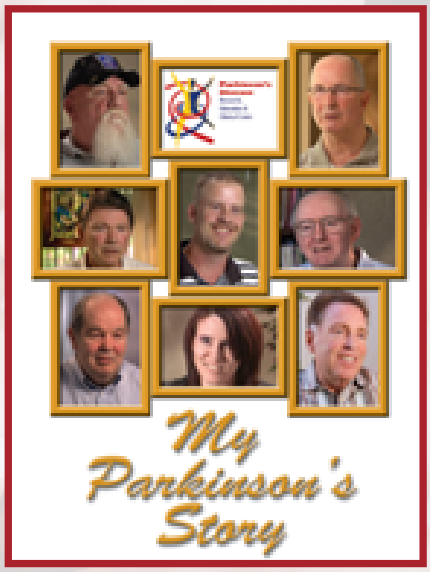
Early Onset Support Group
for people diagnosed before age 50
Meetings: 2nd Wednesday of the month @ 5:30pm EST
Location: Virtual
Contact: Jessica Kaplan or 804-675-5931

Caregiver Support Group
Meetings: 3rd Monday of the month @ 10:00 am EST
Location: Virtual
Contact: Jessica Kaplan or 804-675-5931

www.parkinsons.va.gov/patients.asp

Online Resources

My Parkinson's Story: A series of short videos prepared by the VA PADRECCs addressing various aspects of Parkinson's disease



Suggested Education Essentials for Veterans with PD- this document contains useful website links for topics such as: Overview of PD, Exercise, Medications, Nutrition, and National/Regional Organizations

PADRECC Brochures: check out the newly updated PADRECC education brochures:

- Agent Orange & Other Toxic Exposures
- Exercise & Physical Activity
- Fall Prevention
- Motor Symptoms
- Non Motor Symptoms

CLINICAL RESOURCES

Movement Disorders Series

Knowledge-based webinars providing VHA healthcare professionals with current practice standards and emerging trends in the treatment of Parkinson's disease and other movement disorders. Continuing Education for Professionals is typically provided for the live webinars. They are offered 2 times a year and are approximately 4 hours in length.

Transmitter

Bi-monthly email providing:

- 3 recent movement disorder articles reviews
- PADRECC committee updates
- PADRECC and PD organizations' education offerings

Case Conferences

Regularly scheduled case conferences that serve as a platform for an educational exchange amongst movement disorder providers regarding clinical aspects of PD, research topics, and VHA patient care standards. If you are interested in attending one of the below conference calls please reach out to the listed contact person.

Houston

When: Third Thursday of the Month

Time: 12:30 - 1:30pm CST

Description: Discussion of complex cases: medication problems, orthostatic hypotension, psychiatric co-morbidity management, tremor and other common movement disorder scenarios.

Via TEAMs: Click here to join the meeting

Contact: Anthony Washington6@va.gov

Philadelphia

When: **Last Monday** of the Month

Time: 12:00pm EST

Description: Video case conference of difficult cases are presented.

Via TEAMs: contact Dawn McHale for link

Contact: Dr. John Duda

West LA/San Francisco

When: Fourth Tuesday of the Month

Time: 12:00pm PST

Description: Present interesting and clinically relevant articles and invite a speaker to discuss the article. Recent discussants have included Mike Okun, Ray Chaudhuri, Alfonso Fasano, to name a few. The UCLA and UCSF fellows share responsibility arranging discussant, creating slides and presenting the articles.

Via Zoom:

Contact: Dr. Indu Subramanian

Contact Gretchen Glenn to be added to the PADRECC email list to receive education updates

PARKINSON'S FOUNDATION RESOURCES

VHA/Parkinson's Foundation partnership renewed - August 2023!

PATIENT DIGITAL RESOURCES

Dedicated Veterans Webpage: Veterans & Parkinson's | Parkinson's Foundation

Frequently Asked Questions for Veterans with PD and Care Partners

Digital Resource Guide for Veterans: collection of digital books, fact sheets, videos webinars and podcasts

PROFESSIONAL RESOURCES

PF Digital Resources for VA Health Professionals Treating Veterans with PD: wide range of online training and education resources

PF Team Training Program: teaches medical professionals from diverse

PF Learning Lab: learn and apply best-care PD knowledge through PF's multiple in-depth accrediated and non-accredited online training courses for health professionals

Education Series for Community Providers
FREE online education courses, offering CEUs for healthcare professionals to learn more about PD. The education series is designed for healthcare providers who are not Parkinson's specialists, but who want to be better prepared to provide optimal PD care. Register today to help improve care for all people living with PD. Education.Parkinson.org/ProfCommProviders

VETERAN WEBINARS

Upcoming

Planning for the Future: 10/26/2023

Environmental Exposures -12/14/2023

Past Veterans & Parkinson's Webinar Recordings

Exercise, Nutrition & Wellness

Mobility and Driving Safety

A Team Approach to Living Well

Environmental Exposures in Veterans with PD

What You Need to Know

Parkinson's Foundation

VETERANS & PARKINSON'S POSTCARD & FACT SHEET

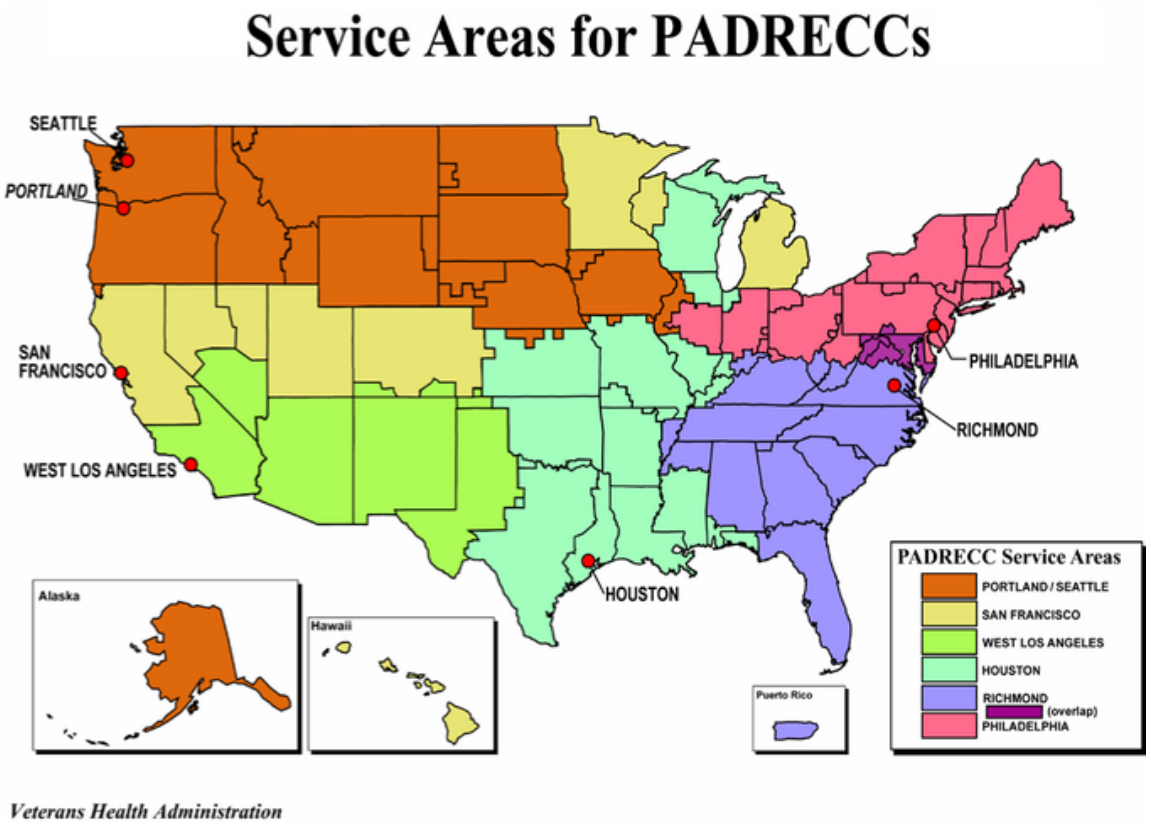
These resources provide a quick introduction to Parkinson's disease, the benefits available through the VA, and where one can go to learn more and access support. Great to have on-hand to share with Veterans and their loved ones! To place an order, view the Parkinson's Foundation's Order guide for Professionals or call the Parkinson's Foundation Helpline at 1-800-4P-INFO (1800-473-4636)

Consortium National Office	Consortium Center Referral Line	Newsletter Editors
John Duda, MD, Chairperson Dawn McHale, Administrator	Tonya Belton 1-800-949-1001 x 205769	**Gretchen Glenn** National VA PD Consortium Education Subcommittee Chair **Jessica Kaplan, RN** SE PADRECC Nurse Coordinator **Emily Hall, LCSW** SE PADRECC Social Worker

PADRECC National Directory

Center	Medical Center	City, State	Director	Telephone
Houston	Michael E. DeBakey VAMC	Houston, TX	Aliya I. Sarwar, MD	713-794-7841
Southwest	VA Greater Los Angeles Health Care System	Los Angeles, CA	Indu Subramanian, MD	310-478-3711 ext. 48001
Northwest	Portland VAMC VA Puget Sound Health Care System	Portland, OR Seattle, WA	Amie Hiller, MD	Portland: 503-721-1091 Seattle: 206-277-4560
Philadelphia	Corporal Michael J. Crescenz VAMC	Philadelphia, PA	James F. Morley, MD, PhD	215-823-5934 or toll free 888-959-2323
Southeast	Hunter Holmes McGuire VAMC	Richmond, VA	Jessica B. Lehosit, DO	804-675-5931 or toll free 800-784-8381 ext 5931
San Francisco	San Francisco VAMC	San Francisco, CA	J. Rafael P. Zuzuarregui, MD	415-379-5530

Service Areas for PADRECCs



Veterans Health Administration