



The VA Parkinson Report

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A Newsletter for the Parkinson’s Disease Research, Education and Clinical Centers and The National VA Parkinson’s Disease Consortium

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Pressing Gaps in Care in Parkinson’s Disease

By: Dr. Indu Subramanian, Southwest PADRECC Director

The COVID-19 pandemic has highlighted tremendous gaps in care of people living with PD. I highlight here 3 major areas of focus that I have become passionate about and hope that a silver lining of this turbulent time is that we can all work together towards improving care for all PWP worldwide in 2022 and beyond.

Mental Health

There have been tremendous barriers to accessing mental health care in PWP and their caregivers. We highlighted these barriers in our paper entitled “*Mind the Gap: Inequalities in Mental Health Care and Lack of Social Support in Parkinson Disease*” published in PRD in 2021. Most providers still focus on the motor issues such as tremor, stiffness, slowness and gait disorders in people living with PD. There is very little attention paid to non-motor issues let alone mental health issues in PWP. A survey of PWP showed that 59% felt “doctors were not sensitive enough about PD-related issues in MH treatment.” Psychological symptoms can be as disabling as motor symptoms and are a key predictor of quality of life. MH issues often go undiagnosed because many patients and their caregivers do not know that apathy, depression, or anxiety can be associated with PD. MH issues in PD are often heavily stigmatized and patients often feel embarrassed or hesitant to disclose issues in MH unless specifically queried.

There have been tremendous disparities in care that are based on race, gender/sex (highlighted below), age, geography, disability and sexual orientation. Multidisciplinary specialty centers and advanced therapies are disproportionately accessible to affluent, married, urban-dwelling, Caucasians. Minorities may not have equal access to interventions such as deep brain stimulation (DBS) surgery, which is offered less often to black women than other populations. Less than 1% of all DBS in the USA was performed in African Americans. There is a lack of inclusion and diversity in research, such that the majority of PD clinical trials do not report race or ethnicity statistics. Among those that do, Black and Hispanic participants each constitute

Pressing Gaps in Care in Parkinson's Disease (continued)

less than 1% of study populations. Young-onset PD is group with additional MH stressors including the impact of PD on romantic relationships, family dynamics, and employment in this age group. Anxiety and impulse control disorder are more prevalent in young onset PD. A recent review highlighted the higher burden of social isolation, discrimination and stigma in gay, bisexual, transgender, queer and intersex (sexual and gender minority groups) PWP that could lead to higher MH issues and barriers to care. Intersectional aspects of identity may compound the impact of a PD diagnosis. A young, black, woman facing economic hardship or a migrant farm worker who does not speak English are a few examples of persons who face unique challenges that must be proactively addressed.

There is a scarcity of resources to address the mental health needs of PWP. Telehealth has been proposed as one solution; however, many at-risk PWP cannot afford a computer, smart-phone, or internet access. This lack of access to technology is an obstacle for virtual visits, which have been essential during the pandemic and are often proposed as a way of reaching geographically underserved populations. Some PWP may not be literate with this technology. This barrier excludes the most vulnerable populations from the remote care models and inhibits social prescription strategies that have been relied upon during the pandemic.

COVID has unmasked the MH crisis and is compounding the effects of earlier traumas, including Adverse Childhood Experiences (ACES) and their consequences, such as post-traumatic stress disorder (PTSD). Little attention has been paid to the effects of trauma on PD and the ongoing societal burden of the lingering mental and physical health consequences of COVID. Many PWP have had loved ones pass due to the virus and have not had the chance to grieve due to social distancing. Some PWP have had COVID and are dealing with the physical and psychological after-effects of Long-COVID syndrome. Caregiver MH and burnout is a major issue as well. Social isolation has increased the burden on caregivers, both directly, in that they have reduced opportunities for respite, and indirectly, as increased MH issues in the PWP is associated with greater strain and depression in caregivers.

The current model of health care delivery has led to a lack of focus and time to address MH issues in PD. In many countries with an insurance-driven healthcare system, a fee-for-service model leads to little or no incentive to pursue patient-centered care. MH care in particular tends to be reactionary rather than emphasizing prevention. Most physicians see patients every 6 months for 15-30 minutes which is insufficient to address all of the issues in the motor and non-motor domains. Even when identified, MH complaints are often inadequately addressed, with 38.5% failing to receive a referral for MH care. During the pandemic, reduced in-person contact and mask use (which obscures expressions) further complicate the identification of disordered mental states. Neurologists spend most of the visit adjusting medications for motor impairment, while MH issues are often unrecognized until they become a crisis. Erratic time points for accessing MH resources leads to a relationship with MH providers that lacks continuity. Hence, PWP may not have long-term treatment relationships to develop coping strategies to reinforce emotional well-being.

Women Living with PD

Women's issues in PD especially from a psychosocial standpoint have been an overlooked field. We highlighted these issues in our paper on "[Unmet Needs of Women Living with Parkinson's Disease: Gaps and Controversies](#)" published in Movement Disorders in 2022. Specifically, we highlighted gaps in research, advocacy, and management of WWP. We were surprised to find a striking lack of data in many areas. The existing data is very conflicting in almost every aspect of this field. This paper provided an overview of the current knowledge, gaps and possible strategies to deal with the unmet needs of women living with PD with a focus on the clinical and psychosocial aspects. Another unique perspective of this paper is that it was

Pressing Gaps in Care in Parkinson's Disease (continued)

written along with three women living with PD who are in health care and lend their voices to this publication. The gaps we identified included the following:

Key research areas include women-inclusive drug and device studies, genetic, and hormonal considerations. Moreover, women with PD need to get educated and empowered on how to communicate their symptoms and needs, get engaged in research, get organized as a community, and to support one another. Women with PD need tools to help track and convey their unique motor and non-motor symptoms, psychological and social support needs. The management of PD needs to be customized to include the unique stages of women's lives including menstrual cycles, pregnancy, peri-menopause, menopause and post menopause. Specific guidelines for use of hormonal treatments and customized dopamine replacement dosing need to be developed. Women need guidance on culturally-sensitive wellness and self-care strategies that are customized for them. Basic core competencies in knowledge for all clinicians treating women with PD need to be established, including how to accurately diagnose, proactively identify and treat the symptoms of PD in women, and to ensure timely referral for specialty care, advanced therapies and research studies. Caregivers and families need guidance on holistically supporting women with PD.

PD is often thought of as a disease affecting a specific demographic, i.e. older white men. This stereotype is reflected in the long-standing illustration of the stooped elderly man that dominates medical media. This perception has been further documented by a survey of public knowledge where the most frequently mentioned group nominated as more likely to suffer from PD were elderly males. Although recently there have been efforts to modify this attitude, more needs to be done. For women, there is a delay in both getting an accurate diagnosis of PD and a referral to movement disorder specialist. Clinical differences in presentation are not solely responsible for delays in diagnosis of PD in this population. Some factors lie with women themselves, such as a decreased tendency to disclose or emphasize bothersome symptoms during medical assessments. Perceptions by physicians that PD is more common in men may also contribute to delays. These inequities are further magnified in marginalized communities within countries where traditionally underserved minorities are more likely to have missed or delayed diagnosis.

Delays in diagnosis may lead to more dissatisfaction with care in women with PD versus men with PD. Women with PD can feel like they are not being heard or that what matters to them most is not taken into consideration. Negative care experiences can impact symptom reporting. Women may not consistently share their concerns or symptoms with their providers, particularly around mental health, and other sensitive topics (e.g., pelvic floor problems), and are hence not treated for these issues. Research showed that women with PD have worse pelvic floor health issues than control women and are less likely to report their symptoms. Women with PD get accustomed to living with associated discomfort. They may downplay their symptoms and may not realize the association of these symptoms with their PD and hence do not receive treatment. The cultural behaviors associated with sex and gender in relation to how people living with PD feel about their lived experience of their symptoms is rarely researched or discussed. A study of older people with PD found that women prioritize symptoms that affect their ability to organize and strengthen social relationships. Women were more likely to become distressed when unable to fulfill their domestic responsibilities. The current momentum in addressing disparities in healthcare must include women's issues in PD. The voices of women living with PD must be amplified to catalyze real change in this neglected field and represent the true heterogeneity of this progressive disease.

Loneliness in PD

In our paper "[Synergy of Pandemics- Social Isolation is Associated with Worsened Parkinson Severity and Quality of Life](#)" published in NPJ Parkinson in 2020, we highlighted the negative effects of loneliness in

Pressing Gaps in Care in Parkinson's Disease (continued)

cohort of PWP. The goal of this study was to survey individuals with PD to evaluate whether social isolation is associated with PD symptom severity and quality of life. The primary outcome measures were the Patient-Reported Outcomes in PD (PRO-PD) and questions from PROMIS Global related to social health. PRO-PD scores increased as social performance and social satisfaction scores diminished. Individuals that reported being lonely reported a 55% greater symptom severity ($P<0.01$). Individuals that documented having a lot of friends had 21% fewer symptoms ($P<0.01$). Social isolation was associated with greater patient-reported PD severity and lower quality of life, although it is unclear whether this is the cause and/or a consequence of the disease. In essence, the Parkinson pandemic and the pandemic of social isolation have been further compounded by the recent COVID-19 pandemic. The results emphasize the need to keep PWP socially connected and prevent loneliness in this time of social distancing. Proactive use of virtual modalities for support groups and social prescribing should be explored.

Some important things to highlight include: In aging populations there have been comparisons in the literature of social isolation being as detrimental to health as smoking or obesity. After accounting for multiple covariates, one key study reported the increased likelihood of death was 26% for reported loneliness, 29% for social isolation, and 32% for living alone. Researchers have identified three dimensions of loneliness reflecting the particular relationships that are missing. Intimate or emotional, loneliness is the yearning for a close confidante or emotional partner. Relational or social, loneliness is the longing for close friendships and social companionship. Collective loneliness is the need for a network or community of people who share one's sense of purpose and interests. Loneliness can be felt if any one of these dimensions is not satisfied and hence it is possible to be happily married and still feel lonely.

Social prescribing is a novel concept in which clinicians recommend or prescribe resources or activities in the community to help patients develop healthy social connections. The Veteran's Administration has recently created the "Compassionate Contact Corps Program" using volunteers to call Veterans who are lonely and check in on them. Volunteering can help loneliness as well, so it has been proposed that Veterans can be paired up with each other to make such calls. The National Health Service in the United Kingdom have designed a link worker social prescribing program that was recently highlighted in the NEJM article, where they list referrals to group exercise classes, art-based therapies, volunteer opportunities, self-help groups for specific conditions and community activities such as gardening, cooking and befriending as examples of social interventions. In the paper we concluded that proactive screening of PwP using questions from the UCLA loneliness scale and then referral of lonely PWP to social support resources could be a possible intervention to help keep PWP socially connected during the pandemic and beyond. This study emphasizes the lack of attention paid to social determinants of health that have historically been neglected in PD.

Taking time to reflect on who we are not serving well and how we can do better has been an important consequence of this pandemic. Addressing disparities in care of women living with PD, improving barriers to mental health care and keeping PWP socially connected have been exciting areas to educate and empower our patients around.

For full articles please click below:

[Mind the gap: Inequalities in mental health care and lack of social support in Parkinson's disease](#)

[Unmet Needs of Women Living with Parkinson's Disease: Gaps and Controversies](#)

[Synergy of Pandemics- Social Isolation is Associated with Worsened Parkinson Severity and Quality of Life](#)

Promoting Patient-Centered Dysphagia Management

By: Caitlin R. Kane, M.Ed CCC-SLP, Speech Pathologist, Philadelphia VAMC

Patient-centered dysphagia management was the overarching theme at a recent PADRECC virtual support group talk hosted by **Catie Kane, speech pathologist** at the Philadelphia VAMC.

Emphasis was placed on empowering patients to be involved in therapeutic decision-making. An instrumental swallow study, via endoscopy (FEES) or fluoroscopy (MBS) is considered the gold standard for evaluation of a swallowing disorder. Following completion, the patient and family should be educated about the results and the most relevant, evidenced-based therapy options or compensatory recommendations, rather than told by the clinician what they can or cannot eat or drink. The intervention should always be based off the individual's objective swallowing study (as no two cases of dysphagia are the same) and be led by the patient's wishes once the proper education is provided and options are explained.

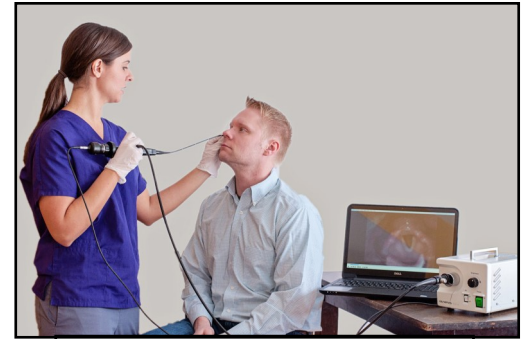


Image of endoscopy (FEES)

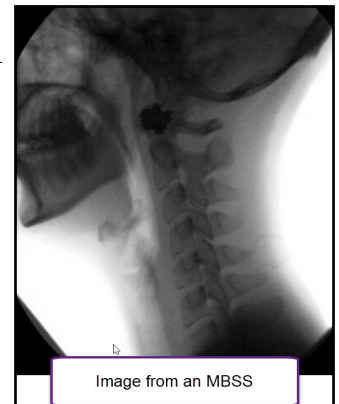


Image from an MBSS

Additional efforts from the speech-language pathology department in Philadelphia have focused on increasing appropriate referrals and avoiding delay of care for patients with swallowing complaints, as studies show early dysphagia intervention can slow progression of symptoms and lead to better long-term outcomes. A set of clinical questions was provided and encouraged to be used during PADRECC appointments to facilitate appropriate speech pathology referrals for patients with suspected oropharyngeal dysphagia. On the other hand, complaints that point towards more of an esophageal etiology, also common in PD, may be best evaluated with a fluoroscopic evaluation of the esophagus (barium esophagram), completed by a radiologist rather than a speech pathologist. While speech pathologists diagnose and treat oropharyngeal dysphagia, sometimes swallowing impairment related to PD may be best managed by a gastroenterologist. Therefore, clinical review of symptoms and follow-up questions can be essential in determining the best referral. Policies and procedures will vary across facilities, however, collaborative discussions between providers can help ensure the best course of action takes place and that timely and appropriate patient care ensues.

The SLP department also plans to be a part of the newly established deep brain stimulation (DBS) surgery program at the Philadelphia VAMC, providing pre and post-operative evaluations of individuals speech and swallow function. This will allow monitoring of surgery-related changes to the speech and/or swallow mechanism. Dysphagia can be a debilitating symptom of Parkinson's Disease and result in medical complications, as well contribute to feelings of anxiety, depression, or social isolation. By implementing a collaborative, interdisciplinary approach, and maintaining a patient-centered focus throughout the evaluation and treatment process, the goal is to foster an equal partnership between providers and patients and to maximize quality of life for Veterans living with Parkinson's Disease and related disorders.

VHA/PADRECC & Parkinson's Foundation Partnership-2 Years Strong and Building

By: Gretchen Glenn, National VA PD Consortium Education Subcommittee Chair

In 2020, the U.S. Dept of Veterans Affairs and the Parkinson's Foundation (PF) announced their partnership to combine efforts to improve the health, well-being and quality of life of Veterans living with Parkinson's disease. Since then, much work has been done to meet this goal and the partnership continues to thrive. Below are some highlights from fiscal year 2022: (hyperlinks will lead you to PF websites for program recording)

PF National & Regional Events for Veterans, their families and community partners

National Events

- Webinar-[Understanding Parkinson's Disease and Mental Health in the Veteran Community](#)
- Webinar-[Care Partner Town Hall: Care Partners of Veterans with Parkinson's Disease](#)

Regional Events

- Webinar-[Veterans and Parkinson's: Mobility and Driving](#)
- In-person-[Veterans and Parkinson's: Exploring the Multidisciplinary Approach to Care](#)
- Webinar-[Veterans and Parkinson's: A Team Approach to Living Well](#)
- Webinar-[Environmental Exposures in Veterans with Parkinson's](#)
- Webinar-[Veterans and Parkinson's: What You Need to Know](#)

Partner-produced content targeting Veterans and their families

- FAQ Guide: [Frequently Asked Questions: For Veterans with Parkinson's Disease and Their Care Partners](#)
- VAntage Point Guest Blog Posts:
 - * [Webinar to Cover Impact Parkinson's Disease has on Mental Health](#)
 - * [Parkinson's Disease Awareness: Answering 9 Most Popular Parkinson's Questions from Veterans](#)
- My PD Story: [Patrick Welch, PhD, Sgt. USMC \(ret\)](#)
- Updated Digital Resource Kits
 - * [For Veterans with Parkinson's Disease and their Care Partners](#)
 - * [For VA Health Professionals Treating Veterans with Parkinson's Disease](#)

Trainings or protocols created through or as a result of the partnership

- **Updated Protocol:** VA Health Professionals can now call or email the Parkinson's Foundation Helpline to order their bulk materials for Veteran patients – living with PD and their care partners
- **Trainings:**
 - * **Parkinson's Foundation Advance Team Training** for Alumni (of PF Team Training): Scholarship (BOGO) for VA clinicians (Aug. 2022)- 4 VA attendees
 - * **Parkinson's Foundation Virtual Team Training-** Spring 2022: Scholarship (BOGO) for VA clinicians - 14 VA attendees
 - * **Parkinson's Foundation Virtual Team Training-** Fall 2021: Scholarship (BOGO) for VA clinicians- 24 VA attendees
 - * **Parkinson's Foundation 2022 In-Person Centers of Excellence Leadership Conference:** PADRECCs invited to attend, 7 PADRECC attendees (May 2022)
 - * **Parkinson's Foundation 2021 Virtual Centers of Excellence Leadership Conference:** PADRECC and CC members invited to attend, 6 VA attendees

Research or studies conducted through or as a result of partnership

- Richmond PADRECC participating in Palliative Care Research Project, "[Implementing Team-Based Outpatient Palliative Care in Parkinson Foundation Centers of Excellence](#)"
- Parkinson's Foundation Survey-[Understanding health care needs among Veterans with Parkinson's disease: A survey study](#)

VHA/PADRECC & Parkinson's Foundation Partnership-2 Years Strong and Building

The PADRECCs and PF look forward to continuing to work together to expand awareness of resources available to Veterans and their families ensuring their access to the highest level of care available. In addition, the partnership will continue to explore education opportunities for VA clinicians and PF Centers of Excellence to close knowledge gaps for movement disorders care and VA resources. We look forward to what's ahead next year!

If you would like to be included on PADRECC email blasts to receive updates on PADRECC & PF resources, please email Gretchen.glenn@va.gov

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Virtual PD Wellness Group

By: Brittany R. Reed, Speech Language Pathologist, Southeast PADRECC

In honor of Parkinson's Disease Wellness Month (April) the Physical Medicine & Rehabilitation (PM&R) Team at the Central Virginia VA Healthcare System in Richmond, VA, partnered with the PADRECC to launch a **VIRTUAL PD WELLNESS GROUP**. The wellness group design was created in the wake of COVID-19. With many PD programs ceasing or pausing due to the pandemic, the team hoped virtual programs would increase access to care, motivate them to continue home exercises, allow for exploration of new management options, and equip them and their care partners with the knowledge needed to advocate for their continued needs. "The use of group telehealth is an effective extension of rehabilitation services that allows to reach multiple Veterans across multiple states while providing relevant and helpful information in managing PD related impairments. Allowing collaboration between Veterans is an added bonus," says Physical Therapist, Karissa Serio.

The aim of this group was to increase awareness and provide education for available treatment options and resources to manage challenges related to PD. Virtual programming included presentations from Physical Therapy, Occupational Therapy, Speech-Language Pathology, Music Therapy, Assistive Technology, Psychology, and Dietary services. 20 medical professionals participated throughout the month. Education sessions focused on a variety of topics to include movement, relaxation, sleep, self-care, swallowing, communication, mental health, intimacy, and care partner resources and guidance. The virtual group met daily, Monday-Friday, at 10:00AM and was catered towards Veterans and their care partners; it provided an intimate environment where participants had an opportunity to exchange dialogue with experts in the field. Participants were recruited through their PADRECC providers or Primary Care. The group was limited to 25 participants to allow an opportunity for everyone to engage as desired. Veterans participated primarily through VA Video Connect (VVC) while Webex was utilized for Friday education sessions as a way for care partners and community members to participate.

The group was well-attended and reached maximum registration with 25 participants. Speech-Language Pathologist, Lauren Sharpe-Payne shares, "I enjoyed hearing the experiences from the Veterans related to the management of their PD symptoms, as well as being able to provide them with relevant education and

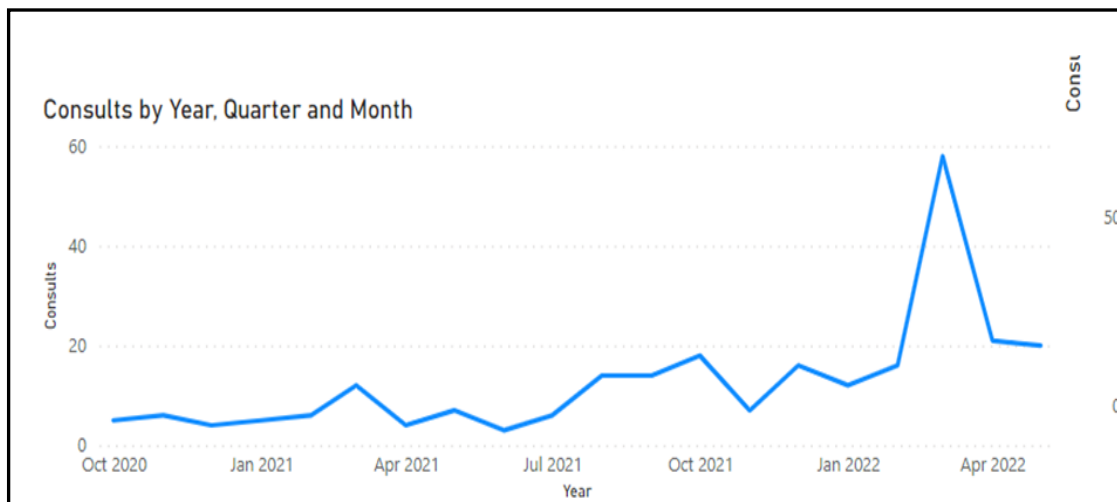
Virtual PD Wellness Group (continued)

information.” The PD Wellness Group preparation required increased time on the provider part. Calls were placed prior to the start of the group to obtain patient goals and complete an outcome measure. The rehabilitation team used the Parkinson’s Disease Questionnaire – 8 as an outcome to gauge patients’ current abilities. Specific consults, note titles, and templates were created to streamline notes for providers and to be able to track outcomes in the future by creating health factors. These health factors populate into a dashboard through Power BI. Information obtained will be utilized for future PD Wellness topics and programs.

Overall, the group was successful. 91% of Veterans said they learned something new and 91% were either satisfied or very satisfied with the PD Wellness Group. Veterans were engaged and were exposed to several therapeutic approaches to manage PD symptoms. Neurologic Music Therapist, Hope Kumme, was elated with the success of the group, "The Parkinson's Disease Wellness Group telehealth experience provided a wonderful opportunity for our Veterans to learn about the research and benefits of neurologic music therapy for Parkinson's. The Veterans were able to engage in interactive discussions and participate in a hands-on experience. It was an excellent platform in reaching and educating Veterans who may not have known about this beneficial service."

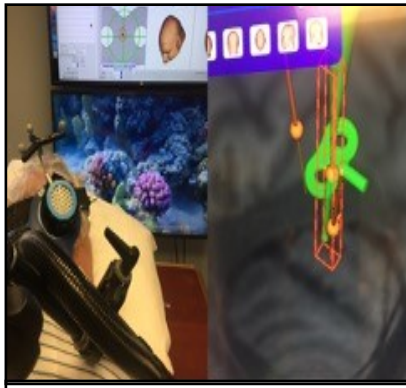
The PM&R team plans to offer future wellness activities to empower and support Veterans throughout their journey of managing PD symptoms. While the frequency has not been determined, a monthly wellness topic is being considered. Occupational Therapist, Erin Buckley reports, "I appreciated the opportunity to get to address a fuller scope of Occupational therapy practice with Veterans including addressing sleep hygiene, energy conservation, engaging in leisure activities, and providing Veterans the opportunity to see and hear from other Veterans with Parkinson's Disease. "

In summary, the group was well received and as a result, referrals to therapy services have increased by roughly 60%. Ultimately, the PD wellness group has allowed providers to reach Veterans and provide a broader scope of rehabilitation services that is so beneficial to PD management.



Cerebellar Repetitive TMS for Postural Instability in PSP (continued)

Preliminary results in six subjects are as follows: After cerebellar rTMS, average total sway area on the Neurocom improved 49.9% and medio-lateral sway range improved 23.4%. With Opal sensors, total sway area improved 43.8%, medio-lateral range improved 31.8%, and sway jerk improved 56.0%. Gait speed improved 12.2% and stride length improved 6.4%. On average, sham TMS did not improve gait and balance measures.



Cerebellar TMS Targeting

The larger, future goals of this work are the development of strategies for TMS-augmented physical therapy/rehabilitation programs and possible new targets for deep brain stimulation to improve postural instability.

We are grateful to NINDS for K23 career development support of this project (K23 NS121402-01A1), and we acknowledge the mentorship of Dr. Fay Horak (OHSU), Dr. Joseph Quinn (OHSU and Portland VA Medical Center), Dr. Robert Folmer (Portland VA Medical Center), and additional collaborators and advisors, including Dr. Mark George (Medical University of South Carolina) and Dr. Mark Hallett (NINDS). We also thank our patients who have generously given their time for this study.

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National PADRECC Education Subcommittee Update

The PADRECC Education Subcommittee had a productive year. Below are some highlights:

- **Movement Disorders Series Webinar:** reformatted the program to offer two half-day webinar sessions .
 - * **Movement Disorders Series Webinar Part 1** was held on February 10th, 2022 and targeted clinicians new to movement disorders. EES reported over 500 people registered for the webinar.
 - * **Movement Disorders Series Webinar Part 2** schedule for **October 13th, 2022** and will target the more advanced practitioner. **Register here:** [Movement Disorder Series Part II](#)
- [Nursing Care Across the Parkinson's Disease Spectrum: An Introduction](#)- Knowledge-based, live virtual training that provided nurses an overview of the different nursing roles across the PD spectrum. Approximately 206 participants from across the country attended.

National PADRECC Education Subcommittee Update

- **Parkinson's Foundation Centers of Excellence Leadership Conference (CLC)-**

PF extended invitations for PADRECC representatives to attend the conference held May 11-13, 2022 in Boston, MA. Each of the six PADRECCs were represented. The conference was an excellent opportunity to expand outreach and networking with PF and their Centers of Excellence. Many collaborative ideas were generated that the committee hopes to pursue with PF in the coming year.



Pictured Left to Right: Susan O'Connor-Northwest/Portland, Elizabeth Wong-San Francisco, Gretchen Glenn (back)-Philadelphia, Annie Li Wong-San Francisco, Dr. Amie Hiller-Northwest/Portland, Jessica Kaplan-Southeast/Richmond, Patricia Pittman-Southwest/West LA, & Dr. Joe Quinn-Northwest/Portland

Northwest PADRECC added as site for “Rural Veterans with Depression and Parkinson’s Disease: A Telehealth Psychotherapy Solution” program

By: Susan O'Connor, RN & Joel Mack, MD, Northwest PADRECC

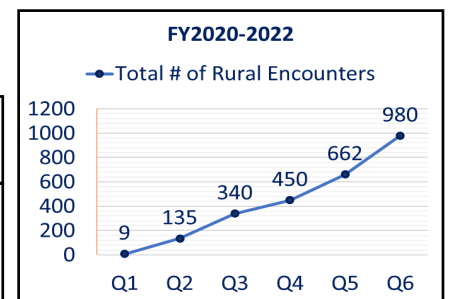
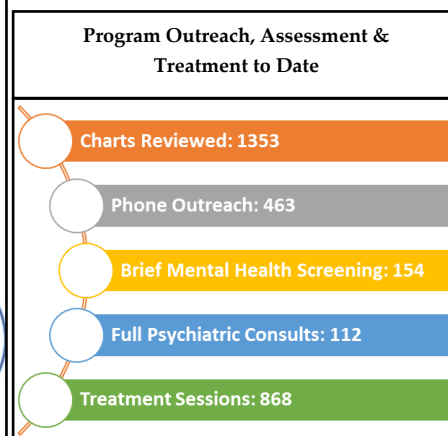
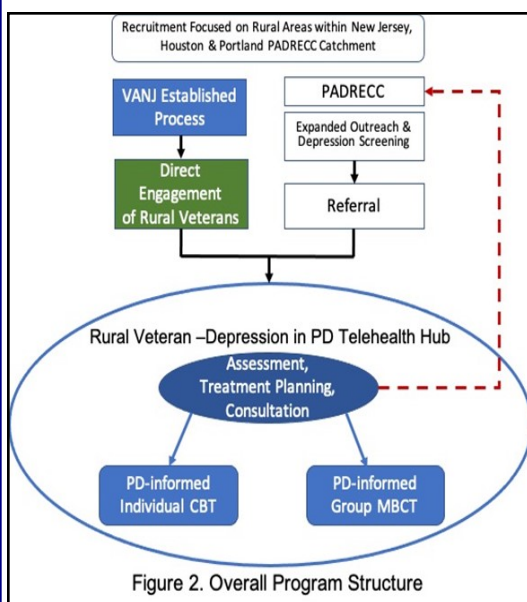
People with PD experience high rates of depression and anxiety, yet these neuropsychiatric issues are under-recognized and under-treated. Veterans living in rural areas are disproportionately impacted by PD and face additional barriers to PD-specific mental health care including geographic and transportation limitations, lack of access to specialist providers, and lack of awareness regarding the range of PD symptoms.

In an effort to ameliorate the mental health disparities for rural Veterans with PD, the NW PADRECC at the VA Portland Health Care System has joined the VA New Jersey Health Care System (Doctors Dobkin & Interian) and VA Houston (Dr Marsh) in FY22 as a third collaboration site for an innovative Office of Rural Health PD-informed telemedicine program. Established at VA New Jersey, the program remotely delivers specialized consultation and evidence-based psychotherapy directly to rural Veterans with PD across several states. Eligible veterans are identified in one of two ways: contact by mail followed by an outreach telephone call or direct referral from treating providers within the VA Portland Movement Disorders Clinic or mental health clinics. Interested Veterans are screened by phone then offered a full consultation followed by

Northwest PADRECC added as site for “Rural Veterans with Depression and Parkinson’s Disease: A Telehealth Psychotherapy Solution” program (continued)

enrollment in the program where they can receive PD-informed individual Cognitive Behavioral Therapy and/or group Mindfulness-Based Cognitive Therapy (see figure). Exclusions to the program are active psychosis, diagnosis of dementia and patient with known factors that may keep them from actively participating in either therapy. Across sites, the program has shown high levels of Veteran engagement and satisfaction and significant reduction of anxiety and depression symptoms for rural Veterans with PD. To date, 112 Rural Veterans received specialized evaluation and treatment, resulting in 980 clinical encounters. Despite chronic symptoms, 42% had never received any past mental health care and 65% had never received psychotherapy prior to program engagement. The Portland Hub is off to a quick start; within the first two months of project implementation, 81 letters were mailed to rural Veterans with PD and 103 Veterans were reached by phone, resulting in 43 phone screens and 33 completed consults thus far. The program is ongoing and welcomes any referrals from within NW PADRECC service area.

For additional background information on the intervention, please see: Dobkin RD, Mann SL, Weintraub D, Rodriguez KM, Miller RB, Dt Hill , King A, Gara MA, Interian A. [Innovating Parkinson’s Care: A Randomized Controlled Trial Of Telemedicine Depression treatment](#). *Mov Disord*. 2021 Nov; 36(11):1549-2558.doi:10.1002/mds.28548



Please contact us for more information on the program or to discuss referrals:
Kristi Ketchum, LCSW- Program Coordinator
Joel Mack, MD- Site Psychiatrist
Susan O'Connor, RN- NW PADRECC Clinic Coordinator

Philadelphia PADRECC Update

Clinical Update

The Philadelphia PADRECC is back to face to face visits with 75% of clinical care being provided in this modality. Virtual care continues to be offered for those who are still not comfortable coming in person or distance/travel to Philadelphia is an issue. This has greatly expanded access to care for Veterans in our service areas.

Telehealth Update: The PADRECC continued to provide care through the COVID 19 pandemic. A telephone clinic was developed to check in on patients who did not have the ability to do a video visit. Total virtual care encounters in FY21 increased by over 67%.

Philadelphia PADRECC Update (continued)

Dr. Daniel Weintraub continues to provide initial psychiatric consult services for patients with PD and psychiatric-cognitive symptoms. This service has expanded significantly and is now servicing 46 VAMCs. Psychiatric symptoms in patients with PD have a large impact on quality of life and managing these symptoms can be difficult and should be done by a subject matter expert. Please contact Dr. Weintraub at daniel.weintraub@va.gov if you think your PD patients could benefit from such a service

Staffing Update: In FY22 the Philadelphia PADRECC added 2 clinical nurse specialists (back filling 1 position), a new neurologist and brought back neurosurgeon-Dr Casey Halpern to restart our DBS surgical program. In addition, an Advanced Practice Pharmacist clinic has been established for medication management and will expand to managing essential tremor patients.

Palliative Care Collaboration: Developed and implemented a referral process to medical center Palliative Care Team to address the palliative and end of life needs of PADRECC patients.

My HealthVet (MHV): A process has been developed to enroll more PADRECC Veterans in MHV so they can take advantage of the many benefits such as emailing with providers, renewing medications and receiving education updates.

Education Update

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

PD 101: This biannual patient education program was held virtually in April in celebration of PD Awareness Month. The program provided an overview of PD symptoms, treatment and the Philadelphia PADRECC team.

Community Outreach: Clinical staff have continued outreach efforts via video conferencing modalities and have presented at several virtual support groups. In addition, continued partnership with The Philadelphia Museum of Art which hosted an art exhibit by artists with PD that showcased the work of Veterans who participated in their programs.

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.

Fellowship Program: Two fellowship spots a year are shared with the Parkinson's Disease & Movement Disorders Center at Pennsylvania Hospital. Clinical observations are also hosted for Geriatric, Pain Medicine and Geriatric Psychiatry Fellows as well as medical students from area Medical Schools.

Research Update

Current Projects:

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.

Philadelphia PADRECC Update (continued)

Behavioral or Solifenacin Therapy for Urinary Symptoms in Parkinson's Disease-continuing to support Dr. Camille Vaughn (Atlanta VA) on a VA RR&D Merit Award study for overactive bladder symptoms in PD. Dr. Morley is site PI

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 VA Medical Center, 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.

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.

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 serving as the VA coordinating site for the trial of a new under the skin pump for levodopa/carbidopa.

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 (CMCVAMC/ Department of Otolaryngology) are collaborating with Dr. Hong Wang from Monell Chemical Senses Center on a project looking to identify PD biomarkers in nasal cavity mucus to aid in the clinical diagnosis and identification of PD.

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 MJFF Foundation. The five-year program is looking to identify PD genes in >150,000 volunteers around the world to further understand genetic risk factors of 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.

Houston PADRECC Update

The Houston PADRECC is housed in the Michael E DeBakey VA Medical Center and 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, Kentucky, Illinois and Wisconsin (Houston PADRECC Consortium).

Consortium Update

Mia Ko, MD who transferred from Temple VA to Austin VA (CTVHCS) was added as a new member in April 2022. She did her movement disorders fellowship at NYU from 2016-2017.

Roshni Patel, MD and **Roneil Malkani, MD** are two movement disorders trained neurologists from Jesse Brown VAMC, who joined our consortium group in October 2021.

In FY 22, we have continued 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.

Administrative Update

We are extremely delighted to welcome **Mr. Anthony K. Washington, MBA**, who re-joined Houston PADRECC as the Administrative Officer in May 2022. He had previously served in this capacity from 2013-2017. Houston PADRECC functioned without any dedicated administrative support from late March 2017 until May 2022.

We are now actively recruiting for our Research Health Science Specialist's position.

Clinical Update

Beth Boncher, RN who held Nurse Supervisory position in our organizational chart officially left Houston VAMC in May 2022. Over the years she had transitioned to a supervisory role in the Neurology and Rehab clinics. She will be missed!

Houston PADRECC is continuing its robust clinical performance with a year over year increase in service demands.

Education Update

Houston PADRECC offers a broad range of educational programs for the staff, medical and allied health trainees, junior physicians, patients, and caregivers. We have expanded our educational programs and outreach over the last 5 years despite an approximate 50% reduction in workforce and unfilled Associate Director of Education position since 2018.

We currently offer:

- ◇ **Five Patient-Centered Education Programs:** Support groups, Educational Conferences, Clinic based 1:1 Education, Community Educational Conferences, and Educational Newsletters. We also offer bi-lingual (Spanish /English) education sessions (1:1) and Spanish patient education materials.
- ◇ **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, and National or Local Educational Teleconferences. Our strong educational program is driven by our philosophy that "High quality, relevant education delivered to the patients and the clinical care team in a timely manner is crucial for optimal clinical outcomes."

Houston PADRECC Update (continued)

Research Update

We currently have **11 active** research projects. Recruitment is still halted in our Circadian Rhythm/ Sleep Study due to COVID 19 pandemic related precautions. Our collaborative project with the GI department entitled "High Resolution Manometric Abnormalities of the Esophagus and Clinical Features of Gastroesophageal Reflux in Patients with Parkinson's Disease" concluded in December 2021. We are actively working to begin CSP 2015 study.

New Research Initiatives in FY22

H-50496: 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: Melissa B. Jones, MD, Co-investigator and mentor, Aliya I. Sarwar, MD.

BH-50119: Precision Medicine for Alzheimer's Disease and Related Dementias. This is a longitudinal observational prospective cohort biomarker/gene association study. VA subjects will be enrolled and studied at BCM/Methodist using techniques including amyloid and tau PET imaging, metabolomics, and whole genome sequencing. PI: Shulman, J, Site PI: Jackson, GR.

H-50443: Association between SSRI and SNRI use and worsening of Parkinson's disease in a veteran population. A retrospective data analysis (chart review) collaborative project between the department of pharmacy and Houston PADRECC to study the association between the use of SSRI/SNRI and worsening parkinsonism in PD. PI – Mitchell, B Pharm D, Co-investigator Sarwar, A, MD.

Publications and other Research Presentations: (10/1/2021 – 05/30/2022)

Abstracts/posters = 4 (accepted and/or presented)

Manuscripts = 4 (2 published or accepted, 1, under review, 1 in development)

Other Research Related Contributions

Associate Director for Research- **George R. Jackson, MD, PhD** has joined the local VA R&D committee. Previously he served as a backup for the sub-committee on research safety for the VA R&D committee. Since 2021, he has participated in research/administrative activities for the center for Alzheimer's and Neurodegenerative Disease (CAND) at BCM, including chairing the scientific review committee for the inaugural CAND Scholars Award and is currently serving on the new faculty search and recruitment committee. Dr. Sarwar is serving as a mentor for CANDS grant (Jones, M) and unfunded pharmacy research studies (Mitchell, B).

Southeast/Richmond PADRECC Update

The SE PADRECC is located in Richmond, VA at the Central Virginia VA Healthcare System.

Clinical Update

Interdisciplinary Team (IDT) Clinic

The Southeast PADRECC is excited to announce that on June 16, 2022, we began to see patients in our new Interdisciplinary Team (IDT) Clinic. Currently, two Veterans are scheduled to participate in this clinic every Thursday from 9am-12pm, seeing various providers including PT, OT, Speech, assistive technology, palliative care NP, PADRECC sleep neurologist and a PADRECC physician or NP. The specific type of provider seeing the patients can be tailored to the needs of the individual Veteran for that IDT clinic.

Southeast/Richmond PADRECC Update

Following the IDT clinic, the team virtually meets to discuss and establish an integrated and complementary care plan for each patient. Veterans have voiced appreciation for the care and attention they receive, and we are currently conducting an after-clinic survey to evaluate best practices and areas for potential changes/growth. “Every provider looks at a patient through their own lens of expertise, and when we all come together, the whole picture of a patient emerges,” says nurse coordinator, Jessica Kaplan. This interdisciplinary and integrated care model for our patients enables a patient-centered approach based on treating the whole person, promoting health and wellbeing.

Palliative Care Integration

A [PCORI-funded study](#) found that a team-based palliative care program improved quality of life, symptom burden, and grief for patients with PD. It also improved caregiver burden, anxiety, and spiritual well-being for family care partners. Richmond PADRECC has partnered with the Parkinson’s Foundation (PF) and University of Rochester project team to implement this quality improvement program as the only VAMC PADRECC site along with 34 medical centers designated by PF as Centers of Excellence. The project was implemented to address patients’ non-motor symptoms, care partner needs, emotional and spiritual concerns, advanced care planning, and specialist palliative care and hospice referral. A total of 40 new palliative care consults with **72 unique** palliative care visits were completed in FY22 Q1-3 with nearly a three-fold increase in visits between Q1 and Q3. 15% of Veterans seen for palliative care consultation enrolled in hospice over the same interval. Palliative and neurology providers are supported through coaching calls with neuropalliative experts and virtual education modules, Team-based Palliative Care Essentials for Parkinson’s Disease. Richmond’s PADRECC director and palliative care nurse practitioner participated in the first ever offering on June 4, 2022. EPEC-N educational in-service for the PADRECC interdisciplinary team is planned for August 2022.

Sleep Medicine Integration

Sleep Medicine integration within PADRECC continues to evolve with our two board-certified sleep physicians, **Dr. Leslee Hudgins** and **Dr. Elsa Mathew**. They are primarily telehealth providers, supporting the national PADRECC virtual expansion goals. We have just increased clinic time to 2-full days specific to PADRECC-Sleep patients. Dr. Elsa Mathew presented a PI project on 7/8/2022 entitled “Incorporating Sleep Medicine Within PADRECC.” This project focused on the importance of mitigating sleep disturbances in the movement disorders population.

Office of Rural Health Partnership

During FY21, with the support of the Office of Rural Health (ORH), PM&R and PADRECC partnered to build a comprehensive care team designed to expand the use of telehealth in the treatment of rural Veterans with PD. As a result, PADRECC has increased consults to speech, occupational, and physical therapies by 140%! In addition, consults sent directly to the Assistive Technology department have doubled so far this year. This data is proving the benefits a comprehensive care team can provide by increasing the diversity of services offered. ORH has agreed to increase funding support during FY23 so that we can continue to expand both our reach and our services offered to Veterans with PD.

Southeast/Richmond PADRECC Update (continued)

AAN Quality Measures

In 2021, the AAN Quality Measures Subcommittee updated the 2015 Parkinson's Disease Quality Measurement Guidelines. Jessica Kaplan and Dr. Lehosit collaborated with the Richmond Informatics CAC team to create a specific CPRS template to allow for easy review and documentation of these measures. This AAN PD Measure template specifically addresses all the AAN PD QM guidelines and additionally has imbedded direct consultation options for therapy (PT, OT, AT, SLP), palliative care, whole health, neuropsychological testing, dermatology and sleep medicine. This template can be modified and used by other providers in the VA system and is being implemented in the Cerner neurology pathway. Other sites wanting to use this template can reach out to Brad.Dunn@va.gov.

Education Updates

Outreach Efforts

The SE PADRECC continues to increase PADRECC awareness at the Central Virginia VA Health Care System and to other neurology services in VISN 6. Dr. Lehosit and Jessica Kaplan RN have given in-service presentations to general and surgical hospitalist teams, emergency department providers, primary care service and inpatient nursing departments on hospitalizations and PD. These presentations include general PD information, recommendations for hospitalization plan and medication guidance/avoidance information. The goal is to provide awareness around the complexities of both inpatient and outpatient PD care, while encouraging providers to reach out to PADRECC staff when they encounter our patients in the hospital or outpatient setting.

PD Wellness Fair

The SE PADRECC aligned with the Greater Richmond YMCA to plan a **PD Wellness Fair** in April during Parkinson's Awareness Month. The fair was held outdoors at the Tuckahoe Family YMCA on a lovely Friday morning. Exercise demos were offered by various local Parkinson's exercise programs, including Rock Steady Boxing, POP Heat, Pedaling for PD (YMCA), Movement for PD (YMCA), LSVT BIG and Dance for Parkinson's. Participants earned prizes for their participation in the demos. The McGuire Research Institute was able to provide snacks and a DJ to keep it lively and fun and the YMCA provided waters. Tables were set up around the field for various organizations and vendors. HCA, VCU, Parkinson's Foundation, APDA, PD Self, as well as drug and DBS reps were in attendance. The event had good attendance and vendors expressed gratitude at being invited to participate. Another community collaboration being planned for the Fall.



Southeast/Richmond PADRECC Update (continued)

Staff/Training Updates

Through a combination of local and national funds, SE PADRECC hired a nurse coordinator in 2021 and have approval to hire full time social worker in 2022. A full-time research coordinator is currently being hired through the McGuire Research Institute.

This Spring the SE PADRECC had 4 team members complete the Parkinson's Foundation Virtual Team Training. Jessica Kaplan RN, Lesa Beatty LPN, Brittney Reed SLP and Lauren Sharpe-Payne SLP were able to complete the online lectures and 3-day virtual LIVE training, thanks to our partnership with the Parkinson's Foundation. We have recently partnered with CVHCS Physical therapy to recruit two more physical therapists to our interdisciplinary team. These two PTs, **Kayla Thompson** and **Angela Connell**, specialize in pelvic floor therapy. They completed a Herman & Wallace Continuing Education course on PD and Pelvic Rehabilitation in July and will hopefully help serve patients who suffer from incontinence, constipation, and other troubling pelvic floor symptoms.

Research Updates

BOSS-PD-Urinary incontinence in PD: Open and enrolling. The SE PADRECC is a co-PI site for a MERIT funded collaborative study based out of the Atlanta GRECC. This study aims to determine the non-inferiority of pelvic floor muscle exercises to drug therapy that may cause side effects such as cognitive slowing.

Eye Movement Research: On-going, large scale, multi-centered study. Utilizing a 5-minute data recording from the eye tracking device, specific oculomotor parameters can be used to differentiate 25+ neurological movement disorders with >90% sensitivity and specificity. Intellectual property resulting from this research has been licensed to RightEye LLC, which has achieved global sales of the device for use in neurology offices as a diagnostic aide. This technology is patented and has been granted FDA Breakthrough Device Designation. Recently, the Federal Labs Consortium (FLC), awarded Drs Gitchel and Baron the "Impact Award" for 2022 for development of the eye tracking device and software. This Impact Award is the first to be awarded to a VA laboratory.

nQ Medical remote monitoring pilot: Open and enrolling. The neuroQWERTY platform utilizes the kinematics of typing on a laptop or smartphone keyboard to determine progression and/or severity of PD, as well a medication efficacy and compliance. The Richmond PADRECC is assisting in collection of pilot data for validation of the technology.

Accolades

Dr. Jessica Lehosit was recognized at the VCU resident graduation for her education efforts by being awarded the VCU School of Medicine - M3 Neurology Student Teaching Award. SE PADRECC continues to be a training site for medical students and residents from neurology, PM&R, internal medicine and has partnered with pharmacy education to incorporate two MH/neurology PGY2 pharmacy residents into the clinic for two-week blocks throughout the year.



Southwest PADRECC Update

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.

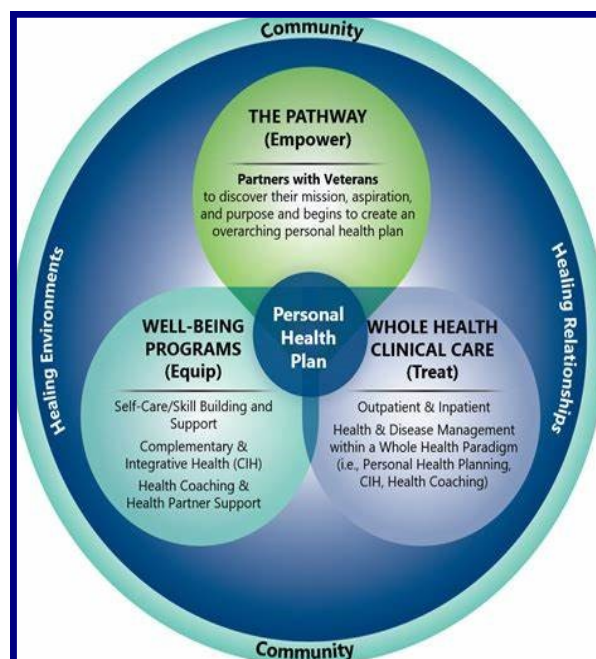
It emphasizes the partnership between provider and patient and meeting the patients where they are especially from a cultural context. She is working on further solidifying the concept of wellness - where patients proactively make lifestyle choices to help them thrive. From a loneliness perspective, 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 <http://parkinsonsecrets.com/>

Whole Health Coach: Patricia Pittman, RN, MBA, Clinical Nurse Coordinator was selected to receive training as a Whole Health Coach, within the VA system.

The Whole Health Coach provides care to Veterans seeking self-directed, lasting changes aligned with their values. The Coach provides care to Veterans seeking services that promote health, and wellness, enhance well-being, improve health related outcomes, reduce likelihood of inpatient admissions, and improve quality of life. The PADRECC team is excited about incorporating Integrative Medicine and Whole Health Coaching to show Veterans how to support their own self-care and self-management, which aligns with the mission of the National PADRECC.; “to support quality of life by providing comprehensive medical and surgical care to Veteran patients with Parkinson’s Disease and other Movement Disorders...” The team envisions the Clinical

Coordinator facilitating a group of Veterans with weekly topics related to the “Circle of Health”, which is from the VA Office of Patient Centered Care and Cultural Transformation. The future goal would be to integrate Whole Health throughout the National PADRECC Centers of Excellence.

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.



Southwest PADRECC Update (continued)

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. Due to COVID-19, the symposium has been placed on hold, pending assessing other means to provide this valuable service to the Veterans (i.e. Microsoft Teams).

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.

See article on [page 1](#) of this newsletter to learn more about **Gaps in Care for Women with Parkinson Disease** as well as **Barriers to Mental Health Access for People Living with PD**.

Northwest PADRECC Update

The Northwest PADRECC is comprised of the VA Portland Health Care System and the Puget Sound VAMC and consortium sites.

Clinical Updates:

Dr. Joel Mack has joined Dr Daniel Weintraub (Philadelphia PADRECC) in providing initial psychiatric services for patients with PD and psychiatric-cognitive symptoms via telehealth.

Dr. Amie Hiller along with second year fellow **Jocelyn Jiao** have initiated a Palliative Care clinic at the VA Portland. This is a multidisciplinary clinic with both MD's, SW, RN and chaplain. Palliative care is a growing field that aims to **improve the quality life** of patients and their families, especially those with chronic or life-threatening illness. This includes Parkinson's disease and other diseases such as cancer, heart failure, and kidney disease. For all of these various diseases, palliative care aims to **address suffering** of any kind: physical, emotional, psychological, existential, and/or spiritual. Palliative care in Parkinson's disease, specifically, can improve numerous aspects of patient care; the goals include addressing the widespread symptoms of Parkinson's disease beyond motor symptoms, alleviating the psychological distress caused by the disease, providing multidimensional support to care partners, and helping patients proactively plan

Northwest PADRECC Update (continued)

for the short and long-term future. Palliative care focuses on patients' quality of life, comfort, symptom relief and tends to be provided through a team approach. Put simply palliative care is helping people live as long as possible as well as possible. This clinic meets once per month seeing 4 patients per clinic day.

Education Updates

VA Portland has integrated their patient/caregiver educational offerings with their monthly support group. Every other support group meeting date is now an educational offering that is provided virtually and offered to a larger audience. Meetings are the second Friday of the month.

Research Updates

Dr. Cyrus Zabetian was recently awarded a grant from the Michael J. Fox Foundation to establish a consortium within the VA Health Care System to study the genetics of Parkinson's disease in underrepresented populations. This project, the Veterans Parkinson's Disease Genetics Initiative (Vet-PD), will include over twenty sites among the PADRECCs and National VA PD Consortium Centers. The research will be carried out in partnership with the Global Parkinson's Genetics Program (GP2) and the NIH. In addition, biospecimens and data will be archived in a repository at the VA Puget Sound for use in future studies

Dr Marian Dale was awarded a five-year K23 Career Development Award from NIH/NINDS in May, 2022 for a project titled "Cerebellar TMS for postural instability in progressive supranuclear palsy" (K23 NS121402-01A1).

Selected Publications/Abstracts FY22:

Scott, Gregory D, Lim, Miranda M, Drake, Matthew G, Woltjer, Randy, Quinn, Joseph F. Onset of Gut and Genitourinary Prodromal Parkinson's Disease: A Study of 1.5 Million Veterans. Published online 3 May 2021 in Wiley Online Library(wileyonlinelibrary.com). DOI: 10.1002/mds.28636

Veerappan V, Anderson S, Safarpour D, Hiller AL. Role of Directional Configuration in Deep Brain Stimulation for Essential Tremor: A Single Center Experience. Tremor Other Hyperkinet Mov (N Y). 2021 Nov 10;11:47. doi: 10.5334/tohm.628. PMID: 34824890; PMCID: PMC8588889.

Dale, Marian, Prewitt, Austin L, Harker, Graham R., McBarron, Grace E, Mancini, Martina. Perspective: Balance Assessments in Progressive Supranuclear Palsy: Lessons Learned. *Frontiers in Neurology*, Jan 2022, Vol 13.

Estes RE, Lin B, Khera A, Davis MY (2021). Lipid Metabolism Influence on Neurodegenerative Disease Progression: Is the Vehicle as Important as the Cargo? *Frontiers in Molecular Neuroscience*, 14. <https://doi.org/10.3389/fnmol.2021.788695>

Cholerton BA, Poston KL, Yang L, Rosenthal LS, Dawson TM, Pantelyat A, Edwards KL, Tian L, Quinn JF, Chung KA, Peterson-Hiller AL, Hu SC, Montine TJ, Zabetian CP (2021). Semantic fluency and processing speed are reduced in non-cognitively impaired participants with Parkinson's disease. *J Clin Exp Neuropsychol* 43:469-480

Hwangbo N, Zhang X, Raftery D, Gu H, Hu SC, Montine TJ, Quinn JF, Chung KA, Hiller AL, Wang D, Fei Q, Bettcher L, Zabetian CP, Peskind ER, Li G, Promislow DEL, Davis MY, Franks A (2022). Predictive modeling of Alzheimer's and Parkinson's disease using metabolomic and lipidomic profiles from cerebrospinal fluid. *Metabolites* 12:277

Northwest PADRECC Update (continued)

Loesch DP, Horimoto ARVR, Heilbron K, Sarihan EI, Inca-Martinez M, Mason E, Cornejo-Olivas M, Torres L, Mazzetti P, Cosentino C, Sarapura-Castro E, Rivera-Valdivia A, Medina AC, Dieguez E, Raggio V, Lescano A, Tumas V, Borges V, Ferraz HB, Rieder CR, Schumacher-Schuh A, Santos-Lobato BL, Velez-Pardo C, Jimenez-Del-Rio M, Lopera F, Moreno S, Chana-Cuevas P, Fernandez W, Arboleda G, Arboleda H, Arboleda-Bustos CE, Yearout D, Zabetian CP; 23andMe Research Team, Cannon P, Thornton TA, O'Connor TD, Mata IF (2021). Latin American Research Consortium on the Genetics of Parkinson's Disease (LARGE-PD). Characterizing the genetic architecture of Parkinson's disease in Latinos. *Ann Neurol* 90:353-365

Active Research Projects:

STAT-PD: Preventing Levodopa Induced Dyskinesia in Parkinson's Disease with HMG-CoA Reductase Inhibitors (OHSU eIRB #17302; VA MIRB # 3869). VA CSR&D Merit Review Grant. Dr. Kathryn Chung is conducting a research study looking at involuntary abnormal movements in Parkinson's disease. In this study, the association of statin use in relate to initiation of levodopa-therapy will be examined.

Genetic Movement Disorders: Etiologies and Pathogenesis (I01CX001702-05; 01/01/2018 - 06/30/2026; IRBNet ID #1587920). The major goal of this VA CSR&D Merit Review Award, led by Dr. Cyrus Zabetian, is to identify the molecular etiologies of genetic movement disorders as an important step towards improving diagnoses, elucidating pathogenesis, and facilitating efforts to develop targeted therapies.

Investigating the role of lipid metabolism in protein aggregation and neurodegenerative disease progression (R01NS119897-01; 12/01/2020-11/30/2025). The major goal of this project, led by Dr. Marie Davis, is to understand how mutations in *GBA* influence the spread of protein aggregation via extracellular vesicles

Investigating a neuroprotective role of GBA in astrocytes (R21 NS118476-01; 4/01/2022-3/31/2024). The major goal of this project, led by Dr. Marie Davis, is to investigate a possible role for GBA in astrocytes in restricting the spread of Lewy pathology.

Developing a novel model of X-linked Parkinson's disease due to *RAB39b* mutations in *Drosophila* and human iPSC-derived neurons (VAPSHCS R&D Seed Grant 4/01/2022-3/31/2023). The major goal of this project, led by Dr. Marie Davis and in collaboration with the Zabetian lab is to understand how the missense mutation p.G192R in the gene *RAB39B* causes X-linked dominant parkinsonism.

San Francisco PADRECC Update

New Staff

Nurse Coordinator



Elizabeth Wong joined the San Francisco PADRECC team in November 2021! She hit the ground running on Day 1 and has not stopped since. She brings with her over 10 years of nursing experience at the VA.

Chief of Chaplain Services

We are also fortunate to have the Chief of Chaplain Services at SFVA, **Alejandro De Jesus**, join our PADRECC team. He has been reaching out and providing spiritual support to our Veterans and caregivers.

San Francisco PADRECC Update (continued)

Education Updates

We have made changes to our fellowship program to enhance the partnership between the San Francisco PADRECC and our university affiliate, the University of California, San Francisco. **Dr. Nicholas Galifianakis** will be transitioning the fellowship director role to **Dr. Rafael Zuzuarregui** at SFVA and **Dr. Ethan Brown** at UCSF. The changes will increase access for our first-year fellows to initial programming of deep brain stimulators, as well as improve academic time to facilitate involvement with clinical research across both sites. We are incredibly grateful to Nick for all his hard work in developing the fellowship over the many years that he served as director, and we look forward to growing our program even further in the coming years.

Research Updates

The SFVAMC PADRECC continues to prepare for the start of **CSP #2015: Use of Seroquel versus Pimavanserin for Psychosis in Parkinson's Disease**.

Clinical Updates

We are now partnering with our university affiliate, UCSF, to provide our patients with tremor and/or Parkinson's disease with access to high-intensity focused ultrasound as a treatment for these issues. Patients who are high risk surgical candidates for deep brain stimulation or who are looking for an alternative to deep brain stimulation may now be evaluated for this procedure in our clinic.

Recent Events

San Francisco PADRECC has been involved in some fun events this past year! Unfortunately, we are bad at taking pictures, so you'll have to take our word for it.

For **Parkinson's Awareness Month (April)** we had a booth at our weekly Farmer's market to raise awareness about Parkinson's disease and provide PADRECC resources. Our booth was a hit! We provided information to medical staff and to veterans and their families. We gave away Parkinson's Foundation "Aware in Care kits" to inpatient nursing staff and Veterans who stopped by to learn more about the disease. We hope to do more outreach and targeted education in the near future.

National VA Parkinson's Disease Consortium Center Updates

VA Ann Arbor Healthcare System

The PD consortium site at the VA Ann Arbor Healthcare System (VAAAHS; Ann Arbor, MI) includes 4 Movement Disorders Neurologists--**Nicolaas Bohnen MD PhD, Vikas Kotagal MD MS, Daniel Leventhal MD PhD, and Peter Todd MD PhD**—and a Neurology Movement Disorders fellow (**Amelia Heston MD**). We hold 3 dedicated Neurology Movement Disorders clinics each week and follow a patient panel including more than 200 individuals with PD. Since 2016, our site has featured an active and expanding DBS program for movement disorders coordinated by Drs. Emily Levin (Neurosurgery) and Daniel Leventhal (Neurology) that currently serves Veterans from Michigan, Indiana, and Ohio. Drs. Bohnen and Todd each serve as principal investigators on investigator-initiated VA funded MERIT awards focusing on clinical and translational science relevant to Movement disorders and neurodegenerative disease. Our center at VAAAHS will be a performance site for the multicenter VA Cooperative Studies Program C-SAPP Study of Pimavanserin vs. Quetipaine for PD psychosis with Dr. Kotagal serving as the local site investigator. **Dr. Roger Albin MD**, who serves administratively at VAAAHS as the Associate Director for Research in the VAAAHS Geriatric Research and Clinical Education Center (GRECC), has active facilitates collaborations between our PD consortium site and the University of Michigan NINDS Udall Center of Excellence for Parkinson's Disease Research.

National VA Parkinson's Disease Consortium Center Updates

St. Louis Consortium Center

In FY22, the St. Louis Consortium Center held a successful virtual educational event in conjunction with the Parkinson Foundation on October 30th on "Veterans and Parkinson's: What You Need to Know". We welcomed research coordinators **Fahreta Hamzabegovic** and **Brooke Watkins** to our consortium center team. Dr. White began recruitment for his VA Merit study, which is investigating markers of neuroinflammation in PD. Preparations for CSP 2015 are well underway, and STL plans on participating in Vet-PD. Team members Corliss Burton, LCSW; Ben Dons, PT; Megan Young SLP; and Anndee Glick NP all completed the Parkinson's Foundation team training and found it to be very beneficial. We recently welcomed **Andrew Flint, OT** to our multidisciplinary movement disorders clinic.

Edward Hines, Jr., VA

In the last year, **Dr. Colletta** has started the Multidisciplinary Movement Disorder Clinic which is comprised of 10 clinicians and therapists in specialties ranging from Sleep Medicine to Psychiatry, Neuropsychology, and Neurology, plus PT, OT, speech therapy, nutrition, social work, and research. We have 3 VA funded studies (PI: Sandra Kletzel, PhD) currently recruiting Veterans with Parkinson's Disease. **Dr. Kletzel** has (i) an RR&D CDA2 randomized control trial (RCT) assessing effects of repetitive transcranial magnetic stimulation (rTMS) for Veterans with PD and mild cognitive impairment (PD-MCI), (ii) an RR&D SPiRE RCT assessing effects of an at-home cognitive intervention with prospective memory implementation strategies in Veterans with PD-MCI and (iii) Hines Serwa Center on Aging funded pilot study assessing intrinsically photosensitive retinal ganglion cells as a biomarker for PD, both in terms of disease severity and cognitive function. Dr. Kalea Colletta is recruiting for a newly VA-approved pilot study assessing an at-home exercise program using Rhythmic Auditory Stimulation for Veterans with Parkinson's Disease and is involved in research regarding Camp Lejeune and Parkinson's Disease and other movement disorders. Hines is a recruitment site for the on-going TOPAZ multisite study, and will also be a study site for the upcoming CSP2015 and G2P.

Jesse Brown VA Medical Center



Our movement disorders section has tripled with the addition of two new doctors trained in movement disorders. **Dr. Roshni Patel (pictured left)** is building up our neuromodulation program, in collaboration with our Neurosurgeon Dr. Slavin and partnerships with local academic centers. In doing so, we are evaluating Veterans with Parkinson's disease and Essential Tremor for deep brain stimulation and focused ultrasound thalamotomy. She has received a pilot grant (CINCCCH SWIFT grant) and is working with collaborators at Hines VA to perform a retrospective study to assess patterns of telemedicine utilization amongst PD patients during the pandemic, and associated outcomes.

Dr. Roneil Malkani is dual certified in sleep and has recently developed a sleep consultation program for patients with neurodegenerative disease including Parkinson's disease, other movement disorders, and dementias and for those at risk, such as RBD. In development is a specialized teleneurology RBD program for diagnosis, management, and long-term monitoring.

Dr. Brandon Barton is coordinating entry into the VET-PD genetics study with GP2, and is presenting research on the influence of PTSD diagnosis on the clinical aspects of Parkinson's disease, while expanding the telemedicine movement disorders program to northeast Indiana.

Consortium Coordinating Center

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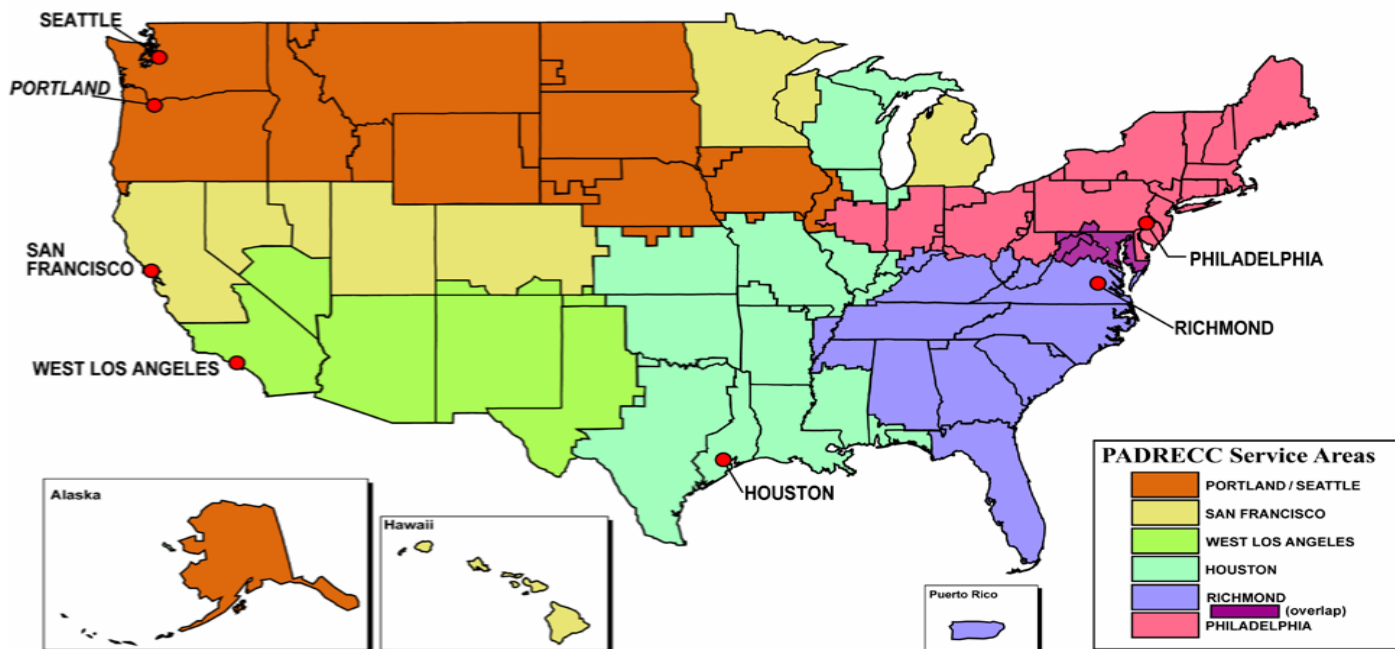
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Service Areas for PADRECCs

Veterans Health Administration