



# 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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**Parkinson's Foundation Partnership:  
Improving the Health, Well-Being & Quality of Life of Veterans Living with  
Parkinson's Disease**

By: John Duda, MD, Philadelphia PADRECC Director

It is with great excitement that I report that the **U.S. Department of Veterans Affairs (VA)** and the [Parkinson's Foundation](#) announced recently that they have signed an agreement to combine their efforts to improve the health, well-being and quality of life of veterans living with Parkinson's disease. (PD) The Parkinson's Foundation is one of the largest patient-centered organizations and is leading the way in the development of novel resources for the benefit of all people with PD. Their mission includes a goal to help improve the lives of everyone affected by this illness including people with PD and their caregivers, and it was readily apparent to myself and the other Directors of the VA Parkinson's Disease Research, Education and Clinical Centers (PADRECCs) that many of the resources developed by the Foundation would be helpful in educating and managing Veterans with PD. The Foundation also felt that the VA could help expand awareness of the resources they provide to Veterans with PD.

Therefore, an agreement was developed and signed between the VA and the Parkinson's Foundation with the following objectives:

- 1) Increase Veterans' and providers' access to PD information and resources.
- 2) Educate VHA staff on PD disease management and modifying therapies.
- 3) Improve service coordination and navigation for Veterans with PD.



## Partnership with the Parkinson's Foundation (continued)

These efforts to meet these objectives have already started to be put into place, with advances in both the VA and the Foundation. The VA has begun working to expand awareness of Parkinson's Foundation educational resources, hospital kits and functions. Recently, the Foundation has undertaken a large refocusing of their educational activities to online formats in this age of social distancing. These include excellent weekly presentations on various aspects of living with PD including 'Mindfulness Mondays', 'Wellness Wednesdays' and 'Fitness Fridays' ([visit www.Parkinson.org/PDHealth](http://www.Parkinson.org/PDHealth)), as well as innumerable recorded versions of many years worth of past presentations available for streaming. The Foundation also offers a free information Helpline for anyone with questions regarding PD (1-800-4PD-INFO (473-4636)) and VA representatives have already met with some of the members who answer the Helpline to help expand awareness of Veteran-related issues regarding PD and how Veterans can take advantage of the resources provided by the VA.

The VA is also expanding access to Foundation related materials through our own website at <https://www.parkinsons.va.gov/>. It is my hope that Veterans who end up on the Parkinson's Foundation webpages or their Helpline will find it easier to navigate to the PADRECC website for information relevant to Veterans and conversely, that Veterans on the PADRECC website will find it easier to take advantage of all of the resources at the Parkinson's Foundation.

One valuable resource that we have been taking advantage of for several years from the Parkinson's Foundation is the [Parkinson's Hospital Kit](#) which is designed to improve the Parkinson's patient's experience when hospitalized. I highly recommend that all people with PD obtain a free kit and complete the forms included so that they will be ready if and when you need them. The information included will help admitting physicians better understand their patients needs and wishes while hospitalized.

I am very optimistic that this agreement between the VA and the Parkinson's Foundation will greatly improve the lives of Veterans living with PD. It is a great example of how two organizations can combine their efforts to accomplish more than either could alone. For more information about the Parkinson's Foundation, please visit their website at [www.Parkinson.org](http://www.Parkinson.org) or call (800) 4PD-INFO (473-4636).

## Embracing Telemedicine during the Coronavirus Pandemic

By: Dr. Adrienne Keener, Southwest PADRECC



The coronavirus pandemic has brought numerous challenges and opportunities in healthcare. The VA Greater Los Angeles (GLA) PADRECC recognized the need to protect our patients and their families, as well as the healthcare providers in the face of this public health crisis. Elective procedures, including DBS surgeries, DBS programming, and botulinum toxin injection procedures were temporarily put on hold. Overnight, we converted our clinic visits to virtual appointments, reaching out to patients personally by phone to orient them to the new reality of patient care. Many embraced the opportunity to bring visits into their homes using VA Video Connect (VVC) technology, while others opted for Telephone visits. Using telemedicine, we continued to incorporate our interdisciplinary team including Geriatric Psychiatry and Neuro-Pharmacology to deliver patient care. We continued to conduct DBS evaluations from our referring PADRECC Consortium sites using VVC telemedicine. We also were able to continue our mission to educate trainees at all levels – fellows, residents, and

## Embracing Telemedicine during the Coronavirus Pandemic (continued)

medical students by having multiple participants log in to the video visit to meet with our patients, and by utilizing web-based conferencing to deliver lectures and engage in journal club discussions.

Recently, at the GLA PADRECC, we have been able to re-open our botulinum toxin clinic utilizing appropriate PPE, to resume these procedures, and starting in July will resume DBS surgeries. One of the silver linings of the coronavirus pandemic is that telemedicine is here to stay. Even prior to the pandemic, an emerging body of evidence demonstrated the feasibility and benefits of telemedicine in the care of patients with Parkinson's disease (1-6). The International Parkinson and Movement Disorders Society as well as the American Academy of Neurology have created tools for clinicians to ease the transition to telemedicine (7,8). Throughout this pandemic both patients and providers have become more adept at utilizing this technology, enabling us to maintain a high standard of care and to support our patients and their families during this difficult time. We hope to build upon this experience to further assess the impact and unique barriers to telemedicine, to enable us to address gaps in care and enhance care delivery for our PADRECC patients.

### References:

1. Beck CA, Beran DB, Biglan KM, et al. National randomized controlled trial of virtual house calls for Parkinson disease. *Neurology* 2017;89:1152-1161.
2. Korn RE, Shukla AW, Katz M, et al. Virtual visits for Parkinson disease: A multicenter noncontrolled cohort. *Neurol Clin Pract* 2017;7:283-295.
3. Wilkinson JR, Spindler M, Wood SM, et al. High patient satisfaction with telehealth in Parkinson disease: A randomized controlled study. *Neurol Clin Pract* 2016;6:241-251.
4. Dorsey ER, Venkataraman V, Grana MJ, et al. Randomized controlled clinical trial of "virtual house calls" for Parkinson disease. *JAMA Neurol* 2013;70:565-570.
5. Cubo E, Gabriel-Galan JM, Martinez JS, et al. Comparison of office-based versus home Web-based clinical assessments for Parkinson's disease. *Mov Disord* 2012;27:308-311.
6. Dorsey ER, Deuel LM, Voss TS, et al. Increasing access to specialty care: a pilot, randomized controlled trial of telemedicine for Parkinson's disease. *Mov Disord* 2010;25:1652-1659.
7. Telemedicine in Your Movement Disorders Practice: A Step-by-Step Guide (April 2020). Retrieved from <https://www.movementdisorders.org/MDS/About/Committees--Other-Groups/Telemedicine-in-Your-Movement-Disorders-Practice-A-Step-by-Step-Guide.htm>
8. Telemedicine and Remote Care: Teleneurology and COVID-19 (updated May 28, 2020). Retrieved from <https://www.aan.com/tools-and-resources/practicing-neurologists-administrators/telemedicine-and-remote-care/>

## Risk of Social Isolation in the Parkinson's Disease Population

By: Dr. Indu Subramanian, Director, Southwest PADRECC

The risk of social isolation in this vulnerable Parkinson Disease (PD) population, is of huge concern. Social isolation in the pre-COVID era, has been identified as a significant risk factor for negative outcomes in aging populations as is smoking or obesity. The additional stress and strain and social distancing due to COVID-19, has added to the burden of care of the PD patient and the toll of loneliness. Veterans, in general, take a lot of comfort in coming to the VA for their care and to see fellow Vets. Many of our patients spend the whole day at the VA, during their appointments, in order to commune with other Vets with whom they have formed a social network. The team at the Southwest PADRECC, led by Dr. Subramanian, have crafted a possible solution to this isolation, via virtual support group meetings in collaboration with the Parkinson & Movement Disorder (PMD) Alliance. Increased mental and emotional stress due to the barrage of negative stories in the media, lack of control and uncertainty of the future, can lead to worsening of both motor and



## Risk of Social Isolation in the Parkinson's Disease Population (continued)

non-motor issues in PD. [3,4,5]. We described a virtual support group intervention for Patients with PD (PWP).

PD treatment is approached through a combination of pharmacological, surgical and lifestyle/wellness approaches. The concept of diet and exercise as medicine, has increasingly become an integral part of PWP counseling from day one of diagnosis. There has been a huge emphasis on early institution of physical therapists, daily exercise, group classes and support groups. PWP have felt empowered to help their own disease by staying motivated and keeping involved in several activities, "prescribed to them" by their health care team. Patients look forward to engaging with their therapists, yoga, and boxing instructors. Many patients feel a sense of purpose and connection through caring for their grandkids or through volunteering. The sudden need to socially distance has literally ripped these therapeutic lifestyle strategies away from our patients overnight. PWP and practitioners alike, have been left to scramble to find ways to fill this huge void in their lives. The need for social distancing has put a tremendous strain on caregivers who were already at risk for burning out, getting isolated and getting sick themselves.

Virtual support groups, using video-conference technology, serves as model intervention to keep PWP connected, educated and empowered. The model that we have adopted includes the following: Partnering with a PD advocacy organization that has used Zoom technology in the past. Patients can learn and troubleshoot the Zoom technology for 30 minutes before each support group session. The host is a neurologist with expertise in PD who hosts each session 2 times per week. An average group size of 60-200 PWP and their caregivers are in attendance. Sessions are archived on YouTube within hours of the group meeting so that patients can re-watch the sessions at their convenience. Sessions are held at noon for convenience of the speakers and attendees. The host interviews the speakers in the following format: Introduction with waving together, Speaker gives slides, or talks about a topic for 20-30 minutes; Host interviews the speaker for 10-20 min; Question and Answer for 10 minutes, Close with waving together.

The goal of this virtual support group is to prevent the downward spiral of worsened PD symptoms and quality of life for both the patient and their caregiver that may be induced by the consequences of COVID-19 and social distancing. This model of virtual support groups can be emulated anywhere in the world since the speakers themselves are remote. Additionally, this model can be replicated in other chronic disease states.



### Acknowledgement:

The author would like to acknowledge the PMD Alliance and Sarah Jones for their help.

#### References:

1. [Papa SM, Brundin P, Fung VSC, Kang UJ, Burn DJ, Colosimo C, Chiang HL, Alcalay RN, Trenkwalde C. MDS-Scientific Issues Committee.](#) Impact of the COVID-19 pandemic on Parkinson's disease and movement disorders. [Mov Disord.](#) 2020 Apr 6.
2. [Stoessl AJ, Bhatia KP, Merello M.](#) Movement Disorders in the World of COVID-19. [Mov Disord.](#) 2020 Apr 6.
3. [Helmich RC, Bloem BR.](#) [J Parkinsons Dis.](#) The Impact of the COVID-19 Pandemic on Parkinson's Disease: Hidden Sorrows and Emerging Opportunities.. 2020;10(2):351-354.
4. Ben-Pazi H, Browne P, Chan P, Cubo E, Guttman M, Hassan A, Hatcher-Martin J, Mari Z, Moukheiber E, Okubadejo NU, Shalash A; International Parkinson and Movement Disorder Society Telemedicine Task Force. [The Promise of Telemedicine for Movement Disorders: an Interdisciplinary Approach.](#) [Curr Neurol Neurosci Rep.](#) 2018 Apr 13;18(5):26.
5. Hemmerle AM, Dickerson JW, Herman JP, Seroogy KB. [Stress exacerbates experimental Parkinson's disease.](#) [Mol Psychiatry.](#) 2014 Jun;19(6):638-40.
6. <https://www.pmdalliance.org/social-distancing-coronavirus/>

**Cooperative Studies Program #2015**  
**Multicenter, Randomized, Double-Blind Comparator Study of Antipsychotics**  
**Pimavanserin & Quetiapine for Parkinson's Disease Psychosis (C-SAPP)**

By: Daniel Weintraub, MD Philadelphia PADRECC

We are pleased to announce that the **Department of Veterans Affairs** recently funded **Cooperative Studies Program (CSP) #2015, "Multicenter, Randomized, Double-blind Comparator Study of Antipsychotics Pimavanserin and Quetiapine for Parkinson's Disease Psychosis (C-SAPP)**.

Most (60%) of patients with Parkinson's disease (PD) experience psychosis (PDP) long-term. Not only is PDP very common, it is associated with decreased quality of life, caregiver burden, at times agitation and aggression; sleep disruption, hospitalization, institutionalization and increased mortality. PDP presents difficult treatment decisions for providers in terms of managing motor symptoms (i.e., parkinsonism) in the face of psychosis. Evidence for treatment of PDP is very limited. Among antipsychotics (APs), clozapine is effective for PDP but is rarely used. Quetiapine is the most commonly used AP for PDP, but evidence for its efficacy in PDP is lacking. Pimavanserin is a newer AP for PDP that was FDA-approved on the results of a single positive study, but questions remain about its efficacy for and safety in PDP, and it is expensive. Approximately 110,000 Veterans have PD, 50,000 receive care at a Veterans Affairs (VA) in any given year, and an estimated 30,000 of existing PD patients receiving care at a VA facility will experience psychosis at some point. The results of the proposed study will provide crucial information for VA administrators and clinicians managing PDP.

C-SAPP is a 6-year study that will enroll approximately 360 PD participants. It is a randomized, intent-to-treat, double-blind, two-arm, parallel design, multicenter comparator study. Each of the 6 Parkinson's Disease Research, Education and Clinical Centers (PADRECCs) and approximately 20 other National VA PD Consortium sites will participate. Eligible participants (those with Neuropsychiatric Inventory (NPI) hallucinations or delusions score of  $\geq 4$ ) will be randomized to fixed-dose Pimavanserin or flexible-dose quetiapine, stratified by cognitive impairment. Assessments will be collected at multiple time points, including global improvement (CGI-I), PDP symptoms (SAPS-PD), motor abilities (MDS-UPDRS III), nighttime sleep and daytime sleepiness (SCOPA-S NS/ESS), adverse events (TESS) and ECG monitoring, caregiver burden (Zarit), cognition (MoCA), and function and well-being (PDQ-8). Qualitative interviews as part of an implementation science initiative will be conducted with providers, patients, caregiver and VA stakeholders at study initiation and completion. The primary efficacy endpoint is overall improvement in psychosis on the 7-point CGI-I. The primary objective is to assess the superiority of Pimavanserin versus quetiapine. Should superiority not be established, a noninferiority test will be performed to determine if quetiapine is no worse than Pimavanserin. Each study participant (randomized 1:1 to quetiapine or Pimavanserin) will be followed for 8 weeks (Phase 1). Non-responders or poor tolerators from Phase 1 will be assigned to the other study medication for an additional 8 weeks (Phase 2). Responders from Phase 1 will continue on assigned study medication for another 44 weeks (Phase 3) to assess durability of treatment response, mortality, morbidity, and long-term tolerability.

There is also an implementation science component to the study. Using constructs from the Consolidated Framework for Implementation Research (CFIR), we will define the inner setting (e.g., culture, leadership) and outer setting (e.g., patient needs and resources) for treatment of PDP among Veterans. Our objective will be to describe stakeholder perspectives of the current environment of treatment for PDP within the

## Cooperative Studies Program #2015 (continued)

Veterans Health Administration. We will assess providers' current informational sources, policy influences and decision-making processes when prescribing AP medication to PD patients. We will also explore patient and caregiver influences and attitudes regarding AP medication in PD. A better understanding of the current practices and attitudes around treatment for PDP will provide valuable information for translation of RCT findings into practice. Data collection will proceed in two phases. In the first phase, we will conduct qualitative interviews with providers and patients/informed others to understand attitudes and needs. Qualitative interviews will be conducted over the course of the study starting at baseline with providers and enrolling patients/informed others gradually throughout subsequent years. In the second phase, when the results of the trial are known, we will present our qualitative findings about the inner and outer setting along with trial results to a panel of stakeholders with the goal of assembling recommendations for implementation.

### **Can Dyskinesia Development Be Reduced or Prevented by Use of Statin Medications?**

**By: Kathy Chung, MD, Northwest PADRECC**

Levodopa (LD) is the most important medication that Veterans with PD will take to control their symptoms and has remained so since its discovery in the 1960s. Unfortunately, early recognition of the benefits of LD against the stiffness, slowness and tremor of PD was accompanied in many cases by the side effect of dyskinesia, or unwanted purposeless excessive movements. Dyskinesias, which appear choreic, jerky or dystonic become more severe over time and have few treatment options, including reducing dopaminergic medications, which can lead to intolerable worsening of parkinsonian symptoms. Other options include amantadine, or deep brain stimulation. These treatments are not suitable for all patients, illustrating the need for other strategies including preventive, or "disease modifying" approaches.

In animal models, statins applied concomitantly with first ever LD ingestion interrupted the dyskinesia priming process as proven by reduction in not only dyskinesia biomarker levels, but significantly lessened future expression of dyskinesia<sup>1,2</sup>. In our project, we are performing a retrospective cohort study using VA databases to select 40 Veterans with PD who have been prescribed statins prior to or concomitant to being prescribed LD for PD for several years (giving him/her ample time to potentially develop dyskinesia) and compare with a group of who never used statins. We are measuring dyskinesia that has developed in these cohorts precisely using not only current standard methods but our unique methods of data gathering which includes a LD infusion and electronic dyskinesia measurements. We will determine if statin exposure was protective, resulting in less severe dyskinesia expression years later. We are also studying a third 40 subject cohort prescribed a statin after LD initiation, to see if the eventual severity of dyskinesia is lessened, implying slowing of rate of dyskinesia progression (secondary prevention). The power of the VA databases is in identifying subjects with the correct order of administration of statin and levodopa as well as continued administration through the years, along with baseline characteristics so that appropriate cohorts can be generated in sufficient numbers. By the end of our project, we will determine if statin exposure at the beginning of LD use is important to retarding the priming process for dyskinesia development, and whether there is still room for modifying the rate of progression of dyskinesia even if started late. If our study shows that statins do modify the rate of dyskinesia progression, then a multicenter prospective trial of statins would certainly be warranted. A means of preventing a dreaded complication of PD treatment would be welcome.

## Can Dyskinesia Development Be Reduced or Prevented by Use of Statin Medications?

(continued)

In the first months of our Merit Review funded study (until Covid-19 precautions stopped clinical investigations) we recruited 15 subjects including 3 from our collaborating VA site in Seattle. We look forward to the resumption of our project once the VA ORD deems it safe to begin recruitment again.

### References

- Wang T, Cao X, Zhang T, Shi Q, Chen Z, Tang B. Effect of simvastatin on l-DOPA-induced abnormal involuntary movements of hemiparkinsonian rats. *Neurol Sci* [Internet]. Springer Milan; 2015;1397–402
- Schuster S, Nadjar A, Guo JT, Li Q, Ittrich C, Hengerer B, et al. The 3-hydroxy-3-methylglutaryl-CoA reductase inhibitor lovastatin reduces severity of L-DOPA-induced abnormal involuntary movements in experimental Parkinson's disease. *J Neurosci*. 2008;28(17):4311–6.

## Philadelphia PADRECC Update

### Clinical Update

Due to the COVID 19 pandemic the Philadelphia PADRECC shifted to telemedicine for patient care (except for urgent matters) offering either telephone or video visits. Recently, visits have resumed for chemodenervation therapy and deep brain stimulation management following strict VA health and safety guidelines.

**Telehealth Update:** Prior to the COVID 19 pandemic the Philadelphia PADRECC had a very active Telehealth clinic with 276 encounters in FY19 (both new visits and follow up care) servicing 25 facilities, including 2 State Veterans Homes. Since the COVID 19 pandemic, VA Video Connect (VVC) telehealth services into the Veteran's home have already increased 400% over last fiscal year's total VVC encounters offering patients VVC as an alternate to in-person visits.

Dr. Daniel Weintraub, in collaboration and funded by the National Telemental Health Center continues to provide initial psychiatric consult services for patients with PD and psychiatric-cognitive symptoms to the following VAMCs: Bronx, Northport, Albuquerque, San Diego, Tampa, Ann Arbor, Dallas, Flint, Northport, Toledo and Portland (OR). 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](mailto:daniel.weintraub@va.gov) if you think your PD patients could benefit from such a service.

### Accolades

**Dr. John Duda**, Philadelphia PADRECC Director was recognized with a **Senior Clinician Scientist Investigator Award** from the Biomedical Laboratory Research and Development Service of the Department of Veterans Affairs for his long career in VA research.



### Education Update

**National Caregivers Month:** To recognize our Veterans' caregivers, the Philadelphia PADRECC held a **Close Contact for Couples** program by Judith Sachs, a *Dance for PD® Certified Teacher in Philadelphia and is the Founder and Director of ANYONE CAN DANCE®*. This program explored ways to communicate with body, eyes and words and experiment with different ways of assisting one another. Techniques to move from bed to chair, chair to floor and down the street as partners were practiced to make movement easier and safer.

## Philadelphia PADRECC Update (continued)

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

**Community Outreach:** Prior to COVID 19 pandemic, clinical staff attended several local community health fairs and presented at local support groups and professional conferences providing information on topics related to PD. Clinicians will continue outreach efforts via video conferencing modalities as requested.

### Research Update

**Current Projects:** During FY 20, the Philadelphia PADRECC had **10** active research projects.

**Clinical Research:** Prior to the COVID19 administrative hold on non-essential human subjects research, recruitment was ongoing for several studies.

#### Exercise and Recovery in Drug-Induced Parkinsonism and Parkinson Disease

Dr. Morley continued to enroll subjects in a 1 year randomized control trial of aerobic walking vs. normal care. The study will examine the effect of exercise on motor symptoms, non-motor symptoms, plasma biomarkers and changes in dopamine transporter imaging in early/mid-stage PD.

#### Understanding Physical Activity and Exercise in Parkinson Disease

Dr. Morley is studying physical activity habits and attitudes about exercise of people with PD. Participants are asked to complete a series of questionnaires to assess exercise and activity habits, attitudes about exercise, sleep, mood, memory, and other symptoms. Veterans were also asked to wear FitBit devices to track daily step count and activity levels. This study will examine feasibility of using wearable technology in Veterans with PD (enabling future interventional studies to increase activity levels) and investigate association between activity levels and the various clinical characteristic measured.

#### Bacteria and Parkinson's Disease - The Role of Bitterome and Microbiome In Parkinson's Disease

Dr. Duda, in collaboration with Dr. Noam Cohen from the ENT, continue to study how bacteria that colonize our body might contribute to the risk of PD. It has been shown that these bacteria are different in people with PD compared to people without PD. This study is trying to understand if there are genetic reasons why some people have certain types of bacteria in the hopes of developing new therapies in the future.

### Lab Projects:

#### Traumatic Brain Injury studies

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

## Philadelphia PADRECC Update (continued)

### Neurorestoration in Parkinson's Disease

Dr. Duda and his colleagues Dr. Kacy Cullen and Isaac Chen from the Center for Neurotrauma Neurodegeneration, and Restoration (CNNR) at the Crescenzo VA Medical Center, continue to investigate whether one of the main brain pathways affected in PD, the nigrostriatal pathway, can be generated in a petri dish and transplanted in animal models to reverse the motor symptoms in PD. The success of their efforts to date have led to several publications and special recognition at several different scientific meetings and additional research grants to continue these studies. The team has been successful in implanting these bioengineered pathways into a rat model of PD and are now funded to do the same in pigs, which more closely resemble what would need to be achieved to begin trying this approach in humans.

### Upcoming Projects:

**Summer/Fall 2020: 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 strategies 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. *(To learn more about this study see article on page 5 of this newsletter)*

**Summer/Fall 2020: Behavioral or Solifenacin Therapy for Urinary Symptoms in Parkinson's Disease**

The Philadelphia PADRECC (Morley, site PI) is collaborating with Dr. Camille Vaughn on her VA RR&D Merit Award study for lower urinary tract symptoms in PD. Eligible patients will be randomized to either medication or behavioral treatment (pelvic floor muscle exercises) to determine if both are equally effective in controlling frequent urination.

**Fall/Winter 2020: 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 plans to be the VA coordinating site in this trial of a novel subcutaneous delivery system for levodopa/carbidopa.*

### Publications and other research presentations:

Abstracts/posters = 5 (accepted or presented)

Manuscripts = 22 publications

## 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.

### Consortium Update:

**VA North Texas Health Care System** at Dallas, TX was added as a new consortium center site in February 2020. **Meagen Salinas, MD**, a movement disorders neurologist is the site director.

## Houston PADRECC Update (continued)

In FY 20, 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.

### Clinical Update

Houston PADRECC is functioning without any dedicated administrative support. In FY 20, our last remaining administrative support position (Program Support Assistant, Office Automation Clerk) was vacated at the end of October 2019 following the retirement of Mr. Arnold Love. This along with our Administrative officer's (vacant since 2017) and Research Health Science Specialist's positions are unfilled to date due to SCS hiring freeze and/ or lack of funding support. Our 4th movement disorders neurologist position (funded by the facility) also remains vacant.

Despite this personnel shortage, in keeping with our past performance, Houston PADRECC remained ahead of all other PADRECCs (single hospital comparison) with respect to patient encounters until March 2020, prior to being impacted by the COVID 19 pandemic.

In late March 2020 due to the health precautions related to the pandemic, Houston PADRECC shifted to 100% tele-medicine with no face to face encounters (except to address urgent matters) until the last week of May 2020, when we re-opened our Neurotoxin injection clinics, while strictly following VA health and safety guidelines.

### Accolades:

Beth Boncher RN was inducted in the selection committee of the **VA STAR** program.

Dr. Michele York received the following Awards in FY20:

- **Women of Excellence Award**, Baylor College of Medicine, 2020
- **Houston Business Journal Health Care Hero, 2019-** The annual award recognizes outstanding healthcare practitioners, physicians and rising stars who make a difference in healthcare
- **Star Clinician Excellence Award**, Baylor College of Medicine, 2019

### Education Update

Houston PADRECC 's Associate Director for Education position still remains unfilled due to SCS hiring freeze.

We have continued our 16 educational programs geared towards patients/caregivers, medical trainees and practicing healthcare providers.

These include : 1) Clinic based patient/caregiver education, 2) Patient's monthly educational support group, 3) Patient and Caregiver educational conference (Educational Forums), 4) Collaborative Patient Educational Programs with Community groups, 5) Patient and Caregiver based educational newsletter (PADRECC Pathways), 6) Medical Staff's weekly educational conference, 7) Medical staff's monthly journal club, 8) Physicians' Clinical Case Discussions, 9) Medical staff's monthly inter-disciplinary surgical case discussion series, 10) Monthly Consortium based tele- educational meeting, 11) PADRECC based BCM neurology residents monthly elective rotation, 12) PADRECC's joint educational venture with Pharmacy residency training program, 13) In-patient medical student and medical residents hands on educational experience, 14) PADRECC physicians' lectures (including grand rounds, invited lectures) at the VA, BCM, national and international locations, 15) Contribution to the transmitter (e-newsletter) 16) Nurse lecture series.

## Houston PADRECC Update (continued)

### New Initiatives:

- In FY20, Dr. Sarwar began QI (quality improvement) lecture series geared towards our nurses regarding latest management guidelines (nursing perspective) pertaining to PD and related movement disorders. (once/month)
- Initiated PADRECC based Geriatric Fellows movement disorders rotation (Baylor College of Medicine, MED VAMC) 2-4-week training of geriatric fellows at Houston PADRECC (1-2 fellows/FY).
- Neurology Residents Tele-Medicine Training

### Accolades:

- Dr. York received *Norton Rose Fulbright Educational Award for Enduring Educational Materials*, Baylor College of Medicine in Nov. 2019
- Dr. Jamal received *Norton Rose Fulbright Educational Award for Teaching and Evaluation*, Baylor College of Medicine in May 2020
- Dr. Jamal received the "*Clerkship Teaching Award*", July-December 2019 and Faculty Teaching Award at BCM Neurology in June 2020.

### Research Update

We currently have **11** active research projects. In FY20, we continued recruitment in our Circadian Rhythm/Sleep Study and screening subjects for a 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" until the face to face aspect of the research studies was halted in March 2020 due to COVID 19 Pandemic related health precautions.

### New Initiatives in FY20:

*(grants submitted and new collaborations)*

- **Rural Health (ORH grant)- "Rural Veterans with Depression and Parkinson's Disease: A Telehealth Psychotherapy Solution."** Collaborative project with MH, (PI: Interian, MD, Co-I: Sarwar, MD) ~ Submitted
- **H-47756. Houston Alzheimer Disease Research Center Consortium: Clinical Cohort. Submitted to IRB.** Pilot enrollment of MEDVAMC dementia patients, including neurological and neuropsychological exams, banking of blood for whole genome sequencing, and tau PET. Pilot funds provided through BCM including for completion of tau PET at Houston Methodist. PDD and DLB patients from PADRECC will be eligible in the expanded protocol. Preparation for revision of P30 for Sept. 2020  
( <https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-21-019.html> ).  
Jackson, GR, MD, PhD (Co-I)
- **Tryptophan metabolism, gut microbiome, and sleep deficiency",** Li Jiao, MD, PhD (PI), Sarwar, AI (Co-I)

### Publications and other research presentations: (10/1/2019 – 05/30/2020)

Abstracts/posters = 7 (accepted or presented)

Manuscripts = 10 (5 published or accepted, 3, under review, 2 in development)

## Southeast/Richmond PADRECC Update

The Richmond Southeast PADRECC provides interdisciplinary care to meet the unique needs of eligible Veterans and their care-partners. PADRECC staff offer specialized care including neurology, nursing, neuropsychology, psychiatry, physical medicine and rehabilitation and surgical services.

### Clinical Update

During fiscal year 2019, over 1100 Veterans were evaluated in our clinic and over 3200 face-to-face encounters were provided. In addition to our face-to-face clinics, the Richmond Southeast PADRECC has robust neurology and surgical telehealth clinics for Veterans who do not live locally and/or for whom travel to Richmond is difficult. They have the option to be seen remotely at their home VA hospitals, community outpatient clinics or from the comfort of their homes through VA video connect. Over 650 Veterans were evaluated via telehealth in fiscal year 2019, making the PADRECC telehealth clinic one of the largest telehealth clinics at the Richmond VAMC. Deep brain stimulation (DBS) preoperative and postoperative evaluations and DBS programming support is available face-to-face or via our DBS telehealth clinic. This highly specialized procedure is performed in Richmond using a frameless method of stereotaxy. 118 DBS evaluations and 64 DBS-related surgeries were performed last year.

### Education Update

In addition to our clinical and research programs, the Richmond Southeast PADRECC is involved in community outreach including a 2-hour, monthly support group meeting. The first hour is an educational session with a guest speaker. Topics have included music therapy, understanding care benefits, benefits of anti-inflammatory eating, freezing of gait interventions, speech and swallowing changes, caregiver stress, and the benefits of physical therapy to name a few. Following the educational session, participants break into separate discussion groups for people with PD and their care-partners. The groups are led by PADRECC nursing staff and a social worker. The support group is well attended by our Veterans and care-partners and is open to the community as well. In addition, PADRECC clinical staff provided over 25 presentations to support groups throughout Virginia and at professional conferences. The Richmond PADRECC has strong collaboration with the mental health service through an attending Psychiatrist embedded in the clinic 1 half day per week, specifically focusing on co-managing the mental health issues associated with Parkinson's Disease and other complex movement disorders.

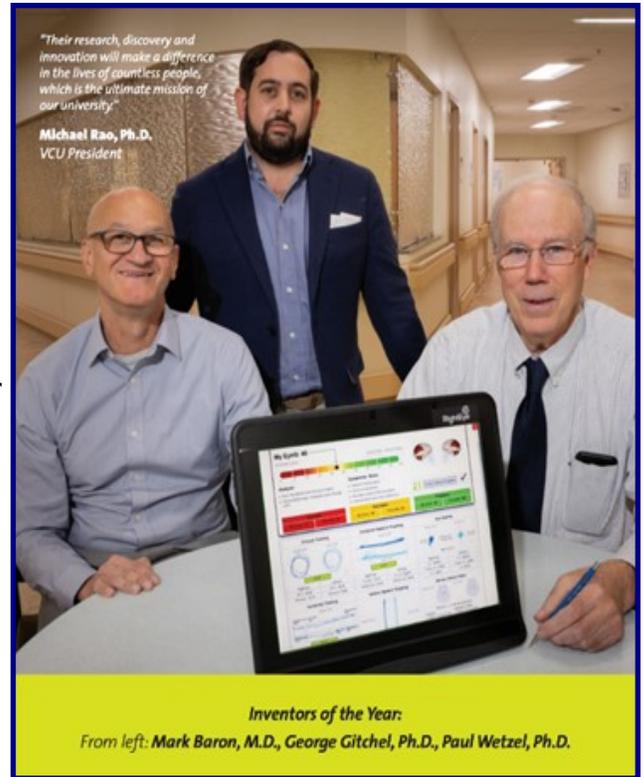
The Richmond Southeast PADRECC was a sponsor of the annual **Virginia PD Education Day**. PADRECC staff helped with conference planning and were guest speakers. Topics included panel discussions on living with PD and updates on research, and breakout sessions were available on nutrition and PD, exercise in PD, and caring for the caregiver to name a few. It was a successful event with over 300 people in attendance.

### Research Update

Over ten research projects are underway at the Richmond Southeast PADRECC with several others awaiting IRB approval. These include, but are not limited to a Merit funded study on urinary incontinence in PD, a locally funded study examining the gut-microbiome, two studies involving the use of transcranial magnetic stimulation – one for cognition and attention and the other for speech dysfunction in PD, a study examining the accuracy of DBS targeting and clinical implications, two Michael J Fox stimulation data registry and another for eye movement research. The latter is a long-standing study that started approximately 10 years ago with many thousands of subjects enrolled. This study resulted in intellectual property and

## Southeast/Richmond PADRECC Update (continued)

the resulting technology was successfully licensed to RightEye LLC. Through development with Dr. George Gitchel, it has resulted in a commercial product with active units in all 50 states and 20 countries, from which the VHA is regularly receiving royalties. In fiscal 2019, this technology was awarded United States Patent number US10575726B2. This technology was granted FDA Breakthrough Device designation, one of fewer than 200 devices ever granted such status. The proposed indication is for a Parkinson's disease diagnostic aid, and approval for indications are expected in mid-late 2021. Finally, as a result of this work, Drs. Gitchel and Mark Baron (along with their collaborator from the local university) were named the Virginia Commonwealth University Inventors of the Year for 2019 (*pictured in photo*).



In addition to these projects, Dr. Mark Baron's lab, located at the Richmond VAMC, is dedicated to investigating the pathophysiology of movement disorders in rodent models. This lab is funded through the VA's Biomedical Lab Research & Development (BLR & D) Merit Review Award Program. The investigators have recently discovered that they can induce pure parkinsonism with a high focused lesion in the dorsal motor territory of globus pallidus externa (GPe) and can induce dystonia via a highly focused more ventral lesion. Using transsynaptic viral tracers, they have traced the parkinsonian territory to a highly focused premotor cortical region and have traced the dystonia locus to the primary motor cortex suggesting that parkinsonism and dystonia originate along distinct premotor and primary motor sub-circuits. The investigators intend to investigate the potential for therapeutically targeting these specific cortical territories.

## Northwest PADRECC Update

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

### Clinical Update

Due to COVID-19 precautions, clinical activity has changed in the NW PADRECC from primarily in-person face-to-face visits to telephone, telehealth, and/or virtual visits (VVC). In quarter 3 (April – June, 2020), phone visits have increased 85% compared to the same quarter in FY19 to 459 encounters and telehealth saw an increase of 58% to 104 encounters.

We have been using multiple modalities to see patients virtually. We have used Doximity, Web-Ex and CVT at home site if available.

## Northwest PADRECC Update (continued)

Portland has completed 7 DBS surgeries and 10 battery changes. We use the 3 systems available to us, Medtronic, Abbott, and Boston Scientific. All DBS surgeries have been on hold since mid-March. We have done 5 necessary battery changes during the COVID 19 restrictions.

This year we had a mini residency training for Dr. Heidi Heller from Spokane on DBS programming. She had a full day visit with multiple patients needing programming and then had an on-site patient that we assisted with telehealth for 2 sessions for his initial and follow up programming.

**Botox:** Portland and Seattle continue to have very active Botox injection clinics. We easily see over 500 visits per year. Staff was currently trained in the use of the ultrasound, useful for patient in need of injections for sialorrhea as well as spasticity. Due to COVID-19 precautions, quarter 3 at both Portland and the Puget Sound saw a decrease of 25-27% in Botox encounters. We believe that after the restrictions are lifted at both facilities, that the high volume of activity will return to normal.

### Education Update

NW PADRECC Portland hosted its annual CME "Neurology Updates for General Practice". This year for the first time this was offered as a virtual only class. The topics vary from year to year. This year the topic titles are: "Pitfalls in the care of Parkinson's Disease patients", "Delirium: Recognize and Treat", "Palliative Care", and "Differential Diagnosis Exam Tips in Patients with Weakness". Registration for this event is in TMS and CME credit was given. We had over 50 participants.

NW PADRECC continues with a once per month support group for veterans with PD and their caregivers. We have continued this group virtually during these COVID 19 restrictions and maintain a good turnout for each meeting.

### Research Update

#### Active Research Projects:

**Describing the differences between disease process and treatment effect (ATAx; OHSU eIRB # 18608; VA MIRB # 4299).** *Initiated by Dr. Jennifer Nichols (fellow 2017-2019), currently run by Dr. Venka Veerappan (fellow 2018-2020).* The study aims to characterize ataxia occurring in essential tremor and essential tremor with DBS.

**Characterizing Biomarkers of Early Parkinson's Disease Progression (TREG; OHSU eIRB # 18545; VA MIRB # 4277).** *Initiated by Dr. Jill Baird (fellow 2017-2019), currently run by Dr. Lee Neilson (fellow (2019-2021)).* The study aims to characterize the rate of change in a peripheral blood marker of inflammation (T-reg percentage) and three quantitative motor measures (finger tapping, 9-hole peg test, and peak turn velocity) in a cohort of 25 untreated PD patients.

**Clinical Characteristics of Parkinson's Disease Subjects with Severe Hypertension During Motor OFFs (CLIN-HTN; VA IRB # 4202).** *Initiated by Christopher Way (fellow 2016-2018).* This study aims to characterized blood pressure changes in relation to the levodopa cycle.

**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 relation to initiation of levodopa-therapy will be examined.

## Northwest PADRECC Update (continued)

**Measuring Cortisol Levels in Persons with Parkinson's Disease (CORT-PD; OHSU eIRB # 15183; VA MIRB: 3794).** *Huntington's Disease Society of America Grant.* Dr. Amie Hiller is conducting a research study looking at cortisol levels in Parkinson's Disease (PD), Huntington's Disease (HD), and Healthy Controls (HC).

**Pacific Northwest Udall Center (PaNuC): Clinical Core and Specimen Collection (VA IRB # 2332; OHSU eIRB # 6154).** Dr. Joseph Quinn is conducting this research study to examine the changes in thinking and memory of Parkinson's disease patients over time

### Selected Publications FY20

- Nutt JG, Curtze C, Hiller A, et al. Aromatic L-Amino Acid Decarboxylase Gene Therapy Enhances Levodopa Response in Parkinson's Disease. *Mov Disord.* 2020;35(5):851-858. doi:10.1002/mds.27993
- Cholerton B, Poston KL, Tian L, et al. Participant and Study Partner Reported Impact of Cognition on Functional Activities in Parkinson's Disease. *Mov Disord Clin Pract.* 2019;7(1):61-69. Published 2019 Dec 14. doi:10.1002/mdc3.12870
- Wilson EN, Swarovski MS, Linortner P, et al. Soluble TREM2 is elevated in Parkinson's disease subgroups with increased CSF tau. *Brain.* 2020;143(3):932-943. doi:10.1093/brain/awaa021

### Accolades

On December 19, 2019, **Susan O'Connor RN**, our Acting Administrative Officer and Clinical and Research Coordinator was celebrated with the presentation of the DAISY award. The DAISY award Foundation (Diseases Attacking the Immune System), works in partnership with healthcare organizations to honor nurses who go "above and beyond" and make extraordinary differences in patients and families experiences in healthcare with not only outstanding clinical skills but especially for special acts of kindness and compassion. Here at the VA, the nurses are nominated by a veteran, the nominations blinded and sent to a committee who scores the nomination on the ICARE values. Susan was nominated by a veteran who lives in Montana who has Parkinson's disease, and as his disease progressed he was referred here for care, treatment and then DBS. He wrote a wonderful story of how she helped him to navigate the system from travel to lodging to appointment coordination, making his journey with the VA that was far from home so much easier.

From the patient" We have joked many times about "who ya gonna call" when we had a problem. That answer was always Susan."



## 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 makes use of all appropriate therapies. (See Dr. Subramanian's article on page 3, "Risk of Social Isolation in Parkinson's Disease Population").

**Whole Health Coach:** Patricia Pittman, RN, MBA, Clinical Nurse Coordinator was selected to receive training as a Whole Health Coach, within the VA system, June and July 2020. Due to COVID-19, the training was cancelled, pending rescheduling.

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.

**Telehealth:** Under the direction of Dr. Adrienne Keener, the PADRECC clinic is expanding access to care by integrating VA Video Connect (VVC) into their clinical practice. (See Dr. Keener's article on page 2, "Embracing Telemedicine During Coronavirus").

**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

**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 topics were



## Southwest PADRECC Update (continued)

Parkinson's, medications, mood, cognition and psychosis. Patients participated in a range of fun and beneficial demonstrations.

**PD at Home:** VA GLA PADRECC hosts the PD at Home teleconference held the 2<sup>nd</sup> Tuesday of every month from 10:00 – 11:00 am PST, via toll free number 1.800.767.1750 code 5431#. The teleconference is facilitated by **Patricia Pittman**, RN, MBA, Clinical Nurse Coordinator. The PADRECC Education Committee seeks out speakers who present diverse topics on PD.

### 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. Five manuscripts have been published describing gene polymorphisms and progression of PD; more manuscripts have been submitted. Additional NIH funding is being requested to follow this cohort to determine genetic and environmental factors that alter progression of PD. 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 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.

## San Francisco PADRECC Update

### Staff Update

#### New Director



#### **J. Rafael P. Zuzúárregui, MD, Director PADRECC-San Francisco**

Dr. Zuzúárregui joined the San Francisco PADRECC September 2019 under the mentorship of Caroline M. Tanner, MD, PhD. As of July 2020, Dr. Zuzúárregui advanced to Director, PADRECC San Francisco and Dr. Tanner transitions to Associate Director of Research.

Rafael Zuzúárregui is board certified in Neurology, he completed his fellowship in Movement Disorders at Boston University School of Medicine and fellowship in Sleep Disorders at Stanford University. He earned his medical degree from Boston, came to UC-Fresno for his internship, returned to complete his residency at Boston University School of Medicine where he was Chief Resident.

Dr. Zuzúárregui's focus is in the treatment of Movement Disorders and various sleep disorders, as well as the use of Botox and Deep Brain Stimulation (DBS). His research is on the intersection between movement and sleep disorders with particular focus with the impact of DBS on various sleep parameters. He also has a strong interest in medical education.

## San Francisco PADRECC Update (continued)

He is currently researching the relationship between toxicant exposures during Gulf War deployment and prodromal Parkinson's disease; the impact of Globus Pallidus Deep Brain Stimulation on Sleep Disorders in Parkinson's Disease

### Selected Publications:

*Medical education in movement disorders during the COVID-19 pandemic.*

Zuzuárregui JRP, Bledsoe IO, Brown EG, Dietiker CG, Galifianakis NB. *Parkinsonism Relat Disord.* 2020 Jun 15;77:11-12. doi: 10.1016/j.parkreldis.2020.06.013. Online ahead of print. PMID: 32570192

<https://pubmed.ncbi.nlm.nih.gov/32570192/>

*The Impact of Deep Brain Stimulation on Sleep in Parkinson's Disease: An update.*

Zuzuárregui JRP, Ostrem JL. *J Parkinsons Dis.* 2020;10(2):393-404. doi: 10.3233/JPD-191862. PMID: 32250316

<https://pubmed.ncbi.nlm.nih.gov/32250316/>

*YouTube: on Sleep and Parkinson's disease*

<https://www.youtube.com/watch?v=WXotD8HA5Po>

### New Associate Director of Clinical Care



**Cameron Dietiker, MD** becomes Associate Director Clinical Care for PADRECC San Francisco.

Dr. Dietiker is a graduate of University of California San Diego (UCSD), followed by two years research for the Collaborative Study on the Genetics of Alcoholism (COGA) under the Veterans Medical Research Foundation. She acquired her medical degree from NYMC, completed her neurology residency training at UCSF, and in 2017, the PADRECC movement disorders fellowship at UCSF and San Francisco VAHCS.

Dr. Dietiker is Assistant Clinical Professor in Neurology at UCSF.

As a movement disorders specialist, Dr. Dietiker's clinical practice encompasses Parkinson's disease, Huntington's disease, ataxia, tremor, and dystonia, among other disorders. She is knowledgeable in the administration of botulinum toxin as well as deep brain stimulation (DBS) programming. Her current research endeavors include clinic trials in Parkinson's disease, Huntington's disease, multiple system atrophy, and essential tremor.

### San Francisco PADRECC Recent Publications

Brown EG, Bledsoe IO, Luthra NS, Miocinovic S, Starr PA, Ostrem JL. **Cerebellar Deep Brain Stimulation for Acquired Hemidystonia.** *Mov Disord Clin Pract.* 2020;7(2):188-193. Published 2020 Jan 8. doi:10.1002/mdc3.12876

Caroff SN, Yeomans K, Lenderking WR, Cutler AJ, Tanner CM, Shalhoub H, Pagé V, Chen J, Franey E, Yonan C. **RE-KINECT: A Prospective Study of the Presence and Healthcare Burden of Tardive Dyskinesia in Clinical Practice Settings.** *Clin Psychopharmacol.* 2020 May/ Jun;40(3):259-268. doi: 10.1097/JCP.0000000000001201. PMID: 32332461

## San Francisco PADRECC Update (continued)

Chen W, de Hemptinne C, Miller AM, Leibbrand M, Little SJ, Lim DA, Larson PS, Starr PA. *Prefrontal-Subthalamic Hyperdirect Pathway Modulates Movement Inhibition in Humans*. *Neuron*. 2020 Feb 26;S0896-6273(20)30135-5. doi: 10.1016/j.neuron.2020.02.012. Online ahead of print. PMID: 32155442 <https://pubmed.ncbi.nlm.nih.gov/32155442/>

Dietiker C, Kim S, Zhang Y, Christine CW. **Characterization of Vitamin B12 Supplementation and Correlation with Clinical Outcomes in a Large Longitudinal Study of Early Parkinson's Disease**. *J Mov Disord*. 2019 May; 12(2):91-96. PMID: 31158942.

Luo M, Larson PS, Martin A, Miga MI. *Accounting for Deformation in Deep Brain Stimulation Surgery with Models: Comparison to Interventional Magnetic Resonance Imaging*. *IEEE Trans Biomed Eng*. 2020 Feb 14. doi: 10.1109/TBME.2020.2974102. Online ahead of print. PMID: 32078527

Luthra NS, Marcus AH, Hills NK, Christine CW. (2020) **Vitamin B12 measurements across neurodegenerative disorders**. *Journal of Clinical Movement Disorders*. 7:3. doi: 10.1186/s40734-020-00085-8

Pahwa R, Dhall R, Ostrem J, Gwinn R, Lyons K, Ro S, Dietiker C, Luthra N, Chidester P, Hamner S, Ross, E and Delp S. (2019). **An acute randomized controlled trial of non-invasive peripheral nerve stimulation in essential tremor**. Manuscript accepted for publication in *Neuromodulation: Technology at the Neural Interface*.

Zuzuárregui JR, Ostrem, JL. **The Impact of Deep Brain Stimulation on Sleep in Parkinson's Disease: An update**. *J Parkinsons Dis*. 2020;10(2):393-404. doi: 10.3233/JPD-191862.

## National VA PD Consortium Center Updates

### Philadelphia PADRECC

James J. Peters VA Medical Center, Bronx, NY

Director: Ruth Walker, MD

With the start of the COVID-19 pandemic and the shutdown in New York State in the middle of March, Drs. Melissa Nirenberg and Ruth Walker rapidly expanded their telehealth services to care for almost all patients remotely. The only exception has been for occasional in-person clinic visits for botulinum toxin injections and DBS programming.

While there was a learning curve for most patients and family members, many have expressed great appreciation for the ability to maintain continued access to medical care without exposing themselves to potential infection risk, an issue of particular importance in our vulnerable patient population. Even as our clinic slowly reopens in the coming months, we will continue to utilize telehealth for the majority of appointments for the foreseeable future.

We were excited to schedule a James J. Peters VA Patient Awareness Day for May 27th, sponsored by the American Parkinson's Disease Foundation, and equally disappointed when we needed to postpone indefinitely due to Covid-19. We look forward to scheduling a new live event when circumstances permit, or switching to a virtual format.

## National VA PD Consortium Center Updates (continued)

Throughout the pandemic, we have continued to recruit patients for our neurodegenerative disease brain donation registry, and to pursue active research about the neuropathological and genetic substrates of movement disorders with collaborators at Mount Sinai.

### Recent publications

Feinstein E, Walker RH (2020) Treatment of secondary chorea: A review of the current literature *Tremor and Other Hyperkinetic Movements* 10(1): 22, pp. 1–14. doi: <https://doi.org/10.5334/tohm.351>

Martinez-Ramirez D, Walker RH, Rodriguez-Violante M, Gatto EM (in press) Rare hereditary and acquired chorea: A review of the differential diagnosis *Tremor and other Hyperkinetic Movements*

### Southwest PADRECC – Consortium Update

#### VA Loma Linda Health Care System

**Dr. Dorothee Cole** manages the Movement Disorders clinic, which provides specialty care for patients with PD, including DBS programming, Duopa pump programming and botulinum toxin therapy. In addition, she treats other movement disorders such as myoclonus, tremor, Huntington’s disease, and ataxia. She provides teaching to medical students, neurology residents, and clinical pharmacy residents.

#### VA San Diego Health Care System

**Dr. Stephanie Lessig and Dr. Caitlin Mulligan**, serves as attending neurologists in weekly Movement Disorders and Botulinum Toxin clinics.

Dr. Lessig is the Co-Principal Investigator at UCSD for the nationally recognized PPMI study by the Michael J Fox Foundation that targets newly diagnosed Parkinson’s patients throughout the community and the VA. Dr. Lessig collaborates extensively with the Neuropsychology department at VA San Diego and participates in many protocols analyzing cognition in PD. She is Co-Investigator on the protocol “Investigating Exercise-Induced Neuroplasticity and its Mechanisms in Parkinson’s Disease: Targeting Executive Function and Brain Circuitry”.

#### New Mexico (Albuquerque) VA Health Care System

**Dr. Sarah Pirio-Richardson and JoAnn Harnar, RN**, run the PADRECC clinic in Albuquerque, New Mexico. Clinical activities include specialty care for patients with tremor, ataxia, PD and dystonia. botulinum toxin injections and DBS programming are done for patients in VISN 18 from Eastern Arizona, Southern Colorado, New Mexico and Western Texas. Teleneurology and nurse education sessions are important parts of these services.

#### Las Vegas VA Health Care System

**Dr. Selina Parveen** provides movement disorder, DBS and botulinum toxin management to a large catchment area in Nevada, Arizona and Utah in VISN 22. She is often a guest speaker at the community support group, Friends of Parkinson’s, in which many Veterans attend. She teaches medical students at UNLV school of medicine and has academic affiliation at Touro Medical College.

## National VA PD Consortium Center Updates

### Southern Arizona (Tucson) VA Health Care System

**Scott Sherman, MD, PhD** and his research laboratory, focus on developing novel therapies for PD and have several translational research projects. His research led to the discovery that neurotrophic factors, Vascular Endothelial Growth Factor-B and a PEDF, a factor derived from the retina, are neuro-protective. Basic laboratory studies in these areas are continuing.

Dr. Sherman has been working to repurpose the anesthetic drug, ketamine, as a treatment for dyskinesia and non-motor symptoms of PD. They originally reported the clinical observations that low dose infusions of ketamine for a period of 72 hours led to sustained benefits in reducing levodopa-induced dyskinesia (LID). The doses used did not cause any significant side effects or sedation and had effects lasting several months. The next goal is to design a prospective, randomized, placebo-controlled Phase 2 clinical trial to further confirm this result. To properly design this trial, they have developed a pre-clinical rodent model of LID to predict the dose response, duration of response and mechanism of action of ketamine. They have found shorter infusions (10 hrs. or less) in the sub-anesthetic range are still effective in the rodent model. If this translates to humans, then it may be feasible to use an abbreviated outpatient treatment regimen. In addition, they have made significant progress in understanding the mechanism of action of ketamine in this model system. They have found that ketamine acts to alter long-term oscillatory behavior of cortico-striatal circuits in manner analogous to DBS. They are also investigating the role of the neurochemical BDNF that is likely up-regulated by ketamine treatment. In 2019, they were successful in obtaining funding from the Arizona Biomedical Research Council (750,000 over 3 years to conduct this research).

Dr. Scott Sherman's research laboratory is a major collaborator on an NIH funded project to develop neuro-protective molecules in rodent models of PD. NINDS (1 R01 NS 091238-01A1, 09/30/15 to 06/30/20, PACAP/VIPV).

### VA Long Beach Health Care System

**Dr. Steven Schreiber** is Chief of Neurology and oversees the PADRECC clinic. He was instrumental in developing the first Teleneurology program in the VA system. **Dr. An Tran**, Movement Disorders Specialist, runs the botulinum toxin, Movement Disorders and DBS clinics. **Megan Gomez, PhD**, a licensed clinical psychologist in the Primary Care Mental Health Integration Clinic, specializes in neuropsychology and neurodegenerative diseases and facilitates a monthly Parkinson's Support Group.

Due to COVID-19 pandemic, the VA Long Beach has converted some of the PADRECC appointments to VA Video Connect (VVC) and the rest to a telephone clinic. This has enabled the facility to continue providing care to Parkinson/Movement Disorders patients while keeping Veterans safe at home. The VA Long Beach is also a participant in the Parkinson's Disease National TeleMental Health Center consultation (PD NTMHC) service. This service provides neuropsychiatry consultation to Parkinson patients. Dr. Weintraub assists in managing Parkinson's Disease patients with complex diagnostic or psychopharmacological questions. The program brings experts in Parkinson's Disease psychiatry to Veterans throughout the country, regardless of how remote their location.

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**Newsletter Editors**  
**Gretchen Glenn**  
 National VA PD Consortium Education Subcommittee Chair  
**Eileen Hummel**  
 Nurse Coordinator, Philadelphia PADRECC

## 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	Joe Quinn, MD	Portland: 503-721-1091 Seattle: 206-277-4560
Philadelphia	Corporal Michael J. Crescenz VAMC	Philadelphia, PA	John Duda, MD	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. Zuzúárregui, MD	415-379-5530

