PARKINSON’S DISEASE RESEARCH, EDUCATION AND CLINICAL CENTERS

ANNUAL REPORT 2023

[Document subtitle]
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PADRECC 2023 Annual Report

Introduction: The Parkinson's Disease Research Education and Clinical Centers (PADRECCs) were established through RFP in 2001, then amended into Public Law 109-461. There are six Centers of Excellence: Philadelphia, Southeast (Richmond), Houston, Northwest (Portland/Seattle), San Francisco, and Southwest (West Los Angeles).

Our Mission: To provide comprehensive, state-of-the-art care to assure the highest quality of life for Veterans afflicted with Parkinson’s disease and related Movement Disorders (PDMD); to advance investigation into the cause, treatment, and cure for those disorders; and to enhance understanding of those disorders by developing education programs for practitioners, patients, and caregivers.

Brief Description: The PADRECCs provide access to comprehensive, advanced medical and surgical care for Veterans afflicted with PDMD.

The focus of our educational and training programs is sharing contemporary information on the management of PDMD with clinicians, patients, and their families.

The PADRECC’s research program focus is on advancing investigations into the epidemiology, treatment, prevention, and basic pathophysiology of PDMD.

Complementing the research and clinical care at the PADRECCs is the National VA Parkinson’s Disease Network (formerly known as the National VA Parkinson’s Disease Consortium), a professional consortium comprised of VA physicians, nurses, therapists, and pharmacists with interest and expertise in the field of movement disorders. The PADRECCs launched the consortium (network) in 2003 to expand Parkinson’s disease awareness and education across VA. It offers peer networking, consultative services, education, and training. PADRECC Associated Sites (PAS) (formerly known as Consortium Centers) are VA clinics that offer specialized Parkinson’s disease and movement disorder specialty care to Veterans who cannot travel to a PADRECC. These centers are staffed by movement disorder specialists or clinicians with vast experience and/or interest in the field of movement disorders. Together, the six PADRECCs and over 50 PASs provide convenient and state-of-the-art care to Veterans throughout the country.

FY23 Administrative Highlights: The National Neurology Program Office formally introduced John Duda, MD as the National PADRECC Clinical Lead and Dawn McHale as the Acting National PADRECC Administrator. These positions were created, at the request of VA Central Office, to provide oversight of the national PADRECC program and to standardize the national reporting structure throughout all the neurology centers of excellence.

With the national structure in place, change management was introduced to the PADRECCs to assist in the re-organizational shift from Specialty Care Program Office organizational chart to that of the PADRECC host facilities. The re-organization would also affect how funds are disbursed to the facilities. Three members of the PADRECC leadership team completed the three-day VHA Change Practitioner Training, while several other leaders completed the VHA Change Management Training. PADRECC leadership worked closely with change management champions and the national neurology program office to develop facility level communication strategies and memorandums of agreement to move the re-organization forward. After thoughtful consideration, Specialty Care Program Office is now leading this effort, focusing on communication and slowly rolling out the re-organization at the VISN level.

In February 2023 the PADRECCs received an unexpected disbursement of $2,000,000. Given that the PASs have been an unfunded initiative since its inception in 2006, the PADRECC utilized most of those funds to support many of the PASs. The funds supported clinical FTEE, equipment, education, and travel to CEU programs. The funds also provided Cognitive Behavior Therapy (CBT) training to an additional six psychologists or social workers in preparation of expanding the CBT for Depression in PD program to all six PADRECCs.

Specialty Care Program Office and PADRECC entered into an MOA with SALIENT to evaluate the program based on these key objectives: (a) develop the PD cohort from FY2018-2022, (b) describe the characteristics and utilization
of Neurology/PD Specialty Care, and (c) conduct geospatial mapping and multivariable analyses regarding this PD cohort in FY22. Below is the final report completed in October 2023.

PADRECC_Report_Final.pdf

FY23 Education Highlights

*Professional Education: Training the next generation of neurologists, movement disorders and ancillary specialists.*

The PADRECCs host clinical rotations for medical students, residents (neurology, pharmacy, PM&R and psychiatry) and fellows (geriatric, psychiatry, palliative care, PM&R and geriatric psychiatry). Northwest, Philadelphia, Southwest and San Francisco PADRECCs collaborate with the Office of Academic Affiliation to participate in the Advanced Fellowship in Movement Disorders Program. San Francisco has an additional slot for fellowship in Stereotactic and Functional Neurosurgery. Each fellow is required to complete a rigorous curriculum which includes didactic clinical training, mentored clinical outpatient and inpatient service, mentored research, and teaching.

During FY23: The PADRECC program trained 22 Movement Disorders Fellows and provided clinical rotations for 165 residents, 170 medical students and 25 clinical specialty fellows. PADRECC clinicians serve as faculty for the neurology residency program didactic lecture series at the affiliate university. In addition, PADRECC staff gave 166 lectures at local, regional, national, and international conference and symposia, participated in Journal Clubs and led video case conferences. The Philadelphia PADRECC monthly Video Case Conference has been expanded to include all VA providers and continued to grow in participation in 2023.

**PD Rehab Community of Practice** - This is a collaboration with rehabilitation subject matter experts across the VA with interest in PD with the goal to develop a platform to share evidence-based knowledge to inform PD specific rehab practices, provide access to up-to-date resource, program success and opportunities for improvement.

Other national education resources for providers and trainees can be found on the PADRECC website: [Parkinson’s Disease Research, Education and Clinical Centers Home (va.gov)](https://www.va.gov/parkinsons).

**Patient Education: Sharing contemporary information on the management of Parkinson’s disease with Veterans and their families.**

The PADRECCs multi-faceted patient education program provides relevant information on disease management to Veterans and their family in several different ways. Education starts at diagnosis – clinicians have thoughtful conversations with the Veteran and family to explain the disease and ascertain appropriate, personalized treatment. Written material is available in the clinic for Veterans and family members and the PADRECC website is full of helpful information. Veterans and their caregivers have access to support groups and formal education programs planned by the PADRECCs as well as programs provided by our community partners. In FY23 PADRECC held 38 VA support group meetings and 17 patient education programs; PADRECC providers presented at 21 community support group meetings and 13 community patient programs.

The Department of Veterans Affairs partnership with the Parkinson’s Foundation continues to be productive and beneficial for our Veteran population. The objectives of the partnership are to:

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.

Activities of the partnership during FY23
• MOA renewed through 2027.
• 1910 unique Veterans and their care partners who registered for an event, requested resources, or contacted the Parkinson’s Foundation Helpline in FY 2023 (10/1/22-8/31/23)
• 6 Regional events
  o Veterans and Parkinson’s: Exercise, Nutrition and Wellness – Speakers Dr. John Duda and Dr. James Morley, Philadelphia PADRECC - 312 registered.
  o Surgical Options for Veterans Living with Parkinson’s –Speakers: Dr. Scott Lewis and Dr. Robert McGovern, Minneapolis VA, PAS - 66 registered.
  o Veterans and Parkinson’s: In person event, Columbus, OH – 51 attendees.
  o Veterans and Parkinson’s: Resources for Veterans with Parkinson’s- Gretchen Glenn, Philadelphia PADRECC co-presenter – 913 registered.
  o Veterans and Parkinson’s: Managing Anxiety, Depression and Apathy – Speaker -Dr. Megan Gomez, VA Long Beach Healthcare System, PAS – 612 registered.

FY23 Research Highlights

**PADRECC research: To advance investigation into the cause, treatment and cure for Parkinson’s disease and related disorders.**

PADRECC’s groundbreaking research continues to be published in scholarly journals. Through these efforts, the VA has been internationally recognized as a principal player in the field of movement disorders and has joined forces with other key organizations such as the Department of Defense, Centers for Disease Control and Prevention, Michael J. Fox Foundation, and the Parkinson’s Foundation. In FY2023 the PADRECC investigators had 72 funded research projects (44 clinical, 8 health services, 11 epidemiology and 9 basic science), published 98 articles in scholarly publications, and presented 37 posters at national and international conferences or symposia.

Multi-center research that PADRECC Investigators participated in during FY2023:

• Multicenter, Randomized, Double-Blind Comparator Study of Antipsychotics Pimavanserin and Quetiapine for Parkinson’s Disease Psychosis (C-SAPP Study) – VA CSP #2015
• The Veterans Parkinson’s Disease Genetics Initiative (Vet-PD) – Michael J. Fox Foundation
• Behavioral or Solifenacin Therapy for Urinary Symptoms in Parkinson’s Disease – VA R&D Merit
• Rural Veterans with Depression and Parkinson’s Disease: A Telehealth Psychotherapy Solution. – VA Office of Rural Health
• PPMI - The Parkinson’s Progression Markers Initiative – Michael J. Fox Foundation
• ENROLL-HD: A Prospective Registry Study in a Global Huntington’s Disease Cohort -CHDI Foundation, Inc.

FY23 Clinical Highlights

There has been increasing recognition that PD involves both motor and non-motor symptoms and that the best care requires a multi-disciplinary approach. Motor symptoms include tremor, stiffness, slowness and gait dysfunction. The most common non-motor symptoms in Veterans from the SALIENT report include falls (20.3%) depression (32.8%), PTSD (20.3%), anxiety (20.1%), dementia (31.4%), sleep disorders (40.3%), constipation (25.8%) and dysphasia (17.9%). PADRECCs have established nationally recognized indicators of quality care (Cheng et al. Mov Disord. 2004;19:136-50) and have proven that specialist involvement in care and multidisciplinary care improves outcomes (Carne et al. J Rehabil Res Dev. 2005;42:779-86; Carne et al. NeuroRehabilitation. 2005;20:161-7; Cheng et al. Parkinsonism Relat Disord. 2008;14:8-14). The PADRECC system of care provides Veterans with Parkinson’s disease and related movement disorders optimized care, in the appropriate location, time and capacity as dictated by the natural progression of disease. This not only includes access to state-of-the-art diagnostic and treatment modalities through the course of the disease, but also access to social work services, spiritual care
services and interdisciplinary care involving access to speech therapy, occupational therapy, physical therapy, and other physician specialists to care for the specific needs of Parkinson’s disease and movement disorder patients in an integrated fashion. PADRECCs deliver comprehensive care with special expertise in chemodenervation, DBS surgery, neurostimulator programming, intestinal levodopa administration and telehealth.

Each PADRECC has one or more of the above disciplines in their clinic and have access to all the above therapies. However, the Richmond PADRECC has managed to organize the disciplines and has implemented an **Interdisciplinary Treatment (IDT) clinic.** The IDT clinic is held one day a week for a four-hour block, during which three of their Veterans are assessed by appropriate therapists and or disciplines either face to face or VVC. At the end of the session the team meets to discuss treatment plans and needs. Veterans who have been evaluated (120) in the IDT clinic have provided positive feedback.

The Houston PADRECC’s interdisciplinary approach to DBS care includes a monthly meeting with neurosurgery, social work services and beneficiary travel to ensure proper arrangements are in place for Veterans traveling long distances who are scheduled for DBS surgery.

In addition to PD, the PADRECCs provide specialized care for Veterans with other movement disorders as well. A functional movement disorder (FMD) sometimes referred to as psychogenic movement disorders occurs when you experience unusual, involuntary movements or body positions. It is caused by a problem with the way signals are sent throughout the brain. The Northwest PADRECC (Portland/Seattle) is tackling this disorder using a combination of PT and cognitive behavioral therapy (CBT) for Veterans with (FMD). In 2023, Dr. Mack also spearheaded the development of a workbook-based therapeutic care program for people with FMDs, that he is now offering to Veterans. In addition, Dr. Joel Mack provides education on FMD locally and nationally through lecture speaker series. He also assists other VAMCs with identifying FMD in Veterans and recommending strategies to assist with treatment.

The San Francisco PADRECC is rebuilding its unique multidisciplinary **palliative care** clinic to improve the quality of life for Veteran’s with advanced PD dealing with significant non-motor symptoms. The team is comprised of a palliative care specialist, nurse, social worker, chaplain and other ancillary professionals depending on the needs of the Veteran. The team works with the Veteran and family to provide medical, social, emotional, and practical support.

The Philadelphia PADRECC’s **Brain Wellness** Clinic embraces Whole Health principles by teaching Veterans with PD and other chronic nervous system disorders how dietary choices, fitness routines, stress management techniques, sleep routines and social connection can affect their brain health. Veterans who participate in the clinic get a thorough introduction to the benefits of lifestyle modifications for brain health and, jointly with Dr. Duda, develop a plan for modifying their own lifestyles accordingly. Regular follow-up in conducted to assess progress and modify or adopt new plans.

Continuing with the Whole Health principles, the West LA PADRECC utilizes a holistic approach to treating the whole Veteran, not just their movement disorders. Providers assess and address the unmet psychosocial needs of Veterans with PD such as loneliness and stigma. Resources are provided to Veterans and their family to help combat these feelings.

**Mental Health in PD** – Depression and anxiety are two of the most reported non-motor symptoms by Veterans. To address this, two PADRECC psychiatrists, Dr. Daniel Weintraub and Dr. Joel Mack, partnered with the VA National Expert Consultation & Specialized Services – Mental Health(NEXCSS-MH) formerly known as the National Tele-mental Health Clinic, to provide consultative service to 56 VAMCs for Veterans with neuropsychiatric complications. In addition, the PADRECCs provided funding to train additional psychologists or social workers in CBT to expand the CBT for Depression in PD program to all six PADRECCs.
Clinical Data

**Telehealth Encounters**

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Appendix A - SOUTHWEST (WEST LA) PADRECC

Publications


Staying hidden: The burden of stigma in PD. Bradley McDanielsa, PhD, Gregory M. Pontoneb,c, MD, Soania Mathurd, MD, Indu Subramaniane,f, MD, Parkinsonism Related Dis Sept 2023 epub.

Validation of the UCLA Loneliness Scale 8- and 3-Item versions in people with Parkinson’s Disease. Indu Subramanian, 1,2 MD, Bradley McDaniels,3 PhD, Laurie K. Mischley,4,5 ND, PhD, MPH, Devon J. Fox,5 MS Movement Disorders Clinical Practice 2023 (Submitted – under review).


Webinars and Blogs
Subramanian, I. Medscape Neurology- Blog and webinar-Wellness For PD -2023

Subramanian, I. Medscape Neurology- Blog and webinar- Contemplative medicine-

Subramanian, I. Medscape Neurology- Blog and webinar-PD and trauma-

Subramanian, I. Medscape Neurology- Blog and webinar- AAN highlights-

Subramanian, I. Medscape Neurology- Blog and webinar-PD Biomarkers-


Professional Education – Presentations

Subramanian, I.
“Integrative Approaches to Blepharospasm”- BBERF- Phoenix, Az- Oct 2022
“Wellness in PD”- Ukrainian Neurological Society Virtual Conference- Nov 2022
“Cultural Considerations in Palliative Care in PD”- “PDPal Conference”- U of Padua, Italy- Nov 2022
“Cultural context of PD Palliative Care” Webinar Series- U Of Padua/PD Pal- Dec 2022
“Loneliness in PD”- MIRECC/PADRECC Symposium- Virtual- March 2023
“Social Connection in PD”- AAN-Boston, April 2023
“Loneliness in PD”- AAN- Boston, April 2023
“World Parkinson Congress”- Barcelona, Spain-July 2023

Keener, A.

Lessig, S “Medical Education and Residency Clinical Educator Track” UCSD Neurology Department Grand Rounds 6/9/23.

Pirio Richardson S
“Botulinum toxin for tics” TOXINS 2024 7th International Conference Berlin, Germany 2023.
“Clinical Trials: What are the obstacles to testing new options?” 6th International Dystonia Symposium Dublin, Ireland 2023.

Video Workshop on “Diagnostic Approach to Patients with Hyperkinetic Syndromes” XXVIII World Congress on Parkinson’s Disease and Related Disorders Chicago, Illinois 2023.

Presentations to Health Professional Trainees

**Subramanian, I**
Geriatrics Lecture WLA VA- “Parkinson Disease Treatment” – WLA VA, Jan 2023

**Lessig, S**
“DBS Programming Basics Part I and Part II” Fellow didactics, 8/25/23

“Movement Disorders Billing Basics” Fellow didactics, 6/19/23

“Communication of Diagnosis of Functional Neurologic Disorder” Residency didactics, 6/19/23
“Tardive syndromes” Fellow didactics, 12/16/22

“Wilson’s disease” Fellow didactics, 12/16/22

**Keener, A**

“Introduction to Movement Disorders” UCLA School of Nursing, Master of Science in Nursing – Advanced Practice Program, Course N239C Nov 22.


“Dystonia” Neurology Resident lecture, UCLA Nov 2022.

“Beyond Parkinson’s Disease: Differential diagnosis of tremors and parkinsonism”.
Invited Speaker, Geriatric Medicine Fellowship Thursday Lecture Series, UCLA Feb 2023

“Tardive Syndromes” Invited Speaker, Geriatric Psychiatry Fellowship lecture, UCLA Feb 2023


Disorders of the Cerebellum UCLA DGSOM 1st year medical student lecture and interactive large group session Jul 2023.

**Overview of Movement Disorders Neurology Resident Summer Stock lecture. UCLA Aug 2023.**

**Patient Education**

**Subramanian, I**


The missing piece in the PD puzzle-Dietitians”- World Parkinson Congress- “Barcelona, Spain July 2023.


Parkinson’s Assn of Northern California- Keynote Speaker- Sept 2023.

“Living Well with Parkinson’s Disease” Parkinson’s Association of Santa Barbara annual seminar in Santa Barbara, CA April 2023.

“Navigating Hospitalization with Parkinson’s Disease” Parkinson’s Community Los Angeles Let’s Talk Parkinson’s virtual webinar series, Los Angeles, CA Aug 2023.

Interview with Veterans Impact Day- Dec 2022.


## RESEARCH

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<th>Name of Staff</th>
<th>Title of Research Project</th>
<th>Type of Project (Biomedical, applied clinic, HSR&amp;D, Rehab)</th>
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<td>Pirio Richardson, Sarah, MD</td>
<td>ABP-1900: A Phase 2 Randomized, Double—Blind, Multicenter, Placebo-Controlled Study of Intramuscular ABP-450 Injection for the Treatment of Cervical Dystonia</td>
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<td>Andrew Wilson (co-PI)</td>
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APPENDIX B - SOUTHEAST (RICHMOND) PADRECC

Publications


Posters


Professional Education - Presentations

Lehosit, J
PADRECC COE Neurology Community of Practice Updates – VISN6 ICC, November 2022.


“PD inpatient management” PM&R staff meeting presentation, February 2023.

PADRECC Neurology Staff Development and QI initiatives, March 2023.

Lindsey, D (NP)


Kaplan, J (BSN, RN)


Mathew, E “Integrated Care Model for Obstructive Sleep Apnea”, AAN, June 2023.

Holloway, K

“Symptom Specific Sweetspot, DTI, and Resting State Fmri Analysis of the STN and Gpi Regions in the CSP 468 Randomized Controlled Trial of DBS Stimulation in Parkinson’s Patients.” American Academy of Neurosurgeons, April 2023.


“Expanding Low vision strategies to veterans with excess disability”, Blind Rehab Services VACO, March 2023.

Presentations to Health Professional Trainees

Lindsey, D (NP) Presented to Neuropsychology fellows and residents. “Not all that shakes is Parkinson’s disease”. May 2023.
Kaplan, J (BSN, RN) In-service to on PD Polytrauma. February 2023.


Patient Education
Lehosit, J
“Advanced treatments for PD: when your typical medications aren’t cutting it.” Richmond/Philly PADRECC support group, March 2023.


Kaplan, J
“PADRECC/caregiving tips”. Caregiver support resource fair, Feb 2023.


“PADRECC and Interdisciplinary Team Approach” to VA Beach APDA support group, March 2023.


Lindsey, D

Hall, E


Mathew, E

Buckley, E

Baron, M

Open discussion/Q&A to PADRECC early onset support group July 2023.

Jennings, C
“Palliative Care in PADRECC” – GEC Provider Meeting Presentation, 10/26/22.

“Palliative Care for Person’s with Parkinson’s” – HPNA Central Virginia Chapter presentation on 10/20/22.
<table>
<thead>
<tr>
<th>Name of Staff</th>
<th>Title of Research Project</th>
<th>Type of Project (Biomedical, applied clinic, HSR&amp;D, Rehab)</th>
<th>Funding Source</th>
<th>Total Amount Of Funds</th>
<th>Total Direct Costs</th>
<th>Beginning/End Dates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baron &amp; Gitchel</td>
<td>Oculomotor functions in persons with movement disorders</td>
<td>Applied clinical research</td>
<td>Royalties from licensed IP.</td>
<td>$250,000</td>
<td>No additional cost</td>
<td>2017– May 2023</td>
</tr>
<tr>
<td>Baron</td>
<td>Rodent model of dystonia</td>
<td>HSR&amp;D</td>
<td>VA MERIT</td>
<td>$650,000</td>
<td>No additional cost</td>
<td>Jan 2019-Dec 2022</td>
</tr>
<tr>
<td>Baron</td>
<td>Cortical neuromodulation of pathological basal ganglia-thalamocortical sub circuitry for treatment of movement disorders</td>
<td>HSR&amp;D</td>
<td>VA MERIT</td>
<td>$708,431</td>
<td>No additional cost</td>
<td>2022-2026</td>
</tr>
<tr>
<td>Baron</td>
<td>Safety and efficacy of portable exoskeletons to improve mobility in Parkinson’s disease</td>
<td>HSR&amp;D</td>
<td>SPIRE</td>
<td>$225,500</td>
<td>No additional cost</td>
<td>7/26/23-present</td>
</tr>
<tr>
<td>Baron</td>
<td>Development of focused TMS to generate localized modulations in motor pathway network.</td>
<td>HSR&amp;D</td>
<td>VCU Presidential Research Quest Fund</td>
<td>$10,000</td>
<td>No additional cost</td>
<td>7/01/2023-12/31/2024</td>
</tr>
<tr>
<td>Holloway</td>
<td>DBS of the NBM: the role of stimulation parameters in neurogenesis</td>
<td>HSR &amp; D</td>
<td>NIA</td>
<td>$200,000</td>
<td>No additional cost</td>
<td>2022-2024</td>
</tr>
</tbody>
</table>

**Primary Projects**

<table>
<thead>
<tr>
<th>Principal Investigator</th>
<th>Title of Research Project</th>
<th>Purpose/Hypothesis</th>
<th>Method Sample (size/selection)</th>
<th>Measures/ Criteria</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jessica Lehosit, DO</td>
<td>BOSS-PD, Urinary incontinence in PD</td>
<td>This study aims to determine the non-inferiority of pelvic floor muscle exercises to drug</td>
<td>IPD patients Urinary score qualifying</td>
<td>Behavioral vs medication treatment of urinary</td>
<td>Closed to recruitment. Awaiting data analysis.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Project Title</td>
<td>Description</td>
<td>Target Group</td>
<td>Recruitment Status</td>
<td></td>
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</tr>
<tr>
<td>Jessica Lehosit, DO</td>
<td>Bile Acids and Gut Microbiome</td>
<td>Investigating the microbiome of patients with cirrhosis. Patients with PD are being recruited as a secondary arm to the study due to their known gut motility and microflora changes.</td>
<td>IPD Patients</td>
<td>Still in recruitment</td>
<td></td>
</tr>
<tr>
<td>Mark Baron, MD</td>
<td>Quantified Rigidity Monitor</td>
<td>This is a device that has been built in collaboration with the department of biomedical engineering at the local university. The device is a reliable, repeatable, quantifiable method to assess muscle rigidity in patients with PD.</td>
<td>IPD patients, number TBD</td>
<td>Still in design/testing phase of product development</td>
<td></td>
</tr>
<tr>
<td>Mark Baron, MD</td>
<td>Eye Movement Research in PADRECC</td>
<td>Utilizing a 5-minute-long data recording from an eye tracking device, the specific oculomotor parameters can be used to differentiate numerous neurological movement disorders.</td>
<td>Recruitment: &gt;3,600 subjects to date. Inclusion: any manifest neurological movement disorder or prodromal PD (as captured in subjects with RBD). Exclusion: Blindness. Numerous oculomotor parameters (saccades size, speed, smooth pursuit, etc). Raw data are cleaned and compiled into ~620 individual parameters, and finally reported out as ~42 individual statistics.</td>
<td>Closed to recruitment. Data analysis stage.</td>
<td></td>
</tr>
<tr>
<td>Kathryn Holloway MD</td>
<td>Optimization of Nucleus Basalis of Meynert stimulation for the treatment of dementia</td>
<td>This pilot study is intended for studying various parameters effecting memory through nucleus basalis of Meynert (NBM) stimulation and collecting data for larger grant. Our goal is to gain a better understanding of how we can effectively stimulate this nucleus to overcome the devastating effects of dementia.</td>
<td>Initial pilot targeting 5+ subjects with dementia.</td>
<td>Collecting preliminary data. Project has not started yet.</td>
<td></td>
</tr>
<tr>
<td>Kathryn Holloway, MD</td>
<td>Long-term effects of stimulation induced neurogenesis in dementia rats</td>
<td>This project assesses the long term effects of NBM stimulation on learning, neurogenesis, cholinergic neuronal preservation and reversal of the cortical atrophy associated with cholinergic degeneration by assessing these over 2 years.</td>
<td>Pilot grant</td>
<td>Data collection underway.</td>
<td></td>
</tr>
<tr>
<td>Project Description</td>
<td>Principal Investigator(s)</td>
<td>Data Registry</td>
<td>Data Collection</td>
<td>Outcomes of DBS</td>
<td>Status</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Kathryn Holloway, MD: Registry for the advancement of DBS in Parkinson’s disease.</td>
<td>Kathryn Holloway, MD</td>
<td>Data registry, Michael J Fox Foundation</td>
<td>Data registry</td>
<td>Outcomes of DBS</td>
<td>Data collection, 5-year project. Recruitment has been completed.</td>
</tr>
<tr>
<td>Kathryn Holloway, MD: Physiological Brain Atlas Development</td>
<td>Kathryn Holloway, MD</td>
<td>Data registry</td>
<td>Data Registry</td>
<td>Outcomes of DBS</td>
<td>Data collection and recruitment</td>
</tr>
<tr>
<td>Kathryn Holloway, MD: Accuracy of targeting subthalamic nucleus vs globus pallidus and clinical implications</td>
<td>Kathryn Holloway, MD</td>
<td>To determine accuracy of targeting STN and GPI and clinical implications using data from CSP 468 clinical trial “A comparison of best medical therapy and deep brain stimulation of subthalamic nucleus and globus pallidus for the treatment of Parkinson’s disease”</td>
<td>Analysis of CSP 468 data</td>
<td>Outcomes of DBS</td>
<td>Data analysis underway.</td>
</tr>
<tr>
<td>Kathryn Holloway, MD: Assessment of the utility of QEEG during deep brain stimulation programming and correlation with dementia rating scale scores</td>
<td>Kathryn Holloway, MD</td>
<td>To determine how the electrical activity in the brain changes during DBS programming.</td>
<td>Analysis of EEG data</td>
<td>EEG changes in DBS programming</td>
<td>Analysis underway</td>
</tr>
<tr>
<td>Mark Baron, MD: Ocular tremor as a biomarker for manifest and prodromal Parkinson’s disease</td>
<td>Mark Baron, MD</td>
<td>To validate the findings of our longstanding oculomotor control study in a double blinded, multisite, open enrollment study/</td>
<td>Targeting 80 subjects each in the categories of PD, control, and “other movement disorders”. Additionally, targeting 120 subject with RBD.</td>
<td>Similar oculomotor recording analysis, as well as timed pegboard test, UPDRS, timed-up-and-go walking test, MOCA.</td>
<td>Closed to recruitment. Data analysis stage.</td>
</tr>
<tr>
<td>Jessica Lehosit, DO: VET PD</td>
<td>Jessica Lehosit, DO</td>
<td>To find genes that increase risk of development of PD.</td>
<td>Under-represented population with PD; goal to enroll 50 patients</td>
<td>Under-represented population with PD; cheek swab and blood sample</td>
<td>Recruiting.</td>
</tr>
<tr>
<td>Jessica Lehosit DO, Cameron Jennings NP, Jessica Kaplan BSN: PCORI Study with PD foundation</td>
<td>Samantha Denis</td>
<td>Palliative care integrative study in PD clinics</td>
<td>Develop and enroll patients in Palliative Care PD clinic</td>
<td>PD patients with palliative care needs</td>
<td>Continuing palliative clinic development and implementation</td>
</tr>
</tbody>
</table>
APPENDIX C - San Francisco PADRECC

Publications


Posters


Professional Education


Wang, D “Future of Parkinson’s Disease (PD) and HiFu”. San Francisco Neurological Society: Parkinson’s Disease Symposium, October 2022.

Dietiker, C “Huntington’s Disease Clinical Trials Update”. Huntington’s Disease Society of America / UCSF Education Day, December 2022.


“Progression of Parkinson’s disease – what does this look like?” Parkinson’s Foundation Fresno, Parkinson’s Disease Symposium, February 2023.


Presentations to Health Professional Trainees


Patient Education

Greater Fresno Parkinson’s Disease Support Group - Presentation by Rafael Zuzuarregui at the PF sponsored annual symposium in Fresno, CA.

Huntington’s Disease Society of America/UCSF Education Day - Presentation by Cameron Dietiker on Huntington’s Disease Clinical Trials Update.

Exercise for Life Foundation - Presentation by Rafael Zuzuarregui at the annual fundraiser for a PD focused non-profit organization in Fresno, CA.

UCSF Movement Disorders and Neuromodulation Center Parkinson’s Disease Symposium - Presentations by Nicholas Galifianakis and Tamara Stiep at the patient focused annual symposium.

### RESEARCH

#### Funded

<table>
<thead>
<tr>
<th>Name of Staff</th>
<th>Title of Research Project</th>
<th>Type of Project (Biomedical, applied clinic, HSR&amp;D, Rehab)</th>
<th>Funding Source</th>
<th>Total Amount Of Funds</th>
<th>Total Direct Costs</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Co-PI: Rafael Zuzuarregui, MD (PI: Caroline Tanner)</td>
<td>PPMI - The Parkinson’s Progression Markers Initiative. The primary objective of this study is to identify clinical, imaging, and biologic markers of Parkinson’s disease progression for use in clinical trials of disease-modifying therapies. I primarily functioned as a sub-investigator to perform clinic visits for participants but became the co-investigator for a new observational arm of the study focusing on recruitment of participants with REM Behavior Disorder and tracking progression over time with use of biomarkers as noted above.</td>
<td>Epidemiology</td>
<td>Michael J. Fox Foundation</td>
<td>$555,453</td>
<td></td>
<td>04/01/2010 – 12/31/2025</td>
</tr>
<tr>
<td>Sub-Investigator Rafael Zuzuarregui, MD (PI: Caroline Tanner)</td>
<td>Prevention of Hip Fracture in Patients with Parkinson’s Disease (PD)</td>
<td>Clinical research</td>
<td>NIH/NIA grant</td>
<td>$573,094</td>
<td></td>
<td>09/01/2018 – 11/31/2024</td>
</tr>
<tr>
<td>Sub-Investigator Rafael Zuzuarregui, MD (PI: Caroline Tanner)</td>
<td>Determining the circuits and signals of sleep dysfunction in Parkinson’s disease through chronic intracranial recordings and closed-loop Deep Brain Stimulation</td>
<td>Clinical research</td>
<td>NIH/NIA grant</td>
<td>$3,977,653</td>
<td></td>
<td>04/01/2023 – 03/31/2026</td>
</tr>
<tr>
<td>Name of Staff</td>
<td>Title of Research Project</td>
<td>Type of Project (Biomedical, applied clinic, HSR&amp;D, Rehab)</td>
<td>Funding Source</td>
<td>Total Amount Of Funds</td>
<td>Total Direct Costs</td>
<td>Beginning/End Dates</td>
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<tr>
<td>Sub-Investigator: Tamara Steip, MD (PI: Caroline Tanner)</td>
<td>ENROLL-HD: A Prospective Registry Study in a Global Huntington's Disease Cohort (CHDI Foundation, Inc.). This is a longitudinal, observational, multinational study that integrates two former Huntington's disease registries and expands site inclusion, with the primary objective of developing a comprehensive repository of prospective and systematically collected clinical research data and biological specimens from individuals with manifest HD, non-manifest mutation carriers, and control participants.</td>
<td>Epidemiology</td>
<td>CHDI Foundation</td>
<td>$555,453</td>
<td>04/01/2010 – 12/31/2025</td>
<td></td>
</tr>
<tr>
<td>Sub-Investigator: Cameron Dietiker (PI: Michael Geschwind)</td>
<td>A Phase I/II, Randomized, Double-blind, Sham Control Study to Explore Safety, Tolerability, and Efficacy Signals of Multiple Ascending Doses of Striatally-Administered rAAV5-miHTT Total Huntingtin Gene (HTT) Lowering Therapy (AMT-130) in Early Manifest Huntington Disease</td>
<td>Clinical research</td>
<td>uniQure</td>
<td>1,830,444</td>
<td>05/01/2020 - ongoing</td>
<td></td>
</tr>
<tr>
<td>Sub-Investigator: Cameron Dietiker, MD</td>
<td>READISCA, an observational, international, multi-site study aiming to establish clinical trial readiness by enrolling/combining large cohorts of patients with pre-manifest/early SCA1 and SCA3. This population is likely to benefit most from disease-modifying interventions prior to irreversible brain damage.</td>
<td>Epidemiology</td>
<td>Michael J. Fox Foundation</td>
<td>$555,453</td>
<td>12/08/2020 – present</td>
<td></td>
</tr>
</tbody>
</table>
This study will also gather clinical outcome assessment data, bio-fluid samples, and validate biochemical and functional biomarkers.

**Sub-Investigator:** Cameron Dietiker  
(Pi: Michael Geschwind)

**BH4V4157-201:** A Phase Ib/III, Randomized, Double-Blind, Placebo-Controlled Trial of Troriluzole in Adult Subjects with Spinocerebellar Ataxia. Phase Ib/III trial investigating the drug Troriluzole for its efficacy, safety, and tolerability in spinocerebellar ataxias. It is thought to work through its main byproduct, riluzole, but can be dosed less frequently and potentially may have fewer side effects. It will be compared to placebo for its ability to improve ataxia symptoms in SCA types 1, 2, 3, 6, 7, 8, and 10.

**Clinical research**  
Biohaven Pharmaceuticals  
07/01/2021 - ongoing

**Sub-Investigator:** Cameron Dietiker, MD  
(Pi: Caroline Tanner)

**PASADENA:** A randomized, double-blind, placebo-controlled, 52-week phase II study to evaluate the efficacy of intravenous ROT046015 (PRX002) in participants with early Parkinson’s disease with a 52-week blinded extension. (F. Hoffmann-La Roche Ltd). Phase 2 clinical trial to evaluating safety and efficacy of of intravenous PRX002, a C-terminus alpha-synuclein antibody, in participants with early Parkinson’s disease.

**Clinical research**  
Roche Genentech  
07/01/2021 - ongoing

**Sub-Investigator:** Cameron Dietiker, MD  
(Pi: Michael Geschwind)

Clinical Research Consortium for the Study of Cerebellar Ataxia (CRC-SCA), funded by the National Ataxia Foundation, a natural history and biomarker development study aiming to understand factors that determine disease progression in cerebellar ataxia with the goal of enhancing knowledge of the disease process, treatments, and development of disease modifying therapies (for SCA types 1, 2, 3, 6, 7, 8, and 10).

**Epidemiology**  
National Ataxia Foundation  
07/01/2021 - ongoing

**Principle Investigator:** Cameron Dietiker, MD

**AMULET,** funded by H. Lundbeck A/S, a phase 2 trial designed to assess the safety and tolerability of LuAF82422 and its ability to slow disease progression in patients with MSA. LuAF82422 is a human recombinant monoclonal antibody that recognizes all major species of alpha-synuclein and targets extracellular α-synuclein, inhibiting seeding and spreading of pathological forms.

**Clinical Research**  
H. Lundbeck A/S  
$29,835  
03/29/2022 - present
### Primary Projects

<table>
<thead>
<tr>
<th>Principal Investigator</th>
<th>Title of Research Project</th>
<th>Purpose/Hypothesis</th>
<th>Method Sample (size/selection)</th>
<th>Measures/Criteria</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rafael Zuzuarregui</td>
<td>Use of Seroquel versus Primavanserin for Psychosis in Parkinson's disease.</td>
<td>The primary objective of this study is to evaluate use of Seroquel and Primavanserin for treatment of psychosis in Parkinson's disease in a randomized controlled trial.</td>
<td>20-30</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>Ellen Bradley</td>
<td>Examining ketamine effects on depression, neuroplasticity, and inflammation in Veterans with Parkinson's disease</td>
<td>The primary objective is to evaluate the use of ketamine for treatment of anxiety and depression in Parkinson's Disease in a clinical trial</td>
<td>30-50</td>
<td>N/A</td>
<td></td>
</tr>
</tbody>
</table>

### Collaborative Projects

<table>
<thead>
<tr>
<th>Principal Investigator</th>
<th>Title of Research Project</th>
<th>Purpose/Hypothesis</th>
<th>Method Sample (size/selection)</th>
<th>Measures/Criteria</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tamara Stiep, MD</td>
<td>An investigation of the relationship between toxicant exposures during Gulf War deployment and prodromal Parkinson's disease.</td>
<td>The primary objective of this study is to evaluate the relationship between toxicant exposure during Gulf War deployment and prodromal Parkinson's disease.</td>
<td>50</td>
<td>N/A</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX D - Northwest (Portland/Seattle) PADRECC

Publications


Posters


**Professional Education**

Davis, M


“Mechanisms underlying Parkinson’s disease: Insights from the genetic risk factor GBA” [Presentation]. University of Wisconsin-Madison, Department of Neurology Grand Rounds. Madison, Wisconsin, United States, 2023


Neilson, L “Diagnosis and Treatment of Functional Movement Disorders” [Virtual], MIRECC Presents {mental health professionals and allied health professionals}, 2023.


Presentations to Health Professional Trainees

Davis, M

“Genetic movement disorders” [Lecture]. UW NEURO502 Introduction to Neurobiology. Seattle, Washington, United States, 2023


Hu, SC


Kraakevik, J
Willamette Valley Medical Center Grand Rounds {Student/Resident} Clinical Assessment of Falls [Virtual], 2023.

Samii A.


Quinn, JF
Portland VA Geriatric Medicine Fellow lecture Diagnosis and Management of Parkinson's Disease, 2023.

PMDA Cognitive changes in Parkinson’s Disease: What we know and what we need to know Virtual],2023.


“Medical Management of Parkinson’s”. OHSU Primary Care CME {Student/Resident}, 2023.

“Genetics and the brain”. OBI Outreach {Neighborhood House 8-10 year old summer program students}, 2023.


Neurobiology of Disease Course Alzheimer's Disease, 2023.


Zabetian, CP
“Differential Diagnosis of Parkinsonism and Management of Parkinson’s Disease” [Lecture]. VAPSHC Bldg. 100, Rm 5B-103. Seattle, Washington, United States, 2022


“Parkinson’s Disease; Differential Diagnosis and Management” [Lecture]. VAPSHCS, Bld 100, Rm 5B-103 Seattle, Washington, United States, 2023.


Patient Education


### RESEARCH - Grants by Employee

**Chung, Kathryn**

2019 – 2023  
VA Merit Review Award (HSR&D) I01 CX001547 (Co-I) STAT-PD: Preventing Levodopa Induced Dyskinesia in Parkinson’s Disease with HMG - CoA Reductase Inhibitors $539,361.00

**Dale, Marian (Livingston)**

2022 - 2023  
OHSU Parkinson Center Pilot Grant (PI) Supplementary motor area TMS for freezing of gait in Parkinson’s disease $50,000.00

**Davis, Marie**

2020 – 2025  
NINDS R01 NS119897 (PI) Investigating the role of lipid metabolism in protein aggregation and neurodegenerative disease progression $1,963,232.00

2017 - 2026  
VA Merit Review Award (CSR&D) I01 CX001702 (Co-I) Genetic Movement Disorders: Etiologies and Pathogeneses $1,247,989.00

**Hiller, Amie (Peterson)**

2023 - 2025  
Department of Defense PD220064 (Co-PI) Cognitive Functions Impairment as a Novel Paradigm for Delineating Cognitive Dysfunction in Parkinson’s Disease (PD-CFI) $1,200,000.00

2021 – 2023  
Department of Defense PD200016 (Site PI) Ontology-based, Real-time, Machine learning Informatics System for Parkinson’s Disease (ORMIS-PD) $400,000.00

**Hu, Shu-Ching (Gene)**

2020 - 2033  
Michael J Fox Foundation (Site PI) Parkinsons Progression Markers Initiative (PPMI) 2.0 Clinical - Establishing a Deeply Phenotyped PD Cohort $2,080,000.00

2019 - 2025  
NIA R21 AG064271 (PI) Use of wearable sensors to improve the early diagnosis of DLB $2,539,873.00

2016 - 2027  
NINDS U01 NS100610 (Co-I) Dementia with Lewy Bodies Consortium $8,085,540.00

**Mack, Joel**

2022 – 2027  
VA Cooperative Studies Protocol #2015 (Site PI) Multicenter, Randomized, Double-Blind Comparator Study of Antipsychotics Pimavanserin and Quetiapine for Parkinson’s Disease Psychosis (C-SAPP Study) $668,534.00

**Neilson, Lee**

2022 - 2027  
VA CSR&D CX002539-01A1 (PI) Biomarkers of disease severity and progression in Parkinsons (MITOPD) $1,393,704.00

**Quinn, Joseph**

2016 – 2018  
Department of Defense PD200016 (Site Co-PI) Ontology-based, Real-time, Machine learning Informatics System for Parkinson’s Disease (ORMIS-PD) $400,000.00

2021 –  
Astra Zeneca (Site PI) A Randomized, Double-blind, Placebo-controlled Study of the Safety, Tolerability, Pharmacokinetics, and Pharmacodynamics of Multiple Ascending Doses of MEDI1341 in Subjects with Parkinson’s Disease
<table>
<thead>
<tr>
<th>Year</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>2021 –</td>
<td>EIP-Pharma (Site PI) Expanded Access to Neflamapimod for Patients with Dementia with Lewy Bodies (DLB) Who Participated in and Completed Treatment in Study EIP19-NFD-501</td>
</tr>
<tr>
<td>2020 – 2025</td>
<td>NCCIH U19 AT010829 (Co-I) Botanicals enhancing neurological and functional resilience in aging (BENFRA) $6,000,000.00</td>
</tr>
<tr>
<td>2020 – 2025</td>
<td>NIA P30 AG008017 (Biomarker &amp; Genetics Core Leader) Oregon Alzheimer Disease Center $1,999,896.00</td>
</tr>
<tr>
<td>2020 –</td>
<td>Proseek (Site PI) A Phase 2, Randomized, Double-Blind, Placebo-Controlled Study of K0706 in Subjects with Early Parkinson’s Disease</td>
</tr>
<tr>
<td>2020 –</td>
<td>Biogen LRRK2 (Site PI) A Phase 1 Single- and Multiple-Ascending-Dose Study to Assess the Safety, Tolerability, and Pharmacokinetics of BIIB094 Administered Intrathecally to Adults With Parkinson’s Disease</td>
</tr>
<tr>
<td>2019 – 2024</td>
<td>NIA RF1 AG059392 (Co-I) Establishing microRNA biomarkers for diagnosing Alzheimer’s disease and predicting progression $3,429,850.00</td>
</tr>
<tr>
<td>2019 –</td>
<td>Hoffman-LaRoche (Site PI) A randomized, double-blind, placebo-controlled, 52 week Phase II study to evaluate the efficacy of intravenous R07046015 (PRX002) in Participants with early parkinson’s disease (open label extension)</td>
</tr>
<tr>
<td>2018 –</td>
<td>Sanofi (Site PI) Multicenter randomized, double-blind, placebo-controlled study to assess the efficacy, safety, pharmacokinetics, and pharmacodynamics of GZ/SAR402671 in patients with early-stage Parkinson’s disease carrying a GBA mutation or other pre-specified variant</td>
</tr>
<tr>
<td>2017 –</td>
<td>Vtesse, Inc (Site PI) Intrathecal 2-hydroxypropyl-b-cyclodextrin for neurologic decline in patients with Niemann-Pick type C</td>
</tr>
<tr>
<td>Samii, Ali</td>
<td></td>
</tr>
<tr>
<td>2021 - 2026</td>
<td>Prilenia Therapeutic PL101-HD301 (Co-I) A Phase III, Double-blind, Placebo-Controlled Study to Evaluate the Efficacy and Safety of pridopidine in Patients with Early Stage of Huntington Disease $242,050.00</td>
</tr>
<tr>
<td>2020 - 2026</td>
<td>UniQure () A Phase I/II, Randomized, Double-blind, Sham Control Study to Explore Safety, Tolerability, and Efficacy Signals of Multiple Ascending Doses of Striatally - Administered rAAV5 - miHTT Total Huntingtin Gene (HTT) Lowering Therapy (AMT - 130) in Early M $450,000.00</td>
</tr>
<tr>
<td>2012 – Indefinite</td>
<td>CHDI Foundation A-4908 (PI) Accelerating Therapeutic Development for Huntington’s Disease Indirect and Out - of - Pocket costs on Huntington’s disease in the United States $439,189.00</td>
</tr>
<tr>
<td>2012 –</td>
<td>CHDI Foundation A-5807 (Site I) A Prospective Registry Study in a Global Huntington’s Disease Cohort $439,189.00</td>
</tr>
<tr>
<td>2007 - 2023</td>
<td>American Parkinson Disease Association (Co-PI) Washington Parkinson Disease Registry $25,000.00</td>
</tr>
<tr>
<td>Su, Kimmy</td>
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</tr>
<tr>
<td>2020 - 2033</td>
<td>Michael J Fox Foundation (Co-I) Parkinsons Progression Markers Initiative (PPMI) 2.0 Clinical - Establishing a Deeply Phenotyped PD Cohort $2,080,000.00</td>
</tr>
<tr>
<td>2019 - 2025</td>
<td>NIA R21 AG064271 (Co-I) Use of wearable sensors to improve the early diagnosis of DLB $2,539,873.00</td>
</tr>
</tbody>
</table>
Zabetian, Cyrus
2020 – 2024 NIA RF1AG068406 (Co-I) Extracellular Vesicle Transport of Brain-derived Proteins to the Blood in Alzheimer Disease $2,981,849.00
2020 - 2033 Michael J Fox Foundation (Co-I) Parkinsons Progression Markers Initiative (PPMI) 2.0 Clinical - Establishing a Deeply Phenotyped PD Cohort $2,080,000.00
2020 – 2025 Department of Defense PD190043 (Co-PI) Blood-Based Exosomal α - Synuclein Aggregates as a Quantifiable Biomarker of Parkinson’s Disease $998,711.00
2020 – 2023 NINDS/NIMH R33 MH118160 (Co-I) Characterization and quantification of CNS cell specific extracellular microvesicles in blood $2,026,902.00
2019 – 2023 VA Merit Review Award (HSR&D) I01 CX001547 (Co-I) STAT-PD: Preventing Levodopa Induced Dyskinesia in Parkinson’s Disease with HMG - CoA Reductase Inhibitors $539,361.00
2017 - 2026 VA Merit Review Award (CSR&D) I01 CX001702 (PI) Genetic Movement Disorders: Etiologies and Pathogeneses $1,247,989.00
2016 - 2027 NIA T32 AG052354 (Co-PI) Neurobehavior, Neuropathology, and Risk Factors in Alzheimer’s Disease $3,919,397.00
2016 - 2027 NINDS U01 NS100610 (Co-I) Dementia with Lewy Bodies Consortium $8,085,540.00
2007 - 2023 American Parkinson Disease Association (PI) Washington Parkinson Disease Registry $25,000.00
APPENDIX E - Philadelphia PADRECC

Publications


Posters


Shi Y, Gadani S, Mills K. White Matter Lesion Characteristics of Patients with Multiple Sclerosis and Parkinsonism. Accepted to 2023 International MDS Congress.


Professional Education

**Weintraub, D**


“Parkinson Disease: The Interface of Psychiatry & Neurology”, Department of Psychiatry Grand Rounds (Taylor Lecture), University of Maryland School of Medicine, Baltimore, Maryland, March, 2023.

“Neuropsychiatry, Cognition and Non-motor Fluctuations in PD”, MDS Parkinson’s Disease Educational Course for Industry Professionals, Copenhagen, Denmark, Aug, 2023.


**Morley, J**

“Exercise is medicine for Parkinson's Disease”, Parkinson's Foundation Caring for Veterans Symposium (virtual), Oct 2022.


"Evidence for the benefit of physical Activity in Parkinson’s Disease". 13th PADRECC/MIRECC Symposium, A CME certified course, March, 2023.


**Vaswani, P**


**Duda, J**

"The Whole Health Approach to Parkinson's Disease", 13th PADRECC/MIRECC Symposium entitled, 'Lifestyle Interventions to Promote Brain Health in Neuropsychiatric Disorders'. Virtual meeting, March 2023.

"A Human Tissue Engineered Nigrostriatal System as a Testbed for Understanding PD Pathophysiology and Therapeutic Development", International Congress of Parkinson’s Disease and Movement Disorders, Copenhagen, Denmark, August 2023.

Kannarkat, G
“Assessment of the Perceived Benefit and Barriers of a Virtual Neuroscience Course for Practitioners in Low- and Middle-Income Countries.”, American Neurological Association Annual Meeting, Chicago, IL, USA, Oct 2022.


Presentations to Health Professional Trainees


Cohen, J

“Translational Research Immersion Program: Mentor-Mentee Communication, ITMAT Phila., PA, June 2023

Patient Education


**RESEARCH Funded**

<table>
<thead>
<tr>
<th>Name of Staff</th>
<th>Title of Research Project</th>
<th>Type of Project (Biomedical, applied clinic, HSR&amp;D, Rehab)</th>
<th>Funding Source</th>
<th>Total Amount Of Funds</th>
<th>Total Direct Costs</th>
<th>Beginning/End Dates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morley (PI)</td>
<td>Effect of Exercise on recovery in Drug-Induced Parkinsonism and Parkinson Disease</td>
<td>Clinical (Rehab)</td>
<td>VA RR&amp;D CDA-2</td>
<td>$1,140,300</td>
<td></td>
<td>2017-2022</td>
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<tr>
<td>Duda, Weintraub (mentors)</td>
<td>Developing Personalized Medicine Strategies to Increase Physical Activity in Parkinson’s Disease (PD) through Digital Health Technology</td>
<td>Clinical Trial</td>
<td>DoD CDMRP NETP</td>
<td>$758,712</td>
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<td>09/01/21 - 03/31/24</td>
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<tr>
<td>Morley (co-PI)</td>
<td>Parkinson’s Disease Biomarkers In Human Olfactory Cleft Mucus</td>
<td>Observational Clinical Trial</td>
<td>NIA R21</td>
<td>$144,000</td>
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<td>10/1/2022-9/30/2024</td>
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<td>Morley (co-PI)</td>
<td>Multicenter, Randomized, Double-Blind Comparator Study of Antipsychotics Pimavanserin and Quetiapine for Parkinson’s Disease Psychosis (C-SAPP Study)</td>
<td>Interventional Clinical Trial</td>
<td>VA CSP</td>
<td>$19,362,320 total for study $537,842 Phila. PADRECC</td>
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<td>01/15/20 - 01/14/26</td>
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<td>Duda</td>
<td>Tissue engineered Nigrostriatal Pathway as a testbed for evaluating axonal pathophysiology in Parkinson’s disease</td>
<td>Biomedical Lab</td>
<td>VA BL R&amp;D MERIT</td>
<td>$710,000</td>
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<td>4/01/2020- 3/31/2024</td>
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<td>Duda (PI)</td>
<td>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)</td>
<td>Interventional Clinical Trial</td>
<td>Neuroderm</td>
<td>Allotted per patient enrolled</td>
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<td>2022-2027</td>
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<tr>
<td>Duda (PI)</td>
<td>Nigrostriatal Pathway as a testbed for evaluating axonal pathophysiology in Parkinson’s disease</td>
<td>Biomedical Lab</td>
<td>I01 BX005079-01 BLR&amp;D Merit Award</td>
<td>$177,500</td>
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<td>3/1/2020- 2/28/2024</td>
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<td>Principal Investigator</td>
<td>Title of Research Project</td>
<td>Purpose/Hypothesis</td>
<td>Method Sample (size/selection)</td>
<td>Measures/ Criteria</td>
<td>Findings</td>
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<tr>
<td>Morley (PI)/Duda (co-I)</td>
<td>Developing Personalized Medicine Strategies to Increase Physical Activity in Parkinson’s Disease (PD) through Digital Health Technology</td>
<td>Test strategies to increase physical activity using digital health technologies</td>
<td>Ambulatory Veterans with PD</td>
<td>pre-planned interim analysis demonstrated a significant increase of 20% in average daily step count during the intervention phase</td>
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<tr>
<td>Morley (PI)/Whitley Aamodt (co-PI)</td>
<td>Freezing of Gait in the Evaluation of Drug Induced Parkinsonism and Parkinson’s Disease</td>
<td>Evaluate freezing of gait to learn how certain walking/ balance problems are associated with PD.</td>
<td>Veterans with PD or drug-induced parkinsonism and previous DAT-SPECT imaging</td>
<td>Ongoing</td>
<td></td>
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<tr>
<td>Duda/Weintraub (National co-PIs)/Morley (Site PI)</td>
<td>Multicenter, Randomized, Double-Blind Comparator Study of Antipsychotics Pimavanserin and Quetiapine for Parkinson’s Disease Psychosis (C-SAPP Study)</td>
<td>Compare effectiveness of Pimavanserin and Quetiapine for PD psychosis</td>
<td>Veterans with PD and symptoms of psychosis</td>
<td>Ongoing</td>
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<tr>
<td>Duda (PI)</td>
<td>A Multi-center, Randomized, Active-controlled, Double-blind, Double-dummy, Parallel Group Clinical Investigationing ND0612 (form of levodopa/carbidopa (LD/CD) delivered as a continuous</td>
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<td>Veterans with PD and Caregiver Partners</td>
<td>Ongoing</td>
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<td>Title</td>
<td>Summary</td>
<td>Department</td>
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<tr>
<td>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)</td>
<td>subcutaneous infusion as a possible treatment for PD</td>
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<tr>
<td>Duda</td>
<td>Tissue engineered Nigrostriatal Pathway as a testbed for evaluating axonal pathophysiology in Parkinson’s disease</td>
<td>Biomedical Lab</td>
<td>See Appendix C</td>
<td></td>
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<tr>
<td>Duda (PI)</td>
<td>Nigrostriatal Pathway as a testbed for evaluating axonal pathophysiology in Parkinson’s disease</td>
<td>Biomedical Lab</td>
<td>See Appendix C</td>
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<tr>
<td>Duda (PI)</td>
<td>Development and Testing of a Human-Scale Tissue Engineered Nigrostriatal Pathway</td>
<td>Biomedical Lab</td>
<td>See Appendix C</td>
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<tr>
<td></td>
<td>To screen multiple human stem cell sources while employing novel biofabrication and quality assurance techniques to develop human-scale implantable brain pathways for treatment of Parkinson’s disease.</td>
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<tr>
<td>Principal Investigator</td>
<td>Title of Research Project</td>
<td>Purpose/Hypothesis</td>
<td>Method Sample (size/selection)</td>
<td>Measures/Criteria</td>
<td>Findings</td>
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<tr>
<td>Morley (co-I) Duda/ Wilkinson/ Weintraub (co-PIs)</td>
<td>Markers for Diagnosis and Prognosis in Parkinson’s Disease</td>
<td>Determine markers that improve diagnosis of PD or better predict the development of movement, Psychiatric, and cognition complications</td>
<td>Veterans with PD</td>
<td></td>
<td>See Appendix C</td>
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<tr>
<td>Morley (site PI) Duda (site co-I)</td>
<td>Behavioral or Solifenacin Therapy for Urinary Symptoms in Parkinson’s Disease</td>
<td>Compare Solifenacin with pelvic floor exercise for overactive bladder symptoms in PD patients</td>
<td>Veterans with PD and overactive bladder symptoms</td>
<td></td>
<td>recruitment completed. In data analysis</td>
<td></td>
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<tr>
<td>Noam Cohen (PI)/ Duda (co-PI)</td>
<td>The Role of Bitterome and Microbiome In Parkinson’s Disease</td>
<td>Investigate whether DNA affect bacteria in the nasal cavity and colon differently in veterans with PD vs. healthy controls.</td>
<td>Veterans with PD and healthy controls</td>
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<td>N/A</td>
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<tr>
<td>Morley (co-PI)</td>
<td>Parkinson’s Disease Biomarkers In Human Olfactory Cleft Mucus</td>
<td>Examine protein biomarkers derived from olfactory cleft mucus to distinguish between subjects with PD and healthy controls</td>
<td>Veterans with PD and healthy controls</td>
<td></td>
<td>Ongoing</td>
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<tr>
<td>Morley (PI) Duda (co-I)</td>
<td>The Veterans Parkinson’s Disease Genetics Initiative (Vet-PD)</td>
<td>To collect and share DNA, clinical/demographic data, and plasma biomarkers from a diverse PD cohort with the Global Parkinson’s Genetics Program (GP2) for use in its ongoing PD genome-wide</td>
<td>Veterans with PD divided into two groups based on self-reported race and ethnicity</td>
<td></td>
<td>Ongoing</td>
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<tr>
<td>Duda (co-I)</td>
<td>Transplantable Micro-Tissue Engineered Neural Networks to Restore the Nigrostriatal Pathway in Parkinson’s Disease</td>
<td>Further develop micro-tissue engineered neural networks as a possible implantable construct to recapitulate the nigrostriatal pathways.</td>
<td>Biomedical Lab</td>
<td></td>
<td>See Appendix C</td>
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<tr>
<td>Chen (PI)</td>
<td>Designing neuronal tissue that mimics</td>
<td>To use recent advances in the fields of neural tissue engineering and</td>
<td>Biomedical Lab</td>
<td></td>
<td>See Appendix C</td>
<td></td>
</tr>
<tr>
<td>Duda</td>
<td>brain-specific architecture</td>
<td>stem cell biology to engineer autologous neural tissue with complex cortical architecture for the purpose of treating brain injury.</td>
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<tr>
<td>Duda</td>
<td>Restoring the nigrostriatal pathway with living micro-tissue engineered axonal tracts</td>
<td>This project utilizes preformed micro-tissue engineered neural networks to physically reconstruct the axonal connections from the substantia nigra pars compacta to the striatum in a rodent model of Parkinson’s disease. This project explores the optimal dose, encasement, and starting biomass for this regenerative therapy.</td>
<td>Biomedical Lab</td>
<td>See Appendix C</td>
<td></td>
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<tr>
<td>Duda</td>
<td>Chronic Neurodegenerative Sequelae Driven by Neuroinflammation After Mild TBI</td>
<td>This project will investigate the role of neuroinflammation as a major driver of chronic neurodegeneration following mild traumatic brain injury (TBI).</td>
<td>Biomedical Lab</td>
<td>See Appendix C</td>
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<tr>
<td>Duda</td>
<td>Biological “Living Electrodes” Using Tissue Engineered Axonal Tracts to Probe and Modulate the CNS</td>
<td>This project will mechanistically assess the ability of micro-Tissue Engineered Neural Networks to serve as biological “living electrodes” for neural-electrical interface. This project will focus on the ability of “living electrodes” to provide synaptic specificity, targeted inhibition/excitation and biological multiplexing in comparison to conventional neural interface modalities.</td>
<td>Biomedical Lab</td>
<td>See Appendix C</td>
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</tbody>
</table>
This project is investigating the potential of using engineered tissue constructs to recapitulate the nigrostriatal pathway in rodent models of Parkinson’s disease.

APPENDIX F - Houston PADRECC

Publications


Posters
Sarwar Al, MD. Risk factors of sleep disordered breathing in Veterans with Parkinson’s disease. Accepted for publication and presentation at the International Congress of Parkinson’s Disease and Movement Disorders®, in Copenhagen, Denmark from August 27-31, 2023.

Jamal F, Jackson JR, Sarwar Al. Mandava P. Age at onset and therapeutic efficacy of Primidone in Essential Tremor patients. Accepted for publication and presentation at the International Congress of Parkinson’s Disease and Movement Disorders®, in Copenhagen, Denmark from August 27-31, 2023.


Jamal F, Sarwar Al. Implementing a model of comprehensive care in Parkinson’s Disease. Accepted for MEDVAMC QI &M summit. September 2023.

Professional Educations


Sarwar, A “Insight into brain stimulation for treating neurological disorders.”, University and NSF I-Corps Program Presentation, Houston, TX, August 09, 2023.

“Sleep Issues in Parkinson’s Disease”. Parkinson & Movement Disorder Alliance. PMD Alliance Programs programs@PMDAlliance.org. National virtual lecture. July 12, 2023

“Parkinson’s Disease Therapeutics”. Virtual lecture. CHK, Karachi, Pakistan. July 26, 2023

“Circadian Dysregulation in PD” (Target Audience – PADRECC and Houston Consortium physicians and nurses), Oct 2022

“Whole Health for Parkinson’s Disease”, Feb 2023.

Jamal, F “Non-Motor Features of Parkinson’s Disease”. Internal Medicine Grand Rounds, BCM, MEDVAMC. October 2022.

Presentations to Health Professional Trainees

Jackson, G

York, M


 Jamal F.
MEMED 607B, Elective for BCM first year medical students: “Clinical cases in medicine, Neurological disorders”, April 3rd, 2023


BCM Resident lecture: Thalamus. July 20, 2023

BCM Resident lecture: Cerebellum. July 25, 2023

Patient Education

Sarwar, A

“Autonomic dysfunction in PD”. PD Community Caregiver discussion. August 22, 2023


RESEARCH

Funded

<table>
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<tr>
<th>Name of Staff</th>
<th>Title of Research Project</th>
<th>Type of Project (Biomedical, applied clinic, HSR&amp;D, Rehab)</th>
<th>Funding Source</th>
<th>Total Amount Of Funds</th>
<th>Total Direct Costs</th>
<th>Beginning/End Dates</th>
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</thead>
<tbody>
<tr>
<td>PI (Scheibel, Co-I (Sarwar, Jackson, Jamal)</td>
<td>A longitudinal study of chronic TBI in OEF/OIF/OND veterans and service members</td>
<td>Applied Clinic/Rehab</td>
<td>VA Merit Review Grant</td>
<td>$1.1 million total</td>
<td>$189,100 initial yr.</td>
<td>2012-2026</td>
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<tr>
<td>PI (Interian)</td>
<td>Rural Veterans with Depression</td>
<td>Applied Clinic</td>
<td>Department of VA-Office of Rural Health</td>
<td>$300,839 ($50,000 – 1 year)</td>
<td>$300,839 ($50,000 – 1 year)</td>
<td>7/2020-2024</td>
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<tr>
<td>PI (Shulman) Co-I, (Jackson)</td>
<td>Houston Alzheimer’s Disease Research Center Consortium P30AG066510-A1</td>
<td>Biomedical, applied clinic</td>
<td>NIH</td>
<td>N/A</td>
<td>N/A</td>
<td>4/1/2020-3/31/2025 Unfunded (modified and re-submitted to Fidelity Foundation-see below)</td>
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Primary Projects

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<th>Principal Investigator</th>
<th>Title of Research Project</th>
<th>Purpose/Hypothesis</th>
<th>Method/Selection</th>
<th>Measures/Criteria</th>
<th>Findings</th>
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</thead>
<tbody>
<tr>
<td>Sarwar, AI</td>
<td>H-20822: Circadian Dysrhythmia &amp; Common Sleep Complaints in Parkinson’s disease</td>
<td>To study the distribution of different “chronotypes” and their association with sleep complaints (excessive sleepiness, insomnia etc.) in Veterans with PD</td>
<td>Sample size: 300 Sleep diary, Questionnaires (PSQI, VA sleep lab) I RBD, PTSD, GDS Actigraphy(grant) DLMO (grant)</td>
<td>Data from Standardized Questionnaires Actigraphy, DLMO for Study objectives</td>
<td>18 published abstracts (2011-2023) * MOST RECENT: Sarwar AI. Risk factors of sleep disordered breathing in Veterans with Parkinson’s disease Presented at the International Parkinson Disease and Movement Disorder Society meeting, Copenhagen, Denmark August 27-31, 2023.</td>
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<tr>
<td>Jamal, F</td>
<td>H-43032 Study of clinical characteristics of tremor in veterans 2018-2026</td>
<td>To study the demographics and clinical features of Essential Tremor (ET) in veterans, for better understanding of ET phenotypes.</td>
<td>Sample size: Local: 1600 Worldwide: 1600</td>
<td>Descriptive Statistics from Chart review for study objectives</td>
<td>Six abstracts and a manuscript have been published. Shah C., Jackson GR, Sarwar Al, Mandava P., Jamal F. Treatment Patterns in Essential Tremor: A Retrospective Analysis. Tremor &amp; Other Hyperkinetic Movement disorders. 2022 Mar 23; 12:10. Jamal F, Jackson GR, Sarwar Al,</td>
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<tr>
<td>Authors</td>
<td>Title</td>
<td>Abstracts</td>
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<tr>
<td>Jamal, F</td>
<td>H-34191: Parkinson’s disease and Vit D deficiency in Veterans 2014-2026</td>
<td>To determine the characteristics of PD in Vitamin D deficiency Sample size: Local: 3000 Charts review for vitamin D levels, demographic and clinical parameters Vit D levels are correlated with extracted variables.</td>
<td>Abstracts: (3) Vitamin D Deficiency and Severity of Parkinson’s Disease in Veterans. WPC 2016 Vitamin D and Clinical Phenotypes of Parkinson’s Disease MDS 2017 Vitamin D assessment in veterans with Parkinson’s disease. AAN (May 4-10, 2019)</td>
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Mandava P. Age at onset and therapeutic efficacy of Primidone in Essential Tremor patients. International Congress of Parkinson’s Disease and Movement Disorders®, in Copenhagen, Denmark from August 27-31, 2023. Published [abstract]. Mov Disord. 2023; 38 (suppl 1)

Jamal F Noorbhai IZ, Jackson JR, Sarwar Al. Racial Differences in Essential Tremor. International Parkinson Disease and Movement Disorder Society meeting, September 15-18, 2022. Published [abstract]. Mov Disord. 2022; 37 (suppl 1.) One in 2019, two in 2020, one in 2021
<table>
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<th>Principal Investigator</th>
<th>Title of Research Project</th>
<th>Purpose/Hypothesis</th>
<th>Method/ Sample (size/selection)</th>
<th>Measures/ Criteria</th>
<th>Findings</th>
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<tr>
<td>PI (Scheibel), Co-Sarwar, AI, Jackson GR, Jamal, F</td>
<td>H-32150</td>
<td>A longitudinal study of chronic TBI in OEF/OIF/OND veterans &amp; service members</td>
<td>To characterize the long-term effects of TBI on cognition, neuroimaging, and functional outcome in veterans &amp; service members</td>
<td>Sample size: Local: 200 Worldwide: 270 Questionnaire/survey/imaging</td>
<td>Lifetime TBI history, cognition, functional and neurological status, blood biomarkers, brain structural &amp; functional imaging. Slight bradykinesia, rigidity and tremor was observed on 52 standardized quantitative neurological examinations using the Neurological Outcome Scale for TBI.</td>
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<tr>
<td>PI: Viswanathan, Ashwin Co-I (Sarwar A, Jamal F, York, M)</td>
<td>H-42723</td>
<td>Analysis of human cortical and subcortical electrophysiological recordings during deep brain stimulator implantation</td>
<td>To analyze human electrophysiological data collected during deep brain stimulator implantation through a combination of subcortical and cortical recordings, with the goal of understanding brain physiology and optimizing DBS placement</td>
<td>Pilot Sample size: 20 Neural signal power spectrum analysis and correlation with physiological parameters</td>
<td>LFP correlation with tremor activity. LFP can guide placement. of DBS.</td>
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<tr>
<td>PI: Sharafkhaneh Co-I (Sarwar)</td>
<td>H-32672</td>
<td>To define the health care utilization including inpatient &amp; outpatient health care use before and after therapy with CPAP adjusted for various comorbid conditions and demographic characteristics.</td>
<td>As per the title</td>
<td>N = 250000 Retrospective cohort study of patients with SRBD compared to non-SRBD cohort of veterans</td>
<td>Comparison of health care utilization and clinical outcomes of patients with SRBD treated with CPAP vs matched controls. Data is being analyzed.</td>
</tr>
<tr>
<td>PI: Sharafkhaneh Co-I (Sarwar)</td>
<td>H-35366</td>
<td>Sleep apnea, incidence and prevalence of various chronic medical conditions, and related mortality in veterans</td>
<td>To determine whether Veterans who are diagnosed with sleep apnea and other sleep disorders have increased prevalence and incidence of various chronic and acute medical conditions</td>
<td>N=1,000,000 Retrospective data base review</td>
<td>Identifying multiple various comorbid conditions &amp; their relationship with presence of OSA or other sleep disorders and its treatment. On-going</td>
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</table>
| PI: Jones  
Co-I (Sarwar, Jackson)  
2021-2026  
BCM/VA | H-50496  
Screening for prodromal markers of alpha-synucleinopathies in post-9/11 veterans | To assess prodromal features and investigate REM sleep without atonia using polysomnography to optimize screening methods for RBD and develop standardized protocols for detecting prodromal markers of synucleinopathies in post-9/11 Veterans.  
N=35 Pilot, cross-sectional Questionnaire/survey/interview | Early features of synucleinopathies (REM sleep without atonia/rapid eye movement sleep behavior disorder, olfaction loss, subtle parkinsonism, autonomic and quantitative motor dysfunction) | On-going |
|---|---|---|---|---|
| Site PI: Jamal  
08/12/2022-09/13/2027  
International Parkinson's and Movement Disorder Society | A multi-center observational study on the Prevalence of Loss of benefit after DBS for medication-refractory tremor | To determine factors governing loss of neurostimulation benefit in medication refractory tremor | Observational Prospective | MDS-Tremor Study Group Defined Criteria  
Initiated in FY 23  
3 subjects have been recruited so far |