SUMMER 2022

Parkinson Update

OHSU

Center Founders Honored, Surprise Announcement

In our last edition, we announced two endowed chairs named in honor of Drs. John Hammerstad and Jay Nutt. Both physicians currently reside at Mary's Woods, which feted their accomplishments and the endowed chair recipients — Drs. Vivek Unni and Fay Horak — on a grand scale last month. More than 250 Mary's Wood residents and OHSU Parkinson Center specialists and staff gathered to learn more about the exceptional work being done by Drs. Unni and Horak while enjoying delectable sweets and toasting with champagne.

The honors were not limited to just these four. OHSU Parkinson Center Medical Director Joe Quinn, M.D., made a surprise announcement honoring the third founder of the OHSU Parkinson Center, Julie Carter, ANP. In honor of Ms. Carter's research and special interest in PD caregiver issues, as well as her 30-plus years in helping form and grow the OHSU Parkinson Center with Drs. Hammerstad and Nutt, Dr. Quinn announced funds had been set aside to establish the Julie H. Carter Caregiver Program. This will be a groundbreaking project, which will be developed under a special committee to include PD experts and care partners over the next two years.

Founders and Professors:
(L-R) Julie Carter, RN, M.N., ANP, Jay Nutt, M.D., John Hammerstad, M.D.

Award Recipients:
Vivek Unni, M.D., Ph.D., Fay Horak Ph.D., PT

Director's Corner:

Spotlight on Gene Research in PD

Joe Quinn, M.D.

There's a saying that only half of what they teach you in medical school is true, and the trick is figuring out which half. The older I get, the more I appreciate this. For example, the textbooks I used as a medical student and neurology resident actually said, "There is no genetic contribution to Parkinson's disease." Parkinson's disease (PD) was long considered a sporadic condition with no genetic risk factors. As it turns out, we still don't identify relevant genes in most people with Parkinson's, but there is now a long list of genes that have been implicated in a significant minority of PD patients. These identifiable genes may one day have implications for therapy. For example, some of the biochemical pathways defined in gene carriers may also be relevant to non-gene carriers with PD. The other strong possibility is that therapies may be tailored to specific genetic versions of PD, just as therapies are already tailored to specific genetic variants in other areas of medicine, such as oncology.

As I've described in this column in the past, "precision medicine" research trials are already underway targeting specific genetic pathways in PD. One recent example targeted the GBA gene, which is present in about 5% of people with PD. The GBA gene has been studied for decades as a cause of a rare pediatric disease, so the chemical pathways are well defined and medications have been developed to treat this rare disease. As it became clear that the same gene is involved in some cases of PD, these medications were applied to GBA-PD in a rigorous placebo-controlled trial, which was completed in 2020. Sadly, the drug was not effective in this case, but it was the first example of a large precision medicine trial in PD, and a great deal was learned that will be applied to future studies of this variant. A second example targets PD patients with the LRRK2 gene, which is present in about 1% of PD patients. This study uses snippets of DNA-like material called anti-sense oligomers, injected into the

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A PUBLICATION OF
THE OHSU PARKINSON CENTER

Parkinson's Foundation
CENTER OF EXCELLENCE

Care Partner Corner

2022 CarePartner Connections a Success!

More than 85 family caregivers gathered online on February 17 for our annual CarePartner Connections assembly to share their experiences and learn about self-care and how to connect to specific solutions.

Cognitive Impairment and Care Partner Burden was the focus of our first presentation by Allison Lindauer. The program was rounded out by a candid talk with our Care Partner Panel, a meditation and movement break, and a presentation by our own education director, Jeni Bednarek, on sensory routines and how they can be used for self-care. A special thank you to Ethel Campbell and Betty Colley for sharing their candid care partner experiences.

And there are many more insights and inspiring words shared by these wise, amazing family care partners. You will want to view it more than once! If you missed any part of these powerful presentations or simply want to revisit them, you may view them online at **https://www.avcast.me/ohsu-pd**.

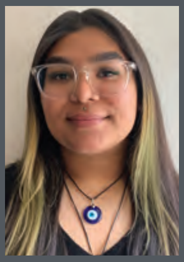
To watch a recording of our most recent CarePartner Connections assembly visit https://www.avcast.me/ohsu-pd.

NEW Pilot Program Coming: Caregiver Academy

Thanks to Drive Toward a Cure's 'Access to Care Fund' donations provided to the Parkinson's Foundation, and additional funding from Drive Toward a Cure regional programs based in the Pacific Northwest, the OHSU Parkinson Center is piloting a new program: Caregiver Academy. We sent a survey to caregivers asking them which topics they felt they needed to know more about in two areas: caring for their loved one and self-care. Caregiver respondents said the top three educational priorities were for delivering care, fall prevention and choosing a caregiving agency. The top three self-care topics were cognitive decline, mood (depression, anxiety, apathy) and lifestyle (daily activities, diet). So, we'll be presenting three virtual programs on advance care planning and self-care during cognitive decline by the end of the year. For now, these programs will be done live on Zoom as this was the education mode most caregivers preferred. We'll have in attendance PD medical team subject experts and, most importantly, the true experts — caregivers. This program will be interactive, not just talking heads. We want to know how we can understand better and help you with challenging situations and have you share with others pearls of care and self-care you've learned. We will let you know when we have firm dates so you can join us.

Welcome, New Team Members

Our team is growing to better serve you! We are honored to announce two great additions to the OHSU Parkinson Center team. You may be working with them when you call the office trying to reach your provider or to participate in an educational event. Please join us in welcoming:



Elena Fierros Mendoza

Patient Access Specialist

Tested and approved: Elena tested us out last year while working as a temporary patient access specialist. We didn't want to let her go, and apparently, we passed her test, because she stayed! She officially became part of the growing OHSU Parkinson Center support team last November. She's lived with her family in Salem for many years, graduating from McKay High School and then taking a job in health care. She moved to Portland in May 2021, shortly after starting with us. She has enjoyed exploring the many fun activities in the "big" city and exploring all that the Pacific Northwest offers. Elena says of her work at the OHSU Parkinson Center: "I'm grateful for being part of this team. I enjoy contributing to the team's daily efforts to help patients and their families in any way we can."

Jhaline Mast

Office Specialist

Jhaline won our hearts quickly after taking the newly created office specialist position. She is now assisting with everything from managing calendars to helping folks register for events. Jhaline and her fiancé moved to Oregon in March of 2021 after both graduated from UC Santa Cruz. Having lived in Southern California for most of her life, Jhaline has fallen in love with the rainy Portland weather and many beautiful hiking trails. When asked why she loves working at the Parkinson Center, Jhaline said, "From my first day here, it was clear that the OHSU Parkinson Center was a place of community and growth. I have learned so much during my time here and look forward to continuing to work with such an incredible group of people!" Please join us in welcoming Jhaline to the team.

2022 Care Partner Summit in Portland

As a Parkinson's Foundation Center of Excellence, the OHSU Parkinson Center is excited to announce that Portland, Oregon is one of five sites live hosting the Parkinson's Foundation Care Partner Summit this fall. The program will occur on two Saturdays with both in person venues and online live streaming as well. The first session will be on Saturday, October 29, 2022 in Kansas City, Missouri and White Plains, New York. Portland's session will occur on Saturday, November 5, 2022 with concurrent live sessions in Atlanta, Georgia, and Milwaukee, Wisconsin.

All locations will highlight two key topics:

- Managing Your Evolving Role and Identity
- Identifying and Addressing Your Loved One's Cognitive Changes

The Summit is designed with care partners in mind and is recommended for anyone caring for someone living with PD, including spouses, partners, children or friends. More information and registration will be forthcoming from the Parkinson's Foundation at **www.parkinson.org/summit**. You can also watched past summit programs which are archived at the summit website as well.

So mark your calendars to save the date and watch our facebook page, **https://www.facebook.com/OHSUPCO** or the Parkinson's Foundation website for more information.

Palliative Care: Not What You Think It Is....

By Amie Hiller, M.D. and Jocelyn Jiao, M.D.

What do you think of when you hear "palliative care"? Too many people think end of life or hospice. Actually, palliative care should begin at the time of diagnosis, because it is so much more.

Palliative care is a growing field that aims to improve the quality of life of patients and their families, especially those with chronic or life-threatening illness. This includes Parkinson's disease and other diseases such as cancer, heart failure and kidney disease. For all these various diseases, palliative care aims to address suffering of any kind: physical, emotional, psychological, existential and/or spiritual. Palliative care in Parkinson's disease can improve numerous aspects of patient care; the goals include addressing the widespread symptoms of Parkinson's disease beyond motor symptoms, alleviating the psychological distress caused by the disease, providing multidimensional support to care partners, and helping patients proactively plan for the short- and long-term future. Put simply, palliative care is helping people live as long as possible as well as possible.

> Put simply, palliative care is helping people live as long as possible as well as possible.

Like hospice, palliative care focuses on patients' quality of life, comfort and symptom relief and tends to be provided through a team approach. Unlike hospice, palliative care is not limited to the last six months of life — in fact, it can be introduced even at the time of diagnosis. A palliative care approach can be delivered by neurologists, primary care providers, specialist palliative care physicians, nurses and social workers, among others. Palliative care can be delivered in various settings: the outpatient clinic, the inpatient hospital and at home; palliative care clinics are in some settings also known as supportive care clinics. Specific palliative care specialists are generally utilized when there are complex decisions or discussions around future care plans or medical decision making.

The Parkinson's Foundation, which designates clinics like the OHSU Parkinson Center as a Center of Excellence, is championing a nationwide Palliative Care Initiative, which aims to integrate palliative care into the routine delivery of excellent clinical care from the time of diagnosis. There are five specific goals of the program:

- Systematic management of nonmotor symptoms
- Routine assessment of psychosocial concerns
- Support for care partners
- Annual advance care planning
- Timely referral to hospice and specialist palliative care

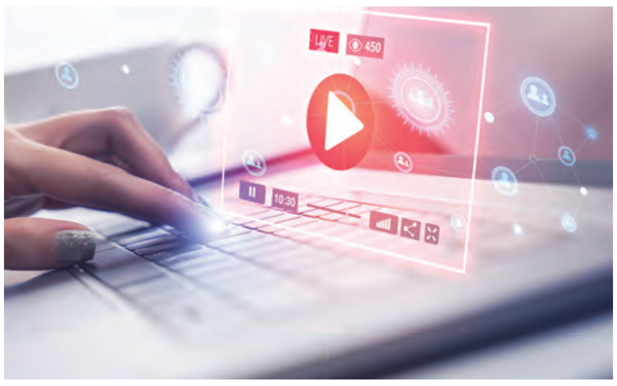
The OHSU Parkinson Center uses a team approach for all patients, believing that nursing care, physical therapy, social work, counseling and the integration of these services and others is optimal care. Our experience has been that integrating this sort of care from the beginning will improve care throughout the course of the disease. We also have a specific advanced disease palliative care team clinic known as Next Step Clinic for persons experiencing major life changes as their disease enters a more advanced stage. Partnering with the Parkinson's Foundation in this initiative will take things to a new level of care here at OHSU for persons with all stages of Parkinson's.

DIRECTOR'S CORNER *(continued)*

spinal fluid, to precisely shut off the LRRK2 gene in the brain. That study is ongoing at OHSU and elsewhere, and other studies targeting LRRK2 are also underway.

One of the bottlenecks slowing progress is the fact that genetic testing is not part of standard practice in Parkinson's disease. Outside of research, this makes sense, since there are currently no treatment recommendations that hinge on genetic testing. Fortunately, the Parkinson's Foundation has stepped in with an initiative to generate the genetic information that the research community needs without imposing additional costs or burden on patients or on the health care system. The initiative is called PD GENEration, and it offers free testing for the top seven genes associated with PD, including GBA and LRRK2 as well as five less common genes. Participation involves signing a research consent document, providing some background information about yourself and then providing a cheek swab for genetic analysis. The testing is performed in an appropriately certified lab (CLIA approved) and the results are shared with the patient. If necessary, genetic counseling is available for explaining complicated results. Our goal is to test as many as possible of the 1,500 or so PD patients in our practice, in order to identify the 150 or so PD patients who have one of these genes. Gene carriers may then be directed to appropriate clinical trials. The study is confined to people with a diagnosis of Parkinson's disease, so it is not available for predictive testing. The study is also open to PD patients outside of our practice, so we are happy to provide this service to others.

To participate, please contact the research team at PDResearch@ohsu.edu and include "PD GENE" in the subject line or call 503-418-4387 to speak with our research associate, Emily Leonard.



OHSU Parkinson Center Events Still Available Online!

Virtual events ready for your viewing pleasure

Since June 2020, our events have continued virtually. You can still view these presentations on a variety of topics includiing DBS, Anxiety, THC/CBD, REM Sleep Behavior disorder, research and more at **www.avcast.me/ohsu-pd**.

To watch presentations previous to June 2020, visit our video library at https://tinyurl.com/pco-videos.

Research Opportunities

Please note: You may not personally benefit from participating in a research study. However, by service as a subject, you may help us learn how to benefit patients in the future.

Research database

Title: Department of Neurology Research Contact & Health Information Repository
Purpose: This research database allows staff to collect information about patients who are willing to consider participation in upcoming clinical research projects.

Participation Requirements:

- You are age 18 or older
- You are willing to provide health information to research staff
- You have a neurological diagnosis OR you do not have a neurological diagnosis

Participation details: You will be asked to complete an Informed Consent Form, which allows research staff to include your information in the research database. The form asks for information about your health history, medications, and the types of research that may interest you. Completing the consent form does not mean you have agreed to participate in a specific study, but you are giving research staff authorization to include your health information in the database for future reference. When a study is starting and we are looking for eligible participants, we will search through the database to find people who fit the profile for the study. If your information matches, study staff will contact you to discuss the study in further detail and ask if you are interested in participating.

For more information: contact study staff at **503-418-4387** or PDResearch@ohsu.edu and reference IRB #8049 in your message. **(OHSU eIRB #8049)**

Newly Diagnosed with Parkinson's Disease

Have you been diagnosed with Parkinson's disease in the last 3 years and are not currently taking carbidopa/levodopa or dopamine agonists?

Purpose: This study explores the ability of K0706, an experimental drug, to slow the progression of Parkinson's disease (PD). K0706 aims to block an enzyme called "Abl" which may play a role in PD. There are currently no drugs available proven to slow the progression of PD.

Participation Requirements: In order to participate in the study you must have been diagnosed with PD within the last 3 years, are older than 50 years of age, and have no history of taking dopaminergic drugs for more than 30 days previously. You must be able to have an MRI and DaT SPECT.

Participation Details: Study participation occurs over a period of 44 weeks and includes 11 visits to OHSU if deemed eligible after an up to six week screening period. Visits occur every 2 to 8 weeks. If enrolled, you will take K0706 in powder form mixed with a glass of water once daily and record your daily dose in a journal. This study is placebo-controlled, meaning that you may receive a placebo instead of study drug. Eligible participants will receive study-related evaluations at no cost, possibly including an MRI and DaT SPECT. Participants are compensated for their time and travel after visits are completed.

For more information please contact study staff at **PDResearch@ohsu.edu** and reference #20122 in the subject line. (eIRB #20122)

Have you been diagnosed with Parkinson's disease (PD) but have not started taking PD medications?

Title: Characterizing Biomarkers in Early Parkinson's Disease Progression
Purpose: The purpose of this study is to look at a biological marker of inflammation found in blood, and find out if this biomarker could indicate progression of Parkinson's disease over time.

Participation requirements:

- You have not been treated for Parkinson's disease with levodopa (also called Sinemet) or a dopamine agonist (Mirapex®, Apokyn®, Requip®, or Neupro®) and are able to walk up and down a hallway several times.

Participation details: There are three visits to the Portland VA over the course of 1 year. The first visit is 2.5 hours and will consist of a neurological examination, medication reviews, a test of hand dexterity, and a blood draw. The second and third visits (at 6 months and 1 year) are 1.5 hours and will repeat many of the measurements from the first visit. You will be compensated $ 25.00 for each visit completed for a total of $ 75.00. If during the study you or your physician decide that you need to start on Parkinson's medications, then your study participation will be terminated.

For more information, please contact: Brenna Lobb at **503-220-8262** extension **51871** or by mail at 3710 SW US Veterans Road, P3-PADRECC, Portland, Oregon 97239. IRB # 18545; MIRB # 4277

Have you been diagnosed with Parkinson's disease (PD) within the past 3 years but have not started taking PD medications?

Title: Study in Parkinson's Disease of Exercise Phase 3 Clinical Trial (SPARX3)
Purpose: SPARX3 is a research study to learn more about the effects of aerobic exercise on people with Parkinson's disease who have not yet started medication for their PD. It will compare the effects of moderate intensity treadmill exercise to high intensity treadmill exercise on the signs and symptoms of Parkinson's disease.

Participation requirements: We are seeking subjects who satisfy the following criteria:

- Between 40 and 80 years of age
- Diagnosed with primary PD with disease duration less than 3 years
- Has not yet started medication for PD
- Not likely to begin dopaminergic therapy within the next 6 months

Participation details: First, you will complete two screening visits to confirm that you meet the criteria to participate in the study. These visits consist of physical and memory/thinking assessments, a blood draw for exercise clearance, a questionnaire to screen for depression, and a brain scan (DaTscan) that helps confirm diagnosis of PD. These screening activities are explained in further detail below.

If you are eligible to participate in this study, you will then complete a series of visits, which consist of more physical and memory/thinking assessments, questionnaires, blood draws, exercise tests, and brain scans. You will also be randomized (like flipping a coin) to one of two exercise groups. You will be asked to exercise, at a specific rate/intensity, 4 days per week for approximately 30 min, while we will closely monitor you. Your participation in this study, including study visits and the exercise sessions will last approximately 2 years (24-26 months).

For more information, please contact: Graham Harker at **503-418-2601** E: harkerg@ohsu.edu or Austin Prewitt at **503-418-2600** E: prewitta@ohsu.edu for more information. (eIRB# 21483)

Memory and Cognition

Have you been diagnosed with Alzheimer's disease, mild cognitive impairment, another type of dementia, OR are healthy and would like to participate in research?

Title: Peptide Biomarkers for Alzheimer's disease
Purpose: The purpose of this study is to see if biological molecules in the blood and cerebrospinal fluid (CSF) can help detect Alzheimer's disease (and other types of dementia) at an earlier stage.

Participation requirements:

- You are between 55 and 80 years old
- You are a healthy volunteer (no neurological diagnosis), or have a diagnosis of AD, mild cognitive impairment, Parkinson's disease, fronto-temporal dementia, or dementia with Lewy Bodies.
- You have a study partner who will attend study visits with you.
- You are not taking warfarin or other blood thinners.
- You have no lower back problems and/or surgeries.

Participation details: This study involves collection of blood from a vein in your arm, and collection of CSF through a lumbar puncture (spinal tap). There are two study visits over approximately 1 month and one follow up phone call. You will receive study-related evaluations at no cost and will be compensated $100 for time and transportation for the lumbar puncture visit.

For more information please contact: Keenan Ashby at **503-494-7245** or PDResearch@ohsu.edu, IRB #18193

Are you interested in participating in a study to learn more about role of genes in thinking and memory in Parkinson's disease?

Title: Pacific Northwest UDALL Center (PANUC): Clinical Core and Sample Collection
Purpose: This study aims to characterize the changes in thinking and memory of Parkinson's disease patients over time and to determine the role genetics plays in cognitive impairment in Parkinson's disease.

Participation requirements:
You have a diagnosis of Parkinson's disease or you are willing to participate as a healthy volunteer.

Participation Details: This is a long-term study and your participation would last 5 years or more. The study involves at least two visits to the VA Portland Health Care System. At each visit, you will undergo tests of thinking and memory, have a neurological exam, fill out questionnaires, and have a blood draw. Each visit will last for about three to four hours. After the first visit, you have the option to undergo a lumbar puncture. A lumbar puncture is known as a spinal tap. A spinal tap is where a special needle is inserted between bones in your back and fluid is removed. The spinal tap will take about two to two and a half hours. You have the option to undergo a second spinal tap three years after the first spinal tap. In between visits at the VAPORHCS you will have a telephone interview with questions regarding your thinking and memory. These interviews will last about 30 minutes. You will be compensated $200.00 for each spinal tap that you complete.

For more information please contact: Micki Le at **503-220-8262 x54688** or by mail at 3710 SW US Veterans Road, Portland, Oregon 97239. IRB#6154, MIRB #2332

Other Parkinson's disease research studies can be found at these sites:

- OHSU Parkinson Center Research: **https://tinyurl.com/PDresearchOHSU**
- Michael J. Fox Trial Finder: **https://foxtrialfinder.michaeljfox.org**
- National Institutes of Health: **https://clinicaltrials.gov**
- Washington State PD Registry: **www.registerparkinsons.org**

Do you have a Parkinson's disease diagnosis and no falls over the last 12 months?

Title: Mobility in Daily Life and Falls in Parkinson's **Disease:** Potential for Rehabilitation
Purpose: This study involves wearing mobility sensors at home for one week to learn about mobility patterns in people with Parkinson's disease (PD).

Participation requirements:

- You are 55-80 years old with Parkinson's disease
- You have not experienced any falls in the last 12 months
- You can walk for two minutes unassisted
- You are taking a stable dose of Levodopa medication
- Willing to wear mobility sensors for 1 week and track your falls for 12 months
- You have no other neurological or musculoskeletal issues

Participation details: If you decide to take part in this study, you would be asked to wear a set of mobility monitoring sensors for one week and to track your falls for one year through email survey. The sensors collect information about your balance and mobility and are worn on the feet and around the waist (3 total sensors) for up to 10 hours per day for 7 days. Participants will also be asked to complete several surveys and questionnaires during two separate visits with study staff members (visits may be virtual for long distance individuals). Participants are compensated $130 for completing the study.

For more information, please contact: Graham Harker at **503-418-2601**. IRB#: 18978

Do you have a Parkinson's disease diagnosis and at least one fall over the last 12 months?

Title: Mobility in Daily Life and Falls in Parkinson's Disease: Potential for Rehabilitation
Purpose: We are investigating if a rehabilitation training program focused on turning and balance can improve mobility in people with PD.

Participation requirements:

- You are 55-80 years old with Parkinson's disease
- You have experienced at least one fall in the last 12 months
- You can walk for two minutes unassisted
- You are taking a stable dose of Levodopa medication
- Willing and able to visit OHSU's Marquam Hill campus 3x/week for 6 weeks
- Willing to wear mobility sensors for 2 weeks and track your falls for 12 months
- You have no other neurological or musculoskeletal issues

Participation details: The study would involve coming to our Balance Disorders Laboratory at OHSU and performing walking and balance tasks while wearing mobility sensors on your arms, legs and torso as well as sensors measuring brain activity on the head. You would also be asked to wear three mobility monitoring sensors for one week and to track your falls for one year through email survey. The sensors collect information about your balance and mobility and are worn on the feet and around the waist (3 total sensors) for up to 10 hours per day for 7 days. Participants will also be asked to complete several surveys and questionnaires during three separate visits with study staff members. Participants are compensated $300 or $450 depending on randomization.

For more information, please contact: Jacquie Ellison or Austin Prewitt at **503-418-2600**. IRB#: 18978

Blood Pressure

Do you take levodopa for Parkinson's disease and experience blood pressure changes when your medication wears off?

Title: Clinical Characteristics of Parkinson's Disease Subjects with Severe Hypertension During Motor Offs
Purpose: This study is looking at blood pressure changes in Parkinson's disease (PD).

Participation requirements:

- You have been diagnosed with Parkinson's disease
- You have been taking levodopa for at least 3 years
- You have a history of your levodopa wearing off within 4 hours
- Your blood pressure increases during "off" periods
- You are not taking beta blockers daily
- You do not have Diabetes mellitus or other condition known to alter autonomic functions

Participation details: This study involves two visits with one at-home monitoring period in-between the visits. The first visit will happen at the VA Portland Health Care System and last about one hour. During this visit, you will answer questions about your Parkinson's disease and have a physical examination. You will then be sent home to monitor your blood pressure in relation to your levodopa dose cycle for the next couple of days. The second visit will last 4 to 8 hours depending on your levodopa cycle. You will arrive at 08:00 am OFF of your levodopa. You will undergo various measures of your vitals, movements, and answer questionnaires about how Parkinson's affects you. The study visit will last until 3:00pm or until your levodopa wears off. There is no compensation for participation in this study.

For more information, please contact: Brenna Lobb at **503-220-8262** extension **51871** or by mail at 3710 SW US Veterans Rd, P3-PADRECC, Portland, Oregon 97239. IRB #17490; MIRB #4143

Motor Fluctuations with Carbidopa/Levodopa

The Effect of GOCOVRI on Quantity and Quality of Gait in Parkinson's Disease

IRB# 20105, PI: Amie Hiller
This study is investigating the effect of GOCOVRI (extended release Amantadine) on activity levels in people with Parkinson's disease that experience Levodopa induced dyskinesia (LID). The study includes 2 remote/virtual visits and two 1-week periods of home monitoring with wearable sensors and medication tracking. Participants will take GOCOVRI for a total of 5 weeks. We are looking for people ages 50-70 years old that have idiopathic Parkinson's disease and at least 1 hour/day of ON time with Levodopa induced dyskinesia, no other neurological or musculoskeletal disorders, and no renal impairments. For more information, please contact Graham Harker harkerg@ohsu.edu / **503-418-2601**. This study is virtual/remote.

STAT-PD: Preventing Levodopa Induced Dyskinesia in Parkinson's disease with HMG-CoA Reductase Inhibitors (OHSU eIRB # 17302; MIRB # 3869)

Almost all PD patients will develop involuntary movements overtime with treatment of levodopa. This study involves two visits. The first visit, a screening visit, will happen at the VA Portland Health Care System or virtually (over the internet) and last about two hours. During this visit you will complete some questionnaires, answer some questions about your Parkinson's disease and have a physical examination. The second visit will happen at Oregon Health & Science University and will last 8 to 9 hours depending on your levodopa cycle. You will arrive in the morning at 08:00 am in an "OFF" state. You will eat breakfast. You will undergo various measures of your Parkinsonism, movements, and answer more questionnaires about how Parkinson's affects you. You will receive an intravenous levodopa infusion from 09:30 am to 11:30 am. Every half hour starting at 09:00 am, we will measure your movements, Parkinsonism, and complete some questionnaires. The study visit will last until 03:00 pm or when you turn "OFF". You will receive $10 for the screening visit and $50 for completing the all-day visit, for a total of $60 compensation. You may not personally benefit from participating in this study. However, by service as a subject, you may help us learn how to benefit patients in the future. For more information on how to participate, please contact Brenna Lobb, Research Coordinator, at **503-220-8262** extension **51871** or by mail at 3710 SW US Veterans Rd, P3-PADRECC, Portland, Oregon 97239.

Progressive Supranuclear Palsy (PSP)

Have you been diagnosed with progressive supranuclear palsy (PSP)?

Title: Cerebellar Transcranial Magnetic Stimulation for Motor Control in Progressive Supranuclear Palsy
Purpose: To investigate whether transcranial magnetic stimulation (TMS) effective for treating issues with balance and speech in progressive supranuclear palsy (PSP).

Participation requirements:

- Age 40-85
- You have been diagnosed with supranuclear palsy (PSP)
- You are willing to refrain from other physical and speech therapy programs for the duration for the study
- You are able to remain on stable doses of medications for the duration of the study
- You do not have any other significant neurological disorders (including seizures) or inner ear disorders.
- You do not have medical implants (such as a pacemakers, defibrillators, or cochlear implants) or material containing metal in your eyes, head, or body

Participation details: This study involves 24 total visits that may include balance and gait testing, an MRI scan of the brain, cognitive testing, and TMS or a "sham" treatment.

For more information, please contact: Austin Prewitt at prewitta@ohsu.edu or 503-418-2600. IRB #66152

Healthy Control

Have you been diagnosed with Alzheimer's disease, mild cognitive impairment, another type of dementia, OR are healthy and would like to participate in research?

Title: Peptide Biomarkers for Alzheimer's Disease
Purpose: The purpose of this study is to see if genes and biomarkers in the blood and cerebrospinal fluid (CSF) can help detect Alzheimer's disease (AD) at an earlier stage. Researchers would like to learn more about specific types of genes and biomarkers in blood and CSF to help understand the biology of AD. If a gene or genes that cause AD can be found, the diagnosis and treatment of AD may be improved.

Participation Requirements:

- You are 55-80 years old
- You have a diagnosis of Parkinson's disease, Alzheimer's Disease, fronto-temporal dementia, dementia with Lewy Bodies or no neurological diagnosis
- You are in good health
- You have someone willing to attend study visits with you
- You are taking warfarin or other blood thinners
- You have lower back problems/surgeries

Participation details: This study involves collection of blood from a vein in your arm, and collection of CSF through a lumbar puncture (spinal tap). There are two study visits over approximately 1 month. Eligible participants will receive study-related evaluations at no cost. Participants will be compensated for their time and transportation for the lumbar puncture visit.

For more information, please contact us at **503-494-7245** or PDResearch@ohsu.edu. eIRB #18193

Upcoming OHSU events

Newly Diagnosed Parkinson's Workshop (virtual and in-person)

July 13, Aug. 10 and Sept. 14, 10–11:30 a.m.
The OHSU Parkinson Center offers a 90-minute virtual session for people recently diagnosed with PD and their spouses or family members on the second Wednesday of each month. The workshop is led by Shannon Anderson, a physician assistant with extensive knowledge of Parkinson's disease. She is joined by Pat and Dan Baker, who has lived with Parkinson's for more than a decade.

$10/couple. For dates and to register, go to **https://tinyurl.com/OHSUpdedu** or email pcoeducation@ohsu.edu with questions.

Essential Tools for Mid-Stage PD Series 2022

This four-part series addresses key issues encountered by people with PD and their loved ones during the middle stages of the disease. In a two-hour program, topics will be presented by experts, with time for audience interaction.

- **Thurs., July 28** Take a sneak peek behind the medical curtain! Meet our compassionate care team with a behind-the-scenes look at the OHSU Parkinson Center.

Registration will open a month prior; visit **https://tinyurl.com/OHSUpdedu** or email **pcoeducation@ohsu.edu** with questions.

Great Salt Lick Art Auction Is BACK!

Sat., Sept. 17, 2022 — Baker City, Ore.

The Great Salt Lick Art Auction, and founder Whit Deschner, RIDE AGAIN!

Yes, this unique fundraiser is a phoenix rising from the ashes of the pandemic. Put a visit to Baker City on your September calendar to attend! Where else can you see and purchase bovine-crafted art? It's a lot of fun and supports a good cause — the work of the OHSU Parkinson Center. Plan to join in the fun and hilarity of this unique event next fall as a kickoff to the World Parkinson Congress. For a glimpse of what to expect, see the feature on OPB's "Oregon Art Beat" at **https://watch.opb.org/video/oregon-art-beat-september-22-2011**.

Options & Opportunities, 38th Annual Symposium

Sat., Oct. 29

Join the OHSU Parkinson Center for our 38th annual symposium to learn the latest in treatment and research and ask questions of our panel of movement disorder specialists. People living with Parkinson's and those who support them are invited to join us virtually or in-person.

- Registration will open in September 2022.
  https://tinyurl.com/OHSUpdedu

The Care Partner Summit is Back!
Join online or in person in Portland, OR

Save the Date
November 5, 2022

Look for more information soon
at Parkinson.org/Summit

Save the date!

Portland, Oregon is one of five sites live hosting the Parkinson's Foundation **Care Partner Summit** this fall. See page 2 for more details.

In the Parkinson's community

Parkinson's Resources Of Oregon

Parkinson's Resources continues to offer a variety of programs and services for PwP and caregivers alike. Most activities can now be accessed online or by telephone. Chair-based movement, education, support groups, singing and more. For the current schedule and registration information, visit the website at **www.parkinsonsresources.org** or call the PRO helpline at **800-426-6806**.

- **Sole Support for Parkinson's**

  Portland @ Oaks Park: Sept. 17
  Vancouver @ Esther Short Park: Sept. 24
  Eugene @ Alton Baker Park: Oct. 2
  Bend @ Drake Park: Oct. 9

  Sole Support for Parkinson's is a fundraising and awareness walk with locations in Portland, Bend, Eugene and Vancouver. Proceeds from this family-friendly walk series help sustain free local programs and activities such as support groups, webinars, counseling and case management. Details at **www.solesupport.org** or call Parkinson's Resources of Oregon (PRO) at **800-426-6806**.

- **Patterned for Parkinson's**

  Do you have a unique or creative idea to solve one of the many challenges of getting dressed and looking good while living with a movement disorder? We want to hear from you! In anticipation of the inaugural Patterned for Parkinson's, Designs for Independence fashion showcase coming this fall, PRO has launched a design contest and we would love to see what you have in mind. Winning concepts will receive cash awards and winners may even see their idea brought to life! Scan the QR code for all the important details! For more information call PRO or visit **https://www.parkinsonsresources.org/get-involved/patterned-for-parkinsons**.

Brian Grant Foundation

Helping people with PD live active, fulfilling lives through wellness and community. Information about these courses and registration details are at **briangrant.org/events**.

- **Expert Q&A Series,** every second Wednesday
- **Breath by Breath Mindfulness Drop-in Class**
  Every Tuesday, 11:30a.m.–12:30 p.m.
- **Mindfulness-Based Stress Reduction Course**
  Sep. 20–Nov. 8, 2022, online every Tuesday from 9–11 a.m.

NW PADRECC

The Northwest Parkinson's Disease Research, Education and Clinical Center (NW PADRECC) is a collaborative effort of the **VA Portland Health Care System** (affiliated with Oregon Health & Science University) and the **VA Puget Sound Health Care System** in Seattle. Both sites offer clinical, research and educational services and activities for veterans living in the Northwest PADRECC service area, as well as interested clinicians. Visit **parkinsons.va.gov/northwest** for more information on upcoming events and to watch the My Parkinson's Story videos online. This series of videos features real veterans telling their Parkinson's stories with commentary provided by VA medical providers.

OHSU Parkinson Center

Oregon Health & Science University
Department of Neurology
OHSU Parkinson Center, OP32
3181 S.W. Sam Jackson Park Road
Portland, OR 97239-3098

Medical Director
Joseph Quinn, M.D.

Newsletter Coordinators
Lisa Mann, R.N., B.S.N., M.A.
Jeni Bednarek RN, B.S.N., ACRP-CP
Kellie Keith, B.A.
Jennifer Carpenter

Mailing List/Change of Address:
503-494-7231
pco@ohsu.edu

Charitable Giving
800-462-6608
www.ohsufoundation.org
Maddy Abulencia
Director of Development
Direct: 503-552-0663
abulenci@ohsu.edu

Neurosciences Development Office
OHSU Parkinson Center
Phone: 503-494-7231
Fax: 503-494-9059
www.ohsubrain.com/pco

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