Director’s Corner:
Honoring the Past with an Eye for the Future

Joe Quinn, M.D.

In the fall of 2017, we invited a group of prominent Parkinson’s disease physician-scientists to review our plans for the OHSU Parkinson Center. They pointed out that one of the missing pieces was an endowed professorship, which is a mark of excellence at outstanding academic medical centers. Endowed professorships are signs of stability and of institutional support, which serve to attract and retain the best and brightest doctors and scientists. They are also expensive, relatively rare at OHSU, and in 2017 an endowed professorship was out of reach for the OHSU Parkinson Center.

Then in the fall of 2020, an anonymous donor made a large gift to the OHSU Parkinson Center, large enough to permit us to establish not one but two endowed professorships. We decided to earmark one for clinical research and one for basic laboratory research, with the understanding that excellence in both areas will be necessary to improve treatment options for people with Parkinson’s and related disorders. The professorships were announced in September 2021.

The clinical research professorship has been awarded to Dr. Fay Horak, Ph.D., an internationally known neuroscientist studying human gait and balance disorders. Dr. Horak supervises the OHSU Balance Disorders Laboratory, which is intertwined with the OHSU Parkinson Center. She works on strategies for rehabilitating gait disorders in PD and related diseases, and has developed and mentored the next generation of scientists to carry on this work. Many of our physician-scientists rely on Dr. Horak’s expertise and equipment to conduct their research, and Dr. Horak also collaborates with physicians and scientists around the world. Dr. Horak has received numerous awards, including recognition in 2020 by the American Physical Therapy Association (APTA) as a Catherine Worthingham Fellow, APTA’s highest honor.

The basic science professorship goes to Dr. Vivek Unni, M.D., Ph.D. Dr. Unni is a physician-scientist studying the biology of alpha-synuclein, the material that makes up the “Lewy body” in Parkinson’s disease. Many scientists are trying to “target” the “bad” forms of alpha-synuclein as a novel therapy for PD, but it remains unclear what exactly the alpha-synuclein does in cells, both in the healthy and diseased state. Dr. Unni has pioneered an innovative approach to imaging misbehaving alpha-synuclein in the brains of living animals, and he has also developed a novel theory of alpha-synuclein’s physiological role in the cell. His

Continued on page 2
work is highly respected and likely to yield great insights and to impact our therapies in the future. In recognition of Dr. Unni's emerging leadership in this field, the American Parkinson's Disease Association conferred one of their highest research honors on Dr. Unni, the Dr. George C. Cotzias Memorial Fellowship, in 2016. Since 2020 Dr. Unni has served as the interim director of the Jungers Center for Neuroscience Research at OHSU. In many cases, an endowed professorship is named for the donor, but in this case the donor was determined to remain anonymous, and endorsed a plan to honor two of our emeritus faculty by naming the professorships for them. So, the first professorship is the Jay Nutt, M.D., Professor of Clinical Research of Movement Disorders, honoring the most recent director of the OHSU Parkinson Center. The second is named the John Hammerstad, M.D., Professor of Basic Research of Movement Disorders, honoring another co-founder of the Center. Dr. Hammerstad also has the distinction of hiring a young Jay Nutt to join the OHSU faculty. Drs. Nutt and Hammerstad were also two of my favorite teachers in the early 1990s when I began training in neurology, and I still have much to learn from them. This represents a landmark in the history of the OHSU Parkinson Center, and one that has a durable, long-term impact. It is regrettable that we were unable to honor more of the many deserving individuals, but we hope to do that in the future. For now, these professorships allow us to look to the past with appreciation and affection, and to the future with hope. Please join us in congratulating our honorees.
Science and Art featured in the 37th Annual Options & Opportunities Symposium

More than 200 people with PD and their family caregivers participated in two days of presentations, resources and panel discussions during our 37th annual symposium during October 14–15, 2021. Research was the focus of day one, with presentations on Intervention Study Opportunities for Walking, Balance, and Falls by Fay Horak, Ph.D., P.T., and Genetic and Environmental Risk Factors for PD, from Ian Martin, Ph.D. Dr. Jeff Kraakevik’s talk on Stages and Guideposts to Gauge Progression of PD explored how to mark progression in PD and measure the steps anticipated as patients move from pre-diagnosis to mild/moderate/severe disease.

A very special thank you to the incredibly talented artists and hobbyists that participated in our first-ever virtual Creativity and Parkinson’s Showcase. Our panel of artists spoke candidly of how their relationship to their art influences their journey with Parkinson’s. We were inspired to learn how they’ve adapted their art when presented with challenges from PD. Trisha Hassler spoke about her solution: “Paint bigger! Bigger canvases, bigger strokes. They don’t need to be as perfect.”

Eugenia Parker shared, “Five years after taking up painting, I was diagnosed with Parkinson’s. I have learned to adjust how I paint as the disease has progressed. When I am painting, I stop and see the beauty around me. It also gives me a sense of accomplishment, and that really feels good.”

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.

Education Pearls

Free program for Parkinson’s care partners

November was Caregiver’s Month and all of us here at the OHSU Parkinson Center know how amazing PD caregivers are. In case you haven’t heard, we are excited to share a new resource created just for you at the Parkinson’s Foundation website: Care Partner Program: Building a Care Partnership. This program consists of a variety of self-paced online courses intended for Parkinson’s care partners. It covers topics such as caregiver burnout, staying healthy as a care partner and many other important and under-discussed topics. The courses feature care partners and experts alike and capture excellent information for all care partners and loved ones with PD.

We’re sure you’ll appreciate this new resource and hope you will explore and access it when the time is right.

Thank you for all you do for your loved ones!
parkinson.org/carepartnerprogram

Artists featured: Painters Richard Armstrong, Elizabeth Murphy-Green, & Eugenia Parker. Dale Bennett’s photography is part of a series “Portraits of Parkinson’s Ancestors” by Barry Wolf

A boat needs an anchor to prevent it from floating aimlessly away, with no direction. The boat may rise and fall with changing tides, but the anchor keeps it steady and in one place.

Likewise, we have and need “anchors” in our lives to prevent us from losing control and moving aimlessly through the world. These anchors can be many things: family members, reliable friends, spiritual/religious faith, education and skills, other strengths, etc.

Everyone needs anchors, but perhaps those of us with a chronic illness such as PD, especially need to utilize our reliable anchors.

Personally, some of my anchors are loving relationships, caring friends, the limited but real ability to exercise and have some bodily control, continuing interests in current events, ideas, literature. A useful exercise is to draw a simple sketch of a boat on the water (artistic skill not needed) and two or more lines down from the boat to anchors beneath the water. Label each anchor. Consider how each one helps or could help you in rough waters.
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 you decide to participate, 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 PDRResearch@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?

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 (SPARK3)
Purpose: SPARK3 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)

Have you been diagnosed with Parkinson’s disease (PD) but have not started taking PD medications? Or do you have a known risk factor for developing PD?

Or are you a healthy person willing to participate in PD research?

Title: Parkinson’s Progression Markers Initiative
Purpose: PPMI is an observational study sponsored by The Michael J. Fox Foundation for Parkinson’s Research. PPMI aims to better understand and measure Parkinson’s disease to speed new treatments. It does not test a new therapy or intervention.

Participation open to:
- People who have been diagnosed with Parkinson’s disease within the last two years and are not currently taking PD medications
- People with and without PD who have a first-degree family member (parent, child, sibling) with PD
- People who have risk factors for the development of PD (known genetic mutation, loss of smell, history of physically acting out dreams during sleep and others)
- People without PD and no known risk factors to develop PD to act as a comparison group

Participation details: If you are eligible for PPMI screening, we will ask you to come for a visit to OHSU. We will review your medical history and we will ask you to complete several tests such as a smell test and a brain scan.

If the screening shows you are eligible for PPMI, we will ask you to come back to the research clinic for study visits 1-2 times a year for at least five years. During these visits, you will be asked to give biosamples, have physical and neurological examinations, and undergo brain imaging. Enrollment is voluntary and you may leave the study at any time. You will be paid for completing in-person study visits based on the following schedule:
- $100 for a screening visit
- $200 for a baseline visit
- $200 for each in-person visit that occurs in the research clinic thereafter

For more information, please contact: Katrina Wakenam at 503-494-1382 or by email at wakenam@ohsu.edu. OHSU IRB #21802, WCG IRB 20200597.

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 PDRResearch@ohsu.edu IRB #18193
The sensors collect information about your balance in this study, you would be asked to wear a set of mobility monitoring sensors for one week and to track your falls for 12 months. Participants will also be asked to complete several surveys and questionnaires during two separate virtual visits with study staff members. Participants are compensated $130 for completing the study. This study is entirely virtual/remote.

For more information, please contact: Graham Harker at 503-418-2601. 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

Participating in 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 6 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 3:00 pm 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

Purpose: 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 levodopa 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 have 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 harkergh@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 and 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 Coordinatior, 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 and 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 PD or MS) or ear disorders
• You do not have medical implants (such as 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
Your Newly Diagnosed Education Team:
Pat and Dan Baker, Shannon Anderson, PA-C

Upcoming OHSU events

Newly Diagnosed Parkinson’s Workshop
February 9, March 9, April 13
This workshop is designed for patients diagnosed within the past three years. The workshop is led by Shannon Anderson, a physician assistant with extensive knowledge on Parkinson’s disease. She is joined by Dan and Pat Baker, who have 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 (virtual)
Jan. 20, March 17, 1–3 p.m. PT
Critical issues encountered by people with PD and their loved ones during the middle stages of the disease will be presented throughout the year. In a two-hour program, topics will be presented by experts, with time for audience interaction.
- Jan. 20: The Role of Diet & Nutrition in Parkinson’s Disease
- March 17: How to Have Difficult Conversations
Registration will open a month prior; visit https://tinyurl.com/OHSUpdedu or email pcoeducation@ohsu.edu with questions.

CarePartner Connections (virtual)
Feb. 17, 1–3 p.m. PT
This annual OHSU Parkinson Center event celebrates family care partners with special acknowledgment of their sacrifices for their loved ones. We will come together virtually to gather new information and enjoy one another’s support. Don’t miss our care partner panel to learn firsthand about our panelists’ thoughts and experiences of caring for their loved ones. Our speakers will address the tough questions that spark conversations with an open and honest dialog.
Registration will open in January 2022. https://tinyurl.com/OHSUpdedu

Virtual events will continue in 2022
We will continue to hold events virtually during the first few months of 2022, including our Newly Diagnosed Education Session and the Essential Tools Mid-Stage Series. We want to ensure everyone stays as safe as possible until the pandemic is resolved.
We look forward to seeing you all in person soon.

In the Parkinson’s community

Parkinson’s Resources of Oregon (PRO)
Parkinson’s Resources continues to offer a variety of programs and services for PwP and caregivers alike. Many activities can now be accessed online or by telephone. Visit the website at www.parkinsonsresources.org or call the PRO helpline at 800-426-6806 for additional information.

Upcoming programs:
- Planning for the Unexpected, Mon. Jan. 24
- Personal Care Series, Tues., Feb. 8 & 15 This program is intended for family caregivers only.
- New Support Group at PRO for Adult Child Caregivers Caring: The third Thursday of every month, 5–6 p.m.

Brian Grant Foundation
Helping people with PD live active, fulfilling lives through wellness and community.

- Expert Q&A Series
  Every second Wednesday of the month — January through December, noon – 1 p.m. PT.
  Features different Parkinson’s topics and speakers presenting online.
- Shake It Till We Make It Gala and Auction
  Fri., May 20, 2022, 6 p.m.
  Castaway Event Center, Portland, Oregon, with a virtual presentation.
  For more information about the gala and upcoming 2022 events, visit briangrant.org.

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