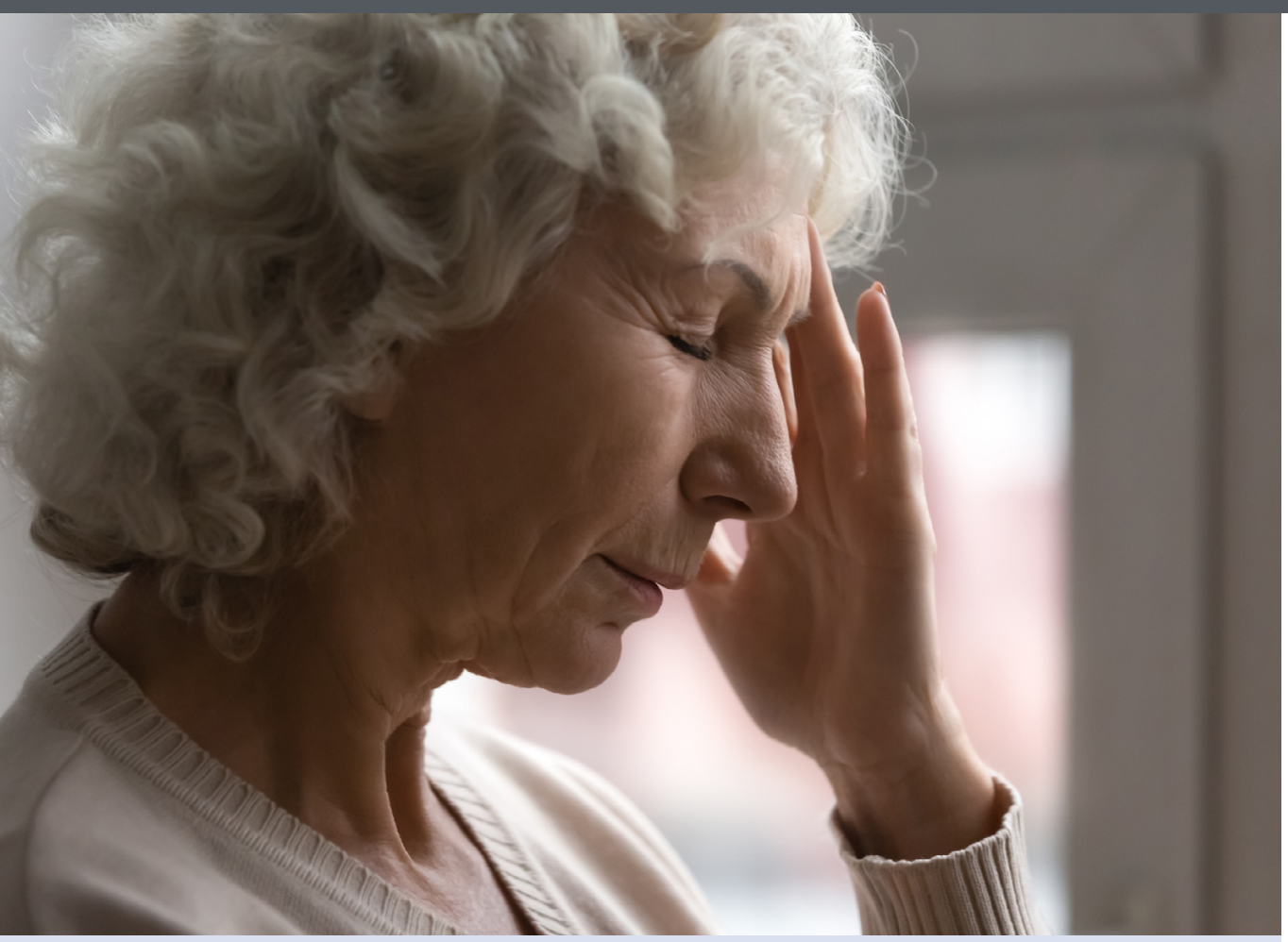
SUMMER 2021

Parkinson Update



Head Rush? Orthostatic Hypotension in Parkinson's Disease and Related Disorders

Lee Neilson, M.D. — OHSU Parkinson Center Fellow

The autonomic nervous system is considered the "automatic" nervous system. That's because it manages functions that we don't need to think about. This includes breathing, making our heart beat, or absorbing nutrients from the gut.

Another key function is making sure that blood continues to supply oxygen and nutrients to our essential organs no matter what position we find ourselves in. Gravity is a powerful force that pulls things downward; if we stand up, blood is going to naturally get pulled into our legs and thus be diverted away from our brain. Our autonomic nervous system detects these position changes and ensures our heart, muscles and blood vessels react to keep a normal blood supply to our brain. If it fails to do so, we feel lightheaded to prompt us to sit down. In the extreme, it may cause us to pass out. It's a clever, but unpleasant, protective mechanism. We call this autonomic failure **orthostatic hypotension** (low blood pressure [hypo = low, tension = pressure] that occurs on standing [ortho = straight/upright, static = to make stand]).

Everyone has probably experienced this at one point or another at least once, probably on a hot day when we didn't drink enough water. We see it as more persistent in the Parkinson population. At some point, 50% of people with PD will experience this. It is likely more common, and more severe, in some variants of PD such as multiple system atrophy (MSA).

When we encounter this problem, we take many approaches to addressing it. The first is looking for non-PD-related causes of orthostatic hypotension. These include anemia, or a low blood count. Without enough red blood cells you can't store as much oxygen and deliver it to important organs like the brain. This can be checked fairly easily and it may be because of low iron, low vitamin B12 or other causes. Other medical conditions such as heart failure, adrenal gland problems and thyroid problems can contribute. There are also several medications that can contribute, as can alcohol, and you should review these with your neurologist or primary care doctor. Another important consideration is

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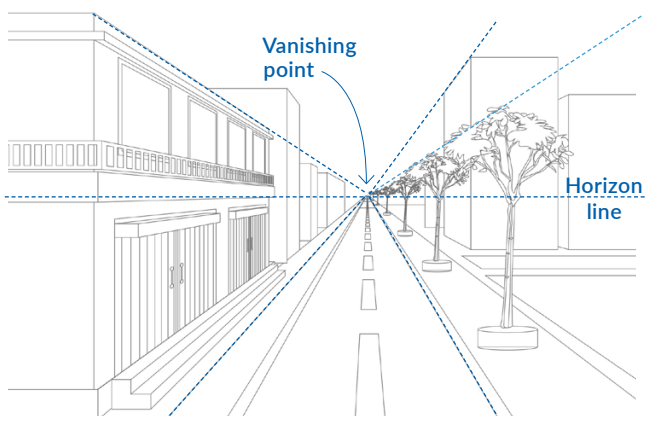
Perspectives

A.C. Woolnough

It was magic. I failed fingerpainting in kindergarten. In first grade, my yellow sun (stuck up in the corner of the page) illuminated a distorted box purported to be our house and stick figures representing family and pets. The front door and windows were misshapen rectangles — maybe even trapezoids. The cat ended up with a forked tail. As sibling rivalry reared its ugly head, I deliberately drew my brother with only one arm and one leg. In second grade, my drawings of flowers were simply blobs of color with no relationship to reality. This inability to draw, to represent reality on paper or canvas, was a source of frustration and embarrassment to this seven-year-old. By fourth grade, I was an art school dropout. That was not magic, it was disappointment.

Magic arrived in the form of the vanishing point—where parallel lines recede into the distance. Suddenly, I could draw buildings and street scenes that looked more realistic. The world tapered off into the distance. Closer objects were larger — further away, smaller. Using a ruler, I could draw straight lines and elements in the drawing became recognizable. It was still not art, but I was satisfied. It's all about perspective.



An example of parallel perspective, where all parallel lines running from you meet at one vanishing point.

Perspective is a wonderful word. It has a least three primary meanings, but all relate to looking or seeing. In the previous paragraph, perspective can mean the direction or angle we see things or our point of view. Further, our point of view can also mean two things. Literally, it is where we stand in relation to our environment. Figuratively, it alludes to how we choose to see, to interpret and to make judgments about the world. Roget (of thesaurus fame) would suggest outlook, vantage point and viewpoint as synonyms for perspective.

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A PUBLICATION OF
THE OHSU PARKINSON CENTER

Parkinson's Foundation
CENTER OF EXCELLENCE

DIRECTOR'S CORNER

Joe Quinn, M.D. — Medical Director

Since I spent my space in the last newsletter reflecting on the year of the pandemic, I intended to focus here on the year ahead. But first I need to comment on a major change in our Center. **Diana Potts**, our program manager, is moving on after 20 years with our program. For many of our patients and families, Diana has been the face of the Center, and her dedication to our patients, caregivers and staff is evident to anyone who has had even casual contact with our programs. Diana has been relentless in her many efforts on behalf of the Center, and her enthusiasm, creativity and optimism are greatly appreciated by patients and staff. We will miss her, and we wish her well in her next venture.

As for looking forward: What's next for Parkinson's care at OHSU? How about precision medicine, the idea of tailoring medical care to each person's individual characteristics? An imagined future with this approach might involve collecting a DNA sample at the time of diagnosis and using genetic information to customize each patient's treatment to suit their genetic makeup. Efforts to date have focused on genes that contribute to the risk of PD in a small but significant proportion of patients, including the GBA gene (about 5% of PD patients) and the LRRK2 gene (about 1% of PD patients). The OHSU Parkinson Center recently participated in the largest trial of a GBA-specific treatment strategy, which reported results in February 2021. In this international phase 2 study, 270 patients with PD who carried the PD-associated GBA gene variant were randomized to study drug (venglustat) vs. placebo. This was important as the largest study to date of genetically distinct PD, and paves the way for future studies in this important population. Although the treatment did not have the desired effect of preventing progression of PD, the result is critical in establishing the feasibility of this precision approach and in evaluating one particular treatment strategy (substrate inhibition in this case). This is an important first step.

The OHSU Parkinson Center is also actively engaged in another early-phase trial focused on the other gene mentioned above, LRRK2. This trial employs a remarkable technology called antisense oligomer therapy, which is an emerging technology in which small snippets of DNA are injected into patients to very precisely turn genes on or off. The potential of this approach is illustrated by antisense oligomer therapies that are already FDA-approved for other diseases, including a pediatric disease that was once uniformly fatal and is now effectively managed with this strategy. The LRRK2-PD study is still in the early phases, but it is nevertheless remarkable that this type of precision approach is coming to PD.

One of the hurdles to the conduct of these studies, however, is the fact that testing for these genes is not part of the standard of care for PD patients at present. After all, there is no point in testing for these genes as part of routine care unless there is a therapy specific to the genes — but the catch is that there may never be a therapy unless we start genetic testing so we can identify appropriate candidates for clinical trials.

The good news is that the Parkinson's Foundation has stepped in with a program to resolve this dilemma. The "PD GENEration" study will begin offering genetic testing to PD patients at no cost in 2021. We are currently working on regulatory issues, but we anticipate that OHSU patients will be offered the option of genetic testing in the second half of 2021. The results will be shared with the clinician and the patient. This will represent a very concrete first step toward making precision medicine a reality for PD and will enhance OHSU's ability to contribute to these efforts.

As exciting as these possibilities are, we also recognize that precision medicine based on genetics should not allow us to lose sight of a holistic approach to patient care, which encompasses patient-specific recommendations for nutrition, exercise, stress management and general health. There are several important efforts underway in the Center in these areas as well, but that will be a topic for another column…

Welcome our newest team member:

In her free time, Kellie enjoys hiking and camping on Mount St. Helens, coaching youth soccer, and following women's athletics

Kellie Keith — Program Manager

We are pleased to announce that Kellie Keith is the new Program Manager for our center. Kellie joined the OHSU Parkinson Center in 2012 as a clinical trial coordinator, after studying psychology and sociology and then working in municipal finance and teaching.

She quickly became expert in the details of clinical research and assumed leadership of the clinical trials program, supervising a team of study coordinators while managing the administrative and regulatory details of clinical trials. Kellie's initiative and creativity have been very effective in revising and standardizing many aspects of the Parkinson Center clinical trials program. This combination of administrative and supervisory experience, combined with her knowledge of our center, made her an obvious choice for the position of Program Manager. We are delighted that she has accepted this position. Please join us in welcoming her in this new leadership role.

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ORTHOSTATIC HYPOTENSION *(continued)*

exercise. We know exercise helps with sleep, pain, mood and balance, and even slows the progression of the disease. It also strengthens your muscles and heart and helps with the return of blood flow. You might be too dizzy to stand and exercise but there are adaptive exercises you can do to keep yourself safe, whether that is using a recumbent bicycle or swimming in a pool.

In addition to the above measures, the easiest method of addressing orthostatic hypotension is increasing fluid intake — but it has to be the right kinds of fluids. This means water, milk and sports drinks (in moderation) like Gatorade/Powerade. Beverages like coffee and alcohol, though they are "wet," are diuretics — they increase your need to urinate. Alcohol, in addition to being a diuretic, also causes your blood vessels to dilate, which means blood pools and cannot be driven upward to the brain as easily. You don't need to cut it out entirely, but remember to drink extra water to compensate. The other time you want to compensate is on those hot, humid days when you are sweating. The goal for hydration should be around eight glasses, or 64 ounces, of water. If sipping on water all day sounds unpleasant, I want to highlight one very interesting study. In it, researchers asked people to drink two glasses (or a little under a half-liter) of water in just 20 minutes. Then they recorded the blood pressure every minute after that. What the researchers noticed is that blood pressure increased dramatically for the whole next hour. Drinking using this bolus method is almost as effective as getting fluids through an IV line.

Beyond drinking extra fluid, there are other lifestyle changes that we typically recommend to combat orthostatic hypotension. One option is wearing thigh-high compression stockings and/or abdominal binders; these items work against the problem by squeezing your legs and/or abdomen and thereby keeping the blood from pooling south of your head and brain. Another option is pumping your legs up and down when sitting, before your stand up; this gets the blood in your legs moving, so that when you stand up, it is not pooling as much in your lower body. For all people with orthostatic hypotension, we recommend making positional changes slowly — for example, when getting out of bed, sit up at the bedside for a few minutes before standing up. This allows your autonomic nervous system some time to adjust to the changes in position and also protects you from getting lightheaded too quickly, causing you to fall.

Sometimes we make these lifestyle changes and orthostatic hypotension remains a persistent problem. This is when we consider pharmaceutical options. We will typically draw from the following medicines:

Midodrine — Midodrine causes your blood vessels to contract and increase your blood pressure. This is often taken three times per day.

Droxidopa — Droxidopa works to increase adrenaline (the neurotransmitter we use in the sympathetic fight or flight response) to increase our blood pressure. It is also taken three times per day.

Fludrocortisone — This is a hormone that signals your adrenal gland to hold on to salt and water and keep the fluid in your vessels. It is a way of hydrating you better. It only needs to be taken once per day.

Pyridostigmine — This can be used up to four times per day to try to boost blood pressure. It comes with a lot more side effects than some of the others, including diarrhea, abdominal cramping, urinary incontinence and drooling.

Orthostatic hypotension when standing or when sitting up is a particularly prominent symptom in multiple system atrophy (MSA). In addition to the lifestyle and medication approaches discussed above, sometimes it is necessary to reduce a person with MSA's dosage of levodopa in order to better control their lightheadedness. Dr. Larry Golbe provides a description of orthostatic hypotension in MSA in the following video: https://www.youtube.com/watch?v=nXRahOo7za8&t=56s

Neurologists are keenly aware that orthostatic hypotension can be a problem and are continually working to find better therapies. There is currently a new drug under investigation called TD-9855. It has been previously studied, and approved, in people with fibromyalgia and attention deficit hyperactivity disorder (ADHD). One of the side effects was higher blood pressure, which should come as no surprise, because it also works by boosting adrenaline levels, similar to droxidopa. Many centers around the world, including OHSU, are currently recruiting people with PD, MSA and pure autonomic failure to investigate whether this drug, taken once a day, can improve symptoms of orthostatic hypotension. You can find more information about this study and other studies for orthostatic hypotension by going to the website clinicaltrials.gov and then searching for "orthostatic hypotension" in the condition or disease block and "TD9855" in the other terms block.

PERSPECTIVE *(continued)*

So what does this have to do with my journey with Parkinson's disease? First a quick refresher: PD is a progressive neurodegenerative disease (thousands of brain cells are already dead or dying!) with unknown causes and no cure. The results are motor symptoms (like tremor and freezing of gait) and non-motor symptoms (like soft voice, depression, loss of smell and sleep disorders).

One of my favorite sayings (by Alphonse Karr): "We can complain because rose bushes have thorns or rejoice because thorn bushes have roses." It is all a matter of your perspective. Vivian Green expressed the concept using different words: "Life isn't about waiting for the storm to pass, it's about learning to dance in the rain."

Parkinson's disease sucks. There is no cure, and it is progressive. It is going to get worse. Yet, a common metaphor used to describe PD is "gift." Gift? Having a condition that chips away at your quality of life and ability to move is a gift? You're crazy.

Indeed, I may be crazy, but from my perspective (and I'm the one with Parkinson's) it is a gift. That does not mean I think people should line up and ask for PD. Instead, I choose to acknowledge Parkinson's has enriched my life in many ways. Appreciation and gratitude have taken on a richer, more emphatic meaning with this perspective.

The easiest example of this is travel. As a result of working with the Parkinson's community, my wife and I have traveled to New York and Washington (both new to Pamela), Colorado Springs, and Miami. Of course, we can't forget Kyoto, Japan in 2019 for the World Parkinson Congress!

I've been able to visit the National Institutes of Health, Columbia University, Oregon Health and Sciences University (OHSU) to participate in research. I have visited the National Primate lab at Emory University. I have reviewed research grant proposals for the Department of Defense. I've hiked over 125 miles of the Pacific Crest Trail. None of these opportunities would have come my way without Parkinson's. Yes, PD is a gift.

As a former teacher and principal, Parkinson's has given me the chance to continue to try to make a difference. I participate on Councils, advocate for funding, work with support groups, write my column, promote the World Parkinson Congress (Barcelona, Spain in 2022) and present at conferences. Parkinson's has kept me busy in my retirement years — much to Pamela's relief! PD is a gift for her as well.

Most important has been the opportunity to make new friends and join a community of incredible people: ParkyWorld. Some of these folks are fierce Parkinson's warriors and advocates, some are quietly and almost invisibly working behind the scenes as researchers, others are providing support and encouragement as we fight to maintain and improve our quality of life. What we all share is a determination to make a difference and to help beat Parkinson's. Whether we participate in clinical trials, support our foundations with money, lobby Congress to provide funds for research or share tips for living better with PD, we know we can count on each other. That, my friends, is truly priceless. People with Parkinson's may not have the choice of having it miraculously disappear, but we can choose our point of view. We can choose our perspective.

Volunteers needed
Are you interested in helping the OHSU Parkinson Center advance their mission of caring for people with PD? Contact Jenn Carpenter at **pcoeducation@ohsu.edu** to learn more.

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)

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**

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**

Balance & Gait Studies

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 involved 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 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

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

Have you been diagnosed with Parkinson's disease (PD), multiple system atrophy (MSA), or pure autonomic failure (PAF) experience dizziness, light-headedness, feeling faint, or feeling like you might black out upon standing?

Title: Clinical Effect of Ampreloxetine (TD-9855) for Treating snOH in Subjects with Primary Autonomic Failure

Purpose: This study will help determine if the study drug is effective in people diagnosed with Multiple System Atrophy (MSA), Parkinson's disease (PD), or Pure Autonomic Failure (PAF) who also experience symptoms of orthostatic hypotension, or low blood pressure upon standing. In people with conditions such as PD, MSA and PAF the autonomic nervous system may not work as well at regulating your blood pressure.

Participation requirements:

- Age 30 years or older
- You experience symptoms of orthostatic hypotension
- You have been diagnosed with MSA, PD, or PAF
- You do not have Diabetes mellitus or other condition known to alter autonomic functions
- You are not taking medication for hypertension
- You are not participating in any other research study in which you are receiving study drug

Participation Details: The study will involve up to seven visits to the OHSU neurology clinic over about 3 months. The visits may include testing your blood pressure in different positions (laying down, siting, and standing), questionnaires, a blood draw, home blood pressure monitoring, and completing diaries in between visits. If you enroll in the study you will have a 50% chance of receiving a placebo (inactive medication). You will be compensated $50 per visit or $300 if entire study is completed.

For more information please contact: Monica Arena at (503) 494-7235 or PDResearch@ohsu.edu IRB #19533

Motor Fluctuations with Carbidopa/Levodopa

Have you been diagnosed with Parkinson's disease and currently take carbidopa/levodopa?

Purpose: The purpose of the study is to learn if a person's response to levodopa is affected by problems with the digestive system. We are hoping to find out if a delayed or lack of response to some or all daily doses of levodopa can be due to changes in how long it takes the medication to move through the digestive system.

Participation requirements:

- Age 50-89
- You have been diagnosed with Parkinson's disease and are currently take carbidopa/levodopa (Sinemet)
- You are able to swallow a large capsule (similar to the size of a fish oil capsule).
- You have not had gut surgery or bowel disease
- You do not an implanted medical device (such as cardiac device, gastric stimulator, insulin pump, or deep brain stimulator)
- You do not have Diabetes or hypothyroidism

Participation details: Study participation lasts about two weeks and involves four visits to OHSU. During the study, participants will be asked to swallow one SmartPill, under the supervision of the study investigator. The SmartPill is an FDA-approved single-use capsule that travels through the GI tract and wirelessly transmits data about your GI tract to a receiver worn on a belt clip or pouch. You need to keep the receiver within three feet of your body for five days following ingestion of the SmartPill. You will be asked to return the receiver after five to seven days. The SmartPill will be passed naturally by your body, and you will not be asked to return the pill. You will receive study-related evaluations at no cost.

For more information please contact: Monica Arena at (503) 494-7235 or PDResearch@ohsu.edu IRB #20012

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.

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

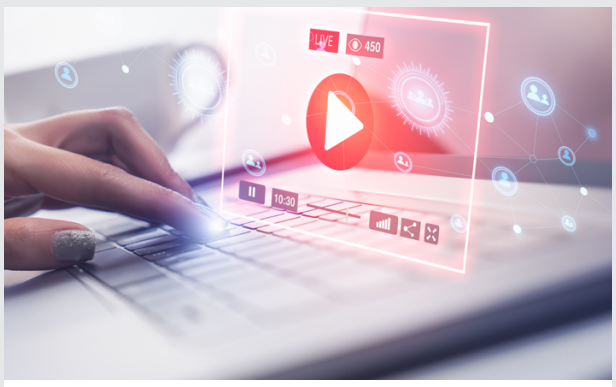
Purpose: To investigate whether transcranial magnetic stimulation (TMS) effective for treating issues with balance and speech in progressive supranuclear palsy (PSP).

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



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.**

Upcoming OHSU events

Newly Diagnosed Parkinson's Workshop

July 14, September 8, October 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.

Your Newly Diagnosed Education Team: Pat and Dan Baker, Shannon Anderson, P.A.-C.

Essential Tools for Mid-Stage PD Series 2021

Creating Resiliency with Parkinson's

August 19, 1–3 p.m. PT

Join the August Essential Tools Workshop to learn more about Resiliency & PD. Dr. Amie Hiller will talk about using resiliency tools to proactively manage health and wellbeing. She will focus on how stress, exercise, and loneliness can impact the health of persons with Parkinson's Disease. She will also present ways to incorporate the following tools – mindfulness, exercise, and socialization into your life.

Registration will open a month prior at **https://tinyurl.com/OHSUpdedu**

Options & Opportunities Virtual Symposium

October 14, 15, 1–3 p.m. PT

Our 37th annual symposium will be virtual with a two-hour format in October.

Registration will open in early September **https://tinyurl.com/OHSUpdedu.**

2021 event update

We will continue to offer events virtually for the remainder of the year. We look forward to seeing everyone in person in 2022!

In the Parkinson's community

Parkinson's Resources

Parkinson's Resources of Oregon (PRO)

Parkinson's Resources continues to offer a variety of programs and services for PwP and caregivers alike. Most activity 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

Sole Support Walk for Parkinson's *Every Step is Personal*

The Sole Support 1k and 5k walk series is a powerful opportunity to raise awareness and support for those living with Parkinson's and PD+, ensuring no one has to face this disease alone.

Take the first step, register today online at **www.solesupport.org** or call Parkinson's Resources at 800.426.6806!

September 25, 2021
— Portland Walk at Zidell Yards

October 2, 2021
— Vancouver Walk at Esther Short Park

Brian Grant Foundation

BRIAN GRANT FOUNDATION

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

- Expert Q&A – Every second Tuesday, 12–1 p.m.
- Chef Kenny James on Instagram Live – July 14, September 15
- And special events each month

For more information about upcoming events, visit **www.briangrant.org**.

PADRECC Portland/Seattle
Parkinson's Disease Research, Education and Clinical Center

PADRECC

The Veterans Administration Parkinson's Disease Research, Education and Clinical Center (PADRECC). Serving our veterans with PD through research, education and care. 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

OHSU Parkinson Center

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