PASS TO PASS MISSION STATEMENT
• Raise awareness about PD and its symptoms
• Demonstrate the benefits of exercise in managing the symptoms of PD
• Provide opportunities for people with PD to participate in backcountry activities

2020 TRIP DATES
July 31–August 15

PASS TO PASS: Trail of Discovery and Support
Joe Quinn, M.D. — OHSU Parkinson Center Medical Director

I’m an enthusiastic day-hiker but like to end a hiking day with a shower and a nice meal, so overnight backpacking has never particularly appealed to me. When my 25-year-old son started trying to talk me into a backpacking trip, I had the feeling that this was going to be payback for everything I made him do as a kid. Then he bought me a pack for Christmas. And then AC Woolnough, one of our patient advisors, asked me to join a backpacking trip with a group of people with Parkinson’s (Parkies) called “Pass to Pass.” And before I knew it, I was backpacking.

Pass to Pass is an annual backpacking trip on the Pacific Crest Trail and was founded by Bill Meyer, a Parkie from Spokane. It’s designed to raise awareness about Parkinson’s disease, and in particular to raise awareness about the importance of exercise. A group of Parkies, along with a matched group of “support hikers,” cover a stretch of the Pacific Crest Trail selected by Bill, assisted by the preferred pack animal for carrying gear on the PCT: llamas.

So in August 2019, my son Charlie and I joined three other support hikers, five Parkies and four llamas at Chinook Pass in Washington and started heading south. We covered about 6 miles per day and 30 miles total and exited at White Pass, turning over the llamas to the next group of Parkies, support hikers and llamas. There were three consecutive hikes of about 30 miles each. The scenery was spectacular and the company was even better. I got tutorials in backpacking and in llama wrangling, but most of my education was about resilience. “Spokane Bill,” our leader, told me how broken-hearted he had been to have to stop backpacking due to Parkinson’s disease, and how excited he was to return to his lifelong passion after successful DBS surgery. The only problem was the wires under his skin that made it challenging to wear a full pack, and led to the decision for pack animals to help with gear and ultimately to our llama companions. One of the other Parkies described being unable to walk around the block before she was appropriately diagnosed and treated, and how satisfying it was to be able to participate in such a strenuous and challenging adventure. Another person struggled for each mile, but never gave up, never complained and amazed the rest of us with his grit and his attitude. It was a privilege to participate and to witness these great spirits.

And it was also great fun. The hike was amazing, and swimming in the mountain lakes at the end of a day of hiking was almost better than a hot shower. We also had great fun with the other hikers we saw, who always asked about the animals. We had them believing that they were “mountain camels” (“They lose their humps when you take them out of the desert”). And the campsite conversations and laughter at the end of each day were awesome. But please don’t believe AC if he tells you I cheat at cards — that is a complete fabrication.

Check out www.passtopass.org and consider participating, donating or serving as a “trail angel.” You won’t regret it.
The Importance of Socialization in Parkinson’s Disease

Parkinson’s disease currently affects approximately one million individuals in the United States alone. Despite being part of such a large community of people, a single person living with Parkinson’s disease can easily feel socially isolated. This sense of social isolation can occur for a variety of reasons and can occur at any stage of the disease. A person living with Parkinson’s disease may begin to feel functionally limited by motor symptoms (poor balance for example) or may feel tied down by a complicated medication schedule. Some individuals feel embarrassed by symptoms that are visible to others, such as tremor, or may find it difficult to communicate effectively due to change in speech or facial expression. Mood changes, including anxiety, depression and apathy, are also very common in Parkinson’s disease and could lead one to withdraw from their usual activities. Regardless of the reason for social isolation, we know that overall quality of life can suffer for the individual experiencing this. This is true not only for the person living with Parkinson’s disease but also for care partners.

New book by OHSU specialists tells the story of balance difficulties in Parkinson’s disease

Each person with Parkinson’s disease has a unique combination of balance challenges. To improve balance in people with Parkinson’s disease, clinicians need to assess the specific balance difficulties in every individual patient. All too often balance is an overlooked component of gait disturbances in PD and transitions. For instance, changing direction while walking (turning) is almost never measured in clinical settings. These balance problems can trigger gait-related disability and falls, a leading cause of physical and psychosocial disability. People with Parkinson’s can improve their balance with exercise and rehabilitation when the intervention is targeted to the specific type of balance issues unique to each person.

Martina Mancini, Ph.D., shares with us what Balance Dysfunction in Parkinson’s Disease: Basic Mechanisms to Clinical Management is all about.

In writing this book I had the pleasure and honor to work with two recognized international experts on balance and Parkinson’s disease here at OHSU — Fay Horak, Ph.D., and John “Jay” Nutt, M.D. This book integrates over 100 years of research not only from our own work but from scientific literature to help other health care professionals better understand how balance is affected in Parkinson’s disease.

In Balance Dysfunction in Parkinson’s Disease, we first present a framework for understanding balance problems in PD to help clinicians evaluate the aspect of balance most affected in their patients. Next, we review the main aspects of balance and how they are affected by PD: balance during quiet stance, reactive adjustments to external perturbations, anticipatory postural adjustments in preparation for voluntary movements, dynamic balance during walking. In addition, effects of levodopa, deep brain stimulation and rehabilitation intervention for each balance aspect are also reviewed.

We recommend this book for clinicians, neurologists (especially movement disorders specialists), physical therapists, students, translational neuroscientists, clinical researchers and anyone interested in how and why balance is affected by PD and what the effects are of current therapies on balance.

Together, we dedicate this book to all the patients who participated in research studies and have taught us so much about Parkinson’s disease.

TEACHING OTHER HEALTH CARE PROVIDERS:

- www.parkinson.org
- www.briangrant.org
- www.parkinsonsresources.org
- www.ohsubrain.com/pco
- www.parkinson.org
Welcome our newest team member:

Jocelyn Jiao, M.D. — Fellow

Jocelyn Jiao grew up in Cupertino, California. She attended college at Stanford University and graduated with a B.A. in Human Biology. She thereafter moved to New York City for her graduate studies; there, she obtained a M.S. in Narrative Medicine from Columbia University and completed her medical degree at Icahn School of Medicine at Mount Sinai, graduating with a Distinction in Research. Since completing her Neurology residency at LAC+USC/Keck School of Medicine in Los Angeles, Dr. Jiao has this summer relocated to Oregon to start movement disorders fellowship at OHSU and the Portland VA Medical Center. She looks forward to cultivating the interdisciplinary space between palliative care and movement disorders, as well as exploring the lush outdoors that Oregon has to offer.

Solutions for making your home safe and easier to navigate

AARP has guides, worksheets and pamphlets available to download that will help you incorporate home design principles that are adaptable for everyone. The HomeFit Guide includes information about making your home suitable for aging or for disability, including modifications for specific needs such as moving, seeing and reaching. Visit www.aarp.org/livable and scroll down to the publications/Livable Library section. Many items are available in English and Spanish.

Educational Pearls

OHSU Parkinson Center education report

The Parkinson’s Foundation Care Partner Summit | Cumbre Para Cuidadores is now online. To watch the 2020 Summit sessions as individual videos visit www.parkinson.org/Summit.

Habla español?

Parkinson’s disease resources are now available online in Spanish at www.parkinson.org/espanol.

A shout out of gratitude to our educational sponsors

We would like to thank the following sponsors for their support in bringing you educational programs throughout this year.

EDUCATION GRANT
Parkinson’s Foundation

GOLD
Boston Scientific & Lundbeck

SILVER
Abbott, Abbvie, Acorda, Amneal, US World Meds / Supernus

Check out the topics for 2020 presentations at our video library

Missed an event? Our video library is growing with presentations recorded of our recent events and arranged by topic. Visit and watch great presentations featured during the last few years for our annual Options & Opportunities, Essential Tools Mid-Stage Series, and Caregiver Connections. Available at: https://tinyurl.com/pco-videos. You can find past issues of the newsletter here as well.
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.

Parkinson's Registry
The Parkinson Foundation has launched a Patient Registry at all Centers of Excellence, which includes OHSU.

Title: Parkinson’s Outcomes Project
Purpose: The purpose of the registry is to better understand Parkinson’s disease (PD) and find out what treatments are associated with the best outcomes for patients.
Participation requirements: You receive care for Parkinson’s disease at the OHSU Parkinson’s Center Neurology Clinic and are able to give written informed consent.
Participation details: Once per year at your follow-up visit in our neurology clinic, you will meet with a staff member to for a 10-15 minute consultation and a questionnaire.
For more information please contact: Melissa Gittings at 503-494-7245 or PDResearch@ohsu.edu, IRB #5508

Ununtreated Parkinson's
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

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: Melissa Gittings 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 VAPORCHS 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 #2322

Balance & Gait Studies
Have you been diagnosed with Parkinson’s disease and have low back pain and sudden freezing while walking?
Title: Spinal Cord Stimulation to Improve Balance, Gait and Freezing in Parkinson’s Disease
Purpose: This study aims to learn more about the effect of spinal cord stimulation (SCS) on balance, walking, and freezing of gait in people with Parkinson’s disease (PD).
Participation requirements: Volunteers age 55–85 with Parkinson’s disease with low back pain and freezing of gait who have not benefited from other forms of treatment (conservative or medical therapy, back surgery), and have no other neurological or musculoskeletal issues.
Participation details: If you decide to take part in this study, you will have a spinal cord stimulator (SCS) surgically inserted into your back and receive three different types of stimulation for 2 weeks at a time. Your participation in the study over 1 year will consist of 4 clinical visits to the Neurosurgery Clinic to perform SCS programming, 6 study visits to the Balance Disorders Laboratory (OFF anti-Parkinson medication), and wearing sensors at home for 7 days repeated 7 times over the year. Visits will last up to 4 hours. In addition, you will track any falls in a diary. You will be compensated $600 for time and transportation.
For more information, please contact: Makena Strand at 503-418-2601, IRB#: 20442

Blood Pressure
Do you take levodopa for Parkinson’s disease and experience blood pressure changes when you 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

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

Balance & Gait Studies
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- 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
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 have an implanted medical device (such as cardiac device, gastric stimulator, insulin pump, or deep brain stimulator) that could be damaged by the SmartPill

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 PDRearch@ohsu.edu, IRB # 19553

Stress

Have you been diagnosed with Parkinson’s disease, Huntington’s disease, or are a healthy volunteer willing to participate in research on the stress hormone, cortisol?

Title: Measuring Cortisol Levels in Persons with Parkinson’s (PD) [CORT-PD]

Purpose: Cortisol is a hormone that is normally released in response to events and circumstances such as waking up in the morning, exercising, and stress.

Participation requirements:
- You have been diagnosed with Parkinson’s disease, Huntington’s disease, or are willing to participate as a healthy volunteer.
- You are willing to give saliva samples.

Participation Details: This study will last about 1 week. There are two paths for participation. Option 1 has three (3) days of saliva collection at home and one visit to the Portland VA (VA Portland Health Care System). Option 2 has two visits to the Portland VA. Visit one will last approximately 30 minutes and include questionnaires of mood and quality of life. For PD and HD participants, a disease specific exam will be performed. You will collect your saliva, complete some diaries, and wear some sensors for three days at home. You will return to the Portland VA for a visit that lasts about five minutes to return the sensors, diaries, and saliva. The visit will last approximately 30 minutes and include questionnaires of mood and quality of life. You will be compensated $25.00 for participation in this study. We will reimburse travel expenses up to $50.00 round trip.

For more information please contact: Brenna Lobb at 503-220-8262 extension 51871 or lobb@ohsu.edu, IRB #15183

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 of 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 prewittta@ohsu.edu or 503-418-2600. IRB #66152

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

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 Makena Strand strandm@ohsu.edu/503-418-2601. This study is virtual/remote. IRB# 20105, PI: Amie Hiller
Upcoming OHSU events

Newly Diagnosed PD Education Session — Virtual

The second Thursday of each month the OHSU Parkinson Center offers a 90-minute virtual session for people recently diagnosed with PD and their spouses or family members. Participants may ask any and all questions of a PD specialist and longtime patient and care partner.

$10/couple. For dates and to register go to http://tinyurl.com/NewParkinson or email pcoeducation@ohsu.edu with questions.

Options & Opportunities Virtual Symposium — Sep. 2020

Our annual symposium will be virtual with a two-hour format in September. For more information, please check our education website in August at https://tinyurl.com/OHSUpdedu.

Essential Tools for Mid-Stage PD Series 2020

WEBINAR — Oct. 29, 2020 at 1:00 PM

Key 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 90-minute program, topics will be presented by experts with time for audience interaction.

Registration will open a month prior at https://tinyurl.com/etools2020.

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.parkinsonresources.org or call the PRO helpline at 800-426-6806.

Sole Support for Parkinson’s

Sole Support for Parkinson’s awareness and fundraising walks for Parkinson’s Resources will be held in September and October. This year the walks will feature drive through packet pick up and curated walk options in five host communities. Gather your friends and family to help create an event that is safe and physically distant, yet socially connected! www.solesupport.org

Brian Grant Foundation

Helping people with PD live active, fulfilling lives through wellness and community. For more information about upcoming events, visit www.briangrant.org.

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.

Your Newly Diagnosed Education Team:
Pat and Dan Baker, Shannon Anderson, PA-C