

SUMMER 2019

Parkinson Update



Barbara Lee, OHSU Parkinson patient, on a very windy, “spectacular” January day at Baker Beach on the Oregon coast, camping with her husband, embodies here the best approach to Parkinson’s — a positive attitude: *“Even with Parkinson’s, life is so rich!”*

Advancing care for women with Parkinson’s disease

Recognizing longstanding gender disparities in Parkinson’s research and care, the Parkinson’s Foundation Women and Parkinson’s Initiative has created the first patient-centered action agenda to maximize quality of life for women with Parkinson’s disease.

Over the past two years, the Parkinson’s Foundation hosted 10 regional forums (including one hosted by the OHSU Parkinson Center in April 2018) and one national forum where women with Parkinson’s and health care professionals gathered to recommend priorities in research and care. Through this collaboration, the Parkinson’s Foundation has developed comprehensive, patient-centered priorities that provide an

“Gender accountability in medical research and care — that women experience Parkinson’s disease differently from men — is patient-centered outcomes research at its best,” said Ann Boylan, M.A., Parkinson’s advocate and woman living with PD. “We need updated and comprehensive information looking at how women are impacted by PD. This is a medical first, and I am grateful to the Parkinson’s Foundation for leading the way.”

opportunity to change the ways in which Parkinson’s is studied and treated in women.

Thank you to all the women and care partners who participated in this initiative here in Oregon. A special thank you to Carol Clupny, who served on the Oregon regional organizing committee representing women with

PD in the Northwest. Her insights and representation were invaluable both at our local Women and Parkinson’s Teams to Advance Learning and Knowledge (Women and PD TALK) program and at the national forum, which she attended as well.

For more information on the Women and Parkinson’s Initiative, visit <https://parkinson.org/pd-library/books/women-and-pd-agenda> for the full report and research agenda.

A PUBLICATION OF
THE OHSU PARKINSON CENTER



Inbrija: A new rescue medication for sudden OFF symptoms?

Venka Veerappan, M.D. — OHSU Movement Disorders Fellow

In December 2018, Inbrija, one of the newest formulations of levodopa, was approved by the FDA for symptomatic management of Parkinson’s disease. It has long been known that dopamine loss causes symptoms including rest tremor, rigidity, slowness of movement and difficulty with balance and walking. Consequently, the standard of care since the 1960s has been to use dopamine replacement, with the mainstay of therapy being levodopa.

Though levodopa is very effective, the sustained benefits of this medication can decrease over time due to progression of the underlying disease, which often leads to increased dosing, shorter intervals between doses and/or adding dose-prolonging medications. Additionally, patients may experience fluctuations which are often described as a delay in ON time (period of symptom control), sudden OFF times (period of symptom return), or even lack of response

with every dose. With this in mind, the SPAN-PD trial was developed to investigate whether a new inhaled formulation of levodopa may serve as a potential rescue therapy for these sudden OFF periods (Lancet Neurology 2019 Feb;18(2):145-154).

The recent Phase 3 trial of Inbrija enrolled over 350 patients and demonstrated improvement in clinical measures as it relates to comparison of evaluations pre-dose and 30 minutes post-dose, with sustained benefits lasting up to an hour after the dose. Of note, the speed of symptom improvement below 30 minutes was minimal and reduction in total daily OFF time when compared to placebo was no different. Furthermore, it was deemed to be safe and well tolerated, with a comparable side effect profile to levodopa, aside from additional pulmonary-related side effects such as cough, upper respiratory tract infection and sputum discoloration.

Inbrija is self-administered through an inhaler similar to what you might see people using for illnesses like asthma. This medication is not to be used on its own and is to be used in conjunction with traditional levodopa therapy to specifically help with sudden OFF periods in select patients. Overall, this promising new formulation of levodopa appears to possibly fulfill an important unmet need for rescue therapy in PD. However, as with all new medications that come to market, there are certainly some limitations that warrant further investigation, including research assessing long-term safety and efficacy outcomes.

Director’s Corner: “Parkinson’s Plus” On Our Radar

Joe Quinn, M.D. — OHSU Parkinson Center Medical Director

As if Parkinson’s were not enough of a challenge, there is also “Parkinson’s plus.” This term refers to a set of disorders including progressive supranuclear palsy (PSP), multiple system atrophy (MSA) and Lewy body dementia, among others. Each of these conditions is often initially diagnosed as Parkinson’s disease, with the diagnosis subsequently revised when Parkinson’s medicines fail to help much, and when other symptoms which are atypical for Parkinson’s disease start to appear; hence the term “Parkinson’s plus.” The OHSU Parkinson Center recognizes the importance of serving these individuals, and several efforts are underway that we’d like to share in this update:

- 1) We have increased our participation in clinical trials for patients with Parkinson’s-plus syndromes. For example, we participated in a small trial of a repurposed FDA-approved drug for the treatment of PSP, in collaboration with physician-scientists at the University of California San Francisco, and we are continuing our participation in a multicenter trial of immunotherapy for PSP. The latter trial is no longer recruiting, but our enrolled PSP patients will continue to receive antibody infusions for a year or more. A new trial that will enroll MSA patients is focused on poor blood pressure regulation, or “orthostatic hypotension.” That study will start enrolling in summer 2019.
- 2) The OHSU Parkinson Center has been designated a Lewy body dementia Research Center of Excellence by the Lewy Body Dementia Association (LBDA). This new network of centers is working on collaborations to improve treatments for this challenging condition.
- 4) Basic science research into these conditions is underway. Genetically modified mice which express brain abnormalities seen in PSP and related disorders are being studied in OHSU laboratories and candidate therapies are being tested in them.
- 5) While we are awaiting improved therapies from these research efforts, we recognize the special challenges these diseases present to patients and families, so we have established a special multidisciplinary clinic to allow these individuals to access a specialist, physical therapist, speech pathologist, social worker and nurse in our comprehensive Next Step Clinic.

We are committed to improving therapies for all the diseases in our area, so we will continue to seek research opportunities and collaborations with respect to the Parkinson’s-plus syndromes. We continue to be inspired by these patients and their families and appreciate the urgency of research in this important area.



Interested in research participation when trials become available?

Register for the NeuroNext Registry by contacting Kellie Keith at 503-494-9531 or keithk@ohsu.edu.

For an appointment with the Next Step Clinic team

Ask your OHSU Parkinson Center provider for a referral or contact Lisa Mann, RN at 503-494-5620 or mannli@ohsu.edu.

Alternative and Complementary Therapies for Parkinson’s Disease

Jill Baird, M.D. – OHSU Movement Disorders Fellow

In a recent study, 40 percent of Parkinson’s patients in the United States use at least one complementary or alternative therapy to treat their disease. This rate is probably even higher in Oregon! There are many reasons people

Parkinson’s progression), tai chi (improves motor function and balance) and tango (improves balance). Acupuncture has been well studied as an effective treatment for pain; however, in Parkinson’s disease the best-

What’s the bottom line? Patients, doctors and caregivers should work together to make sure that we are treating the “whole person.”

are interested in exploring other avenues of treatment for Parkinson’s disease alongside the care they get from their doctors: There are no prescription medications that actually slow down the disease, many of the non-motor symptoms of Parkinson’s disease can be difficult to treat, and most importantly, patients and their caregivers want to feel empowered and hopeful, that they are doing everything they can to fight their disease.

Many of these therapies have not been well studied or are very difficult to study in traditional ways. It’s hard to give everyone the same “dose” of exercise, or to evaluate the effect of diet as a whole on Parkinson’s. However, our goal should be to use the best evidence available to help you decide whether a therapy is safe, helpful and cost effective.

Most physicians and other providers who treat Parkinson’s recommend exercise and mind-body therapies because they are safe, likely helpful and often low cost. The best-studied forms of exercise in Parkinson’s disease are aerobic exercises like biking or walking (which has been shown to slow down

quality trial showed no benefit over random needling. A certain type of massage technique called trigger point pressure improved motor function in a small

study of PD patients, and patients reported benefit after three months of a postural awareness therapy called the Alexander technique.

There are a multitude of herbs, vitamins and minerals that have been tried to help treat Parkinson’s disease, and while many of these

are probably safe, it is always important to let your doctor know what you are taking, since some can interact with the medications you are prescribed. At this point, we don’t have solid evidence that there is any vitamin or herbal supplement that will slow down or “cure” Parkinson’s disease. Perhaps the most common supplement that has been used to treat Parkinson’s symptoms is the mucuna bean (*mucuna pruriens*). This bean naturally contains a form of dopamine and has been shown in small trials to help with the motor symptoms of Parkinson’s; however, many patients don’t tolerate it well due to nausea, and it is often combined with a carbidopa prescription to help with this side effect. A word of caution — researchers at OHSU looked at the levels of dopamine in the same dose of several different brands of mucuna and found that the levels differed widely.

What’s the bottom line? Patients, doctors and caregivers should work together to make sure that we are treating the “whole person” with Parkinson’s with the best therapies available. Let your doctor know about the supplements and other therapies you are using to treat your Parkinson’s and ask questions!



OHSU Parkinson Center Receives Community Grant



care in the local communities where people with Parkinson’s live their everyday lives,” said Lisa Mann, education director at OHSU Parkinson Center. “We are thrilled to receive a Parkinson’s Foundation Community Grant. It will enable us to pilot a unique medical education initiative to serve people with PD wherever they live in Oregon.”

For the full list of the 2019 Parkinson Foundation Community Grant recipients, visit parkinson.org/2019grants.

This spring, the Parkinson’s Foundation awarded more than \$1.5 million to 111 community grant projects in 38 states; OHSU Parkinson Center received the only grant awarded in Oregon. The Community Grant proposals focused on three areas: programs that provide a service for underserved PD communities, initiatives that reach the newly diagnosed, and clinical trial education and participation that reach those underrepresented in the PD community.

The OHSU Parkinson Center Project is focused on underserved PD communities. The funds will help develop a unique telehealth education initiative to train health care providers in rural and underserved areas to better meet the needs of people with Parkinson’s disease. Based on a successful medical education model called Project ECHO, the OHSU Parkinson Center team will develop the first Project ECHO in the world to train other health care providers about Parkinson’s disease.

“Most people with PD are cared for by non-specialist, local healthcare providers. Part of our mission is to train other health care teams to provide best-practice

OHSU Parkinson Center

Changing the course of Parkinson’s disease through Research

Have you been diagnosed with Parkinson’s disease with mild cognitive impairment or Parkinson’s disease dementia?

Purpose: The purpose of this study is to see if a new drug is safe and well-tolerated in people with Parkinson’s disease (PD) and mild cognitive impairment or dementia. Right now the study drug is not approved for treatment of PD because we don’t know enough about it. **Participation Requirements:** In order to participate in the study you must have been diagnosed with PD in the past year, have been diagnosed with or experience mild cognitive impairment or dementia, and are 40-85 years old. You must have recently been on a stable dose of your medications, have a study partner who can attend study visits with you, and be able to have a MRI scan (no metal in your body, no intense fear of enclosed spaces). You must not have a history of bleeding disorders, take a blood thinning medication, have a history of stroke or heart disease, have active liver disease or uncontrolled diabetes, or have extreme difficulty with giving or receiving fluids intravenously (through a vein in your arm).

Participation Details: Study participation lasts about 7 months. During that time, you will be asked to come to both outpatient (similar to a lengthy doctor’s appointment) and inpatient (similar to a hospital stay) visits at OHSU. There are 8 outpatient visits and two inpatient periods, each lasting 5 days/4 nights. The two inpatient periods are separated by about 3 months. Each day of the inpatient stay, you will receive study drug or placebo via an intravenous (IV) infusion through a vein in your arm. Participants will be randomized (like the flip of a coin) to receive either the study drug or identical placebo for the entire length of the study. A placebo is a drug that looks like the study drug but has no real medicine in it. Neither the participant nor the study doctor can choose whether study drug or placebo is assigned. Eligible participants will receive study-related evaluations, laboratory tests, and the study drug at no cost. Participants will be compensated for their time and transportation. For more information please contact Susan Bonner at 503-418-4387 or bonnesu@ohsu.edu. **eIRB #19203**

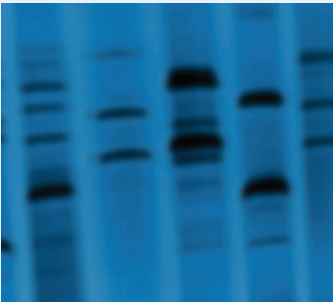
The OHSU Parkinson Center is a national leader in Parkinson’s disease (PD) research, and is involved in many studies that are fully recruited and others that are being planned. For more information, contact Susan Bonner at 503-418-4387 or at bonnesu@ohsu.edu

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

- Michael J Fox Trial Finder: <https://foxtrialfinder.michaeljfox.org>
- National Institutes of Health: <https://clinicaltrials.gov>

Have you been diagnosed with Parkinson Disease (PD) and are you also a known heterozygous carrier of a glucocerebrosidase gene (GBA) mutation to participate in this clinical research study.

The short name for the study is MOVES-PD and the study medication is GZ/SAR402671. An estimated 5 – 10% of Parkinson’s disease patients carry a mutation of the glucocerebrosidase (GBA) gene that allows lipids called glycosphingolipids to build up in cells. The molecule being studied, GZ/ SAR402671, reduces the production of glycosphingolipids. This is an international study



that will be run in 2 parts at sites located in the United States, Canada, Europe, Asia and Israel. The purpose of this study is to evaluate the possible risks and the effectiveness of the study medication GZ/SAR402671 in the treatment of PD patients carrying a (GBA) mutation. GZ/SAR402671 is an oral medication in development for GBA associated PD, but has not yet been approved by the U.S. Food and Drug Administration (FDA) for treatment of PD. You may be eligible to participate in this study if you meet several criteria include the following: diagnosis of PD and are a known heterozygous carrier of a GBA mutation associated with PD, age18 to 70 years, have symptoms of PD for ≥2 years, and if you are taking levodopa or any other PD medication, you must be on a stable dose for at least 30 days prior to randomization. If you do not already know your status, you can speak with the site personnel to find out how to get tested for the GBA gene. Please contact the study’s coordinator Maggie Flood at 503-494-0276 or 7245.floodma@ohsu.edu for more information.

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?

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: In order to participate in the study you must be a healthy control (no neurological diagnosis), or have a diagnosis of AD, Parkinson’s disease, fronto-temporal dementia, or dementia with Lewy Bodies. You must be age 55-80 years old, have a study partner who will attend study visits with you, be in general good health, not be taking warfarin or other blood thinners, and have no lower back problems and/or surgeries. 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 Jean Allen at allenjea@ohsu.edu. **eIRB #18193**

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

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

Measuring Cortisol Levels in Persons with Parkinson’s (PD) [CORT-PD] (OHSU eIRB # 15183)

Dr. Amie Hiller is conducting a research study looking at cortisol levels in Parkinson’s disease (PD), Huntington’s disease (HD), and in healthy controls. Cortisol is a hormone that is normally released in response to events and circumstances such as waking up in the morning, exercising, and stress. We are recruiting Parkinson’s disease patients, Huntington’s disease patients, and healthy controls. To be a healthy control, you must not have a neurological disorder. Both groups must be willing to give saliva samples. This study will last for approximately 1 week. There are two option 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 car-alternative travel expenses up to \$50.00 round trip. This is a research study and not for treatment or diagnosis of PD or HD. You may not benefit from participating in this study. However, by serving as a subject, you may help us learn how to benefit patients in the future. For more information on how to participate, please contact Brenna Lobb, Research Coordinator, at 503-220-8262 extension 51871 or by mail at 3710 SW US Veterans Road, P3-PADRECC, Portland, Oregon 97239.

Parkinson’s Outcome Project

The National Parkinson Foundation has launched a Patient Registry at all NPF centers of excellence, which includes OHSU. The purpose of the Registry is to collect data on individuals with Parkinson’s disease (PD) to better understand the illness and the effects of various treatments. The ultimate goal is to improve the care of people who have PD. This study was started in 2009 and has been reopened for recruitment. Data will be gathered once a year at a follow-up visit in our clinic, and will consist of a 10-15 minute consultation and a questionnaire. For more information please contact Maggie Flood at 503-494-7245 or floodma@ohsu.edu . (OHSU eIRB #5508)

Balance & Gait Studies

Balance and Gait Disorders Associated with Genetic Inheritance in Parkinson’s Disease (also known as UDALL)

This study is looking at the relationship between balance and gait, cognition, and genetic markers in people with Parkinson’s Disease via balance and gait testing and Transcranial Magnetic Stimulation. This study is recruiting both healthy controls and Parkinson’s subjects, and requires a visit to the Portland VA and a visit to OHSU. There will also be follow-up testing two years after initial test dates. Please contact Grace McBarron at 503-418-2600 if you are interested or have any further questions. IRB# 15018, PI: Fay Horak

MobilityLife

We are seeking volunteers that have been diagnosed with Parkinson’s disease or Multiple Sclerosis for a study looking at gait in individuals with neurological conditions. The purpose of this study is to quantify gait during daily activities using body-worn sensors. This study requires: 1) one visit that will take about four hours to complete where gait and balance will be tested, 2) wearing movement sensors at home for one week, and 3) tracking your falls for 6 months via online surveys. Please contact Graham Harker at 503-418-2601 if you are interested in participating. IRB# 15578, PI: Fay Horak

Using Sensors to Monitor Motor States in Parkinson’s Disease

This study will be investigating how small sensors placed on the upper body/forehead can detect different activities and medication status in people with Parkinson’s Disease. You must have Parkinson’s Disease to participate in this study. Participation involves one visit to the Balance Disorders Laboratory at OHSU lasting 4 to 4.5 hours, with testing in both ON and OFF Parkinson’s medication states. If you are interested or have any questions, please contact Grace McBarron at 503-418-2600. IRB# 18134, PI: Fay Horak

Brain Mechanisms Underlying Response to Visual Cues in Gait Impairment in Parkinson’s Disease

The purpose of this study is to investigate brain activity while walking and turning in Parkinson’s disease with and without visual cues. This study consists of one visit lasting about 4 hours and doing walking and turning tasks, with and without visual cues, while wearing and EEG cap. There will also be basic clinical, cognitive, and visual assessments. Participants come in ON medication and must have Parkinson’s disease Contact Makena Strand at 503-418-2601 with any interest or questions. IRB# 9903, PI: Martina Mancini

ZeroG TRIP: Training Responses in Postural Rehabilitation

The purpose of this study is to determine the feasibility of using a motorized, overhead support system as a method of balance rehabilitation in people with Parkinson’s Disease. Participation requires one visit to the Balance Disorders Laboratory at OHSU, lasting approximately two hours. This study is recruiting both healthy controls and people with Parkinson’s Disease, and testing will consist of questionnaires and standing and walking tests with programmed balance challenges. Contact Grace McBarron at 503-418-2600 with any interest or questions. IRB# 17619, PI: Laurie King

Thinking and Memory

Pacific Northwest UDALL Center (PANUC): Clinical Core and Sample Collection

Dr. Joseph Quinn is conducting this research study to examine the changes in thinking and memory of Parkinson’s disease patients over time. A second goal is to determine the role genetics plays in cognitive impairment in Parkinson’s disease. You must have a diagnosis of Parkinson’s disease to participate in this study. 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 and have a blood draw of about four tablespoons. Each visit will last for about two 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 hour. You have the option to undergo a second spinal tap three years after the first spinal tap. You will be compensated \$200.00 for each spinal tap that you complete. 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. This is a research study and not for treatment or diagnosis of Parkinson’s disease. You may not benefit from participating in this study. However, by serving as a subject, you may help us learn how to benefit patients in the future. For more information on how to participate, please contact Sam Jewell, BA, Study Coordinator at (503) 220-8262 x54688 or by mail at 3710 SW US Veterans Road, Portland, Oregon 97239. (VA IRB # 2332; OHSU IRB # 6154)

Dyskinesia

Evaluation of Buspirone and Amantadine for Dyskinesia in Parkinson’s disease

This research study looks at the effect and the safety of buspirone, in combination with amantadine on abnormal involuntary movements (dyskinesia) in Parkinson’s disease (PD). In order to take part in this study, participants must: have PD, take at least 200 mg of Amantadine a day, and started taking levodopa more than three (3) years ago. This study will last for 6 weeks with 4 of those weeks



on study drug and require three (3) visits to the Portland VA. The first visit lasts approximately 2 – 3 hours and involves general physical, neurological, and Parkinson’s disease specific examinations, and assessments of your abnormal movements. If you do not meet the criteria for abnormal movements in the study, you may not be randomized or receive study drug. All participants will take the study drug (buspirone) and the placebo. At the end of each treatment period, all participants will have another visit

to assess the effect of the drug on their symptoms. This is a double-blinded study which means that you and the research staff will not know what study treatment you are taking at any point. You will not be compensated for participation in this study. This is a research study and not for treatment or diagnosis of PD. You may not benefit from participating in this study but will have a no cost neurological exam. However, by serving as a subject, you may help us learn how to benefit patients in the future. For more information on how to participate, please contact Brenna Lobb, Research Coordinator, at (503) 220-8262 extension 51871 or by mail at 3710 SW US Veterans Road, P3-PADRECC, Portland, Oregon 97239.

Cortisol in PD

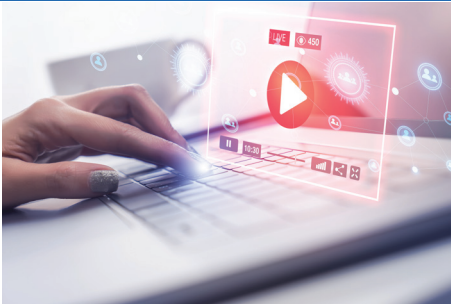
Measuring Cortisol Levels in Persons with Parkinson’s (PD) [CORT-PD]

Dr. Amie Hiller is conducting a research study looking at cortisol levels in Parkinson’s disease (PD). Cortisol is a hormone that is normally released in response to events and circumstances such as waking up in the morning, exercising, and stress. We are recruiting both Parkinson’s disease patients and healthy controls. To be a healthy control, you must not have a neurological disorder. Both groups must be willing to give saliva samples. This study will last for approximately 1 week with three (3) days of saliva collection at home. There will be one visit to the Portland VA (VA Portland Health Care System). The visit will last approximately 30 minutes and include questionnaires of mood and quality of life. For PD participants, a Parkinson’s focused exam will be performed. You will not be compensated for participation in this study. This is a research study and not for treatment or diagnosis of PD. You may not benefit from participating in this study. However, by serving as a subject, you may help us learn how to benefit patients in the future. For more information on how to participate, please contact Brenna Lobb, Research Coordinator, at (503) 220-8262 extension 51871 or by mail at 3710 SW US Veterans Road, P3-PADRECC, Portland, Oregon 97239. (OHSU eIRB # 15183)

Visit and watch great presentations featured from this year’s events at our video library.

Our video library is growing with presentations recorded at our recent events. Visit and watch great presentations featured from this year’s Caregiver Connections Conference and Essential Tools For Mid-Stage Parkinson’s Disease Series.

Great news! This summer our video library will be receiving a new look. This upgrade will allow you to easily search by topic rather than event. You may watch these powerful presentations from our PD Video Library: <https://tinyurl.com/pco-videos>



Video Library: Parkinson’s Disease

- Caregiver Connections
- Essential Tools for Managing PD Series

OHSU PARKINSON CENTER EVENTS REPORT

The Great Salt Lick Auction 2018 Whit Rides Again!

In Baker City, they don't pay their artists; in fact, sometimes they eat them! Led by Whit Deschner, Baker City and Crossroads Carnegie Art Center held another exciting Great Salt Lick Auction on September 15, 2018, that raised over \$20,000 toward research at the OHSU Parkinson Center. Attendees voted on their favorite salt licks, with the tiebreaker judge being a goat that "licked" the first-place-winning sculpture. The sculptures come in all shapes and sizes, and include forgeries (created by a human), licks with poems, licks with additional art adornments, and licks as part of theme baskets. During the viewing and voting, the event offers appetizers and libations, contributed and served by local businesses and FFA volunteers. The live auction proved energetic, with attendees outbidding their neighbors. In the interest of fun, some bidders began requesting that in order to agree to the next bid increment, a sponsor should throw in logo wear, or that a neighbor include his hat in the package! This annual event has raised over \$130,000 toward Parkinson's research in the last 12 years! A big thank you to this small community that has made a huge impact on the future of Parkinson's disease!

CarePartner Connections Join us Sept. 21st in Baker City!

<https://whitdeschner.com/the-great-salt-lick-contest/>



Eighty-five family care partners gathered on Feb. 7 for our annual CarePartner Connections assembly to share their experiences and learn about self-care and how to connect to specific solutions.

Susan Hedlund, director of Patient and Family Services, Knight Cancer Institute at OHSU, gave an insightful presentation on "Cultivating Resilience While Providing Care." The afternoon was rounded out by a candid talk with our Care Partner Panel, a meditation and movement break, and a closing session on resources in care. A special thank you to our faithful volunteer Ethel Campbell for her countless contributions in planning and event support.

Essential Tools for Managing PD

This five-part series addresses key issues encountered by people with PD and their loved ones during the middle stages of the disease. Earlier this year we tackled nutrition, cognition, pain and alternative therapies. **Please join us on July 11** for some straight talk on intimacy and **on Sept. 5** for advanced planning resources.

We simply could not offer these programs without the generous support of our sponsors. A giant thank you to Amneal and Boston Scientific for sponsoring our education programs at the gold level!

IN THE PARKINSON'S COMMUNITY



UPCOMING OHSU EVENTS

Newly Diagnosed PD Education Session — Monthly

Each month the OHSU Parkinson Center offers a three-hour 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 caregiver.

\$20/person; refreshments served.

Register online at <http://tinyurl.com/NewParkinson> or call 503-494-9054 with questions.

Next sessions will be June 13, July 11 and Aug. 8.

Essential Tools for Mid-Stage PD Series 2019

Key issues encountered by people with PD and their loved ones during the middle stages of the disease.

- July 11: Intimacy and Relationships in PD
- Sept. 5: Self Efficacy and Advanced Planning

More information and registration available at <https://tinyurl.com/etools2019>.

Sat., Oct 26, 2019 – Portland, OR Options & Opportunities: 35th Annual Symposium

Managing Motor Complications in Advanced PD

As PD advances and higher doses of levodopa are required, it can be challenging to walk the line between ensuring optimal physical function and avoiding problematical side effects of levodopa, such as dyskinesia, motor fluctuations, and psychosis. This year's program will present how to address these problems with a team of experts.

Marriott Downtown Portland, 10 a.m. – 2:30 p.m.

Details and registration will be available in August at www.ohsubrain.com/pco.

IN THE PARKINSON'S COMMUNITY Parkinson's Resources of Oregon (PRO)

Serving the PD community through education and advocacy. PRO has numerous ongoing educational events. Call 800-426-6806 or visit their website at www.parkinsonsresources.org or www.pro.eventbrite.com for more information.

It is the 15th anniversary for Sole Support!

Sole Support for Parkinson's is a series of awareness walks for Parkinson's disease. It is also a fundraiser to benefit local programs offered through PRO. Each walk is family friendly with wheelchair- and walker-safe routes. 1K or 5K distance. Details and registration at www.solesupport.org.

BEND: September 8 @ Drake Park

EUGENE: September 22 @ Alton Baker Park

PORTLAND: September 28 @ World Trade Center

VANCOUVER: October 5 @ Esther Short Park



Brian Grant Foundation

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

www.briangrant.org

For more information about upcoming events, visit <https://briangrant.org/community-events>.

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.



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