Could stress reduction be a means to fight Parkinson's disease (PD)? While more research is needed, I think the most likely answer is yes.

**What we do know** is that there are many ways that emotional stress can negatively affect the brain, such as increasing inflammation, increasing oxidative stress and worsening degeneration. There is some variability but a couple of studies have suggested that persons with more stressful life events are more likely to develop PD. Another area with few studies but in which there is a general agreement is that stress worsens some symptoms of PD. Symptoms that seem particularly sensitive to stress include tremors, dyskinesias and freezing of gait. Lastly, and the area with the least research, is that high stress may contribute to faster progression of PD symptoms.

**What can we do about high stress** so it doesn't worsen PD symptoms? Thankfully, there are a lot of things that can be done to reduce stress. If someone has significant anxiety, which is often present along with depression, discussions with a medical provider and referral to a mental health professional are generally appropriate. Activities that can help lower stress include exercise, yoga and meditation. An area that has received a lot of attention in the popular media in the last few years is mindfulness. Mindfulness is often defined as "a means of improving mental health and reducing symptoms of stress. It is a moment-to-moment nonjudgmental awareness and a means to reduce stress and improve coping." Programs focus on tools to cope with intense physical and emotional situations, relaxation practices such as meditation and yoga, and discussion of techniques. The most commonly used mindfulness approach is known as mindfulness-based stress reduction (MBSR). MBSR is generally taught with a fairly consistent curriculum as an eight-week course meeting two hours once a week, with daily "home work" and a half-day retreat.

**Mindfulness** has only been studied in PD in a couple of very small studies, so it is hard to describe specific effects in PD. In persons without PD the strongest and most consistent effects have been reduction in anxiety and depression. MBSR classes are regularly taught at OHSU through March Wellness and the Knight Cancer Center. Online resources include the University of Massachusetts and University of California at San Diego, both with Centers for Mindfulness. I am currently interested in studying MBSR specifically in PD and will hopefully be starting classes within the next year. My goal is to help persons with PD better manage their disease by better managing their stress to improve symptoms and quality of life.

If you would be interested in learning more about PD research and participating in current or future studies, Fox Trial Finder (https://foxtrialfinder.michaeljfox.org/) is an excellent resource. Both persons with and without PD can register and will be updated as trials that match your profile become available.
Director's Corner: 2018 Year in Review

Joe Quinn, M.D. — Medical Director

It's hard to believe another year has gone by and that it's already time to review another year of growth in the OHSU Parkinson Center:

**Patient care:** While impaired movement continues to be a focus of care for our patients, we recently took steps to improve our care of some “non-motor” aspects of Parkinson’s disease and related disorders. In response to some strong opinions from our Parkinson’s Patient Advisory Committee, we have added a clinician to help with mental health assessment and treatment.

**Dr. Louise Marasco** is a psychologist who has in the past seen many of our patients in her private practice in the South Waterfront area. Starting in September 2018, she is spending half of her time at OHSU, including one day per week serving patients in our center. We are pleased to add her expertise to our team and anticipate that this service will continue to evolve over time to meet the needs of our patients and caregivers.

We have also initiated a Cognitive Health Clinic starting this fall, where patients with Parkinson’s and related disorders can be referred for cognitive assessments and guidance on best practices for preserving cognitive health. Starting in January, we will have a neuropsychologist on staff to help support this clinic.

**Education:** We graduated two movement disorder fellows who now provide specialized Parkinson’s care in New Orleans, La., and Sunnyvale, Calif. (Bay area), respectively, and welcomed two new fellows to begin training. We were also busy with patient and caregiver education programs. Perhaps you attended one of the five Essential Tools for Mid-Stage programs or the annual Options & Opportunities symposium or the Caregiver Connections conference. If you were unable to attend, please visit our website video library if you would like to catch up on the presentations made at these events (see page 5).

**Research:** Work toward better treatments for Parkinson’s disease and related disorders continues on several fronts. Alpha-synuclein, the chief component of Lewy bodies, is under study in Dr. Vivek Unni’s NIH-funded laboratory, and under investigation in living patients, as we contributed to a Phase 1 study of an antibody directed at alpha-synuclein (published in June 2018) and started activity in a Phase 2 study with the same drug.

Genetic contributions to Parkinson’s disease are under study in Dr. Ian Martin’s laboratory, at the same time that we are participating in a “precision medicine” clinical trial for patients with a genetically defined version of Parkinson’s disease. Dr. Fay Horak’s team continues to investigate how to better treat gait disorders in PD, and the multicenter NIH “Udall” grant continues to investigate the basis of cognitive changes in Parkinson’s disease, with the goal of developing better therapies for these aspects of PD. We have also been following the advice of our 2017 Scientific Advisory Board to take steps to support our established scientists and to begin efforts to recruit additional scientists. (See currently recruiting research studies on pages 4–5 if you would like to participate.)

In summary, it has been a busy and productive year. As usual, we are dependent on our patients and families for research participation and guidance, and we are grateful for all your support. As I write this, we approach the Thanksgiving holiday, and we offer you all a warm thank you and, as we approach the year’s end, we also wish you a happy new year!

If you are interested in referrals to:

► Psychotherapy with Louise Marasco, Ph.D.

► Cognitive Health Clinic

Please mention this to your OHSU Parkinson Center specialist.
New Movement Disorder Fellows
Continue Legacy of Excellence

Andrew Giritharan, M.D.
OHSU Movement Disorders Fellow

Dr. Giritharan grew up in southern Illinois. He attended University of Missouri Medical School before moving to Nashville, Tennessee, for neurology residency at Vanderbilt University Medical Center. The experiences he had caring for patients with Parkinson's disease and related conditions inspired him to specialize in movement disorders. He is excited to be joining the OHSU team and looks forward to continuing to learn from his patients and colleagues.

Venka Veerappan, M.D.
OHSU Movement Disorders Fellow

Dr. Veerappan grew up all across the world in different countries including Malaysia, England and Ireland, before finally settling down in Las Vegas, Nevada. He attended medical school at the University of Nevada and completed his neurology residency training at the University of North Carolina, Chapel Hill. He is new to the Portland area and is excited to start fellowship training at OHSU. He is very interested in providing longitudinal clinical care to patients with movement-related disorders and the advancement of novel therapeutics for management of neurodegenerative diseases.

How to Get the BEST Treatment From Your Clinician

Lisa Mann, R.N., B.S.N., M.A.

Getting excellent advice and health care from your Parkinson's specialist or any health care provider is a bit like using a computer: garbage in, garbage out. If you don’t put in the correct information, what you get back is mediocre at best, unusable at worst. Health care providers are highly trained, but they have two primary tools for individually tailoring treatment: their objective examination and the information you or your partner give them describing how you actually feel and function. If you give them good, thorough, relevant information, you will help them treat you appropriately.

So, how do you do this? It’s really quite simple. Before you call or go to an appointment with your specialist, be prepared with clear answers to the following questions:

• What is the specific problem? Is it pain, balance, worsened symptoms, medication problems?
• When did the problem start? Be as specific as possible. Remember the date it started and the time of day it occurs.
• Is it constant or intermittent? If intermittent, do you notice any pattern? For example, is it connected to when you take medications or a specific event or a certain time of the day?
• Where is the problem? Left hand? Right foot? Again, try to be as specific as possible.
• What happens during these episodes? For example, describe a typical incident: “My right hand tremor worsens and it becomes jerky, and my right foot starts to jerk, too.”
• What makes the problem better? What makes it worse? Bring information on any treatments or positions or medications you have tried that either help or don’t.
• On a scale of 0–10, with 10 being the worst, how would you rate the severity of the problem and why? “Physically, it’s about a 5, moderately disabling, but it’s an 8 because it is so distressing emotionally.” You may want to assign a number based on how much it bothers you and affects your quality of life as well.
• What are your current medications? Be ready with a full list of your medications, how much you take of each, what dosage, when and what times of day or how often, and what you take each one for. Also, be prepared to list any allergies or medications you’ve tried that didn’t work for you and why. Always carry a list of all your medications with this information with you, especially to your appointments.
• Have you had any recent incidents (infection, illness, surgery, falls, lifestyle changes, etc.)? This may not seem connected to you; however, infections, changes in environment, stress, new medications, or pain all can cause a worsening of symptoms for Parkinson’s patients.

Your answers should be brief and to the point (your specialist will appreciate you for this and readily return your calls because he or she knows you will be prepared with the information that’s really needed). If you have more than one issue, prioritize them in case you or the specialist runs out of time, and find out who (probably his or her nurse) you can call to get what you need.

Finally, when you see your specialist, don’t be afraid to do the following:

• Ask questions. Write them down before you come in or call.
• Bring someone with you to take notes.
• Ask for referrals to other health care providers for consultations if desired, including mental health counselors.
• Remember to request periodically, or when a change occurs, to have a referral to physical, occupational and/or speech therapists for individualized evaluation and treatment plans.

Health care providers are here to work with you to maximize your quality of life, but it is truly a team effort. You and your partner are the team leaders!
The OHSU Parkinson Center is a national leader in Parkinson’s disease 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

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 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- to 15-minute consultation and a questionnaire. For more information, please contact Maggie Flood at 503-494-7245 or floodma@ohsu.edu. (OHSU IRB #E5508)

Balance and Gait Studies
EE FOR PD — Exercise and Education for Parkinson’s Disease (healthy volunteers needed as well) is a study looking at the effect of exercise and education on Parkinsonism. The objective is to understand how exercise and education affect balance, gait and cognitive function in individuals with Parkinson’s disease and frontotemporal gait disorder (vascular or lower-body Parkinsonism). The program involves attending six weeks of exercise (90-minute classes, three days a week) and six weeks of educational classes (90-minute class, one day a week). There are also three test periods where balance, walking, cognition and brain imaging (MRI) are assessed. The lab is looking for individuals diagnosed with Parkinson’s disease or other types of Parkinsonism to take part in this study. Participants will receive $25 per testing session and $5 for each class attended. The lab is also seeking healthy individuals 50 years of age and older to volunteer as controls for this study. Participants will take part in a two-day study that involves tests of gait, balance and cognition, as well as completion of an MRI of the brain. Individuals with Parkinson’s disease or frontotemporal gait disorder who are unable to participate in the exercise and education classes can take part in the two-day study as well. Participants will receive $25 per testing session. Contact the OHSU Balance Disorders Laboratory at 503-418-2601 or balance@ohsu.edu, Dr. Fay Horak, Ph.D., P.T. (OHSU IRB #E4131)

Improving Walking Automaticity in Parkinson’s Disease: Levodopa or Donepezil? The purpose of this study is to investigate the effect of donepezil on gait and balance in Parkinson’s disease. The study involves three visits to OHSU over six weeks. During these visits, you will wear your gait and balance assessed as well as undergo cognitive testing. The first study visit will last approximately three hours and each subsequent visit will last approximately two hours. There is also an optional testing where you will undergo transcranial magnetic stimulation (TMS) to assess neurotransmitter function. As part of the study, participants will take donepezil and placebo. The medications will be taken separately for two weeks each with a two-week break in between. To qualify for the study, you must be 55–90 years old, diagnosed with idiopathic Parkinson’s disease, taking levodopa, not currently taking donepezil, and able to stand and walk unassisted for two minutes. Eligible participants will receive study-related evaluations and the study drug at no cost. Participants will be compensated for their time. For more information, please contact Georgeann Booth at 503-418-2602 or bootge@ohsu.edu. (OHSU IRB #17805)

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# 15138, 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 six months via online surveys. Please contact Graham Harker at 503-418-2601 if you are interested in participating. IRB# 15578, PI: Fay Horak

Exercise, Brain Imaging, Cognition and Gait in Parkinsonism We are looking for Parkinson’s patients who experience shuffling/freezing of gait and healthy control participants with good, unimpaired mobility for a study looking at balance, gait and cognition. Subjects must be 50–90 years old, have no neurological issues other than Parkinson’s disease, vestibular (inner ear) impairment or orthopedic problems. Participation requires two four-hour visits to OHSU and includes an MRI of the brain. For more information, please contact Graham Harker at 503-418-2601 or balance@ohsu.edu. IRB# 04131, PI: Fay Horak

Effects of Dopaminergic Medication on Cortical Excitability in Parkinson’s Disease This is a novel study which uses noninvasive brain stimulation (transcranial magnetic stimulation) to assess the impact of carbidopa-levodopa, a common Parkinson’s medication, on the neurotransmitter acetyl choline. Study participation involves a single visit to OHSU lasting approximately four hours and includes TMS, gait/balance tasks and clinical evaluations. Contact Graham Harker at 503-418-2601 with any questions or if you are interested in participating. IRB# 17168, PI: Douglas Martini and 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 four to four and a half 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

Staying Upright in Parkinson’s: A Novel Wearable Postural Intervention This study is investigating a wearable sensor to help with posture in people with Parkinson’s disease. The sensor is a small device that sticks to your upper back, connects to a smartphone to track your posture and provides a vibration when it comes out of alignment. The study is a single two-hour visit ON medication with sitting, standing and walking tasks as well as memory and attention tasks. You must have Parkinson’s disease to participate in this study. If you are interested or have any questions, please contact Makena Strand at 503-418-2601. IRB#16574, PI: Martina Mancini

Brain Mechanisms’ Underlying Response to Visual Cues in Gait Impairment in Parkinson’s Disease The purpose of this study is to investigate brain activity in Parkinson’s when walking and turning, with and without visual cues. This study consists of one visit lasting about four hours and doing walking and turning tasks, with and without visual cues, while wearing an 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. The primary goal is to determine how 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 hours. 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 VA Portland Health Care System, you will have a telephone interview with questions regarding your thinking and memory. The interview 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, B.A., study coordinator, at 503-220-8262, ext. 54688, or by mail at 3710 S.W. US Veterans Road, Portland, OR 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. 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 in the last 3 years ago. This study will last for six weeks, with four of those weeks on study drug, and require three (3) visits to the Portland VA. The first visit lasts approximately two to three 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, ext. 51871, or by mail at 3710 S.W. US Veterans Road, Portland, OR 97239. (P3-PADRECC, Portland, OR 97239. (OHSU eIRB # 15183)

Essential Tremor
Have you been diagnosed with Essential Tremor, experience moderate or severe hand tremor, and have been on a stable dose of tremor medications (if applicable) for at least 30 days?

Purpose: Essential Tremor (ET) is a common movement disorder in the United States in which people experience involuntary shaking of the hands, head, and/or voice that can range from mild to severe in intensity. Tremor intensity increases as a person ages and can affect one’s ability to perform tasks of daily living. This study will evaluate the effects of the study device, a watch-like device worn on the wrist, on hand tremor in people with Essential Tremor over the course of three months. Right now the study device is not approved for treatment of ET hand tremor because we don’t know enough about it.

Participation Requirements: In order to participate in the study you must be at least 22 years old. Diagnosed with ET, currently have moderate or severe tremor, and if applicable, have been on a stable dose of tremor and/or depression medications for the past 30-90 days. You cannot have an implanted medical device (pacemaker, defibrillator, deep brain stimulator [DBS]), have had surgery to treat your tremor, have had botulinum toxin (i.e. Botax) injections for hand tremor in the past 6 months, or be pregnant or planning to become pregnant. There are a total of 3 study visits over approximately 3.5 months. You will be asked to use the study device at home twice per day (40 minutes per session) during the study. Eligible participants will receive study-related examinations and the study device at no cost. Participants will be compensated for their time and transportation. For more information please contact Maggie Flood at (503) 494-7245 or floodma@ohsu.edu. eIRB #19069

Cortisol in PD
Measuring Cortisol Levels in Persons With Parkinson’s [CORT-PD]

Dr. Amie Hiller is conducting a research study looking at cortisol levels in Parkinson’s disease. 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 one 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, ext. 51871, or by mail at 3710 S.W. US Veterans Road, Portland, OR 97239. (OHSU eIRB # 15183)

Clinical Core and Sample Collection

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.
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.proresources.org or www.pro.eventbrìte.com for more information.

Friday, April 6, 2019 — Hilton Hotel, Eugene, Ore.
Educate. Inspire. Empower.
Parkinson’s Resources of Oregon’s annual Parkinson’s disease education conference features leaders in the field of treatment and care as key presenters discussing a variety of topics of interest to people with PD, care partners and professionals.

You’re Invited!

5th World Parkinson Congress, Spring 2019

What do you call nearly 5,000 people in the Parkinson’s community — people with Parkinson’s, researchers, clinicians, care partners, therapists and family members — from over 60 different countries all gathered together at the same time in the same place? The one and only World Parkinson Congress.

Held every three years, the 5th World Parkinson Congress is scheduled for June 4–7, 2019, in Kyoto, Japan. It is a unique, international and interdisciplinary forum for everyone researching, treating or living with Parkinson’s disease.

Have a question about cutting-edge research? In Kyoto, you will have the opportunity to talk to the people directly involved. Do you need ideas for improving your support group? Set up a lunch meeting with others like you. If it is PD-related, you’ll find it in Kyoto.

As part of the pre-Congress activities, there is a video contest and a song contest. Sample entries are posted on the everything you ever wanted to know about the 5th World Parkinson Congress website: www.wpc2019.org. There you will find information on registration, housing, program, travel and more.

Still not convinced to attend? Here are a few more reasons: hear inspiring speakers; learn new strategies for living and coping with PD; discover new friends; interact with researchers, clinicians and therapists; and experience a new culture — located in a World Heritage Site — in Kyoto, Japan.

It’s not too late to plan the trip of a lifetime with thousands of your Parkinson’s disease friends from all over the world! For additional information, email me, your WPC 2019 ambassador (USA), A.C. Woulnough (ac@worldpdcollection.org).

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