Dear Parkinson’s community,

Your continued support for the OHSU Parkinson Center in 2014 has helped us advance our three missions:

• Providing comprehensive and compassionate care
• Educating patients, caregivers, professionals and researchers
• Investigating Parkinson’s disease (PD) and new treatments

Below is an outline of our accomplishments this past year. Thank you: Without your support, none of what follows would be possible.

Comprehensive quality care update

• Cared for more than 1,150 PD patients
• Center of Excellence designation renewed by the National Parkinson Foundation
• Grew the deep brain stimulation (DBS) program
• Performed over 120 surgeries
• Trained physicians in DBS evaluation, programming and management
• One of only a few programs utilizing intraoperative imaging for DBS — which allows the procedure to be done under anesthesia
• Participated in educational programs for people contemplating DBS and for professionals
• Offered a comprehensive team approach to the evaluation for surgical candidacy involving neurologists, neurosurgeons, physical therapists, neuropsychiatrists and speech pathologists
• Employed a new imaging technique to measure the dopamine nerve terminals in the brain (DATscan)

Education and outreach update

For patients and families

• Offered newly diagnosed workshops to anyone recently diagnosed: small group sessions for the newly diagnosed to ask questions and feel hope
• Over 475 people attended the 31st annual PD symposium: Options and Opportunities, at which presenters provided the latest information on diet, exercise and brain wellness to live optimally with PD
• Distributed 6,500 Parkinson Update newsletters in June and December which offered informative articles on a variety of topics of interest to people with PD and their loved ones
• Distributed 1,200 e-newsletters, Changing the Course of PD
• Specialists gave numerous talks to local support groups
• Partnered with Parkinson’s Resources of Oregon through a conference in southern Oregon to reach over 100 people living with PD
• Presented webinar on medication management reaching the northwest PD community through NWPF Lunchtime Laboratory
• Improved patient care for people with PD through hospital training initiatives for physician

**Research update**

**Highlights only are listed, but be assured even more is going on behind the scenes.**

**Developing better tools for research:**

• Searching for MRI methods of imaging dopamine cells in the brain stem

• Exploring brain circuits important to balance and walking using cutting-edge MRI techniques.

• Studying the benefit of using MRI-guided surgical techniques for DBS

• Studies of “biomarkers” in blood and spinal fluid for diagnosing and monitoring PD are under way.

• Researching better treatment of symptoms:
  - The effect of a nutritional supplement in the prevention of dyskinesias
  - Effects of vitamin D on gait and balance in PD
  - The effect of multiple nutrients upon cognitive function in PD

**Researching prevention of disease progression:**

• The effect on PD of a “re-purposed” drug originally FDA-approved for high blood pressure is being examined in a national multi-center trial

• A collaboration with scientists at UCSF is examining the efficacy of innovative gene therapy for PD

• Treatments aimed at regulation of alpha synuclein (the protein that accumulates in nerve cells in Parkinson’s disease) are being studied in animal models

• A clinical trial of an antibody directed against alpha synuclein in Parkinson’s patients has begun recruiting

We are committed to improving the lives of people with PD and their families, today and in the future. Please help us continue in 2015 to grow in our care, education and research missions and foster another year of shared success.

With gratitude,

Joe Quinn

Medical Director, OHSU Parkinson Center

---

**Trekking Trend**

Jynthia Schaille, P.T.

Walking is one of the most important forms of physical activity a person can do. It has shown to reduce the prevalence of chronic diseases in all populations and has shown positive impact on reducing resting heart rate, reducing blood pressure, improving maximal oxygen consumption and improving quality of life.

People with Parkinson’s disease often worry about safety while walking and may decrease their overall activity due to a fear of falling. Trekking poles were introduced nearly 20 years ago in central Europe as a simple way to improve walking economy. Since then, trekking poles have been used throughout the United States to improve not only walking economy, but also safety while walking. Research has shown that people with Parkinson’s disease can have a significant improvement in independence, walking speed and distance and quality of gait.

When using walking sticks, the brain perceives input through the person’s arms as to where the body is in space. Thus, if you are walking on uneven ground, the trekking poles not only aid in supporting you, but also provide feedback to your brain that allows you to make adjustments at the level of your feet to improve safety while walking.

If you are considering a way to make your daily walks more effective and safe, consider acquiring trekking poles from your local sporting goods store. The height of the trekking pole should form a 90-degree angle at your elbow when you are fully erect. When walking with trekking poles, they should touch the ground naturally, with the rhythm of your arm swing. A physical therapist can help if the fit doesn’t feel correct.

If you would like to know more about how to keep your exercise routines productive and safe in light of your Parkinson’s disease, have your PD specialist refer you to our PD trained physical rehab therapists at the OHSU Neuro Rehab Department, 503 494-3151. We’d like to recognize Poster Garden Fund for the Arts, Culture, and Gardens and 9 Portland Parks & Gardens who generated donation of $400 trekking poles for people with PD at our center for our Paws fundraising, annual symposium, and rehab programs.

---

**Options and Opportunities: A Healthier You!**

More than 500 people gathered October 12 for the 31st annual Options & Opportunities symposium on PD. This year’s theme, developed based on participant requests, was “A Healthier You: Diet, Exercise, and Cognitive Wellness in PD.”

Our keynote speaker was Dr. Christine Tangney, an expert in nutrition and the brain from Rush University in Chicago. Speaking from years of research and clinical experience, Dr. Tangney offered tips about healthy eating for PD. Dr. Fay Harak, renowned gait and balance expert, presented on the latest science surrounding exercise and PD with Nancy Nelson and two of her students demonstrating. OHSU Parkinson Center Medical Director Dr. Joe Quinn finished up with practical tips on brain health. Caregivers were treated to a special breakout (and chocolates) with Elaine Sanchez, co-founder of caregivinghelp.com, who has a way of sharing that puts everyone at ease with humor and one of the best medicines for health—laughter. Dr. Brian Fiske, the vice president for research at the Michael J. Fox Foundation was the final presenter with an update on the hottest topics for research in PD.

But that was not all! We also had short PD Profiles by Dan Baker and Phil Myers (both with PD), and Pat Baker (Dan’s wife) helped round out a very positive day with personal stories of resiliency and practical advice from the true experts of how to live well with PD. Also, there were dozens of educational and vendor displays. All in all, it was a very full and eventful day.

---

**Ask the Expert**

**Parkinson’s disease is a neurodegenerative condition classically characterized by slowed movements (bradykinesia and rigidity) and tremor; however, there are other non-motor complications of Parkinson’s disease. One of the first to arise can be loss of the sense of smell, also known as hyposmia.**

Hyposmia can also be associated with other neurodegenerative conditions such as Alzheimer’s disease, but can also be the results of head trauma or chronic sinus infections. About 90 percent of people with Parkinson’s disease lose their sense of smell, and this can occur up to 20 years prior to the development of problems with movement. It usually develops slowly and is often not noticed by those who are hyposmic. However, friends and family may notice that they loved one does not notice when the garbage needs to go out or complains that food has no taste.

It is not precisely known why people with Parkinson’s disease develop hyposmia; however, the prevailing theory is that the same process that causes degeneration of the substantia nigra (and thus movement difficulties) also affects the nerves in the nose and brain that detect odor.

Since hyposmia can occur years before movement problems there are ongoing research studies to determine whether hyposmia can be used as a screening tool to detect кто will eventually develop Parkinson’s disease. So far, this research has been inconclusive.

Unfortunately, there is no cure or treatment for hyposmia. Managing the condition usually centers on making sure the affected person is safe. Because we use our sense of smell to alert us of dangers such as fire, spoiled food or chemicals in the air, those with hyposmia can be at risk for inadvertently harming themselves. If you feel you or a loved one has hyposmia, talk to your doctor about getting your sense of smell checked.

---

**EVENT REPORTS**

**SAVE THE DATE: Saturday, Sept 26, 2015**

**HUNDREDS MOBILIZED TO PARTICIPATE IN THE EXERCISE DEMONSTRATION.**

---

**With gratitude,**

Joe Quinn

Medical Director, OHSU Parkinson Center

---

**Our keynote speaker was Dr. Christine Tangney, an expert in nutrition and the brain from Rush University in Chicago. Speaking from years of research and clinical experience, Dr. Tangney offered tips about healthy eating for PD. Dr. Fay Harak, renowned gait and balance expert, presented on the latest science surrounding exercise and PD with Nancy Nelson and two of her students demonstrating. OHSU Parkinson Center Medical Director Dr. Joe Quinn finished up with practical tips on brain health. Caregivers were treated to a special breakout (and chocolates) with Elaine Sanchez, co-founder of caregivinghelp.com, who has a way of sharing that puts everyone at ease with humor and one of the best medicines for health—laughter. Dr. Brian Fiske, the vice president for research at the Michael J. Fox Foundation was the final presenter with an update on the hottest topics for research in PD. But that was not all! We also had short PD Profiles by Dan Baker and Phil Myers (both with PD), and Pat Baker (Dan’s wife) helped round out a very positive day with personal stories of resiliency and practical advice from the true experts of how to live well with PD. Also, there were dozens of educational and vendor displays. All in all, it was a very full and eventful day.
Freezing of gait is a temporary inability to take a step. It is sometimes preceded by small, shuffling steps, and during a freeze, legs may tremble. Freezing is more common when turning or starting to walk, when there are lots of distractions (such as a busy supermarket), or when you feel stressed or very tired. Despite the name freezing of gait, freezing can sometimes occur in the arms or hands during repetitive movements such as brushing teeth or using a whisk.

Freezing is more common later in the progression of PD, and some people with PD never experience it. Specifically, about 25 percent of people early in the course of PD experience freezing, and about 80 percent of people with PD experience freezing at some point in their lives.

What causes freezing?

Although we aren’t sure exactly why freezing occurs or why some people with PD never experience freezing, scientists and clinicians believe freezing may be related to a combination of things including subtle changes in cognition and in coordination of movement.

Cognition: Freezing can be more prevalent when there are distractions, such as busy rooms, when stepping into or out of an elevator, or when crossing the street. In each example, there are multiple places to put your attention. That these situations often elicit freezing suggests freezing may be related to changes in one’s ability to control attention — specifically, the ability to divide attention and to switch attention between multiple places.

Coordination: Another task that can cause freezing is turning. It is believed that turning is especially difficult for people who freeze because it requires more planning and thinking than walking in a straight line. In fact, it supports the theory that freezing may be related to dividing attention. Turning also requires more coordination than forward walking, suggesting that freezing may be related to coordinating the legs, or to coordinating movements (such as turning and stepping).

Treatments for freezing

Like many symptoms of PD, common treatments may reduce freezing, but do not stop it altogether. For example, levodopa may lessen the frequency and severity of freezing (especially early in the course of PD), but does not get rid of it entirely. Similarly, deep brain stimulation (DBS) of the globus pallidus or subthalamic nucleus may improve freezing in some cases, but typically does not stop it from occurring. Recently, surgeons have begun placing stimulators in another region of the brain — the pedunculopontine nucleus. DBS in this region may have a more prominent effect on freezing, however, more research will be needed before we can say this for sure.

There are tricks that some people use to overcome freezing episodes. External cues can sometimes be helpful to break a freezing episode. For example, a line or stick on the ground may act as a visual cue. Auditory cues, including a metronome, can also sometimes help to avoid freezing by keeping steps consistent. As with many other symptoms of PD, staying safely active can be beneficial for freezing. Further, completing exercises which tax not only your body, but also your brain may be especially beneficial. For example, there is preliminary evidence that practicing multiple tasks together in a safe environment may be beneficial for reducing freezing.

As with many symptoms of PD, there are no magic bullets for freezing of gait. However, we are continuing to investigate pharmacological, surgical and exercise treatments to reduce freezing. We hope that with a better understanding of why freezing occurs, we can improve these treatments and reduce the burden of freezing on people with PD.

---

Paws Produces! Dog-Fun Days Raises $150,000

Our annual fundraiser, Paws for a Parkinson’s has helped raise over $150,000 for OHSU Parkinson Center projects in the last four years. In the past, these funds have helped provide social work support, allowed special research projects to be done and develop pioneering treatment programs for people with Parkinson’s disease and their caregivers. This year is no different. The $40,000 raised is being targeted for a variety of projects that would otherwise not have been possible, including an innovative programming and pilot research projects.

While we say goodbye to our annual fundraiser, we now focus on developing the patient services and outreach programs to empower individuals and families to overcome the challenges of Parkinson’s disease. We hope you can continue to support our work through direct donations by visiting our website at www.ohsubrain.com/pco/giving.


---

Shaken Not Stirred: Parkinson’s with a Purpose

John Rivelli

Isn’t it great that we have choices? That’s what I had 22 years ago when diagnosed with Parkinson’s disease and I still have choices 22 years later, every day.

From the instant of being diagnosed, my world was forever changed and the disease would affect every choice I made in my life. I had to choose between ‘yes’, ‘I can’t’ or no. I can’t but for me being in my early 30s when diagnosed there could only be one choice “yes, I can”.

Webster’s Dictionary refers to Parkinson’s as a “degenerative disease of later life.” But I am proof that maybe instead it should read “degenerative disease of life.” Throughout my life when faced with a difficult situation, I deal with it the best way I can, which is with humor and determination to turn a negative into a positive. Since I am stuck with it I might as well make the best of it. Besides, what other choice do I have?

Two things I was assured of when diagnosed was that the disease would spread throughout my body and the symptoms would get worse. But being so young, I still had a lot of life I wanted to live, except now it may take a little longer.

Each morning while I lie in bed, I think about the things I want to do that day, never the things I can’t do. I leave no room in my day for depression or self-pity. Before I take my first dosage of the day when my Parkinson’s is at its worst, I tell myself that if it progresses no further and symptoms get no worse then I could deal with it. Fortunately, my progression is slow, and there are times when my symptoms are well under control. My friends and family tell me how good I look and can’t even tell that I have Parkinson’s. I just tell them to give it a little time, and I will be back to normal. I refuse to let it dictate my social life. If others notice my shuffling or tremor I simply explain my situation and besides, I figure I will probably not see them again anyway. Along with being born with a heart murmur, which limits certain activities, a few years ago I was diagnosed with debilitating arthritis in my toes. Now, if I have trouble walking with painful arthritis in my toes or with freezing or shuffling from the Parkinson’s, I tell myself and others around me that I would make a lousy thief, and I keep moving. My health may have three strikes against me but I am not out of the game yet, I still have several innings left to play.

Besides, what other choice do I have?

Along with the progression of the disease, progression of the medication has increased as well. Currently I take up to 24 pills a day which can be depressing, thinking that I will be taking medication for the rest of my life. But 24 pills a day is better than 25 pills a day! I like dealing with even numbers anyway. I know the importance of exercise which can decrease mood and reduce the amount of medication taken. Besides, what other choice do I have?

In looking back over the last 22 years, I can see how the Parkinson’s has tried to control my day-to-day choices. But that doesn’t mean I have to accept it. It may want to control my body but I control my mind. I remember the adage that says “If you want a job done then do it yourself.” It is because of this mindset, determination and at the encouragement of Julie Carter, I have written a book called Shaken Not Stirred: Parkinson’s with a Purpose which tells my story from when diagnosed and my acceptance of the disease, but in name only, along with humorous uses for the disease, which tells my story from when diagnosed and my acceptance of the disease, but in name only, along with humorous uses for the disease, such as when writing a doctors signature. They say that laughter is the best medicine, and if this is true, then I must have one hell of a prescription.

Hopefully my story can help others in their battle for control of the choices in their day-to-day lives. Accept what you have to, but control what you can.

Besides, we have no other choice.

If you are interested in reading John’s humorous look at his own experience with Parkinson’s disease, his book — Shaken Not Stirred: Parkinson’s with a Purpose — is available for $8. We can put you in contact with him by emailing us at pco@ohsu.edu.

---

Living with Parkinson’s Day-to-Day

John Rivelli

Isn’t it great that we have choices? That’s what I had 22 years ago when diagnosed with Parkinson’s disease and I still have choices 22 years later, every day.

From the instant of being diagnosed, my world was forever changed and the disease would affect every choice I made in my life. I had to choose between ‘yes’, ‘I can’t’ or no. I can’t but for me being in my early 30s when diagnosed there could only be one choice “yes, I can”.

Webster’s Dictionary refers to Parkinson’s as a “degenerative disease of later life.” But I am proof that maybe instead it should read “degenerative disease of life.” Throughout my life when faced with a difficult situation, I deal with it the best way I can, which is with humor and determination to turn a negative into a positive. Since I am stuck with it I might as well make the best of it. Besides, what other choice do I have?

Two things I was assured of when diagnosed was that the disease would spread throughout my body and the symptoms would get worse. But being so young, I still had a lot of life I wanted to live, except now it may take a little longer.

Each morning while I lie in bed, I think about the things I want to do that day, never the things I can’t do. I leave no room in my day for depression or self-pity. Before I take my first dosage of the day when my Parkinson’s is at its worst, I tell myself that if it progresses no further and symptoms get no worse then I could deal with it. Fortunately, my progression is slow, and there are times when my symptoms are well under control. My friends and family tell me how good I look and can’t even tell that I have Parkinson’s. I just tell them to give it a little time, and I will be back to normal. I refuse to let it dictate my social life. If others notice my shuffling or tremor I simply explain my situation and besides, I figure I will probably not see them again anyway. Along with being born with a heart murmur, which limits certain activities, a few years ago I was diagnosed with debilitating arthritis in my toes. Now, if I have trouble walking with painful arthritis in my toes or with freezing or shuffling from the Parkinson’s, I tell myself and others around me that I would make a lousy thief, and I keep moving. My health may have three strikes against me but I am not out of the game yet, I still have several innings left to play.

Besides, what other choice do I have?

Along with the progression of the disease, progression of the medication has increased as well. Currently I take up to 24 pills a day which can be depressing, thinking that I will be taking medication for the rest of my life. But 24 pills a day is better than 25 pills a day! I like dealing with even numbers anyway. I know the importance of exercise which can decrease mood and reduce the amount of medication taken. Besides, what other choice do I have?

In looking back over the last 22 years, I can see how the Parkinson’s has tried to control my day-to-day choices. But that doesn’t mean I have to accept it. It may want to control my body but I control my mind. I remember the adage that says “If you want a job done then do it yourself.” It is because of this mindset, determination and at the encouragement of Julie Carter, I have written a book called Shaken Not Stirred: Parkinson’s with a Purpose which tells my story from when diagnosed and my acceptance of the disease, but in name only, along with humorous uses for the disease, such as when writing a doctors signature. They say that laughter is the best medicine, and if this is true, then I must have one hell of a prescription.

Hopefully my story can help others in their battle for control of the choices in their day-to-day lives. Accept what you have to, but control what you can.

Besides, we have no other choice.

If you are interested in reading John’s humorous look at his own experience with Parkinson’s disease, his book — Shaken Not Stirred: Parkinson’s with a Purpose — is available for $8. We can put you in contact with him by emailing us at pco@ohsu.edu.
The OHSU Parkinson Center is a national leader in research and recognized as a National Parkinson Foundation Center of Excellence. The OHSU Parkinson Center is involved in many studies that are fully recruited and others that are being planned. The following research studies are currently looking for participants. For more information, contact the individual listed for each study or for questions of general interest, contact Andy Fraser at 503 418-4387.

### BALANCE AND GAIT STUDIES

**PARKINSON'S DISEASE (PD) AND BALANCE/GAIT**

**Purpose:** Evaluate if the drug donepezil (commercially known as Aricept) may help improve measures of gait and balance in those experiencing Parkinson's disease.

**Participation requirements:** Participants must be at least 30 years old, have been diagnosed with idiopathic Parkinson's disease and experience problems with balance and gait. Additionally, they will need to be able to walk unassisted for at least two minutes.

**What is involved:** The first treatment phase is six weeks long. During this period participants will take one pill in the evenings and will follow this initial treatment period with a six-week withdrawal period during which they will not take any study medication. They will then begin a second six-week treatment period with either the placebo or donepezil, whichever was not taken during the initial treatment period. The total duration of the study is 20 weeks and will require four in-person clinic visits along with weekly phone visits.

**Compensation:** Eligible participants will receive study-related evaluations, laboratory tests and the investigational drug at no cost. Subjects will be compensated for their time and transportation costs.

Contact: Andrew Fraser, 503 418-4387 or fressam@ohsu.edu. IRB #:10745

**EE FOR PD: EXERCISE AND EDUCATION FOR PARKINSON'S DISEASE**

**Purpose:** Evaluate if the drug donepezil (commercially known as Aricept) may help improve measures of gait and balance in those experiencing Parkinson's disease.

**Participation requirements:** Participants must be at least 30 years old, have been diagnosed with idiopathic Parkinson's disease and experience problems with balance and gait. Additionally, they will need to be able to walk unassisted for at least two minutes.

**What is involved:** The first treatment phase is six weeks long. During this period participants will take one pill in the evenings and will follow this initial treatment period with a six-week withdrawal period during which they will not take any study medication. They will then begin a second six-week treatment period with either the placebo or donepezil, whichever was not taken during the initial treatment period. The total duration of the study is 20 weeks and will require four in-person clinic visits along with weekly phone visits.

**Compensation:** Eligible participants will receive study-related evaluations, laboratory tests and the investigational drug at no cost. Subjects will be compensated for their time and transportation costs.

Contact: Michael Fleming, 503 346-0842 or Flemnic@ohsu.edu. IRB #:10745

**EE FOR PD: EXERCISE AND EDUCATION FOR PARKINSON'S DISEASE**

**Purpose:** Investigate effects of exercise and education on posture/gait and cognitive function in people with vascular or lower body Parkinson's disease.

**Participation requirements:** Participants must have PD, experience problems with balance and gait. Participants must be between the ages of 18–80.

**What is involved:** Six weeks of exercise (90 minutes, three days a week), plus six educational classes. There will be pre-, post- and mid-point questionnaires about balance, neurological examinations, and also MRI brain imaging.

**Compensation:** Participants will receive $25 per test session and $50 for each class attended.

Contact: Mike Fleming, 503 346-0842 or Flemnic@ohsu.edu. IRB #:1141

**UNDERSTANDING GAIT AND COGNITION IN VASCULAR PARKINSONISM**

**Purpose:** Understand if cognitive problems (for example, difficulty in planning and performing complex tasks) are related to the walking changes in people with vascular risk factors, in those experiencing Parkinson’s disease.

**What is involved:** Tests of balance, gait and thinking ability, MMSE and two 1-hour sessions.

**Compensation:** Participants will receive $25 per test session, as well as care fee if needed.

Contact: Michael Fleming, study coordinator, 503 346-0842 or Flemnic@ohsu.edu.

### REDUCING DYSKINESIA IN PARKINSON'S DISEASE WITH OMEGA-3 FATTY ACIDS

**Purpose:** Measure the safety (side effects) of an omega-3 fatty acid called docosahexaenoic acid (DHA) and the dyskinesia (involuntary movements) in Parkinson's disease.

**Participant requirements:** Participants must have PD, be about to start levodopa and be able to stand for one minute unaidsed.

**What’s involved:** This study will last for one-and-a-half years and will involve six visits. The first visit is a screening visit and includes a neurological examination and completion of several questionnaires. After the screening visit participants will be randomized to either DHA or a placebo (sugar pill). The next five visits are overnight stays in the Oregon Clinical and Translational Research Institute (OCTRI) at OHSU. Participants will be admitted to the OCTRI the evening before study tests begin and then their usual PD medications will not be given again overnight, so that the Levodopa cycle may be observed the next day.

**Compensation:** Participants will be compensated $50 for each overnight visit completed for a total of $250.

Contact: Brienna Lobb, M.S., MPH, study coordinator, 503 220-8262 extension 5187; VA IRB #:2907; eIRB #:8012

### MIDDLE OR LATE STAGE PARKINSON'S DISEASE (ON PD MEDICATIONS)

**TOPIMARATE AS AN ADJUNCT TO AMANTADINE IN THE TREATMENT OF DYSKINESIA IN PD**

**Purpose:** To examine the safety and effectiveness of topimarate in people with Parkinson's disease.

**Participant requirements:** Participants must have PD, experience problems with balance and gait during PD medication. A subset of subjects, who experience freezing of gait, will be randomized to complete the 2nd part of the study. EE for PD (Exercise and Education for Parkinson’s Disease). This involves completing six weeks of exercise sessions with a trained exercise educator to learn how to better live with Parkinson’s disease. The EE for PD subset will repeat the MRI, balance and thinking tests after six weeks of classes and again after the 12 weeks of classes.

**Compensation:** Participants will receive $25 per day for the initial test sessions of gait/balance/cognitive testing and MR. Subjects in EE for PD will also receive $5 for each education and exercise session attended (minimum of $5 – $150).

Contact: Susan O’Connor, RN, Study Coordinator, 503 273-5336 or Michael Fleming, 503 346-0842, VA IRB #:8797

**THE EFFECTS OF VITAMIN D ON BALANCE IN PD**

**Purpose:** To examine the effect of vitamin D on balance in people with Parkinson's disease.

**Participation requirements:** Participants must be able to walk 50 feet without the use of a cane or other walking device, be over age 50 and have no history of renal stones or hypercalcemia. They must have at least one or more falls per month and must not be taking another type of vitamin D supplement.

**What is involved:** This study involves a total of six visits to OHSU and lasts 16 weeks with an additional eight weeks of follow-up. Participants will have tests of thinking and memory, and routine examinations about balance and strength, plus blood draws, questionnaires, gait tests, balance tests and strength. One week after the last visit, participants will take a fourth dose of vitamin D and repeat the tests of balance and strength and diaries of near falls and falls. Participants will take vitamin D for the entire length of the study. While in the study, the EE for PD subject will repeat the MRI, balance and thinking tests after six weeks of classes and again after the 12 weeks of classes.

**Compensation:** Participants will receive $25 per day for the initial test sessions of gait/balance/cognitive testing and MR. Subjects in EE for PD will also receive $5 for each education and exercise session attended (minimum of $5 – $150).

Contact: Susan O’Connor, RN, Study Coordinator, 503 273-5336, VA IRB # 1291

**PARKINSON’S DISEASE (PD) AND CHRONIC CONSTIPATION**

**Purpose:** Evaluate if a new drug is effective, safe and well-tolerated in treating constipation.

**Participant requirements:** Participants must have experienced and been treated for chronic constipation (on average, three or fewer bowel movements per week) for the past three months, and be dissatisfied with existing treatment. Participants must not have an age of the same 18-80.

**What’s involved:** This will be a total of five study visits over approximately two months. The study drug is a self-administered injection given in the abdomen. Subjects will complete questionnaires and a clinical evaluation at each visit. Subjects will also complete weekly questionnaires. Some subjects will receive placebo for both dosing periods. This is a randomized study. Subjects will not be able to take other medications for treating constipation during the study. However, there are medications available in the event of a subject going four days or more without a bowel movement during the course of the study.

**Compensation:** Eligible participants will receive study-related evaluations, laboratory tests and the study drug at no cost. Subjects will be compensated for their time and transportation.

Contact: Kellee Kinis at 503 494-9531 or kenis@ohsu.edu. IRB #:10706

### HEALTHY VOLUNTEERS

**THE PARKINSON’S PROGRESSION MARKERS INITIATIVE (PPMI)**

**Purpose:** Help define biomarkers, or indicators of PD progression and investigate certain risk factors of PD, including the relationship between Parkinson’s and sense of taste.

**Participant requirements:** Participants are who are over age 60 and who do not have PD.

**What’s involved:** Find out if you are eligible to participate by taking the small survey on the PPMI website at takethesurvey or call 877 525-PPMI. If you have Parkinson’s disease, (PD), you will be helped to reach the 10,000 people without PD who may qualify.

Contact: Alicia Porto at 503 494-1382 or portolio@ohsu.edu. IRB #:6459.
The past several years have brought the therapeutic benefits of yoga to the forefront of movement capitalization on many aspects of neurological function. This makes yoga a perfect candidate for someone with Parkinson’s disease.

Ron Blehm, P.T., at the Veterans Administration, and I, a yoga therapist and movement expert, were inspired to put together a small unfunded trial using the Gentle Yoga DVD I had created with the Veterans Association. This program uses exercise in a unique way, attempting to integrate it into ADLs (activities of daily living) rather than segregate it to an isolated activity completed only a few times a week at best. It brings exercise techniques, such as yoga, into small segments. These can be accessed many times throughout the day, creating a greater awareness of one’s daily habits, both positive and negative.

During the trial, the instructional DVD, which demonstrated yoga movement patterns and a stretching to be integrated into daily routines, was given to people with Parkinson’s who were already participating in ongoing VA exercise groups with a physical therapist. They were asked to participate with the DVD as often as they wanted for a three-month period. They also kept a log of how often they worked with the DVD, hoping that it would become integrated into their normal, daily functioning.

Based on this small, unfunded study, we have concluded that having Parkinson’s patients exercise at home with this instructional DVD may be effective for improving some aspects of ADLs and self-care. Being able to continue to be independent and active affects more than just activities at home. It creates a sense of confidence which increases the desire to stay connected with the community, which improves not only quality of life, but longevity as well. Further study would be warranted to determine whether or not we could create even more significant and sustained improvement.

Any exercise program should be undertaken with the approval of your physician and is best engaged under the guidance of a physical therapist and exercise specialist knowledgeable in PD.

Anya has been deeply involved in the workings of the body for the better part of 20 years. She began teaching yoga over six years ago and has since focused on the therapeutic aspects of many movement-based modalities. Her approach is simple: To have as many tools as possible available, to learn how clients live in their bodies, and to design the best possible program from all she has at her disposal. If you wish to contact Anya, see her website at www.elementumnw.com.

Introducing the Future of PD Care and Research

The OHSU Parkinson Center is committed to training the next generation of PD specialists. These young neurologists are furthering their training and expertise to improve the lives of people with PD.

Victoria Holiday, M.D.

Dr. Holiday was born in the small town of Beattyville, Kentucky, and studied medicine at the University of Kentucky before moving to Salt Lake City, Utah to train in neurology. She chose to pursue the study of movement disorders at OHSU because she enjoys the detailed patient interactions and procedures that the clinical practice of movement disorders allows. Fellowship at OHSU allows a great balance of patient care, procedures and research that Dr. Holiday hopes to carry forward with her when she graduates.

Nicole Licking, D.O.

Dr. Licking grew up near Lexington, Kentucky. She attended medical school at Touro University - College of Osteopathic Medicine in Vallejo, California. She completed her neurology residency at Geisinger Medical Center in Danville, Pennsylvania. She enjoys neurology and movement disorders because of the connection with the patients. She is hopeful that this fellowship will help her to maintain her enthusiasm for learning through direct patient care and participating in clinical research.

Keirian Tuck, M.B.B.S.

Dr. Tuck was born in Medford, Oregon, and moved to the San Francisco Bay Area at a young age. He studied medicine in Sydney, Australia and completed his neurology residency at OHSU. He enjoys treating people with Parkinson’s disease and movement disorders because of the long-term connections between doctors and patients. It also fits well with his research interests in palliative care.

Son raises funds for OHSU Parkinson Center

Gears, Grit, and Gray Hair—The Ride Across America

Douglas Hopper and Jon Stoner, along with their team manager, Terri Hopper (Doug’s wife), spent a good part of the summer bike riding across America to raise funds to fight Parkinson’s disease. Doug and John’s adventure honors Doug’s mom and the OHSU Parkinson Center. Doug says, “Parkinson’s disease affects approximately 1.5 million people in America. My mother happens to be one of them. While on her own 27-year journey with Parkinson’s, the OHSU Parkinson Center has allowed her to have a good life by providing medical services, counseling services and support. In addition to these services, the Center also conducts nationally recognized research to find a permanent cure.” With pledges per mile or one-time donations, Doug and Terri are raising $4,400 for the OHSU Parkinson Center.

Thanks, gentlemen (and Terri too), for your sense of adventure, strength and support. We are honored to be recipients of your trust in care for your mother and funds in support of our research and care initiatives for people with PD.

For more on their adventures, from this last summer and next, visit https://sites.google.com/site/gearsgritandgrayhair/
OHSU Parkinson Center & Parkinson’s Resources of Oregon cordially invites you to…

Caregiver Connection
A night just for family caregivers of Parkinson’s disease.

“Relax & Connect” Reception
Keynote Understanding and Coping with Caregiver Depression and Grief
Elaine Sanchez
Author, Speaker, Co-Founder CaregiverHelp.com

Breakouts
Practical Tips for Daily Caregiving
Julie Carter, RN, MS, ANP

Difficult Discussions:
Tackling Tough Issues with Your Loved One
Jason Malcom, LCSW

Registration at www.ohsubrain.com/pco
$15/pp
Scholarship available

OHSU Parkinson Center
Elaine Sanchez

---

CALENDAR

OHSU PARKINSON CENTER
THURS., FEB. 12 — Caregiver Connection: A Night to Relax and Learn!
A special evening just for caregivers of people with Parkinson’s disease. It will be a time to connect with old friends, make new ones, and gain new ideas for caring for yourselves and your loved ones. See details above.

NEWLY DIAGNOSED WITH PD?
Every other month the OHSU Parkinson Center offers a three hour session for people recently diagnosed with PD and their spouse or family member. Participants may ask any and all questions of a PD specialist and long-time patient. $20/person; refreshments served. http://tinyurl.com/NewParkinson.

SAVE THE DATE: SEP 26, 2015
Options and Opportunities
32nd annual Parkinson’s disease symposium for people with Parkinson’s disease and their families held in Portland, Oregon. More information to come in our June newsletter.

PARKINSON’S RESOURCES OF OREGON (PRO)
503-594-0901 800-426-6806
Join PRO at one of three locations this spring for renewal and new information about managing Parkinson’s disease.

SAVE THE DATE: MAY 8
Celebrate Hope Dinner and Auction
Benefit fundraiser for PRO local programs and services. Tickets on sale January 1, 2015.

VA PARKINSON CENTER: PADRECC
FRI., DEC. DEC. 12
Exercise and PD: Movement for Life
Presented by Dr. Laurie King, OHSU Parkinson Center PD exercise expert
Auditorium BLDG 100, 10:00 a.m. to 11:30 a.m.
Call 503 721-1420 to sign up.

Videos from past patient education lectures and handouts are available, plus watch My Parkinson Story Videos:
A series of videos featuring real veterans telling their Parkinson’s stories with explanation and commentary provided by VA medical providers.