



Parkinson Update

UPCOMING EVENTS

Challenges & Champions Outreach Symposium
Tri-Cities, WA

Wednesday, April 9th
1:00pm - 4:30pm



Shakers' Ball
Sunday, April 26th



Strike Out PD
Saturday, May 2nd



26th Annual Parkinson Disease Symposium: Options & Opportunities

Saturday, Sept 12th
9:00am - 3:30pm

More info on back page.

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Parkinson Center of Oregon
National Parkinson Foundation
Center of Excellence

Keeping it in Balance: Falls in PD

Jeff Kraakevik, MD

Everyone has experienced times where balance is not at its best. Sometimes it is by surprise when you hit an unexpected patch of ice on the sidewalk or a toy car parked in just the wrong place, or stumble off the Tilt-A-Whirl at the amusement park. In all of these settings, anyone feels unsteady and a little worried about taking a tumble.

In Parkinson's disease (PD), balance can be affected so that this sensation of uneasiness when walking is a daily reminder and not just an occasional annoyance. As with everything in PD, everyone is very different in terms of the extent that balance is affected. Most people don't have large problems with balance until later in the disease. Even so, when I talk to people in clinic who have even mild disease, most admit that their balance is not as great as it used to be. If there is a problem with balance, falls are more likely.

How can falling (defined as any unintended event in which you contact the ground, floor, or lower level) affect the life of a person who has fallen. Well, there are the obvious immediate concerns of injuries directly related to falls. Most falls just leave painful bumps and bruises, but some can cause more serious troubles. This would include broken bones, broken hips, or bleeding into the brain. Thankfully these serious problems are much less common. Another issue which can affect daily life, but is a

little less obvious is that people who have had a fall may be worried that they will have another fall. If a person is worried about falling, this can have a downstream affect on many activities. Every time they want to go out and do something, they consider whether it is worth the risk of having

Many factors contribute to our ability to walk without falling:

- Sensory capability (particularly vision)
- Gait mobility and balance:
 - Stance
 - Stride length
 - Arm swing
 - Truncal stability
 - Cadence
 - Directional variations
 - Adaptability
 - Turning
- Muscle strength
- Mental factors
- Other medical issues
- Prescribed medications
- History of falling
- Social interaction and support

a fall. This has been proven to reduce trips out to do various activities like meeting friends for a meal, attending club and organizational meetings, going to religious activities, and going to family get-togethers. There is also a tendency to reduce exercising as well. This all can add to many things like fatigue and depression. So, what can we do to try to prevent these falls?

Pictured above: At OHSU's high tech balance and gait laboratory, researchers use equipment to take sophisticated measurements of a patient's balance.

Well, unfortunately there is no magic wand to make your balance better. There are no simple answers as the brain's control of balance is not a simple mechanism. No, there are many inputs and outputs in the brain that are necessary to allow us to stay on our feet. As there are so many facets to balance control, there are also many facets to working to prevent falls. Probably the best way to improve the balance is to do exercises that put the balance to the test. This would include things like Tai Chi, yoga, or Pilates. These exercises make you get into a position where you need to focus on your balance to keep yourself upright. Think of this the same as you think of lifting weights where huge rippled muscles are end products of religiously lifting weight. In the same way tightrope walkers need to practice for a long time to be able to successfully improve their balance enough to perform those marvelous feats over the big top. I'm not suggesting that everyone with PD take up tight rope walking, I'm just saying just like hard work helps the tight rope walker's balance, so can other exercises improve your balance. Also strengthening exercises to keep the legs and trunk in good shape may also help. If you don't know where to start with this, a physical therapist is a great person to get to know as they have plenty of suggestions on exercises to do.

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Our Research Mission: Improving Care through Research

Jay Nutt, MD - PCO Director

Julie H. Carter, RN, MS, ANP - PCO Associate Director

Research and clinical care are inextricably linked at the PCO. Our clinical care mission is to provide the best care; care that is cutting edge,

comprehensive, and compassionate. But we also continue to push the envelope to define what best care is. For some therapeutic questions, we have rigorous clinical trials to guide us in choosing among the immediate benefits and risks to be expected for drug and surgical treatments. But we also want to know what the most appropriate therapy is if we take the long view, looking at the disease course over decades. And what and how do we gauge disease course? How can we improve living with Parkinson's disease (PD)? And the list of questions goes on, as does our commitment to find answers to as many of them as possible to better the lives of those living with PD.

The primary purpose of our OHSU Parkinson Center and Movement Disorder Program clinic is to offer our patients the best care, but the clinic is also a laboratory. Many clinic patients, and often their spouses and caregivers, volunteer to participate in studies and thereby become an integral component of clinical research. Participation in research is an opportunity for patients to have a role in the battle against PD and to advance the hope for a better future for all who have PD. This article will review some of the research projects currently underway in the OHSU PCO clinic/laboratory.

Finding new and better drug treatments for PD is a long tradition at the OHSU PCO. Currently, several new drug treatments are under study to reduce involuntary movements induced by levodopa (dyskinesia), to slow the progression of PD, to treat depression, and to reduce falling. But

the study of PD treatment has expanded beyond drugs and surgery. Other studies are investigating the effects of cognitive behavioral therapy to combat depression and how intensive, targeted exercise might improve balance and walking.

Measuring the way in which PD affects motor function and other activities is important for any research that is attempting to minimize the consequences of PD. The new faculty addition to the OHSU PCO, Dr. Fay Horak, and a new collaborator from Portland State University's Engineering Department, Dr. James McNames, are developing instruments to measure balance, walking, other motor activities and dyskinesia. These instruments are being tested on volunteers with PD in the OHSU PCO clinic.

Questionnaires that many of you fill out in the clinic are to measure mood, sleepiness, and caregiver strain to help the clinician that is caring for you but also are a basis for understanding how parkinsonism affects people and families. I am part of a National Parkinson Foundation committee that is examining measures of quality of care and of disease progression that might be followed in the NPF Centers of Excellence to guide improvements in care. Finally, a collaborator from New Zealand and I are working on methods of analyzing the databases of large clinical trials in PD to ferret out what affects the long-term progression of the disease.

Other OHSU PCO studies are directed at understanding features of the disease that, in turn, will lead to better care. PCO investigators are studying heart rate variability and sense of smell as markers for early PD, perhaps even preceding the motor symptoms, which might help diagnose the disease earlier. The ability to arise from the floor is being investigated as a predictor of falls.

Your Donations Keep Us Going.

OHSU Parkinson Center of Oregon's research, education and comprehensive clinical care programs are nationally renowned and regionally treasured. OHSU is a leader in Parkinson's disease (PD) research and care today in part because caring people support these programs with charitable gifts. Many supporters give in memory of a loved one who received exceptional care here, or who believed in the value of our cutting-edge research. Your gift in honor or memory of a special person with PD is a meaningful investment in fighting PD for future generations. And, 100 percent of your gift dollar goes directly to support care or research. Whether you wish to make a gift or pledge today, or prefer to give to the OHSU Parkinson Center of Oregon through your estate or other form of deferred giving, our development staff can help you create a gift that achieves your philanthropic and personal goals. For information about investing in the future of the OHSU Parkinson Center of Oregon, please contact Lori Sweeney at 503 494-7455, sweeneyl@ohsu.edu; Nicole Good at 503 494-7504, goodn@ohsu.edu; or visit the web-site at www.ohsufoundation.org.

Thank you!

Levels of vitamin D in people with PD are being examined to see if they show a relationship with the diagnosis of PD, balance or injuries. Other studies are examining freezing of gait, when the feet seem to stick to the floor and interrupt walking.

We hope you are as proud of this clinical research portfolio as we are. It is only possible through your participation in studies. Therefore, it is, in reality, the research portfolio of the OHSU PCO and the community of people it serves.

Jay Nutt, M.D.

Applying for Social Security Disability

Jason Malcom, MSW

Making the decision to apply for federal Social Security Disability (SSD) can be a difficult one. The decision to apply can be complex, as there are many factors to consider prior to completing your application. Personal factors such as your age, your finances, how much your condition interferes with your ability to do your job, the possibility of working in another form of employment, and how much you have worked in the past should all be considered prior to applying for SSD. You should also consider the meaning and value you place in your work and what it will mean to you to stop working. Making the decision to apply for SSD is a personal one, but it can be helpful to discuss the above factors with loved ones prior to your application.

It can also be helpful to remember that applying for and receiving federal Social Security Disability

is a right of every American citizen. It is not a welfare program, but an insurance program that all workers in the United States pay into. In fact the full name of the federal disability program is Social Security Disability Insurance (SSDI). SSDI is part of the Social Security Act, which was signed into law as part of the New Deal by President Franklin Delano Roosevelt in 1935.

Once you have made the decision to apply for SSD you will want to familiarize yourself with the process of the application and with the criteria the Social Security Administration (SSA) utilizes to determine whether or not you meet their criteria for disability. A good place to start familiarizing yourself with the process is the website www.ssa.gov. Although somewhat difficult to navigate at first, this website has information on everything you will need to apply for SSD. The website has many links and documents you can download if you prefer working with paper rather than the computer. Two good documents from the www.ssa.gov website to start with are the Social Security Disability Benefits (SSA Publication No. 05-10029) document, and the Adult Disability Starter Kit (Form SSA-3381).

Once you are ready to apply for federal disability benefits, don't delay! Do not worry if you are unable to gather all the information quickly, apply anyway. The SSA will help you gather missing information during the application process. To apply you will need to complete two packets. These packets are the application for Social Security Benefits (form SSA-16-BK) and the Disability Report (SSA-3368-BK). Both of these packets can be found at www.ssa.gov.

There are two ways you can apply for Social Security Disability benefits. You can apply online at www.ssa.gov or you can apply by calling 1-800-772-1213 to set up an appointment to apply over the phone. The Social Security Administration recommends that people apply online using their electronic format, as electronic applications are processed

faster than telephone applications. The Social Security Administration (SSA) uses the following five steps to determine if you meet their criteria for disability:

1. Are you working?
2. Is your medical condition severe?
3. Is your medical condition on the List of Impairments? (Parkinson's disease is on the list.)
4. Can you do the work you did before?
5. Can you do any other type of work?

SSA will first check to see if you have worked enough years to qualify for federal disability. They will also evaluate your current work activities. Once you have met these requirements, the SSA will send your application off to the Disability Determination Services office in your state. Doctors and disability specialists at this state agency will then ask your doctors for information about your condition. They also will ask your doctors for information about your ability to do work-related activities, such as walking, sitting, lifting, carrying and remembering instructions. Your doctors are not asked to decide if you are disabled during this process.

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* Form Enclosed in This Issue* Critical Information for Caring for the Parkinson's Patient

Developed jointly by the OHSU Parkinson Center of Oregon (PCO) and Parkinson's Resources of Oregon (PRO), the *Critical Information for Caring for the Parkinson's Patient* form has helped numerous patients and their carepartners receive better care from healthcare professionals in hospitals and care facilities who are not familiar with the unique aspects of caring for someone with Parkinson's disease (PD).

While not legally binding, this document provides you with an opportunity to express your unique needs/symptoms and also can serve as an education tool for care staff you may interact with. Because symptoms and medication regimens frequently change, it will be important that you periodically review and update this information.

If you have additional questions regarding the use of this document, please contact either of us at the number(s) listed below.

Lisa Mann, RN
OHSU PCO
503-494-5620

Holly Chaimov, Director
PRO
800-426-6806



MEET OUR NEW SOCIAL WORKER & FAMILY CAREGIVER SPECIALIST: JASON MALCOM, MSW

Jason Malcom joined the OHSU PCO in August 2008. Jason recently earned his masters of social work degree from Portland State University. Prior to this Jason worked in child and family mental health for 10 years with children and families throughout Oregon. Jason has also managed both residential and outpatient mental health programs in Oregon. Jason provides resources and support to patients and families in the Movement Disorders clinic and is involved in program outreach and development for issues important to patients, families, and health care professionals.

Making Your Meds Work Better!

Lisa Mann, RN



It's all in the timing!

Your clinician may prescribe your medications, but how you take them is what makes or breaks their success in controlling your Parkinson symptoms.

Early in PD, when you first start medication, your body is more forgiving of late or missed doses. But as the dopamine supply in the brain continues to decline, compliance with the increasingly complicated dosing schedule outlined by your PD specialist or neurologist is critical to keeping you active and engaged.

So how do you manage to remember multiple doses, multiple medications, and a complex timing schedule where taking a pill 15 minutes too early or late can make a difference in how you move, how you look, and how you feel? Follow these steps.

First, recognize that it is not easy, and help may be necessary. The goal is to concentrate on living and enjoying life, not obsessing about your medications. So commit to finding a workable system to ensure compliance.

Secondly, know your medications: what each one looks like, why you take it, when you take it, and what

your body is like when it works or when it doesn't. For people with PD, that means knowing when you are "on" (medication is working and controlling whatever motor symptoms you have—tremor, slowness, rigidity) or "off" (symptoms aren't controlled adequately). Carry a list of your medications with you at all times.



Next, honestly assess physical or memory limitations you or your loved one has that will complicate further an already complex drug schedule. Then find a tool that matches your needs.

Choosing a device: Research which system or device will best respond to the needs you've identified. It may be as simple as having your meds listed on a piece of paper and checking off when you take each one. You may need an alarm to remind you. If so, research medication timers online or by calling companies and asking about features. The adjacent chart shows some of the pros and cons of a variety of medication reminders.

Do your homework and faithfully use an appropriate system, and you can improve your medication "on" time and worry less about your PD meds.

When choosing a specific medication timer/reminder, determine the following:

1. How many times a day you take medication—2, 3, 5, 8 times per day?
2. How many pills at a time do you take?
3. Do you need a reminder that can also hold pills and travel with you or can it be separate (like a watch)?
4. Do you need an audible reminder or is a vibrating one better?
5. Does tremor, freezing, or problems with dexterity hinder taking medications?

Some medication reminder resources:

- www.medclock.com part of epill.com - 800-549-0095
- www.productsfor seniors.com - 800-566-6561
- www.911medalert.com - 805-482-3565
- www.forgettingthepill.com



[* Cost: if cost is a problem; save a few dollars a month until you can purchase it or consider asking a family member or friend for it as a gift.]

Type of Device	PRO	CON
Self Cost: none	Simplicity.	Fallible. Chance for error – high. Mistakes can occur in dosing and timing so medications appear not to work. If memory or judgment is impaired, may take too many pills or not enough. If compulsive about PD meds, may overdose or become anxious between doses.
Carepartner (spouse, family, friend) Cost: none	Same as above	Same as above. Not always available.
Paper and pen checklist Cost: none	Same as above	No audible alert. No backup if don't refer to list. Distractions mean missed meds. Memory, judgment, and anxiety unresolved.
Take at meal time. Cost: none	Same as above	Mealtimes may vary from day to day. Mismatch; more frequent dosing than standard three meal times per day may be necessary. CAUTION: Medication may not be compatible with food (e.g. protein can reduce or eliminate effectiveness of Sinemet® / carbidopa-levodopa).
Interval timer Cost: \$45-\$50	Vibration and alarm. Can set for 99 hours. Multiple med alarms.	Cost. * Pills must be stored separately.
Pager Cost: \$80-\$90	12 alarms possible. Reset not necessary. Easily transported.	Cost. * Programming necessary. Some require monthly fee. Pills must be stored separately.
Wrist alarm (e.g. wrist watch) Cost: \$75-\$85	Easily transported. 12 alarms available.	Cost. * Complexity of setting alarms. Audibility if hearing a problem. Pills must be stored separately.
Alarm pill boxes Cost: \$45-\$60	Pill storage included.	Cost. * Size: may be bulky. Limited alarms and pill containers; make sure you find one with at least six per day.
Automatic pill dispenser Cost: \$200-\$900	Limits access if individual has memory issues or tends to take too much medication.	Cost. * Size: most are limited to at-home use.
Cell phone Cost: varies widely and monthly plan necessary.	Convenience (most people have and carry cell phones). Multiple alarms possible. Notes about purpose of alarm possible.	Cost. * Cell phone may not have multiple alarms. Programming may be complicated. May need to reset daily.
PDA (Personal Data Assistant) Cost: varies for full service PDA; programmable watch available at medclock.com (\$80-\$90).	Programmable. Multiple repeating alarms. Description detail possible. Computer interface. Programmable watch available.	No vibration. Programming may be difficult if dexterity is a problem. Computer eases programming, but not everyone may have or know how to use a computer. Size.

Continued from Page 1 -- Falls in PD

There are many other things that can be done. You can have your house looked over by occupational therapy for fall hazards. You should have night lights on at night or turn on a lamp if you need to get up to use the bathroom. As our balance is affected, the brain relies more heavily on what we see to be sure we keep upright, so walking without lights on is not a great idea. If safety while walking is a concern, you should talk to your doctor or physical therapist about whether you should use a cane or a walker. I realize it is not always the coolest way to get around, but I'd rather have my patients safe and get around by walker, than have a fall, and need to get around in an ambulance.

You should also talk with your doctor about some medical issues that can lead to balance problems. Although Parkinson's medications don't help balance much specifically, an increase in these medications can often lead to better mobility which can help you get around. The effects of deep brain stimulation surgery (DBS) on balance in PD are still being sorted out. It may improve mobility, just like the PD medications, but there is actually a large group of researchers who feel that balance may be made worse with DBS. There is ongoing research into this and if there may be other areas of the brain to stimulate which may actually help with balance. Certain medications can affect the balance, so especially if you

are on a lot of medications, have a doctor review all your medications to insure that they are indeed all still necessary. Sometimes light-headedness or fainting can lead to falls, and this needs to be addressed by your doctor to come up with a strategy to treat this. Sometimes falls are due to dizziness from inner ear problems which can also be addressed by your doctor. So, you can see that each person is going to need a slightly different approach based on where the potential problems arise. So, if you have PD and you find

How to Prepare and What to Do If You Do Fall

Ron Blehm, P.T. - VA PADRECC

There are several things you can do to prepare for a fall.

- * Have someone check on you daily.
- * Keep a list of emergency numbers near the phone.
- * Always have a way to call for help whether it be a cell phone or talk to your doctor about getting a home monitoring service.

If you do start to fall, try to relax your body. This will reduce the impact off the fall. Try your best to stay calm. Press your monitor button if you have a home monitoring service or call for help using a cell phone. Make sure that you check with your healthcare provider for any injuries.

that your balance is just a little off or if you have already had a fall due to balance problems, there is a lot you can do to help prevent future falls. Consult with your physician to plan now for preventing falls.

More in depth information on fall prevention, a nice review of recent research in falls, see Boonstra, et al. *Cur Opin in Neurology* 2008; 21:461-471.

Five Things You Can Do Today to Help Prevent Falls

Ron Blehm, P.T. -- VA PADRECC

Falls are one of the leading causes of injury in adults over 50 years old. Compound that with a chronic illness such as Parkinson's and the risk for suffering an injurious fall skyrockets. When you suffer an injury your body has to spend valuable resources, healing resources, that are no longer available to keep you active. For someone who has difficulty getting around as easily as they would like, facing the prospect of being less active for weeks or months could very likely mean the end of walking, the end of your independence, or even admittance into a nursing home. Here are five things you might try, starting today, to keep yourself safer.

Exercise: One of the greatest predictors of falls is falls. Once you start falling down

you are more likely to fall down again. I believe that the best defense is a good offense so start exercising and being more active now, today, even if you've never fallen in your life. What's more, exercising helps to keep you stronger and healthier and who doesn't need that?

Balance Drills: This ties in closely with the thought above. I tell my patients that even the professional athletes making millions of dollars have to practice little

drills – like shooting free-throws. So, why shouldn't you practice little skills like balancing? Stand just next to your bed (bed behind you) and try to lean back without falling. If you can lean and then recover you are learning how to recover from falling backwards! Hold onto the kitchen counter or walker and do several sideways or backwards single-leg kicks - Do this with music to add some fun.

Tai Chi or Aquatics: Research is showing that Tai Chi or group exercises are not just good for the body but good for the mind too. Group exercise keeps Parkinson's Disease from being quite so isolating and gets you out of the house. I don't know of anyone who has fallen while in the water so aquatics can be a safe exercise option too.

Assistive Devices: Rehabilitation may also offer you an assistive device such as a cane or walker. These can be very effective in helping to improve your ability to walk and more importantly, they can drastically reduce your risk for falling. The tough thing about these devices is that they can't help that much if you do not use them, so leaving the cane in the car won't keep you from falling in the home.

Think about it: If you are sitting in the passenger's seat of a car and you need to get out of the car, which leg goes out first? Answer, not the left one! Slow down, look at your surroundings and take some time to think about your next move. Put the outside leg out first...get both feet out before standing...get your feet (and your walker) under you and get your balance before trying to take steps. If something isn't working don't keep rushing headlong into trouble! Stop...think...start over.

The PCO at OHSU is a national leader in Parkinson's disease research and is recognized as a National Parkinson Foundation Center of Excellence. The PCO is involved in many studies that are fully recruited; other studies are in the planning stage. Those already fully recruited include studies on drugs to delay progression, new symptomatic drugs, family care research, fatigue, balance, falls, magnetic stimulation, genetics, and sleep. The following research studies are currently needing participants.

EARLY STAGE PD (NOT on PD medications)

Is your Parkinson's disease affecting your mood and ability to handle stress? **Purpose:** This purpose of this study is to learn more about Parkinson's disease. We are interested in stress, mood, and fatigue. This information will be used to help design larger studies looking at meditation-based, complementary and alternative therapies for mood in Parkinson's disease. **Participation Requirements:** Participation in this study will require 1 clinic visit that will include an assessment for signs of Parkinson's disease and completion of several questionnaires and a computer test. Additionally, we will be recording EEG brain waves and heart rate. To qualify for this study you must be diagnosed with Parkinson's disease, and not currently be treated with levodopa/carbidopa. There is compensation available for participants of this study. Dr. Jaskrit Wild is the investigator for this study. For more information, please contact Dr. Jaskirat Wild at 503-494-7219 or wildja@ohsu.edu. eIRB# 4106

MID- to LATE-STAGE PD (on medications)

Can creatine slow the progression of Parkinson's disease? **Purpose:** The purpose of this study is to evaluate whether the study drug, creatine is able to slow the progression of Parkinson's disease (PD). In this study, you will be randomly assigned to receive the study drug or placebo (inactive substance). Neither you nor the investigator will know whether you have received the study drug or placebo. **Participation Requirements:** Participation in this study will require 9 clinic visits and 3 telephone contacts. The investigator will follow the progress of participants for a minimum of five years, performing physical exams, tests of thinking, mood and evaluations of quality of life to monitor signs of disease progression. To qualify for this study you must have been diagnosed with PD within 5 years and you must have been treated with and been responsive to treatment with dopamine agonists or levodopa for at least 90 days but not more than 2 years. Julie Carter is the investigator for this study. For more information, please contact Megan Murray at 503-418-4387 or murrayme@ohsu.edu. eIRB #3112

Do you have dyskinesia (involuntary movements) and Parkinson's disease? **Purpose:** The purpose of this study is to evaluate whether the study drug, fipamezole, is able to lessen dyskinesia (involuntary movements) caused by PD medications and shorten the "off times" between doses of medications for PD. In this study you will have a 3 in 4 chance of receiving active study drug and a 1 in 4 chance of receiving a placebo (a tablet that looks like the study drug but has no real medicine in it). **Participation Requirements:** Participation in this study will require 6 clinic visits which will last for 2 to 6 hours over a period of 2 months. For three days prior to the clinic visits you will be asked to record your dyskinesia in a paper diary. To qualify for this study you must have dyskinesia caused by PD medications for at least 25% of the day. Dr. Jeff Kraakevik is the investigator for this study. For more information, please contact Megan Murray at 503-418-4387 or murrayme@ohsu.edu. eIRB #4063

Do you have Parkinson's disease and currently take carbidopa/levodopa (Sinemet)? **Purpose:** The purpose of this study is to see how low doses and high doses of the study drug, carbidopa affect movement in subjects with Parkinson's disease. **Participation Requirements:** Participation in this study will require 4 clinic visits, 2 three day hospital stays, and a phone call. The study will take 12 weeks to complete. In order to qualify for this study you must be diagnosed with Parkinson's disease and currently taking carbidopa/levodopa, which may be labeled as Sinemet. Dr. Jason Aldred is the investigator for this study. For more information, please contact April Wilson at 503-418-1769 or wilsonap@ohsu.edu. eIRB#4133

MARKERS/GENETICS

Do you have Parkinson's disease and a living family member who is also affected? **Purpose:** The purpose of this study is to learn more about the genetics of Parkinson's disease from diagnosed individuals who have a living family member with the disease. **Participation Requirements:** Participation in this study will require 1 clinic visit consisting of a neurological exam, a blood draw (2-3 tablespoons), and questionnaire, which will take approximately 1 1/2 to 2 hours. To qualify for this study you must be diagnosed with Parkinson's disease and have a living family member that also has PD. Julie Carter is the investigator for this study. For more information, please contact Pamela Andrews at 503 494-0965 or andrewsp@ohsu.edu. eIRB #5367

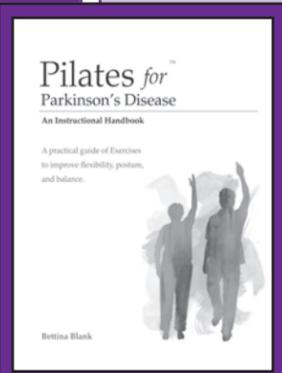
Parkinson Associate Risk Study (PARS): Evaluating Potential Screening Tools for Parkinson Disease (VA IRB ID: 2021; VA IRB Grant Number: # 05-0307) Dr. Penny Hogarth is conducting this research study to estimate the frequency of olfactory loss in first-degree relatives of Parkinson's patients. Participation by a first-degree relative of a Parkinson's patient would require 6 one hour annual visits to the Portland VA Medical Center and completion of 6 annual smell tests by mail. The study would require travel to Connecticut for a brain imaging procedure. All costs for travel to Connecticut will be paid by the study sponsor. All first-degree relatives of PD patients above the age of 50 or within 10 years of the age of diagnosis of PD are invited to participate. This is a research study and not 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 Susan O'Connor, RN at (503) 721-1091.

If you would like more information about participating in research studies, contact the PCO (see ongoing research & contact information above) and/or request a copy of the National Parkinson Foundation brochure: "Should You Volunteer? PD Research Studies" by calling NPF at 800-327-4545 or visiting their website, www.parkinson.org.

Pilates for Parkinson's Disease: An Instructional Guide - Now Available!

Two years ago, the OHSU Parkinson Center of Oregon partnered with Pilates instructor, Bettina Blank, to develop a PD Pilates class. The results was a class that received national news attention and immediately gathered an enthusiastic and loyal following of people with PD. Ms. Blank has trained other instructors and the class has expanded to five different locations in the Portland metro area. Because of the positive response and continued calls from people with PD and Pilates instructors, Ms. Blank has authored an instructional guide for people interested in following this beneficial program. Easy to follow instructions and pictures make the program accessible to everyone.

To order a copy, contact Sara Duran at 503-494-7231 or durans@ohsu.edu (cost: \$17.95, includes shipping and handling).



DEPRESSION IN PD

Do you have Parkinson's disease and untreated depression? **Purpose:** The purpose of this study is to find out how to better treat depression in patients with Parkinson's disease. The study will examine the use of two FDA approved anti-depressants, Paxil CR and Effexor XR to see how these drugs affect depression in Parkinson's patients. **Participation Requirements:** Participation in this study will require 7 visits to the clinic and 2 phone contacts and will take 16 weeks to complete. To qualify for this study you must be diagnosed with Parkinson's disease and have had no recent use of antidepressants. Dr. Matthew Brodsky is the investigator for this study. For more information, please contact April Wilson at 503-418-1769 or wilsonap@ohsu.edu. eIRB # 1407

Do you have Parkinson's disease and receive treatment for depression? **Purpose:** The purpose of this study is to determine if taking omega-3 fatty acids along with your current anti-depressant helps with symptoms of depression in people with PD. In addition we will determine if omega-3 fatty acids decrease blood levels of substances that are associated with depression. **Participation Requirements:** Participation in this study requires 3 clinic visits and will take 3 months to complete. To qualify for this study you must have a diagnosis of PD, currently on a stable dose of anti-depressant medication, and be between the ages of 18 and 85. Dr. Lynne Shinto is the investigator for this study. For more information, please contact Dr. Lynne Shinto at 503-494-5035. eIRB # 0179

BALANCE / EXERCISE

Are you interested in exercise for your Parkinson's Disease? **Purpose:** OHSU's Human Balance Disorders Laboratory is seeking subjects with Parkinson's disease to study the effect of two types of high intensity exercise on Parkinson's Disease. **Participation Requirements:** Participation in this study requires being randomized into one of two exercise groups and going to OHSU to participate in the exercise program, 4 times a week for 4 weeks and 2 times a week for 2 weeks. You will also undergo tests of your balance and physical performance 3 times (twice before the exercise program begins and one time after). To qualify for this study you must have a diagnosis of Parkinson's disease, be free of other neurological disorders, have no significant orthopedic muscular, or cardiovascular impairments. Dr. Laurie King is the investigator for this study. For more information, please contact Triana Nagel-Nelson at 503-418-2602. eIRB #4402.

Do you have Parkinson's disease and difficulty with balance? **Purpose:** OHSU's Human Balance Disorders Laboratory is seeking patients with Parkinson's disease for a study of the effect on the balance function of Parkinson's while on and off Levodopa. **Participation Requirements:** Participation in this study requires 1 clinic visit that will take approximately 4 hours to complete. To qualify for this study you must have a diagnosis of Parkinson's disease, be free of other neurological disorders, have no significant orthopedic or muscular impairments for standing and be able to stand independently for at least 20 minutes. You will receive payment for your participation. Dr. Fay Horak is the investigator for this study. For more information, please contact Triana Nagel-Nelson at 503-418-2602. eIRB #811.

Healthy Volunteers Needed for Balance Study. **Purpose:** OHSU's Human Balance Disorders Laboratory and Human Spatial Orientation Laboratory are seeking healthy individuals to serve as age-matched controls for patients with neurological involvement for studies in balance function. **Participation Requirements:** Participation in this study requires 1 clinic visit that will take 2 to 4 hours. To qualify for this study you must be 18-80 years of age, in excellent general health, and have no history of dizziness or balance problems. You will receive payment for your participation. Dr. Fay Horak and Dr. Bob Peterka are the investigators for this study. For more information, please contact Emilie Weed at 503-418-2618 or Triana Nagel-Nelson at 503-418-2602. eIRB #s 177, 675, 677, 811, 1080, 1065 and 5696.

OTHER MOVEMENT DISORDERS

Do you have Huntington's disease? **Purpose:** The purpose of this study is to evaluate the effectiveness of tauroursodeoxycholic acid in treating HD. In this study, you will receive a capsule to take twice a day. You have a 2 in 3 chance of receiving the study drug Ursodiol, and a 1 in 3 chance of receiving a placebo, (a tablet that looks like the study drug but has no real medicine in it). Ursodiol is approved for treatment in other disorders, but not Huntington's disease. **Participation Requirements:** Participation in this study requires 5 visits to the clinic, and will take 8 to 9 weeks to complete. You will need to bring a family member, close friend or guardian to at least the first visit. During your visits, you will do some simple tests of coordination and balance, and you will have an EKG (a record of your heartbeat), blood draw, and urine test at some of the visits. You will also have a lumbar puncture (spinal tap) at two of the visits. To qualify for this study you must be diagnosed with Huntington's disease. You will receive payment for your participation. Dr. Penny Hogarth is the investigator for this study. For more information, please contact April Wilson at 503-418-1769 or wilsonap@ohsu.edu. eIRB# 1927

Do you have Progressive Supranuclear Palsy or Corticobasal Degeneration? **Purpose:** The purpose of this study is to evaluate the safety and tolerability of lithium in patients with PSP or CBD. **Participation Requirements:** Participation in this study requires 7 visits to the clinic, and will take 30 weeks to complete. You will need to have a study partner who can attend all study visits with you. You may have a lumbar puncture (spinal tap) procedure at two of the visits. To qualify for this study you must be 40-80 years of age and diagnosed with PSP or CBD. Some travel costs will be reimbursed. Dr. Penny Hogarth is the investigator for this study. For more information, please contact April Wilson at 503-418-1769 or wilsonap@ohsu.edu. eIRB# 4524

Continued from page 2 -- Disability

The application process itself can be long; SSA estimates that applications are currently taking 3-5 months to fully process and arrive at a determination. Once SSA makes a determination about your eligibility for SSD, they will send you a letter. If your application is approved, the letter will show the amount of your benefit and when your payments start. If your application is not approved, the letter will explain why and tell you how to appeal the decision if you do not agree with it.

Applying for federal Social Security Disability benefits can be a long and daunting process. However there is help available to you! If you have questions about whether or not you think the time is right to apply for disability or a question about the application process itself, please call me

Jason Malcom, MSW
503-418-1661 or malcomja@ohsu.edu

www.ssa.gov was referenced to help write this article.

Training BIG to achieve faster movements; a therapeutic approach to treating PD

Laurie King, Ph.D., P.T.

One of the common manifestations of Parkinson's disease is that people begin to move more slowly and with smaller movements. For example, their steps become shorter and shorter as the disease progresses. However, to successfully negotiate our ever-changing environments, it is very important to be able to generate movements of all sizes and speeds. It is known that there is a relationship between the speed and size (amplitude) of movements. For example, in walking, writing, and speaking, larger amplitude movements are generally accomplished with greater movement speed. In other words, if you take a bigger step, it will most likely also be a faster step. Studies have also shown that training larger amplitude movements also increases movement speed.

The theory of training amplitude was first applied, over 15 years ago, using the Lee Silverman Voice Training method (LSVT).¹ In addition to changes in motor skills, PD progression can also affect voice. Speech in people with PD can include reduced loudness, reduced pitch inflection, monotone speech and imprecise articulation. LSVT is an intensive one-month rehabilitation program that teaches people with PD to speak louder, while using self-monitoring techniques to understand the effort

it requires to produce and sustain such acoustic power. This therapy stresses the principles of intensity, complexity and repetition. LSVT has had great success over the years and from this, another amplitude training was born, 'Think BIG', which focus on everyday gross motor skills.

'Training BIG' was developed by Becky Farley as a means to reduce motor bradykinesia or slowness of body movement. The same treatment principles are used (intensity, complexity and repetition) and the training course is intense: 60-minute sessions; 4 times per week for 4 weeks. The idea is that a generalized training to target whole body movements and to systematically increase the amplitude of such movements, will carry-over to more functional and isolated everyday movements. A recent study showed improvements in the length of steps and size of isolated movements after whole-body 'Think Big' training.^{2,3}

Although OHSU does not have a certified training program, our physical therapy programs

do incorporate principles of 'Think Big' into our therapy for PD. We currently have a clinical trial assessing effectiveness of two different intensive exercise approaches, both of which incorporate principles of 'Think Big' into the therapy protocol.

For more information on participating in the research on intensive exercise, contact Andrea Serdar at 503-494-3151 or serdara@ohsu.edu. Your healthcare provider can refer you for physical therapy with any of our neurological rehab physical therapists by contacting OHSU Outpatient Neurological Rehab at 503-494-3171.

References:

1. Cynthia M. Fox, Lorraine O. Ramig, Michelle R. Ciucci, Shimon Sapir, David H. McFarland, Becky G. Farley. *The Science and Practice of LSVT/LOUD: Neural Plasticity-Principled Approach to Treating Individuals with Parkinson Disease and Other Neurological Disorders*
2. Farley BG and Koshland GF. 2005. *Training BIG to move faster: the application of the speed-amplitude relation as a rehabilitation strategy for people with Parkinson's disease*. 2005. Exp Brain Res
3. www.lsvt.org - this website gives information on training 'BIG' and 'LOUD', how to access lectures and courses and also how to find certified therapists in your area.

Motor Fluctuations: What, When, & Why

Jason Aldred, MD - OHSU Movement Disorders Fellow

Beginning with the discovery of levodopa in the 1960's the treatment of Parkinson's disease has focused on dopaminergic therapy for the symptoms of rigidity, slow movement, and tremor. In the following years other medications come along. A neurologist may start the dopamine agonists ropinirole (Requip) or pramipexole (Mirapex) when symptoms are milder, and carbidopa/levodopa (Sinemet) when symptoms worsen. The benefit from these medications may continue for several years without much noticeable change.

Typically when levodopa is started the effect lasts most or all day. This long duration effect enables patients to miss an occasional dose of medication and not notice wearing off. Regularly dosed medication may control the symptoms of tremor, rigidity, and slow movement through the entire day. This is known as the long duration response, and it may last for several years. Over time the long duration response is replaced by a short duration response. In this situation the duration of benefit from levodopa is reduced and "motor fluctuations" may occur, where one may fluctuate between states of more smooth movement without tremor, and the parkinsonian state of tremor, rigidity, and

slow movement. The noticeable reduced effect of medications between each dose is termed "wearing off" or "OFF time." This contrasts with the periods good tremor control and supple and more fluid movement termed "ON time."

Medication wearing off usually begins at the end of each dose and thirty minutes or so before the next dose of levodopa. As Parkinson's disease progresses, wearing off from levodopa occurs earlier and earlier. Some people notice "sudden OFF's," which is switching from ON to OFF in a matter of minutes.

Dyskinesia is the abnormal involuntary movement of the arms, legs, neck, or torso. It often appears as fidgeting. Another type of dyskinesia involves involuntary contraction of muscles and is called dystonia. Dyskinesia is a very common side effect of levodopa and tends to go hand in hand with "ON time." Dyskinesia usually shows up around the time motor fluctuations begin. It is most noticeable when the levodopa is at its peak dose, within an hour or two of taking the pill. This is known as peak-dose dyskinesia. For some dyskinesia is most severe just as levodopa takes effect and when it is starting to wear off. This is called biphasic dyskinesia. Learning to characterize dyskinesia may be difficult for the individual patient and often requires help from an observant family member or neurologist.

Clinical research has shed light on possible mechanisms of motor fluctuations. Early in Parkinson's disease it may be that an area in the brain called the striatum can store relatively large amounts of dopamine. As Parkinson's disease progresses the brain's ability to store dopamine decreases. In this case the brain relies on a steady supply of the dopamine precursor, levodopa, from the blood. Numerous studies have shown the improvement in parkinsonian symptoms reflects the minute to minute concentration of levodopa in the blood. Other research suggests a more complex process may result in motor fluctuation. One leading hypothesis suggests that the pathway stimulated by dopamine receptors changes over the course of Parkinson's disease. This may depend on whether dopamine receptors are stimulated continuously throughout the day or in short bursts. So when levodopa reaches the brain in surges from oral medications, instead of more continuously, this may change dopamine receptors in a way that predisposes to motor fluctuations.

Many studies have determined that levodopa absorption may be the most important step in getting a good medication response. Since levodopa is taken orally, the bowel must absorb it into the blood before it is transported to the brain for neurotransmission. When levodopa is taken along with large amounts of protein this may interfere with transport into the brain. Probably even more important is the tendency

of meals (particularly those high in protein) to delay absorption. This often results in a delay in "ON time."

The overarching message in the current medical treatment of motor fluctuations in Parkinson's disease is to keep it steady. First, the dose of levodopa must be sufficiently high to result in improved symptoms. Then levodopa should be given often enough to keep the clinical response smooth throughout the day, and sometimes night. Drugs like entacapone and tolcapone are COMT inhibitors, and reduce the breakdown of dopamine and increase "ON time." These medications are given with each dose of carbidopa/levodopa. Dopamine agonists pramipexole and ropinirole have a weaker but longer duration of effect than levodopa. These are often started before carbidopa/levodopa. However, a clinician may try to continue them even after a patient starts carbidopa/levodopa to fill in the gap when wearing off occurs. Selegiline is a MAO inhibitor and like dopamine agonists it may be used early in Parkinson's disease. It is another medication that may be used to reduce the severity of wearing off in between doses of carbidopa/levodopa.

It is important to take carbidopa/levodopa regularly since this is the best way for a neurologist to determine the medication response and make the most appropriate changes. Taking levodopa 30 to 60 minutes before meals may speed the absorption and result in more quickly achieving ON time. Eating a few crackers with the carbidopa/levodopa is a good way to settle the stomach if this is a problem. Another strategy to get quicker ON time is to crush up regular release carbidopa/levodopa. This may shorten the amount of time needed for digestion. In some instances mixing the daily dose of carbidopa/levodopa with slightly acidic water and taking it in liquefied form may help smooth out motor fluctuations. (Ask your neurologist before trying this.)

Deep brain stimulation (DBS) can be particularly effective for people with Parkinson's disease who have severe motor fluctuations and the abnormal involuntary movement known as dyskinesia. This is something a neurologist may bring up if the medication options have been exhausted. For the right patient at the right time DBS is a good compliment to medications.

Currently there are several studies at OHSU focused on the problem of motor fluctuations in Parkinson's disease. One study is looking into whether carbidopa given in high doses can enter the brain and decrease the amount of available dopamine and worsen motor symptoms. Other studies are investigating the effects of dyskinesia on motor function. Please contact the OHSU PCO if you would like to learn more about participating in clinical research.

Research on supplements will look at delaying progression of PD

Along with numerous other sites in the US and Canada, the OHSU Parkinson Center of Oregon is conducting two placebo-controlled studies to learn whether the progression of Parkinson Disease (PD) can be slowed by the use of the nutritional supplements Coenzyme Q10 or creatine. One study is evaluating people NOT taking medications for PD, and the other enrolls people who ARE taking PD meds. If you are interested in participating, contact our research coordinators for these projects, Pamela Andrews or Megan Murray, as noted below.

> The **Coenzyme Q10** study (called "QE3") will enroll participants who have been diagnosed with Parkinson disease within 5 years and do NOT yet require medications for treatment of PD symptoms. The study period is 18 months. The person to contact for more information is Pamela Andrews, 503-494-0965.

> The study of **creatine** is now enrolling participants who have been diagnosed with PD within 5 years of beginning the trial and are now treated with dopamine agonists or levodopa for at least 90 days but not more than 2 years. Participation is for 5 years. For more information about this study (called LS-1), call Megan Murray at 503-418-4387.



OHSU Parkinson Center of Oregon

5th Annual Outreach Symposium Challenges & Champions

OUTREACH SYMPOSIUM NE Oregon & SE Washington

Tri-Cities, Washington
Thursday, April 9, 2009
1:00pm - 4:30pm

OHSU PCO's annual, rotating outreach symposium is slated to return to the Tri-Cities, Washington area this spring. With the assistance of TNRC (The Neurological Resource Center) at Kadlec Medical Center, we have secured the Three Rivers Convention Center for this year's event. Our presentation topics will include:

- ◆ Managing Your Non-Motor Symptoms
- ◆ Building Your Championship Healthcare Team
- ◆ Top 10 Things to Know about PD Medication Management

A brochure will be mailed in late February. If you would like further information before that time, please call Sara Duran at 503-494-7231 or email her at durans@ohsu.edu.

PD Media Magnets

- **Meeting the Challenges of PD:** The inveterate Thom Rock was featured in *The Oregonian* on September 16, 2008. Sharing what it has been like to live with PD since he was diagnosed at 47 years old, Thom helps bring better understanding of the challenges to the public at large, and shares his amazing attitude for coping with this challenging disease. If you'd like us to send you a copy of the article, please contact us at 503-494-7231.
- **Webcasts on PD:** In early September, our faculty was featured on the popular www.patientpower.com webcast website. You can still hear those presentations now:
 - o 9/3/08 – *Why should people with PD exercise?* – Fay Horak, Ph.D.
 - o 9/17/08 – *PD Diagnosis in the Young* – Matt Brodsky, M.D.

25th Annual Symposium Reviews Research and Treatment of PD from Past, Present, & into the Future



Presenters respond to questions from the audience.

Our 25th annual Options & Opportunities Symposium held at the Holiday Inn Convention Center was a great success. Parkinson's disease (PD) research history and progress were highlighted by each speaker as we looked at the latest trends and future hope for better management of PD. More than 20 information booths and vendors from a variety of organizations provided educational and service information for the more than 250 attendees.

A special carepartner breakout celebrated spouses and loved ones who are such an integral part of living successfully with PD.

A DVD of the symposium is available for \$10. If you are interested in purchasing one, please contact Amy Achterman at 503-494-9054.

Mark your calendars now for next year's symposium: Saturday, September 12, 2009 at the Red Lion – Jantzen Beach. See you there!



Presenter, Kari Lyons, LCSW, and PCO's Jason Malcom, give prizes to caregivers.

Sharing Expertise

PD Training for Healthcare Professionals

As medical professionals, medical educators, and specialists in Parkinson's disease, we feel strongly about educating fellow healthcare providers (HCP) in how to better care for their patients with PD. We've found that many HCP are either not up to date on treatment options or are unaware that each person with PD will experience the disease differently and need very individualized therapy. Beginning last year, we have started an annual physician training for primary care providers to teach them about the state-of-the-art treatment for both Parkinson's disease and Alzheimer's disease by partnering with our partners at the Layton Aging and Alzheimer's Disease Center.

As the only movement disorder and Parkinson's disease specialists and researchers in the state, we also feel particularly obligated to train HCP outside of our immediate geographic area. Over the past four years, we have traveled annually to different areas of the region and given patient/family educational symposia, lectures to area physicians, and specialized training to community neurologists on PD. Last

year, for the first time, we instituted a new training as part of our outreach to non-metro service areas where we train a team of allied health therapists (physical, speech, occupational therapists) in the team approach to treating people with PD. The goal of this particular outreach component is to develop a Parkinson network (ParkNET) of therapists who have access to specialized training and resources in treating local people with PD.

For 2009, we will be holding the following outreach trainings.

- **April 9, 2009** – Tri-Cities, WA
 - o Challenges & Champions Outreach Symposium for Patients & Families
 - o Physician education at the Kadlec Medical Center Grand Rounds.
- **April 10, 2009** – Tri-Cities, WA
 - o ParkNET training for Kadlec Medical Center allied health therapists.
- **April 17, 2009** – primary care provider medical education conference about PD – Benson Hotel.

Change Service Requested

OHSU Parkinson Center of Oregon



Center of Excellence



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www.ohsu.edu/pco

E-NEWS format coming! In the coming year, we will be switching to an electronic newsletter format for the "Parkinson Update." Please complete the enclosed pre-paid information card and mail it back to us to make sure we have your e-mail address.

Calendar of Events

THU, APR 9 - TRI-CITIES, WA CHALLENGES & CHAMPIONS

Outreach symposium for patients and families living in NE Oregon and SE Washington region. Join us at the Three Rivers Convention Center on Thursday, April 9 from 1pm - 430pm in Tri-Cities, WA. See information above. A registration brochure will be sent in late February or you can call Sara Duran at 503-494-7231 to register early.

SUN, APR 26 - PORTLAND, OR SHAKERS BALL BENEFIT CONCERT

Local bands will shake things up Sunday, April 26 at this year's 5th annual Shaker's Ball, a benefit concert to aid Parkinson's disease research, which will be held again at the popular McMenamin's Kennedy School. The concert is family friendly with arts and crafts provided. The Bart Ferguson Band, Pilar French, and Lisa Mann will perform. Tickets will be available at the door or in advance by calling 503-494-9054.

PRO (Parkinson's Resources of Oregon)

- **Feb 20:** Lunchtime Lecture: Occupational Therapy for Tremor Control
- **Mar 18:** Lunchtime Lecture: Stress & PD
- **Apr 3-4:** PRO Annual Education Conference in Eugene, OR
- **Apr 26:** Shakers' Ball*
- **May 2:** Strike Out PD Bowling Event*
- **Jun 19:** 7th Annual PRO Charity Golf Tournament

For more information on these events, contact PRO at 503-594-0901 or 800-426-6806 (* Joint event with the OHSU PCO; see above.)

NEWLY DIAGNOSED WITH PD?

EVERY OTHER MONTH the OHSU PCO 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. Call Amy at 503-494-9054 for more information.

SAT, MAY 2 - BEAVERTON, OR 5th ANNUAL STRIKE OUT PD!

Bowl to Benefit OHSU PCO & PRO Portland Yes! It is that time of year again and you won't want to miss the fun at Sunset Lanes in Beaverton, 10:45am - 1:30pm. Lunch is included. Sign up to bowl, donate raffle items, sponsor a team or a lane or just come to watch and join the fun! For more information, call Roger or Karen Anderson at 503-579-7615.

SAT, SEP 12 - PORTLAND, OR OPTIONS & OPPORTUNITIES

SAVE THE DATE and join us for our 26th annual PD symposium for patients and families which will be held at the Red Lion Jantzen Beach.

Veterans Administration's PADRECC (Parkinson Disease Research, Education, and Care Center) Lecture Series

- **Mar 13:** Caregiver Resources (10am-11am)
- **May 8:** Genetics (10am-11am)
Dr. Zabetian
- **Jul 10:** Exercise & BBQ (11am-1pm)
Dr. Horak; Ron Blehm, PT;
Bettina Blank, Pilates Instructor.

Free to the public. All lectures held in the Portland VA Medical Center Auditorium. Call Jeremy at 503-721-1091 for more information.

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