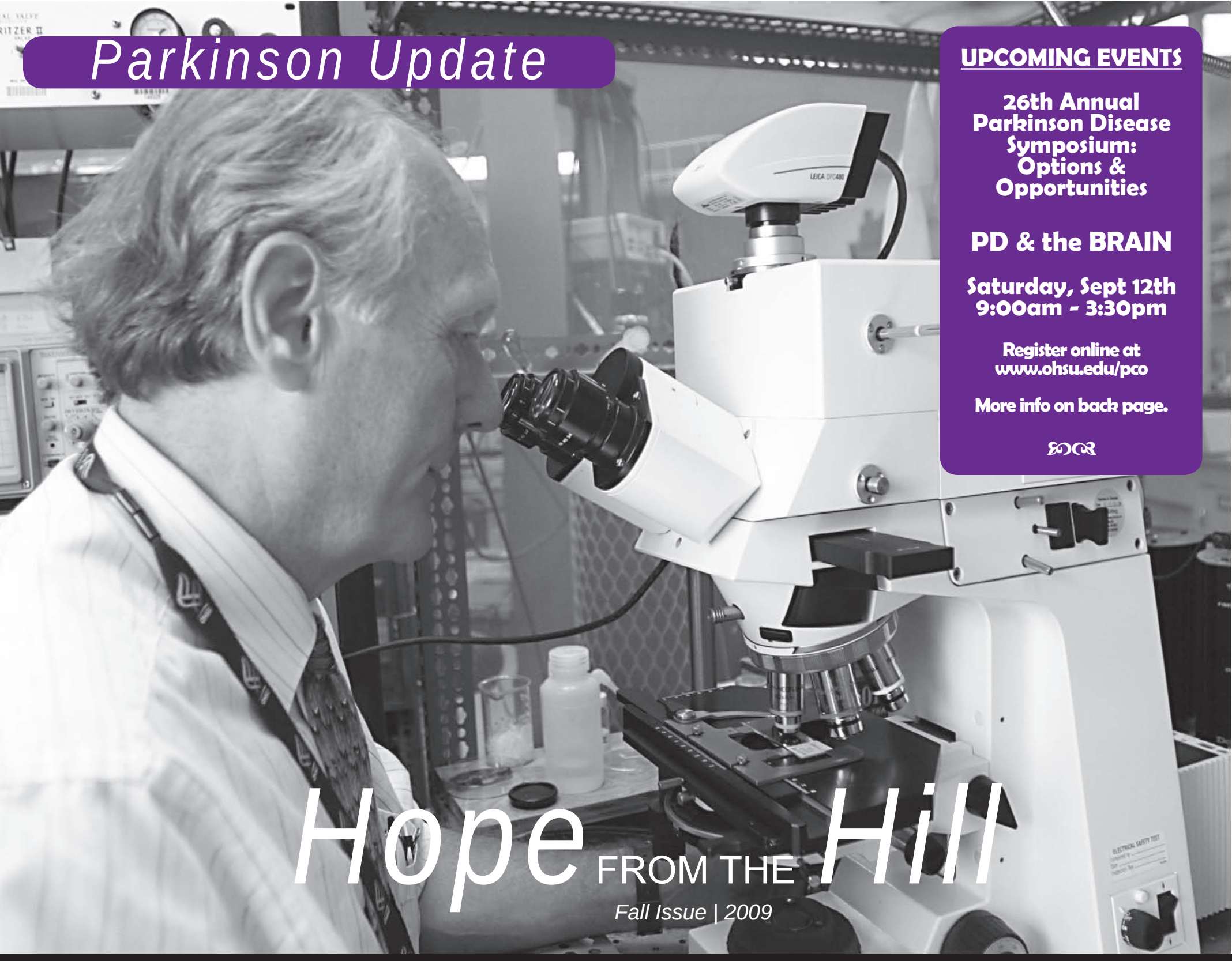
Parkinson Update



Hope FROM THE Hill

Fall Issue | 2009

Published by the Parkinson Center of Oregon
A National Parkinson Foundation Center of Excellence

UPCOMING EVENTS

26th Annual Parkinson Disease Symposium: Options & Opportunities

PD & the BRAIN

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

Register online at www.ohsu.edu/pco

More info on back page.

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OREGON HEALTH & SCIENCE UNIVERSITY

Parkinson Center of Oregon
National Parkinson Foundation Center of Excellence

Genetics Spotlight: What Genes Are Telling Us about PD

Haydeh Payami, Ph.D.

You may remember when PD was thought to be a purely environmental disease. It wasn't until the 1990's when family studies began reporting evidence for a considerable genetic component, which has now been confirmed and documented world-wide. The first paper was actually from OHSU, led by myself and Dr. Jay Nutt; the research was based on approximately 200 PD patients and healthy volunteers from Portland. (Our study has now grown into a national consortium with about 5000 patients and healthy volunteers; more on that later.)

Several genes have since been identified as causes of familial forms of PD. Some are rare; but others are relatively common. The LRRK2 G2019S mutation is the most common cause of PD identified to date, accounting for 1-4% of all cases of PD, and up to 30% in Ashkenazi Jews. Parkin is another common PD gene that accounts for about 10%-50% of young onset PD. The alpha-synuclein is an important gene, because it plays a role in all cases of PD. The alpha-synuclein gene encodes the alpha-synuclein protein, which is the major component of Lewy bodies, the hallmark brain lesions in PD. The significant aspect of alpha-synuclein is that the normal gene can increase the risk of PD if it is over expressed (i.e., it makes too much of the protein it is designed to make; too much of a normal protein can be detrimental). Knowing this has opened the door to novel and exciting research, currently underway, for molecular therapies to remove the excess alpha-synuclein protein. This is an example of how discovery of disease genes can empower development of treatments that could be more effective than what is available now, because they target the molecular problem at its root.

The majority ~ nearly 70% ~ of PD patients have no other relative with PD, which, in the old days, was used to argue for absence of genetic involvement in the common forms of PD. Not true. Increasing evidence is showing that most cases of PD arise from a complex interaction between one's environment (life style, diet, exposure to toxins and protectants), and one's genetic make-up, which determines how one responds to these external insults. The genes involved in common forms of PD are called susceptibility genes, and are different from those that cause the familial forms of PD. Each susceptibility gene has only a small effect on the overall risk of developing PD, but, in combination with other susceptibility genes and environmental factors, they can raise – or more importantly, lower – the risk by ten-fold (that is one-thousand percent).

Continued on page 3

Pictured above: Dr. Steven Johnson, one of our Parkinson's specialists, does basic science research on a high powered microscope.
Photo by Sara Duran

23andMe: Potential and Pitfalls

John Nutt, M.D.

The personal genetics firm, *23andMe*, has launched a Parkinson's disease genetics initiative this spring. The National Parkinson Foundation has encouraged people with Parkinson's disease to participate. However, it is important to understand what you may or, more importantly, may not learn in the process before deciding to have your DNA tested and how this data might be used.

First, *23andMe* is a commercial firm that provides information about a person's genetic makeup based on a saliva sample. DNA extracted from the sample is examined for differences in the sequences of nucleic acids of DNA that are like the letters in a sentence. The laboratory method used by *23andMe* detects the change in a single nucleic acid in a particular place in the DNA.

continued on page 2

Director aNd Associate Director's CORNER

23andMe

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

continued from pg 1

Using letters and words as an analogy for nucleic acids and DNA, the laboratory method might only detect changes in the second letter of the word "complicated." Thus it would tell you if there were an "o" or an "u." It would not tell you about any other letters in the word nor would it tell you about the second letter in any other words. The vast majority of the differences that are examined by *23andMe* are not mutations in genes but simply markers of variability in the DNA. However, this variability may be associated with an increased risk for a certain disease. Continuing our analogy with words, "cumplicated" with a "u" instead of an "o" in the second position might be more common in a group of people with diabetes, suggesting an association of that genetic variability with the disease. The *23andMe* report for an individual client gives these types of associations of genetic markers with various diseases and traits. Some of the associations have not been confirmed in more than one study and often the association increases a person's risk by only a small amount. Finally, it is important to realize that the associations indicate that a certain form of genetic variability is more common in people with a trait or disease; it does not indicate that an individual person will have the trait or disease. Thus interpretation of the report generated by *23andMe* requires a genetic sophistication that many clients are unlikely to possess.

Second, one of the markers used by *23andMe* detects a mutation in a gene that causes some cases of Parkinson's disease, the LRRK-2 gene, which may be responsible for up to 6-8% of cases of Parkinson's disease in some US patient populations. However, only one common mutation in the gene is detected, and it is known that there are a large number of mutations in the LRRK-2 gene that can cause Parkinson's disease. Thus if *23andMe* does not detect the mutation in LRRK-2, it does not mean that you do not have another mutation in LRRK-2 or, for that matter, a mutation in other genes that can cause Parkinson's disease. Further, having the mutation does not mean that you have, or will have, Parkinson's disease. Some people with the mutation do not develop Parkinson's disease.

Third, *23andMe* Parkinson's Disease initiative is having 10,000 people with Parkinson's disease take the *23andMe* genetic test and fill out a questionnaire on the internet in which the person gives details about their Parkinson's disease, as well as information about exposure to various environmental factors such as insecticides, welding fumes, agent orange and other environmental factors. This information will be used to search for new associations between genetic markers, Parkinson's disease and environmental exposures. The power of the *23andMe* Parkinson's disease initiative is that it may collect much more information than a group of investigators could collect over decades of work. Large numbers of subjects allow detection of associations that are not obvious when working with smaller numbers of subjects which has characterized all the studies to date. Thus *23andMe* may pioneer new ways to understand the genetic forces that cause Parkinson's disease.

Jay Nutt, M.D.

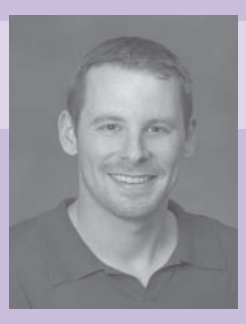
News from the National Parkinson Foundation

Quality Improvement Initiative
Successful companies use quality improvement initiatives (QII) to create safer and better products. NPF, in partnership with our Centers of Excellence, has launched the first data-driven quality improvement initiative to systematically improve care for every patient diagnosed with Parkinson's disease. The centerpiece is a registry that tracks each Parkinson's patient in the Centers and their treatments over time. The goal is to explore the variation in current clinical practice in order to determine what constitutes exemplary care for patients. Our ultimate aim is to create and share models of excellent care, so that every Parkinson's patient receives the most effective treatment options available, whether they are seen by a specialist at a NPF Center of Excellence, a general neurologist or their primary care physician.

The registry is just being pilot-tested in a few NPF Centers of Excellence, one of which is the OHSU Parkinson Center of Oregon. If you volunteer, your participation in the registry will be a contribution to information that will be used to improve the care of people with PD and their carepartners. eIRB#5508.

Ask a Social Worker

Jason Malcom, MSW



"I was recently diagnosed with Parkinson's disease, and I currently work full time. I am determined to continue to work for several more years, but I am concerned about how or if I should talk about my PD at work. I think they might be understanding with me about it, but I'm concerned about how they might respond or treat me once they know I have PD. Where do I start?"

Consider several factors before deciding to disclose your diagnosis. In this article, I will address preparing to disclose your diagnosis (should you or shouldn't you); in the next issue, I will address how and when.

First, take time to understand your own response to being newly diagnosed with Parkinson's disease. When first diagnosed, many people experience a range of emotions from shock, anger, or disbelief to feeling a sense of relief for being able to put a name to the symptoms they have been experiencing. Take time to adjust to this new information yourself. It is natural to have some questions and concerns about how your employer may respond to your new diagnosis, so write these down as you think of them, but wait to address them until you are ready.

Second, there are many factors to consider in deciding whether or not to tell your employer, some of which may not readily be apparent at the time of a new diagnosis. This is a decidedly personal and individual decision. You have no legal obligation to tell your employer about your diagnosis. However, once you have told your employer, there is no taking it back. For this reason, you should not make a hasty decision.

Until you have made your decision, guard your privacy at work.
- Don't keep your medical appointments on your work calendar or scheduling devices.
- Don't send or receive e-mails with any information about your health condition on your work e-mail account.
- Consider how you might respond if your employer asks about your need for multiple medical appointments before you are ready to speak openly.

After taking the above steps to help ensure your privacy, carefully examine reasons to disclose or not disclose your condition . Write out a list of your reasons. It may be helpful to enlist a trusted friend or loved one to help make your list. The list below may help as you think about these options.

Possible reasons to disclose:
- Avoid the stress that comes with hiding your symptoms.
- Unless you disclose your health condition, you are not protected by the legal protections under the Americans with Disabilities Act (ADA). ADA requires an employer to make reasonable accommodations.
- You may gain the support from a surprisingly supportive employer.
- You may be able to speak more openly to your employer about any issues that arise for you.
- Generally speaking, what you disclose to your employer must be kept confidential. (Note: Your co-workers are not your employer, and thus are not bound to confidentiality.)
- You can take your drugs and other treatments without having to hide them.
- Your job requires skills that may be impaired by PD symptoms or may threaten your safety or others. List out skills required by your job in one column and how PD might affect them in the second. Remember medications and therapy can help control symptoms for a long time.

The primary reason not to disclose, of course, is a negative response from your employer. Although your employer must make reasonable accommodations under ADA to keep you in your position, it is still possible that you may encounter discrimination despite the law. This could include anything from being passed over for a raise or a promotion to having your employment terminated. There are resources to ensure this is avoided, but it is something to consider.

After making your list, put it away for a couple of days, then take it out and look it over again. You may have a different perspective after a few days, and you may have some reasons to add or take away from your list. Everyone's employment and relationship with their employer is unique, so you may have additional reasons or other circumstances to consider.

Taking the time to carefully consider the reasons on either side of the equation will help you feel more confident you have made the right decision. My next installment of "Ask a Social Worker" will examine the factors associated with your decision and how to move forward. Look for it in our new e-newsletter in the fall and reprinted in our February 2010 issue.

References: *www.pdf.org*; *www.survivorshipatoz.org*

Genetics Spotlight

continued from page 1

If we are clever enough – and if we have the research funds – we should be able to use what we are learning about gene-environment interaction to prevent PD. If predisposition to PD is determined by cumulative and interactive effects of genes and environmental factors, protection against PD should also be possible if the right therapy is targeted on the specific genotypes that promote their beneficial effects. I envision that in the near future (maybe 5-10 years, if research funds are available and research continues to accelerate at the present rate), when you go to your doctor, she will be able to take a drop of blood, put it on a computer chip, and tell you if you are at risk for PD, and depending on your genetic composition, what you should do to avoid it. Genome chips are already available. Companies like *23andMe* market them directly to the public. The chips even have some of the PD genes on them, but the science to interpret the results and put it to use for disease management is not yet fully developed. That is what we and other research groups in the US, Europe and Japan are working on.

The goal of our research studies is to prevent PD from ever developing in people who are predisposed to it, and to slow, halt or maybe even reverse the course of disease for people who have already been diagnosed. With over 5,000 research volunteers nation-wide, we have tremendous analytical power and are therefore able to take on a comprehensive whole-genome, gene-environment interaction approach to PD. These are some of the studies that are ongoing in our laboratories.

Studies aimed at prevention are carried out through
- genome-wide association studies to identify genes that affect risk and age at onset of symptoms;
- identification and validation of protective factors (diet, lifestyle, and drugs) that could be used for intervention; and
- gene-environment interaction studies to delineate genetic backgrounds that would be most responsive to each intervention.

Studies aimed at slowing disease progression include:
- clinical and genetic studies to predict prognosis and treat patients early to avoid disease complications and disability;
- studies to delineate, at the molecular level, why some patients respond well and others poorly to treatment; and
- pharmacogenomics studies to develop novel neuroprotective therapies that can be customized to the individual's genetic make up for maximum efficacy and safety, and minimum side effects.

I want to say "thank you" to the 200 original OHSU patients and volunteers who got this research off the ground and the other 1000 who have joined us since. Your support, commitment, and continued active participation (via your DNA and data) have been tremendous. With your help, we will keep forging ahead.

Dr. Payami is a well-known geneticist, research scientist, and Professor of Molecular Genetics and Neurology at the New York State Department of Health Wadsworth Center. Before relocating to the east coast, Dr. Payami was a faculty member and research scientist here at OHSU. She continues to collaborate with the OHSU Parkinson Center of Oregon.

The Role of Basic Science Research in PD

Dr. Haydeh Payami (above) and Dr. Steven Johnson (on our cover and inset) are key players in basic science research on Parkinson's disease. So, what is basic science research and what is its role in treating and eventually curing Parkinson's disease? Dr. Johnson explains:

"Basic science research is essential for developing a cure for Parkinson's disease. The most common form of Parkinson's disease is called "idiopathic" because medical doctors do not know the true cause of the disease. However, it is becoming increasingly clear that the likelihood of developing Parkinson's disease is influenced by both genetic and environmental factors as Dr. Payami explained in her article. But teasing apart environmental factors is difficult to do in the human population because no two people have exactly the same life situation. Also, even with a clearly defined genetic mutation, scientists often cannot use human subjects to study the biochemical consequences of the genetics that might lead to this disease. Because controlled experimental conditions are usually needed to discover the biochemical and physiological effects of genetic and environmental influences, these studies often cannot be done in people. This is why basic science research using laboratory animals, tissue culture, biochemistry, and computer simulations are vital for progress in Parkinson's disease research."

RESEARCH FOCUS

Help Us Learn How Low Vitamin D Affects People With PD

Amie Peterson, MD

Do you have issues with poor balance and/or falling?

Recent studies have shown that people with Parkinson's disease are more likely to have low vitamin D levels than healthy people or those of the same age with Alzheimer's disease. Also, the effects of vitamin D in the body have recently been found to be greater than realized in the past. Vitamin D's effect on bones has been known for decades, but more recent research also shows effects on muscles, the hormone system, and possibly in the brain. Vitamin D receptors are widely present in the brain, especially in an area called the "substantia nigra," which is one of the places affected by Parkinson's disease (PD). Studies have shown that when people with PD who had low vitamin D levels and also had problems with falling and balance were given vitamin D supplements, they fell less often.

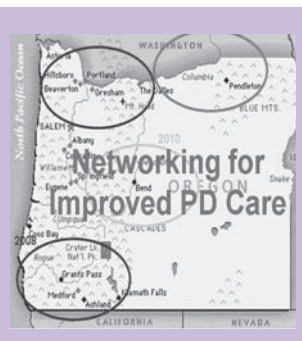
Knowing that poor balance and falls can become a big problem for people with Parkinson's disease, I am conducting a new study to learn more about the connection between Vitamin D and balance in PD. The goals of the study are: 1) to first measure whether people with balance problems in PD have lower than normal vitamin D levels and 2) to lay the ground work for a future project where I will measure changes in balance and falling after giving Vitamin D to people with PD who have low levels at the beginning. I am now looking for people with PD and balance problems or falls to participate in the single study visit. You must not have severe memory problems and must be able to walk without help from another person; it is fine to use a walker or a cane. The visit will take about two hours at OHSU and will include some memory tests, balance tests, and a blood sample to measure vitamin D. If you have poor balance and/or falls and would like to participate in "A Pilot Study of Vitamin D and Balance in Parkinson's Disease," please contact Rebecca Conroy at 503-494-9531 or conroy@ohsu.edu. IRB #4266

Don't have PD, but want to help?

OHSU's Human Balance Disorders Laboratory is seeking healthy individuals to serve as age-matched controls for patients with Parkinson's disease for studies in balance function.

If interested, call Triana Nagel Nelson, 503-418-2602.

IRB#: 177, 675, 811, 1065 and 2487.



Parkinson NETwork Grows with Challenges & Champions

Our annual outreach to non-metro areas in Oregon and SE Washington scored another success: training the KADLEC Medical Center neuro rehab team in PD. In April, our education team visited Tri-Cities, WA and presented two days of education and training events to help the community and healthcare providers better understand how to live with and treat PD.

In partnership with the VA PADRECC and The Neurological Resource Center in Richland, WA, we presented a half day educational symposium entitled "Challenges & Champions" for people with PD, their families, and the community at large. Well attended, more than 115 people participated.

Next, our own Dr. Kraakevik held a Grand Rounds for physicians at KADLEC Medical Center instructing them in the latest in PD treatment.

Finally, we spent a half day with the KADLEC outpatient neuro rehab team presenting and discussing how to better treat and serve people with PD in the community. Now part of our growing ParkNET network, these skilled professionals have greater understanding of PD and how to approach its treatment as a coordinated team. We will continue to stay in contact and support them to enhance quality of care in the region.

If you live in the area and would like to know how to be seen by the KADLEC team for physical, occupational, or speech therapists, contact Polly Shupe, Therapy Services Manager, at 509-942-2660.

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!

RESEARCH OPPORTUNITIES

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. Jaskirat 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*

Announcing a New Research Opportunity for Patients with Parkinson Disease who do not require PD treatment medications. *Oregon Health & Science University is conducting a Multicenter, Double-Blinded, Placebo Controlled study: Effects of Coenzyme Q10 in Parkinson Disease - Phase III (QE3). Purpose: The purpose of this study is to evaluate whether the nutritional supplement Coenzyme Q10 is able to delay the progression of Parkinson disease (PD). Participation Requirements: In order to qualify for this study, participants must:*

- *Be at least 30 years old*
- *Have been diagnosed with Parkinson disease within 5 years*
- *Not require medications for treatment of Parkinson disease symptoms*

In this study, you will have a 2 in 3 chance of receiving active study drug 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.) Study visits will take place at the Center for Health and Healing at Oregon Health & Science University. There will be 7 study visits over 16 months.
Study visits will include:

- *Physical and neurological examinations*
- *Electrocardiogram at screening visit (EKG, a record of your heartbeat)*
- *Evaluations of memory and mood*
- *Blood and urine samples at some of the visits*

There will be no costs for you to become involved. Study drug will provided at no cost. Please contact Rebecca Conroy at 503-494-9531 or conroy@ohsu.edu if you are interested in participating. eIRB #4373

Do you have early Parkinson's disease (PD) that you aren't currently treating with any PD medications?
There is some recent evidence that higher levels of urate may be related to a slower decline in Parkinson's disease. Purpose: The purpose of this study is to see if inosine can safely be used to raise urate levels in people with early Parkinson's disease. This information will help us decide if we should continue with a larger study of inosine's ability to slow down the rate of progression or worsening disability in PD. Participation Requirements: In order to participate in the study you must have been diagnosed with PD within the last three years. You must have been age 30 or older at the time of your PD diagnosis. You also must not be taking any medications for your Parkinson's disease. In this study you will be randomly assigned to receive the study drug, inosine, or a placebo (inactive substance). Taking the study drug poses small but likely increased risks of gout and kidney stones (made of uric acid). This is because the study drug is known to raise blood levels of urate. Therefore, if you have a history of gout or kidney stones you will not be eligible to participate in the study. There will be 16 clinic visits over 27 months. Eligible participants will receive study-related evaluations, laboratory tests, and the investigational drug at no cost. For more information please contact Megan Murray at 503-418-4387. eIRB #5081

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 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. Lissa Brod is the investigator for this study. For more information, please contact April Wilson at 503-418-1769 or wilsonap@ohsu.edu. eIRB#4133*

Does continuous or intermittent administration of the drug apomorphine provide better control of motor fluctuations and dyskinesias in people with Parkinson's disease? *Purpose: The purpose of this study is to determine whether a continuous or intermittent delivery of the anti-parkinson drug apomorphine works best to control some of the symptoms of Parkinson's disease. The drug apomorphine will be given as either an injection or as a subcutaneous (SQ) (underneath the skin) infusion via an infusion pump for 12 hours a day for 6 months. We will measure the reductions in dyskinesia and the amount of "on" time subjects experience throughout the trial. Participation Requirements: The study requires 13 clinic visits and two inpatient visits; these visits include a 5 day stay in the inpatient Clinical and Translational Research Center at OHSU at the beginning of the study and a 2 day inpatient stay at the end of the study. To qualify, you must have Parkinson's disease and experience dyskinesia 20% of the day and "off" periods for 20% of the day. You also must be willing to learn how to operate an infusion pump and to insert a subcutaneous (SQ) needle into your abdomen, as well as how to give yourself SQ injections. If you are interested in this study contact April Wilson at the Parkinson Center of Oregon, OHSU, 503-418-1769 or wilsonap@ohsu.edu. eIRB #2167*

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 ½ 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 April Wilson 503-418-1769 or wilsonap@ohsu.edu. eIRB #2246*

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 sub-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.*

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

A Pilot Study of Vitamin D and Balance in Parkinson Disease.
Purpose: The purpose of this study is to find out what the relationship between low vitamin D levels and balance in subjects with Parkinson's disease is. Participation Requirements: You may be eligible to participate in this research study if you:

- *Have Parkinson's disease*
- *Can walk 50 feet without help*
- *Are greater than or equal to 21 years of age*

This study requires 1 visit to the clinic. Once the entire study is done, we will call you to tell you if your vitamin D levels are low or not. For more information call Rebecca Conroy at 503-494-9531 or conroy@ohsu.edu. IRB#4266

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*

If you would like more information about participating in research studies, contact the PCO (see ongoing reresearch & 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.

Occupational Therapy Targets Solutions for PD Hand Tremors & More

Amy Fielder, OTR/L, RN

People with Parkinson's disease are often affected by upper extremity (arm/hand) tremors, muscle rigidity, and difficulty with movement (slowness and freezing). These issues can affect one's ability to perform financial, work, leisure, and self-care tasks (known as "activities of daily living" or ADLs). If you have difficulties with one of these tasks, your doctor may refer you to see an occupational therapist (OT). OT's often treat the following issues secondary to Parkinson disease: functioning with a hand tremor, initiating movement due to freezing, and home safety.

Many people with Parkinson disease have difficulty with their activities of daily living due to a hand tremor. This may affect:

- Fastening buttons
- Toileting
- Using a spoon/fork
- Making a meal
- Handwriting
- Using the computer mouse or keyboard

There are tremor reducing strategies and adaptive devices that can help lessen the impact of tremors. Strategies typically involve stabilization and adaptive equipment which may include using bigger or heavier handles. One benefit of seeing an OT is the ability to try and practice these devices to determine which works the best. OT's encourage clients to continue to use their hands as much as possible to prevent disuse weakness, which can result in further decline of independence. Often this can be done using adaptive equipment or with compensatory strategies.

Home safety is often a major concern for clients and family members. No matter what level of assistance a person may need, a home safety assessment is helpful to prevent falls and increase a person's independence. OT's can assist the family member or caregiver on ways to cue the person to make it easier and safer for them to participate in activities of daily living. OT's will also make recommendations regarding the environment and equipment. Recommendations may include bathroom equipment, lighting, moving and removing scatter rugs and clutter.

Reference: The National Parkinson Foundation publishes a booklet on "Activities of Daily Living: Practical Pointers for Parkinson Disease." This is a free publication.

Mouse Adapter Reduces Tremor Impact

Amy Fiedler, OTR/L, RN

Hand tremor is a common concern that occupational therapists (OTs) address in people with Parkinson's disease (PD). OTs work with an increasing number of people with PD who are technologically savvy and desire to continue to use their computers for both work and home. Hand tremors make it difficult to use the keyboard and control the mouse, including navigation and registering double clicks. But there is a new option to help you reduce the frustration.

In 2005, IBM invented a computer mouse adapter called the Assistive Mouse Adapter, which aids in eliminating excessive cursor movement. The device uses similar technology as the image stabilizing systems used for cameras. The computer's mouse plugs into the adapter, which then plugs into the computer. The adapter has different filter settings which can be adjusted depending on the severity of the tremor. The adapter also includes a button delay switch, which suppresses unintentional rapid clicks and a double click switch, which assists with double clicking.

IBM has licensed this product to Montrose Secam Limited (www.montrosesecam.com). The Montrose web site has a current list of equipment options that can be used with the mouse adapter, frequently asked questions and a user manual. The adapter is available for purchase at the Montrose website or at www.essentialtremor.org for a reduced cost of $154.95. Before investing in the adapter, it is a good idea to work with an OT to test the device. People with PD should have an individualized assistive technology assessment and would benefit from a trial using a variety of filter settings and alternative mouses during the OT session to maximize outcome.

If you are interested, our OHSU Neuro Rehab has the assistive mouse adapter and can assist in helping you evaluate how to reduce the impact of your tremor and keep your computer usage frustration free. Call 503-494-3171 or ask your primary care physician or neurologist for a referral.

SLEEP: Setting the Stage

Lisa Mann, RN

Sleep disturbances are no small matter in Parkinson's disease. Forty-seven percent of people with PD will experience sleep problems.[1] These can range from REM Sleep Behavior Disorder and Restless Legs Syndrome to fragmented sleep--frequent awakenings because of discomfort and stiffness or to get up to urinate--to excessive daytime sleepiness with nighttime wakefulness.

In other words, sleeping well with PD can be a challenge. Before turning to medications to aid in sleep (many of which can be habit forming), implement the following sleep hygiene tips from the National Parkinson Foundation's book: *Mind, Mood, and Memory* (available online at www.parkinson.org).

SLEEP HYGIENE: Good Habits for Better Sleep[2]

Daytime Tips:

- Wake up the same time everyday. Set an alarm if you have to.
- Get out of bed right after you wake up. Too much time spent in bed can lead to more waking up at night.
- Limit daytime naps. They can make sleep at night more difficult.
- Eat regular, healthy meals. Eat at the same time every day. Three to four small meals are better than 1-2 large meals.
- Do not drink coffee, tea, sodas or cocoa after noon. They contain caffeine and can interfere with normal sleep.
- Do not drink alcohol after dinner. It may help you fall asleep faster, but makes sleep shallower later in the night. Alcohol can also make snoring and sleep apnea worse.
- Use caution when taking headache and cold medicines. Some contain stimulants that can affect sleep.
- Stop smoking. Cigarette smoking stimulates the body and makes sleep difficult.
- Increase or start doing daily exercise. Regular exercise helps to deepen sleep. The best time to exercise is early in the morning. Avoid heavy exercise 2 hours before bedtime.

Nighttime Tips:

- Get into bed only when you are sleepy.
- Do not use over-the-counter sleeping medications. They may help you to fall asleep faster, but they do not help you to get deeper sleep. They can also make snoring and sleep apnea worse.
- Develop a sleep ritual. Do something relaxing before bed such as reading or listening to music. This tells your body that it is time to settle down.
- A warm shower or bath an hour before bedtime can help you to fall asleep.
- If you tend to worry about things while lying in bed, make an effort to do your worrying outside of bed. Before going to the bedroom, make a list of things to deal with tomorrow.
- If you are hungry at bedtime, eat a small snack or drink a glass of milk. Do not eat sugary snacks or chocolate or drink tea or coffee. Large meals before bedtime can worsen sleep.
- Use your bed only for sleep or sexual activity. Do not do anything else in bed such as reading, watching TV, arguing, catching up on work, smoking, etc.
- Keep the bedroom dark and the temperature comfortable.
- Block out noise as much as possible. Occasional loud noises disturb sleep even in people who cannot remember them in the morning. The hum of a fan can help cover up some noise.
- Do not watch the clock and worry about lost sleep. Turn the clock face away.
- Do not try to force sleep. If you cannot fall asleep:
  - Get out of bed…
  - Move to another room and watch TV, read, or listen to soothing music until you are sleepy…
  - Go back to bed…
  - If you still can't sleep, repeat the cycle until you fall asleep.

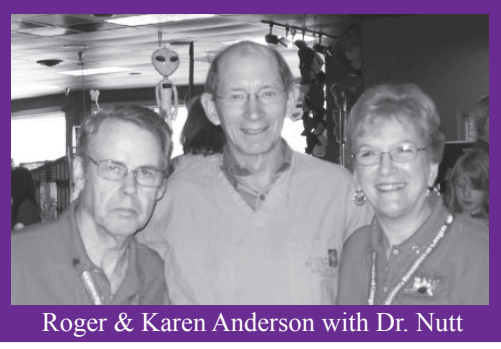
References

1. Shulman, M. Comorbidity of the nonmotor symptoms of Parkinson's disease. Mov Disord 2001. 16(3): 507-510.
2. Boeve, B; Silber, M. "Sleep and Parkinson's Disease," Parkinson Disease: Mind, Mood, & Memory. (2nd edition.) National Parkinson Foundation, April 2007.

PCO Team: No pros here!

Strike Out PD!

The 5th annual Strike Out Parkinson's Disease event was a great success. On Saturday, May 2, 2009, Sunset Lanes donated their facility and staff to support the OHSU Parkinson Center of Oregon and Parkinson's Resources of Oregon. Over 200 people attended the event, contributing to over $8,000 raised! Event coordinators Roger and Karen Anderson had the pleasure of giving away a deluxe *Wii* package, an iTouch, and a variety of other prizes during the raffle. A special thanks to the Andersons and Sunset Lanes for their generosity and hard work!



Roger & Karen Anderson with Dr. Nutt

Shakers' Ball 2009!

The 5th Annual Shakers' Ball Musicfest held April 26th had an excellent turnout this year. The Kennedy School gymnasium and courtyard was filled with music lovers of all ages. Those who came listened and danced to The Bart Ferguson Band, Lisa Mann, Pilar French Intention and Keeter Stuart. Several participants left happy after the raffle drawings with their hands full of hotel, restaurant and salon certificates as well as wine, flowers, music lessons, music concerts and CDs. The event made almost $2,600 which benefited both the OHSU Parkinson Center of Oregon and Parkinson's Resources of Oregon.

Supporters sing and dance for a good cause. Pictures by Michael D. Winter.

OHSU Parkinson Center of Oregon

26th Annual Symposium
Options & Opportunities

PD & the BRAIN

Twenty-six years and still going strong!

You won't want to miss this year's symposium as we explore how our understanding of the brain's ability to adapt and change can inform our approach to living with and treating Parkinson's disease. We are fortunate to feature the Northwest's own, Monique Giroux, M.D., as our key note speaker.

Topics of interest include:
- Parkinson's Disease: Brain Conversations
- Enhancing Resiliency
- Keeping the Brain Sharp!
- Brain Queries: PD Research and Expert Panel
- *Special Caregiver Breakout:*
  Caregiver Connections

Saturday
Sept. 12, 2009
Red Lion Inn
Jantzen Beach
9:00am - 3:30pm

Exhibitors will also share helpful information on PD treatments and activities.

If you are a ***PD artists and/or hobbiest***, we would love to have you share your talents and exhibit your work (call Amy at 503-494-9054 if you are interested).

If you haven't already received a registration brochure, visit our website at www.ohsu.edu/pco or call 503-494-7231. The registration deadline is September 5th. We hope to see you there!

E-NEWS format coming! Before year's end, we will be adding an electronic newsletter format for the "Parkinson Update." If you haven't already, please complete the enclosed pre-paid information card and mail it back to us to make sure we have your e-mail address.

PD Heros

Meeting the Challenges of PD

Photo courtesy of Michael J. Fox Foundation.

Brian Grant, former Trail Blazer and professional basketball player, recently shared his diagnosis of Parkinson's disease with the world. Already, Mr. Grant has used his fame to raise awareness of young onset Parkinson's disease and is committed to fighting the disease personally and publically.

Thank you, Mr. Grant, for your example and support of all people with PD.

For more on Mr. Grant's story, visit www.oregonlive.com and search: Brian Grant.

PD PILATES LOCATIONS EXPAND

- ***Circle Studio*** - 1231 NW 11th, Portland - 503-504-7596 - www.circlestudio.biz. Instructor: Bettina Blank.
- ***Pacific NW Pilates*** - 5201 SW Westgate, Ste#115 Portland - 503-292-4409, www.pacificnwpilates.com.
- ***Pilates Plus Northwest*** - 1010 NE Broadway, Vancouver, WA - 360-574-7800, www.pilatesplusnorthwest.com. Instructor: Shanel Riley.
- ***Portland Pilates Studio*** - 333 S. State, Lake Oswego - 503-880-0969. Instructor: Debra Burchiel.
- **NEW!** ***Spring Pilates Studio*** - 12 SE 28th, Portland - 503-235-8445, www.springpdx.com. Instructor: Irene Stevens.

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Center of Excellence

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www.ohsu.edu/pco

Calendar of Events

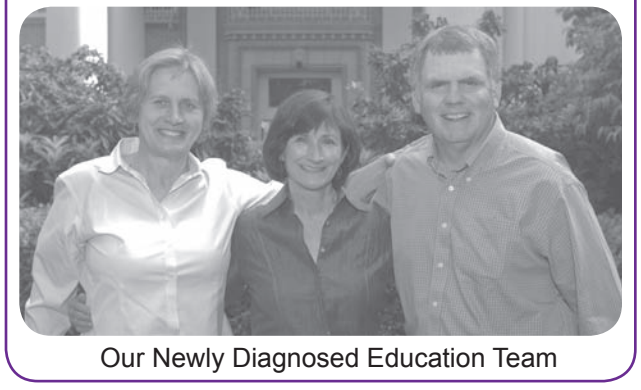
SAT, SEP 12 - PORTLAND, OR
OPTIONS & OPPORTUNITIES
Join us for our 26th annual PD symposium. See detailed information above.

SAT, SEP 19 - BAKER CITY, OR
3rd ANNUAL SALT LICK CITY
Don't miss this unique fundraiser to benefit the OHSU Parkinson Center. If you can't be there in person, participate online at www.saltlickcity.com.

THU, NOV 12 - BEND, OR
CHALLENGES & CHAMPIONS
Join us in beautiful Central Oregon for the 6th Annual Outreach Symposium for patients & families. More information will be available on our website and by mail the near future.

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.



Our Newly Diagnosed Education Team

New PRO DBS Support Group

If you have DBS or are considering the surgery, you know that there is much you can only learn from someone who has already been through the experience.

This fall, a new support group is starting to help connect people with Parkinson's who have undergone the procedure. The group will meet monthly at Parkinson's Resources of Oregon in Lake Oswego.

To receive an invitation to join the group, or find out more, call Holly or Anna at PRO. 800-426-6806.

PRO (Parkinson's Resources of Oregon)

September is Sole Support Season! Sole Support for Parkinson's is a fundraising and awareness walk to benefit Parkinson's Resources of Oregon, a regional support and advocacy organization.
- Medford: Sat, 9/19 - Hawthorne Park
- Eugene: Sun, 9/20 - Alton Baker Park
- Portland: Sun, 9/27 - Willamette Park

1k or 5k Routes Activities Begin at 12:00 pm. REGISTER NOW! Call 800.426.6806 or www.SoleSupport.org

Save the Date - March 26 & 27, 2010 *Educate. Inspire. Empower.* PRO's Annual Parkinson's Education Conference at Valley River Inn, Eugene, OR. Call Parkinson's Resources of Oregon for information - 800-426-6806

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

The VA offers PD specific lectures free to the public throughout the year. All lectures held in the Portland VA Medical Center Auditorium. For dates, times, and topics, call Jeremy at 503-721-1091 for more information.