

Hope

FROM THE
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Hill of Oregon Parkinson Center

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Discoveries in the Genetics of Parkinson's Disease

by Tatiana Faroud, Ph.D.

It was not so long ago that many scientists believed Parkinson's disease (PD) was solely the result of environmental factors. In fact, many studies have been done on pesticides, heavy metals and other potentially harmful substances that are found where people live who have PD in higher numbers than the normal population. But nothing conclusive has been discovered. In the past decade, however, scientists have discovered that genetics may play a role. They have now identified five genes that can cause PD when their DNA sequences are altered.

This can be somewhat confusing, so it's important to understand some basics of genetics. Most cells of the body have 46 chromosomes, grouped into 23 pairs. One member of each chromosome pair is transferred from parent to child during fertilization. These chromosomes are composed of deoxyribonucleic acid (DNA), which is the genetic material. DNA is the code that tells each cell in the body what its' function is — eye color, hair color, gender, everything. The combinations are endless and that is why we are all different.

PD GENE ROSTER
Genes identified in families with onset under 50 years old:
- alpha synuclein (PARK1)
- parkin (PARK2)
- PINK1 (PARK6)
- DJ-1 (PARK7)

Genes identified in families with onset after 50 years old:
- LRRK2 (PARK8)

Initial PD genetic studies focused on those families in which members developed PD at an early age, typically younger than 50. While these early onset families comprise a small proportion of all cases of PD, they have provided important information about the genetics of PD. Changes in the DNA sequence (termed mutations) in four different genes (see insert) have been found to cause PD in some of these families. Mutations in the parkin gene are found in approximately 10 percent - 20 percent of individuals who have onset with PD before age 40. Mutations in the other three genes are quite rare causes of PD.

The majority of PD cases have an onset after age 50. These later-onset cases of PD are less likely to have a mutation in the sequence of the "before 50" genes. Rather, a recently identified gene, called LRRK2 (PARK8), appears to be important in PD patients that have onset of disease after the age of 50. Changes in the DNA sequence of the LRRK2 gene have been found in about 5 percent of individuals with PD who also have a parent or other family member with PD. About 1 percent to 2 percent of individuals without a family history of PD have a mutation in the DNA sequence of LRRK2.

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OHSU Researchers Help Advance Genetic Research

by Jonathan Modie

For Portland-area residents Kathy Grunwald and Marilyn Belanger, there's no question genetics plays a role in Parkinson's disease. Grunwald, 61, of Tualatin, and Belanger, 68, of Gresham, are sisters and both have been diagnosed with the progressive neurological disorder. They also have a cousin who has the disease. But until Belanger was diagnosed two years ago, neither woman thought Parkinson's might run in their family.

"It never entered my mind that I would have it, too," Belanger said. "My brothers think that one of our uncles had it as well, but we never knew that."

Grunwald and Belanger are participating in a national study, through the Parkinson Center of Oregon at Oregon Health & Science University, that is recruiting 1,000 sibling pairs with Parkinson's disease whose DNA will undergo genetic linkage analysis.

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Pictured above: Tatiana Faroud, Ph.D., speaks at the 2005 PCO annual symposium.

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OHSU

Director's Soapbox: Exciting Times Ahead for Parkinson's Disease Research

by John G. Nutt, M.D.

Jack and Becky Benaroya, of Seattle, have just announced a gift of \$1,250,000 to the PCO. These monies will be placed in the Benaroya Parkinson Disease Discovery Fund as an investment in research into causes and treatment of Parkinson's disease. This is a significant step forward in our \$10,000,000 vision for transforming Parkinson's disease research at OHSU.

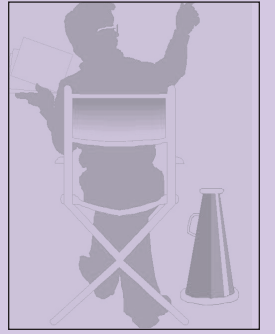
Discovery is the product of research. A key element of discovery is innovation. The best manner to foster innovation is to promote interactions between scientists with different skills and talents to develop novel approaches to problems.

OHSU currently has extremely strong basic neuroscience - focused on the function of the nervous system at the level of single molecules and very simple neurological systems. OHSU neuroscience programs are num-

ber two in the U.S. in terms of grants funded by the National Institutes of Health (NIH). The OHSU PCO is widely recognized for its clinical research. The Discovery Fund will be used to bridge the gap between the basic and clinical researchers by recruiting researchers focused on Parkinson's disease translational research - research to convert basic research findings into clinically useful strategies and to develop a basic understanding of observations that come from the clinical arena. PD translational researchers, by their interactions with clinical and basic neuroscience researchers, will catalyze innovation in research on Parkinson's disease.

We are very pleased by the Benaroyas' confidence in the PCO and their vision of elevating PD research to the highest level at OHSU. Exciting times are ahead for PD research at OHSU.

Every donation will help us toward fulfilling our mission of improving treatment and care as well as finding a cure for PD. Please consider joining the Benaroyas in giving to PCO research.



Allied Health Therapists Play Vital Role in Living with Parkinson's Disease

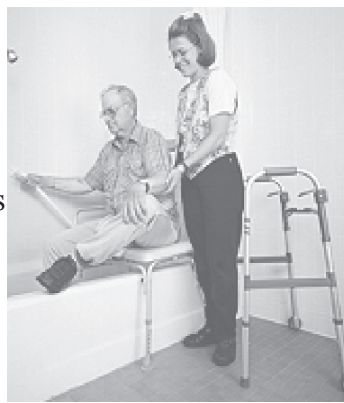
by Christine Trexel, O.T.

Allied health therapists—physical, occupational, and speech therapists—are critical players in helping people with Parkinson's achieve the highest quality of life. The earlier these individuals establish contact with therapists, the better! Early contact allows Parkinson's patients and their families to participate actively in managing their own care, a key to coping with the myriad of problems that may occur during the course of the disease.

Areas that may be addressed during therapy may include the following:

- Communication and speech techniques to express thoughts both clearly and with adequate volume.
- Memory and concentration training, including speed of information processing, recall, new learning, problem solving, and initiation.
- Vision improvement strategies.
- Education and training to improve posture and joint mobility through individualized stretching and exercise programs.
- Strategies and equipment to help with such tasks as eating, dressing, bathing, cooking and home management.
- Balance training for walking on even and uneven surfaces.
- Assessment of need for assistive devices or adequacy of present devices.
- Family education and training about the disease process, home safety issues, home care and modification needs, and adaptive techniques.
- Referral to exercise programs, agencies, recreation or vocational resources, and educational systems as needed.

A carefully designed course of therapy and seeing therapists at regular intervals can help an individual stay as active as possible for as long as possible. The therapy team should be part of your medical team. Here at OHSU, the Outpatient Rehabilitation Therapy Clinic offers comprehensive team evaluation and treatment for individuals with Parkinson's disease. They communicate closely with the clinician and meets on a monthly basis with the Parkinson Center of Oregon nurse and social worker to coordinate care.

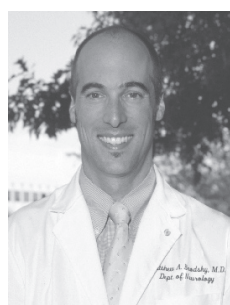


To pursue therapy through OHSU or with any other neurological rehab therapist, simply ask your treating internist or neurologist for a referral.

For more information on OHSU's rehabilitation program or to find out how to get a referral, contact Aimee Mooney, clinical coordinator and speech and language pathologist at 503-494-3151, or email her at mooneya@ohsu.

The Future is Now: Going Electronic...Join Us!

The PCO has regularly offered a bi-annual newsletter of education on the latest treatments, research, and care options for people and families with Parkinson's disease. For some time, we have wanted to expand our distribution and add a third issue. We are fortunate to do this and introduce you here, to our winter issue. However, the costs associated with newsletter production is too excessive to do a third issue each year except in electronic version. So we will continue this third issue, but in future years it and many other educational materials will be offered via the internet. We would like to start receiving your newsletters via email, we invite you now to **submit your email address** for our publications listing. Simply, go to our website—www.ohsu.edu/pco—and select "Contact Us" then "Guest Book." Thank you for joining us on-line!



Restless Legs Syndrome (RLS) & Parkinson's Disease

by Matthew Brodsky, M.D.

Restless Legs Syndrome (RLS) is a condition in which one experiences unpleasant sensations in the limbs, typically the legs, which improve with movement. While it is a common syndrome on its own, affecting roughly 9 percent of the general population, it occurs more commonly in people who suffer from Parkinson's disease (PD) than in the general population. The symptoms have been variously described as burning, itching, cramping, throbbing, "water under the legs," and a "creepy-crawly feeling," to name a few. Patients with mild or moderate RLS characterize these sensations as uncomfortable; for the most part, they are not perceived as painful. Discomfort occurs most frequently in the evening, and can often interrupt normal sleep. Many of those with RLS have persistent leg movements while they are asleep. This may be detected by a sleep study and help aid in making a diagnosis. In more severe cases, these involuntary leg movements may occur while awake, often mimicking the levodopa-induced dyskinesias that occur in PD. Because RLS can disrupt normal sleep patterns, it may lead to excessive daytime sleepiness, which may be further exacerbated by many of the medications used to treat PD and RLS.

The most effective treatment for RLS are dopaminergic medications, such as dopamine agonists and levodopa. The medication ropinirole (Requip®) recently received FDA approval for the indication to treat RLS, and pramipexole (Mirapex®) and carbidopa/levodopa (Sinemet®) are two other commonly used medications that are effective for RLS. Therefore, many PD patients are treated simply by adjusting their current medications. The doses needed to effectively treat RLS are usually lower than those needed to treat PD symptoms. Iron deficiency can worsen RLS symptoms, and when this is detected, simple replacement of iron in the diet may help. In the more severe cases that do not respond to dopaminergic drugs, benzodiazepines, opioids, or anticonvulsant medications are often used. While the majority of cases respond nicely to low-dose dopaminergic therapy, the real issue with this syndrome is recognizing it in the first place as a treatable problem.

More information about RLS is available through the RLS Foundation at www.rls.org or by contacting local RLS support groups: RLS-Portland, 503-646-8925; RLS-Southern Oregon, 541-955-2978.

PD EDUCATION ON-LINE

Ever feel like you live too far away to travel to the symposia the PCO or the National Parkinson Foundation sponsors each year? More and more are being filmed for later web casting.

The PCO has three presentations from our Medford symposium, which will soon be available on our website (www.ohsu.edu/pco):

- Those Symptoms You Didn't Think Were Parkinson's Disease – Julie Carter, ANP, PCO Associate Director
- Facing Serious Illness – Vicki Wolff, LCSW
- Secrets to Taking Control of Your Health Care Team – Lisa Mann, RN

The NPF's website has videos presented at their Young Onset conference in Phoenix last July 2005. (link: <http://event.netbriefings.com/event/npf/Archives/webcast/>)

- Parkinson Disease, Mind-Body Healing & the Emerging Environmental Health Movement – Michael Lerner, author of "Choices in Healing"
- Keeping Intimacy Alive: Managing Relationships in the Midst of Parkinson Disease – Sage Bolte, MSW, LSW
- Panel Presentation: Parkinson Disease and Exercise – Mickie Welsh, MSN, DNSc; Giselle Petzinger, MD; Becky G. Farley, PhD, PT.
- Medication Management - Holly Shill, MD; Mark R. Comes, RPh.
- Know Your Rights: Disability and the Workplace – John D. Kemp, JD.
- Advocacy: What Is It, and What Does It Have to Do with me and Parkinson Disease? – Jackie Hunt Christensen.
- Healing Conversations...What to Say When You Don't Know What to Say – Nance Guilmartin.

Dear Vicki...

(PCO's Family Care Specialist Offers Insight)

I have Parkinson's disease (PD) and live alone. Although I am pretty independent now, I am worried about how I will manage as my disease progresses. What can I do to cope with the changes in my life and help ensure that my needs will be met?

Although there are extra considerations that you need to address to live alone with PD successfully, there are many steps you can take right now to improve conditions and alleviate your worry.

Foster and maintain supportive relationships: Studies show that depression rates are higher among people who live alone. Also, people with PD are more vulnerable to depression because of the biochemical and neurological aspects of the disease. So it is easy to become sad and depressed if you isolate yourself, and there is no one to catch you if you are experiencing a downward slide.

It is therefore imperative that you reach out to others and create your own support network. Find a friend, a family member, spiritual community, or peers and support groups; someone you trust who reminds you that you are not alone. Shore up the connections with those individuals by frequent contact. A person with PD can also build their network through participation in peer support groups. Many people with PD report that support groups provide camaraderie, advice, acceptance and inspiration to live successfully with Parkinson's disease.

Address the practicalities of living alone. Everyone with Parkinson's can benefit from some home adaptations that increase safety and make life easier. For many single people, these adaptations are critical because there is no one in the next room to extend a helping hand.

In terms of basic home safety, a common concern is fear of falling, but a lot can be done to make the home less hazardous. There are several tools available through the PCO or online that can suggest home modifications. However, an occupational or physical therapist can help identify the specific modifications and equipment that may be most useful to you and how to use it.

Home medical alert systems may also be worth considering if you are worried about being on your own. A medical alert system allows you to call for help in an emergency, either by hitting a special button on your phone or pressing the alarm on a special device worn around your neck or wrist. When the alarm is activated, it alerts people at a 24-hour response center who then get the appropriate help.

Investigate your options for home care and community resources before you need to utilize them. Home care can cover basic tasks, such as grocery shopping, laundry, and housekeeping; or physical assistance with bathing, dressing, and managing medications. Depending upon your economic situation, you may need to pay for these services privately, or you may be entitled to assistance from the state's Department of Human Services. Contact your local senior and disabled services office for more information on programs and services that exist for individuals with disabilities.

Plan for the future: The earlier you start to plan for the future, the more control and choice you will have as your disease progresses. In the event that you are not able to direct your health care, you can ensure that your health care wishes are fulfilled by completing a medical advance directive and designating a legal power of attorney for health care. You can also designate a financial power of attorney to help you manage your finances and direct your assets to pay for your care.

You may also reach a point when you do not want to live by yourself or living alone may not meet all of your needs, so now is the time to explore alternative living arrangements. Choosing another living environment is an important transition and one that you do not want to make in a crisis. Planning ahead gives you more control, choice and assurances that your needs will be met. So, while there is no way to plan for every possible change in living with PD, allowing yourself to consider the available housing options will help relieve the confusion and trauma of a sudden move.

You may also want to meet with a financial adviser or elder law attorney who can help you complete an advanced directive, designate a power of attorney, understand your financial situation, and plan how to pay for long term care.

Help is available, so take advantage of the support and resources today. If you have any questions or would like more information about the above services, please call me (503) 418-1661.

Sincerely,

Vicki

Discoveries in Genetics (continued from page 1)

PD researchers have been trying to understand how changes in the DNA sequence of these genes might cause PD. Researchers believe that each of these genes is important in helping remove unnecessary and unneeded proteins from the brain, a process which acts a bit like the brain's garbage disposal. With the identification of each new PD gene, we learn more and more about what has to go wrong in the brain to cause PD. Armed with this new knowledge, scientists hope to devise new ways to combat the disease so future generations will not suffer from it.

Genetic Research at PCO (continued from page 1)

Known as Parkinson's Research: The Organized Genetics Initiative, or PROGENI, the National Institutes of Health-funded project is hunting genes that predispose an individual to develop Parkinson's disease.

Julie Carter, M.S., A.N.P., associate professor of neurology in the OHSU School of Medicine and associate director of the Parkinson Center of Oregon, is a principal investigator for PROGENI and a member of the Parkinson Study Group, a team of neurologists from throughout the United States, Canada and Puerto Rico that is helping lead the effort. The Parkinson Center of Oregon is one of PROGENI's top-three recruiting and evaluating centers, among 64 centers nationwide.

The genetic information retrieved by PROGENI, along with occupational, environmental and other risk factor data, is expected to improve preclinical detection of Parkinson's disease and foster the development of more effective therapies, organizers say.

More information on PROGENI can be obtained by calling Pamela Andrews at the PCO (503-494-0965).

Discoveries in genetics have thus spurred PD research in new areas, and it is drastically reshaping how scientists and clinicians view the disease. In turn, advances in genetic research will spark new approaches to treatment. Researchers are already trying to take advantage of the new knowledge and are devising new approaches to treating PD. Time, money, and participation by people with Parkinson's in clinical trials will all be needed to make significant progress. But new understanding of the role of genetics is already making a difference that will eventually pay off in improving lives for those who suffer from PD.

Tatiana Foroud, Ph.D., is professor of medical and molecular genetics at the Indiana University School of Medicine and a PROGENI research leader. She was the keynote speaker at the Parkinson Center of Oregon's 22nd Annual "Options & Opportunities" symposium this fall.

The Art of Giving

Continued on page 4

PCO Alliance Raises Over \$20,000 for Research & Care Projects

Mission Possible



PCO Alliance volunteers were responsible for successful fundraisers as they organized logistics, recruited help, donated talent, services and products and enabled nearly 100% of the money raised to go to the research and education programs of the PCO.

"Celebrate the Treasures of Oregon"

Bethel Heights Vineyard opened their winery just before Thanksgiving to benefit the Parkinson Center of Oregon (PCO). Hosts Terry Casteel and Marilyn Webb invited Chef Vitaly Paley to prepare a dinner from the bounty of Oregon's land. A variety of Bethel Heights estate wines complemented the 6-course meal for the 37 guests.

Chef Paley, of Paley's Place in NW Portland, is the 2005 James Beard Best Chef: Northwest/Hawaii Award winner. He graciously donated his time and talent. The family-owned Bethel Heights Vineyard donated their acclaimed wines. An anonymous donor covered the costs of the event which raised more than \$11,000.

Terry Casteel welcomed the guests and spoke of the gifts of Oregon – the bounty of the land, the vineyards, the generosity of family and friends and the Parkinson Center of Oregon. Dr. Jay Nutt and Ms. Julie Carter spoke of work in progress and their hopes for the future of the PCO, which can only be realized through continuing donations to OHSU's PCO.

Winter Concert Benefited the PCO

Violinist Aaron Meyer and guitarist/accompanist Bill Lamb headlined a concert at St. Mary's Academy in Portland, the only all-girl school in the state of Oregon. A highlight of the evening was a tribute to Sister Pat McKenzie, a beloved retired staff member who lives with Parkinson's disease, with a performance by the Marian Singers, the school's vocal ensemble. Refreshments were served in the school's rooftop commons area. Wine was donated by Duck Pond Winery and baked goods donated by Zee Cakes of Portland. Over \$9,000 was raised for the PCO.



DO YOU WANT TO RAISE FUNDS TO FURTHER PCO'S RESEARCH FOR PEOPLE WITH PARKINSON'S DISEASE? EFFORTS ARE ON-GOING; PLEASE CONTACT THE PCO ALLIANCE WITH YOUR IDEAS (PCOALLIANCE@COMCAST.NET).

REMEMBER: WE ARE ALL IN THIS TOGETHER! THE PCO IS HERE TO ADVANCE THE FIGHT FOR A CURE FOR YOU, YOUR LOVED ONE, AND ALL PEOPLE WITH PD. EVERY DONATION HELPS, BECAUSE ONLY THROUGH RESEARCH WILL THE CURE BE FOUND.

THANK YOU FOR YOUR SUPPORT.

We gratefully acknowledge the following contributors who have made gifts to the Parkinson Center of Oregon from July 2005 through October 2005. We have made every effort to compile a complete list of donors; we apologize for any omissions and ask that, if we missed you, please alert us so we can include you in our next newsletter.

If you are interested in supporting the Parkinson Center of Oregon, please send your tax-deductible donation to: Parkinson Center of Oregon, Oregon Health & Science University Foundation, Mail Stop 45, P.O. Box 4000, Portland, OR 97208-9852. Please make your check payable to: [OHSU Foundation/PCO](#). For professional assistance with your charitable giving, please contact David Matthews at (503) 494-7504. Thank you for your continued support of the PCO!

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Patching Up PD

by Jeff Kraakevik, M.D.

The doctor enters with a flashing gizmo and waves it over your arm. He looks concerned and pushes a button on the wall. A machine that makes a "ping" sound slowly rolls into the room. It flashes more lights, and "pings" again. The doctor looks you squarely in the eye, and says, "Well, that was close, but we took care of all your problems. We'll see you again in six months."

We all have visions of medicine in the future made up primarily of scenes from science fiction movies. Who wouldn't want to throw away all their pills and be treated in a big tub of goo like Luke Skywalker in "The Empire Strikes Back"? Well, some of those visions of futuristic medicine are becoming a reality. We are not talking about using goo to treat Parkinson's disease. But we are talking about a new way to replace some of those pills you take with something a little easier to swallow.

In fact, you don't have to swallow this stuff at all. The medicine is called rotigotine (Neupro®); and it comes as a patch you put on once a day. Rotigotine is not so new in how it acts or what it does to the symptoms of Parkinson's. In fact, research, conducted in part through the Parkinson Center of Oregon at Oregon Health & Science University, revealed that rotigotine is similar

to already available dopamine agonists such as pramipexole (Mirapex) and ropinerole (Requip). People with Parkinson's disease treated with rotigotine in these studies experienced a similar decrease in Parkinson's symptoms to what was previously shown with these older medications. Like Mirapex and Requip, rotigotine was used both when it was taken by itself early in the disease, and when added to Sinemet later in the disease. The good news is that rotigotine maintained fairly even blood levels during the day, and it also exits the bloodstream reasonably fast if the patch is stopped for any reason. Research participants also experienced similar side effects to those seen with Mirapex and Requip, including the possibility of nausea, confusion, excessive sleepiness, and hallucinations.

So although rotigotine does not quite match up to a machine that goes "ping," it does provide a look into the future of medicine. No, this medicine will not likely replace Sinemet as the most effective form of treatment of Parkinson's disease. And, no it will not likely be much different from Mirapex or Requip. But it will provide an option for people who have early stage Parkinson's disease and don't want to bother with remembering to take pills three or four times per day. It will likely also be useful in people with swallowing troubles.

Those considering taking rotigotine should first talk to their doctors. You should also know that rotigotine has not yet been approved by the U.S. Food and Drug Administration, and it may not be available until some time later this year. That said, it will be nice to have a piece of the future today.

If you would like more information about participating in research studies, contact the PCO (see ongoing research and contact information below) 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.

The following studies currently are looking for participants. The Parkinson Center of Oregon is involved in many other studies that are fully recruited. These include studies on drugs to delay progression, new symptomatic drugs, family care research, fatigue, balance, falls, magnetic stimulation, genetics, and sleep. Stay tuned for results from these and other PCO research studies in upcoming issues of the newsletter.

Looking for Unique Markers in Cerebrospinal Fluid.

The purpose of this study is to identify unique biologic markers in the cerebrospinal fluid (the fluid surrounding the brain and spinal cord) in people with Parkinson's disease. To participate, you must be older than 18, have PD, and be willing to undergo a lumbar puncture (where a special needle will be inserted in between two bones in your lower back). 2 visits are required (one for physical examination and a second for the lumbar puncture), but they may be combined on the same day. Participants who complete all study tasks will receive \$200. For more information, call Bethany Carey, MPH at (503) 418-1668. eIRB #462

Do you have end of dose wearing off and want to participate in a dopamine agonist study?

Oregon Health & Science University is conducting a double-blinded placebo-controlled crossover study with the FDA approved dopamine agonist, Mirapex. The purpose of this study is to better find out how to treat Parkinson's disease with the use of dopamine agonist and levodopa. There will be four visits in a period of 8 weeks. You must be diagnosed with Parkinson's disease and have moderate to severe symptoms, are presently taking Sinemet and have dyskinesia. Dr. Matthew Brodsky is the clinical investigator responsible for this study and Michele Barnard is the contact person if interested. If you are interested please contact Michele at (503) 494-1382. eIRB # 697

Do you have Parkinson's and untreated depression?

The Parkinson Center of Oregon is currently conducting a research project for patients with depression that have 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. 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 and Michele Barnard is the person to contact if interested in participation at (503) 494-1382. eIRB # 1407

Do you have Parkinson's disease and a living brother or a sister who is also affected?

The Parkinson Center of Oregon is conducting a study to learn more about the genetics of PD from people with Parkinson's disease who have a living sibling with the disease. Participation would involve one visit at OHSU consisting of a neurological exam, a blood draw (2-3 tablespoons), and questionnaire, which will take approximately 1 1/2 to 2 hours. For more information call Pamela Andrews at 503 494-0965. IRB #5367

Balance/Falls and Parkinson's disease.

The purpose of this study is to find out if a medication that increases levels of a brain chemical called acetylcholine will improve balance and reduce falls in people with Parkinson's disease who have poor balance and are falling or nearly falling on a daily basis. In order to take part in this study, you must be 21 or older. You must have balance impairment that results in 2 falls or near-falls per week. For more information, please call Bethany Carey, MPH at 503-494-9055 IRB# 7950

Help uncover the relationship between Parkinson's disease and chronic pain.

OHSU's Department of Neurological Surgery is seeking subjects, age 50-80 years, with either Parkinson's disease or Parkinson's disease accompanied by chronic pain. We are using a non-invasive technique called MR Spectroscopy to measure neurodegeneration in brain areas related to Parkinson's disease and pain processing. Participants will visit the Advanced Imaging Research Center (AIRC) at OHSU for approximately 1 hour of questionnaires, followed by a 90 minute MRI scan. Compensation for the single visit is \$25, along with a copy of all MRI images on CD. Please contact Melanie Hart at (503) 494-7138 for information about enrolling in this study. IRB #8261

Healthy Volunteers Needed for Balance Study.

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. Participants must be 18-85 years of age, in excellent general health, and have no history of dizziness or balance problems. In exchange for each 2-to-3-hour session, participants will receive \$25-35. Please contact Triana Nagel-Nelson with any questions @ 503-418-2602 or nagelnel@ohsu.edu. eIRB#811

Investigational new drug for Parkinson's disease.

The Parkinson Center of Oregon is conducting a placebo-controlled study with an investigational new drug. The purpose of this study is to understand more about the safety and effectiveness of this new drug when used by itself in patients with Parkinson's disease. Participants must be at least 30 years old and cannot have taken other Parkinson's drugs for at least 30 days before the study. The study will take 13-17 weeks. If interested please call Bethany Carey, MPH at 503 418-1668. eIRB # 1485.

Are you interested in an experimental drug study that might help treat fatigue in Parkinson's Disease?

Study drug and evaluations will be provided at no charge. You would have a 1 in 2 chance of receiving placebo (like a sugar pill) instead of the active study drug. Participation would last 8 weeks. You may take your normal anti-Parkinson's medications while participating in this study. You must be in good health except for Parkinson's disease. Participation would consist of 4 clinic visits during an 8-week period. If interested, please contact Diana Dimitrova (503-494-7269, dimitrov@ohsu.edu). eIRB #298

Help Investigate Fatigue in Parkinson's Disease.

This study investigates how levodopa and acupuncture may affect fatigue and muscle function in people with Parkinson's disease. You may receive either real levodopa/acupuncture or placebo. Our subjects will have different chances of placebo, and you will be told if you have a 100%, 50%, or 0% chance of receiving placebo. Study interventions and evaluations will be provided at no charge. Study procedures include TMS (a non-invasive type of brain stimulation), a blood draw, and personality surveys. You must be in good health except for idiopathic Parkinson's disease. Participation would consist of 3 laboratory visits. Each visit will last about 3 hours. Study pays \$30 for each visit that you attend, for a total of \$90 for the entire study. To participate, you must refrain from taking your anti-Parkinson's medications for 12 hours before the final two visits. All study visits and procedures take place at OHSU. If interested, please contact Diana Dimitrova (503-494-7269, dimitrov@ohsu.edu) or Melanie Davis (503 494-4987). eIRB #761

DBS Movement Control Study.

The purpose of this research is to determine how deep brain stimulation (DBS) and levodopa influence abnormal patterns of gait, balance, face and jaw movements in people with Parkinson's disease. What is involved in this study?

- Balance Testing: You will be asked to keep your balance on a movable platform, take a few steps or stand quietly while a computer records your body movements.
- Oromotor Testing: In this study you will be asked to voluntarily move your jaw or clench your teeth while a computer records your jaw movements.

We will compare balance and oromotor coordination once before and once after DBS surgery. Travel expenses and an honorarium will be paid. Please contact Triana Nagel-Nelson with any questions @ 503-418-2602 or nagelnel@ohsu.edu. IRB#4925

Electronically Measuring Walking Speed May Help to Learn More About Parkinson's.

Oregon Health & Science University is conducting a study among newly diagnosed patients with Parkinson's disease. The purpose of this study is to learn if we can use a home monitoring system to measure walking speed, which may help us find better ways to measure motor problems that occur in PD. There will be 4 visits over a period of 6 months. To participate you must be:

- Between 18-90 years of age.
- Newly diagnosed with Parkinson's disease (showing symptoms for a maximum of three years).
- On no anti-Parkinson drugs and not anticipated to require treatment within 6 months
- Live in your own home.
- Be willing to wear a watch-like device during waking hours, at home, for 6 months.

This study is of no cost to you. Home monitoring systems to measure walking speed will be put in your home by appointment and removed at the end of the study. If you are interested in participating, please call Bethany Carey, MPH at 503-418-1668. eIRB# 1680

OHSU is currently participating in a large national study evaluating DBS for the treatment of Parkinson's Disease*.

Neurosurgeons at OHSU have been performing Deep Brain Stimulation (DBS) surgery for several years. In this surgery, electrodes are implanted deep in the brain, and connected by a wire extension to a battery-operated device (similar to a pacemaker), which is implanted just beneath the skin in the chest or abdomen. This generator can then be "programmed" to deliver a mild electrical impulse to an area of the brain that controls movement. Patients most likely to benefit from DBS are those with advanced disease, who get a good response from Sinemet, and who do not have dementia or mental illness. Most patients having this surgery will experience decreased Parkinson's symptoms, and longer "on time" with less dyskinesia. There are openings for at least twelve more subjects to enter this study. For more information about DBS, call Susan Loehner, RN, at 503-494-7950. IRB# 1114

Your PCO Team--People News



NEW RESEARCH COORDINATOR

Our newest addition, Haley Holmer, received her degree in neuroscience from Middlebury College in 2002. After graduating she spent two years researching the neural circuitry of Parkinson's disease. In order to broaden her world view and her desire to help others, she traveled to Tanzania to spend a year teaching in a Maasai village. She returned from east Africa with many wonderful experiences, friends and a dedicated desire to focus on clinical research and the improvement of disease management in Parkinson's patients. When she's not globe trotting, her hobbies include soccer (playing and coaching), running, hiking, and snorkeling!

The Parkinson Center of Oregon at OHSU

Second Annual Rural Symposium
Set for Tri-Cities Region
April 13, 2006

Don't miss this opportunity to learn more
about PD from the experts!

OHSU's Parkinson Center
2nd Annual
Challenges & Champions:
Summit on Parkinson's Disease
(Columbia Basin)

Thursday, April 13, 2006
1:00pm – 5:00pm

Cost: \$10 per person before 3/31/06
\$15 per person after 4/1/06
scholarships available

Red Lion — Columbia Center
1101 N. Columbia Center Blvd, Kennewick, WA

Parkinson Center founders, clinicians, and researchers—**Dr. John Nutt** and **Julie Carter, ANP**—will team with Tri-Cities' neurologist, **Dr. Toomas Eisler**, and OHSU's Parkinson Center nurse, **Lisa Mann, RN**, to present the latest information on treatment, disease management, and coping techniques for people, families and health-care providers who are challenged daily with Parkinson's disease.

**To Register Now: Call 503-494-9054 or
e-mail pco@ohsu.edu**

The Parkinson Center of Oregon at OHSU
invites all individuals 60 and younger living with PD,
family members, friends, support persons, and
health care professionals to

A SYMPOSIUM FOR YOUNG PEOPLE LIVING WITH PARKINSON'S DISEASE

Saturday, March 4, 2006
9 a.m.-4 p.m.
Double Tree Hotel Lloyd Center
Portland, Oregon

While Parkinson's disease is often considered an older person's condition and the average age of diagnosis is early 60s, many people younger than this are living with the disorder. In fact, approximately 10 percent of the population diagnosed with the condition are younger than 40. While the disease has the same name whether the diagnosis comes at age 35 or 65, the psychological, social, and medical management implications are much different for young people with Parkinson's. The Parkinson Center of Oregon created this symposium to address the unique needs of people 60 and younger who have Parkinson's disease.

This year's symposium will feature the latest information on:

- PD treatment and research.
- Awareness and advocacy.
- Legal and financial planning.
- The benefits of exercise.
- Maintaining emotional and physical intimacy.

We also will have a panel of young individuals who will share their experiences of being diagnosed. This event is a great opportunity to meet and connect with other young individuals with PD and their significant others. We hope to see you for what promises to be an educational and enriching experience.

Parkinson Center of Oregon
For additional information, please call (503) 494-9054

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Calendar of Events

EVERY OTHER MONTH at OHSU
PCO's Newly Diagnosed Educational Session - Three hour session for people recently diagnosed with Parkinson's disease and their partners to ask a PD expert all the questions that have arisen since their diagnosis. PCO's Associate Director, Julie Carter, ANP, and a patient, who has had PD for 15 years, provide answers in an informal small group atmosphere. \$20/person. Call Malia at 503-494-9054 for more information.

Feb 23-26 - WASHINGTON, DC
World Parkinson Congress, a forum of unprecedented scale for scientists, physicians, people and families with Parkinson's, Parkinson organizations, and government representatives from throughout the world, will convene to review the most current developments in Parkinson's research, education/training, care, and quality of life issues.

Mar 4 - PORTLAND, OR
A Symposium for Young People Living with Parkinson's Disease - This program was created to address the specific needs of individuals 60 years old and younger who have Parkinson's disease. For more information, see article above.

April 13 - SE WASHINGTON & NE OREGON
The second annual "Challenges & Champions" Rural Symposium will be held in Tri-Cities, WA at the Red Lion Columbia Center from 1p-5p. Featured speakers include PCO experts--John Nutt, MD; Julie Carter, ANP; Lisa Mann, RN--and local Tri-Cities neurologist, Toomas Eisler, MD. Register by calling 503-494-9054 or e-mail: pco@ohsu.edu. Cost: \$10 per person before 3/31/06 and \$15 per person thereafter; scholarships are available.

Apr 29-30 - NEWPORT, OR
Parkinson's Resources of Oregon (PRO) presents their annual Parkinson's Conference at the Agate Beach Best Western Inn in Newport, OR on April 30, 2006. Keynote speaker is Dr. Howard Hurtig from the University of Pennsylvania, as well as several other speakers from across the Northwest. For more information, call PRO at 503-413-7717.

May 11 - PORTLAND, OR
The 2nd Annual Shaker's Ball will rock the historic White Eagle Saloon in north Portland on Thursday, May 11th. Back by popular demand, Rob Barteletti, his band the Shadows, and other local bands will play for fans and donate all ticket/door receipts to the PCO & PRO. For more information, you can visit Rob's website at: www.rbarteletti.com.

Sept 9 **SATURDAY - PORTLAND, OR**
The PCO's 23rd Annual Symposium: "Options & Opportunities" will be held at Portland's Red Lion Hotel - Jantzen Beach. Both medical experts and inspirational speakers will present information and practical suggestions for people with Parkinson's, their families, healthcare professionals, and professional caregivers.

Feb 11 - EUGENE, OR
Parkinson's Resources of Oregon's (PRO) PD 101 Class in Eugene will be held February 11, 2006 at 9:00am. Location: Cascade Health Solutions; Upstairs Conference Room; 2650 Suzanne Way, Eugene, OR 97408. For more information, please call PRO at 503-413-7717.