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.
DoubleTree Hotel
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% of the population recently 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 advice for families
- Legal and financial planning
- The best 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.

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

Change Service Requested

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

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 by Tatiana Faroud, Ph.D.

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

PARKINSON’S DISEASE

• PD-GENE BOASTER: Genes identified in families with onset under 50 years old:
  - alpha synuclein (PARK1)
  - parkin (PARK2)
  - pink1 (PARK6)
  - DJ-1 (PARK7)

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 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 all 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 LRRC6 (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 LRRC6 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 LRRC6.

Continued on pg 3
Allied Health Therapists Play Vital Role in Living with Parkinson’s Disease

by Christine Trolle, O.T.

Allied health therapists—physical, occupational, and speech therapists—are critical pieces of the human network that support people living with Parkinson’s disease and their families. They work to maximize mobility, limit disability, and support overall quality of life. The earlier these individuals establish contact with therapists, the better! Early contact allows Parkinson’s patients and their families to participate in comprehensive team evaluation and treatment planning.

Education and Training to Improve Posture and Joint Mobility

Individualized stretching and exercise programs.

Memory and concentration training, including speed of information processing, recall, new learning, problem solving, and initiation.

Communication

Education and training to improve posture and joint mobility individually tailored stretching and exercise programs.

Coordination and equilibrium to improve balance and walking by catching balance, 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.

Swallowing

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 exercises for individuals at risk can help an individual stay as active as possible for as long as possible. The therapy team should be skilled in the following areas:

- Prevention of falls.
- Outpatient Rehabilitation Therapy Clinic offers comprehensive therapy team evaluation and treatment planning for individuals with Parkinson’s disease. They communicate closely with the clinician and members of a monthly basic needs support group.
- 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.

More information about OHSU’s therapy programs can be found at www.ohsu.edu/pco.

PD EDUCATION ON-LINE

feel even like you live too far away to travel to the symposia the PCO or the NPF offer? You have a team of experts who can provide you with more information on the latest research and treatment options. The Parkinson Center of Oregon supports a wide range of educational opportunities for people with Parkinson’s disease and their families, including online seminars, webinars, and live events. Check out our schedule of upcoming programs and events at www.ohsu.edu/pco.

The Future is Now: Going Electronic…Join Us!

OHSU has regularly offered a brochure on an overview of Parkinson’s disease and related research. The most current version of the brochure can be downloaded at www.ohsu.edu/pco.

PD Education on-Line:

For more information on OHSU’s rehabilitation program or to find out how to receive a referral, contact Anne Money, clinical coordinator and speech and language pathologist at 503-494-1131, or email her at moneyanne@ohsu.edu.

The Next Step: Going Electronic…Join Us!

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 Parkinson Foundation brochure: “Should You Volunteer? PD Research Studies” by calling NPF at 800-327-2141 or visit their website, www.parkinson.org.

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

Jack and Becky Benavente, of Seattle, have just announced a gift of $1,250,000 to the PCO. These monies will be placed in the Benavente Parkinson Disease Fund as an investment in research in 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.

The OHSU Parkinson’s Disease Research Center (PDRC) has created a new research agenda focused on the biological mechanisms that underlie movement disorders, with a particular emphasis on Parkinson’s disease.

The PDRC is a multidisciplinary team of basic scientists and clinical researchers who work together to develop new strategies to understand, diagnose and treat movement disorders. The PDRC is led by Dr. Myron F. Brodsky, who is also the Director of the Parkinson Center of Oregon.

The PDRC has several key goals:

- To identify new targets for drug development.
- To develop new diagnostic tools.
- To improve our understanding of the underlying causes of movement disorders.

The PDRC is currently conducting a number of research projects that are focused on understanding the underlying mechanisms of movement disorders.

- A study to identify new targets for drug development.
- A study to develop new diagnostic tools.
- A study to improve our understanding of the underlying causes of movement disorders.

The PDRC is also excited about the potential of new research directions, such as the use of stem cells to repair damaged neurons in Parkinson’s disease.

The PDRC is committed to translational research, which is the process of taking basic research findings into clinical applications and developing new treatments.

The PDRC is also focused on training the next generation of scientists who will be leaders in the field of movement disorders research.

The PDRC is a leader in the field of movement disorders research and is dedicated to finding new treatments for movement disorders, including Parkinson’s disease.

PD Research Studies (RLS) & Restless Legs Syndrome (RLS)

by Matthew Brodsky, M.D.

Restless Legs Syndrome (RLS) is a condition in which a person experiences uncontrollable, uncontrollable, and uncomfortable sensations in the legs, which improve with movement. While it is a common syndrome on its own, affecting roughly 90 percent of the general population, it occurs more commonly in people who suffer from Parkinson’s disease (PD) than in the general population. PD patients with RLS have restlessness, leg movements, itching, cramping, thrashing, “water under the legs,” and a “creepiness-crawly” feeling. RLS is a relapsing-remitting disease characterized by uncomfortable sensations in the legs. The symptoms improve with movement and may occur at any time, but they are usually worse at night or when the person is sitting or lying down. The symptoms may become severe enough to interfere with sleep and daily activities.

RLS is a common condition that affects millions of people worldwide. It is a chronic syndrome that can be managed with medication, lifestyle changes, and supportive care.

The best treatment for RLS is medication, which can be prescribed by a doctor. The medication most effective for RLS is dopamine agonists, which are drugs that increase the amount of dopamine in the brain. This helps to reduce the symptoms of RLS. Other medications that can help treat RLS include gabapentin, pregabalin, and baclofen.

The Parkinson Center of Oregon is conducting a study of a new investigational drug for RLS. More information about this study is available by calling (503) 494-1382 or eIRB# 1407.

Are you interested in an experimental drug study that might help treat Parkinson’s disease?

The Parkinson Center of Oregon is currently conducting a research project for people with depression that have Parkinson’s disease. The study will examine the use of two FDA-approved antidepressants, Prozac and Effexor XR to see how these drugs may benefit people with Parkinson’s disease and have no recent history of antidepressants. You must be 18 years or older and have had Parkinson’s disease for at least 5 years. If you are interested please contact the Parkinson Center of Oregon at (503) 494-1382 or eIRB# 4925.

Healthy Volunteers Needed for Balance Study

Oregon Health & Science University is conducting a study among newly diagnosed Parkinson’s disease patients who have had Parkinson’s disease for less than 5 years and who have been in good health, except for idiopathic fluctuations during the previous 3 years. If you are interested please contact the Parkinson Center of Oregon at (503) 494-1382 or eIRB# 1680.

Electronically Measuring Walking Speed May Help to Learn More About Parkinson’s Disease

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Dear Vicki,

(FCO’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 extraneous considerations that you need to address to live alone with PD successfully, there are many ways 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. Also, try to maintain 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 improve their quality of life, provide 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 that you may not be able 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.

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

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/acompanist Bill Lamb headlined a concert at St. Mary’s Academy in Portland, the only all-girl school in the state of Oregon. 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 roof-top 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.
Boehringer Ingelheim Pharmaceuticals, in collaboration with Oregon Health & Science University, revealed that rotigotine is similar to already available dopamine agonists such as pramipexole (Mirapex) and ropinirole (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, including the possibility of nausea, confusion, excessive sleeping, 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 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.
The following studies currently are looking for participants. The Parkinson Center of Oregon is involved in many other studies that are not currently recruiting. These studies include ongoing clinical trials, new family care research, new genetic research, new sleep research, new neuroimaging studies, new cognitive intervention studies, new memory and learning research, new medication studies, new symptom research, new treatment studies, and new research on how the disease impacts quality of life. For more information about these studies, please call the Parkinson Center of Oregon at 503-494-1382.

**受试者的个人信息会受到严格保密，仅用于研究目的。**

**请在下面的区域填写您的全名和电子邮件地址。**

**保存电子邮件地址，以便我们进行后续通信。**

**我们保证您的个人信息将被保密。**

**如果您是受试者并且担心个人信息可能会被滥用，请告诉我们。**

**如果您的个人信息被滥用，请告诉我们。**
Nonprofit Org.

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 3/1/06; $15 per person after 4/1/06
scholarships available

Red Lion — Columbia Center
1101 N. Columbia 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
A National Parkinson Foundation Center of Excellence

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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 it’s function is—eye color,
hairstyles, gender, everything. The combinations are endless and that is why we are all different.

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Discoveries in the Genetics of Parkinson’s Disease
by Tatiana Faroud, Ph.D.

PD-Gene Roster

<table>
<thead>
<tr>
<th>Gene</th>
<th>Population of PD</th>
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<tbody>
<tr>
<td>Alpha synuclein (PARK1)</td>
<td>0.5% of all PD cases</td>
</tr>
<tr>
<td>Parkin (PARK2)</td>
<td>0.5% of early onset PD cases</td>
</tr>
<tr>
<td>PINK1 (PARK6)</td>
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<tr>
<td>Alpha synuclein (PARK1) &amp; Parkin (PARK2)</td>
<td>5% of early onset PD cases</td>
</tr>
<tr>
<td>LRRK2 (PARK8)</td>
<td>5% of late onset PD cases</td>
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</tbody>
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Continued on pg 3

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- Current Research Projects Seek Participants
- PCO Alliance Events Raise Funds for PCO projects.
- New Drug Reviewed: Rotigui-
tine, “The Patch”
- Upcoming PCO Educational Symposia Highlight Young People with PD & Rural Outreach

Published in the Winter 2006