Why is it relevant?
The path to a cure for Parkinson’s disease (PD) is still not a clear one. The development of “neuroprotective” or “disease-modifying” therapies has become a central focus in the PD research community. Developing a cure, however, will likely require identifying individuals who are destined to develop PD prior to having the symptoms that we most commonly associate with this disease. There is presently no method to accurately diagnose PD prior to the onset of motor signs. Motor symptoms do not appear until approximately two-thirds of the brain cells that store and release dopamine have already ceased working. At this point, there is already a breakdown of the normal cell function in the basal ganglia, which is a type of relay circuit in the brain that is essential to normal movement. In order to successfully find a treatment that slows or stops progression of disease, we may need to identify people at risk for developing symptoms of PD prior to the onset of these symptoms, so that an intervention can occur in a preventative manner. Neuroprotective therapy for individuals with PD may only be effective if implemented at the earliest possible moment.

Possible Methods
Non-motor signs
PD has traditionally been viewed as a neurodegenerative disorder primarily affecting cells in the “midbrain,” and it is progressive loss of these cells that are thought to lead to the cardinal signs of PD: resting tremor, slowed movement, and muscular rigidity. In addition to these motor features, there are many non-motor manifestations of PD, including autonomic dysfunction, loss of sense of smell, and change of sleep habits. These non-motor features often occur early and may give us an opportunity to detect PD before motor symptoms begin.

The autonomic nervous system is the part of our nervous system that regulates functions such as heart rate, blood pressure, pupillary function and gastrointestinal movement. Changes in this part of the nervous system may take place at the earliest stages of Parkinson’s disease and before the midbrain is affected. There are a number of ways to study autonomic nervous system function, and in fact some have already been explored as a method of early PD detection. There is evidence that the nerves that control heart rate are not functioning normally in the earliest stage of PD. Variability of heart rate at rest declines as people age, and this variability may be affected to a greater extent in PD. This can be easily tested by obtaining an electrocardiogram (EKG) at rest, and is potentially a cheap and widely available screening tool. Other early autonomic markers for PD that have been studied include alteration of normal constriction and dilation of the pupil, and slowed gastrointestinal motility.

The association of PD with an impaired sense of smell was first reported about thirty years ago. Since then, it has become quite firmly established that olfactory dysfunction is one of the first and most prevalent clinical manifestations of this disorder. A validated smell test is now in use to assess risk for developing PD. A condition called REM sleep behavior disorder, where the normal paralysis of muscles during the dream phase of sleep is lost, is also more common in early PD. Combining all of these early non-motor signs in a test battery could potentially give us a powerful screening tool for early detection of PD.

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Our Mission: Comprehensive Care for Patient and Family

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

The OHSU Parkinson Center of Oregon (PCO) has three missions: care of people with Parkinson’s disease, education about Parkinson’s disease, and research into causes of and treatments for the disease. In this issue of the newsletter, we will discuss our clinical care mission. The PCO goals within this mission are to offer expert, comprehensive care to the person with Parkinson’s disease as well as to their families.

The range of symptoms and signs of Parkinson’s disease is very large. Furthermore, no two people with Parkinson’s disease are alike. From these two facts, it follows that extensive experience with diagnosing and treating the disease is an advantage in caring for people with Parkinson’s disease. The OHSU PCO clinics are staffed by people with subspecialty, fellowship, and training in Parkinson’s disease and related movement disorders, whose medical careers are focused on the disease. These trained and experienced PCO clinicians offer a unique expertise in Parkinson’s disease.

Expertise in Parkinson’s disease also means that new findings in research are immediately translated into clinical practice. Because we also have a research mission, it may mean opportunities to participate in research with new experimental drugs. PCO clinicians’ expertise also may help people separate out fads that have no rationale or evidence to support their use from new approaches for which there is rationale and preliminary but not conclusive evidence of benefit.

Because of the wide range of symptoms of Parkinson’s disease, no single clinician is able to assess and treat all the symptoms. This means that comprehensive care requires a team effort. The PCO allied health rehab team—namely speech therapy, physical therapy and occupational therapy—are important components of our care, and their value is increased by specialized training in applying their specialty to Parkinson’s disease. The allied health team at the PCO has had this training. They are now involved in teaching other allied health providers the approaches that are successful with Parkinson’s disease to create a network of allied health providers with expertise in Parkinson’s disease in Oregon and southwest Washington (see inset for related article).

Parkinson’s disease may cause symptoms that are best managed by other medical specialties such as dollyangology, gastroenterology, urology, and psychiatry. The PCO establishes a network with these other medical providers to consult on our patients when needed. Finally, every person with PD has, or should have, a primary health care provider. The PCO and its affiliated organization at the Portland VA Hospital, the Parkinson Disease Research, Education and Clinical Center (PADREC), are focusing on education of primary care practitioners to make them more aware of the special needs of people with Parkinson’s disease (see related article on page 3). This is an effort to expand the network of clinicians that are knowledgeable about PD.

It is not just the person with PD who is impacted by the disease; families, particularly and other caregivers and friends are also affected. We consider them part of the team supporting the person with PD and at the same time are concerned about their own well being. Questionnaires filled out by caregivers help us detect the early signs of caregiver burn out. Further, we offer programs for the caregivers to help them maintain and support their PD patients while at the same time are concerned about their own well being.

The clinical care mission of the PCO is not static but is always evolving. In one sense, it is part of our research. We are constantly seeking better ways to deliver expert, comprehensive care to the person with the disease and to their families.

Thank you to our many donors, contributions of exceptional research, comprehensive care, and education. Due to issues of privacy, we are no longer listing the names of our donors in our newsletter. This does not reflect our lack of appreciation to the generous individuals that make contributions. We are grateful that each year, more than 1,000 of you choose to support the OHSU Parkinson Center of Oregon and we appreciate your ongoing commitment.

Recent Events Benefit OHSU Parkinson Center

We have many talented and generous folks who support the work—research, education, and medical care—of the OHSU PCO. Without private donations, most of our programs would cease to exist. So thank you everyone for your donations. Here are a few very innovative and successful fundraisers that occurred in 2008.

Shakers’ Ball

The 4th Annual Shakers’ Ball took place April 27 at the McMenamins Kennedy School for the second year in a row. It was an open house style concert with bands such as Sisters in Crime, Blue Moon Highway and Miriam’s Well playing from noon to 6 PM. A craft table entertained children in the outside courtyard while adults danced away inside. The event benefited both the OHSU Parkinson Center of Oregon and Parkinson’s Resources of Oregon, and was spearheaded once again by founding musician/songwriter Andrea Serdar.

Strike Out PD

The 4th Annual Strike Out PD event was a great success. On Saturday, May 3rd, Sunset Lanes donated their facility and staff to support the OHSU Parkinson Center of Oregon and Parkinson’s Resources of Oregon. Over 120 bowlers attended the event, contributing to the $11,500 raised! Event coordinators Roger and Karen Anderson had the pleasure of giving away 32” LCD TV, among many other prizes, during the raffle. A special thanks to the Andersons and Sunset Bowl for their generosity and hard work!

How and when does PD start? Help us find out...

The Parkinson Associated Risk Study (PARS) is trying to answer that question and we need your help to answer it! When did your Parkinson disease begin? Was it when you first noticed a tremor in one hand, or when your walking and balance didn’t seem quite right? Or was it years before these symptoms? There is evidence that PD may in fact start without the motor (movement) symptoms, but instead many years earlier with changes in olfaction (sense of smell) or with sleep, constipation or other problems. A national research study is trying to discover what the very earliest signs of PD are, by examining first-degree relatives of people with PD. A first-degree relative is a child, a sibling or a parent. These relatives of people with PD are being recruited as study subjects for two reasons: evidence suggests that they may have a slight increase in risk of developing PD, and they may be more motivated to participate in a study like this than people who have no relatives with PD. Those who participate in this study fill out a brief questionnaire and return it by mail. If eligible for the study, they are seen for a scratch and sniff “smell test” and questionnaires to complete and mail back. Those with abnormal smell tests (and some with normal tests) are then invited to come to one of the centers participating in the study for examination, and also to have special imaging done at another center.

You can find out more about the Parkinson Associated Risk Study (PARS) on the “study opportunities” column on page 4 of this newsletter.
Complementary and alternative therapies, such as acupuncture, are extremely popular. A 2001 study found that 40% of persons with Parkinson’s disease used some form of alternative or complementary therapy. Many more people appear interested in complementary therapies but may not have tried them yet: in a veteran population, 90% were using or interested in using these therapies. Acupuncture is one of the most popular therapies used by about 10% of persons with Parkinson’s disease and ranking in the top three among alternative therapies. A number of small studies have attempted to look at the effects of acupuncture in a systematic manner. There are a couple of difficulties in designing studies of acupuncture. One is that there are a number of different ways to perform acupuncture. Also designing a placebo arm has been difficult. In research, having a placebo (a pill or therapy that is not actually therapeutic, but the research subject does not know if they are receiving a placebo or the real therapy) is essential to making sure the effects observed are truly attributable to the therapy being tested. Of the studies I reviewed, none showed statistically significant improvement in any PD symptoms. Also, the areas of improvement were not consistent among different studies. Some have suggested an improvement in sleep, depression, and self-rated quality of life. Patients often report a subjective improvement in individual symptoms including tremor, walking, and handwriting, but these are not always reflected in objective measures. While studies have consistently shown that it is safe with negligible side effects, research has not shown a clear or consistent benefit from acupuncture. Further well-designed, larger studies are needed in order to understand the potential role of acupuncture in the treatment of Parkinson’s disease.

As the Neurology Wellness Clinic’s acupuncturist, Dr. Steven Dardis remarked, “People often seek acupuncture treatment as an adjunct to their Western medical regimen. Acupuncture’s intent is to optimize a person’s overall health and well-being being that whether is subjectively or objectively determined. Acupuncture is not a cure for PD but a medical modality to be used in conjunction with other treatment methods to improve a person’s short and long term quality of life.”

Is Acupuncture a Good Treatment for Parkinson’s Disease?
Amie Peterson, M.D. - Movement Disorders Fellow

Have you ever experienced...?

If you answer ‘yes’ to any of the questions below, you should consider asking your physician for a referral for occupational, physical, or speech therapy or to see our entire team for a full evaluation.

OCCUPATIONAL THERAPY QUESTIONS:
• Trouble “getting started” in the morning?
• Trouble with zippers or buttons?
• Not able to stand up from the toilet?
• Trouble figuring out which way a shirt goes on?
• Difficulty telling how far down a step is from your foot?
• Problems writing out a check because your handwriting has changed?
• Not enough energy to get through the day?

PHYSICAL THERAPY QUESTIONS:
• A fall, near falls or stumbling?
• Problems going up or downstairs?
• Difficulty turning around or turning corners while walking?
• Difficulty standing up from a chair or getting out of bed?
• Stiffness and you don’t know how to stretch?
• Need new equipment (walker or wheelchair)?
• Don’t know where to start?
• Increased stress and unable to relax?
• Pain in your back or shoulders?

SPEECH-LANGUAGE PATHOLOGY QUESTIONS:
• People having difficulty understanding you?
• Have the word on the ‘tip of your tongue’ without being able to find it?
• Difficulty remembering details of daily routine, conversations, etc?
• Easily distracted; Short attention span, etc?

INTERDISCIPLINARY QUESTIONS:
• Concerns with maintaining employment?
• Questions about caregiver safety or burn-out?
• Questions about changes in your home for safety?

Description of Therapy Services for People with PD

Occupational Therapists (OT) help with:
• Activities of Daily Living including eating, dressing, bathing
• Remembering when to take pills
• Getting out of bed or a tub, or off the toilet seat
• Vision problems
• Falls in the home environment
• Writing, using cooking and feeding utensils

Physical therapists (PT) help with:
• Balance
• “Freezing,” taking small steps or having problems with turning
• Flexibility and strength
• Exercise programs
• Equipment to increase mobility and safety
• Standing straight (improving your posture)
• Pain management

Speech and Language Pathologists help with:
• Communication: Finding the right words, organizing your thoughts, etc.
• Speech: being able to be understood by others
• Loudness: level of speaking
• Swallowing safely and easily
• Memory, attention, initiation, speed of information processing, problem solving,
• Interdisciplinary: Coordination of care among disciplines, etc.

Table: Description of Therapy Services for People with PD
Options & Opportunities

PARKINSON’S DISEASE SYMPOSIUM

HOPE IN RESEARCH

Saturday, September 20th

OHSU’s Parkinson Center of Oregon (PCO) and our co-sponsor—the VA PADRECC (Parkinson’s Disease Research, Education, and Clinical Center)—are proud to present the 25th Annual “Options & Opportunities Symposium on PD.” This year’s theme, “Hope in Research,” focuses on the impact research has had, is having, and will have on the treatment of PD. We are lucky to welcome back a popular keynote speaker with exceptional experience in PD research—Dr. Ron Pfeiffer of the University of Tennessee.

AGENDA

9:00 am Registration
9:30 am Keynote Speaker: Ron Pfeiffer, MD

“Parkinson’s Disease Research: Where we’ve been, where we are going”

10:30 am Break

10:45 am “Diagnosis and Genetic Therapy” - Matt Brockdyke, MD

11:30 am “Ask the Experts” Panel

12:45 pm Lunch & Exhibits*

1:45 pm “Current Research in PD” - Julie Carter, PCO Associate Director

2:30 pm Break

2:45 pm “DBS Past, Present, Future” - Penelope Hogarth, MD

3:30 pm Closing Remarks

Dr. Pfeiffer will discuss the impact research has had, is having, and will have on the treatment of PD.

“Parkinson’s Disease: From the Inception to the Fulfillment”

Keynote Speaker: Kari Lyons, LCSW, with more than 10 years of experience helping people and their families manage chronic illnesses, such as Parkinson’s disease. Her work is infused with a holistic perspective. Kari believes that only when we con-scientiously connect and call on all parts of self (mind, body, spirit), that true healing and transformation can and does occur.

SPECIAL EVENTS

3:30 pm Dessert & Discussion

OHSU 25th ANNUAL SYMPOSIUM:

NEWLY DIAGNOSED WITH PD?

Friday, September 19th

Are you under 60 years old and have Parkinson’s disease? Then this event is for you!

The OHSU Parkinson Center of Oregon is holding its “Young People with Parkinson’s Disease Conference: An Evening of Discovery” on Friday, September 19, 2008 at the Doernbecher Vey Auditorium from 5:30pm to 9:30pm.

Keynote Speaker: Kari Lyons, LCSW, as we embark on this healing journey!

SPECIAL EVENTS

September 20th - West Portland

Parkinson’s Resources of Oregon’s monthly Brown Bag Lecture: Coping With Depression in PD. The speaker for this presentation is Dr. Paul Conti. The talk will be held at the Providence St. Vincent Hospital in the Southern Classroom. Please call PRO to register for this free lecture. 503-594-0901.

PRO SOLE SUPPORT - SEP 14th & 21st

Help raise awareness and funds for services and people with Parkinson’s disease. Parkinson’s Resources of Oregon invites you to join them for their 4th annual Sole Support for Parkinson’s Walks in Portland and Eugene this September! The Portland Walk is on Sunday, September 14th at Willamette Park. The Eugene Walk is on Sunday, September 21st at Alton Baker Park. Activities for both walks begin at noon, the walks kick off at 1:30. There are 1K and 5K wheelchair accessible walk options. Registration is $15 for an adult, $10 for children.

What is dyskinesia?

Many patients who are treated for Parkinson’s disease suffer from dyskinesia, or involuntary disorganized or excessive movements of the body. The movements may appear as jerking, twisting, fidgeting, or dance-like motions of the upper or lower body. Dyskinesia is most often a side effect of levodopa (Sinemet®, Parcopa®; generic: car-bidopa/levodopa), which is a common treatment for patients with Parkinson’s disease.

A patient may develop dyskinesias as dosing of levodopa is increased with the disease’s progression. The frequency and intensity of dyskinetic movement may vary, and tends to be the most extreme during the peak effect of a dose of levodopa. However, some people may experience dyskinesia as their medication takes effect and/or at the end of their dose. Patients who have severe dyskinesia may benefit from changes or addition of medications or deep brain stimulation (DBS) surgery.

At the PCO there are currently many study opportunities investigating treatments and prevention methods for those suffering from dyskinesia. If you are interested in participating, please speak with your physician or call April Wilson at 503-418-1769 for more information.

For more information please visit www.ohsufoundation.org.

Brochures for each event are being mailed in early August or visit our website at: www.ohsu.edu/pcocapo.

OHSU PCO EVENT CONTACT: Sara Duran, 503-494-7231 or by email at durans@ohsu.edu.