



# The Parkinsonian

❄️ *Winter Issue, 2010*



Northwest PADRECC  
Parkinson's Disease Research, Education & Clinical Center



## PANUC

*Pacific Northwest Udall Center*



**Thomas J. Montine, MD, PhD, Director**

The VA Puget Sound Health Care System PADRECC and the Portland VA Medical Center PADRECC were awarded a grant to create the Pacific Northwest Udall Center (PANUC). This center is designed to study cognitive impairment in Parkinson's disease (PD). While PD is typically known for its motor symptoms (tremor, slowness of movement), it is increasingly recognized that cognitive impairment, including dementia, frequently occurs in PD. In fact, up to 80% of PD patients may eventually develop dementia. It is now recognized that this "non-motor" problem is linked to increased disability in the PD patient, is more stressful to caregivers of PD patients than the typical motor symptoms, and is associated with a shortened lifespan. Unfortunately, while there are excellent treatments for the motor symptoms of PD, there are very limited treatment options for cognitive impairment in PD. In large part this is due to a poor understanding of the causes of this problem in PD. The PANUC will address this limitation through the study of PD patients and the development of models to better understand what brain changes lead to cognitive impairment.

There are two main objectives of PANUC. The first is to characterize the motor (physical movement), cognitive (thinking), and behavior in subjects with Parkinson's disease over time. The second objective is to look for genetic causes and biomarkers (traits used to measure or indicate the effect or progress of a disease) in PD. Genetic information decides many human characteristics such as the color of your eyes, height, and hair color. This information is carried by a chemical structure called DNA. Your DNA is found in your blood. Other chemical traits (biomarkers) will be determined through cerebrospinal fluid (CSF). CSF is a watery fluid which flows within and around the surface of the brain and spinal cord. Your CSF fluid also carries proteins. The kinds and amounts of these proteins may lead to a biomarker. Patients with Parkinson's disease will be recruited to one of two PD subject samples. The clinical sample will be a large sample designed to allow the examination of genetic factors for cognitive impairment in PD. The clinical sample will undergo a limited motor and cognitive evaluation and blood draw for DNA and biomarkers twice over five years. The annual sample will be a smaller sample of PD patients that will undergo a more extensive evaluation. This will include more detailed motor and cognitive evaluation on an annual basis. In addition to blood draw for DNA and biomarkers, these subjects will undergo lumbar puncture for cerebrospinal fluid (CSF) biomarker studies and will be asked to participate in the autopsy protocol. By examining patients and their genetics, PANUC aims at better characterizing Parkinson's disease patients, and possibly find genetic causes and biomarkers.

The PANUC will bring together a multidisciplinary group of investigators focused on improving our understanding of cognitive impairment in PD. Equally important, the PANUC will be an invaluable resource for other investigators interested in the study of PD, including those in other Udall centers across the country.



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## Center for Organization, Leadership, and Management Research (COLMR) Study: Updated Results

To determine the effectiveness of the Parkinson's Disease Research, Education and Clinical Center (PADRECC) programs, the VA's Health Services Research and Development funded the study entitled "The Center for Organization, Leadership, and Management Research" (COLMR) study conducted out of the VA Boston Healthcare System. The study includes surveys from PADRECC patients across the nation and their caregivers, service utilization information, and interviews with VA employees. Recently the group published some of their early findings which included surveys from 2,375 patients and 818 caregivers.

They found that 74 percent of patients and 37 percent of caregivers were over the age of 70. Also, 82 percent of the patients claimed to receive care from their spouse. Overall, caregivers felt that they were healthier than patients. The study found that 45 percent of patients did not engage in regular exercise and 40 percent reported experiencing depression, while 22 percent of caregivers did not engage in regular exercise and 26 percent reported experiencing depression. Patients reported experiencing moderate levels of impairment during the times that their medications were the most effective, with 22 percent experiencing hallucinations. About half of the caregivers reported having less personal freedom and time for themselves. While 55 percent reported it being painful to watch the patient age, 67 percent also experienced positive feelings in regards to their relationship with the patient.

Only 16% of patients surveyed reported using VA education and support services. The most common reasons for not using these resources included never being asked to participate, not knowing about the services, and distance or transportation difficulties. Patients reported satisfaction with attention to personal preferences, access to care, and emotional support. They felt that needs were unmet in areas of individualized goal-setting and treatment planning, problem solving, patient activation, delivery system design, and follow-up/coordination. Overall PADRECC patients used less long-term outpatient care and more neurology care than other VA Parkinson's disease patients.

### What is Restless Legs Syndrome (RLS)?

*By: Lissa Brod, MD, Parkinson's Disease Research, Education, and Clinical Center Fellow*



Restless legs syndrome (RLS) is a disorder causing spontaneous leg movements associated with unpleasant sensations and an urge to move, usually worse later in the day and at night. The unpleasant sensations occur at rest and are relieved (temporarily) by moving. Some patients with RLS also have movements of their legs during sleep, called periodic leg movements of sleep (PLMS).

Many patients with Parkinson's Disease (PD) have RLS, though a diagnosis of RLS does not mean a patient has or will develop PD. RLS is more common as people age, though it peaks around age 79. It occurs more commonly in women than men. Family history of RLS in a parent increases the risk as well. The disorder ranges in severity from a minor, occasional annoyance (in up to seven percent of the population) to a moderate-severe problem impacting sleep (up to three percent of the population). The disorder affects the sleep of the patient, as well as the patient's bed-partner, and often causes patients to have to sleep in separate beds from their significant others.

RLS can occur on its own, or it can be a symptom of another medical problem, such as blood iron deficiency or diabetes. Therefore, your doctor may need to do some blood tests for other conditions if you have RLS.

There is no cure for RLS, but there are therapies that can help patients feel better. These include stretching before bed, treating any other conditions like iron-deficiency, and special medications. These medications include dopamine agonists (ropinerole, pramipexole), levodopa, gabapentin, benzodiazepines (clonazepam, diazepam), low-strength opiates (codeine). Other medications, as well as caffeine, nicotine, and alcohol may worsen RLS symptoms, so your doctor may have you stop these. Treatment is customized for each patient, depending on their overall medical condition and severity of symptoms. Each therapy has its advantages and disadvantages.

RLS is not dangerous, but may be uncomfortable and disruptive to sleep. It cannot be treated unless your doctor knows you have it. Be sure to talk to your doctor if you experience RLS symptoms!

## PADRECC Website



Check out the newly updated PADRECC Website at:  
<http://www.visn20.med.va.gov/portland/PADRECC>

The PADRECC website provides information about Parkinson's Disease and other movement disorders, as well as services available to veterans and their caregivers. Here are some things you can find on the website:

- ◆ PADRECC clinic, staff, and contact information.
- ◆ Information about Parkinson's Disease and its treatments.
- ◆ Information about support groups and outside resources.
- ◆ Patient Education events.

## Recruiting VA Studies

### Memory and Movement Disorders Demonstration Project (VA IRB ID: 1585 VA IRB Grant Number: #02-2202)

Dr. Joseph Quinn, MD is conducting this research study in order to track the frequency and types of changes in mental functioning that occur over time in Parkinson's patients. Participants would be asked to attend one or more study visits. All study visits would take place at the Portland VA Medical Center. The first visit would take less than twenty minutes. If asked to continue in the study there would be a second 90 minute visit and then follow-up examinations once a year for the next 3 years. All patients in the Parkinson's Disease Research, Education and Clinic Center (PADRECC) are invited to participate in this study. You may or may not personally 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.

### 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.

## Recruiting OHSU Studies

### Fish Oil for Depression in Multiple Sclerosis (MS) and Parkinson's Disease (PD)

The Parkinson's Center of Oregon at Oregon Health & Science University is looking for people with a confirmed diagnosis of PD who are suffering from Depression. The purpose of the study is to determine if taking omega-3 fatty acids along with your current antidepressant helps with symptoms of depression in people with PD. In addition we will determine if omega-3 fatty acids decrease blood levels of substances that are associated with depression.

You may be eligible to participate in the study if you meet all of the following criteria.

- Have a definite diagnosis of PD
  - On a stable dose of anti-depressant medication
- Between 18-85 years of age

This is a three-month pilot study in which 60 participants with either PD or MS will be randomly assigned to receive either fish oil capsules (which have high amounts of omega-3 fatty acids) or placebo capsules. The study requires 5 visits to OHSU. The research study will pay for all costs associated with the participation in this study. You will be responsible for any expenses that have to do with other aspects of your participation such as childcare and transportation. If you meet the eligibility requirements described above and are interested in participating in this study please call Dr. Lynne Shinto at (503) 494-5035.

## Calendar of Events

Upcoming classes, support groups, and other events related to movement disorders

### Parkinson's Resources of Oregon

**Education. Inspire. Empower.:** Friday, March 26 and Saturday, March 27, 2010 - 2010 PRO Annual Educational Conference in Eugene, Ore. For more information please call (800) 426-6806

### Movement Classes

Weekly class held in a variety of locations providing instruction in the technique created by John Argue (The Art of Moving) for people with Parkinson's. Call: (503) 413-7717 Ask for: Holly

### Parkinson's Center of Oregon (PCO)

**Newly Diagnosed Educational Session:** Occurs every other month. For more information call (503) 494-9054.

### Portland Patient Education Talks

All talks listed will be held in the Portland VA Medical Center Auditorium from 10 a.m. to 11 a.m. unless otherwise noted. Please arrive early for parking. For more information or to register call (503) 721-1091.

**Friday, January 15, 2010: Restless Legs** - Lissa Brod, MD, Parkinson's Disease Research, Education, and Clinical Center

**Friday, March 19, 2010: Driving with Parkinson's disease** - Speaker to be announced



Image by Dan North who is a patient at the Portland VA PADRECC

### Want to Contribute?

*This newsletter is yours, and we think you should be involved. If you have any art, poems, stories, or articles you would like to share with other Parkinson's patients, please send them to the address listed below or e-mail them to [nwpadrecc@va.gov](mailto:nwpadrecc@va.gov) with newsletter submission as the subject line.*

**Portland VA Medical Center**  
Attention: Susan O'Connor  
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To receive the Parkinsonian by e-mail please forward a request to [nwpadrecc@va.gov](mailto:nwpadrecc@va.gov). Call 503-721-1091 to be removed from our mailing list



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