

The Parkinsonian

* Fall Issue, 2009



Northwest PADRECC

Parkinson's Disease Research, Education & Clinical Center

A Letter from a Patient

Dear Dr. Amie Peterson and Dr. Kim Burchiel,

It has been about 2 months since my deep brain stimulation surgery on the 1st and 5th of December 2008.

Last night I had an episode to remind me. About 11:30 p.m. I was finishing up with my computer e-mails, when my right hand began to shake rather violently. Just half an hour before I had taken my usual meds. This continued to get worse as the minutes rolled by. I took another dose of my meds and woke up my wife. I had her place the remote against the generator and push the on button --it beeped and 3 green lights lit up and immediately my violent shaking of my right hand stopped --it seemed to me to be a miracle. Since the 5th of December and 9th of January I have been relatively free of shaking and mouth dyskinesias.

I am so grateful to you both. You have given me a new lease on life. Thanks to you and your team that made it possible. Thanks for your continued dedication and the many sacrifices

you have made to gain the knowledge and skills to be able to do these small miracles. My friends and family notice a night and day difference. And my hair is almost back to normal.

Thank you, A Grateful Patient



Tips from a Reader

Thank you for the summer issue of the Parkinsonian Newsletter. I found it very interesting and have a couple of procedures to pass on. I suffer with daily back pain as well as early Parkinson's. As a



result my back is very sore and stiff when I first get out of bed in the morning. At the suggestion of Dr. Hutton of Port Townsend, WA, I take one tab of Carbidopa 50/ Levodopa 200 mg an hour or more before getting up and I find the back soreness and stiffness is almost non existent.

Also I walk about 2 miles every day. Because of the newsletter I found out Parkinson's is a contributor to the tendency to lean forward when walking as well as my back problems. To counteract this tendency I adopted the Asian custom I observed by older people in Korea where they fold and grasp their arms in the small of the back when walking. This reduces both the pain and strain, and I find it becomes normal to walk up strait.

I hope this helps persons with similar conditions

Richard G. Petit

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Calendar of Events

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

Parkinson's TeleHealth Program

The Parkinson's TeleHealth Program broadcasts live, interactive educational talks to a network of rural communities in the Northwest. All sessions start at 2:00 p.m. (Pacific Standard Time).

Monday, September 21, 2009: Happy Faces and (Not) Drooling: Sara Nielsen, M.A.

Monday, October 19, 2009: Freezing: Len Norfleet, PT/ACT from NKS Rehab

Monday, November 16, 2009: Living with Visual Impairment and Parkinson's Disease: Holly Gallow, OTR/L Occupational Therapist

Please call for more information and to register:

Anchorage, Alaska,	Rose Lahti	(907) 278-7500
Billings, Mont.,	Mark Horn or Mike Roscoe	(406) 657-4870
Clarkston, Wash.,	Francie Jacobson	(509) 758-7070
Coeur d'Alene, Idaho,	Tom Hauer	(208) 666-2987
Grangeville, Idaho,	Karla Kroug	(800) 772-5137
Kennewick, Wash.,	Angel L. Trump	(509) 586-5119
Kirkland, Wash.,	Shelly Henderson	(425) 899-2660
Pendleton, Ore.,	Mary Finney	(541) 276-1881
Sandpoint, Idaho,	Sue Fox	(208) 265-3390
Seattle, Wash.,	Alecha Newbern	(877) 980-7500
Spokane, Wash.,	Larry Campbell	(509) 232-8134
Walla Walla, Wash.,	Debbie Deccio	(509) 522-5835 ext. 2835

St. Charles Medical Center - Bend, Ore.

Parkinson's Exercise Class: \$35 for a six week session. Located in the St. Charles Training Room E in Bend, Ore. For more information call Terry Shelby at (541) 706-6390.

PADRECC Patient Education Talks

All talks are held in the Portland VA Medical Center Auditorium from 10 a.m. to 11 a.m. Please arrive early for parking. To register call (503) 721-1091.

Friday, October 16: Essential Tremor: Speaker is to be decided

Friday, January 15: Restless Legs: Speaker is to be decided

Parkinson's Resources of Oregon

Saturday, September 19, 2009
Sole Support - Hawthorne Park Pavilion,
Medford, Ore.

Sunday, September 20, 2009
Sole Support - Alton Baker Park, Eugene, Ore.

Sunday, September 27, 2009
Sole Support - Willamette Park, Portland, Ore.

All walks include activities and registration beginning at 12:30 p.m. There are options of a 1k or 5k walk, and walkers are encouraged to form teams and raise money for Parkinson's disease. Registration fees are \$15 for adults (13 and over), \$10 for children between 12 and 4. Children under 3 are free, and if you register them they will receive a Sole Support t-shirt, too. Participants may register online (recommended), by mail, or at the event. We encourage everyone to walk as a team and fundraise to help exceed our goal of \$110,000! Event festivities will include live music, snacks and refreshments, a vendor fair, children's activities, and honorarium opportunities. Questions? 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.

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 with newsletter submission as the subject line.

Portland VA Medical Center Attention: Jessie Little P3-PADRECC

3710 SW US Veterans Hospital Rd.

Portland, OR 97239

PADRECC Website



Check out the 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 treatments.
- Information about local 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 you 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.

Missed a Patient Education Event?

We understand that not everyone can make it to our patient education events. As a result, the PADRECC records all of their patient education events. This way anyone who lives too far away or is unable to attend for other reasons, but wants to know more about the topic is able to view the event from their own home. Below is a list of available events. To request a copy of an event on DVD please call Jeremy Cook at (503) 721-1091.

Alternative Therapies in Parkinson's Disease Friday, October 17, 2008 Lynne Shinto, ND

Cognitive Issues and Brain Exercises Friday, July 11, 2008 Joe Quinn, MD

Nutrition, Speech, and Swallowing Friday, October 12, 2007 Erin Bookout and Marcy Fitterer, RD, LD

Fatigue in Parkinson's Disease Friday, May 18, 2007 Gordon Campbell, ANP

Exercise, Balance, and Tai Chi for Parkinson's Disease

Friday, January 19, 2007 Fay Horak, PhD and Strawberry Gatts, PhD

Staying Fit with Parkinson's Disease: Exercise Fair

The topic for the final patient education event this year was exercise. Patients arrived to a myriad of different booths ranging from physically therapy and exercise classes to fitness for the brain. Lunch was provided, and Sue Scott, M.S., an active-living and balance specialist for renewable fitness began her lecture. She discussed the different ways in which exercise has been proven to counteract the effects of Parkinson's Disease. Sue stressed that the best exercise for patients with Parkinson's Disease is any exercise that you will do. She went what types of different exercise will help different parts of the body. The event came to a close after a short patient involved exercise program.



Patients exercising at the Portland VA Medical Center

To receive the Parkinsonian by e-mail please forward a request to nwpadrecc@va.gov. Call (503) 721-1091 to be removed from our mailing list.



Portland VA Medical Center

P3-PADRECC 3710 SW US Veterans Hospital Rd. Portland, OR 97239 Phone: (503) 721-1091

Seattle VA Puget Sound Health Care System

Neurology 127 1660 S. Columbian Way Seattle, WA 98108 Phone: (206) 764-2021

nwpadrecc@va.gov http://www.visn20.med.va.gov/portland/PADRECC/