



Northwest PADRECC

Fall/Winter 2012

Insider



Traveling with Parkinson's Disease

"For my part, I travel not to go anywhere, but to go. I travel for travel's sake. The great affair is to move."

-Robert Louis Stevenson

Travel for most of us means time spent with family, seeing new places, and enjoying a relaxing vacation. Traveling gets our bodies moving, which is great therapeutic exercise for PD. But how can you prepare your patients for a safe and fun trip despite limitations related to their health? Let's talk about some ways to help keep travel a fun and refreshing activity.

- ⇒ 1. Patients should always travel with a companion and carry a medical alert card (similar to those provided by the National Parkinson Foundation) to explain that they have Parkinson's disease and what the symptoms may look like. Also they should carry a list of medications and scheduled administration times.
- ⇒ 2. When traveling by plane, patients should carry their medication in a carry-on and keep some in each of their bags. One never knows when bags carrying medications can become misplaced, causing a delay or cancellation of their trip.
- ⇒ 3. Patients should refill their medication 1-2 weeks prior to their trip. That way they have a full supply available to bring with them to their destination and they won't have to worry about finding a pharmacy while away.
- ⇒ 4. Have them bring a copy of their doctor's contact information, pharmacy information, a brief medical history, insurance card, and an emergency contact name and number (other than the person with whom they are traveling).
- ⇒ 5. Patients should try to pack lightly, including loose comfortable clothing and great walking shoes!
- ⇒ 6. Advise patients to pack snacks and carry a bottle of water at all times for those medication doses that are due while they are out and about.
- ⇒ 7. Advise patients to request a handicap accessible room from the hotel/motel at which they are staying. If they require a wheelchair, request to borrow one from the hotel. Most hotels provide this service for free or with a small fee.
- ⇒ 8. Schedule a short nap (30 minutes) into their

PADRECC Welcomes New Administrative Officer

Carolina Mann Main assumed the role of Administrative Officer for the NW PADRECC in May 2011.

Carolina is studying for her Master's in Public Health from Portland State University. Over the past 16 years, Carolina has served as the Residency Coordinator for the Department of Neurology at Oregon Health & Science University. In this position, Carolina coordinated all activities in the training of future neurologists. Carolina is enthusiastic about the experiences and challenges ahead as NW PADRECC's Administrative Officer.

Contact Carolina, if you are interested in joining the PADRECC Consortium.



- daily itinerary. Even if they don't sleep during this time, simply taking the time to relax and recharge can make the day's activities manageable and allow them to enjoy their time more.
- ⇒ 9. If traveling by air, patients should request transport from the door to the gate so they do not spend their energy getting to the plane instead of on their vacation. Also, check as many bags as possible.
 - ⇒ 10. Utilize travel books about handicap-accessible travel. If there is a travel agent available, they should explain their medical needs to see what suggestions they have to make the trip most enjoyable.
 - ⇒ 11. If crossing time zones, patients should take their medications on schedule based on their home time zone for the first day of travel, even taking an extra dose or two if they are traveling for 24 hours straight. Then get on the new time zone schedule the first day they are at their destination location.

The most important thing to remember is that this is supposed to be a rejuvenating and enjoyable trip! Helping patients prepare for the unexpected will help make that come true.

Safe travels everyone!

Allison Lipnick, MSW, LCSW
Clinical Social Worker/Family Care Specialist

PADRECC Welcomes New Movement Disorder Fellow



Joanna O'Leary, M.D. joins NW PADRECC as a new Movement Disorder Physician Fellow. Dr. O'Leary earned her medical degree from Rush University, School of Medicine. She completed her neurology residency at Oregon Health & Science University. Dr. O'Leary enjoys being a mom, running, and reading in her spare time. She is excited to further her knowledge of Botox injections and DBS programming.

The NW PADRECC welcomes Dr. O'Leary to the team!

PADRECC Welcomes New Program Assistant



Please welcome, Elizabeth (Betsy) Minium who joined the NW PADRECC in July 2011 as the new Program Assistant. Betsy is currently working on her Masters of Art in Communication and Leadership Studies at Gonzaga University. Betsy is the live voice every patient hears when they call our office! Betsy revamped the NW PADRECC website to make it the shining star it is today!

PADRECC Website

Check out the PADRECC Website at:
<http://www.parkinsons.va.gov/NorthWest/Index.asp>



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 local support groups, and outside resources.
- ◆ Patient and provider education events.
- ◆ Video library of past education events.

NW PADRECC Patient Education Events

October 12, 2012
Dystonia

December 7, 2012
Medications and PD

February 8, 2012
Speech and Swallowing

All of our patient education events are currently being provide by V-Tel to participating sites. If you want to participate, contact us.

Recruiting VA Studies

Pacific Northwest Udall Center (PANUC): Clinical Core and Sample Collection
(VA IRB # 2332; OHSU IRB # 6154)

Dr. Joseph Quinn is conducting this research study to examine the changes in thinking and memory of Parkinson's disease patients over time. A second goal is to determine the role genetics plays in cognitive impairment in Parkinson's disease. You must have a diagnosis of Parkinson's disease to participate in this study. There are two different groups in this study. The first group is the clinical group. The clinical group will make two visits over five years to the Portland VA Medical Center. At each visit, you will undergo tests of thinking and memory and have approximately four tablespoons of blood drawn. Each visit will last for about one to one-and-a-half hours. The second group is the annual group. The annual group will make five visits over five years to the Portland VA Medical Center. At each visit, you will undergo tests of thinking and memory and have approximately four tablespoons of blood drawn. Each visit will last about two hours. After the first visit, you will undergo a lumbar puncture. A lumbar puncture is known as a spinal tap. A spinal tap is where a special needle is inserted between bones in your back and fluid is removed. The spinal tap will take about two to two-and-a-half hours. You have the option to undergo a second spinal tap three years after the first spinal tap. You will be compensated \$200.00 for each spinal tap that you complete. This is a research study and not for treatment or diagnosis of Parkinson's disease. 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, Study Coordinator at (503) 721 - 1091 or by mail at 3710 SW US Veterans Road, P3-PADRECC, Portland, Oregon 97239.

Recruiting VA Studies

Using Multiplex Families to Map Genes that Modify Susceptibility and Age at Onset in Parkinson's Disease (VA IRB # 2371)

Dr. Kathryn Chung is conducting this research study to identify genes that increase a person's risk of developing Parkinson's disease (PD) or related disorders. The goal of this study is to better understand and treat PD and other related disorders. If a gene or genes that cause(s) PD can be identified and characterized, the diagnosis and treatment of PD will be improved. The overall goal of this study is to find genes that increase the likelihood of developing Parkinsonian symptoms and certain PD-related problems, such as difficulties with thinking and memory. You are eligible to participate in this study if you have two or more individuals in your family that are living with Parkinson's disease. Your family members must also enroll in this study. This study involves one visit to the Portland VA Medical Center. At this visit, you will undergo a physical examination, questions about your family history, a brief test of thinking and memory and have a blood draw of about four tablespoons. This visit will last for about two-and-a-half hours. This is a research study and not for treatment or diagnosis of Parkinson's disease. 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. There is no compensation for participation in this study. For more information on how to participate, please contact Susan O'Connor, RN, Study Coordinator at (503) 721 - 1091 or by mail at 3710 SW US Veterans Road, P3-PADRECC, Portland, Oregon 97239.

The Effects of Vitamin D on Balance in Parkinson's disease (VA IRB #2393; OHSU eIRB # 6482)

Dr. Amie Peterson is conducting this research study to examine the effect of vitamin D on balance in Parkinson's disease patients. This study involves a total of six visits to Oregon Health & Science University and lasts 16 weeks with an additional 8 weeks of follow-up. You must be able to walk 50 feet without the use of a cane or other walking device. You must be between the ages of 50 and 75, and have no history of renal stones, or hypercalcaemia. You must not be taking another type of vitamin D supplement. You will be given tests on thinking and memory, questionnaires about your balance, neurological examinations, tests of balance and strength, and keep diaries of near falls and falls. You will be taking calcium supplementation and either vitamin D or a sugar pill for 16 weeks. Neither you nor the study staff will know which pill you will be taking. The first and last visit will last for two hours and the second, third, and fourth visit will last for a half-hour. Each visit will occur four weeks after the last visit. You will be compensated \$10.00 for each visit you complete for a total of \$60.00. This is a research study and not for 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 Brenna Lobb, MS MPH, Study Coordinator, at (503) 220-8262 extension 51871 or by mail at 3710 SW US Veterans Road, P3-PADRECC, Portland, Oregon 97239.

Reducing Dyskinesia in Parkinson's Disease With Omega-3 Fatty Acids (RLID-PD) (VA IRB #2907; OHSU IRB #8012)

Dr. Kathryn Chung is conducting a research study looking at the safety and effectiveness of Omega 3 Fatty Acids. The purpose of this research study is to measure the safety (side effects) of an Omega 3 Fatty acid called docosahexanoic acid (DHA) and measure the dyskinesia (involuntary movements) in Parkinson's disease (PD). In order to take part in the study, participants must have Parkinson's disease, be about to start levodopa, and be able to stand for one minute unaided. This study will last for one-and-a-half years and will involve six visits. The first visit is a screening visit and includes a neurological examination and completion of several questionnaires. After the screening visit you will be randomized to either DHA or placebo (sugar pill). Neither you nor the researchers will know which pill you will be receiving. The next five visits are overnight stays in the Oregon Clinical and Translational Research Institute (OCTRI) at Oregon Health & Science University (OHSU). You will be admitted to the OCTRI the evening before study tests begin. Your usual PD medications will not be given overnight, so that the levodopa cycle may be observed the next day. You will be studied on a force plate during performance of simple mental task for an entire levodopa cycle the next day. You will be given intravenous levodopa at these visits. You will be compensated \$50.00 for each overnight visit you complete for a total of \$250.00. This is a research study and not for treatment or diagnosis of PD. You may not benefit from participating in this study but will have a no-cost neurological exam. 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 Brenna Lobb, MS MPH, Study Coordinator, at (503) 220-8262 extension 51871 or by mail at 3710 SW US Veterans Road, P3-PADRECC, Portland, Oregon 97239.

The Washington State Parkinson's Disease Registry (VA IRB# 31675)

If you have a diagnosis of Parkinson's disease or atypical parkinsonism, you are eligible to participate in the Washington state Parkinson's Disease Registry which is co-directed by Cyrus Zabetian, MD, MS and James Leverenz, MD. This is a research registry which notifies participants about clinical studies in which they may be eligible to participate. Enrollment occurs by phone and consists of 15 screening questions and an interview about diagnosis, symptoms, medications, and family history. This usually takes less than 30 minutes. For information on how to participate, call toll free (888) 365-9901 or visit our website at www.registerparkinsons.org, where you can start the screening process online.