



THE PARKINSONIAN

NORTHWEST PADRECC/Parkinson's Disease Research, Education & Clinical Center

Daytime Sleepiness


Amie Peterson, MD


According to a 2008 study, daytime sleepiness occurs in approximately a quarter of people with Parkinson's disease (PD). There are many factors that appear to relate to daytime sleepiness in PD. Two common ones are the biological changes that occur as part of the PD and the medications used to treat the disease.


A normal circadian rhythm generally makes people want to sleep as the evening approaches and wake in the morning. In PD this is disrupted. People with PD tend to have a shift, causing their sleep urge to be low in the very early hours of the morning. This can cause early morning awakenings at four or five a.m. Rather than getting sleepy at nine or ten at night, they start to feel sleepy as early as the late morning or early afternoon, often resulting in daytime sleepiness and an early bedtime.


In regard to medications, most often levodopa (Sinemet) and dopamine agonists (Requip and Mirapex) are the most likely to cause sleepiness. The dopamine agonists generally cause more sleepiness than levodopa. Many patients note feeling very sleepy thirty minutes to an hour after taking a dose of these medications. Some people even experience sleep attacks with a sudden onset of extreme fatigue or sleep that is unexpected. These can be dangerous in regard to driving safety.


There are some general suggestions to help with daytime sleepiness.


 Try to maximize good sleep; this may include an afternoon nap.

 Be sure that you are not depressed. A low mood can often cause a feeling of fatigue and increase the desire to sleep.

 Be careful to avoid sedating medications. These can include over-the-counter medications like Tylenol PM or Benadryl.

 Get regular exposure to sunlight and get regular exercise.

 Talk with your PD doctor about possibly changing some of you PD medications to longer-acting forms or taking more levodopa and less of your dopamine agonists.

 If the above treatments are not effective and you do not have another sleep disorder, occasional caffeine may be appropriate or some people may be helped by a medication called modafinil (Provigil).

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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 e-mail them to nwpadrecc@va.gov with "Newsletter submission" as the subject line.

Or mail to: Portland VA Medical Center
P3-PADRECC
3710 SW US Veterans Hospital Rd.
Portland, OR 97239

Dee Goes to Washington

WHAT IS DYSTONIA?

Dystonia is a movement disorder that causes muscles to contract and spasm involuntarily. Muscle contractions can force the body into repetitive and often twisting movements as well as awkward, irregular postures. Dystonia may affect a single body area or be generalized throughout multiple muscle groups. Dystonia affects men, women, and children of all ages and backgrounds. There is no one cause for this disease. It can be a result of trauma, certain medications, or in some cases, a genetic disorder. There are treatment options for dystonia, as well as active research trials.

For more information on dystonia, causes, symptoms and treatments go to:

www.ninds.nih.gov/disorders/dystonias

OR

www.dystonia-foundation.org/pages/what_is_dystonia_/26.php

My name is Dee Linde. Every year, at the beginning of May, I travel to Washington, DC along with about 100 or so other volunteers from the Dystonia Advocacy Network (DAN). The DAN is comprised of five patient groups: the Benign Essential Blepharospasm Research Foundation (BEBRF), the Dystonia Medical Research Foundation (DMRF), the National Spasmodic Dysphonia Association (NSDA), the National Spasmodic Torticollis Association (NSTA), and ST/Dystonia, Inc.

The DAN advocates for all persons affected by dystonia and supports a legislative and policy agenda that meets the needs of the dystonia community. This year I had the honor of presenting an award to Senator Wyden (staff member) in recognition of his support for issues impacting the dystonia community. Also, for the past two years I had the honor of testifying before Senator Inouye and the Defense Appropriations Subcommittee to keep dystonia on the DOD list of the 20 eligible conditions for research funding. This list has to be renewed every year and dystonia has been included on the list for the past three years. As a Navy veteran and a person with dystonia, I feel very strongly about advocating for my fellow veterans and dystonia sufferers.



L-R: Paula Schneider, Dee Linde, Bruce Austin, Diane Zaia, & Stephanie Zaia

Dee Goes to Romania

How I Spent my Summer Vacation: Going Global with Dystonia Awareness

For more than seven years I have been e-mailing with a young Romanian woman who has adult onset generalized dystonia. Sabina was bedridden for several years until she had DBS surgery in 2007, and it has helped her tremendously. The Romanian National Health Plan does not cover botulinum neurotoxin injections or deep brain stimulation (DBS) for dystonia patients so most go without treatment. After Sabina was diagnosed, doctors told her there was nothing they could do for her. Being the fighter that she is, Sabina did her own research and learned about DBS. She wrote to several hospitals here in the United States, as well as doctors in Germany and other parts of Europe, explaining her circumstances. A doctor in Germany agreed to help her, and after a consultation, said she was a candidate for DBS. Sabina's family sold their house, and her village held fund raisers so she could afford to go to Germany for the surgery.

Sabina's motto is "pay it forward." Shortly after her recovery, Sabina and her mother, Adriana, started a non-profit organization in Romania called Asociația "Children's Joy" to help spread dystonia awareness and to help others who have dystonia. This past July I had the honor and privilege of being a guest speaker at the First National Conference on Dystonia in Romania! About fifty people from all across Romania attended the conference, along with several doctors. I spent a little over three weeks with Sabina and her family and got to experience firsthand these two amazing women in action. Their village of Sighisoara, located in Central Romania, is one of the few inhabited
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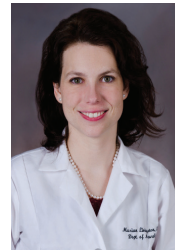
fortified towns in the world and is a perfectly preserved medieval town. It has been inhabited since the 6th century BC. Through their organization, Sabina and Adriana hope to provide educational resources for doctors and support for patients, as well as to convince the National Health Ministry to implement a diagnostic code for dystonia so that people can get the treatment they need. Sabina requested educational materials from the Dystonia Medical Research Foundation and translated them into Romanian. She worked with a doctor to translate some of the medically oriented articles from the Dystonia Dialogue in hopes of publishing their own dystonia newsletter.

Sabina introduced me to another young Romanian woman, Catalina Crainic, who has cervical dystonia. I was lucky enough to also visit Catalina's village of Timisoara in western Romania, which has been inhabited since 200 BC. Catalina, her husband, Marius, and their young daughter, Carmina, are very involved with the Asociația "Children's Joy," holding workshops, meeting with doctors, and spreading awareness in Timisoara. Catalina travels to Hungary to get botulinum neurotoxin injections, which she has to pay for herself.

I was so impressed with the friendliness of the people I met, and overwhelmed by their kindness, generosity, and compassion for each other. I will never forget Sabina and Adriana Gall and all of my new friends in Romania! I never thought dystonia would make me a world traveler. I never thought I would find myself standing in beautiful medieval villages. I thought being diagnosed with dystonia meant the end of my life - little did I know it was just the beginning!

If you are interested in participating in cervical dystonia research, call Susan O'Connor at (503) 721-1091.

Dee Linde, M.A. was an Aerographer's Mate in the Navy from 1978-1982 and worked as a licensed Marriage and Family Therapist for 15 years. Dee was diagnosed with tardive dystonia in 1997. In 2000 she had successful deep brain stimulation (DBS) surgery. In 2002, Dee founded the DBSforDystonia Bulletin Board which offers online support and information to those on the DBS journey. Dee also leads the Portland and Southwest Washington Dystonia Support Group. Dee is an active legislative advocate and testified twice before the Senate Defense Appropriations Subcommittee on behalf of veterans with dystonia. She is a frequent guest speaker at DMRF events - including the recent 2013 Leadership Conference in Chicago, a frequent guest author in the Dystonia Dialogue, and now serves on the Dystonia Dialogue Editorial Board.



Meet our newest PADRECC team member! Marian Livingston, M.D. joins NW PADRECC as a Movement Disorder Fellow. Dr. Livingston earned her medical degree from Medical University of South Carolina. She completed her neurology residency at Maryland Medical Center. Dr. Livingston enjoys outdoor activities and dancing swing and the Argentine tango in her spare time. Please help us to welcome Dr. Livingston!

Caregivers' Corner

Reserve your space for the upcoming Savvy Caregiver Program series
New classes will begin in January 2014.

What is the Savvy Caregiver Program? – Savvy Caregiver Program is a six-week series, specifically designed for caregivers providing care to a person diagnosed with a dementia. Over the six-weeks, caregivers will learn what dementia is, and how it affects functioning, while developing skills and strategies to make their caregiving job more manageable. Finally, caregivers learn the importance of scheduling time for themselves, and how good self-care often contributes to providing better care to their loved one.

Who can attend? – Caregivers are defined as anyone providing unpaid care to a person with a dementia diagnosis including, spouses, partners, children, friends and neighbors. This can be a Veteran caring for a person with a diagnosis, or a caregiver providing care for a Veteran.

***** Classes are starting up again in January 2014 *****

East Portland - Tuesdays, January 21 – February 25

Hillsboro - Thursdays, January 23 – February 27

If you are interested in learning more about this series, or would like to reserve a spot, please contact:
Jen Lawrence, Social Worker at: (503) 220-8262 ext. 58594

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

CALENDAR OF EVENTS

PORTLAND PADRECC

PD AND YOU: MANAGING YOUR PARKINSON'S SYMPTOMS
Presented by Dr. Amie Peterson.
January 24, 2014 10:00am to 11:30am Pacific Time.

HOW CAN WE HELP YOU? THE ROLE OF SOCIAL WORKERS IN
PARKINSON'S DISEASE.
Presented by Jen Lawrence, Social Worker.
March 7, 2014 10:am to 11:30am Pacific Time.

Please join us in the Portland VA Medical Center Auditorium.
Please arrive early for parking. For more information or to
register please call (503) 721 - 1091.

Portland patient education talks are now available via
video-teleconference (V-tel)!



Current V-tel locations are:

Anchorage, AK	Roseburg, OR
Boise, ID	Salmon, ID
Brookings, OR	Seattle, WA
Caldwell, ID	Spokane, WA
Couer d'Alene, ID	Walla Walla, WA
Eugene, OR	Wenatchee, WA
North Bend, OR	White City, OR

Not offered for every program. Please call for availability.

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

PARKINSON'S RESOURCES OF OREGON (PRO)

Save the Date!
ANNUAL PD EDUCATION CONFERENCE
April 12, 2014.

POWERFUL TOOLS FOR CAREGIVERS

This 6-week educational series is designed to help unpaid family caregivers take care of themselves while caring for a relative or friend with a chronic illness. Caregivers develop a wealth of self-care tools to reduce personal stress, communicate their needs effectively in challenging situations, deal with difficult emotions, and make tough caregiving decisions. Class size is limited, and registration is required. Please call 503) 719 - 6980 for class times and locations.

Check out our website:

www.parkinsons.va.gov/northwest

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
- Video library

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 2 1/2 hours.

This is a research study and not for treatment or diagnosis of Parkinson's disease. You may not benefit from participating 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) 220 – 8262 extension 53262 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 (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 (1) minute unaided. This study will last for one and a half (1.5) years and will involve six (6) 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 (5) 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 over night, 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.

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 involves two visits over five years to the Portland VA Medical Center. At each visit, you will undergo tests of thinking and memory and have a blood draw of about four tablespoons. Each visit will last for about one to one and a half hours.

The second group is the annual group. The annual group involves five visits over five years to the Portland VA Medical Center. At each visit, you will undergo tests of thinking and memory and have a blood draw of about four tablespoons. Each visit will last for 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 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, 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 over age 50 and have no history of renal stones, or hypercalcaemia. You must have at least 1 or more near falls per month (some balance problems). You must not be taking another type of vitamin D supplement. You will have tests of your thinking and memory, questionnaires about your balance, neurological examinations, tests of balance and strength, and 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 and a ½ hours and the second, third, and fourth visit will last for a half hour. Each visit will occur four weeks apart. 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, Portland, Oregon 97239.