



THE PARKINSONIAN

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

DBS FAQ's: Frequently Asked Questions about Deep Brain Stimulation for Parkinson's Disease

By Shannon Donovan, PA-C and Hunter O'Harrow, BA from the Parkinson Center of Oregon and Susan O'Connor, RN at the Portland VA Medical Center PADRECC

Q Am I a candidate for surgery?
When is a good time to have the surgery?

A The best way to figure this out is to talk to your neurologist. At the VA, all patients go through a workup which includes appointments with a movement disorders trained doctor, the neurosurgeon, a physical therapy assessment, and a neuropsychiatric assessment prior to having surgery. The information gathered at these appointments is helpful in developing a risk/benefit analysis of having the surgery that is specific to you.

Which symptoms does DBS improve?

DBS helps treat the side effects of levodopa - specifically **dyskinesias** (defined as random, involuntary movements) and **dystonia** (defined as cramping or tightening of muscles that is caused by taking your medication). DBS also helps with

your Parkinson's motor symptoms such as tremor, slowness of movement, and muscle rigidity.

Q Which symptoms does DBS not help?

A DBS does not help the balance, speech, and swallowing difficulties, nor does it help with non-motor symptoms such as constipation, memory or thinking clearly, depression, anxiety, etc. DBS also does not slow down the progression of Parkinson's disease.

Q Do I have to be awake for the surgery?

A Yes. The VA uses a more traditional method which is a technique called microelectrode recording to locate

Q the target in the brain. Based on how the neurons are firing, the neurosurgeon can tell where

A the target is. This requires the patient to be awake for this part of the procedure. You will undergo general anesthesia when this portion

is completed (about 4-5 hours) to have the generator put in place.

Q Do i have to shave my head?
Will the hair grow back?

A The neurosurgeon will need to shave a small patch on the top of your head for the surgery. Yes, your hair will grow back. No, DBS won't help hair grow if there wasn't any there to begin with, though!

Q How will I know if the surgery was successful?

A This is different for everyone and is based on your goals of the surgery. Prior to having the procedure, it's important to have a conversation with your neurologist regarding your goals of surgery

Q and see if it is reasonable to expect that DBS will help in those areas.

A Can I stop taking my medications after having surgery?

Not necessarily. Some patients

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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

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is being adjusted in the office . You will also be able to feel one or two bumps on the top of your head and the outline of the generator in your chest.

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I really like my local doctor. Do I have to stop seeing him or her after I get DBS?

Absolutely not. You can continue seeing your outside neurologist for your Parkinson's disease. Some neurologists program the stimulator, and some do not. If your provider does not program deep brain simulators, you can have adjustments made at the VA and continue to see your neurologist for other Parkinson's related matters.

Are there support groups for people with or considering DBS?

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Yes, the Parkinson's Resources of Oregon has a quarterly support group meeting in Lake Oswego that is dedicated specifically to DBS. OHSU will also be visiting PRO support groups in Medford, Bend, and Eugene in the coming year to discuss DBS with potential patients as well as patients who have already had the surgery.

What is the "honeymoon" period?

When you have electrodes implanted in your brain, there's a small amount of swelling that occurs. For some patients, this swelling actually improves your Parkinson's symptoms temporarily even though the stimulator has not yet been turned on. This is called the "microlesion effect" or the "honeymoon period." However, much like all good

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honeymoons, it lasts for a short period of time. As the swelling heals, the PD symptoms return. It is impossible to predict who will have a "honeymoon period" and how long it will last. Some people have it for hours, some days, some weeks. Some don't have one at all. It does not reflect how successful your surgery was at all. For most people, the majority of the swelling subsides around one month and your symptoms are back to where they were prior to the surgery. This is why we wait one month to turn on and program your stimulator--we want that swelling to be healed before adjusting.



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

V-tel is not available at all locations for all dates, so call for availability 503-721-1091 or 1-800-949-1004 ext. 51091

Current 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 |

Please welcome our new social worker!



Jennifer "Jen" Lawrence joined the Northwest PADRECC team in July as the Social Worker assigned to Outpatient Neurology - covering the Parkinson's and Dementia clinics. Prior to her work in the clinics, Jen worked on a project to develop resources and training for caregivers caring for a loved one with a diagnosis of Dementia.

Her work has carried over to her new position, and in addition to serving the social work needs in the Parkinson's and Dementia clinics, Jen currently facilitates a six-week educational series called "Savvy Caregiver" at various VA Community-Based Outpatient Clinics (CBOCs) in the Portland/Salem area. This program is designed to specifically address the unique challenges facing caregivers who are providing care to a loved one with a dementia diagnosis, and offers support, education, and linkages to resources that can enhance the caregiving experience.

Jen is a graduate from Portland State University's Graduate School of Social Work, and also holds a Master's degree from Marylhurst University with a concentration in Gerontology. Her background includes working with community-based non-profits and city government. She is also a U.S. Air Force veteran.

While she is away from work, Jen enjoys crafting, gardening and spending time with her husband, and large family, including her "fur-child", Winston, a 10-year old pug.

The Savvy Caregiver Program is a six-week series, designed for caregivers of persons diagnosed with dementia. Over six weeks, caregivers will learn what dementia is and how it affects functioning, develop skills and strategies for making their caregiving job more manageable, and learn the importance of making time for their own self-care.

Caregivers are defined as anyone providing care to a person with a dementia diagnosis. This can mean a veteran caring for a person with a diagnosis, or a caregiver providing care for a veteran. (This course is not available to paid caregivers from agencies.)

Attendees must have a referral to attend this series. For more information, please contact Jennifer Lawrence directly at (503) 220-8262 ext. 58594 or email her at jennifer.lawrence2@va.gov.

Upcoming Sessions - January through April 2013

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|---------------|--|
| Hillsboro | Tuesdays - 1 pm to 3 pm
Jan. 15, 22, 29, Feb. 5, 12, 19 |
| East Portland | Fridays - 1 pm to 3 pm
Jan. 18, 25, Feb. 1, 8, 15, 22 |
| Vancouver | Fridays - 10 am to Noon
Jan. 18, 25, Feb. 1, 8, 15, 22 |

Further sessions will be held in March and April 2013

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.

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.

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.

CALENDAR OF EVENTS

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

PORTLAND PATIENT EDUCATION TALKS

All talks listed will be held in the Portland VA Medical Center Auditorium unless otherwise noted. Please arrive early for parking. Video teleconferences are also available. For more information about the talks, to find a teleconference location, or to register please call (503) 721-1091.

SPEECH AND SWALLOWING IN PARKINSON'S DISEASE.

February 8, 2013, 10:00am to 11:00am Pacific Time.

PARKINSON'S DISEASE HEALTH RESOURCE FAIR.

June 7, 2013, 10:00am to 2:00pm Pacific Time. Please join us to learn more about resources available in the community for both caregivers and patients. Information will be provided by occupational therapists, physical therapists, Medtronic, pharmaceutical companies, and long term care /hospital based home care services. This event is open to everyone at no cost. Refreshments provided.

PARKINSON CENTER OF OREGON (PCO)

For more information about these events please call (503) 494 - 9054

INSIGHTS AND INSPIRATIONS PARKINSON'S DISEASE EVENT FOR PEOPLE 60 AND UNDER.

Saturday, Mar 16, 2013 9:00am to 3:00pm at the Portland Art Museum, 1912 SW Park Ave. This is a symposium designed to address the unique challenges families face when impacted with young-onset Parkinson's disease. The program features a mix of both medical experts and peers living with young onset PD daily. For more information or to register, please contact Julie Doolin at 503-494-9054 or doolin@ohsu.edu. \$25 conference fee.

Save the Date!

CAREGIVER'S CONFERENCE. May 16, 2013

Check out our newly updated website!

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 - Three new videos recently added!

www.parkinsons.va.gov/northwest

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