



The Parkinsonian



Summer Issue, 2008



Northwest PADRECC

Parkinson's Disease Research, Education & Clinical Center



Grateful: A Personal Perspective

In the spring of 2001, I was diagnosed with Parkinson's Disease. In a way this was a relief. To me it meant that I wasn't just nuts and there was a logical reason for all the

strange sensations I was having. But even though I felt relieved on one hand, I did have the symptoms of Parkinson's rushing at me at a speed that was quite disturbing.

In the summer of 2004, I had to give up my job as a worker for the Spokane County Road Department. I continued going to the Veteran's Hospital in Spokane and taking increasingly larger doses of Carbidopa/Levodopa.

Then, at an appointment at the end of last summer, my neurologist in Spokane, Dr. Heidi Heller, asked if I was interested in going to Portland, Oregon for a second opinion and how did I feel about Deep Brain Stimulation (DBS) therapy? I said "yes" and "yes", but inside I was a little freaked out by the idea of DBS and the Frankensteinish visions that it conjured up.

I left her office feeling that it could probably be at least six months before I heard anything from Portland and a year if I was lucky before they'd even see me. To my surprise, I got an appointment in a few weeks.

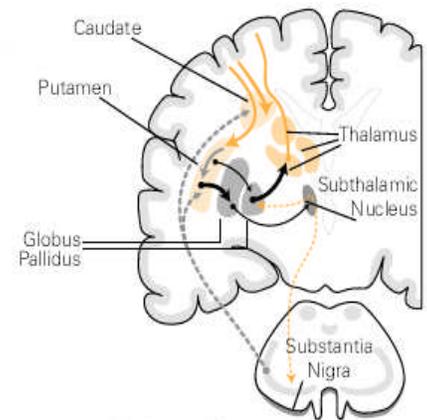
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How Does Deep Brain Stimulation Work?

A complex flow of electrical signals in the brain determine things such as speed of movement, coordination, and muscle tone. Each signal establishes a feedback mechanism the prevents excessive activity by looping back to it's original starting point.

The electrical feedback loops in patients with Parkinson's Disease are cycling abnormally, causing the unwanted movements such as tremor, rigidity, and slowness. Deep Brain Stimulation (DBS) is a surgery in which an electrode is implanted in the

brain that emits an electrical current. The current effectively jams the abnormal signals between brain structures. DBS can be applied to the thalamus, the globus pallidus, and the subthalamic nucleus. DBS does not cure Parkinson's Disease, however, it does reduce the symptoms of Parkinson's Disease.



- Excitatory (Glutamate)
- Inhibitory (GABA)
- Excitatory (Acetylcholine)
- Excitatory and Inhibitory (Dopamine)

Figure 1. Map of basal ganglia showing targets for surgery: globus pallidus, thalamus and subthalamic nucleus

Image courtesy of Parkinson's Disease Foundation

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At my first appointment with Dr. Jason Aldred I was asked a few questions but mostly they were interested in my motor skills. Just as it was getting time to end my appointment I became "off". This piqued their interest and I was put on a list of potential DBS candidates, and an appointment was made for me to come back in a few weeks.

When I came back, I was given some motor skills tests, but primarily I was given psychological tests. I never did particularly well taking tests in school, but something I said or did must have gotten me in because on the 28th of January of this year I had DBS surgery at the VA in Portland, OR.

My stimulator was officially turned on by Dr. Aldred a month later, after my brain had adjusted to the new hardware. Boy, it was amazing the difference that the neurostimulator made. I could hardly stop smiling.

Parkinson's is, however, what Parkinson's is; a progressive degenerative disease of the brain that has no respect for anybody. But still though, I am grateful. Grateful to have another look at life, and to pay more attention to life and less attention to Parkinson's Disease. I've already seen what it can do, and this second time around, with my neurostimulator, I am determined to focus on life even more.

Thanks to all the staff and employees at the Portland VA and Especially to Dr. Jason Aldred and Susan O'Connor.

Gratefully,
Pat Linden
Wellpinit, WA

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.

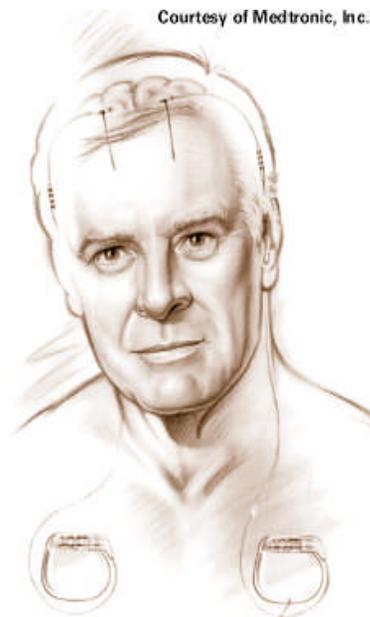
Portland, OR 97239

Commonly Asked Questions About Deep Brain Stimulation (DBS) Surgery

Q: Who is considered a good candidate for DBS?

A: A good surgery candidate is a patient who responds well to carbidopa/levodopa and other anti-Parkinson's medications but experiences dyskinesia or frequent wearing-off spells. These patients usually have had Parkinson's for a long time and are unable to find a sufficient medication schedule to control wearing-off episodes. They must be in good physical and psychiatric health and have no cognitive impairment. People who have never received any benefit from anti-Parkinson's medication or have an atypical form of parkinsonism will not benefit from surgery.

Courtesy of Medtronic, Inc.



Q: What symptoms of Parkinson's Disease does DBS help?

A: DBS surgery does not help all of the symptoms of Parkinson's Disease, however it does improve many of them. Generally the symptoms that respond best to medication also respond the best to DBS. Tremor and rigidity improve the most, however, slowness can improve as well. DBS also reduces the occurrence of drug-induced dyskinesia.

Q: Will DBS surgery allow me to stop my anti-Parkinson's medications?

A: The dependency on medication may be reduced after DBS surgery for many patients. This can be very beneficial for patients who experience side effects such as hallucinations or dyskinesia.

Q: Will my insurance cover the cost of surgery?

A: Most private insurers, Medicare, and Medicaid, will cover some of the expenses for DBS surgery for Parkinson's Disease.

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.

Ability to Arise From the Floor in Persons with Parkinson's Disease (VA IRB ID: 1585 VA IRB Grant Number: #06-1405)

Dr. Jeff Krakkevik, MD is conducting this study to see how well people with Parkinson's Disease can get up from the floor after they experience a fall. Participation would require up to three 30 to 40 minute outpatient visits at the Portland VA Medical center. In order to participate you must be a Veteran treated in the PADRECC Clinic or by the PADRECC physical therapist, Diagnosed with Parkinson's Disease, and at least 30 years of age. You may not be able to participate if you are unable to stand or move without the help of a caregiver, you have other neurological or musculoskeletal abnormalities that might affect your ability to stand from a sitting position, or the investigators determine that you are not eligible for safety reasons. You may not benefit from this study, however if you are found to have difficulty in arising from the floor you may benefit from instruction and advice on how to do so. Study visits would take place at the Portland VA Medical center. 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

Friday, August 22, 2008

Coping With Depression In PD

Free Seminar by Dr. Paul Conti to help patients and their families understand and plan to cope with depression. Providence St. Vincent Hospital. Southern Classroom. Call 503-594-0901 to RSVP.

• **Sunday, September 14, 2008**

Sole Support - Willamette Park, Portland, OR

• **Sunday, September 21, 2008**

Sole Support - Alton Baker Park, Eugene, OR

Both walks include activities and registration beginning at 12:30 pm. 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.

Parkinson's Center of Oregon (PCO) 2006-2007 Annual Events:

Friday, September 19, 2008

OHSU PCO Young People with Parkinson's Conference

An Evening of Discovery— Portland, OR

Were you diagnosed with PD at a young age? Are you under 60 with PD? Then you are invited to join us for an evening just for you, featuring Kari Lyons, L.C.S.W. Vey Auditorium, OHSU Doernbecher's Children's Hospital, Friday evening 5:30 p.m. to 9 p.m.. \$20/per person. For more information call 503-494-7231. **If you are a veteran, and would like to attend free of charge, please call to register at (503) 721-1091**

Saturday, September 20, 2008

OHSU PCO 25th Annual Symposium

Options & Opportunities – Portland, OR

MARK YOUR CALDENDARS NOW! Knowledge is power and that is why the OHSU Parkinson Center has been educating patients and caregivers for 25 years about ways to live well with PD. Caregivers, we will have a special breakout session just for you. We look forward to sharing with you the latest information on PD from the best in the field. See you there! For more information, please call 503-494-7231. **If you are a veteran, and would like to attend free of charge, please call to register at (503) 721-1091**

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



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