



The Parkinsonian

Winter Issue, 2007



Northwest PADRECC
Parkinson's Disease Research, Education & Clinical Center

The Ins and Outs of Research Participation

Research is an important aspect of medical care. Without research we would probably have very little, if any, of the medical technology, medications, vaccines, and cures which we have today. It is people who participate as research subjects who make most research possible. Each person that volunteers a small amount of time is helping to make advances in science and medicine which could help other people. As important as research is, it is also important that every participant makes an informed decision when volunteering to be a participant. This issue of the Parkinsonian will provide some information which can help in the important decision of whether or not to participate in a research project.

then I had been on Parkinson's medications for over 15 years and the drugs were just not working as well. Life seemed bleak.

Then Dr. Nutt suggested that I might be a candidate for a national study being conducted between the VA and OHSU (and at twelve other sites in the country) of deep brain stimulation surgery (DBS). Brain surgery is not something that one goes into lightly but we decided to take the plunge. Because my symptoms fit, I qualified for the study, and because I was a veteran I was able to take part through the Parkinson's Disease Research, Education, and Clinical Center (PADRECC) at the VA. My surgery was performed in August 2003. Dr. Penny Hogarth assumed my care with Susan O'Connor as clinical coordinator. Post surgery I have been thoroughly followed by them, by other researchers in PADRECC, and by physical therapist Ron Blehm. I have been tested and videotaped and I have made new friends in the process. They are outstanding compassionate people.

Three years later these are the results. I have literally no tremor. My on off periods are nothing compared to what I had before the surgery. While I still am on all my medications, they work better. Before the surgery I had some dyskinesia (involuntary movement) and I don't have that now. I try to live my life around the disease. I have taken up singing again and am in the church choir. My biggest problem now is difficulty in initiating walking, literally taking the first step, so I don't play golf much anymore. I do water aerobics and some weight training. Once I get started I can walk a long ways and my wife tells me that when I jog, I jog better than I walk.

I hope this short history of my journey into research is helpful to others. We are all in this together. The staffs at OHSU and at the VA have made that evident.

A Personal Journey with Parkinson's Disease Research

By Dr. Charles Toland
(pictured left with Grandson Brian)



The first time I ever thought that I might have a neurological problem came early in 1986. I had felt abnormally fatigued for a long time and somewhat depressed, but attributed that to delivering

lots of babies, losing sleep, and having four kids in college at the same time. One morning in surgery I tried to use a clamp and my hand literally froze. I recovered fast but it gave me an uneasy feeling. My next symptom was a slight tremor in my right hand. After a period of denial and a worsening tremor – you never think of yourself getting something like this – I was diagnosed in August 1987. I cut back on my practice as an obstetrician-gynecologist and by 1991 I had to retire. For the next ten years my disease began its slow progression. Drs. John Hammerstad and Jay Nutt along with Julie Carter continued to follow my case and I can't say enough about their good care.

I tried to remain active but gradually the "off" times on medication became more frequent than the "on" times. My wife and I tried to schedule everything we did around the on times but they were unpredictable. One night she came home from work to find me on the kitchen floor where I had been lying unable to move for six hours. By

What's Inside

A Personal Journey with Parkinson's Disease Research	01
Informed Consent	02
The Good and The Bad of Research Participation	02
Questions to Ask	02
Recruiting Research Studies	03
Calendar of Events	04

Informed Consent

Before participating in a research study, you must sign an informed consent. This document says that you understand everything that the study entails and that all of your questions were adequately answered by research staff. At the Portland VA hospital, an informed consent is generally 11 pages or longer and can seem very overwhelming. Take it one section at a time and you will have no problem. As you go, make sure that you understand each section. Write any notes, or questions you may have in the margin to help you remember them when you are given a chance to ask questions. Once you feel that you understand the section and your questions have been answered, move on to the next section. In no time you will be at the end.

Here are the sections generally found on a Portland VA hospital informed consent. This should give you a better idea of the information you will encounter.

- **SPONSOR:** If there is a study sponsor, this section tells you who it is.
- **KEY STUDY STAFF:** Lists important study staff members and their phone numbers.
- **CONFLICT OF INTEREST:** This is included if one of the doctors could benefit directly from the study (e.g. if he is on the board of the sponsoring party) .
- **PURPOSE:** Explains why the study is being conducted, and what researchers hope to achieve.
- **DESCRIPTION OF STUDY PROCEDURES:** This section explains exactly what participating will entail (e.g. how many visits, how long each visit should take, and what sorts of tests will be conducted at each visit).
- **RISKS AND DISCOMFORTS:** Any known risks of participating in this study must be listed here even if the risk is minimal.
- **BENEFITS OF PARTICIPATION:** Explains what sort of benefits the patient can reasonably expect, or that the participant may not personally benefit from the study.
- **ALTERNATIVES:** This section states that one does not have to participate in the research study, and lists alternative forms of treatment if applicable.
- **CONFIDENTIALITY OF RESEARCH RECORDS:** This part explains that you will be given a unique code so that you can not be identified, and who on the research staff will be able to identify you.
- **COSTS:** Explains what, if any, costs you will be responsible for during research participation (e.g. the cost of study medication).
- **PAYMENT FOR PARTICIPATION:** This explains whether or not you will be reimbursed for participation or compensated for any of the costs involved in participation.
- **LIABILITY:** Explains who is responsible in the event of an injury due to study procedures.
- **PARTICIPATION:** This section notifies the patient who best to contact if they have any questions. It also states that participation is voluntary, the patient's rights if they

choose not to participate, the patient's right to withdrawal, and the patient's right to get a second opinion.

- **SIGNIFICANT NEW FINDINGS:** States that the doctor is obligated to tell the patient about any new findings which may affect their desire to be in the study.
- **SIGNATURE OF INFORMED CONSENT FORM:** States that the physician has gone over the informed consent with you and that all your questions have been answered. This is the section that the patient signs the consent form, saying that they fully understand the consent form and agree to participate.

The Good and The Bad of Research Participation

Benefits to participating in research:

- Research studies may allow access to new treatments before they become available to the public.
- Research studies offer the possibility of quality medical care at leading institutions, although one can not expect care for medical problems unrelated to the study.
- Research studies provide an opportunity to contribute to medical research that may lead to advancements in medicine and, help others in the future.

Drawbacks to participating in Research:

- The drug or treatment being studied may not be effective for you.
- If the study includes the use of a placebo drug or "sugar pill", you have a chance of receiving the placebo instead of the active drug or treatment.
- You may experience side effects from medications or treatments.
- It takes more of your time and effort than standard treatments prescribed by your regular doctor.

Questions to Ask

Before you agree to participate in a research project, you should be sure to ask plenty of questions. Make a list of what things you feel are important for you to know, and make sure that your questions get answered in an adequate manner. Here are a few questions to get you started.

- Why is the study being done?
- How long will the study last?
- Where will I need to go for study visits?
- How long will each visit take?
- Who will conduct the visits?
- What tests and treatments do I have to take part in?
- Who is responsible for the payment of study visits?
- What are the benefits and the risks?

So now you're ready to be a study participant. The VA PADRECC always has lots of research studies that you may be eligible for. Inform your doctor of your desire to participate, and find out if you are eligible for any of the currently enrolling studies. In no time at all you will be an important part of the research process.



Speaker Fay Horak, Ph.D.

Parkinson's Resources of Oregon (PRO) Annual Parkinson's Disease Conference

In January, Dr. Fay Horak, PhD came to the Portland VA PADRECC and Presented a talk entitled Exercise, Balance, and Parkinson's Disease. Despite the snow that week Fay's talk was a great success. If you missed her talk, you have another chance to hear her speak at the Parkinson's Resources of Oregon Annual Parkinson's Disease Conference held on April 15, 2007 at the Valley River Inn in Eugene, Oregon. Speakers also include Dr. David Heydrick and Dr. Kevin Biglan from the University of Rochester. For more information, please contact Patrick at 800-426-6806.

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.

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

Seattle Patient Education Talks.

All talks listed will be held at the Seattle VA (Building 1, Room 240) from 1:30 PM – 3:30 PM

Tuesday, April 17, 2007: Sleep Disorders
Ted Bushnell, MD

Tuesday, June 19, 2007: Medications in PD
Ali Samii, MD

Event contact info: **Portland PADRECC:** 503-721-1091 **Seattle PADRECC:** (206) 277-4560 **PCO:** 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: Susan O'Connor
P3-PADRECC
3710 SW US Veterans Hospital Rd.
Portland, OR 97239

Portland Patient Education Talks

All talks listed will be held in the Portland VA Auditorium from 10:00 – 11:00 unless otherwise noted
Please arrive early for parking

Friday, March 9, 2007: Parkinson's Disease and Medications
Matt Brodsky, MD

Friday, May 9, 2007: Fatigue in Parkinson's Disease
Gordon Campbell, ANP

Friday, July 27, 2007: Update on Impact and Treatment of Falls in Parkinson's Disease
Jeff Kraakevik, MD and Ron Blehm, BS in PT

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

Newly Diagnosed Educational Session
Occurs every other month

Outreach Symposium: Champions & Challenges (Located in Bend, Oregon)
Friday, March 2, 2007 10:00am - 2:30pm

Parkinson's Disease Awareness Fair

Wednesday, April 18th, 2007 4:00pm - 8:00pm
Kirk Convention Center
OHSU Center for Health & Healing
3303 SW Bond Ave., Portland, Oregon

Please Call 503-721-1091 for more information

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



**Department of
Veteran Affairs**

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