



The Parkinsonian

Fall 2011



Northwest PADRECC

Parkinson's Disease Research, Education & Clinical Center

Agent Orange: What you need to know

In 2010 the VA began offering benefits related to the health effects of Agent Orange exposure. Read on to learn about eligibility and available benefits!



Agent Orange is the name given to herbicides and chemicals that were used in Vietnam to defoliate trees and remove concealment for the enemy.

Agent Orange affected millions of military personnel who served in Vietnam between January 1965 and April 1970. While much of Agent Orange's effects were seen overseas, some military bases in other countries, including the United States, were used for testing and storage of the chemicals.

The VA, as well as other government agencies, has conducted research studies on the long term effects Agent Orange could have on Veterans who were exposed. A list of cancers and other health problems presumed to be related to Agent Orange have been compiled. In 2010 Parkinson's Disease was added to the list. This means that Vietnam-era Veterans do not have to prove a connection between their Parkinson's disease and military service to be eligible to receive VA benefits if they:

- Served in Vietnam anytime between January 9, 1962 and May 7, 1975 (includes brief visits ashore or service aboard a ship that operated on the inland waterways of Vietnam).

OR

- Were in or near the Korean demilitarized zone anytime between April 1, 1968 and August 31, 1971.

Veterans who served on ships off the shore of Vietnam, who served in or near the perimeters of

Some helpful resources:

- ✦ Toll free helpline: 1-800-749-8387 (press 3)
- ✦ **Agent Orange Registry Health Exam: Call your local VA Environmental Health Coordinator**
 - ✦ Portland: Kara Wilson (503) 220 - 8262 x54707
 - ✦ Seattle: Leigh L. Hayes (206) 764 - 2181
- ✦ **Health Care: 1-877-222-8387**
- ✦ **Compensation and Other Non-Health Care Benefits: 1-800-827-1000**
- ✦ **TDD (for hearing impaired): 1-800-829-4833**

military bases in Thailand during the Vietnam era, or who served where herbicides were stored or tested outside of Vietnam may also be eligible for service connection for related disabilities.

Veterans may also be eligible for:

- A free exam by the VA for possible long-term health problems related to herbicide exposure. Most VA medical facilities have an Agent Orange Desk or a Compensation and Pension Office that can help to arrange for an evaluation.
- A full range of medical benefits
- Other non-health care benefits: Home loans, vocational rehabilitation, education and more

Certain Vietnam-era Veterans' children with spina bifida or covered birth defects, as well as surviving spouses, dependent children, and dependent parents of Veterans who were exposed to Agent Orange and passed away as a result of diseases related to the exposure may also be eligible for benefits.

To apply, Veterans can visit www.fasttrack.va.gov or call the Special Health Issues Helpline at 1-800-749-8387 for an accelerated claims process. Veterans who have already filed a claim can contact VA Benefits at 1-800-827-1000. Please be aware that it may take several months before a service connection is established.

Websites with more information regarding Agent Orange benefits:

- www.publichealth.va.gov/exposures/agentorange
- www.publichealth.va.gov/exposures/agentorange/conditions/parkinsonsdisease.asp
- www.vva.org (Vietnam Veterans of America)
- www.vba.va.gov/survivors (Survivors Benefits)
- www.dav.org (Disabled American Veterans)

Sign up for Agent Orange newsletters!
www.easmailcall.aac.va.gov

VA CAREGIVER INITIATIVE

In becoming a Caregiver, you may experience major changes in the roles and responsibilities that likely have been established for a long time. These roles are not easily set aside, and it is common to have feelings of grief, sadness, guilt, reluctance, love, anger, anxiety, and a sense of helplessness. Sometimes distress is heightened because you are not only dealing with changes in roles, but also the need to learn new tasks. Learning a new responsibility, such as keeping the checkbook or washing clothes, also involves energy and effort. This can be difficult when you are faced with the many day-to-day needs of the person with PD, yourself, and your family.

It can be hard for others, who do not share the day-to-day experience of living with a person with Parkinson's Disease, to know what it is really like or how you are feeling unless you tell them. Do not be afraid to ask for help from family, friends, neighbors, volunteers and professional Caregivers. It is important that they give you encouragement and support, help with work, or share some tasks such as dressing, transportation, feeding, medical and/or personal care, grocery shopping, housework, and meal preparation, or they can simply give you, the Caregiver, some time off.

In addition to receiving help from others in your community, the Department of Veterans Affairs has launched a program for Caregivers of Veterans who need assistance due to illness or disability. Trained professionals at the VA can help you find support that best suits your needs whether it be adult day health care, home based care, or respite care. These types of support can help to give the Caregiver a break from the daily routine. The VA Caregiver Support line at **1-855-260-3274** can listen to your concerns, assess what services you may be eligible for, or connect you with the Caregiver Support Coordinator at the VA closest to you. You can also visit their website www.caregiver.va.gov for more information.

Other organizations and websites that offer information and educational materials are:

- * The National Parkinson Foundation provides a helpline and website for caregivers **1-800-473-4636** or www.parkinson.org/caregivers.aspxNPF
- * The National Alliance for Caregiving www.caregiving.org
- * www.caregiver.com
- * www.familycaregiving101.org
- * www.aarp.org/relationships/caregiving

These caregiver resources are available for any spouse, family member, friend, or professional who assists an ill, aging, injured, or disabled person.

And remember, do not hesitate to ask for help regardless of how occasional or often your caregiving duties are.



Have a Question? Ask the Doctor.

Do you have a question about Parkinson's Disease that you would like to see answered in our newsletter by one of our doctors or nurses? If so, please submit your question to nwpadrecc@va.gov or call (503) 721-1091. You can also mail requests to:

**Portland VA Medical Center
P3-PADRECC
3710 SW US Veterans Hospital Rd.
Portland, OR 97239**

PADRECC Welcomes Our New Movement Disorder Fellow

Dr. Bernadette Schoneburg was born and raised in Germany and immigrated to the US in 1995. She completed both her undergraduate training and medical school training at the University of Florida where she received her MD in 2007. She attended Rush University in Chicago for residency training in Neurology and moved to Portland in 2011 to join the PADRECC as a movement disorders fellow.



Dr. Schoneburg has an interest in academic medicine, research, and teaching medical students. She enjoys taking care of patients with a wide spectrum of movement disorders, particularly Parkinson's disease and other forms of parkinsonism.

Having recently moved to Portland, Dr. Schoneburg enjoys exploring the city, eating at the great vegetarian restaurants Portland has to offer, and spending time with her husband and kitty.

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**

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

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 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 2 1/2 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.

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 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 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 hours and the second, third, and fourth visit will last for a half hour. Each visit will occur four weeks after the first 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.

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, M.D., M.S. and James Leverenz, M.D. 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.

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. Please arrive early for parking. For more information or to register call (503) 721-1091.

Exercise and Parkinson's Disease: a Powerful Medicine January 20, 2012, 10:00 a.m. to 11:00 a.m. A presentation on PD and Exercise given by Ron Blehm, Physical Therapist.

Research in Parkinson's Disease: What is New and How Can I Help? March 16, 2012, 10:00 a.m. to 11:00 a.m. Presented by Dr. Amie Peterson, Dr. Joseph Quinn, and Dr. Kathy Chung.

Psychiatric Symptoms Seen in Parkinson's Disease. May 18, 2012 10:00 a.m. to 11:00 a.m. Presented by Dr. Joel Mack, Geriatric Psychiatry Fellow.

Parkinson's Resources of Oregon

Movement Classes: Weekly fitness classes held in a variety of locations providing instruction for people with Parkinson's. Call: (800) 426-6806.

Communication Programs: Classes and groups to help people learn how to keep their voices and expressions loud and strong. Current locations include Corvallis and Portland, OR. Call: (800) 426-6806.

Aware in Care: Learn how to get the best care possible during an unexpected or routine hospital visit during this new workshop developed by the National Parkinson Foundation. Programs are approximately an hour long. Programs are free, but RSVP is required. Call (800) 426-6806 or visit www.PRO.Eventbrite.com to register.

January 6, 2012, 12:00 p.m. Providence Portland Medical Center, Portland, OR

January 27, 2012 1:00 p.m. Eugene Hearing and Speech Center, Eugene, OR

February 4, 2012, 2:00 p.m. The Quarry Senior Living, Vancouver, WA

February 21, 2012, 1:00 p.m. Beaverton Resource Center, Beaverton, OR

Educate. Inspire. Empower: Parkinson's Disease

Parkinson Center of Oregon (PCO)

Newly Diagnosed Educational Session: Occurs every other month. A three-hour session for people recently diagnosed with PD and their spouse or family member. Participants may ask any questions of a PD specialist and long-time patient. \$20/person; refreshments served. For more information, call (503) 494-9054.

Parkinson's Disease Young Onset. March 17, 2012. Discuss challenges facing people with young onset Parkinson's disease. Includes education about PD and community resources. Please call 503 494-7231 for more information.

PADRECC 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

Check out the newly updated PADRECC website!

www.parkinsons.va.gov/northwest



Department of
Veteran Affairs

Portland VA Medical Center

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3710 SW US Veterans Hospital Rd.
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