



# THE PARKINSONIAN

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

## Ask the Doctor: The Genetics of Parkinson's Disease



*Dr. Cyrus Zabetian is a neurogeneticist and Associate Professor of Neurology at the University of Washington and VA Puget Sound Health Care System. His clinical and research interests are focused on how genetics influences the development of Parkinson's disease.*

**Q: How do researchers currently view the role of genetics in Parkinson's disease?**

A: In a small number of patients, Parkinson's disease (PD) is caused by dysfunction of a single gene. But in most instances, we think that PD results from an interaction between multiple genetic and environmental factors. These risk factors each have a small effect, but if someone possesses several of them, they can tip the balance toward developing the disease.

**Q: How does studying the genetics of Parkinson's advance our understanding of the disease?**

A: In PD, cells within the brain known as "neurons" die prematurely, and this only occurs in certain areas of the brain. However, we are just beginning to understand how and why this happens. There are probably several different biological pathways

that if disrupted can cause neurons to malfunction and eventually degenerate. That is where genetics comes into play. By finding specific genes that alter a person's risk for getting PD, researchers can better understand which pathways are most important in protecting against the disease. Our hope is that this knowledge will eventually lead to the discovery of "neuroprotective" therapy—that is, drugs that will slow progression or even prevent PD rather than just treating the symptoms. It is also possible that in the future, a patient's genetic makeup will be used to make better decisions as to which treatments they should try first.

**Q: What is going on locally in genetics research and PD?**

A: The major PD genetics study that is ongoing locally is the Parkinson's Genetic Research Study which goes by the abbreviation "PaGeR." This is a project that I started nearly a decade ago working together with local neurologists. So far, nearly 1,600 patients with PD have joined the study and we have made some important discoveries along the way. In 2009 we received a grant from the NIH to focus on "multiplex" families. These are families in which two or more people

have been diagnosed with PD.

**Q: I have Parkinson's, can I get involved in genetic research? What if I'm outside of the Seattle area?**

A: If you and at least one of your relatives have been diagnosed with PD please call us at (toll free) 1-855-646-4221 to find out more about the PaGeR Study. Though our coordinating center is located at the VA Puget Sound Health Care System in Seattle, we have recruitment sites across the country so we can enroll you in the study no matter where you live.

### 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
- New! - My Parkinson Story Videos  
A series of videos featuring real Veterans telling their Parkinson's stories with explanation and commentary provided by VA medical providers.

[www.parkinsons.va.gov/northwest](http://www.parkinsons.va.gov/northwest)

### IN THIS ISSUE

- Genetics in PD
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### WANT TO CONTRIBUTE?

- 1 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,
- 2 please e-mail them to [nwpadrecc@va.gov](mailto:nwpadrecc@va.gov) with "Newsletter submission" as the subject line.
- 3 Or mail to: Portland VA Medical Center/P3-PADRECC, 3710 SW US Veterans Hospital Rd., Portland, OR 97239
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# Tai Chi!

## PORTLAND PADRECC

### PARKINSON'S DISEASE HEALTH RESOURCE FAIR

June 7, 2013, 10:00am to 2:00pm Pacific Time. Please join us in the Portland VA Medical Center Auditorium 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. Please arrive early for parking. For more information or to register please call (503) 721-1091.

### PARKINSON'S RESOURCES OF OREGON (PRO)

#### DEEP BRAIN STIMULATION PANEL

June 19, 2013, 5:30pm to 7:00pm. If you are considering DBS or just curious to learn more about this treatment option, please join us in the PRO Conference Room, 3975 Mercantile Drive, Lake Oswego, OR. An informal panel, including peers and professionals, will be available to answer your questions. Please contact Sally Stevens (PRO Social Worker) at sally@parkinsonsresources.org to confirm your attendance.

## PARKINSON CENTER OF OREGON (PCO)

### CAREGIVERS CONNECTION

May 16, 2013, 5:00pm to 9:00pm. The Parkinson's Center of Oregon at OHSU invites you to join an evening of education and support. The cocktail social hour will begin at 5:00pm and will be followed by three informational sessions and a dessert reception. The event will be held in the Vey Auditorium at OHSU. This year's keynote speaker will be Dr. John S. Allen, Health Psychologist. Please call (503) 494 - 9054 with any questions.

### PAWS FOR A CAUSE

July 13, 2013, 8:30 am to 12:00 pm. A community dog walk to benefit Parkinson's disease, including vendor fair, pet contests, and games. Please call (503) 494 - 7231 for more information.

### POWERFUL TOOLS FOR CAREGIVERS

This is a 6-week educational series 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.

Tai Chi is a form of exercise that combines meditation and rhythmic breathing with slow, low-impact movements. Research has shown that Tai Chi helps to improve balance and muscle strength, reduce falls and relieve pain, and help with stiffness/rigidity. It also can help a person's ability to walk and move steadily. Because of these benefits, Tai Chi can be a therapeutic choice of exercise to help Parkinson's patients manage their symptoms. One non-profit, Taoist Tai Society, offers health recovery classes in addition to a variety of other tai chi classes. These classes are for people with injury or chronic illness, including Parkinson's disease. Movements are adapted for those with limited mobility, including those who are wheelchair bound. The Taoist Tai Society offers classes at many area locations. Beginners classes are offered at various times during the week/ weekend and a health recovery class is offered on Saturdays. You may attend as many classes at your level a week as you wish! For more information and class locations and times please call (503) 220 - 5970 or visit their website [www.oregon.usa.taoist.org](http://www.oregon.usa.taoist.org).

#### Resources:

[HTTP://ALTMEDICINE.ABOUT.COM/OD/TAICHIQIGONG/G/TAICHI.HTM](http://altmedicine.about.com/od/taichiqigong/g/taichi.htm)  
[HTTP://WWW.WEBMD.COM/PARKINSONS-DISEASE/NEWS/20120208/TAI-CHI-IMPROVES-SYMPTOMS-PARKINSONS-DISEASE](http://www.webmd.com/parkinsons-disease/news/20120208/tai-chi-improves-symptoms-parkinsons-disease)



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

Telehealth isn't just for doctor's visits! The Northwest Parkinson's Disease Research, Education, and Clinical Center (NW PADRECC) has started using V-tel technology to bring patient education events to more veterans in its service area. NW PADRECC staff started a pilot effort in 2011 to engage 5-8 VA sites to act as "remote facilities" which would host veterans for one-hour patient education lectures broadcast via V-tel.

The NW PADRECC serves veterans with Parkinson's disease and other movement disorders in ten states. Veterans can live hundreds of miles from the main PADRECC clinical centers in Portland, Oregon and Seattle, Washington. Tele-education is a way to provide local information and support to veterans who may have limited mobility and/or be unable to travel long distances.

The events also serve veterans in ways which are not so obvious. Veterans and family members receive information at the lectures, but also have a chance to meet others with similar medical issues. Although not a "support group," the education events give veterans a valuable opportunity to socialize and exchange information with others in their area. The V-tel events are interactive, allowing patients to ask questions of the presenter and to interact with other patients virtually.

Although the NW PADRECC has been offering patient education via V-tel for only a few months, the results have been positive. The number of patients able to attend education events has doubled overall, with good feedback and participation from veterans and VA personnel at the remote sites. The staff of the NW PADRECC look forward to improving and expanding on the tele-education effort. The next V-tel event will be in September 2013. Please see the box at right for current V-tel locations, and check our website for details of current events.

#### Current V-tel locations are:

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

Please call  
 503-721-1091 or  
 1-800-949-1004 ext. 51091  
 for availability

# 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](http://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.

# Health & Wellness Fair

## For Parkinson's Disease & Movement Disorders

**Friday, June 7th, 2013**

**From 10:00 a.m. to 2:00 p.m.**

**Portland VA Medical Center Auditorium**

3710 SW US Veterans Hospital Road

Portland, OR 97239

- Refreshments Provided!
- Door Prizes!
- Ask the Experts Booth! Ask questions of Parkinson's and Movement Disorder Specialists!

Exhibits Include: Home Health, Deep Brain Stimulation (DBS) and Surgery, Exercise, Tai Chi, Dance, Caregiver Support, Physical Therapy, Occupational Therapy, Hospice, Social Work Services, Research . . . And More . . .

This event free and open to Veterans, Patients, Caregivers, VA Employees, and Health Care Providers

Call us at 503-721-1091 for questions, or visit our website at [www.parkinsons.va.gov/northwest](http://www.parkinsons.va.gov/northwest)

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