



THE PARKINSONIAN

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

Speech-Language Pathology Services for Patients with Parkinson's Disease

By Erin Bookout, Speech Language Pathologist

Speech-Language Pathologists (SLPs) help patients manage impairments in swallowing, communication, and cognition; areas which are often affected by Parkinson's disease. The most common issues in these domains, both for patients with Parkinson's disease and for SLPs providing care, are described here.

Swallowing

Dysphagia refers to difficulty eating, which may include any of the following: chewing food, swallowing solids and/or liquids, coughing or choking when eating, and having the sensation of food sticking in the throat or chest. The result of these impairments can lead to food or liquid going into the airway, known as *aspiration*, and can cause pneumonia or other serious, even life-threatening, medical problems. Dysphagia can also result in a decreased ability to maintain nutrition.

It is estimated that one-third to one-half of patients with Parkinson's disease report symptoms of dysphagia, and on objective studies nearly all show at least some changes to their swallowing system. To help with this, SLPs can provide evaluations of swallowing using two techniques:

- 1) videofluoroscopic (x-ray)
- 2) endoscopic (direct visualization of the throat with a scope)

They are then able to make recommendations for diet modifications, posture changes, and exercise programs

that can help to reduce aspiration and increase swallowing efficiency, which in turn may improve nutrition.

Talk to your doctor to schedule a SLP consult for a swallowing evaluation if you experience:

- ◆ Coughing or choking during or after eating or drinking
- ◆ Sensation of food stuck in throat
- ◆ Trouble moving food to back of mouth
- ◆ Trouble keeping food or liquid in mouth
- ◆ Trouble swallowing pills
- ◆ Changes in voice quality after eating or drinking

Communication

At some point in the disease process, voice and speech are affected in nearly all patients with Parkinson's disease. Most commonly, patients have difficulties with speaking too softly, called *hypophonia*. Speech may have small and rapid movements, known as *hypokinetic dysarthria*, or stuttering-like repetitions in speech, called *palilalia*. SLPs at the PVAMC evaluate voice and speech and are certified to provide the highly effective, evidence-based Lee Silverman Voice Treatment (LSVT). LSVT is an intensive vocal exercise program that helps to recalibrate voice and speech, as well as to slow further decline in the system.

Talk to your doctor about an SLP consult for a communication evaluation if you

experience:

- ◆ Quiet voice
- ◆ Stuttering speech
- ◆ Listeners asking you to repeat frequently

Cognition

Many patients with Parkinson's disease find that both their short-term memory and their ability to learn new information are affected by the disease. SLPs provide assistance in managing these deficits through the training of memory aids like calendars, daily planners, and smart phones.

Talk to your doctor about an SLP consult for a cognitive evaluation if you experience:

- ◆ Difficulty managing appointments, medications, and finances
- ◆ Trouble with short-term memory that interferes with your ability to do your normal daily activities

For more information, please visit the following websites:

American Speech-Language-Hearing Association: <http://www.asha.org/public/>

Lee Silverman Voice Treatment: <http://www.lsvtglobal.com/>

National Parkinson Foundation: <http://www.parkinson.org/Parkinson-s-Disease/Treatment/Speech---Swallowing>

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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

What is dyskinesia?

Many patients who are treated for Parkinson's disease suffer from dyskinesia, or involuntary disorganized or excessive movements of the body. The movements may appear as jerking, twisting, fidgeting, or dance-like motions of the upper or lower body. Dyskinesia is most often a side effect of levodopa (Sinemet[®], Parcopa[®]; generic: carbidopa/levodopa), which is a common treatment for patients with Parkinson's disease.

A patient may develop dyskinesias as dosing of levodopa is increased with the disease's progression. The frequency and intensity of dyskinesic movement may vary, and tends to be the most extreme during the peak effect of a dose of levodopa. However, some people may experience dyskinesias as their medication takes effect and/or at the end of their dose. Patients who have severe dyskinesia may benefit from changes or addition of medications or deep brain stimulation (DBS) surgery. Dr. Kathy Chung is currently studying the effect Omega-3 Fatty Acid may have on reducing dyskinesia. If you are interested in learning more about this study, please call Alison Rhoads at 503-220-8262.

Letter from a reader

Dear Betsy:

Earl and I would like to thank you and the Portland PADRECC folks for arranging the Parkinson's Disease seminar telecasts at the Boise VA. The first one we attended was Psychological Issues in Parkinson's Disease presented by Joel Mack, MD. The information provided was so helpful. We now have a clearer understanding of the mental side of PD.

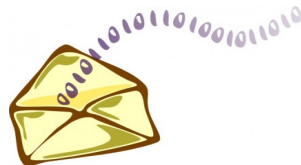
Another benefit we found by attending was connecting with other PD patients and caregivers. We did not know there were three support groups in our area. And, we were able to visit with other attendees and ask questions. The Boise staff were so helpful.

Earl is newly diagnosed with PD so we are just beginning our information journey and being able to attend these seminars locally is awesome! We are looking forward to the next one.

I also want to thank you, Betsy, for being so pleasant on the phone. You have been very patient answering my questions and you are most appreciated.

Sincerely,

Suzi Maggard
Kuna, Idaho



Parkinson's TeleHealth Program

The Parkinson's TeleHealth Program broadcasts live, interactive educational talks to a network of rural communities in the Northwest. At 2:00pm, PST, on the SECOND Monday of each month, a guest speaker presents a topic geared toward the interests of Parkinson's families. The information is designed to help participants to improve their knowledge of Parkinson's disease and in turn, their quality of life.

November 12, 2012: National Caregivers Month: Caregiving for the Caregivers. Presented by Dr. Daniel Burdick, MD, Board Certified Movement Disorder Specialist.

December 10, 2012: The many sides to DBS. Presented by Dr. Jonathan Carlson, MD, and Janie Mark, ARNP.

Please visit <http://www.nwpcf.org/TelehealthNet.aspx> to locate a site participating in the TeleHealth Program.



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!**

Please Welcome Joanna O'Leary, MD to the PADRECC Staff!

Dr. O'Leary grew up in New York state. She studied ancient Greek language and modern dance as an undergraduate at Vassar College. Dr. O'Leary lived all around the US, including Boston, San Francisco, and Chicago, before landing in Portland. She briefly worked as a legal assistant before deciding to pursue a career in medicine. She attended medical school at Rush University in Chicago and then OHSU for her neurology residency. Dr. O'Leary decided to focus on movement disorders because she enjoys spending time with the patients and their families. Her hobbies include chasing her 2 year old son around the house and running in the various parks around Portland. Welcome Dr. O'Leary!



Portland patient education talks are now available via video-teleconference (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
Eugene, OR	Walla Walla, WA
North Bend, OR	White City, OR



www.parkinsons.va.gov/northwest

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 1/2 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.

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. For more information or to register call (503) 721-1091.

MEDICATIONS AND PARKINSON'S DISEASE. December 7, 2012, 10:00am to 11:00am Pacific Time.

SPEECH AND SWALLOWING IN PARKINSON'S DISEASE. February 8, 2013, 10:00am to 11:00am Pacific Time.

PATIENT RESOURCE FAIR. June 7, 2013, 10:00am to 2:00pm Pacific Time.

PARKINSON CENTER OF OREGON (PCO)

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

Save the Date!

YOUNG PEOPLE WITH PARKINSON'S DISEASE SYMPOSIUM. March 16, 2013 at the Portland Art Museum

CAREGIVER'S CONFERENCE. May 16, 2013

PARKINSON'S RESOURCES OF OREGON

ADVANCED STAGE CAREGIVER TRAINING. December 3, 2012 9:00am to 4:00 pm. Corvallis Senior Center. This is an all-day workshop specifically developed for family caregivers of a person nearing or in the advanced stages of Parkinson's disease. Participants will learn critical information that will help in planning, decision making, and build confidence in their ability to cope. \$20 registration fee per participant, scholarships available.

DEEP BRAIN STIMULATION PANEL. December 12, 2012 5:00pm to 7:00pm. PRO Conference Room, first floor, 3975 Mercantile Drive, Lake Oswego, OR 97035. If you are considering DBS, or just curious to learn more about this treatment option, please join us. 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'S RESOURCES OF OREGON (continued)

PARKINSON'S DISEASE HIKE SERIES 3 MILE HIKE with Sukhee So, Physical Therapist. January 15, 2013 at 9:30am. Meeting point: Forest Park Entrance at the end of NW Thurman St. These hikes will be at a moderate pace. This is a great opportunity to get some fresh air, get some physical activity, and meet other people who are living with Parkinson's disease. If you have any concerns about your ability to participate in this type of activity safely, please talk to your neurologist first. Please bring drinking water and appropriate shoes and dress appropriately for the weather. Friendly dogs are welcome on a leash, but no children, please.

For more information on the Parkinson's Resources of Oregon events please call (503) 594 - 0901



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