My Parkinson’s Story –
A Web-based Video Library

Jeff Kraakevik, M.D. – OHSU Parkinson Specialist

Several years ago, I was sitting with Susan Heath, RN, MSN, the DBS coordinator at the San Francisco VA at a meeting, and we were talking about ways to teach patients and families about Parkinson’s disease. We wanted to create something that talked about common problems seen in real world situations. We wanted to include smart healthcare providers with simple and meaningful solutions.

The result of that discussion was a video series called My Parkinson’s Story. This is a video series funded and produced by the VA with the guidance of faculty from the PADRECC (Parkinson’s Disease Research, Education, and Clinical Centers) group. The PADRECC’s are designated centers of excellence for research, education, and care of Parkinson’s disease within the VA system. Susan and I have selected thought leaders from VA medical centers throughout the country to discuss these topics in Parkinson’s disease. We asked them all to identify one person in their clinic that has dealt with the issue we assigned to them. Our producer, Andrew Stephens, then took his camera crews, and spent about a day with each person and their family. He interviewed them, and filmed them, usually at home and in their community, to outline exactly what the problem feels like and looks like. We then asked the experts to weigh in on how to solve the problem. Andrew filmed physicians, nurses, pharmacists, occupational therapists, physical therapists, speech therapists, social workers, case managers, and anybody else who may have had input in the care of that problem.

We’re really proud of the result, and we think you will find it helpful! The videos can all be found on YouTube and are each about 8-10 minutes long. There is a playlist through the VA YouTube channel which has all the videos stored together. The playlist can be found here:

http://tinyurl.com/VAPDvideos

It can also be found by searching YouTube for ‘VA PADRECC Parkinson Playlist’. The topics covered include:

• Early PD
• Depression
• Falls
• Driving
• Exercise
• Caregiving
• Genetics
• Thinking and memory problems
• Environmental exposure

• Medications
• DBS
• Sleep
• Advanced PD
• Hospitalization
• Impulsive behavior
• Speech and swallowing

The videos feature OHSU and Portland VAMC providers with their patients including Drs. Nutt, Peterson, Hogarth, and Kraakevik as well as Julie Carter, ANP. We welcome you to check out any which may be of interest to you!
As I begin my ninth month as director of the OHSU Parkinson’s Center, I remain focused on sustaining the good work that goes on here, but we’ve also been looking to the future and I’d like to share some of that with you.

In November 2013, we held an all-day retreat to define the goals of the clinical, research, and education/outreach missions of the OHSU Parkinson Center, and unanimously concluded that the highest priority is expanding the person-power in the clinical program. We have obtained approval to recruit another neurologist with expertise in Parkinson’s disease and the interview process is well under way. We expect to have another provider on board by this summer and anticipate a dramatic improvement in the wait time for consultations, follow-up visits, DBS evaluations, and other appointments.

Simple approaches to improve constipation include adequately hydrating (drinking 2 quarts of water and other fluids daily), increasing dietary fiber (including whole grain bread, vegetables, legumes, and unskinned fruits with edible seeds such as prunes and strawberries), decreasing dairy in the diet, and daily exercise. Drinking warm liquids (which promotes bowel activity) on awakening and with breakfast, eating meals at the same times each day, and establishing a relaxed, regular time of the day for bowel movements (about ½ hour after a meal is best as there is normally greater bowel activity of the day for bowel movements), daily exercise, and drinking water and other fluids daily), increasing dietary fiber (including whole grain bread, vegetables, legumes, and unskinned fruits with edible seeds such as prune, and strawberries), decreasing dairy in the diet, and daily exercise. Drinking warm liquids (which promotes bowel activity) on awakening and with breakfast, eating meals at the same times each day, and establishing a relaxed, regular time of the day for bowel movements (about ½ hour after a meal is best as there is normally greater bowel activity (from sleeping on one’s back), and decreasing alcohol intake may also be helpful in some cases. Treatment of sleep apnea is important in regard to REM sleep disorder. Visit: www.ohsubrain.com/pcd

These developments are occurring on the backdrop of a continued emphasis on state-of-the-art patient-centered care, led by our most experienced faculty. As bright, well-trained young faculty are being recruited to fill clinical and research needs, we are fortunate to have Dr Nutt continue to work with the National Parkinson Foundation to define best practices for PD care. While it’s exciting to see the growth opportunities in front of us, it is reassuring and stabilizing to have the founders of the program helping to lead us into the future.

**Director’s Corner**

**Moving Forward: A Progress Report**

Joseph Quinn, M.D. - OHSU Parkinson Center Medical Director

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In the research arena, the faculty identified brain imaging expertise as the most important priority for recruitment, and shortly thereafter Dr Horak recruited Dr Brett Fling, a brain imaging specialist, to join the Gait and Balance Disorders Laboratory and provide brain imaging expertise to the clinician-scientists at the OHSU Parkinson Center. We also identified a need for pilot funds to “prime the pump” and facilitate the submission and awarding of federally funded grants. A mechanism for this is under development, and if funding permits, the first applications may be requested in early 2015.

After the clinician recruitment is complete, we will begin recruiting new clinician-scientist faculty to grow and invigorate the research program aimed at improving the treatment of PD and related disorders.

In the area of education and outreach, three priority areas were identified: 1) An improved “Brain Wellness” program for patients with early Parkinson’s disease, 2) improved inpatient care for patients with Parkinson’s disease at any stage, and 3) a better developed palliative care program for patients with later stage Parkinson’s disease. All of these activities are works-in-progress.

**Constipation in Parkinson’s Disease**

Matthew Brodsky, M.D. — OHSU Parkinson Center Specialist

Constipation, defined as fewer than three bowel movements per week, is a common gastrointestinal symptom of Parkinson’s disease. The same changes that occur in the brain in PD that leads to slowed movements also affect the muscles that propel food through the digestive tract. In addition, neurons that line the digestive tract are directly affected in PD, as evidenced by Levy bodies (the pathologic marker for PD) that are found in these cells. In fact, there is evidence that nerve cell damage in the digestive system occurs much earlier than in the brain in PD, and constipation often begins many years before motor symptoms begin.

**Sleep Apnea: Sleep Disturbances in PD, Part 5**

Amie Peterson, M.D. — OHSU Parkinson Center Specialist

There are many issues with sleep in Parkinson’s disease (PD). This is the last newsletter article of a series on sleep issues in PD and will focus on sleep apnea. Apnea means decreased breathing. The major features of sleep apnea are decreased breathing (apneas), shallow breathing (hypopneas), waking related to respiratory effort in sleep, daytime sleepiness, snoring, restless sleep, and reusitiviscus snoring. There are two types of sleep apnea – peripheral and central. Peripheral sleep apnea is also called obstructive sleep apnea (OSA) and occurs when the airway is partially or fully blocked in the very posterior area of the throat. When partially blocked, snoring results and when fully blocked apneas occur. Central apnea is related to decreased contraction and relaxation of the diaphragm. Sleep apnea is common in persons with PD and can be central or peripheral in etiology.

There are a number of treatments for sleep apnea including the use of continuous positive airway pressure devices known as CPAP. Oral appliance, surgery, weight loss (if over weight), changing to a side sleeping positive (from sleeping on one’s back), and decreasing alcohol intake may also be helpful in some cases. Treatment of sleep apnea is important in regard to improving sleep both of the person with apnea and the bed partner. In addition untreated sleep apnea increases the risk of high blood pressure, heart attack, strokes, abnormal heart rhythms, and heart failure.

If you have been told you stop breathing in your sleep, you should ask your primary care doctor or your neurologist for a referral for a sleep study. If you snore, experience daytime fatigue, or have non-remful sleep you should talk with your doctors to see if a sleep study is appropriate.

**TIPS FOR PROMOTING REGULARITY**

Simple approaches to improve constipation include adequately hydrating (drinking 2 quarts of water and other fluids daily), increasing dietary fiber (including whole grain bread, vegetables, legumes, and unskinned fruits with edible seeds such as prunes and strawberries), decreasing dairy in the diet, and daily exercise. Drinking warm liquids (which promotes bowel activity) on awakening and with breakfast, eating meals at the same times each day, and establishing a relaxed, regular time of the day for bowel movements (about ½ hour after a meal is best as there is normally greater bowel activity (from sleeping on one’s back), and decreasing alcohol intake may also be helpful in some cases. Treatment of sleep apnea is important in regard to improving sleep both of the person with apnea and the bed partner. In addition untreated sleep apnea increases the risk of high blood pressure, heart attack, strokes, abnormal heart rhythms, and heart failure.

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**RESEARCH OPPORTUNITY: PD AND CONSTIPATION (PG 4)**
Take a moment to browse their website (https://adrcoforegon.org) to assess your needs. ADRC is run by the Oregon Department of Human Services (the service exists in Washington state as well). The ADRC has trained Assistant Specialists who both provide information and, if requested, help counsel consumers about what care options might best fit their needs. They also have an excellent website that offers information and self-guided tools to find resources near you. Here is just some of what they offer.

- **Assess Your Needs:** Handy, quick online assessment which compiles a specific list of resources tailored to your needs and finances anywhere in the state.
- **Search for Services:** A search engine to find local services for in-home care resources and licensed facilities. Areas referenced include but are not limited to:
  - Adult day care and in-home care
  - Disabilities and rehab
  - End-of-life issues
  - Financial management
  - Financial aid
  - Veterans
- **Family Caregiver Handbook** (downloadable) which deals with common care challenges, such as personal care for your loved one, emotional challenges of caregiving, transitions home from the hospital and more. Each section is written plainly and has additional resources for more in-depth learning.

Take a moment to browse their website (https://adrcoforegon.org) to become familiar with what they have to offer or call a representative. Whether you need it today or in the future, it is a handy option for finding support resources nearby.

### PD Artists Recognized!

If you attended our fall symposium, you were able to see many talented PD artists and their works. Several PD artists from the Northwest were featured in the annual Parkinson Disease Foundation (PDF) calendar for 2014. Two of whom also were at our symposium and were recognized by a feature in the Oregonian recently. Kathy Hartman, a mosaic artist, and Bev Mickelson, an origami artist. Visit Oregon Live at http://tinyurl.com/ParkinsonArt to see several pictures and a video of their art.

Ladies, you’re awesome ambassadors for all people with PD!

### The Great Salt Lick Auction and Fundraiser

Where else is a city dedicating a sculpture to Parkinson’s disease awareness? Only in our very own Baker City, Oregon. What Deschutes’ very special and humorous fundraising event for the OH SU Parkinson Center — the Great Salt Lick Auction and Fundraiser — has not only brought us thousands of dollars for research and care, but also has become a celebrated part of the town’s history. This June, Whit will help the town dedicate a four-foot bronze salt lick for Parkinson’s disease awareness. It will be there for all to see at the next Great Salt Lick Auction slated for September 20th at the Old Armory in Baker. This truly is an event of fun, hilarity, and support for a good cause you won’t want to miss. Put it on your calendar!

### There’s an App for That?!

**How Mobile Devices Can Help Memory and Planning**

**Michal Rubin, CCC-SLP – OHSU Neurological Rehab**

Over the last few years we have had a surge in the availability and affordability of “apps” or programs that can run on your phone, tablet or other mobile device. Many apps promise to make life easier and more convenient. It is sometimes difficult to know if the app stands up to those claims, or whether it would just be easier to set an alarm by the bed, look at a paper calendar on the wall—just like in the good ol’ days. I think it is best to at least try some new things and choose what works best for you. You may be surprised at how easy many of these apps are to use and how they really can help you with a variety of things. The following is a list of apps related to memory or other thinking difficulties as well as those specific Parkinson’s.

**MEMORY**

- **Pill Time** — $0.99. Helps you keep track of medicine and remind you when you need to take them. It takes a while to get them all entered, but once you do it is fairly easy to use. There are lots of pill reminder programs. Find one that fits your best.
- **MedLog** — $4.00. A little hard to use at first but features include: a log of needs taken to bring to appointments to help with compliance issues, connects with the phone’s calendar program, can program reminders down to the second.
- **Spaced Retrieval TherAppy** — FREE. So you did spaced retrieval with your speech therapist and now you want to do more at home with your loved one? Use this app to track how long items have been recalled for and what the next interval should be.
- **Find My i-Phone** — FREE. A location app that tracks wireless devices and enables a you to track where the devices are.

**COGNITIVE EXERCISES**

- **Lumosity** — FREE. Features include: daily games, a good introduction if you are considering the full online version ($14.99/month). Fun and easy to use.
- **BrainHQ** — FREE. Features include: daily games, also a good introduction to the full online version.
- **Matrix Game** — FREE. Helps develop visual perception skills such as visual discrimination. It also helps develop attention and concentration, spatial orientation and principles of classification and categorization. Furthermore, it helps develop executive functions such as planning and perseverance.

**MINDFULNESS/RELAXATION**

- **Breathe2relax** — FREE. Originally developed for Veterans returning with PTSD. This app allows you to complete breathing for relaxation exercises with visual and auditory instructions.
- **The Mindfulness App** — $1.99. Takes you through several relaxation exercises.

**PLANNERS/ORGANIZERS**

- **Things**. $9.99 — A good task manager: it helps get life done. Features include: to-do lists with reminders, projects with specific action items, daily to-do.
- **Evernote** — FREE. Organizes information across devices. Set tasks, reminders, appointments, take notes, pictures.
- **Colornote** — FREE. A great organization/planner/to-do list app.

**SPEECH TO TEXT**

- **Dragon Dictation** — FREE. Dragon Dictation is an easy-to-use voice recognition application that allows you to easily speak and instantly see your text or email messages. Easy to use, but takes some practice.

**PARKINSON’S SPECIFIC APPS**

- **PD life** — FREE. Developed by the Parkinson’s Association of the Rockies. Features include: Record all of your medications and dosages, schedule reminders to ensure you take your medications on time, track and improve your ability to take medications on time, track and report timing of your “OnOff” periods, track and report your symptoms and side effects, track and report your “PD Life Score” take your device with you to your next healthcare visit - make it part of your normal healthcare dialogue.

- **Parkinson’s Central Smartphone App** — FREE. National Parkinson’s Foundation. Features include: “Near Me” tool to find resources in your area, how to get the most out of doctor visits, ins and outs of diagnosis and medication management, tips on how to live well with Parkinson’s, information about insurance and finance, special caregiver content.

Most of these programs are available in both Apple and Android formats.
Purpose: Previous research has found that dopamine can improve balance and fall risk in Parkinson's patients. The purpose of this study is to examine the effect of levodopa on improving balance in Parkinson's patients.

Participation Requirements: Participation in this study includes a total of 4 clinical visits to OHSU for testing. We are looking for patients who have been diagnosed with idiopathic Parkinson's disease and have been treated with levodopa for at least one year. Participants will be asked to stop taking levodopa for three days before each study visit.

Dr. Amie Peterson is conducting this research study at Oregon Health & Science University and can be contacted at balance@ohsu.edu.

Participants will receive study-related evaluations, laboratory tests, and compensation for their time and transportation costs. For more information, please contact Mike Fleming at 503 364-0842 or at mikefleming@ohsu.edu.

THE EFFECTS OF VITAMIN D ON BALANCE IN PD

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 your 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 half hours and the second, and third, and fourth visit will last for half each visit will occur four weeks apart. You will be compensated $10 for each visit you complete for a total of $60. 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 in this study you will help us learn how to benefit patients in the future. For more information on how to participate, please contact Brenna Lobb, M.S. M.P.H., Study Coordinator at 503 220-8262 or 51871 or by mail at 3710 S.W. US Veterans Rd, Portland, OR 97239. (Some balance problems). You must not be taking any other medications for your Parkinson's disease. There will be a total of 5 study visits over approximately 2 months. Subjects will receive AIP-293 capsules, and identical placebo capsules for about two weeks each. A placebo is a capsule that looks like the study drug but has no real medicine in it. This study involves the taking the study drug or placebo for 6 weeks, a 4 week washout period, and then another 6 week period where subject will either be given the study drug or placebo. Between each phase participants will be required to come to OHSU for balance testing and evaluation. If you are interested please contact Mike Fleming at 503 364-0842 or at mikefleming@ohsu.edu.

Research Opportunities

The OHSU Parkinson Center is a national leader in Parkinson's disease (PD) research and recognized as a National Parkinson Foundation Center of Excellence. The OHSU Parkinson Center participates in research studies that are fully recruited and others that are of excellence. The OHsu Parkinson Center is a national leader in Parkinson’s disease research opportunities.
Biomarkers and PD

Mike Fleming — Study Coordinator

What are biomarkers, and why has there been so much chatter about them in the Parkinson’s disease (PD) community lately? A PD biomarker is something that can be measured in the body that can be linked to the presence of the disease and to its progression over time. A neurologic exam by an experienced clinician can confirm the diagnosis of PD in most cases, and how that exam changes over time can certainly inform us about the disease’s progression. However, we would like to have more objective, sensitive ways of detecting PD at its earliest stages and measuring its progress over time; for instance, with a blood test.

We are already identifying potential biomarkers in people newly-diagnosed with PD in a study called the Parkinson’s Progression Markers Initiative. Some of you reading this may even be participants! Now OHSU is again teaming up with the Michael J. Fox Foundation, the University of Oregon (UO), the University of California, Los Angeles, and the University of California, San Francisco, to team up again at key junctures in the progression of PD.

In BioFIND, we will take a variety of biological samples and use them to get an idea of what Parkinson’s ‘looks’ like on a microscopic level, comparing the findings in people with and without Parkinson’s. We hope to identify biomarkers that will allow us to test drugs proposed to slow progression of PD, to diagnose the disease more accurately and at an earlier stage, and even to identify people at risk for developing Parkinson’s with the goal of using preventative treatment to stave off the onset of symptoms.

Participants will be seen at a research center located at the Oregon Health & Science University. The study will take about two weeks to complete and will involve two visits to OHSU. At these visits, we will take biological samples as well as information about medical history, a physical exam, and a neurological exam by a doctor specializing in movement disorders. Both of these visits will take about four hours. There is no cost to participate in this study; reimbursement up to $200 is available for completion of the study.

Understanding how biomarkers change in Parkinson’s disease is an important step toward developing better tests and treatments for Parkinson’s in the future. If you are interested in participating in BioFIND, or if you have questions about the study, please contact Arthur Kline at 503 494-9311 or kline@ohsu.edu.

Ask the Experts: Your Questions Answered; Patients’ Questions from Our Annual Symposium

Marian Livingston, M.D. – OHSU Movement Disorders Fellow

“What form of co-enzyme Q10 was tested in the MitoQ trial? Ubiquininated?”

The MitoQ trial was a study of 128 newly diagnosed Parkinson’s disease patients in Australia and New Zealand who were followed over 12 months on either CoQ10 or a placebo. Unfortunately, there was no improvement in motor scores in the CoQ10-treated patients over the course of this double-blind study. The patients received either 40mg or 80mg of MitoQ, which was a ubiquinatated formulation (i.e., the active antioxidant formulation).

“Can you comment on the use of cannabis and coconut oil for relief of non-motor Parkinson’s Disease symptoms?”

A randomized, double-blind, placebo-controlled trial of oral cannabis extract showed no improved levodopa-related dyskinesias in 19 Parkinson’s disease patients. This was a crossover trial, in which the same patients were tested after taking oral cannabis extract and after taking a placebo pill. There are currently no studies examining the role of cannabis and non-motor PD symptoms. Some patients have experienced a benefit from cannabis for levodopa-related nausea that is refractory to multiple anti-nausea medications. There are presently no placebo-controlled research studies supporting or refuting the benefits of cannabis oil in Parkinson’s disease.

“Is sinemet the combination of carbidopa and levodopa?”

Yes. Levodopa is the active part of the medication; carbidopa prevents the medication from being broken down in the body before it can be transported to the brain. It helps prevent side effects like nausea and vomiting. The etymology or origin of the name sinemet itself is literally ‘without emesis.’

References:
31st Annual Parkinson’s Disease Symposium
A Healthier You!
Diet, Exercise, and Brain Wellness
Sunday, October 12, 2014, 9 a.m.–3 p.m.
Red Lion Jantzen Beach Hotel, Portland

Parkinson’s Disease Symposium Highlights Wellness

We hope you’ll join us for our 31st annual symposium on diet, exercise, and wellness. Our keynote speaker will be Christine Targney, a University professor and clinical nutritionist, who will be discussing the latest research and information in these areas.

Our registration deadline is October 1st. To reserve your spot, call 503 494-9054.

Program, lunch, and materials: $35/pp. Register now at www.ohsubrain.com/pcopo or call 503 494-9054. The registration deadline is October 1st.

We hope to see you there!

OHSU PARKINSON CENTER EVENTS

SAT, JUN 21 – PORTLAND, OR
PAWS FOR PARKINSON’S

A benefit for the OHSU Parkinson Center raised funds for research and care advances while raising public awareness and having fun with your furry or human friends. Go right now and register, start your team, donate, and/or share your story at www.tinyurl.com/paws4PD

SAT, SEP 20 – BAKER CITY, OR
THE GREAT SALT LICK HOOF ARTED CONTEST AUCTION AND BENEFIT

This event was featured on OPB’s Art Beat! This is the 8th annual Great Salt Lick Contest which continues to grow in notoriety every year. Follow on Facebook “The Great Salt Lick” for more details and plan to join in the fun and hilarity of this unique event.

All proceeds from these events fund research and specialized care programs for PD through the OHSU Parkinson Center.

SUN, OCT 12 – PORTLAND, OR
OPTIONS AND OPPORTUNITIES: ANNUAL PD SYMPOSIUM

Mark your calendars for our 31st annual Parkinson’s disease symposium. Detailed information above; registration open now.

What: 1K or 4K walk, vendor fair, silent auction, pet contests, and more!

When: June 21st, 2014 9 a.m.–12 p.m.

Where: Park of the OHSU’s Union

Register: http://tinyurl.com/paws4PD

Bring your friends — furry or human — to this fun, family-friendly benefit walk for Parkinson’s disease (PD). Funds raised will help the Parkinson Center of Oregon further our mission of improving care of people living with Parkinson’s disease through expert and comprehensive care, providing education to patients, families, and professionals, and promoting research into causes and treatment of Parkinson’s disease.

Together, we can make a difference!

Our sponsors:

Abby Road Farm; Impact Printing; Swanson, Thomas, Coon & Newton; Teva Pharmaceutical Industries Ltd; Elite Care; Medtronic; Stella & Chewy’s; Einstein Bagels; Nancy Nelson; PDEX.

10th Anniversary of Sole Support for Parkinson’s 1K & 5K Awareness Walk and Fundraiser for PRO

Sep 6th – Portland at Moda Center
Sep 27th – Medford at Bear Creek Park
Sep 28th – Eugene at Alton Baker Park
Registration and event details at www.soleupport.org

SAT, SEP 20 – BOISE, ID
LIVING WITH PARKINSON’S CONFERENCE

Treatment Options and Strategies for People with Parkinson’s and their Family Members

Presented by Parkinson’s Resource of Oregon and Northwest Parkinson’s Foundation

9 am to 3:30 pm, $20 registration before Sept. 5th, $25 after. Includes lunch. Scholarships available. Registration available at www.nwpf.org

THE VETERANS ADMINISTRATION PADRECC

Visit the VA PADRECC Video Library at www.parkinsons.va.gov/northwest. Videos from past patient education lectures and handouts are available.