Director’s Corner
Joe Quinn, M.D.

As we look forward to the beginning of another year, it is interesting to look back at the events of the last year, as we continue to strive to serve the missions of patient care, education and research.

Patient care:
We are very pleased to welcome a new movement disorder-trained neurologist, Delaram Safarpour, M.D., to our group. Dr. Safarpour trained at the University of Pennsylvania and was selected to join our faculty after a national search. Dr. Safarpour’s background and interests are detailed in another section of this newsletter, so we will confine our comments here to a warm welcome.

We have also convened a Quality Improvement Committee within the Parkinson’s Center, charged with identifying a goal for improved clinical outcomes for our patients. Under the leadership of Jeff Knaasevik, M.D., the committee has decided to focus on fall prevention as the goal for the next year. Details will be forthcoming in the next quarter.

We have also taken the idea of “patient-centered care” to heart, with the creation of a Parkinson’s Patient Advisory Committee, or “Park-PAC.” Diana Potts leads monthly meetings of this group to review and/or propose innovations in clinical care, education and research. The group’s recommendations have already been enacted with revision of the medical history forms provided to patients at clinic visits, and by revisions of some of the educational materials dispensed at the conclusion of clinic visits. Park-PAC members have also given community lectures during Parkinson’s Awareness Month and have promoted clinical research at community support groups.

Education:
Professional education: We graduated two movement disorder fellows who now provide specialized Parkinson’s care in Seattle and Nebraska, respectively, and we welcomed two new fellows to begin training, OHSU Parkinson Center faculty also provided continuing medical education lectures to health care providers through our annual gatherings of Northwest movement disorder specialists (Pacific Northwest Basal Ganglia Conference) and rehab therapists (TEAM-PD).

We were also busy with patient and caregiver education programs. This year we added a very successful bimonthly series called Essential Tools for Managing Mid-Stage Parkinson’s Disease to our annual programming. It joined our already popular Newly Diagnosed Education Series (monthly), Caregiver Connections Conference (February) and Options & Opportunities annual symposium.

Research:
Progress has continued on federally funded studies of gait and balance in PD, cognition in PD, and on molecular mechanisms, including the award of a new NIH R01 grant on “alpha-synuclein” (the chief component of Lewy bodies, which damage the brain in PD) to Dr. Vivek Unni. Progress has also continued in the Pacific Udall Center, an NIH-funded collaboration between OHSU, University of Washington and Stanford University, which produced five publications in peer-reviewed scientific journals in 2017 alone. The OHSU Parkinson Center also has continued to be a leader in multicenter clinical trials, including Parkinson’s Study Group-sponsored trials of repurposed drugs, and an innovative Phase 1 study of an antibody directed at alpha-synuclein (clumps of cells in the Parkinson brain).

As the research enterprise continues to grow, we concluded that it would be wise to step back and do some strategic planning around research, so a Scientific Advisory Board review of our program was conducted on October 13, 2017. Three national leaders in PD research came to OHSU and issued recommendations for supporting research faculty, for developing junior faculty and for targeting recruitment of future faculty. Representatives from the Park-PAC described above also participated in order to ensure that the research program remains patient-focused. The final report of the advisors is not available in time for this newsletter, but we look forward to sharing those thoughts in future messages.

In summary, it has been a productive and satisfying year. As usual, we are dependent on our patients and families for research participation and guidance, and we are grateful for all your support. As I write this, we approach the Thanksgiving holiday, we offer you all a warm thank you, and since this is the first newsletter for 2018, we also wish you a happy new year!

Welcome our newest team member:

Delaram Safarpour, M.D.
OHSU Movement Disorders Specialist

Dr. Safarpour earned her medical degree in Iran. She moved to New Haven in 2009 where she completed a year of postdoctoral fellowship in movement disorders at Yale University. She then did four years of residency in neurology at Temple University Hospital followed by three years of combined movement disorders fellowship and master’s in clinical neuroepidemiology at University of Pennsylvania. She enjoys a patient-centered approach to improve quality of life of her patients with movement disorders. Dr. Safarpour is very excited to join the movement disorders division at OHSU. She looks forward to using her expertise in epidemiological research and patient care in managing patients with Parkinson’s disease and other movement disorders.

Jennifer Nichols, M.D.
OHSU Movement Disorders Fellow

Amantadine immediate release (IR) (Symmetrel) is an anti-influenza drug, has been used to treat Parkinson’s disease since 1969. At that time, it was found to have beneficial effects on the motor symptoms of Parkinson’s disease (PD) while it was being used to prevent the Asian flu. However, it took about 30 years for physicians to discover its beneficial effects on reducing dyskinasias.

Dyskinasias are involuntary ‘wiggly’ extra movements that patients with Parkinson’s may experience as the disease progresses. Dyskinasias can occur in approximately 50 percent of patients treated with levodopa (Sinemet) by five years and in up to 90 percent by 10 years of treatment. Dyskinasias have been proven to impair activities of daily living, increase risk of falls and decrease quality of life.

Amantadine IR has been proven by various studies to be effective at treating dyskinasias caused by high doses of levodopa (Sinemet), and is commonly used by providers for this purpose. Amantadine IR dosing can be limited by side effects, which often include dry mouth, urinary retention, constipation, sleep disturbances and hallucinations.

Recently, a new form of amantadine was trialed — amantadine extended-release (ER) capsule — and approved by the FDA to treat PD-related dyskinasias; its brand name is Gocovri. It is designed to be taken at bedtime and slowly activate overnight with higher levels during the morning and waking hours when patients need the most relief. This summer, the EASE LID 3 study to confirm the safety and efficacy of amantadine ER (Gocovri) was completed. Overall, it showed that there was a statistically significant reduction in the amount of dyskinasias patients experienced while on medication as well as improvement in the amount of dyskinasias during “off” time. Common side effects in at least 5 percent of patients included dry mouth, nausea, decreased appetite, insomnia, lightheadedness, falls, constipation and hallucinations. Most side effects were considered mild to moderate and did not lead to discontinuation of the drug.

At the conclusion of this study, we know that amantadine ER (Gocovri) is considered a safe and efficacious drug at reducing dyskinasias in patients with Parkinson’s disease on levodopa (Sinemet). What we still do not know is if this good safety and efficacy profile will extend out to the two-year mark (a study looking at this is ongoing). We also do not know whether or not amantadine ER (Gocovri) is actually any more effective than amantadine IR at controlling dyskinasias and improving “on” time. Although this new amantadine ER (Gocovri) seems promising, time will tell whether or not it will be deemed safer and/or more effective than tried-and-true immediate release amantadine. Fortunately, research into these questions is under way.

(Contact expected pricing per www.goodrx.com for Gocovri 30# $1220; for amantadine IR 30# $75.)

For references, please email pco@ohsu.edu.

Medication Assistance Resources

Angelle Healy, M.S.W. — OHSU Parkinson Center

Affording medications is becoming an increasing challenge. Here are some resources you may find helpful.

• Veteran? It is often worth taking the time to get a VA primary care physician (PCP) who can write prescriptions for specialty drugs, which can be inexpensive through VAMC pharmacies.
• Native American? If registered with a tribe, the Indian Health Services can help. https://www.ihs.gov; https://www.ihs.gov/portland
• Union member? If so, contact your union representative. Example: http://www.uchd.net/ prescription-assistance

- Patient Access Network Foundation: http://www.pantionfoundation.org/parkinsons-disease. PAN Mission: To help underinsured people with life-threatening, chronic and rare diseases get the medications and treatment they need by paying for their out-of-pocket costs and advocating for improved access and affordability.
- Manufacturer Assistance Programs: Contact the pharmaceutical company directly. Contact information and applications can be found at www.rxassist.org.
- Discount drug card (if not on any insurance plan): http://pharmacycard.org/
- $4 medications: http://i.walmart.com/i/if/hmp/fusion/genericdruglist.pdf
- Needy Meds at http://www.needymeds.org. Also has links to manufacturer assistance programs.
- State (Ore./Wash.) Prescription Drug Program:
  - Oregon: http://www.oregon.gov/oha/pharmacy/OPDP
  - Washington: www.hca.wa.gov/pdp
- Medicare eligible?
  - Part D — Medicare prescription drug plan. Many Medicare drug plans place drugs into different “tiers” on their formularies. Drugs in each tier have a different cost.
  - A drug in a lower tier will generally cost you less than a drug in a higher tier. In some cases, if your drug is on a higher tier and your prescriber thinks you need that drug instead of a similar drug on a lower tier, you or your prescriber can ask your plan for an exception to get a lower copayment.
- On Medicare? SHIBA (Senior Health Insurance Benefits Assistance Program) is a volunteer-based resource for people who are eligible for Medicare and need guidance as to what Medicare advantage plan will make the most sense for their care and financial needs. http://www.oregon.gov/dcbis/insurance/shiba/pages/shiba.aspx
New Movement Disorder Fellows Continue Legacy of Excellence

Jill Baird, M.D.
OHSU Movement Disorders Fellow

Dr. Baird grew up in Ames, Iowa, and attended Dartmouth Medical School before moving to Oregon for neurology residency at OHSU. She is thrilled to stay at OHSU for her movement disorders fellowship, and was inspired to choose this specialty by the Parkinson's and tremor patients she treated as a resident. She looks forward to learning more from her patients and colleagues and pursuing research in new immunotherapies for Parkinson's disease.

Jennifer Nichols, M.D.
OHSU Movement Disorders Fellow

Dr. Nichols grew up in the northern suburbs of Chicago. She attended college and medical school at the University of Illinois at Chicago before moving to Pittsburgh, Pennsylvania, to complete her neurology residency at the University of Pittsburgh Medical Center (UPMC). She decided to continue her training in the field of movement disorders because she enjoys the patient-centered care, varied procedures and clinical research opportunities that the field provides. She is excited to complete her training at OHSU and fulfill her goals of honing her clinical research and diagnostic skills.

Tips to Help Manage Anxiety

Living with Parkinson’s can be stressful, triggering a cascade of worries. Anxiety is common among people with Parkinson’s and can take many forms: general anxiety, panic attacks, social phobia or attacks brought on by stressful situations, to name a few.

Our most recent educational book, Mood: A Mind Guide to Parkinson’s Disease, explains what mood changes people with Parkinson’s can expect, why they might experience these changes and how to treat and cope with them. Here are our best tips on ways you can start to manage anxiety right now from Elaine Book, a clinic social worker at the Pacific Parkinson’s Research Centre, a Center of Excellence, who helps people with PD manage anxiety.

Elaine’s tips:
1. Plan ahead. Consider the worst-case scenario for anxiety triggers and problem solve in advance. For example, if traveling causes anxiety, weeks before your trip refill your prescriptions and call the airline to ask for boarding assistance.

2. Create an affirmation. Think of a short, clear positive statement that focuses on your strengths. Saying a phrase like “I can handle this” in anticipation of an anxiety provoking experience can help.

3. Give it a number. Use a 1–10 scale (1 being a minor hassle and 10 being a catastrophe) to assign a number to whatever is making you feel anxious. This can help put the issue in perspective.

4. Ask for help. It’s a sign of strength. Sourcing out what you need will help you live well with PD.

5. Identify triggers. Then take action to manage them. For example, if crowds make you anxious, avoid them. If running late increases your anxiety, leave early.

6. Exercise regularly. From walking to yoga to yard work, just 10 minutes of exercise can calm your mind, reduce negative emotions and help release muscle tension.

7. Nurture your spirit. Meditation can help reduce excessive worry. Download a free meditation app or try a YouTube meditation video.

8. Think positively. Notice when a negative loop takes hold in your mind, then practice replacing it with an optimistic thought.

9. Get support. Anxiety often diminishes when you share your worries with someone who has experienced similar struggles.

10. Do your groceries online. Remove anxiety triggers associated with grocery shopping. Sign up for a grocery delivery service (like Instacart or Peapod).

11. Talk to your doctor. Adjusting medication doses and timing may help.

12. Take a few deep breaths. Long, slow deep breaths can help refocus your mind.

Tips from Mood: A Mind Guide to Parkinson’s Disease:

13. Say no. Avoid overscheduling your days and focus on freeing up time to do the things that give you energy, like a hobby.

14. Know your limits. Slowing down and taking your time will help you avoid overexertion.

15. Plan your days. Allow adequate time to recharge and rest in your daily routine.

16. Delegate. Hire help for tasks you find particularly stressful or tiring, like mowing the lawn.

17. Eat healthy. A healthy, well-balanced diet can help boost energy and combat fatigue.

For more tips on managing anxiety or to order our free educational book, Mood: A Mind Guide to Parkinson’s Disease, call our Helpline at 1-800-4PD-INFO (1-800-473-4636).

We thank Elaine Book, M.S.W., and the Parkinson’s Foundation for allowing us to reprint this article.
OHSU Parkinson Center Research Studies

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 is involved in many studies that are fully recruited and others that are being planned.

The following research projects are currently looking for participants:

**Balance & Gait Studies**

*Healthy Volunteers Cortisol*  
**Parkinson’s Outcome Project Newly Diagnosed**

For more information, contact Alex Zajack at 503-418-4387 or at zajack@ohsu.edu

**Newly Diagnosed**

1. Have you been diagnosed with Parkinson’s disease (PD) in the last two years and have not started any dopaminergic medication for your symptoms?

**Purpose:** While there are many options for treating the symptoms of PD, there is currently no effective treatment for slowing the progression of PD. The purpose of this study is to see if a new drug is safe, and effective in slowing or halting the progression of PD in people who have been recently diagnosed. The study drug is not approved for treatment of PD because we don’t know enough about it. **Participation Requirements:** In order to participate in the study you must have been diagnosed with PD in the past two years, be between the ages of 40 and 80, are not taking any dopaminergic medication for your symptoms, and do not expect to begin taking medication for your symptoms for at least 52 weeks after your first study visit. You also must not have a genetic cause for your PD, or a history of freezing or falls related to your PD. There will be a total of approximately 34 study visits over 2 years. The study drug is an infusion given by injection into a vein in your arm once per month. Participants will be randomized (like the flip of a coin) to receive either the study drug or identical placebo for the entire length of the study. A placebo is a drug that looks like the study drug but has no real medicine in it. Neither the participant nor the study doctor can choose whether study drug or placebo is assigned. You have a 33% chance of getting the placebo. Eligible participants will receive study-related evaluations, laboratory tests, and the study drug at no cost. Participants and care partners will be reimbursed for their transportation and meals during study visits.

For more information please contact Bess Glickman at (503) 494-7245 or glickman@ohsu.edu. (eIRB #17161)

**Parkinson’s Outcome Project**

2. The National Parkinson Foundation has launched a Patient Registry at all NPF centers of excellence, which includes OHSU. The purpose of the Registry is to collect data on individuals with Parkinson’s disease (PD) to better understand the illness and the effects of various treatments. The ultimate goal is to improve the care of people who have PD. This study was started in 2009 and has been reopened for recruitment. Data will be gathered once a year at a follow-up visit in our clinic, and will consist of a 10-15 minute consultation and a questionnaire. For more information please contact Alex Zajack at (503) 418-4387 or zajack@ohsu.edu. (OHSU eIRB #5508)

**Balance & Gait Studies**

3. **EE FOR PD – Exercise and Education for Parkinson’s Disease** (healthy volunteers needed as well) is a study looking at the effect of exercise and education on Parkinsonism. The objective is to understand how exercise and education effect balance, gait and cognitive function in individuals with Parkinson’s disease and frontal gait disorder (vascular or lower body Parkinsonism). The program involves attending 6 weeks of exercise (90 minute classes, 3 days a week) and 6 weeks of educational classes (90-minute class, 1 day a week). There are also three test periods where balance, walking, cognition and brain imaging (MRI) are assessed. The lab is looking for individuals diagnosed with Parkinson’s disease or other types of Parkinsonism to take part in this study. Participants will receive $25 per testing session and $5 for each class attended. The lab is also seeking healthy individuals 50 years of age and older to volunteer as controls for this study. Participants will take part in a two-day study that involves tests of gait, balance, and cognition, as well as completion of an MRI of the brain. Individuals with Parkinson’s disease or frontal gait disorder who are unable to participate in the exercise and education classes can take part in the two-day study as well. Participants will receive $25 per testing session. Contact the OHSU Balance Disorders Laboratory at 503-418-2601 or balance@ohsu.edu.

Dr. Fay Horak, PhD, PT (OHSU IRB #e4131)

4. **Body-worn sensors to characterize and treat gait disturbances in Parkinson’s disease**

The purpose of this study is to learn more about gait problems, such as inability to initiate or continue walking (Freezing of Gait), in Parkinson’s Disease (PD), and to investigate the effect of vibration on the feet or
Dyskinesia

6. Evaluation of Buspirone and Amantadine for Dyskinesia in Parkinson’s disease

This research study looks at the effect and the safety of buspirone, in combination with amantadine on abnormal involuntary movements (dyskinesia) in Parkinson’s disease (PD). In order to take part in this study, participants must: have PD, take at least 200 mg of Amantadine a day, and started taking levodopa for 6 weeks with 4 of those weeks on study drug and require three (3) visits to the Portland VA. The first visit will last approximately 2–3 hours and involves general physical, neurological, and Parkinson’s disease specific examinations, and assessments of your abnormal movements. If you do not meet the criteria for abnormal movements in the study, you may not be randomized or receive study drug. All participants will take the study drug (buspirone) and the placebo. At the end of each treatment period, all participants will have another visit to assess the effect of the drug on their symptoms. This is a double-blinded study which means that you and the research staff will not know what study treatment you are taking at any point. You will not be compensated for participation in this study. 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, Research Coordinator at (503) 220-8262 extension 51871 or by mail at 3710 SW US Veterans Road, P3-PADRECC, Portland, Oregon 97239.

Cortisol in PD

7. Measuring Cortisol Levels in Persons with Parkinson’s (PD) [CORT-PD]

Dr. Amie Hiller is conducting a research study looking at cortisol levels in Parkinson’s disease (PD). Cortisol is a hormone that is normally released in response to events and circumstances such as waking up in the morning, exercising, and stress. We are recruiting both Parkinson’s disease patients and healthy controls. To be a healthy control, you must not have a neurological disorder. Both groups must be willing to give saliva samples. This study will last for approximately 1 week with three (3) days of saliva collection at home. There will be one visit to the Portland VA (VA Portland Health Care System). The visit will last approximately 30 minutes and include questionnaires of mood and quality of life. For PD participants, a Parkinson’s focused exam will be performed. You will not be compensated for participation in this study. 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, Research Coordinator at (503) 220-8262 extension 51871 or by mail at 3710 SW US Veterans Road, P3-PADRECC, Portland, Oregon 97239.

Huntington’s Disease

8. Irritability & Aggression In Huntington’s Disease

OHSU Neurology Department is currently looking for people with Huntington’s Disease (HD) exhibiting irritability and aggression for a research study conducted by the Network for Excellence in Neuroscience Clinical Trials (NeuroNEXT). Dr. Michael Brownstein (Azevan Pharmaceuticals) and Dr. Steven Hersch (Massachusetts General Hospital) are leading this national study. The National Institute of Neurological Disorders and Stroke (NINDS), a division of the National Institutes of Health (NIH) and Azevan Pharmaceuticals are supporting the trial. The purpose of the research study is to find out if SRX246 is a safe and effective drug for people with HD. The study will enroll 108 people with HD, exhibiting symptoms of irritability and aggression. Participants have a 2 out of 3 chance of receiving study drug, SRX246, and 1 out of 3 chance of receiving placebo. Participants must be at least 18 years old and have a diagnosis of Huntington’s Disease, symptoms of irritability and aggression, and a study partner who is willing to participate in the study. This study is actively enrolling participants. To learn more information, please visit http://www.neuronext.org or contact Kellie Keith at OHSU Department of Neurology by phone (503) 494-9531 or email keithk@ohsu.edu.
Parkinson Center Events Report

Options & Opportunities Annual Symposium
Three hundred and fifty people with Parkinson's disease and their family care partners attended our 33rd annual symposium. This year’s theme was Managing the Challenges of Advancing Parkinson’s Disease. We tackled the tough but necessary subject of cognitive changes, palliative (quality-of-life-focused) care and the importance of advanced planning in later-stage PD. If you’d like to view the presentations, they will be available on our education page at www.ohsubrain.com/pco. We thank our sponsors —Acadia and US World Meds — for their support as well.

The Great Salt Lick: Firsthand report!
I had the great pleasure of joining Whit Deschner and the fine people of Baker City (or Baker for the long-timers), Oregon, for the 11th annual Great Salt Lick auction and fundraiser. What a fantastically fun time everyone had up to the very last break-the-tie judging by an expert sheep artist (really, it was a sheep!). In the end, another $18,700 was raised for the OHSU Parkinson Center. With grateful hearts on behalf of the OHSU Parkinson Center, we thank you for your wonderful generosity.

My hat’s off to you all (cowboy/cowgirl hat, of course), Vivek Unni, M.D., Ph.D.
Save the date: Saturday, September 15, 2018

In the Parkinson’s Community

Parkinson’s Resources of Oregon (PRO)
Serving the PD community through education and advocacy. PRO has numerous ongoing educational events. Visit their websites at www.parkinsonsresources.org or www.pro.eventbrite.com for more information.

Can Diet Change Your PD?
Education Seminar
Medford, Ore.
Saturday, March 3, 2018
Contact PRO at 800-426-6806

Educate. Inspire. Empower. Parkinson’s Conference
Eugene Hilton
Sunday, April 15, 2018
Contact PRO at 800-426-6806

Celebrate Hope Gala & Auction Benefitting Parkinson’s Resources of Oregon
Friday, April 27, 2018
Multnomah Athletic Club
www.PROGALA.org
or 800-426-6806

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Calendar Items

Upcoming OHSU Events
Thursday, January 18, 2018 — Portland, Ore.
Essential Tools for Mid-Stage PD Series 2018
Key issues encountered by people with PD and their loved ones during the middle stages of the disease will be presented throughout the year in January, March, May, July and October 2018. More information and registration is available at www.ohsubrain.com/pco.

Thursday, February 15, 2018 — Portland, Ore.
Caregiver Connections
Program manager of the Beth Israel Deaconess Parkinson Center, Lissa Kapust, M.S.W., will be our keynote speaker for this caregiver-focused conference. A nationally recognized speaker on issues in PD, Lissa will present on how to know when it is time to make those difficult decisions. More information and registration will be available in January 2018 at www.ohsubrain.com/pco.

Saturday, September 22, 2018 — Portland, Ore.
OHSU Parkinson Center 34th Annual Symposium
Save the date! Next year’s symposium will focus on issues encountered during early-stage Parkinson’s disease. We look forward to seeing you there!

Brian Grant Foundation
Helping people with PD live active, fulfilling lives through wellness and community.

Shake It Till We Make It Gala
Friday, May 18, 2018, 6–10 p.m.
More information is available at: www.briangrant.org/gala

Power Through Project relaunched!
www.briangrant.org/register
The Power Through Project is a social network for the Parkinson’s exercise community. Users create a profile and track their workouts to earn fun badges — all while learning how specific types of movement can improve symptoms of PD. You can also make friends, contribute to research and find fitness classes in your area. Check it out!

The Veterans Administration Parkinson’s Disease Research, Education and Clinical Center (PADRECC)
Serving our veterans with PD though research, education and care.

Visit parkinsons.va.gov/northwest for more information on upcoming events and to watch the My Parkinson’s Story Videos online. This series of videos features real veterans telling their Parkinson’s stories with commentary provided by VA medical providers.

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