## Improving Patient Care through Research – 2015 Highlights

**Joseph Quinn, M.D.**

Due in large part to the generosity of our many supporters, the OHSU Parkinson Center had another productive year. As usual, the overall goal is the improvement of patient care, but that involves a “pipeline” of activities that we will try to illustrate here, starting with the culmination in patient care:

Here is how the pipeline worked in 2015 at the OHSU Parkinson Center.

### The Process Begins: Ideas

- **Full-scale clinical trials**
  - A small number of patients test a potential treatment to see if it is helpful in PD

- **Proof of concept trials**
  - A study of the potential disease-modifying effects of a drug which is already FDA-approved for other indications.
  - A study of the anti-dyskinesia effects of a second drug which is also FDA-approved for other conditions.
  - A study of antibody therapy aimed at removing the abnormal substance in the “Lewy bodies” in the brains of PD patients.

- **Animal models**
  - Animal models test potential treatments for safety and effectiveness in people

- **In vitro models**
  - In vitro research looks at how cells function in PD

- **Funded ideas**
  - The process starts with new ideas and funding to test them

### The Process Begins: Ideas

- Two additional neurologists, fellow-trained in Movement Disorders, were hired.
- The fellowship program was expanded to a record five active fellows (neurologists training to become movement disorders specialists).
- Deep Brain Stimulator surgery program expansion plan developed.
- New programs developed to empower newly diagnosed patients (Strive to Thrive) and patients with advanced PD (Next Steps Clinic).
- Efforts to better define “best practices” for treatment of PD were continued, in concert with the National Parkinson Foundation Outcomes Project for Centers of Excellence.

### The Process: Testing and Validation

- **Larger multi-center trials**
  - In 2015, physicians and scientists at OHSU designed and conducted “proof of concept” trials to:
    - test the effect of vitamin D on gait and balance problems in PD.
    - test the effect of a nutritional supplement for its ability to prevent dyskinesias.
    - test the ability of a non-dopamine neurotransmitter drug to improve gait and balance in PD.
    - use advanced MRI and sophisticated gait and balance testing to understand the effects of exercise in PD.
    - use “transcranial magnetic stimulation” to probe the effects of genetics on neurotransmitter levels and cognitive function in PD.
    - test the effects of a gene therapy trial, in concert with collaborators at UCSF.

### The Process: Preclinical Research

- Many of these clinical studies have their roots in “preclinical research” including animal studies:

  Scientists affiliated with the OHSU Parkinson Center used animal models to test:

  - the effect of a naturally-occurring food supplement for its ability to prevent dopamine brain cells from dying.
  - the effect of a cancer drug in preventing PD-associated “alpha-synuclein” from spreading throughout the brain.

### The Process: Preclinical Research

- Animal studies like these are derived from simpler model systems, which are studied in the laboratory.

  In 2015, the OHSU Parkinson Center:

  - hired a new scientist to study a PD-associated genetic mutation “LRRK2” in simple model systems including cell culture and fruit flies.
  - continued to probe dopamine pharmacology in “brain slice” preparations in an established scientist’s NIH-funded laboratory.

### The Process: Preclinical Research

- This pipeline begins with ideas, which often need some financial stimulus to grow into peer-reviewed science. In 2015, the OHSU Parkinson Center launched an annual “pilot grant” program.

  Six excellent proposals were received from junior faculty interested in careers in PD research. Two of the proposals were selected for funding and are now under way. This new program was entirely funded by a generous gift which will continue to support this critical program on an annual basis.

As you can see, our research program is going well, but so are our other two missions—clinical care and education. We have increased clinical capacity by adding two more full-time physician movement disorder specialists (see June 2015 edition). Our patient and caregiver education programs continue and are well attended. We’ve expanded current offerings of our popular Newly Diagnosed Education session and continue to develop new programs, such as Strive to Thrive (see pg 4). Our team also trains other medical professionals in PD care, including five fellows who are training to become movement disorder specialists.

In short, we are committed to improving the lives of people with PD and their families in every way we possibly can. We hope you will continue to help us in the coming year as we strive to grow our care, education, and research missions further to serve you.
Fatigue in Parkinson's Disease

Tyler A. Clark, M.D. – OHSU Movement Disorders Fellow

Fatigue is a major issue for approximately half of patients diagnosed with Parkinson's disease. Fatigue may either present as the initial symptom or may develop later in the course of the disease. It is also important to note that the severity and progression of fatigue is typically independent of the development of motor (movement) and other non-motor symptoms. Symptoms of fatigue, when experienced, may include a sensation of tiredness, lack of energy, or exhaustion; all of which are often unpredictable in onset and duration. Fatigue may be worsened by stress and has the potential to interfere with cognition (thought processes), motor function and the overall quality of life. Fatigue in Parkinson's disease may be either directly due to the disease itself or secondary to another clinical problem.

Inability to get a good full night's sleep, changes in mood, and even muscle stiffness can contribute significantly to the development of fatigue. These conditions may respond well to appropriate treatments that may subsequently lessen fatigue. It is also imperative for patients with Parkinson's disease to adopt a lifestyle that incorporates a balanced diet and activities that are physically and mentally stimulating. If a patient's medical regimen is optimized, the aforementioned conditions are treated and a healthy lifestyle is adopted, many patients may see significant improvement in the severity of their fatigue. At times, an occupational therapist may also be consulted for assistance with fatigue management.

One of the more common causes of fatigue in Parkinson's disease, as mentioned above, is the inability to get a good night's sleep. A common medical condition, which can cause interrupted or "fractured sleep," is obstructive sleep apnea. This condition responds well to treatment and, when treated, can significantly improve a patient's alertness during the day. Patients with Parkinson's disease may also have interrupted sleep due to a phenomenon known as "REM Behavior Disorder" (where patients act out their dreams) or motor symptoms inhibiting their ease of movement and ability find a comfortable position in bed. Both of these typically respond well to medical therapy.

Fatigue that is secondary to the Parkinson's disease itself is less well understood and treating it may be difficult. There are currently ongoing studies attempting to define the underlying mechanisms as to why patients develop this type of fatigue with the eventual goal of developing better treatment options. If all of the aforementioned interventions are attempted and fatigue is still bothersome, additional medical therapy with stimulant type medications may be tried.

Parkinson's disease is a multisystem disorder and may be accompanied by significant fatigue. It is important for patients to speak with their health care providers so that the appropriate diagnostic and therapeutic interventions may be implemented.

Meet the Future of PD Care: Tyler Clark, M.D.

Dr. Clark was born and raised in a small town in southern New Hampshire. After attending college in Chicago, IL, he worked for a year leading urban exposure trips for a small non-profit and coached an electric wheelchair soccer team. In 2011, he completed his medical training at Loyola University in Maywood, IL and subsequently came to Oregon to pursue his neurology residency. Drawing from both his personal experiences with Parkinson’s disease, as well as his interest in continuing to treat patients with movement disorders, he has decided to pursue a fellowship in Movement Disorders through the Portland VA Medical Center and OHSU.

The Gut-Brain Connection in Parkinson's Disease

Mara Seier, M.D. – OHSU Movement Disorders Fellow

There is growing evidence in the scientific literature that Parkinson's disease actually may begin in the digestive tract and not the brain. Pathological studies performed on brains of people with Parkinson’s disease show abnormal clumps of protein called Lewy bodies are found in the gut. The walls of the digestive tract are controlled by the vagus nerve which is an important nerve that connects the brain to the gut. Furthermore, there are animal studies indicating that Lewy bodies are found in the brains of people with Parkinson’s disease also are found in the nerve cells of the gastrointestinal tract.

Non-motor symptoms, such as constipation, occur frequently in patients with Parkinson's disease and can develop up to 20 years before the motor symptoms. Scientists have known for many years that the gut is controlled by the nervous system and neurons can be found in the layer of tissues lining the esophagus, stomach, small intestine and colon. Researchers have discovered recently that the same Lewy bodies that are found in the brains of people with Parkinson's disease also are found in the nerve cells of the gastrointestinal tract.

Furthermore, there are animal studies indicating that the bits of protein that ultimately develop in Lewy bodies can travel from the digestive tract up to the brain via the vagus nerve. The vagus nerve is an important nerve that connects the brain to many of the autonomic functions of the body, which are functions that occur automatically, without conscious control, such as digestion. A recent human population study looking at Danish people who underwent vagal nerve resection (a surgical treatment performed in the past for peptic ulcers) revealed a decreased risk of developing Parkinson's disease over time in persons who had undergone this procedure compared with those who did not have vagal nerve resection. There was another group of patients in the study who only had partial resection (the vagus nerve was not completely cut) and those patients had a similar risk of developing Parkinson's disease compared with the general population. This would suggest that in those persons the gut-brain connection via the vagus nerve was still intact and the disease was still able to "spread" from the neurons in the gut up to the brain.

Although more research is needed to figure out what exactly this means for Parkinson's disease treatment, this study did suggest that patients who lack the normal gut-brain link had a decreased risk of developing Parkinson's disease, even though some people who underwent vagal nerve resection still did go on to develop Parkinson's disease. It is possible that in these patients, the pathologic process already had spread from their gut to the brain by the time they had the vagal nerve surgery. Whether Parkinson's disease starts in the digestive tract and travels to the brain over time via the vagus nerve remains uncertain, but current research seems to suggest there is an association.

The connection between the gut and the brain undoubtedly will continue to be an area of interest and study in the future.

Meet the Future of PD Care: Mara Seier, M.D.

Dr. Seier joins the Parkinson's/movement disorder group this year as a fellow after completing her general neurology residency also at OHSU. She grew up in South Dakota and received her medical degree from the University of South Dakota. She is excited to be starting her fellowship in order to learn how to better take care of patients with Parkinson's disease as she believes OHSU is one of the best places do learn. She is truly passionate about taking care of people with chronic medical conditions. In her spare time she enjoys playing with her new baby boy as well as running and playing/watching sports with her husband.

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Ultrasound Treatment for Parkinson's Disease Under Investigation

Marion Dale, M.D.

Research scientists are investigating the use of MRI-guided focused ultrasound ("MRgFUS") to treat Parkinson's disease. Unlike standard ultrasound technology that sends sound waves from a single transducer and is unable to accurately target areas deep in the brain, the new technology uses a special ultrasound probe with over 1,000 transducers spread across the head of the probe. This new technology can be used to accurately penetrate the skull and target deep brain structures that contribute to tremor and other Parkinson's disease symptoms. After finding the right spot in the brain, the ultrasound is used to slowly increase the temperature at the site to create permanent brain lesions for control of tremor and other Parkinson's disease symptoms. MRgFUS surgery occurs with a patient awake in an MRI scanner, and the surgeons use MRI images captured in real time to accurately focus the ultrasound beam. A special cooling helmet prevents overheating of the skull and other brain structures.

Benefits of MRI-guided focused ultrasound include minimal invasiveness (no cutting into the skull), and the lack of need for general anesthesia for the patient. There is also no internal hardware required, minimizing the risk of damage or infection. The ultrasound technology does not carry the risks of ionizing radiation. However, the lesions created by this procedure are permanent, unlike in deep brain stimulation therapy, and are not adjustable through programming in clinic. The lesions can be surgically expanded at a later time if needed.

A major clinical trial of MRgFUS at the University of Virginia and Swedish Medical Center in Seattle, WA has focused on tremor in Parkinson's disease. The project's enrollment is expected to be completed in winter 2015. The University of Virginia, the University of Maryland, and universities in Toronto, Canada and Seoul, South Korea are also studying MRgFUS for dyskinesia in Parkinson's disease, targeting a brain structure called the globus pallidus. The technology is not yet available for general clinical use. Additional information about clinical trials for ultrasound therapies in Parkinson's disease can be found at www.clinicaltrials.gov and www.fusfoundation.org.

New Imaging Biomarker for Parkinson's Disease

Matthew Brodsky, M.D.

Greetings Pacific Northwest PD Community,

I'm excited to give an update on a promising new noninvasive technique to identify people who have Parkinson's disease, with the hopes that we may be able to harness this diagnostic tool to identify people in the "premotor stage" of PD, test out promising neuroprotective interventions at a stage when they may be most effective, which would in turn inform us about the efficacy of such interventions for people who are already at the "motor stage" of PD. This technique uses magnetic resonance imaging (MRI), with a stronger magnet than is used in most conventional MRIs. The magnetic strength that an MRI generates is measured in Tesla, and most conventional MRIs have a 0.5 to 3.0 Tesla strength. OHSU's Advanced Imaging Research Center houses a 7 Tesla (7T) MRI, which produces much higher resolution images than conventional MRIs.

Our MRI protocol has allowed us to reliably visualize a very small region of the brain called "Nigrosome 1," which is a lens-shaped (just under half the width of a contact lens) cluster of approximately 22,000 dopamine neurons that degenerate to the greatest degree and earliest in PD. This image depicts this structure in someone without PD (on the left, yellow arrows), and the absence of this structure in someone the same age with PD (on the right): 7T MRIs have been in use for research for many years and are generally accepted as very safe. Unlike CAT scans that use ionizing radiation, MRI uses harmless radio waves. Unlike the DATScan, which requires intravenous administration of a radioisotope, takes several hours to complete, has very poor resolution, and in clinical (and research) practice costs approximately $8000, our MRI protocol requires no IV, takes less than an hour, has a resolution of 0.3x0.3x0.8 millimeters, and a research cost of approximately $600. The main contraindications for having an MRI include having certain implanted devices such as a pacemaker or cochlear implant, or other specific metallic implants or metal fragments in your body. Significant claustrophobia is another important consideration given that the MRI requires being in a tube for up to an hour.

Our current research study is recruiting volunteers who are within a year of having developed their initial motor symptoms of PD. We are also looking for volunteers who do not have PD to serve as "healthy controls." The third group of volunteers we seek are those who have a sleep disorder called "REM Sleep Behavior Disorder," a condition where affected individuals routinely act out their dreams during sleep. Such individuals are at significantly increased risk of developing PD within their lifetime. Our plan is to both validate this technique as an imaging diagnostic marker for PD, as well as to explore how the nigrosome 1 signal changes over time in people both with and without PD to assess its utility as a biomarker of disease progression. We are hopeful that this important step may ultimately play a role in finding a cure for PD.

If you are interested in this study, please contact: Kellie Kenis at 503 494-9531.

Ask the Experts

I was once told that pain is not a part of Parkinson's disease. Is that true?

Keiran Tuck, M.B.B.S. – OHSU Movement Disorders Fellow

Pain is a common symptom in people with Parkinson's Disease (PD) and people with PD are more likely to have pain than those without PD. It is unclear what causes this increase of painful symptoms, however. But there are several theories including loss of dopamine or other neurotransmitters (natural chemicals) in the brain, alterations of nerves in the skin, or the general muscle stiffness and reduced movement caused by PD.

Pain in PD is commonly divided into five categories:

- musculoskeletal (inflammation of muscles, tendons, ligaments and bones as in arthritis)
- dystonic (an abnormal pulling or twisting of muscles)
- central (related to changes in the brain)
- akathitic (a restless or uncomfortable feeling)
- radicular/neuropathic (caused by damage to nerves in the back or limbs)

Due to the lack of understanding of the mechanisms of pain in PD there are no guidelines for the optimal way to treat it; however, there are many treatments that can be considered including physical therapy, optimizing PD medications, and using analgesics (medications that treat pain). Treatment is individualized based on the type and location of the pain. If you suffer from pain, please talk to your neurologist about how they can help.

OHSU is looking into ways to learn more about pain in PD. If you are interested in learning more about research opportunities in this area, please contact Rhonda Mulhy at 503 494-7245.

Introduction to our team

Know Your Team: Meet Jenn Brownstein

We'd like to introduce you to the OHSU Parkinson Center's Administrative Assistant, Dr. Quinn’s Executive Assistant, and our Education Coordinator (she's an over achiever), Jennifer "Jenn" Brownstein. Jenn started working at OHSU in the Neurology Clinic in the fall of 2012. We unashamedly stole her last December and have patted ourselves on the back ever since! She brings 12 years of event planning experience (she helped us organize the “Paws for Parkinson’s” fundraiser) and is thrilled to be part of a team that is focused on improving patients’ quality of life. In her spare time, Jenn can be found working in local community theater, dancing salsa or tango, cycling, cooking, traveling, or hanging out with her adorable nephew. She is most looking forward to getting married in Belize this spring.
The OHSU Parkinson Center is a national leader in 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 are being planned. For more information, contact our research office at 503 418-4387.

The following research studies are currently looking for participants:

**MIDDLE OR LATE STAGE PARKINSON’S DISEASE (ON PD MEDICATIONS)**

A Randomized, Double-Blind, Placebo-Controlled, Multiple Ascending Dose Study of PRX002

Administered by Intravenous Infusion in Patients with Parkinson’s Disease

Study PRX002-CL002 is a multicenter study of PRX002, novel therapeutic agent intended for the treatment of Parkinson’s disease. Participants in this study will be randomized to study drug or placebo, as well as to a dose group (1-5). The study is divided into an 8 week screening period, a 16 week single-blind drug administration period, and a 16 week follow-up period. In total you will have about 15 visits to OHSU. During your visits you may be asked to answer questions about thinking and memory, medical history, and have physical and neurological examinations. You will also be asked to provide biological samples including blood, urine, and cerebrospinal fluid. During the screening period, a MRI is done to produce a full image of your brain. Some participants, depending on the diagnosis group to which they are assigned and whether you have been previously treated for your Parkinson’s disease, will be asked to complete a DAlscan, which is an examination of the brain that measures the amount of cells in the brain that produce dopamine. During the study drug administration period, participants will receive three 1-hour infusions of the study drug PRX002 and will be monitored closely for about 4 hours following each infusion. Participants will be asked to complete a lumbar puncture before the initial baseline infusion and another one week after the final infusion. Each participant will be compensated $50 per infusion completed and $100 per lumbar puncture completed for a total of $350. 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 Rhonda Muhly at 503 494-7245 or at muhly@ohsu.edu. (OHSU IRB #10089)

Topiramate as an adjunct to amantadine in the treatment of dyskinesia in Parkinson’s disease

The purpose of this research study is to measure the effect of amantadine and Topiramate on dyskinesia in Parkinson’s disease (PD). Dyskinesias are involuntary abnormal movements caused by the drug Sinemet. In order to take part in the study, participants must: (1) be between 30 and 90 years old, (2) have Parkinson’s disease, (3) have mild to severe dyskinesia, and (4) also be taking at least 200 mg of Amantadine per day. There are seven in-person visits to the VA Portland Health Care System and six phone call visits for this study. This is a drug study. You have a 50/50 chance of receiving the study drug (Topiramate) or the placebo (sugar pill). You will be taking the study medications along with your current Parkinson’s medications for a total of 14 weeks. The total length of this study is 18 weeks. This is a research study and not part of treatment or diagnosis of Parkinson’s disease. You will not benefit by participating in this study but you may learn more about your disease and the medications used to treat your disease. There is no compensation for this study. Dr. Kathryn Chung is the clinical investigator responsible for this study and Susan O’Connor is the study coordinator. If you are interested in participating, please call Susan O’Connor at 503 220-8262 in OHSU IRB #3291.

**BALANCE & GAIT STUDIES**

Do you have Parkinson’s disease (PD) and experience problems with balance and gait?

Purpose:

There is an important medical need for an effective, well-tolerated treatment for improving gait and balance for people with Parkinson’s disease. Gait and balance problems in Parkinson’s disease typically appear within 3 years of diagnosis and progress throughout the course of the disease. Impaired mobility produces disability and reduces quality of life. The purpose of this study is to see if the drug donepezil (commercially known as Aricept) may help improve measures of gait and balance in those experiencing Parkinson’s disease. Right now the study drug donepezil is approved for treatment of Alzheimer’s disease and dementia related memory loss, but has not been approved for treatment of balance and gait problems in Parkinson’s disease.

Participation Requirements:

In order to participate in the study you must be at least 30 years old, have been diagnosed with idiopathic Parkinson’s disease and experienced problems with balance and gait. Additionally, you will need to be able to walk unassisted for at least 2 minutes. This is a double-blind study (meaning that neither you nor the study personnel will know whether you are taking the donepezil or placebo (dummy sugar pill)). Participation in the study will last 7 weeks and will require you to attend four in-person visits along with weekly phone visits. Eligible participants will receive study-related evaluations, laboratory tests, and the investigational drug at no cost. Subjets will be compensated for their time and transportation costs. For more information please contact Anne Gendreau at 503 346-4387 or gendreau@ohsu.edu. (OHSU IRB #10745)

**EE FOR PD – Exercise and Education for Parkinson’s Disease**

Is a research study on the effects of exercise and education for people with Parkinson’s disease. The objective is to investigate effects of exercise and education on posture/gait and cognitive function in people with idiopathic Parkinson’s disease or Frontal Gait Disorder (aka vascular or lower-body parkinsonism). It involves attending 6 weeks of exercise (90 minutes, 3 days a week) and 6 weeks of educational (90 minutes, 1 day a week) classes. There are pre-, post- and mid-point testing of your cognition, balance/walking and MRI brain imaging. We are looking for people with a diagnosis of idiopathic Parkinson’s disease or other types of Parkinsonism with balance or walking problems. The next intervention will be held in Vancouver, Washington, starting in January and ending in April of 2016. Subjects will be enrolled 25 per test session and cost $5 per each class attended. Healthy control subjects are also needed for the study, but only for a two-day baseline assessment (balance/walking and MRI brain imaging). For more information contact: Michael Fleming, 503 346-8042, flemimic@ohsu.edu. (balance/walking and MRI brain imaging). DO YOU SHUFFLE WHEN YOU WALK? Understanding Gait and Cognition in Vascular Parkinsonism. What Are The Objectives? To understand if cognitive problems (for example, difficulty in planning and performing complex tasks) are related to the walking changes in people with vascular risk factors, and to increase understanding of the brain pathways associated with how we can Enroll? People with slow and shuffling gait not caused by Parkinson's disease itself. If you are not sure if you are eligible please inquire! What Is Involved? Tests of balance, gait and thinking ability. MRI, 2-3 hour sessions. Will I Be Compensated? Yes. You will receive $250 per test session and $5 for each class attended. For more information contact: Sam Jewell, BA, Study Coordinator at 503 418-2600 or balance@ohsu.edu. (balance/walking and MRI brain imaging). THINKING AND MEMORY WITH PARKINSON’S DISEASE

Pacific Northwest UDALL Center (PANUC): Clinical Core and Sample Collection

Dr. Joseph Quinn is conducting this research study to examine changes in thinking and memory of Parkinson’s disease patients. The 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 and be 18-75 to participate in this study. This study involves at least two visits to the VA Portland Healthcare System. 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 have the option to undergo a lumbar puncture. A lumbar puncture is known as a spinal tap. A spinal tap is where a special needle is inserted into your back in your fluid is removed. The spinal tap will be taken about 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. In between visits at the VAPORCHS you will have a telephone interview with questions regarding your thinking and memory. These interviews will last about 30 minutes. 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 Sam Jewell, BA, Study Coordinator at 503 220-8262 x54688 or by mail to 3710 SW US Veterans Road, Portland, Oregon 97239. (VA IRB # 3232; OHSU IRB # 6154)

**Strive to Thrive Classes Coming in 2016**

Self-efficacy is the ability of a person to make positive changes in behavior to achieve beneficial health outcomes. Based upon the Chronic Disease Self-Management Program (CDSMP) developed at Stanford University, Strive to Thrive classes combine the proven strategies of the CDSMP with the synergy of learning with people managing the same diagnosis of Parkinson’s disease. This course was developed through a partnership of the OHSU Parkinson Center and the Parkinson’s Resources of Oregon. Led by specially trained people with Parkinson’s disease or their caregivers, there will be two or more classes, starting January 2016. If you are interested in participating, please contact the Parkinson’s Resources of Oregon at 503 594-0901 or visit the registration site at www.pro.eventbrite.com.
EVENT REPORTS

OHSU Parkinson Center: Working for YOU!

Engage & Activate: Self-Empowerment for Change

The 32nd Annual OHSU Parkinson Center symposium, Engage & Activate (formerly known as Options & Opportunities) saw another successful year of 500 participants and a wonderful day of art and learning.

This year’s theme, Self Empowerment for Change, focused on what people with PD and their families can do in their daily lives to better manage the disease and maintain function. Our keynote speaker, Diane Cook, spoke from deep experience about how Parkinson’s patients can use self-efficacy (influence conditions that affect life) to better manage their disease and improve quality of life. Diane has had PD herself for seven years and is actively involved in research and advocacy. Dr. Quinn, the OHSU Parkinson Center Medical Director, gave an amazingly understandable review of current research and how you can participate or contribute. Whit Deschner, creator of the Salt Lick City Fundraiser (see OPB Art Beat highlight at www.opb.org), author, humorist, and person with PD, had everyone laughing with his quick wit and uniquely creative and funny videos. Yoga instructor, Anya Gordon, and VA physical therapist, Ron Blehm, showed how to integrate exercise into daily activities and achieve even more benefit than just going to the gym twice a week. Finally, Dr. Keiran Tuck spoke to the importance of palliation (to ease symptoms and promote quality of life) throughout all stages of PD by planning and utilizing a team of experts in various fields to help you manage PD.

While the speakers were great, the highlight of the day was our PD artists and hobbyists displaying their amazing talents. An inspiration for all! Thank you:


One of our humots, John Kerrigan, with the help of an anonymous donor, created a special 2016 calendar that raised over $1,000 for the OHSU Parkinson Center. Thank you, John!

If you weren’t able to attend, we will be posting a videos of all the presentations on our website at: www.ohsubrain.com/pco under Education & Resources tab. Thank you to our sponsors:

Abbbie, Teva, Lundbeck, Medtronic, National Parkinson Foundation, and the VA Parkinson Research, Education, and Care Center (PADRECC).

NEXT YEAR: We will take a break so EVERYONE can take advantage of a once in a life time opportunity to attend the WORLD PARKINSON CONGRESS in Portland. September 20-23, 2016 — SAVE-THE-DATE!!

Hoof-Arted: The Great Salt Lick City Auction does it again!

Thank you Whit Deschner and Baker City! On Sept 19th the Great Salt Lick City Auction rode the wild range again and brought art enthusiasts together to good-heartedly bid on salt licks, painstakingly fashioned one lick at a time by a variety of livestock “artists.” In its ninth year, Whit and friends raised almost $15,000 and have contributed to date over $75,000 to advance OHSU Parkinson Center research and care initiatives. If you missed the fun this year, you can start planning for next year: Saturday, Sept 17, 2016 and visit OPB’s Oregon Art Beat (www.opb.org) to see a video of the fun that can be had in the great outback of Baker City.

Rock Steady Boxing Comes to Oregon:

Rock Steady Boxing (RSB) is a first of its kind. Though it may seem surprising, this non-contact boxing inspired fitness class is dramatically improving the ability of people with Parkinson’s to live independent lives.

RSB was founded in 2006 by former Indiana county prosecutor, Scott Newman, who was diagnosed with PD at age 39. He believes boxing training changed the course of his disease. Years into his disease, he is better than when he was first diagnosed. Kimberly Berg, M.S., is a clinical exercise physiologist/ certified Rock Steady Coach, who owns and runs Oregon’s only Rock Steady Boxing program.

RSB enables people with PD to fight their disease by providing non-contact boxing style fitness programs that improve their quality of life and sense of efficacy and self-worth. Studies suggest the right intense exercise program may be neuro-protective and actually delay progression of symptoms. RSB classes have proven that anyone, at any age, at any stage of PD can lessen their symptoms and lead a healthier life.

It’s more than a class; it’s a community that attacks PD at its vulnerable neurological points. While focusing on overall cardiovascular fitness, strength, reaction time, and balance, the workouts include a circuit of focus mitts, heavy bags, jump ropes, TRX, hurdle stepping, speed bags and slide boards, while also incorporating voice and cognitive drills. Most of all it’s fun!!

Kimberly, along with Greg Thompson, a professional boxing coach, provide encouragement through a ‘tough love’ approach, inspiring maximum effort, speed, strength and balance and flexibility. Boxing works by moving in all planes of motion while continuously changing the routine as you progress through the workout.

No boxing experience necessary. Boxers are male and female of all ages.

Four things Kimberly and Greg promise:

• Research-based intense workouts geared specifically for PD
• Friendship and camaraderie for fighters and care partners
• Fun atmosphere with great music
• They offer HOPE

To learn more about the benefits of Rock Steady Boxing for Parkinson’s go to www.rocksteadyboxing.org.

For more information about Oregon’s RSB classes, contact Kimberly Berg at kimberly@kimberlyberg.net or 503 407-1335 or visit her website at kimblyberg.net.

Classes are offered:

Mondays and Wednesdays
10:30-11:30 am
Next Level Martial Arts and Fitness
14865 SW 74th Ave. #110
Tigard, OR 97224
A second RSB and more levels will soon be offered in Portland.
The 4th World Parkinson Congress is a unique international event designed to bring together the full spectrum of people who live with Parkinson’s disease and those who serve the Parkinson community. We hope this cross-pollination helps in finding a cure as well as identifying the best treatment practices for people living with Parkinson’s.

www.WPC2016.org
The official language of the WPC 2016 is English.

September 20 – 23, 2016
Oregon Convention Center

60 years old or younger with PD?
Then join us for:

Insights & Inspirations: Young People with Parkinson’s Disease Conference
Saturday, March 5, 2016
9:30 am – 4:00 pm, Portland, Oregon

Join us for a day focused on issues encountered by younger people with PD. We will have experts presenting on how to meet the challenges of Parkinson’s disease while

• staying healthy
• working
• disability consideration
• maintaining relationships

Watch your mailbox or email for more information in January.
Registration will open in January 2016 and will be $25 per person.
www.ohsubrain.com/pco

PORTLAND COUNTDOWN
to World Parkinson Congress

In preparation for the 4th World Parkinson Congress (WPC) in Portland in 2016, two highly experienced journalists (who are also living with Parkinson’s) survey the landscape of Parkinson’s disease research and treatment by interviewing neuroscientists, neurologists, and people with Parkinson’s (PwP).

• Available Dec 1, 2015 — Parkinson’s Plus Conditions
  (Special Guest: Lawrence I. Golbe, M.D.)
• Available Jan 5, 2016 — Genetics and PD
  (Special Guest: Christine Klein, M.D.)
• Available Feb 2, 2016 — L-dopa...waiting for the next act
  (Special Guest: Angela Cenci Nilsson, M.D., Ph.D.)

And more to come, available the first Tuesday of every month until the WPC 2016 in Portland, September 2016! Visit the World Parkinson Congress website at www.wpc2016.org for full details and links.

More OHSU Parkinson Center Events

Researching a cure, better treatments, and offering cutting edge medical management for people with PD.

EVERY MONTH AT THE CENTER

NEWLY DIAGNOSED WITH PD?

Each month the OHSU Parkinson Center offers a three hour session for people recently diagnosed with PD and their spouse or family member. Participants may ask any and all questions of a PD specialist and long-time patient and caregiver.

$20/person; refreshments served.
Register online at www.ohsubrain.com/pco or call 503 494-9054 with questions.

PRO Gala
Friday, April 29, 2016 – There’s No Place Like PRO
5:30 – 9 p.m., The Sentinel Hotel
Portland Oregon

The Celebrate Hope gala and auction fundraiser to support local programs and services offered by PRO. Tickets will be available for $150 in January at www.progala.org. Sponsorships and tables available now – contact lauren@parkinsonresources.org

CALENDAR ITEMS

(PARKinson’s Disease Research, Education and Clinical Center)
(PARKinson’s Disease Research, Education and Clinical Center)

Serving our veterans with PD through research, education, and care.
Visit www.parkinsons.va.gov/northwest for more information on upcoming events and to see:

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.

Brian Grant Foundation
Helping people with PD live active fulfilling lives through wellness and community.
For more information about the Brian Grant Wellness Retreats and Powering Forward Boot Camp visit their website, www.briangrant.org.