OHSU Parkinson Center of Oregon

Insights & Inspiration
59 years old or younger? REGISTER ONLINE NOW!
Join us for a symposium designed just for you and the unique challenges you and your family faces when living with young-onset Parkinson’s disease.

The program features a mix of both medical experts and peers living with young-onset PD daily.

Special Guest:
Brian Gaitt, former Trail Blazer and young person with PD

Keynote:
A Hopeful Vision For Your Future
Matt Brooks, MD, PD Specialist

Prevention of Mobility Constraints: A Tailor Made Exercise Program & Demo

Workshops (choose one)
> Maintaining Intimacy and Emotional Connection
> Parenting with Parkinson’s disease
> Everything You Wanted to Know about Social Security Disability

For more information, please contact Allison Lipnick at lipnick@ohsu.edu or 503-418-1661.

PAWS for A CAUSE
A Benefit for Parkinson’s Disease

WHO LET THE DOGS OUT?!?

They are all in again. Our furry friends had such a fantastic time this year, they are already planning for next year’s howl. So blast their head (aren’t they usually leading us on a walk anywa...”,

What: PAWS - Community Dog Walk & Fair for PD
When: Saturday, July 12, 2013 9 - noon

Participation raises awareness among the growing public (everyone) about Parkinson’s Disease (PD), as well as helping funds to support care and research initiatives to help people throughout the Northwest living with PD.

START THE FUN NOW: www.firstgiving.com/pcoc

Are you a spouse of someone with Parkinson’s disease?

The OHSU Parkinson Center of Oregon is offering a unique and innovative program specifically designed for family caregivers of people with PD called:

THE MINDSET OF HEALTHY CAREGIVING

This eight-week course is designed for 6-8 caregivers of people living with PD. Participants will meet once a week to learn and apply specific, evidence-based skills for use in PD caregiving. The Mindset of Healthy Caregiving is co-facilitated by Julie Carter, ARP and Allison Lipnick, MSW.

Penny Hogarth, M.D.
Diana Potts, B.S., M.P.A.
Julie Carter, A.N.P.

Associate Director
Medical Director
Employer
OHSU is an Equal Opportunity
Portland, OR 97239-3098
3181 Sam Jackson Park Road
Department of Neurology
Oregon Health & Science University
Center of Excellence

PAWS for A CAUSE
NPF Parkinson Center of Oregon

NEW WEBSITE ADDRESS:
www.ohsубrain.com/pcoc

What’s Inside

- Cover Story: Partnering with You (continued inside)
- New OHSU PCO team members enhance care and research
- Round 1: Sleep Fighting
- NPF Hospitalization Kit
- Support Group Benefits
- Jail Break: A Family Caregiver Adventure
- Exercise Update
- MyChart: Staying in Touch
- Exercise Update
- New OHSU PCO team members enhance care and research
- Round 1: Sleep Fighting
- NPF Hospitalization Kit
- Support Group Benefits
- Jail Break: A Family Caregiver Adventure
- Exercise Update
- MyChart: Staying in Touch
- Exercise Update
- New OHSU PCO team members enhance care and research
- Round 1: Sleep Fighting
- NPF Hospitalization Kit
- Support Group Benefits
- Jail Break: A Family Caregiver Adventure
- Exercise Update
- MyChart: Staying in Touch
- Exercise Update
- Options and Opportunities: The 28th annual symposium for patients and families, attended by 500 people, provided updates on treatment and research (see story on page 5).
- Caregiver Connection: A special evening of support and sharing for PD caregivers.
- Newly diagnosed workshops: Very popular small group sessions for the newly diagnosed to ask questions and receive hope. Demand was high, so ten were added this year held with 97 participants.
- Bi-annual print newsletter distributed to over 6,500 each edition and e-newsletters distributed 4-5 times per year with 1,200 each edition.
- TEAM-PD: The OHSU PCO is committed to training health care teams around the Northwest to better care for PD. 2011 brought hands-on training for a capacity audience of over 90 physical therapists from OR, WA, and ID in the use of BESTest, the latest tool in fitness testing for PD.
- Basal Gangia Cateion: OHSU PCO hosted 45 movement disorder specialists from throughout the Northwest to share their research and learn from each other.
- The OHSU PCO was chosen as one of six sites in the country to train nurse faculty members for PD who will then train nursing students in state of the art care of PD.

Thank you: All of these activities were funded in part by your generous donations.

QUALITY CARE 2011

- Our interdisciplinary team is growing with the addition of Allison Lipnick, MSW, Family Care Specialist (see page 2). Our commitment to patient and family centered care continues.

Hope FROM THE Hill

December Issue | 2011
New Family Care Specialist

Allison is an experienced clinical social worker from Houston, Texas, who recently relocated to Portland. She is absolutely thrilled to be living in low humidity and is already enjoying the beautiful landscape of Oregon! Allonsy comes to us from the MS Center at UH (University of Houston), where she worked in a similar position helping patients and families deal with Multiple Sclerosis.

Here at the OHSU Parkinson Center, Allison will be able to pursue her passion for serving people with chronic illnesses and their families by finding their resources and supporting them within their community. Allison is also excited to help develop and teach programs that promote family caregiver skills in coping with the challenges involved in living with Parkinson’s disease. Allison says, “My goal is to partner with families dealing with Parkinson’s disease and help them improve their quality of life in any way I can.”

Allison has a husband, Cristian, a son, Jett, who is two and a half, and a dog, Colonel, Elena, all of whom keep her quite busy in her off time.

We are excited to have Allison as a part of the OHSU Parkinson Center team ready to serve you.

Research 2011

Our program remains committed to transcending science into selected care. Highlighted selections for 2011:

• The addition of Dr. Vivek Unni (see below article) has allowed research to better understand the true potential of the protein alpha-synuclein, which is linked to the cause of PD.
• The impact of exercise, enriched environments and socialization on the PD brain using an animal model.
• Insight into the mechanisms of dyskinesia and improved ways to record and treat this condition.
• Ways to delay or modify the progression of PD through exercise and drugs.
• Understanding and treatment of fatigue. An active gait and balance lab has produced a number of studies to better understand underlying brain mechanisms and how to measure and treat gait and balance problems. Collaborative interdisciplinary efforts to produce evidence for what constitutes the best care for PD.
• The study of biological markers that predict the onset and progression of PD.
• The study of grief in response to loss in family caregivers.

The impact of two new drugs and vitamin D to treat the symptoms of PD.

Thank you!

Clinical research is not possible without volunteers to participate in studies. We are committed to your future. Please help us make 2012 another year of shared success.

With Gratitude,

Jay Nutt, MD
Director

Julie Carter, ANP
Associate Director

New Family Care Specialist

Allison is an experienced clinical social worker from Houston, Texas, who recently relocated to Portland. She is absolutely thrilled to be living in low humidity and is already enjoying the beautiful landscape of Oregon! Allonsy comes to us from the MS Center at UH (University of Houston), where she worked in a similar position helping patients and families deal with Multiple Sclerosis.

Here at the OHSU Parkinson Center, Allison will be able to pursue her passion for serving people with chronic illnesses and their families by finding their resources and supporting them within their community. Allison is also excited to help develop and teach programs that promote family caregiver skills in coping with the challenges involved in living with Parkinson’s disease. Allison says, “My goal is to partner with families dealing with Parkinson’s disease and help them improve their quality of life in any way I can.”

Allison has a husband, Cristian, a son, Jett, who is two and a half, and a dog, Colonel, Elena, all of whom keep her quite busy in her off time.

We are excited to have Allison as a part of the OHSU Parkinson Center team ready to serve you.
Pedaling Hard and Parkinson’s Disease
Andrea Serdar P.T. NCS
OHSU Outpatient Rehabilitation Services

To the surprise of Dr. Jay Alberts of the nervous system, a tandem bicycle ride with a friend to raise awareness of PD resulted in a marked reduction in the PD motor symptoms that his friend experienced. This discovery launched a series of trials in which people with PD rode tandem bikes at a “forced” rate. Riders matched a pre-established pedaling rate of 80 to 90 rotations per minute. They pedaled for an hour three times a week for eight weeks. The trials resulted in a 35% improvement in motor symptoms which persisted for four weeks after the cycling ended.

“Forced” exercise is defined as a longer and harder workload than a person could sustain voluntarily. The tandem bike study and others using treadmills point to findings that PD patients may be experiencing greater improvements when compared to “voluntary” exercise when a workload is harder than a person could sustain voluntarily. “Forced” exercise as defined here is a longer and harder workload than a person could sustain voluntarily.

Forced exercise studies in PD with use of treadmills or tandem bikes are providing clues to the effectiveness of high intensity exercise on the brain. Animal studies have shown more favorable effects on the brain with forced versus voluntary exercise. Intense exercise is also associated with a decrease in expression of developing Parkinson’s disease. Interestingly, functional MRI’s conducted during forced use trials revealed the areas of the brain that were activated with exercise are the same areas activated with PD medications or deep brain stimulation.

Dr. Alberts in cooperation with YMCa’s nationally has developed “Pedal for Parkinson’s.” This program will offer tandem bike riding to people with PD. To learn more about the tandem bike program go to www.pedalingforparkinsons.org.

For more information on “forced versus voluntary” exercise training, contact Andrea Serdar P.T. NCS at 503-494-6991.

New Male Caregiver Support Group
1st Friday of the Month at 10:30 am
Chuck Niggley, Volunteer-Facilitator
For more information, contact Anna at Parkinson’s Resources of Oregon.

The Power of Support Groups
Anna Reed Sanger, Education & Outreach Coordinator
Parkinson’s Resources of Oregon

A support group is a gathering of people who talk about their experiences, share information and resources, and work together to discuss strategies for coping. We’re fortunate to have a local network of support groups in Oregon and Washington that provide this important opportunity across many cities and neighborhoods. Some groups are meant for specialty interests including your personal care provider or therapists only, alternative and complementary therapies, and Parkinson’s-plus issues including MSA and PSP. Each group has its own style, format and set of goals and priorities, but they share many common benefits.

One of the simplest but most powerful benefits is the sense that you are not alone in your experiences with Parkinson’s disease. “It provides a feeling of normalcy with what’s going on” said one participant. “It’s a relief to know that there are other people walking along this same path and that others are facing similar challenges and emotions along the way.” At times when friends and family may not be able to relate to the direct impact Parkinson’s has, support groups are a safe and confidential place to talk about the reality of the disease. For many PD patients may be experiencing greater improvements when compared to “voluntary” exercise when a workload is harder than a person could sustain voluntarily.

For more information on “forced versus voluntary” exercise training, contact Andrea Serdar P.T. NCS at 503-494-6991.

MyChart: Direct Access to Your PD Medical Team
Lisa Mann, RN, BSN, MA
OHSU Parkinson Center of Oregon

Technology is helping people with Parkinson’s disease (PD) to be better informed about living successfully with PD. Technology can also help you enhance your PD care by more easily connecting you to your doctor.

The OHSU Parkinson Center, like many medical centers with electronic medical record (eMR) systems, offers the option for patients to email us securely with non-urgent matters. Daily we receive emails with questions about medications, changes in symptoms, requests for referrals and more. Both the patient and the PD team can benefit from email communication: here is why and how to communicate clearly.

BENEFITS
• More timely response since telephone calls can often be missed by either party.
• Share information between visits about your health and changes in disease status which immediately become part of your eMR.
• Comprehensive documentation and quick responses with clearly written instructions (no more finding a pen and writing down details; just print the message).
• Immediate access for your PD team to your eMR, all the details are there to easily review.
• MyChart is more than a secure email: you may also view your medication list, make and change appointments, and receive test results on MyChart.

TIPS for emailing your healthcare provider:
• Clearly and briefly state your question or concern.
• Send only questions or information directly related to your PD care, avoid quotations.
• Include recent changes in your condition, state:
  • when these occur during the day (all day long, more often in the morning than evening, etc.)
  • your medication list and how long you have been on these medications
  • what is the relation to your PD medication dosing (does it help or worsen the situation or is it no impact).
• If you are requesting a refill, state which drug, dose, and what pharmacy it should go to.
• If issues are urgent, do not email, but place a phone call noting the urgency.

We strongly encourage all our patients to sign-up for MyChart, so that we have another tool to improve your care through increased communication options.

If you haven’t signed up yet, call us at 503-494-7231 and request a MyChart activation letter be mailed to you.

*NEW* NPF Hospitalization Kit: Brilliant!

The National Parkinson Foundation (NPF) has developed a wonderful new tool to help patients and their caregivers proactively prevent errors when hospitalized.

People with Parkinson’s disease (PD) can have a difficult time when hospitalized. Otherwise very meaningful medical personnel (doctors, nurses, surgeons, etc.) not trained in the uniqueness of PD can inadvertently worsen a patient’s condition, complicate their recovery, increase their need for skilled care, and increase the cost of care.

For some time now, we have offered hospitalization preparation and education materials on our website at: www.ohsubrain.com/pco. More is needed, however, and now the NPF will be distributing nationally a great new tool kit to help in this effort. Distribution of the kit, which includes information for medical teams when you are hospitalized to make sure you get the best care possible, will begin after the first of the year.

Also, Parkinson’s Resources of Oregon (PRO) will offer some presentations about this program in January and February (see website for details and events for information).

Visit the NPF’s special website for this initiative: www.arewareincare.org for more detailed information or contact us (503-494-7231) or PRO (800-426-6806).

TIPS for emailing your healthcare provider:

• Clear and briefly state your question or concern.
• Send only questions or information directly related to your PD care, avoid quotations.
• Include recent changes in your condition, state:
  • when these occur during the day (all day long, more often in the morning than evening, etc.)
  • your medication list and how long you have been on these medications
  • what is the relation to your PD medication dosing (does it help or worsen the situation or is it no impact).
• If you are requesting a refill, state which drug, dose, and what pharmacy it should go to.
• If issues are urgent, do not email, but place a phone call noting the urgency.
The Michael J. Fox Foundation has recently awarded a grant to Indiana University that will help researchers better understand one of the causes of Parkinson’s disease.

Our study, the PROGENI Family Study, is part of a larger international consortium of genotypes that are known to be important in Parkinson’s disease, called LRRK2. People who have a defect in the LRRK2 gene have a higher risk for Parkinson’s disease. This study is comparing families with and without a defect in the LRRK2 gene and people who may or may not have Parkinson’s disease, but who have been confirmed to have inherited a LRRK2 mutation.

A goal of this study is to identify early-premotor symptoms among individuals who have inherited a defect in the LRRK2 gene. Through an in-person study visit, we will be able to identify clinical findings and a laboratory test (or biomarker) that can be used to indicate whether or not an individual will develop Parkinson’s disease. The full study schedule will be monitored at a research center located at Oregon Health & Science University. The study visit will consist of a brief neurological examination by a movement disorder specialist.

Participants will be asked to complete questionnaires and to obtain more information about symptoms of PD. Participants will be asked to complete a smell test and to provide a sample of blood and urine. This study will take approximately 1 ½ to 2 hours to complete. There is no cost for participating in this study.

Do you have early Parkinson’s disease that you aren’t currently treating with any PD medications? – Are you interested in learning about a healthy lifestyle that may be important in the development of PD?

Purpose: The Parkinson’s Progression Markers Initiative (PPMI) is an observational research study to identify biomarkers of PD progression that are characteristic in our bodies that is associated with the presence of disease, or that changes over time, and can be linked to the progression of the disease. The purpose of this study is to identify one or more biomarkers of PD. The discovery of a biomarker is critical to the development of new and better treatments for PD, particularly treatments that can slow or stop the progression of the disease, something no currently available treatment can do.

Participation Requirements: This study seeks healthy and healthy volunteers. In order to participate in this study as a PD subject you must be at least 30 years old at the time of your enrollment.

Do you have Parkinson’s disease and involuntary movements from taking levodopa?

Purpose: There is an important medical need for an effective, well-tolerated treatment for involuntary movements (dyskinesia) which develops at least in 40% of patients treated with levodopa. Levodopa is the main medicine given to older patients with PD and renders them dependent on PD symptoms.

A new drug called ADX48621 has shown significant effectiveness in animal models of PD and needs to be tested for safety, tolerability, and effectiveness in humans with PD and dyskinesia. Participation Requirements: In order to participate in this study you must have a diagnosis of PD with dyskinesia caused by taking levodopa, be 30-75 years of age, have normal laboratory values in blood and urine tests before the study. In this study you will be randomly assigned to receive the study drug ADX48621, or a placebo (inactive substance). You will have a 1 in 3 chance of receiving placebo. Eligible participants will receive study-related evaluations, laboratory tests, and the investigational drug at no cost. Remuneration will be provided.

The Effects of Vitamin D on Balance in Parkinson’s disease

Dr. Amie Peterson is conducting this research study to examine the role 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 for 3 months. You will be asked to complete a smell test and to provide a sample of blood and urine. This study will take approximately 1 ½ to 2 hours to complete. Neither you nor the study staff will know which pill you will be taking. The first and last visit will be one 45 minutes or second, third, and fourth visit will last for a half hour. Each visit will occur four weeks after the first visit.

Participation Requirements: In order to participate in this study you must be at least 30 years old at the time of your enrollment. To qualify for this study, you must have been diagnosed with Parkinson’s disease within the last 5 years. You must not be taking any medications that may affect balance or have had surgery for PD in the past year. You must be free of other neurological disorders, and have normal laboratory values in blood and urine tests before the study. In this study you must have a diagnosis of PD with dyskinesia caused by taking levodopa, be 30-75 years of age, have normal laboratory values in blood and urine tests before the study.

EARLY-, MID-, LATE-STAGE PD

Do you have early Parkinson’s disease for less than 5 years and currently taking rasagiline or selegiline as your only treatment for PD?

Purpose: Recent studies show that the study drug prigilizone, currently used to treat Type II diabetes, may protect nerve cells in various ways. This study is designed to determine if the study drug is safe and well tolerated in patients with Parkinson’s disease and if it slows the progression of Parkinson’s disease.

Participation Requirements: Participation in this study will include at least six clinic visits and at least 3 months of study drug or placebo will be taken for 44 weeks. A placebo is a pill that looks like the study drug but contains no medicine. To qualify for this study, you must have been diagnosed with Parkinson’s disease within the last 5 years. You must not be taking any medications that may affect balance or have had surgery for PD in the past year. You must be free of other neurological disorders, and have normal laboratory values in blood and urine tests before the study. In this study you must have a diagnosis of PD with dyskinesia caused by taking levodopa or have a current or active neurological disorder. The study will use a combination of imaging techniques, collection of blood and fluid and clinical tests.

If enrolled subjects will undergo four study visits in their first year, with visits twice a year thereafter. Subjects will be enrolled in the study for 3-5 years depending on their date of enrollment. For more information please contact Emily Pighetti at 503-434-1382 or pighetti@ohsu.edu. eIRB #6459.

BALANCE / EXERCISE

Are you interested in Exercise for your Parkinson’s disease?

Purpose: Clinicians and scientists at OHSU are currently investigating the most beneficial way to deliver an exercise program aimed at promoting mobility and balance problems in people with Parkinson’s disease (PD).

We are testing the same exercise program provided as either a home exercise program, individualized therapy or as a group program. We are also interested in how common comorbidities such as other neurological (Parkinson’s disease), cardiovascular, or orthopedic problems along with PD affect outcomes of exercise. All three arms of the study will be conducted and overseen by physical therapists at OHSU. Participation Requirements: Participation in this study requires being over 30 years of age who exercise within the past year, and who have Parkinson’s disease and are interested in participating in one of the exercise groups and potentially going to OHSU to participate in the exercise program, twice a week for 4 weeks. You will also undergo tests of your balance and physical performance 2 times (once before the exercise program begins and once after). Transportation will not be provided and you will be paid for participation. To qualify for this study you must be at least 30 years old at the time of your enrollment. Dr. Laurie King is the investigator for this study. For more information, please contact Kelsey Priest, (503) 575-8401 and priest@ohsu.edu. eIRB #4402.

Do you have freezing of gait or start hesitation?

OHSU’s Balance Disorders Laboratory is seeking people with Parkinson’s disease and freezing of gait for a study investigating the relations between freezing of gait and brain circuits.

Qualifying participants will have a diagnosis of Parkinson’s disease and experience freezing of gait (repetitive episodes in which they feel “stuck” when trying to walk). Participants must be free of other neurological disorders, and have normal laboratory values in blood and urine tests before the study. In this study you must have a diagnosis of PD with dyskinesia caused by taking levodopa, be 30-75 years of age, have normal laboratory values in blood and urine tests before the study.

Participation Requirements: Participation in this study will include at least six clinic visits and at least 3 months of study drug or placebo will be taken for 44 weeks. A placebo is a pill that looks like the study drug but contains no medicine. To qualify for this study, you must have been diagnosed with Parkinson’s disease within the last 5 years. You must not be taking any medications that may affect balance or have had surgery for PD in the past year. You must be free of other neurological disorders, and have normal laboratory values in blood and urine tests before the study. In this study you must have a diagnosis of PD with dyskinesia caused by taking levodopa, be 30-75 years of age, have normal laboratory values in blood and urine tests before the study.

Participation Requirements: Participation in this study will include at least six clinic visits and at least 3 months of study drug or placebo will be taken for 44 weeks. A placebo is a pill that looks like the study drug but contains no medicine. To qualify for this study, you must have been diagnosed with Parkinson’s disease within the last 5 years. You must not be taking any medications that may affect balance or have had surgery for PD in the past year. You must be free of other neurological disorders, and have normal laboratory values in blood and urine tests before the study. In this study you must have a diagnosis of PD with dyskinesia caused by taking levodopa, be 30-75 years of age, have normal laboratory values in blood and urine tests before the study.
Partnering with You

THANK YOU! Specialized comprehensive care programming and personnel are funded by your donations and grants.

RESEARCH 2011

Our program remains committed to translating science into clinical care. Selected highlights for 2011:

• The addition of Dr. Vivek Unni (see article below) has allowed research to better understand the protein alpha-synuclein, which is linked to the cause of PD.
• The impact of exercise, enriched environments and socialization on the PD brain using an animal model.
• Insight into the mechanisms of dyskinesia and improved ways to record and treat this problem.
• Ways to delay or modify the progression of PD through exercise and drugs.
• Understanding and treatment of fatigue.
• An active grant and balance lab has produced a number of studies to better understand underlying brain mechanisms and how to measure and treat balance and gait problems. Collaborative research at OHSU to produce objective evidence for what constitutes the best care for PD.
• The study of biological markers that predict the onset and progression of PD.
• The study of grief in response to loss in family caregivers.
• The impact of new drugs and vitamin D to treat the symptoms of PD.

THANK YOU! Clinical research is not possible without volunteers to participate in studies.

We are committed to your future. Please help us make 2012 another year of shared success.

With Gratitude,
Jai Nugut, MD
Director

Julie Carter, ANP
Associate Director

NEW TEAM MEMBERS FOR RESEARCH & CARE AT OHSU PARKINSON CENTER

NEW FAMILY CARE SPECIALIST:

Allison is an experienced clinical social worker from Houston, recently relocated to Portland. She is absolutely thrilled to be living in low humidity weather and enjoying the beautiful landscape of Oregon.

Allison comes to us from the MS Center at Boston University. She worked in a similar position helping patients and families dealing with Multiple Sclerosis.

Here at the OHSU Parkinson Center, she will be able to pursue her passion for supporting people with chronic illnesses and their families by finding them resources and support within their community. She is also excited to help develop and teach community programs that promote family caregiver skills in coping with the challenges and insights driving Parkinson’s disease. Allison says, “My goal is to be a partner with families dealing with Parkinson’s disease and help them improve their quality of life in any way I can.”

Allison has a husband, Cristian, a son, Jett, who is two and a half, and a dog, Cleo. She is a scientist. Because she is both a physician and a scientist, she has a unique perspective on how alpha-synuclein can cause Parkinson’s and related disorders. How alpha-synuclein can form many kinds of protein aggregate with itself to form potentially toxic and others which could be protective to cells. One of my goals is to test this hypothesis and to develop new diagnostic and therapeutic techniques that will allow us to determine whether alpha-synuclein with family, can cause the outcome is best for all concerned.

Emily Lempke, LSW

NEW RESEARCH SCIENTIST AND MOVEMENT DISORDER SPECIALIST:

Dr. Vivek Unni

I am very excited to be able to join the Parkinson Center of Oregon and the OHSU community as both a physician and a scientist. Because of my combined interests in taking care of patients with movement disorders and doing basic science research on what goes wrong in the brains of people with Parkinson’s disease, this environment is a fantastic place to work. Dr. Nutt has developed a world-renowned center for the study and treatment of Parkinson’s and I hope to be able to contribute to this center.

After growing up in Ohio, I did my undergraduate work in chemistry and biology at Stanford, so when then I had a great time for the west coast and am happy to be back to return. After Stanford, I moved to Columbia University in New York City to complete training in their MD/PhD program and to finish an internship in internal medicine at St. Luke’s-Roosevelt Hospital. It was during this time that I met my future wife, a fellow graduate student interested in neurology, who is originally from Portland. After New York, we both moved up to Boston to continue our training. I finished my residency fellowship and a fellowship in movement disorder departments at Harvard. In the Massachusetts General Hospital and Brigham & Women’s Hospital program, and she did post-doctoral work in brain development in the Molecular & Cellular Biology Department at Harvard. After fellowship, I stayed at Mass General as a faculty member working in the movement disorders clinic and continuously research began as a fellow on a known as alpha-synuclein.

Many pieces of evidence suggest that increased levels of alpha-synuclein can cause Parkinson’s disease, and alpha-synuclein occurs is still a mystery. One hypothesis is that the protein aggregate with itself to form potentially toxic and others which could be protective to cells. One of my goals is to test this hypothesis and to develop new diagnostic and therapeutic techniques that will allow us to determine whether alpha-synuclein with family, can cause the outcome is best for all concerned.

Since my fellowship I have been developing new approaches to try to study alpha-synuclein in the brain and am currently working on imaging techniques in mouse models of Parkinson’s. We recently published the first study using rodent models to study alpha-synuclein in vivo in this way. I believe understanding how these processes occur in vivo will be very useful for discovering new drug targets for Parkinson’s disease and for developing new treatments for this disease. We are also testing new drugs for Parkinson’s disease that do not have any effect on the protein aggregate that causes Parkinson’s. I am currently working on trying to change that scenario.

I think OHSU and the Parkinson Center of Oregon are the perfect place in the world to make this happen, so I’m thrilled to be here.

Vivek Unni, MD, PhD

JAIL BREAK: A Family Caregiver Adventure by David Gillaspie, PD Caregiver

David Gillaspie had the honor of caring for his father-in-law, Ken, who was diagnosed with PD. In this book, David shares here a 12-week caregiver’s case study and episode of his and Ken’s journey. The book starts with helping to get Ken’s grief on the path to healing by his doctor. While Ken and his family are searching for treatment options, David urges his own caregiving experiences with a crowd of over 100 individuals from 15 hospital-based outpatient rehab programs. They discussed a wide range of topics with the audience sharing their own experiences and questions. As in the past, the PD artists and lobbyist exhibit table and the PD support group continue to provide valuable resources.

Additionally, participants also had access to information on the many specialized services offered by the OHSU Parkinson Center, including speech therapists who treat neuro re-education, neuropsychologists who coordinate brain stimulation surgery and programming, research opportunities, and more.

We are at all again. We want to train more therapy teams in the region. We work with a physical, occupational, or speech therapist, legal expert, and support groups to improve the care of Parkinson’s disease.

As we’ve told you in previous publications, our network now consists of over 100 individuals from 15 hospital-based outpatient rehabilitation programs.

On April 6th we’ll offer a TEAM-PD Basic course for therapists who would like to join the network and on April 7th we’ll train those already in on treating people with MSA (Multiple System Atrophy), PSP (Progressive Supranuclear Palsy), and advanced PD.

So, if you know of any therapist (particularly teams of therapists), who would be interested in receiving information about this training, please contact Lisa Mann, RN at 503-494-9521 or by email at mannt@ohsu.edu.

TEAM-PD EXPANDS AGAIN: APRIL 6-7, 2012

Therapists Educated & Aligned in Parkinson Care

In the brain stimulation surgery and programming, research opportunities, and more.

We are all again. We want to train more therapy teams in the region. We work with a physical, occupational, or speech therapist, legal expert, and support groups to improve the care of Parkinson’s disease.

As we’ve told you in previous publications, our network now consists of over 100 individuals from 15 hospital-based outpatient rehabilitation programs.

On April 6th we’ll offer a TEAM-PD Basic course for therapists who would like to join the network and on April 7th we’ll train those already in on treating people with MSA (Multiple System Atrophy), PSP (Progressive Supranuclear Palsy), and advanced PD.

So, if you know of any therapist (particularly teams of therapists), who would be interested in receiving information about this training, please contact Lisa Mann, RN at 503-494-9521 or by email at mannt@ohsu.edu.

TEAM-PD EXPANDS AGAIN: APRIL 6-7, 2012

Therapists Educated & Aligned in Parkinson Care

In the brain stimulation surgery and programming, research opportunities, and more.

We are all again. We want to train more therapy teams in the region. We work with a physical, occupational, or speech therapist, legal expert, and support groups to improve the care of Parkinson’s disease.

As we’ve told you in previous publications, our network now consists of over 100 individuals from 15 hospital-based outpatient rehabilitation programs.

On April 6th we’ll offer a TEAM-PD Basic course for therapists who would like to join the network and on April 7th we’ll train those already in on treating people with MSA (Multiple System Atrophy), PSP (Progressive Supranuclear Palsy), and advanced PD.

So, if you know of any therapist (particularly teams of therapists), who would be interested in receiving information about this training, please contact Lisa Mann, RN at 503-494-9521 or by email at mannt@ohsu.edu.
OHSU Parkinson Center of Oregon

OHSU Parkinson Center and the Brian Grant Foundation partner to host a symposium for Young People with Parkinson’s Disease

Special Guest: Brian Grant, former Trail Blazer and young person with PD.

Keynote: A Hopeful Vision
Matt Brodsky, MD, PD Specialist

Join us for a day focused on the unique challenges of being under 59 years old and living with Parkinson’s disease. The OHSU Parkinson Center of Oregon is offering a unique and innovative program specifically designed for family caregivers of people with PD called:

THE MINDSET OF HEALTHY CAREGIVING

This eight-week course is designed for 8-8 caregivers of people living with PD. Participants will meet once a week to learn and apply specific, evidence-based skills for use in PD caregiving. The Mindset of Healthy Caregiving is co-facilitated by Julie Carter, APRN and Allison Liprick, MSW.

Next course begins: Monday, May 14, 2012 — 25 per session

For more information, please contact Allison Liprick at liprick@ohsu.edu or 503-418-1661.

What’s Inside

• Cover Story: Partnering with You (continued inside)

• New OHSU PCO team members enhance care and research

• Round 1: Sleep Fighting

• NPF Hospitalization Kit

• Support Group Benefits

• Jail Break: A Family Caregiver Adventure

• Exercise Update

• MyChart: Staying in Touch

• Jail Break: A Family Caregiver Adventure

• TEAM-PD Training

• What’s New on Back Page.

NEW WEBSITE ADDRESS: www.ohsubrain.com/pcoc

OTHER EDUCATION EVENTS

For more information or to register for the below events call Parkinson’s Resources of Oregon (PRO) at 800-426-6060.

AWARE IN CARE
Learn how to get the best care possible during an unexpected or routine hospital visit during this new workshop developed by the National Parkinson Foundation. 
- Fri, Jan 6 – PORTLAND, Providence Portland Medical Center at 12 Noon.
- Sat, Feb 4 – VMC/VICOM.
- Sun, Feb 5 – VMC/VICOM.
- Sat, Feb 11 – VMC/VICOM.
- Sat, Feb 18 – VMC/VICOM.
- Sun, Feb 19 – VMC/VICOM.
- Sat, Feb 25 – VMC/VICOM.

Programs are free but RSVP is required. More dates and locations to be announced soon!

APR 13-14 - EUGENE, OR
EUGENE INSPIRE, POWER, PRO PD Education Conference & Eugene Conference Center.

MAY 5- BEAVERTON, OR
PAWS FOR A CAUSE

INSIGHTS & INSPIRATION:

Special family caregiver program. See details above.

SAT, MAR 5 - PORTLAND, OR
MINDSET OF HEALTHY CAREGIVING
Special family caregiver program. See details above.

SAT, MAR 17 - PORTLAND, OR
INSIGHTS & INSPIRATION:
YOUNG PEOPLE WITH PD CONFERENCE
Join us for a day focused on the unique challenges of being under 59 years old and living with Parkinson’s disease. See above and start your team now!

“SAVE THE DATE”
STRIKE OUT PD
Saturday, May 5th 11:00am – 3:00pm Beaverton, OR
Bowling party for PD families, friends and supporters. More dates and locations to be announced soon!

APR 13-14 - EUGENE, OR
EUGENE INSPIRE, POWER, PRO PD Education Conference & Eugene Conference Center.

MAY 5- BEAVERTON, OR
PAWS FOR A CAUSE

NEWLY DIAGNOSED WITH PD?

Every other month the OHSU PCO offers a three-hour session for people recently diagnosed with PD and their spouse or family member. Participants may ask questions and all questions of long-time patient, $20/person, refreshments served. Call 503-494-8054 for more information.

PARKING UPDATE

Published by the OHSU Parkinson Center of Oregon
A National Parkinson Foundation Center of Excellence

2012 EVENTS

Mindset of Healthy Caregiving
Starts March 5th

TEAM-PD Training
Fri-Sat, April 6-7th

PAWS for A CAUSE
Sat, July 14th

More info on back page. RCOC

QUALITY CARE 2011

• Our interdisciplinary team is growing with the addition of Allison Liprick, MSW, Family Care Specialist (see page 2). Our commitment to patient and family centered care continues.

EDUCATION & OUTREACH 2011

- Options and Opportunities: The 28th annual symposium for patients and families, attended by 500 people, provided updates on treatment and research (see story on page 5).
- Caregiver Connection: A special evening of support and sharing for PD caregivers.
- Newly diagnosed workshops: Very popular small group sessions for the newly diagnosed to ask questions and receive hope. Demand was high, so ten were held this year with 97 participants.
- Bi-annual print newsletter distributed to over 6,500 each edition and e-newsletters distributed 4-5 times per year with 1,200 each edition.
- TEAM-PD: The OHSU PCO is committed to training health care teams around the northwest to better care for PD. 2011 brought hands-on training for a capacity audience of over 95 physical therapists from CR, WA, and ID in the use of BESTest, the latest tool in fitness testing for PD.
- Basal Ganglia Coterie: OHSU PCO hosted 46 movement disorder specialists from throughout the Northwest to share their research and learn from each other.
- The OHSU PCO was chosen as one of six sites in the country to train nurse faculty 10 years ago. PD who will then train nursing students in state of the art care of PD.

THANK YOU: All of these activities were funded in part by your generous donations.