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

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 any and all questions of a PD specialist and long-time patient. $25/person; refreshments served.

Call 503-494-9054 for more information.

The symposium is followed by a ones in the face of Parkinson’s exercise, navigating the workplace, Experts will present on nutrition, and your family face when the unique challenges you symposium just for you and Brian Grant Foundation have Parkinson Center and the just for young people diagnosed with You asked for an annual symposium includes program, lunch, social • • •

See details above.

**SAVE THE DATE**
Thursday, May 16th
Caregiver Connections Symposium
OHSU Vey Auditorium

The Caregiver Connections symposium is an opportunity for caregivers to gather, network, share, and learn about issues to help their journey caring for a loved one with Parkinson’s disease. We are fortunate to have as our keynote speaker, PD counseling expert, John Allen, PhD.

More information to follow after the first of the year via our website (www.ohsbrain.com/pc). email, and mail.

**WHAT'S INSIDE**

• Cover Story: Partnership (continued inside)
• Sleep Series: RLS
• Redefining PD
• Alpha-Syn...What?
• New Column: Ask the Experts—Your Questions Answered

What’s Inside

OHSU PCO Upcoming Events Calendar

For more information or to register for these or other PRO classes and events, call Parkinson’s Resources of Oregon (PRO) at 800-426-6806 or visit their event registration website at www.pro.eventbrite.com.

DEC 3 - CORVALLIS, OR ADVANCE-STANCE FAMILY CAREGIVING PROGRAM

The curriculum was specially designed to prepare families and caregivers to approach the advanced stages of the disease with more confidence.

APR 13 - EUGENE, OR EMPLOYEE PRO EDUCATION CONFERENCE

This year, Parkinson’s resources and support were disseminated to our local community in Eugene through participation in the Parkinson’s Resource of Oregon’s (PRO) annual conference, featuring keynote presentation by Dr. Monique Girouil and an afternoon of breakout sessions.

APR 26 - PORTLAND, OR PRO GALA CELEBRATE HOPE Oregon Ballroom, Oregon Convention Center, Friday, April 26, 2013. Tickets and participation information by PRO at the number listed above.

WEBSITE ADDRESS: www.ohsbrain.com/pc

OHSU Parkinson Center of Oregon
60 years old or younger? Please join us for Insights & Inspirations
REGISTER ONLINE NOW!

You asked for an annual symposium just for you and we have it! The OHSU Parkinson Center and the Brian Grant Foundation have partnered again to design a symposium just for you and the unique challenges you and your family face when living with young-onset Parkinson’s disease.

Experts will present on nutrition, exercise, navigating the workplace, and the common psychosocial aspects of PD and to teach healthy mindset. It is the right time to take a look back at our progress toward our three missions, none of which could be accomplished without your support:

• Providing comprehensive and compassionate care for people with Parkinson’s disease and their families,
• Educating patients, care givers, professionals and researchers about Parkinson’s disease,
• Translating science into clinical care by exploring causes of Parkinson’s disease, new treatments and better management.

COMPREHENSIVE, QUALITY CARE 2012

• Caring for more than 1100 PD patients per year,
• Initiating telemedicine program for eastern Oregon,
• Maintaining National Parkinson Foundation designation as Center of Excellence,
• Growing the Deep Brain Stimulation (DBS) program: Now caring for the second largest population of patients with DBS on the west coast,
• Providing expertise in patient and professional educational programs on DBS,
• Leader in a new surgery approach resulting in improved patient comfort during the process,
• Offering newly diagnosed workshops to anyone recently diagnosed: small group sessions for the newly diagnosed people to ask questions and to receive hope,
• Employing a new imaging technique to measure the dopamine nerve terminals in the brain (DATscan).

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

You are a spouse of someone with Parkinson’s disease.

Led by local PD experts John Allen, PhD, and Julie Carter, ANP. The Mindset of Healthy Caregiving seeks to educate participants about the common psychosocial aspects of PD and to teach healthy mindset strategies that enhance well-being, even in the face of illness.

• 10 weekly, 1-hour sessions
• Learn positive strategies for increased quality of life
• Understand common psychosocial aspects of PD
• Cost Insurance will be billed for each session, plus a $150 administrative fee

Limited space available. For more information, please contact Julie Doolin at 503-494-9054.

Do you work closely with a physical therapist or exercise trainer?

Let them know about the OHSU Parkinson Center’s upcoming event:

State of the Art PD Exercise Integration from Clinic to Community

The course will take place on April 12 & 13, 2013 at OHSU and feature the latest in exercise research in Parkinson’s disease. If your PT or trainer is interested, please have them contact us at 503-494-9054 or by e-mailing mannli@ohsu.edu to make sure they are on our contact list.

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

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OHSU PARKINSON CENTER EVENTS BRING EDUCATION & AWARENESS

ASK THE EXPERTS

Your Questions, Answered: Patients’ Questions from Our Annual Symposium

REDEFINING PARKINSON’S DISEASE

LINDA K. KELLY, M.D.

OHSU Parkinson Center Clinical Professor

Additional funding for the Parkinson’s disease research and care at the OHSU Parkinson Center of Oregon is heavily reliant on donations from the community. Thank you for being a part of an amazing and collaborative enterprise. We can’t do it without you.

PAWS FOR A CAUSE – In its second year, our fun dog-centered event and fundraiser raised awareness about PD to the general public and funds for our mission. Thank you to all who joined us, and thank you, Thank you, Thank you, for your support! We can continue to offer care, education, and support to patients and their families. Please consider being a part of our next event and help us continue to offer care and support to patients and their families.

SAVE THE DATE! JULY 13th!

RISK FOR A CAUSE

Picture shown: First and second place dog and handler at the 2012 OHSU Parkinson Center of Oregon’s Annual Salt Lick Contest. Picture was taken by Bob Taylor.

SAVE THE DATE: September 10th!

Risks for Parkinson’s Disease

How can you help prevent and manage Parkinson’s disease? The OHSU Parkinson Center’s research team is committed to finding new ways to help reduce the burden of Parkinson’s disease.

If you would like to make a donation, please visit our website at www.ohsubrain.com/donating.

THANK YOU!

All of these activities were funded in part by your generous contributions and in support of the Parkinson’s disease research and care at the OHSU Parkinson Center of Oregon.

THANK YOU:

Clinical research is not possible without volunteers to participate in studies. You are the reason that we pursue our missions. But, in addition, you are a critical contributor to our program’s success by your support in funding of many of our activities and by participating in many of our studies.

We are committed to your future. Please help us continue in 2013 to grow in our care, education, research missions and foster another year of shared success.

With Gratitude,

JAY NUTT, M.D.
JULIE CARTER, ANP

RESEARCH 2012

- Exploring the impact of cognitive and motor symptoms on quality of life in people with PD
- Evaluating the effectiveness of a new treatment for PD
- Investigating the role of genetics in PD
- Assessing the effects of exercise on PD
- Studying the impact of diet on PD
- Investigating the use of technology in PD

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If you would like to make a donation, please visit our website at www.ohsubrain.com/donating.
The National Parkinson Foundation: Parkinson’s Outcomes Project

The OHSU Parkinson Center of Oregon has participated in the NPF Outcomes Project (also known as the NPF Registry) since its inception. Dr. Nutt is on the steering committee. As with so many research projects, we have a high number of participants in this project too and are ranked among the top five centers with over 500 participants. Thanks to YOU (our patients and their caregivers) who continually give of themselves, sharing personal information and their time to ensure PD research can be advanced to find better treatments, eventually a cure. THANK YOU for all who participating and all who will!

The National Parkinson Foundation’s Parkinson’s Outcomes Project seeks to determine what care works best in treating and slowing the course of the chronic brain disease. Parkinson’s disease is the second most common neurodegenerative disease after Alzheimer’s, affecting about 1 million people in the United States and an estimated 4 million to 6 million worldwide.

KEY FACTS

• Purpose: To identify and explain factors that result in longer, better, more active lives for people with Parkinson’s disease

• Largest clinical trial of Parkinson’s disease ever conducted

• Started in 2009

• Currently tracks more than 5,500 patients in four countries

• Data is gathered by asking participants a series of questions once a year, every year

• Broadest and most inclusive patient demographics ever assembled in a clinical study of Parkinson’s disease, encompassing the entire spectrum of the disease

• Included in the 5,500 patients:
  - 85% seen in the US and 15% internationally
  - 1,400+ between 55-65 years old
  - 1,000+ within two years of being diagnosed
  - 440+ with onset before age 40, making this the largest clinical study to date of people with Young-Onset Parkinson’s
  - 350+ have had Parkinson’s for more than 20 years
  - 100+ who experienced onset after age 80
  - Data evaluates the full range of factors of Parkinson’s disease: medications and other treatments, motor symptoms, cognition, anxiety and depression, and caregiver burden

• All participants are among those being treated at 20 leading institutions designated by NPF as Centers of Excellence

KEY FINDINGS

• Varieties of Care: Even among leading treatment centers, care and treatment models vary significantly and achieve different health outcomes. Initial findings showed (1) similar patients fare differently depending on their treatment center; (2) most centers use medication differently; and (3) centers refer patients to allied health professionals differently.

• Take away: NPF will further study whether differences in care are the primary reason for better health outcomes.

• Managing Mood: Depression and anxiety are the number one factors impacting the overall health of patients.

• Take away: NPF recommends physicians screen patients for depression at least once a year.

THE FUTURE

The study is expected to grow to follow ten thousand patients with Parkinson’s in the coming years. Future research will continue to evaluate the full range of factors that bear on the experience of the disease to gather what will be the most comprehensive clinical data set on Parkinson’s ever assembled. NPF will routinely report its findings to the Parkinson’s community along the way.

STUDY CO-CHAIRS - John Nutt, MD, Oregon Health and Science University; Tanya Simuni, MD, Northwestern University; Mark Guttmann, MD, Markham Stouffville Hospital; Eugene Nelson, DSc, Dartmouth-Hitchcock Medical Center; and Peter Schmidt, PhD, National Parkinson Foundation.

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For more information, visit “Parkinson's Outcomes Project: Report to the Community” on the NPF website at www.parkinson.org/outcomes.

Always ready to help people and families with PD nationwide—the NPF Helpline can be reached by calling 800-4PD.INFO (473-4636).
Do you have early Parkinson's disease that you aren't currently treating with any PD medications?  

Purpose: The Parkinson's Progression Markers Initiative (PPMI) is conducting an observational study to identify biomarkers of PD progression. A biomarker is a substance or characteristic that can be measured and identified in blood, other bodily fluids or tissues and can be used for the diagnosis or monitoring of disease.

This study is to examine the effects of donepezil on improving balance in Parkinson's patients. Participants in this study include a total of 4 clinical visits to OHSU for testing. We are looking for patients who have been diagnosed with idiopathic Parkinson's disease, have been treated with levodopa for at least one year and have difficulties with balance and falls. Exclusion criteria includes having any other medical conditions other than PD that may affect balance, not being able to stand unassisted for at least 30 minutes, patients who are currently taking anticholinergics or drugs with known side effects. This study involves taking the study drug/placebo for 3 weeks of washout period, and then another 6 week period where subject will either be given the study drug or placebo. Between each phase of dosing, it is required to come to OHSU for balance testing and evaluation. If interested, please contact Anna Lovelace at 503-494-9531 or lovelaca@ohsu.edu. eIRB #7363

What is the effect of vitamin D on balance in Parkinson's disease?  

Purpose: The purpose of this study is to examine the effect of vitamin D on balance in Parkinson's disease patients. This study will recruit both PD subjects and healthy volunteers. In order to participate as a PD subject you must have been diagnosed with PD within the last two years. You must be in excellent general health, be able to stand unassisted for 5 minutes, able to walk unassisted for 50 ft., without worsening their motor symptoms. The study requires 3 visits to the clinic and will last approximately 30-32 months and include 12-17 clinic visits. If interested, please contact Anna Lovelace at 503-418-1769 or wilsonap@ohsu.edu. eIRB #8241

Do you have Parkinson's disease and currently being treated with Bototo? Is an FDA approved drug used to treat cervical dystonia, similar to Bototo. The current standard of care for treating Parkinson's disease involves injection into the affected neck muscles every 12 weeks. However, the OHSU research suggests that some patients may be experiencing significant loss of treatment effect within 10 weeks of injection. The purpose of this study is to evaluate the safety and efficacy of Xeomin in a short dosing period (6-10 weeks) compared to the dose of this study injection every 12 weeks). Participation Requirements: Eligible patients have been diagnosed with cervical dystonia; have received less than 10 weeks of treatment effect in the past 6 months, and receiving less than 10 weeks of treatment effect. Additional requirements include interest in participating in this trial. Dr. Matthew Brodsky is the investigator for this study. For more information, please contact Mike Fleming, 503-346-0842, mrflemimic@ohsu.edu or Fay Horak, Ph.D, PT, eIRB #5279

Do you have cervical dystonia (CD) and currently being treated with Bototo?  

Purpose: This study is looking at the FLEX-321 study. The primary objective is to evaluate the safety and efficacy of Xeomin in patients with cervical dystonia. This study will be conducted in multiple centers across the US in 10 weeks. For more information, please contact Brenna Lobb, MS, Study Coordinator, at 503-418-1769 or wilsonap@ohsu.edu. eIRB #8241

Do you have Parkinson’s disease and currently taking anticholinergics?  

Purpose: The purpose of this study is to investigate if rivastigmine and atomoxetine can improve balance difficulties in Parkinson’s disease patients without dementia. Rivastigmine has been shown to improve attention in PD patients with dementia without worsening their motor symptoms. Atomoxetine has been shown to improve cognitive function in PD patients with cognitive impairments. Participation Requirements: This study requires 3 visits to the clinic and will last 6 weeks to complete. If it is determined that you are eligible to participate, you will be assigned to one of three treatment groups; rivastigmine, atomoxetine, or placebo. The study will be no more than 14 hours, each visit. You must be able to stand unassisted for 5 minutes, be able to walk unassisted for 50 ft., and your balance, neurological examinations, thinking and memory, questionnaires about cognitive function, and tests of balance and strength, and diaries of near falls and falls. You will be taking rivastigmine, atomoxetine or a sugar pill for 16 weeks. You will be compensated $10.00 for each visit you complete for a total of $60.00. For more information on how to participate please contact Brenna Lobb, MS, Study Coordinator, at 503-220-8262 x51871 or by mail to 3710 SW Veterinary Medical Center, Portland, OR, 97239. eIRB #2393

Do you have Parkinson’s disease and interested in participating in a study about attention?  

Purpose: The purpose of this study is to investigate if rivastigmine and atomoxetine can improve cognitive difficulties in Parkinson’s disease patients without dementia. Rivastigmine has been shown to improve attention in PD patients with dementia without worsening their motor symptoms. Atomoxetine has been shown to improve cognitive function in PD patients with cognitive impairments. Participation Requirements: This study requires 3 visits to the clinic and will last 6 weeks to complete. If it is determined that you are eligible to participate, you will be assigned to one of three treatment groups; rivastigmine, atomoxetine, or placebo. The study will be no more than 14 hours, each visit. You must be able to stand unassisted for 5 minutes, be able to walk unassisted for 50 ft., and your balance, neurological examinations, thinking and memory, questionnaires about cognitive function, and tests of balance and strength, and diaries of near falls and falls. You will be taking rivastigmine, atomoxetine or a sugar pill for 16 weeks. You will be compensated $10.00 for each visit you complete for a total of $60.00. For more information on how to participate please contact Brenna Lobb, MS, Study Coordinator, at 503-220-8262 x51871 or by mail to 3710 SW Veterinary Medical Center, Portland, OR, 97239. eIRB #2393

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Do you have freezing of gait or start hesitance?  

Purpose: OHSU’s Balance Disorders Laboratory is seeking people with Parkinson’s disease and experience occasional or frequent episodes in which they feel “stuck” when trying to walk. Participation Requirements: Qualifying participants will have a diagnosis of Parkinson’s disease and experience occasional or frequent episodes in which they feel “stuck” when trying to walk. Each visit will last approximately 1-2 hours. You will be compensated $10.00 for each visit you complete for a total of $60.00. For more information on how to participate, please contact Dr. Anna Lovelace at 503-418-0842 or email at balance@ohsu.edu or call 503-346-0042.

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REDEFINING PARKINSON'S DISEASE

OHSU ParkinSOn Center EVENTS BRING EDUCATION & AWARENESS

Save the date: 3rd annual Parkinson's Awareness Month - October 12th

More than 100,000 Oregonians have Parkinson's disease. In this special event, OHSU will present a day of information, education, entertainment, and inspiration to help our community understand the causes, symptoms, and treatments of Parkinson's disease.

Risks for a Cause - Salk Ltd Contest

The 5th annual Salt Lick contest in Baker City, Oregon will bring a much-needed source of water for Baker City, not only and only, but at least in part, to all those who have been helped by Parkinson's Disease. You can take part in this event with your friends, who may be affected by Parkinson's Disease in their own way and support the important work that is being done.

Ask the Experts

Your Questions, Answered: Patients’ Questions from our Annual Symposium

The OHSU Parkinson Center hosts an annual symposium where patients and their families can learn more about Parkinson's disease. The questions and answers from this year's symposium are compiled and shared to help others understand the disease and its management.

Save the date: 2013:

- June 12th: Parkinson's Disease in Pregnancy
- October 12th: International Parkinson's Disease Awareness Month

Save the date: 2014:

- June 12th: Parkinson's Disease in Pregnancy
- October 12th: International Parkinson's Disease Awareness Month

Additional Resources:
- OHSU Parkinson Center: http://parkinson.ohsu.edu
- Parkinson's Disease Foundation: http://parkinson.org

DONATE NOW:

Support the OHSU Parkinson Center in its mission to improve the lives of Oregonians affected by Parkinson's disease. Your donation helps fund research, education, and patient care.

Thank you for your support!
Due to the unique challenges you are facing in the face of Parkinson’s disease, we have designed the following program just for you and your family.

State of the Art PD Exercise Integration from Clinic to Community

The course will take place on April 12 & 13, 2013 at OHSU and feature the latest in exercise research in Parkinson’s disease. If your PT or trainer is interested, please have them contact us at 503-494-9054 or by e-mailing mann@ohsu.edu to make sure that they are on our contact list.

COUNSELORS TOO
If you are a counselor in your community and work with PD patients and their families, please have them contact us too. There will be a concurrent special session on April 12th entitled Anxiety, Pain, and Depression in Parkinson’s disease for psychologists, psychiatrists, and licensed clinical social workers.

CALLING ALL PTs, EXERCISE TRAINERS, AND PROFESSORS
Do you have a Do you work closely with a physical therapist or exercise trainer? Have you ever wanted to attend a class online? With the increased demand for exercise in Parkinson’s disease, we are fortunate to have as our keynote speaker, Penny Hogarth, M.D., Research Director at the Parkinson’s Disease Research, Education and Clinical Center at OHSU.

The course will take place on April 26, 2013 at the OHSU Parkinson Center and at the Portland Art Museum. The course is designed for PTs and Exercise Trainers to help their journey caring for a loved one with Parkinson’s disease. We are fortunate to have as our keynote speaker, Penny Hogarth, M.D., Research Director at the Parkinson’s Disease Research, Education and Clinical Center at OHSU.

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