## OHSU Parkinson Center of Oregon
### Parkinson Update
#### UPENDING EVENTS
- **29th Annual Symposium**
  **Parkinson’s Weekend in Portland** July 14-16, 2012

#### Shake It Till We Make It
- **Benefit for the Brain Grant Foundation**
  Portland, OR

#### Paws for a Cause
- **A Benefit for Parkinson's**
  Portland, OR
  - **1k or 4 Dog Walk**
  - **Where**: Church Park, Portland, OR
  - **When**: July 4th, 2012

#### Options & Opportunities
- **24th Annual Symposium**
  **Parkinson’s Disease Symposium**
  http://www.ohsuhospital.com

### Featured Event:
#### NMU PARKS IN PORTLAND
- **2012**
- **OHSU Parkinson Center of Oregon**
  **9 am - 3:30 pm**
  **Register online at www.firstgiving.com/pco**

### Other Education Events
- **SAT, JUL 14**, **PORTLAND, OR**
  - **PAWS FOR A CAUSE**
    - Bring your furry or human friends and raise community awareness about Parkinson’s disease.
    - **See above and start the fun now!**

- **SAT, SEP 22**, **PORTLAND, OR**
  - **OPTIONS & OPPORTUNITIES**
    - Mark your calendars now for our 29th annual PD symposium.
    - Detailed information above; registration will open in July.

- **SAT, SEP 22**, **BAKER CITY, OR**
  - **THE GREAT SALT LICK CONTEST & ART DISPLAY**
    - Join OPB’s Art Beat CircuitArt Art Center on Saturday, 5/22/12, 8 pm.
    - See www.whidttdesign.com for more details on this unique fundraising event and animal art show!

### NEWLY DIAGNOSED WITH PD?
**EVERY OTHER MONTH** the OHSU PD office offers new people recently diagnosed with PD and their spouse or family member.
Participate may ask any and all questions of a PD specialist and long-time patient.
$20/person, refreshments served. Call Julie Bolte at 503-484-9504 for more information.

### What’s Inside
- **Cover Story:** Understanding Pain in PD (continued inside)
- **Directors’ Corner:** Growing Options & Opportunities
- **Ask the Experts Panel**
  - **Necesario vs. Necesitan:** Final health care decisions. Don’t miss this opportunity to prepare for the future.

### Understanding Pain in Parkinson’s Disease
Jeffrey Wertheimer, Ph.D.
Clinical Neuropsychologist
Cedar-Sinai Medical Center – Los Angeles, CA

Pain is the most common reason people in the United States visit their doctors each year. Although pain is highly subjective and difficult to describe, a working definition is “an unpleasant sensory and emotional experience associated with actual or potential tissue damage.” Its components are physical, cognitive, behavioral, emotional, and perceptual.

Among people who have Parkinson’s disease (PD), pain is a major complaint. In fact, up to 85 percent of people with Parkinson’s report pain as a troubling symptom. Some of these people experience pain so early in the disease that they had to learn to deal with it.

Understanding Pain in Parkinson’s Disease
- **From the Parkinson’s Weekend in Portland**
- **Saturday, Sept 22nd**
  - **9 am - 12 pm**
  - **Register online at www.firstgiving.com/pco**
  - **Saturday, Sept 22nd**
  - **9 am - 3:30 pm**
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### Parkinson’s Weekend in Portland
- **OHSU Parkinson Center of Oregon**
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### VA DRECC
- **Parkinson’s Disease to Go:**
  - **Traveling with PD**
    - **Continued on page 2**

### Other Education Events
- **FRI, JUN 8**, **PORTLAND, OR**
  - **Parkinson’s Disease to Go:**
    - **Traveling with Confidence**
      - **Presented by Allison Lipnicki, LCSW**
      - **Sunday, June 10, 2012**
      - **10:30 am - 4:45 pm**
      - **Location:**
        - **Portland Portland, OR**
        - **Register online at www.firstgiving.com/pco**

### Conference of Excellence
- **2012**
  - **A National Parkinson Foundation**
  - **Center of Excellence**

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A fun and refreshing activity.

Sleep disturbances in PD, Part 2: Nocturia

Nocturia refers to right frequent awakenings during sleep. It is most often defined as two or more urination events at night, but for some, this does not cause a great deal of problem. For others, it can be very problematic. More than 50% of people with Parkinson’s disease in one survey complained of nocturia (Kim, HJ 2009). Generally sleep disruption in PD is caused by several factors. For people who have severe complications, it can be subjective issue generally in regard to falling risk when trying to ambulate to incontinency or nocturia. Definitions vary but it is excessive urination only at night. Nocturia refers to night time urination and is a problem that occurs. For people who have severe complication and can be subjective issue generally in regard to falling risk when trying to ambulate to incontinency or nocturia. Definitions vary but it is excessive urination only at night.

Excessive urination can be related to diabetes, medications, history of kidney stones, severe heart failure, electrolyte imbalances, and excessive intake of fluids. Generally, nocturia occurring more common as people age and can be related to complications such as high salt intake, edema in the lower extremities, reduced kidney function, low blood pressure, and the autonomic nervous system (which regulates the autonomic nervous system controls involuntary functions such as heart rate, breathing, blood pressure, diameter of the pupil, and much more). Nocturia, decreased bladder contractions, or even the use of a urinal are common in people with Parkinson’s disease. The reason for this, however, is not well understood. People with PD who experience nocturia should discuss this with their doctor.

Nocturia can be related to a number of causes, including:

- excessive urination in general
- excessive urination only at night
- bladder storage volume
- or a combination of these three.

Cost and Complications

The educational offerings of the OHSU Parkinson Center of Oregon (PCO) and growth thanks to our partnerships with you, our donor, and organizations like the Brian Grant Foundation. Diseases that cause movement problems can also cause pain. It is possible to feel pain in one leg, while the other leg feels completely normal. It is possible to feel pain in one leg, while the other leg feels completely normal.

The first step is to talk to your doctor who can assess pain through a clinical examination. A person’s perception of pain can be affected by many factors, including physical, psychological, and social factors. A person’s perception of pain can be affected by many factors, including physical, psychological, and social factors.

A physical therapist can help you select and treat the right exercises for your condition. They can also help you develop a routine to prevent and treat pain. A physical therapist can help you select and treat the right exercises for your condition. They can also help you develop a routine to prevent and treat pain.

Understanding Pain in PD

There are several treatment options for pain in PD. These include over-the-counter analgesics, prescription pain medications, and non-pharmacologic treatments. Some non-pharmacologic treatments include exercise, rest, biofeedback, and lifestyle changes.

Pain management is a complex process that involves collaboration between the patient, the healthcare provider, and the care team. Effective pain management requires a comprehensive approach that addresses the physical, psychological, and social aspects of pain.

Assessment and Management

OHSU PCO Working for YOU!

Your doctor may also ask you to describe characteristics of your pain, for example, when do you feel pain? Where in the body is your pain? Does the pain feel hot or cold? Does it feel like a sensation of burning or itching? Your doctor will also be able to feel one or two bumps on the stimulator is being adjusted in the office. You will also be able to feel one or two bumps on the stimulator is being adjusted in the office.

How long do I have to wait before I start seeing the effects of the medication or stimulation?

The goal of programming the stimulator after surgery is to find the right settings for you. This may take between 2 and 12 months after surgery.

What does it feel like to have the stimulator on?

Once the stimulator has been programmed, you will feel different sensations like pins and needles or muscle tightening when the stimulator is being adjusted in the office. You will also be able to feel one or two bumps on the top of your head and the outline of the generator.

So what if I have a stroke? Can I die after surgery?

No, the DBS surgery is a minimally invasive procedure that is specific to you. DBS surgery is a risk/benefit analysis of having the surgery. Some DBS surgery is a risk/benefit analysis of having the surgery. Some DBS surgery is a risk/benefit analysis of having the surgery.

13. Why are the effects so different for some patients?

This may be due to a number of factors, including the patient’s age, gender, and the specific symptoms they are experiencing. For some patients, the effects of DBS surgery may be more noticeable, while for others, the effects may be less noticeable. For some patients, the effects of DBS surgery may be more noticeable, while for others, the effects may be less noticeable.

TRIUMPH STRIKE OUT PD - CELEBRATION

We set our sights on almost 200 therapists in our TEAM-PD Network ready to help you. We have had the surgery. Stay tuned to PCO and PRO updates in the monitors and on facebook for dates and times.

12. What is the “honeymoon period”?

When you have the stimulator on your brain, there is a small amount of swelling that occurs. This swelling actually improves your symptoms temporarily, but cannot be improved with DBS. Your symptoms may improve during this time, but DBS has not been turned yet. This is called the “recovery period” or the “honeymoon period.” However, much like all good
time therapies, it can make the best decision for you.
Nocturia
Continued from page 2

The first step in evaluating night time urination is to complete a voiding diary (see voiding diary below). More in-depth studies or evaluations may be appropriate after this. Basic lifestyle changes that can be tried include:

- reducing the intake of fluids in the later evening (after 7pm)
- discontinuing diuretics and alcohol intake
- elevating the legs when sitting
- using compression stockings if edema is present
- using CPAP if you have sleep apnea
- talking to your doctor about decreasing diuretics (water pills) if you are on these.

If there are safety issues on making it to the bathroom, bedside urinals may be appropriate after this. Basic lifestyle changes that can be tried include:

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- elevating the legs when sitting
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References available upon request.

Multiple system atrophy (MSA), progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) and dementia with Lewy bodies (DBL) are often collectively referred to as atypical parkinsonian disorders. These disorders, also known as Parkinson plus syndromes, can be quite difficult to diagnose early in the disease process as they share clinical symptoms with idiopathic (where the cause is unknown) Parkinson’s disease (PD). Specifically, individuals with these disorders and individuals with Parkinson’s disease (PD) may have diaphoric PD, those with atypical PD (PD plus) often initially get misdiagnosed as PD. Early diagnosis is important since treatment and prognosis of patients with these disorders differ than those with Parkinson’s disease.

What sets the atypical parkinsonian disorders apart from Parkinson’s disease is their rapid progression of symptoms often leading to balance problems and falls within the first three years of diagnosis. Other features, or “red flags”, that help us differentiate these disorders from PD are lack of or poor response to levodopa (Sinemet® or carbidopa/levodopa), eye movement abnormalities, blood pressure fluctuations, early memory trouble and prominent hallucinations.

Progressive Supranuclear Palsy (PSP). PSP is a progressive syndrome resulting in weakness (“palsy”) of the muscles that move the eyes. The term “supranuclear” refers to the nature of the eye problem seen in individuals affected with this syndrome. PSP affects cells in the brain that control mobility, balance, speech, swallowing and behavior. What sets this syndrome apart from PD is its rapid progression with balance problems and falls within the first year of diagnosis. On average, imbalance and stiffness progresses over 5-8 years resulting in great difficulty with mobility, making walking nearly impossible. Other key features include the development of an eye movement abnormality that makes it difficult for affected patients to move their eyes vertically (especially downwards); early changes in mood, behavior, slurring of speech or difficulty swallowing.

Multiple System Atrophy (MSA). As the name implies, this syndrome results from loss of cells in multiple areas of the nervous system. It is much less common than PD and also less common than PSP. Its most distinguishing features include the development of autonomic dysfunction, which can control over the automatic functions of the nervous system. Symptoms may result in bladder control problems, erectile dysfunction and prominent blood pressure changes often resulting in fainting spells. Other common problems include early balance problems, neck or facial dystonia (muscle contractions) and a high-pitched voice. MSA progresses rapidly, often resulting in people being wheelchair bound 3-4 years from the time of diagnosis.

Corticobasal Degeneration (CBD). This syndrome results from loss of cells in the surface of the brain (cortex) as well as the deep structures of the brain (basal ganglia). The most distinguishing feature is the gradual loss of function of one hand or leg (known as apraxia). The affected limb, typically an arm, may be held in an abnormal dystonic (cramped) posture and may demonstrate rapid jerking movements called myoclonus. Problems with thinking and memory may occur early, but true dementia typically occurs only in the advanced stages of the disease. CBD progresses much quicker than iPD, with people typically becoming immobile within 5 years of symptom onset.

Dementia with Lewy Bodies (DLB). This is a unique illness that results from a build up of certain proteins (Lewy Bodies) inside areas of the brain that control movement and motor function. Like PD, individuals with DLB show signs of slowness and stiffness. What sets it apart from PD is the early, progressive and rapid decline in mental function. Other distinguishing features include prominent visual hallucinations and fluctuations in attention or alertness. As with the other atypical parkinsonian syndromes, response to levodopa is typically mild and short lived and treatment is geared towards managing cognitive and psychiatric symptoms. The average survival after time of diagnosis is 8-9 years.

It is important to remember that, while the Parkinson plus syndromes may be more difficult to diagnose and manage than PD, there are treatments that can make a difference in quality of life. In addition to occasional benefit from carbidopa/levodopa for movement, there are medications that may help manage the symptoms of other impacted systems (such as urinary incontinence, low blood pressure, and depression for example). A great deal of benefit can be derived from working closely with a care team of physical, occupational, and people in the US with knowledge about these rare disorders, all of whom should be consulted routinely throughout the progression of these diseases along with your movement disorder neurologist.

To learn more about Ben and to order his book, you can go to his website at http://www.benpetrick.com

Carol Clupny: HI KING SPAIN & RAISING FUNDS FOR THE OHSU PARKINSON CENTER OF OREGON

Visit Carol’s fundraising page at www.firstgiving.com and learn her story and be inspired by yet another individual with young onset Parkinson’s disease, who has been motivated by a disease that tries to make your body do less.

Support her walk across Spain this summer and help raise funds for research here at the OHSU Parkinson Center of Oregon.

Thank YOU, Carol, for your support of our work! We can’t do it without people like you.

http://tinyurl.com/carolclupny

A Must Read: Ben Petrick’s “40,000 to One”

Ben Petrick is one in a million—one of the million plus people in the US with Parkinson’s disease. He’s also been our patient and supporter since he moved back to Oregon after retiring early, at the age of 22, from a professional baseball career as a catcher for the Colorado Rockies because of his PD. Ben and his family are inspirational examples of what it means to live with PD and to make the most of it. Ben has recently written and published a book, “40,000 to One”, about his journey with PD and its profound impact on his life and those around him. Truly it is a must read for all of us touched by PD.

Thank you, Ben, for bearing your heart and amazing story with us all.

To learn more about Ben and to order his book, you can go to his website at http://www.benpetrick.com

–or his blog–


Page 3
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 an observational research study to identify biomarkers of PD progression. A biomarker is a substance or characteristic in our bodies that is associated with the presence of disease, or that changes over time in a way that can be linked to the progression of disease. The purpose of this study is to identify biomarkers of PD that can be detected in a discovery of a biomarker of PD is critical to the development of new treatments. Early detection allows for earlier treatments that could slow or stop the progression of disease. This testing is being done currently available treatment can do. Participants in this study will be invited to return to the study site at least twice a year thereafter. Subjects will be enrolled in the study if you are: 30 years or older at the time of your PD diagnosis. You must also not be taking any medications for your PD if you continue to participate as a healthy volunteer, you must not have a first-degree relative with a Parkinson’s diagnosis or a diagnosis at 30 years old at the time of the screening appointment and have a confirmed diagnosis of PD. The study will use a combination of imaging techniques, collection of blood, urine, and spinal fluid and the participant’s medical charts. This study includes a total of six visits to OHSU for testing. For more information, please contact April Wilson at 503-418-1769 or wilsonap@ohsu.edu. eIRB# 66459.

Do you have Parkinson’s disease and balance difficulties? What is the effect of levodopa on balance in Parkinson’s disease patients? Purpose: The purpose of this study is to examine the effects of levodopa on improving balance in Parkinson’s patients. Participation Requirements: Participation in this study will require one phone visit to determine eligibility, followed by one visit to the clinic. This study requires participants to have a phone visit to determine eligibility and a visit to the clinic. Your balance may resume their usual medication right after testing.
and what the symptoms may look like, as well as how to treat PD.

1. Always travel with a companion & carry some medications you are taking. Most of this information is selected to treat your Parkinson’s disease, so it is reasonable to expect that DBS will help.

2. DBS is the treatment of choice if you have the right symptoms. In fact, DBS is the only thing that can help you feel better and improve your quality of life. DBS is not a cure for Parkinson’s disease. It is a treatment for certain symptoms of PD. DBS does not help improve symptoms like fatigue, depression, anxiety, or sleep disturbances. DBS may not help improve symptoms like handwriting, tremors, or walking.

3. If DBS is not the right treatment for you, you may still have other options.

4. DBS is not for everyone. It is a serious procedure that involves surgery. The surgical procedure is done under general anesthesia. Your doctor will discuss the risks and benefits of DBS with you. The most common risks of DBS surgery are:

   - Infection
   - Stroke
   - Seizure
   - Bleeding
   - Trauma to brain
   - Improperly placed DBS leads or electrodes

The risks of DBS surgery are not fully understood. There may be other risks that are not fully understood.

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UPCOMING EVENTS

Newly Diagnosed with PD?
Every Other Month the OHSU PCO offers a free hour session for people recently diagnosed with PD and their spouse or family member. Participants may ask all the questions of a PD specialist and long-time patient. $20/person; refreshments served. Call Julie Doolin at 503-494-3054 for more information.

OTHER EDUCATION EVENTS

For more information or to register for the below events call Parkinson's Resources of Oregon (PRO) at 503-426-2222. All programs can also be registered for online at eventbrite.com.

SAT, JUL 14 - PORTLAND, OR
PAWS FOR A CAUSE
Bring your furry and human friends and raise community awareness about Parkinson’s disease. See above and start the fun now.

SAT, SEP 22 - PORTLAND, OR
OPTIONS & OPPORTUNITIES
Mark your calendars now for our 29th annual PD symposium. Detailed information above; registration will open in July.

SAT, SEP 22 - BAKER CITY, OR
THE GREAT SALT LICK CONTEST & ART DISPLAY – as featured on OHSU’s Art Beat Crossroads Art Center Saturday, 5:22/12, 5pm. See www.whitdeschner.com for more details on this unique fundraising event and animal art show!

WHAT’S INSIDE

• Cover Story: Understanding Pain in PD (continued inside)
• Directors’ Corner: Growing Options & Opportunities
• What’s Inside
•紐約時報的報導：理解帕金森病的疼痛

Understanding Pain in Parkinson’s Disease

Jeffrey Wertheimer, Ph.D.
Clinical Neuropsychologist
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Pain is the most common reason people in the United States visit their doctors each year. Although pain is subjective and difficult to describe, a working definition is “an unpleasant sensory and emotional experience associated with actual or potential physical damage.” Its components are physical, cognitive, behavioral, emotional, and perceptual.

Among people who have Parkinson’s disease (PD), pain is a major complaint. In fact, up to 85 percent of people with Parkinson’s report pain as a troubling symptom. Some of these people experience pain as an early symptom of Parkinson’s, before their disease has even been diagnosed. Yet, pain in Parkinson’s disease often remains undiagnosed and untreated. Thus, it is important to understand that pain can be part of the Parkinson’s disease and to learn how to manage it.

CAUSES OF PAIN IN PARKINSON’S

Pain researchers use a classification system that is based on the separation of tissue pain receptors from the nerves that transmit pain signals. Pain can be classified as nociceptive, which relates to tissue damage, or as neuropathic, which implicates the pain receptors in the skin, bones or surrounding tissues; as neuropathic, indicating pain arising in nerves; or as a mixed pain syndrome involving both nociceptive and neuropathic pain.

In Parkinson’s, most pain experiences seem to result from tissue that is injured or has the potential to be damaged: causes include persistent tremor, muscle rigidity, dystonia, musculoskeletal injury (i.e., sprains, bruises, bone fractures resulting from a fall etc.), burns and inflammation. The pain is typically well-localized to the affected body part; it may fluctuate with the medication dosage. Pain caused by dystonia can be diagnosed when there is visible twisting, cramping or posturing of the painful body part. The many common areas of the body where people with Parkinson’s disease experience pain are the neck, upper back and extremities.

In Parkinson’s, neuropathic pain is less common than nociceptive pain, and includes a number of conditions not directly related to PD, such as the side effects of certain pain, carpal tunnel syndrome, diabetic neuropathy, and peripheral neuropathy. The pain may present as burning, numbing and tingling, sharp sensations, or electric shock qualities. Pain due to nerve or root disease is most commonly caused by akathisia, an extreme inner restlessness.

Parkinson’s specialists gain insight from the perspective of the pain specialist, and often select treatments based on the nociceptive versus neuropathic classification. In practical terms, it often proves helpful to conceptualize the experience of pain in Parkinson’s as relating to one or more of the following five categories: pain from the muscles or skeleton, pain from nerves or spinal root, pain related to sustained twisting or writting, discomfort from akathisia and pain caused directly by changes in chemicals in the brain due to Parkinson’s.