



THE PADRECC POST

Winter 2008

THE PHILADELPHIA VA PARKINSON'S DISEASE RESEARCH, EDUCATION AND CLINICAL CENTER

“Tip of the Iceberg” Jayne Wilkinson, MD

Recognized Parkinson's symptoms such as tremors or shaking may just be the “tip of the iceberg”.

Parkinson's disease is a diagnosis that is familiar to most of the general public. If you walk down the street and ask people to list the symptoms of this disease, the most common response would be tremor or shaking. Some people might recognize that slowness, or shuffled gait are also common symptoms. A few people may know it can cause poor balance or falls. All of these symptoms are related to movement, and therefore clinicians refer to them as the “motor” symptoms of Parkinson's disease. What most people do not know, is that these well-known symptoms are now being regarded by Parkinson's disease clinicians and researchers as the “tip of the iceberg”. More importantly, although well-known and well-described, these motor symptoms are often not the most debilitating symptoms of the disease.

What are these other, mysterious and disabling symptoms? Clinicians have coined these collectively as the “non-motor” symptoms of Parkinson's. In a nutshell, they refer to all of the other symptoms of Parkinson's disease. There is a long and rapidly growing

list of symptoms. This growing list is a reflection of the fact that every day we are learning that Parkinson's disease affects many parts of the brain and nervous system, not just the “movement center,” known scientifically as the basal ganglia (substantia nigra). It turns out that damage to the neurons (brain and nervous system cells) occurs in many other areas as well. Involvement of these other areas can cause a wide variety of symptoms. For example, the area

continued on page 3...

PD Non-Motor Symptoms

- Depression
- Anxiety
- Cognitive problems
- Psychosis
- Apathy (loss of interest)
- Fatigue
- Sleep disturbance
- Sexual dysfunction
- Urinary dysfunction
- Frequent urination
 - Incontinence
 - Sense of urgency
- Pain
- Excessive sweating
- Drooling
- Visual Problems

The 5 W's of Hospice Your questions answered.

Eileen Hummel and Heidi Watson

What is hospice?

Hospice offers physical, psychological, social and spiritual care to patients and their families facing life threatening illness, death or bereavement. Hospice care emphasizes improving quality of life through pain relief and comfort for patients in advanced stages of disease and at end of life. Hospice not only provides valuable caregiver

and family support at end of life, but also provides bereavement care for up to 11 months after death.

Which services are provided by hospice?

Hospice care includes a range of services, such as pain control,

continued on page 2...

So You Think You CAN'T Dance or Sing with PD...Let Us Prove You Wrong

On November 19th, 2007 Misty Owens and William Wade of the Mark Morris Dance Group (New York City) led patients and caregivers in a morning of dancing and singing. There were many smiles in the room as everyone let loose and discovered that just because they have a movement disorder doesn't mean you "get down and boogie" with everyone else and belt out a tune too!

Patient and Caregiver Education Programs like this one are developed for you and we encourage you to attend these programs to not only learn something new but for a good time and the opportunity to meet others with PD or related movement disorders.



Lisette Bunting-Perry, Eugenia Mamikonyan, Sarra Nazem, and Renee Hower

The 6th Annual Walk for Parkinson was held on April 21st, 2007 on the beautiful Kelly Drive located in Philadelphia. The walk was organized by The Parkinson Council which is the Delaware Valley affiliated chapter of the National Parkinson Foundation. Over 500 walkers were registered for the 10 mile walk/run along the Drive. Monies raised by the walk will go towards research for a cure right in the Delaware Valley. If you are interested in learning more about the walk or The Parkinson Council please check out The Parkinson Council website at www.theparkinsoncouncil.org.



Congratulations

Lisette Bunting-Perry, RN, MScN, Doctoral Candidate at Penn School of Nursing and a PADRECC Nurse Specialist, received the 2006 Writing Excellence Award from the journal, *Neuroscience Nursing*, for her groundbreaking article on palliative care in Parkinson's disease, *Palliative*

care in Parkinson's disease: implications for neuroscience nursing. : An article from: Journal of Neuroscience Nursing.

The 5 W's of Hospice (continued from front page)

symptom relief, skilled nursing care, counseling, spiritual care, physical therapy, and bereavement support. Some hospices also provide complementary therapies, such as massage therapy, reflexology, pet therapy, and art and music therapies. The patient's hospice needs are assessed upon the initial visit to the patient's home.

Where can I receive hospice care?

Most hospice care is given in the home with the family member or members serving as the main caregiver, with the hospice providing support. Frequency of hospice visits can range from one visit a week to daily visits. Hospice care is also available in hospitals, nursing homes, assisted living residences, or private hospice facilities.

When is hospice care appropriate?

The current Medicare benefit guideline for receiving hospice care is advanced stage of disease with 6 months life expectancy. Traditionally, most hospice care patients have had terminal illnesses, such as cancer. However, hospice is available for chronic diseases, such as Parkinson's disease (PD) even though the trajectory of PD can be long and uncertain. The unpredictability of a chronic illness often leads to confusion that prohibits many healthcare providers and families from exploring the possibility of hospice. In general, conditions such as advanced dementia, frequent episodes of aspiration pneumonia, progressive weight loss, total dependence in Activities of Daily Living (ADLs) and total urinary incontinence are

suggestive of late stage disease and warrant a hospice referral.

Who should I talk to about hospice care for myself/for my loved one?

Any health care provider you see for care at the VA can discuss hospice with you and/or provide a hospice referral. Often these conversations are challenging because of the uncertainty about the course of the disease. It can be an uncomfortable topic to discuss because the word "hospice" connotes certain or impending death. However, hospice does not mean that death is right around the corner. Having a discussion about hospice can provide information to help recognize issues surrounding end of life decisions. Additionally, health care providers can help determine if hospice is a good option for you and your family.

New PADRECC Website

Jayne Wilkinson, MD

In January 2007, the Philadelphia VAMC Parkinson's Disease Research, Education and Clinical Center (PADRECC) webpage was established as another avenue of patient outreach. It was designed to be informative and provide assistance to patients in the Philadelphia PADRECC's service area. This is done through seven links on our page located at: <http://www.parkinsons.va.gov/Philadelphia/>.

On the webpage you will find exclusive Philadelphia PADRECC Information:

- Our Staff Bios
- Directions to Our Location
- Our Services Offered
- How to Schedule an Appointment
- Patient Education Resources & Links
- What's New at Our PADRECC.
- PD Challenge

Come through anytime and take a tour of the website. There are always new and exciting things to the webpage so visit often.

Tip of the Iceberg

(continued from front page)

of the nervous system that controls smell is affected, therefore patients with Parkinson's disease cannot smell normally. Symptoms are as wide-ranging as visual problems to constipation.

Most patients will experience at least one or more of these symptoms and should discuss them with their clinicians. Some of these symptoms can be treated with medications or other interventions. Other symptoms cannot, but it is equally important to recognize that they may be related to Parkinson's disease.

Upcoming Events

January 2008: The PADRECC is introducing a program titled PD 101, which is for newly diagnosed patients to learn more about the disease, the PADRECC program and allow time for individual questions.

April is Parkinson's Awareness Month

April 7th, 2008: The PADRECC Patient and Caregiver Support Group will resume and will be held on the 1st Monday of each month from 1:30-3:00pm. Please note change of day. The schedule will be mailed out soon with speakers and topics.

April 11th, 2008: the PADRECC, in collaboration with Pennsylvania Hospital's Parkinson's Disease and Movement Disorder Center, will hold a Patient Education Program titled: Love, Intimacy and Parkinson's Disease. The presenter, Susan Calne, RN, has been instrumental in developing patient and professional educational materials on a wide array of Parkinson-related topics, including quality of life, late-stage PD, caregiving and sexuality. Currently she serves as the Outreach Coordinator for the National Parkinson's Foundation Center of Excellence at UBC's Pacific Parkinson's Research Centre.

April 19th, 2008: Seventh Annual Walk for Parkinson's at the Philadelphia Art Museum Area. For more information please contact The Parkinson's Council at: 610-668-4292 or check out their website: www.theparkinsoncouncil.org

Yoga for Parkinsonians

Several Yoga studios and instructors in the Delaware Valley are participating in The Parkinson Council's Yoga for Parkinsonians program. If you are interested in learning more about this please contact The Parkinson Council at 610-668-4292 or check out their website at www.theparkinsoncouncil.org. There is a fee involved for this program.

PD Exercise Groups in the Delaware Valley

Chestnut Hill Rehab Hospital

Cost: Free

When: Every Mon., Wed., at 3:00pm

Contact: Betsy Butterworth
215-233-6204

Dan Aaron Parkinson's Rehabilitation Center

330 S. 9th Street
Philadelphia, PA 19107

Cost: Fee is required

When: Every Thurs. at 1:00pm

Contact: Heather Cianci
215-829-3334

Arcadia University Health Sciences Center

Church Rd./Rte. 73 & Limeklin Pike/
Rte. 152, Glenside, PA 19038

Cost: \$50 for 2 sessions/week for 5 weeks; \$100 for 2 sessions/week for 10 weeks

When: Tues., 11am-Noon,
Thurs., 3:30pm-4:30pm

Contact: Carol Leiper, Ph.D, P.T.
215-572-2144

New Support Group Specifically for Partners of Parkinson's Patients Partners Group: A Promise of Privacy

Time: Saturday, February 9th -
10:00am until 12noon

Location: 330 South 9th Street 2FL,
Philadelphia, PA 19107

Phone: Sandra Cohen
(215) 665-8585

Welcome Our New Staff!

Jayne Wilkinson, MD Clinical Director, Movement Disorders Specialist, first joined the PADRECC team in 2006 as one of our Clinical Fellows after she completed her Adult Neurology residency at the Mayo Clinic in Rochester, Minnesota. Previously, she received her Bachelor of Arts at the University of Pennsylvania, received her medical doctorate from Jefferson Medical College, and completed her medical internship at Pennsylvania Hospital. She has research interests including Orthostatic Tremor, which she studied extensively during her residency. She is currently developing research interests in Parkinson's Disease, which include both pain, as well as racial differences in response to Parkinson medications.

Nick Galifianakis, MD, MPH, Clinical Fellow, graduated from the Johns Hopkins University with a degree in behavioral biology. He studied public health at Boston University before heading to Los Angeles for medical school at the University of Southern California. Dr. Galifianakis also completed his neurology training at USC, and was the chief resident his last year there. He is now a movement disorders fellow at the Philadelphia VA PADRECC. His research interests include studying the effects of traumatic brain injury on Parkinson's Disease, and using ultrasound to detect changes in the brain that occur in patients with various movement disorders.

Nabila Dahodwala, MD, Clinical Fellow, graduated magna cum laude from Duke University with a degree in biology and then went on to Columbia University for her medical degree. She spent one year during medical school on a fellowship in Peru investigating patterns of sexually transmitted diseases and risk factors for burns in children. Dr. Dahodwala recently completed neurology residency at the University of Pennsylvania and is now a fellow at the Philadelphia VA PADRECC. She is also a research fellow through the Robert Wood Johnson Clinical Scholars Program. As a clinical scholar, her research interests include health care disparities, movement disorders and expectations on aging.

PADRECC Staff

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Sarra Nazem : Research Assistant
Joe Noorigian : Research Assistant
Lisa Phoung : Research Assistant
Eugenia Mamikonyan : Research Assistant

New Edition to the Extended Family

The PADRECC's Newest Extended Family Member, Cole Christopher Martine, arrived May 14th, 2007. His proud mommy is Rebecca Martine, RN, Clinical Nurse Specialist.

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