

PEP NEWS

Newsletter of the Parkinson Education Program of Greater Cleveland

OCTOBER 2009

Marilyn Brandt, Editor

OCTOBER MEETING

DR. STEVEN GUNZLER

Movement Disorders Department, Neurological Institute
University Hospitals Case Medical Center

“Living with Movement Disorders”

Wednesday, September 2, 2009 – 2:00-3:30 PM
Cleveland Heights Recreation Center
One Monticello Boulevard, Cleveland Heights, OH

Last names A through M please bring light refreshments.

MARILYN'S MUSINGS

(Marilyn Brandt, President of PEP)

Take a step towards the future! The second annual Step-A-Thon (created by Kim Ganley and sponsored by the Ohio Parkinson Foundation Northeast Ohio Region and its support groups of which PEP is one), will be held on **Saturday, September 26**. Teams of walkers and runners will be raising awareness and funds for Parkinson's research.

My family is very excited about this great event. My husband Ray and I and many of our children and grandchildren will be walking and running as Team Brandt. Each of my children has pledged to raise funds and gather sponsors for the event. We are looking forward to spending a wonderful day in the Cuyahoga Valley National Park while raising money for a great cause.

Lace up your sneakers, grab a friend, and join the fun! Can't make it that day? Support this worthy event by sponsoring a team (maybe Team Brandt or Team PEP), or giving a straight donation. We are raising much needed funding for Parkinson's research

and the money will be used locally. Check out the PEP News back page for more information.

On another topic – do you need help and don't know where to turn? United Way's 211/First Call for Help is a free and confidential information service ready to direct you to the health and human services you need in Cuyahoga, Geauga, and Medina counties. Just dial 211 or use the 211 web site. Professional staff is there to help you 24 hours a day, every day. You can get help from agencies that provide services for senior citizens, services for people with disabilities, support groups, health care, home-delivered meals, and much more. PEP has been a part of 211 for many years.

On a personal note, I'm feeling much better and am glad to be working again. I had an allergic reaction to a very common medication and it took quite a while to figure it out. Don't be afraid to question your doctor if your medications seem to be causing problems. Both Ray and I have had adverse reactions to medications.

DISTURBED SLEEP TIED TO PARKINSON'S RISK

(Nathan Seppa – Science News)

Thrashing and flailing during sleep might be a warning sign of future disease or dementia. People who kick and lash out while fast asleep in bed face a high risk of developing Parkinson's disease and certain forms of dementia, scientists report online in a recent issue of *Neurology*.

The condition, called rapid-eye-movement sleep behavior disorder, results when a person's muscles fail to relax during sleep. "During REM sleep, with the most vivid dreaming, mostly we're paralyzed," says neurologist Ronald Postuma of McGill University in Montreal. "The brain shuts off muscle tone. We want to run but we can't." But in people with REM sleep behavior disorder, muscle tone isn't shut down. "As a consequence, you act out your dreams," he says. "People with the condition have been known to break a hand on a wall, hurt a spouse, or fail out of bed," he says.

Postuma and his colleagues have monitored the progress of 93 people who were diagnosed with REM sleep behavior disorder between 1989 and 2006 at Sacre Coeur Hospital, also in Montreal. The team followed some patients for 15 years or more. Roughly 80 percent were men, and most were enrolled while in their 60s.

Of the 93 participants, 26 have developed a neurodegenerative disease during the study years. Of these, 14 developed Parkinson's disease, and 7 developed Lewy body dementia, which is marked by the appearance of Lewy bodies – abnormal protein deposits – in the brain. Four other study participants were diagnosed with Alzheimer's disease, but the researchers suspect that these patients actually have Lewy body dementia. One person developed a less common neurodegenerative condition called multiple system atrophy.

Among the entire group, the average risk of developing one of these diseases within five years of being diagnosed with the sleep disorder was 18 percent, the scientists calculated. For those monitored for 10 years, the risk was 41 percent, and by 12 years it was 52 percent.

By comparison, in the general population the average lifetime risk of developing Parkinson's disease is only 1 or 2 percent, Postuma says. For developing Lewy body disease, the second-most common form of dementia after Alzheimer's disease, the lifetime risk is roughly 1 to 3 percent, he says.

Researchers at the University of Minnesota in Minneapolis first identified the REM sleep behavior disorder in 1986. "We thought it was a cute clinical observation," says Mark Mahowald, a neurologist at the university. But what started out as an academic curiosity now has been shown to be a serious condition and a harbinger of trouble, he says.

Based on past studies and the new report, he says, "There's now just overwhelming evidence that the majority of people who develop REM behavior sleep disorder . . . will eventually go on to develop a neurodegenerative disease."

The sleep disorder is treatable with drugs, such as muscle relaxers, sedatives, anticonvulsants, and other psychoactive drugs. But these address only the symptoms and not the underlying problem.

In normal REM sleep, the brain stem – where the brain meets the spinal cord – blocks motor neuron communication. The resulting paralysis keeps people from physically acting out their dreams. This safeguard is disabled in the sleep disorder, but scientists have yet to sort out how. A key suspect is a protein called alpha-synuclein, which is a component of Lewy bodies. But the precise role of Lewy bodies and alpha-synuclein in these conditions remains unclear, Mahowald says.

Earlier work suggested that REM sleep behavior disorder may arise from damage in the brain stem that alpha-synuclein orchestrates. The protein is also implicated in Parkinson's disease.

"Right now we don't have any medications that would be termed neuro-protective for Parkinson's," he says. "However, when such a drug is identified – and it's just a matter of time before we find one – just about everyone with REM sleep behavior disorder will be placed on that medication."

Meanwhile, Postuma says, people with the sleep disorder should see a neurologist at least once a year to make sure they aren't developing other problems.

"If a cluttered desk is a sign of a cluttered mind, then what are we to think of an empty desk?"
Albert Einstein (1955)

A TO Z OF PARKINSON'S EXPLAINED AT SEPTEMBER MEETING

Using slides, Dr. Steven Gunzler, affiliated with the Movement Disorders Department of University Hospitals Case Medical Center discussed Parkinson's disease, first described by Dr. James Parkinson in 1817. Over 850,000 Americans suffer from PD, with 60 being the average age of onset. Some 5%-10% have symptoms as early as age 40 (early onset PD), and it is slightly more common in men.

Dr. Gunzler explained that movement disorders consist of both increased movement and decreased movement. He listed several "motor" signs of PD such as softer voice, tremors, rigidity, and slowness of movement. Non-motor signs are bowel, bladder and sexual problems, sweating, sleep disorders, and restless leg syndrome. PD patients also suffer from cognitive and psychiatric problems as well.

What causes PD? The genetic factor is small and the environment is suspect, but the medical profession simply does not know the causes. Some people with PD have involvement in other parts of the brain as well. Treatment options are pharmacologic therapy (treating symptoms) and surgical (Deep Brain Stimulation), which helps motor symptoms but not non-motor symptoms.. However, non-motor symptoms must be treated as well.

Things that can be done outside of medications are education (ask questions, read books, join a support group), and exercise (improves mood, energy level and sleep).

Dr. Gunzler went on to explain several different types of medications and went on to state that many good symptomatic therapies exist. He said that symptoms may vary from person to person, that living with Parkinson's disease is challenging and that teamwork and communication is key.

Research is working on gene therapy and stem cell therapy and significant attention is now on developing medications that will slow the progression of PD.

Many thanks to Dr. Gunzler for his informative and interesting lecture.

DISCLAIMER: The material contained in this newsletter is intended to inform. PEP makes no recommendations or endorsements in the care and treatment of Parkinson's disease. Always consult your own physician before making any changes.

Cut here-----

At PEP, we believe it is very important that people have access to our programs, newsletters, and information without having to pay a membership fee. However, we cannot function without the generosity of donors. By donating, you are recognizing the importance of PEP and enabling our group to continue to provide factual information about this disease to the Parkinson's community. Please help us now with a tax-deductible donation to PEP. In each newsletter you will find a list of donors who have supported our organization with a monetary gift. Please make your check payable to Parkinson Education Program.

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COMING MEETING November 4, 2009

*Ellen Walter
will discuss*

SLEEP PROBLEMS

TRIBUTES

We need your donations to continue bringing you the PEP News and for other expenses. A special thanks to those who contribute at the monthly meetings.

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How to reach us

Phone – 216-556-0607 – or

www.ohparkinson.org/ne/education

The Ohio Parkinson Foundation Northeast Region invites you to join in raising awareness and funds for Parkinson's research, Help us take small steps that result in huge strides at the

Courageous Steps for Parkinson's

**SECOND ANNUAL STEP-A-THON
SATURDAY, SEPTEMBER 26, 2009 – 10:00 A.M.
(Registration at 9:00 A.M.)**

Held at the CUYAHOGA VALLEY NATIONAL PARK
15610 Station Road
(off Riverview Road just south of Route 82 in Brecksville, Ohio)
1, 2, & 5 mile walk/run

Contact us for further details or to register:
P.O. Box 41320, Brecksville, OH 44141
800-630-3193

95% of funds raised are to benefit Parkinson's disease research. Simply ask your friends and family to sponsor you and pledge a donation. You are able to walk as an individual or form a team with a group of up to 5 people amongst companies, churches or neighborhoods. Just designate a walker for the event to represent your team! Call or email today to register! Handicap accessible.

www.CourageousSteps.com or CourageousSteps@yahoo.com

MORE GEMS . . .

The nicest thing about the future is that it always starts tomorrow.

Money will buy a fine dog, but only kindness will make him wag his tail.

If you don't have a sense of humor, you probably don't have any sense.

Seat belts are not as confining as wheelchairs.

A good time to keep your mouth shut is when you're in deep water.

How come it takes so little time for a child who is afraid of the dark to become a teenager who wants to stay out all night?

Scratch a cat and you will have a permanent job.

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of Greater Cleveland
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