

# PEP NEWS

Newsletter of the Parkinson Education Program of Greater Cleveland

SEPTEMBER 2008

Marilyn Brandt, Editor

## SEPTEMBER MEETING

*Christina Whitney, RN, DNSc*

UHHS Neurological Institute, Movement Disorders Center

Assisted by

*Cathie Kernich and Susan Sami*

### Small Group Discussions with Caregivers and PDers

Wednesday, September 3, 2008 – 2:00-3:30 PM

Cleveland Heights Recreation Center

One Monticello Boulevard, Cleveland Heights, OH

Last names N through Z please bring light refreshments.

### Notes from the President's Desk

*(By Marilyn Brandt, President of PEP)*

We bid a fond farewell and good luck to Steve Derman, who has moved to Marshfield, Mass. (near Boston). Steve served as our program chairperson and has been a dedicated and valuable asset to our organization in arranging our monthly programs and as co-editor of *PEP News*. He worked tirelessly for our group and for PD in general, attending conventions in Washington, DC and elsewhere, and we will miss his genial manner and pleasant smile. We wish Steve the best in his new endeavors and hope he will continue to contribute to *PEP News* as our east coast correspondent! (See Steve's article on the 6<sup>th</sup> Annual Young-Onset Parkinson Meeting in this issue.)

On a sadder note, I attended the funeral of Phyllis Klein, who was on the PEP board for many years. Phyllis was always cheerful and very dedicated to the PEP mission of getting as much PD information to the community through our speakers and newsletters. She will be sorely missed.

### Welding Workers are at risk for Parkinson's Disease-like symptoms

*(Excerpted from News of the North.net)*

The next preventable work-related health injury litigation is coming to light in a federal District Court in Cleveland, OH. The toxic fumes from welding rods containing manganese used in welding can create PD-like symptoms in welding workers. There are 2,800 cases pending in the Ohio courtroom presided by U.S. District Judge Kathleen O'Malley.

Symptoms such as tremors, speech impairment and walking difficulty are found at a higher rate among welders. To prevent health injuries welders should be wearing air-filled helmets, which reduce the welder's exposure to the white smoke and fumes. The welding industry is fighting this change, because they don't want to admit there is a problem.

Judge O'Malley ordered attorneys for litigants and welding rod manufacturers to provide a full and complete accounting of payments made to researchers

*(Continued on back page)*

## **New Research Center to Study Cognitive Function in PD**

A new research center, The Center for Collaborative Research on Cognition and Parkinson's Disease being established at Rutgers-Newark, will seek to draw on the experiences of patients and doctors worldwide to explore how memory, learning and other cognitive functions are impacted by Parkinson's Disease. The Center will be headed by Mark Gluck, a professor of neuroscience at Rutgers-Newark.

The Center will link cognitive neuroscientists with doctors who are actually treating PD patients for the purpose of exploring how both the disease and medications used to treat it affect the workings of the brain.

The Rutgers scientists have already set up research programs in large medical clinics as far away as Israel, Budapest and Turkey, where PD patients have been engaged in computer-based testing aimed at assessing everything from their memory to decision-making ability. Gluck and his team have also been working with PD experts in the tri-state area at institutions including the University of Medicine and Dentistry of New Jersey and Long Island-Jewish North Shore Hospital.

"It's still a huge understudied area and there are lots and lots of unanswered questions," Gluck said. "This has been evolving. It's not something we're starting from scratch," he stressed, adding their work has been supported in part by grants from the National Institutes of Health.

Gluck, who also heads up a memory disorders program at Rutgers, said the new center's

proximity to major New Jersey pharmaceutical firms will allow it to work closely with the industry in anticipation that any new discoveries with therapeutic potential can be fast-tracked in the laboratory.

Experts say nearly all PD patients will develop cognitive problems, although they may not occur until the latter stages of the disease. That's why many view the Rutgers center as important to furthering the study of this lesser understood and studied part of the disease. Gluck said one aspect of his research has focused on the effects of Levadopa (L-dopa), the most commonly prescribed medication for treating PD, which some evidence suggests may impair areas of the brain related to learning functions.

## **Steve Derman Reports on 6<sup>th</sup> Annual Young-Onset Parkinson Meeting**

The 6<sup>th</sup> Annual Young-Onset Parkinson Network Conference was held at the Omni Hotel in Atlanta, GA on August 7-9. The emphasis of this year's conference committee was to empower and uplift the attendees, and from the wide range of topics covered, this goal was certainly met.

Program highlights included legal and financial issues overview led by an attorney with PD who discussed legal issues, workplace issues, Social Security Disability, and financial and life planning considerations. Other programs included the psychological impact of living with Young Onset and the prevalence of depression in people diagnosed with PD. There

were sessions on nutrition, exercise with after-hour sessions for gentle demonstrations, including therapy which uses the latest Nintendo Wii action games.

A dinner reception Friday evening featured an engaging performance of the Manga African Dance Company, just returned from performing at the opening ceremonies at the Olympics.

The second day featured presentations on neural stem cells in therapeutic applications, genetics of PD, and the latest approaches for clinical research. There were also sessions for caregivers, coping with grief and loss, medication management, and voice, speech and swallowing issues.

The two days were packed with opportunities to learn as well as network some of the country's leading authorities on PD. For me the most difficult part is saying goodbye to old as well as newly-minted friendships.

## **The Michael J. Fox Foundation Funding Philosophy**

The path from research discovery to the creation of a new treatment is often an extremely long one. The average time for the development of a new central nervous system treatment is currently 13 years.

The Michael J. Fox Foundation is helping to speed up drug development for PD with innovative strategies that identify roadblocks along the therapeutic development pipeline. By sharing the risk of drug development with academic and industry researchers alike, we hope to increase the movement of new treatments into the clinic.

## Noah Budin and his lively guitar enhance our Annual Ice Cream Social

A special treat was in store for the folks who attended our Annual August Ice Cream Social. Acclaimed singer, songwriter and recording artist Noah Budin entertained us with his guitar playing and personality. Drawing from diverse musical influences such as Pete Seeger, Peter Yarrow and others, Noah, who believes strongly in the healing power of music, played folk, blues, and gospel tunes to the delight of those present who willingly joined in and sang along with him.

To cap off the afternoon, we all enjoyed making our own ice cream sundaes, topped with chocolate and caramel sauce and even salted peanuts! To the delight of all, Noah (and his mother who joined the audience) stayed and chatted with the group until the conclusion of the meeting and Noah promised that he would return.

We offer a special thanks to our hospitality chairperson Sandy Zelman who, in her cheerful and efficient manner, handled the details of the Ice Cream Social to perfection.

### Parkinson's study reveals 'blood cells link'

*(Excerpted from Healthcare News)*

A gene and protein which cause PD are controlled by genetic mechanisms in blood cells, according to scientists. They found that the activity of three genes, which control the major component of haemoglobin in the blood, precisely matched the activity of the alpha-synuclein gene, which is seen in elevated levels in Parkinson's patients.

According to the researchers from the University of Wisconsin, Harvard University-affiliated Brigham and Women's Hospital, and the University of Ottawa, their finding suggests that a common switch controls both and raises hope for therapies aimed at keeping alpha-synuclein levels within the normal range.

Dr. Clemens Scherzer of Harvard said: "Simply lowering alpha-synuclein levels by 40 per cent may be enough to treat some forms of Parkinson's disease." He added that the problem of alpha-synuclein buildup in PD patients' brains can now be tackled "from the production site" as opposed to previous research which has focused on simply attempting to remove the excess levels.

## COMING MEETING

October 1

**DAVID E. RILEY, MD**

*"What's New in PD"  
(There's always plenty!)*

## TRIBUTES

We need your donations to continue bringing you the *PEP* News and for other expenses.

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*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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studying the effects of manganese on workers. After the ruling, the paper trail revealed companies were willing to pay more than \$11 million for scientific conclusions to shore up their defense in cases brought by injured workers. Companies had paid for scientific findings claiming no connection between welding fumes and workers health problem, according to court documents obtained by The Center for Public Integrity.

The concern over manganese fumes surfaced in 1937 in the U.S. when MetLife published a pamphlet warning about this problem, which was later re-written to tamp down the scare to workers. More warnings came with the Occupational Hazards Inc. of Cleveland, warning about paralysis from fumes and advocated proper ventilation and calling for worker examinations several times a year for early detection of symptoms.

Still today, workers typically receive the rods unwrapped from the original packaging. If warning labels exist on the original packaging, the worker may not be aware of it.

There have been several settlements in the on-going court proceedings in Ohio federal court. To learn more about the toxic danger of welding, click on [www.publicintegrity.org](http://www.publicintegrity.org).

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One of the winners in an International Pun Contest:

A vulture boards an airplane carrying two dead raccoons. The flight attendant looks at him and says, "I'm sorry, sir, only one carrion allowed per passenger."

## ***PEP NEWS***

Parkinson Education Program  
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## **THE BACK PAGE**

### **Some thoughts to ponder**

Can you be a closet claustrophobic?

If quitters never win, and winners never quit, who came up with, "Quit while you're still ahead?"

If a mute child swears, does his mother wash his hands with soap?

What did we do before the Law of Gravity was passed?

What happens if you get scared half to death twice?

You know that little indestructible black box that is used on planes – why can't they make the whole plane with the same substance?

Why is the alphabet in that order?

Why are there Braille signs on drive-up ATMs?

## **FIRST CLASS MAIL**

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