

PEP NEWS

Newsletter of the Parkinson Education Program of Greater Cleveland

MARCH 2009

Marilyn Brandt, Editor

MARCH MEETING

OPEN DISCUSSION – GROUP INTERCHANGE

Experiences, Highs, Lows, Individual Hopes for the Future

Wednesday, March 4, 2009 – 2:00-3:30 PM

Cleveland Heights Recreation Center

One Monticello Boulevard, Cleveland Heights, OH

Last names N through Z please bring light refreshments.

In case of inclement weather, the Cleveland Heights Recreation Center will follow the closing schedule of the local school system.

Older Drugs Better at Fighting Depression in Parkinson's Patients

Study finds more success when multiple brain receptors are targeted

(U.S. News)

Antidepressants that treat multiple brain receptors may be better at treating depression in people with Parkinson's disease than medications that block only the serotonin receptor, a new study says.

The report, published in a late online issue of *Neurology*, found that Parkinson's patients on the tricyclic nortriptyline were almost five times more likely to have their symptoms of depression improve than were those on paroxetine CR. Tricyclics affect the norepinephrine and serotonin receptors in the brain, whereas paroxetine CR is only a selective serotonin reuptake inhibitor (SSRI).

Up to half of all people with Parkinson's experience bouts of depression.

"The study suggests that we may need to use medications that affect both serotonin and norepinephrine, not just serotonin, in the brain to be

successful in treating depression related to Parkinson's disease," study author Dr. Matthew Menza, a professor of psychiatry and neurology at the Robert Wood Johnson Medical School in Piscataway, N.J., said in an American Academy of Neurology news release.

Tricyclics are part of an older class of antidepressants, first used in the 1950s. They carry a higher risk of overdose and death because of the toxic effects they have on the heart and brain.

Newer medications that target both serotonin and norepinephrine should be tested, Menza said.

Marilyn Brandt, president of PEP, has been under the weather for the past several months and has been unable to write her usual column, *Marilyn's Musings*. We are happy to report that Marilyn is feeling better, back at her desk and looking forward to writing her column for the next issue of *PEP News*.

Review of *My Father, My Brother, and Me* that appeared on the PBS edition of "Frontline" on Tuesday, February 3, 2009

In *My Father, My Brother, and Me*, David Iverson sets off on a personal journey to understand the disease that has taken such a toll on his family. Along the way, he meets some remarkable people – a leading Parkinson's researcher whose encounter with "frozen" heroin addicts led to a major breakthrough; a Parkinson's sufferer given a new lease on life by an experimental brain surgery; and a geneticist who helped identify some of the gene mutations responsible for Parkinson's and who is now working on drugs to fix them.

Iverson also has intimate conversations with fellow Parkinson's sufferers actor Michael J. Fox and writer Michael Kinsley, who describe how they became caught up in the politics of Parkinson's research after the Bush administration greatly restricted federal funding for promising stem cell research in 2001, three years before Iverson got his diagnosis. In speaking about the funding restrictions that President-elect Obama has signaled he might soon reverse, Michael Kinsley tells Iverson, "Six years have gone by [since the stem cell restrictions were imposed], and these are pretty important years for people like me." At the same time, Iverson talks to others like the syndicated columnist Charles Krauthammer, who suffers from a spinal cord injury. While Krauthammer is generally supportive of stem cell research from which he might benefit, he believes President Bush drew an important moral line in the sand. "The fact that [an embryonic stem cell] has the potential to become human, and if unmolested and implanted it will become human, deserves a certain kind of respect," he says.

Until recently, genetics was thought to play no real role in Parkinson's disease at all, but Iverson's family history leads him to enroll in a genetic study at the Mayo Clinic in Jacksonville, Fla. To date, researchers have identified at least six genes where mutations can cause Parkinson's, and while the familial form of the disease remains unusual, it may provide researchers with a ready-made target to fix the genes. "We're a lot closer than we were 10 years ago," says Mayo Clinic geneticist Matthew Farmer, "a lot closer."

Finding a cure for Parkinson's disease may still be on the distant horizon, but in the interim, millions of Americans find ways to live with the condition. Iverson examines one of the experimental surgical interventions that attempts to compensate for the lack

of dopamine that characterizes Parkinson's: a fetal brain cell transplant. "Now we talk about the concept of brain repair," says surgeon Ivar Mendez. "Brain repair, when I was in medical school, was not even something that was thought about. So we have advanced tremendously over these years to be able to understand there's the possibility that we can potentially repair the brain." While some forms of fetal cell transplant surgery appear to have yielded positive results, others have proven disappointing, in some cases even making patients worse. Dr. Bill Langston of The Parkinson's Institute tells Iverson: "There's an old saying in science that research is the process of going up alleys to see if they're blind. And more often than not they are. But that's what we do."

Toward the end of the film, Iverson finds a new source of hope in a very unlikely place: new research that indicates that regular exercise may help delay or slow down the progression of Parkinson's. Says one leading researcher: "It's not at all hard for me to imagine that the results of a properly designed exercise program are going to be more effective than many of the medications and surgeries we have now."

(Marilyn clicked onto PBS Frontline for this review and found that it had received many responses from the public. One of the greatest responses came from people who felt the program might have included how difficult it was to diagnose Parkinson's. Read the letter from Peg Huffman on the back page, which deals with this problem.)

PARKINSON SYMPOSIUM

Saturday, April 25, 2009

10:00 AM – 2:30 PM

at the Tallmadge Community Center
80 Community Road, Tallmadge, Ohio

This year's speakers include Dr. Benjamin Walter of UHHS speaking on *What's New in Deep Brain Stimulation*, David Zid and Jackie Russell, authors of *Delay the Disease* addressing the topic *Exercise and Parkinson Disease*, and Dorian Brown, sharing her program *R.K.T. The 10 Step Treatment for Parkinson's*.

A free box lunch will be provided, and door prizes will be given.

Register for the Symposium by calling
1-800-630-3193 before April 17th.

The secret of a good sermon is to have a good beginning and a good ending; and to have the two as close together as possible.

-- George Burns

Take Action

**Urge Obama to Issue Stem Cell Executive Order!
Contact the White House Today!**

(Dated 2/6/2009 – from Parkinson’s Action Network)

Today, the Coalition for the Advancement of Medical Research (CAMR) of which PAN is a founding member, sent a letter urging President Obama to issue a straightforward Executive Order that reverses President Bush’s policy on embryonic stem cell research (ESCR) and calls on the National Institutes of Health to issue appropriate ethical guidelines. While we have no information causing us to believe that the commitment to reverse the restrictive Bush policy will not be kept, the delay in action from President Obama is beginning to cause us concern.

CAMR, the nation’s leading bipartisan pro-cures coalition representing over 100 nationally recognized patient organizations, universities, scientific societies, and foundations, today learned that President Obama has “guaranteed” he will sign an Executive Order to lift the current federal restrictions on funding for ESCR but there has also been recent press reports that suggest President Obama may be considering linking an Executive Order with legislative action. We believe that such action will cause unnecessary delay.

Make your voice heard and let President Obama know that quickly lifting the ban on federally funded ESCR should remain a priority. Contact the White House by calling the White House comment line at 202-456-1111 or by clicking “Take Action” to send an e-mail to President Obama.

COMING MEETING

April 1

(Rescheduled from February)

Dr. Stuart Youngner - “Ethics in Medicine”

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.

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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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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.

To send a donation, please make your check payable to **Parkinson Education Program** and mail to:

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Bob & Marty Peters

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Luann & John Adams

In Memory of Bob Backhaus

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In memory of Robert Saslaw

His family

How to reach us

Phone – 216-556-0607 – o r
www.ohparkinson.org/ne/education

Letter from Peg Huffman, PEP Member

(The author describes her experiences with the difficulty of diagnosing Parkinson's)

In 1999, I was diagnosed with PD after experiencing balance problems, and stiffness. Because I did not have the more usual symptoms such as tremors on one side of my body, I saw another neurologist for a second opinion. He said I had PD. After some trials on different medications, I was prescribed carbidopa/levodopa, the most common PD drug. Later I was given an additional drug, Requip, which I used until 2007. I was withdrawn from a psychotropic drug which has Parkinson's symptom as a side effect. I exercised doing arthritis pool exercises and yoga. The only symptom not controlled was my balance problem and my falling. I continued to exercise and my falling diminished to the point that I did not fall for quite a while, which led to my doubting that I had Parkinson's disease.

After seeing a neurologist at Cleveland Clinic, I was told that he could not diagnose PD and told me to keep on doing what I was doing – exercise almost daily and medication. However, I fell a great deal in 2006 and 2007, which seemed related to stress or fatigue. I was able to get a U-Step walker in the fall of 2007, which lessened my falls greatly. In January 2008 another neurologist said he could not diagnose me with PD. I consulted my primary neurologist who reviewed my chart and said he did not think I had the disease.

I started to withdraw from carbidopa/levodopa slowly. Because I did not think I had the disease I went back to my former psychotropic medication. When I was down to 1 pill 4x day from 2 pills 4x a day, the old symptoms returned: rigidity, balance problems, and tremors. Others said I had a shuffling gait. I was placed back on carbidopa/levodopa and taken off the psychotropic medication and put on a drug which did not cause Parkinson's symptoms.

When I asked my primary physician if my PD symptoms were from the psychotropic drug or were from PD, she said it did not matter as the treatment was the same. In addition to the carbidopa/levodopa medication, I continue to exercise at least five days a week and I watch for signs of stress and fatigue which trigger symptoms. I use HALT.

Don't get too hungry, angry, and lonely or tired, which helps me one day at a time

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Parkinson Education Program
of Greater Cleveland
2597 Guilford Road
Cleveland Heights, OH 44118

FIRST CLASS MAIL

We try to keep our roster current.
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