

# PEP NEWS

Newsletter of the Parkinson Education Program of Greater Cleveland

APRIL 2010

Marilyn Brandt, Editor

## APRIL MEETING

**JAY L. ALBERTS, PhD**

Department of Biomedical Engineering, Center for Neurological Restoration,  
Cleveland Clinic Foundation

***“Improving Motor Function for PD Patients:  
brain surgery or exercise?”***

**Wednesday, April 7 – 2:00-3:30 pm**

**Cleveland Heights Recreation Center  
One Monticello Boulevard, Cleveland Heights, OH**

**Last names A through M please bring light refreshments.**

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

## NOTES FROM PARKINSON'S ACTION NETWORK'S 16<sup>TH</sup> ANNUAL RESEARCH & PUBLIC POLICY FORUM STREAMED LIVE VIA COMPUTER FROM WASHINGTON, D.C., ON FEBRUARY 17, 2010 (by Marilyn Brandt, President of PEP)

The following is a summary of the three main subjects addressed by the Forum and compiled by me.

The first item on the agenda was the need for Parkinson's Disease Data. It is remarkable *how little we know about Parkinson's disease* – even in terms of such basic questions as: 1) How many people have the disease? 2) What factors are correlated with developing Parkinson's? and 3) Are there particular “hot spots” of the disease in this country? PAN worked with the National Multiple Sclerosis Society to get *the National MS and Parkinson's Disease Registries Act* (HR 1362S/1273) introduced in Congress.

To develop the registries, the federal government will use a methodology that *relies on information from existing databases*, such as Medicare, Medicaid, the Department of Veterans Affairs, state registries, pharmacy databases, death certificates, and medical institutions.

The data collected shall include at a minimum, *age, ethnicity, gender, occupation, military service, geographical location, and family history* of individuals who are diagnosed with the diseases. The information gathered through the registries *will provide a foundation for evaluating and*

*understanding disease factors* such as geographic clusters of diagnoses, variances in the gender ratio, disease burden, and changes in health care practices. In addition the data will give us the ability to examine *changes over time*, such as an increasing rate of young-onset Parkinson's disease.

(Continued on next page)

(continued from previous page)

It is our hope that *these registries will facilitate* research that may lead to discovery of breakthrough treatments, and one

day a cure, for PD, MS, and other neurological diseases

The second item on the agenda was the Biomarkers Initiative. Francis Collins, MD, PhD, Director of the National Institutes of Health (NIH), spoke to the Forum participants about Parkinson's research and other initiatives at NIH. A highlight of Dr. Collins's remarks was his announcement of a new Parkinson's disease biomarkers initiative recently approved by the National Institute for Neurological Disorders and Stroke (NINDS). The goal of this much-needed initiative is to pinpoint a biomarker for PD that would be helpful in the development of disease-modifying drugs. Having a validated biomarker would allow us to conduct clinical trials earlier in the disease progression and much more quickly. The initiative would be conducted at clinical sites and data-biospecimen imaging centers nationwide.

The third item on the agenda was the Department of Defense Neurotoxin Exposure Treatment Parkinson's Research (NETPR) program, created in Congress in 1997. Surprisingly, the NETPR program is the only Parkinson's-specific grant program in the federal government

Nearly 80,000 veterans are being treated for Parkinson's disease. Every NETPR program grant must have a direct warfighter application. Troops are often exposed to a wide range of toxins and other external stressors, such as head trauma, that may lead to the development of PD. The program tries to understand how these exposures occur, the incidence of disease afterwards, and how these conditions can be prevented, treated, or cured.

The research project has found that there is a cluster of genes working together that influence environmental susceptibility for PD. Characterizing these gene clusters would provide biomarkers to predict susceptibility, better PD diagnosis, and specific interactions.

There is clearly a PD connection. Military deployment increases the risk of PD nearly twofold. The Department of Defense is looking at traumatic brain injury, depression, chemical exposure (for example, combating malaria from mosquitoes), sleep deprivation, population vulnerabilities, and neuroplasticity and neurogenics.

Genes load the gun – environment pulls the trigger.

But, in addition to helping protect our soldiers, any research breakthroughs in prevention, detection and treatment are immediately applicable to civilians with Parkinson's disease – particularly the 60,000 newly diagnosed cases each year.

NETPR has funded over \$300 million of Parkinson's research since its inception. The yearly funding amount varies – it has been as low as \$10 million and as high as \$26.5 million – and typically averages \$25 million per year. But funding for NETPR is not automatic. Each year, PAN must lead the effort to make sure Congress funds the NETPR program so that it can continue doing this vital research. We rely heavily on our advocates to communicate with their Members of Congress on how important the NETPR program is.

---

## COME DANCE WITH ME

Within the last 50 years, scientists have recognized music's therapeutic value for people with neurological conditions. In 2001 the Brooklyn Parkinson Group teamed with a local professional dance

company to develop *Dance for PD* classes. The dancers and caregivers reported increased flexibility and strength and improved balance and posture. Similar dance programs were started in Phoenix, Tacoma, and the Bay Area. While rigorous scientific studies on the therapeutic effect of dance are scarce, the anecdotal evidence of the benefits for PD is compelling.

The Parma Hospital Parkinson Support Group, has arranged for a pilot dance program. "Come Dance with Me," led by Fred and Dianne Discenzo, is a fun-filled session of music and movement based on popular ballroom dance steps and uses some of the techniques of dance for Parkinson programs. This hour long program is held on the second Saturday of the month at 11 a.m. at the Parma Hospital Education Center at 7300 State Road in Parma, Ohio. People with Parkinson's are invited to leave their troubles at the door and "Come Dance with Me."

Please contact Joyce Eisenmann at 216-524-6354 if you would like further information about this program.

---

**FYI** – Sweden's Karolinska Institute says it will give an honorary degree of medicine to Michael J. Fox for his work to raise money and awareness for Parkinson's disease. The institute, which awards the Nobel Prize in medicine, says the Michael J. Fox Foundation for Parkinson's Research has donated more than \$175 million since 2000.

## BASIC INFORMATION REGARDING PD

# EXPLAINED AT MARCH MEETING

We were pleased to present as our speaker at the March meeting Joseph Zayat, MD of the Cleveland Clinic. He explained that Parkinson's Disease begins before symptoms occur. It is not easy to make a diagnosis of Parkinson's Disease since its symptoms are so varied. In addition to tremor and rigidity, other characteristics are constipation, orthostatic dizziness and hypertension, drooling and runny nose, dry feet, and bladder symptoms such as urgency. Other changes are memory impairment, diminished sense of smell, depression, sleep disorders, and hallucinations.

Neuroimaging is useful to rule out unforeseen conditions and should be done in the course of the condition to rule out other diseases.

Dr. Zayat then listed the various medical treatments available, stressing that medications are tailored to each person's needs. Since PD is dynamic, conditions change and therefore medications change.

Surgical management of PD consists of several procedures, all having risks and benefits.

Many thanks to Dr. Zayat for his informative talk.

Also speaking briefly was Thomas Mera from Cleveland Medical Devices (CleveMed), an established medical engineering company that designs devices to help study movement disorders such as PD.

Some in the group were already familiar with one of their current medical devices being developed with local hospitals, which uses a small wireless motion sensor placed on the finger to record features of Parkinson disease such as tremor. Tom's purpose was to invite the group to join the Movement Disorder Focus Group. As a participant, you will be contacted about future opportunities to get hands-on experience with CleveMed's medical devices, test them out, and provide valuable feedback. Sessions will last no more than a few hours each and will allow you to learn more about CleveMed and how they are working to improve patient therapies. Lunch will be provided.

Those present who were interested could sign up right away. CleveMed is located at 4415 Euclid Avenue (216-426-0365). Others interested can call the above number or sign on to <http://www.clevedmed.com/Kinesia/overview.shtml> for more information.

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

## MAY 5<sup>th</sup> MEETING

**Open discussions:  
Patients/Caregivers**

*Led by Jan Bohinc, ACSW  
from Judson*

## 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:

22171 Harms Road  
Euclid, OH 44143

Gene & Dawn Kotonski  
Rudolf Kuchenmeister  
Betty & George Putrich  
Ted & Linda Ratica

### In Honor of

Arthur J. Ness – by Ruth M. Ness

### How to reach us

Phone – 216-556-0607 – or

[www.ohparkinson.org/ne/education](http://www.ohparkinson.org/ne/education)

*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.*

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.

Name \_\_\_\_\_  
\_\_\_\_\_ Amount \_\_\_\_\_

In \_\_\_\_\_ honor/memory  
of \_\_\_\_\_

Mail to: 22171 Harms Road, Euclid, OH 44143

**Another Reason I Can't POSSIBLY Have  
Parkinson's  
(Anonymous)**

Ok, we already know that caffeine is supposedly neuroprotective and has a role in preventing Parkinson's disease. I have been drinking coffee since I was 14. I have Parkinson's.

We already know that nicotine is supposedly neuroprotective and has a role in preventing Parkinson's disease. I've been a cigar smoker since I was 17. I have Parkinson's.

Here's a NEW reason why I can't possibly have PD. People who regularly take the over-the-counter painkiller ibuprofen may have a lower risk of getting Parkinson's disease, a new study says. Researchers from the Harvard School of Public Health studied more than 136,000 people over six years and asked them about their use of aspirin, ibuprofen and acetaminophen, all classified as non-steroid anti-inflammatory drugs. During the study, 293 people developed Parkinson's disease. That's 0.2 percent of the people. The researchers said in a news release that people using ibuprofen were 40% less likely to develop PD than people who didn't. Also, people who took higher amounts of ibuprofen were less likely to develop PD than people who took smaller amounts of the drug. The results were the same regardless of age, smoking, and caffeine intake, they said. I'd been a regular taker of ibuprofen since my 20s when I first developed arthritis in one of my knees. So, if this is all true . . . I can't POSSIBLY have Parkinson's disease.

So, what the heck is my neurologist talking about?

***PEP NEWS***

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

**CLASS**  
**MAIL**

We try to keep our roster current.  
If you no longer wish to receive this bulletin,  
please call 216-751-5109 to cancel.

**FIRST**

## **Depends on Your Age**

You no longer think of speed limits as a challenge.

You sing along with elevator music.

Your eyes won't get much worse.

Your investment in health insurance is finally beginning to pay off.

Your joints are more accurate meteorologists than the national weather service.

Your secrets are safe with your friends because they can't remember them either.

You can't remember who sent you this list!