

PEP NEWS

Newsletter of the Parkinson Education Program of Greater Cleveland

MAY 2010

Marilyn Brandt, Editor

MAY MEETING

OPEN DISCUSSION: PATIENTS / CAREGIVERS

Led by Jan Bohinc, ACSW
Judson Retirement Community

Wednesday, May 5th – 2:00-3:30 pm
Cleveland Heights Recreation Center
One Monticello Boulevard, Cleveland Heights, OH

Last names N through Z please bring light refreshments.

MARILYN'S MUSINGS

(Marilyn Brandt, President of PEP)

Happy Spring!

What a glorious spring Northeast Ohio has had so far. A month of growth in four days. Daffodils, tulips, weeping cherry trees, magnolia trees, pear trees, violets, myrtle, dogwood trees, Korean azaleas, and trilliums, all blooming at the same time. Nature is a wonderful thing and gives us a feast for our eyes and all our senses.

We, in the Parkinson disease and related disorders community have a wealth of material too for our senses. We have excellent movement disorder specialists—doctors, clinical nurse specialists and support people, speech, occupational and physical therapists, caregiving and elder law people, and our educational and support group meetings. We can access and read many articles about PD in books, periodicals and on our computers. Our NE region has symposiums twice a year. We have the Courageous Steps Walk in September and now the Parkinson's Boot Camp on Saturday, May 22nd (see enclosed flyer), with all kinds of exercise, stress management, PD focus groups, speech therapy, food and drink. We have countless ongoing research studies and the national groups like the Michael J. Fox Foundation The Parkinson Disease Foundation, the Parkinson's Action Network, the National Institute of Neurological Disorders and Stroke division of the NIH, and many others. And don't forget the world organizations like We Move and the World Parkinson Congress.

Now, if we can all work together (that includes you and me and all these groups) and use our senses, hopefully, the cure for PD will be right around the corner.

***FYI** - For the first time ever, on Friday March 26, the US Senate designated April as Parkinson's Awareness Month. Parkinson's Action Network encourages all PD advocates across the country to work with their state and local governments to raise awareness of PD in their communities.*

THE MASK OF PARKINSON'S

(Zikkir Health News)

Linda Tickle-Degnen, professor and chair of Occupational therapy in the Graduate School of Arts and Sciences at Tufts University is one of the researchers exploring the communications hurdles faced by those with Parkinson's disease and how they can be overcome. She studies a video of a man sitting alone, speaking about a wedding he recently attended. On the surface, there's nothing unusual about the conversation but as the tape goes on, a curious flatness in his voice and manner are evident.

To the untrained eye, the man appears disinterested, even bored. But to Tickle-Degnen, it's clear that the subject, a PD patient, is exhibiting "facial masking," a symptom in which facial muscles become immobilized, leaving patients with blank expressions.

"The face is the primary way we communicate with other people," says Tickle-Degnen, who has been researching nonverbal and verbal communication among people with PD and other diseases for the past 20 years. "We tend to believe the actions of a person more than their words. So a person with PD may be saying that they are really enjoying life, but may not be believed."

Work being done at the Tufts Health Quality of Life Lab, which Tickle-Degnen directs, could be instrumental in helping people with PD express themselves better and be understood more clearly. Right now, the research is focused on improving communication in an area where many such patients have important relationships – the health-care system.

"Practitioner-patient interactions are social relationships," says Tickle-Degnen. "If a neurologist, speech therapist or occupational therapist gets the feeling that the person they're working with is disinterested or depressed, then this relationship can be affected." She notes that even experts sometimes fail to ask patients with PD about their feelings because facial masking hides depression, deception, hostility and apathy. "If there were a way that we could train practitioners to better detect how positive or negative a person was feeling, we could help strengthen these relationships," Tickle-Degnen says.

While emotions may not be visible on the faces of many people with PD, it is possible to find out what they are feeling if you focus on what she calls "reliable cues," the ones that don't change even with facial paralysis.

Tickle-Degnen and her team of researchers have conducted and videotaped 500 interviews with PD patients as part of their research. A typical interview consists of a series of positive ("what do you enjoy

doing?") and negative ("describe a frustrating event that occurred last week") response questions. Subjects are then rated using a coding system Tickle-Degnen developed, called the Interpersonal Communication Rating Protocol. Using it, coders look at among other things, the frequency with what subjects express nonverbal clues. "For all interviews, we analyze facial behavior, body movement and voice, and we also do text analysis," says Tickle-Degnen. "I ask them about their feelings: if they are happy, unhappy and so on. We're looking for particular cues."

Beyond feeling and mood, personality is also expressed through the body. "People who are very sociable and extroverted tend to use large motions with their hands and tend to be very facially expressive, meaning that their faces are showing a lot of motion," says Tickle-Degnen. Yes, motion, she says: their faces are moving. "And when they tend to be more introverted or shy, they tend to move less in their whole body. Their body is a little more quiet, and their facial expression is quieter."

Although the research is still being collated, some critical findings have emerged. One is that when patients are asked positive questions, their facial masking is less intense, says Tickle-Degnen.

"This is really important for people who work with PD patients, since many tend to do what is called a problem-oriented interview. "They ask, 'What problems are you here to talk to me about today'? Typically, nobody asks people who PD about positive things, because there's not much positive emotion on their faces," she says.

The next step for the researchers is to train health-care practitioners how to interpret their patients' nonverbal cues and help them focus more on what the patients are actually saying—a practice that goes against the way people intuitively read one another, which is visual.

Once the coding process for the interviews is complete, short clips of them are shown to Boston-area doctors and therapists, whose own responses are then studied and analyzed.

"We ask the practitioners to tell us how happy, depressed or cognitively intact they think the person is. We also ask them to tell us how sociable they think the person is and what mentally challenging activities he or she might be interested in," says Tickle-Degnen, whose research has been supported by the NIH's National Institute of Neurological Disorders and Stroke and National Institute on Aging.

(Article to be concluded in the June edition of PEP News.)

BENEFITS OF FORCED EXERCISE DISCUSSED AT APRIL MEETING

At the beginning of his talk, Jay Alberts, PhD, affiliated with the Department of Biomedical Engineering, Center for Neurological Restoration, Cleveland Clinic Foundation, posed the question, "Is Exercise Medicine for Parkinson's Disease"? He then went on to list the therapies currently in use for PD, including pharmacological, surgical, and behavioral. All of the above focus on treating symptoms. What is most needed, he claims, is a neuroprotective therapy for PD. Forced Exercise (FE), using tandem bikes, can favorably influence the brain, facilitating neuroregeneration.

Human studies using voluntary exercise showed the magnitude of improvement small and the effects not sustained after exercise therapy was discontinued. The exercise regimen prescribed focuses on maintaining abilities rather than improving them.

Raising the bar in terms of intensity was the next step. Using a tandem bike, the exercise rate of 50-60 rpm was increased to 80-90 rpm. FE, using lower extremities, saw improvement in upper extremities. The hypothesis indicated that forced, not voluntary exercise, will result in global motor improvements in PD patients. Two weeks after exercise therapy is discontinued, patients still show good results. However, after three weeks, most benefits are negligible.

So far, the results are promising but preliminary. No cardiac problems have risen and it may be possible to reduce anti-PD meds during an FE exercise routine. Patients should always consult their physician before starting any exercise program.

So, "Is Exercise Medicine for Parkinson's Disease"? Dr. Alberts thinks "yes." Many thanks to Dr. Alberts for a most stimulating program.

PARKINSON'S BOOT CAMP

(By Kim Ganley & Linda Ippolito)

With the visions and hard work of many, we are proud to announce the Parkinson's Boot Camp on May 22, 2010, from 9:00-2:00pm at Cleveland Hilton East, located in Beachwood just off Interstate 271. University Hospitals Movement Disorder Center, in partnership with Courageous Steps for Parkinson's and the Ohio Parkinson Foundation Northeast Region, has developed a spectacular hands-on event for the PD community which will aid patients in the day-to-day management of Parkinson's disease. (Continued on back page)

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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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Mail to: 22171 Harms Road, Euclid, OH 44143

JUNE 2ND MEETING

**ALL ABOUT
NUTRITION**

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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How to reach us

Phone – 216-556-0607 – or
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.

PD Boot Camp (*continued from previous page*)

The event boasts breakout sessions on physical therapy, dance, stress reduction, nutrition, yoga, and relaxation techniques. The camp will even hold a special session specifically for caregivers. The day's agenda will focus on teaching attendees exercise techniques, mind and body wellness practices, and invigorating skills to manage their Parkinson's. The PD Boot Camp will showcase presenters Kimberly Ganley, President of Courageous Steps for Parkinson's, Vice President of Ohio Parkinson's Foundation Northeast Region; David Riley, MD, University Hospitals Center Director, Movement Disorder Center; Benjamin Walter, MD, Medical Director, Deep Brain Stimulation Program; and David Zid, Delay the Disease – Exercise and Parkinson's.

"I am so grateful that we have partnered with two brilliant organizations that share in the passion and long term goal of the development of a local PD exercise program," said Ganley. "It is so exciting to be able to offer this *first of its own kind* program to the Cleveland area. I hope everyone can attend to share in some great knowledge because we understand that together we can and will make a huge difference in the lives of many," she said.

Reservations need to be made as space is limited. If the event is a success, which we hope it is, there will be more events and exercise programs made available to those with PD. Funds raised at the Courageous Steps 2009 Walk are to be presented to University Hospitals Neurological Institute to help fund this event. So mark your calendars for the **PD Boot Camp on May 22nd** and also for the Courageous Steps Walk which takes place on September 25th.

WORDS TO LIVE BY

The trouble with bucket seats is that not everybody has the same size bucket.

Money can't buy happiness – but somehow it's more comfortable to cry in a Corvette than a Yugo.

Do you realize in about 40 years, we'll have thousands of old ladies running around with tattoos? (And rap music will be the Golden Oldies?)

After 50 if you don't wake up aching in every joint, you are probably dead.

Always be yourself because the people that matter don't mind, and the ones who mind don't matter.