

# PEP NEWS

Newsletter of the Parkinson Education Program of Greater Cleveland

AUGUST 2008

Marilyn Brandt, Editor

## BIO

Singer, songwriter, recording artist and performer, Noah Budin brings his unique blend of traditional, contemporary and original folk/pop/rock music to the stage with passion, power and humor. Drawing from a well of diverse musical influences, genres and artists such as Folk Blues, Gospel, Israeli, Eastern European, Pete Seeger, Peter Yarrow, James Taylor and Paul Simon, Noah Budin inspires, informs and entertains.

## AUGUST MEETING

### ICE CREAM SOCIAL

\*\* SPECIAL APPEARANCE \*\*

### NOAH BUDIN

### “Music as Medicine”

Mark your calendar!

Bring your friends!

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Wednesday, August 6, 2008 – 2:00-3:30 PM

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

## NOTES FROM MARILYN

*By Marilyn Brandt, President of PEP*

Recently, I took a much-needed three-week vacation to visit my oldest son in Moscow, Idaho. During the trip, I attended my twin grandchildren's high school graduation and visit the Pacific northwest. We camped in Olympic National Park, hiked the High Rain Forest, and looked in awe from the Olympic Mountains across the San Juan Strait to Canada, and across Puget Sound to Mt. Baker and Mt. Rainier. We drove through the North and South Cascade Mountains, across barren volcanic land to the Grand Coulee Dam on the Columbia River, the forests near Spokane, and the green wheat and lentil fields of the Palouse. What an experience in the extremes of weather, flora and fauna, and geology.

It was a wonderful trip, but I must admit that it was a very difficult choice to make. I really wanted to see my twin's graduation, but I felt very torn about leaving Ray. As his primary caregiver and wife, I feel so much responsibility for his care and well-being.

Research and professionals constantly tell us that caregivers should take breaks, not only for their own mental and physical health, but for the well-being of their loved one. These breaks can range from just a few hours during the week, to an overnight, or an extended trip. However, actually allowing myself to leave Ray was very difficult.

Luckily, I have a great support system. My children and our paid caregivers took wonderful care him while I was gone. And I was able to relax and recharge my batteries. I was surprised by how long it took me to settle down. And I found that I really didn't want the vacation to end. But, by the end of three weeks, I was ready to return home and to return to my role as wife and caregiver. My vacation helped me to become an even better caregiver to my husband.

I recommend a vacation for all of you!

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## Occupational Therapists Use Wii for PD Study

*(Excerpts-Eureka Alert – 4/11/2008)*

It's Ingrid Bell's turn at bat. She steps up to the plate, awaiting the pitch. A 70-mph fastball soars towards her. She swings and connects with the ball.

This baseball game's not taking place on a field, and there's no real bat or ball to be seen. Mrs. Bell is playing the Nintendo Wii as part of her occupational therapy. She is among 30 PD patients participating in a Medical College of Georgia study to determine if occupational therapy enhances the treatment of the disease.

"Occupational therapy looks at how the illness affects the patient's whole life, from the psychological, cognitive and sensory motor standpoints," says Dr. Ben Herz, assistant professor of occupational therapy in the School of Allied Health Sciences and a study principal investigator along with Dr. John Morgan, neurologist. "Our therapists are responsible for helping someone maintain or gain their independence with functional activities."

While occupational therapy is frequently used in the comprehensive care of PD patients, evidence is needed to support its short- or long-term effectiveness, says Dr. Herz.

"We're hoping to show a slowing of the progression of the disease and a decrease in medication while increasing function. If we can teach patients to exercise and do functional activities, maybe we can have them take less medications," he says.

"Because the Wii is interactive and you have to do

certain functional movements to be successful, it's an effective modality for working with PD patients," says Dr. Herz. "One of the therapists uses the Wii for timing and loosening up, and the other uses it for coordination and balance issues."

Participants also perform functional activities, such as dressing and rolling over in bed; fine motor skills, like circling in word searches and carefully moving blocks in the game Jenga; and stretching.

Early results show at least short-term gains. Therapists set goals for each participant prior to treatment. These goals range from independence with daily living activities, such as cooking, dressing or bathing, to functional activities such as sports and leisure without any adaptation. About 98 percent of those goals have been met or surpassed, Dr. Herz says.

### GRANT TO FUND PARKINSON'S STUDY

*(Excerpts-PressConnects.com 6/3/2008)*

A Binghamton University professor has been awarded a \$1.33 million grant to study the treatment of Parkinson's disease and the side effects of medicating the chronic illness.

Christopher Bishop, an assistant professor of psychology, will examine ways to minimize abnormal movements that are a side effect of taking high doses of the most common treatment for PD, a compound called L-DOPA.

"Eventually the side effects become as debilitating as the disease," Bishop said.

L-DOPA is basically a dopamine replacement therapy, Bishop said.

Treatment comes with notable side effects when L-DOPA is taken at high doses, the

most troubling being abnormal, involuntary movements. Patients coping with the disease for more than 10 years typically take high doses as the disease progresses and the loss of dopamine becomes more rapid. If a patient were to stop taking the drug, he or she would have extreme difficulty moving.

With the grant from the National Institute of Neurological Disorders and Stroke, Bishop will do five years of research attempting to find out what causes the movements and how to prevent or lessen them.

Bishop and his co-workers will experiment with different compounds that could reduce the abnormal movements. He believes the movements might be linked to a chemical that aids in motor memory.

### PD Priority Funding Secured!

Your voices were heard! Thanks to the efforts of the PD community, the Fiscal Year 2008 emergency supplemental appropriations bill, passed by the House and the Senate, contains funding for two of PAN's top priorities this year—funding for biomedical research at the National Institutes of Health (NIH) and drug review at the Food & Drug Administration (FDA).

Thursday, June 26, with a vote of 92-6 the Senate adopted the House's version of the emergency supplemental appropriations bill which includes \$150 million for NIH and \$150 million for FDA for this year. This bill will now be sent to President Bush, who is expected to sign it into law next week. Be sure to thank your Members of Congress for including this important funding.

## INNOVATIVE BREATHING TECHNIQUE DESCRIBED AT JULY MEETING

Carol Baglia, CBP, RRT, of Correct Breathing Concepts LLC, became interested in the Buteyko Institute of Breathing and Health when she herself developed asthma in her forties. Following are the highlights of her talk:

Proper breathing is essential to good health, but what makes breathing faster? Emotions, exercise, eating, environment, entertainment, everything (almost). How can breathing be made slower? By meditation, imagery, prayer, yoga, massage, Tai Chi, fasting, aromatherapy. The proper breathing rate for an adult at rest is 6-14 breaths per minute. It is impossible to breathe too little, and we are probably breathing too much. Ms. Baglia claims that "the faster you breathe, the closer you are to death." Heavy breathing brings on the Fight or Flight response, which is a protective mechanism. The body goes on alert. When it becomes chronic, a condition called Hidden Hyperventilation results and creates medical problems, not only with the respiratory system, but with the heart and other systems.

Your respiratory rate can be regulated by the amount of oxygen and the amount of carbon dioxide in the air and blood. According to the handout provided by Ms. Baglia, "Carbon dioxide is just as important for our health as oxygen. We don't exhale to get rid of carbon dioxide. We exhale to regulate the amount of carbon dioxide in our bodies. There is an optimal level of carbon dioxide that our bodies try to achieve. Too much or too little can be a problem. Breathing too fast or deep eliminates excessive carbon dioxide, and this has some serious consequences for our health." Since carbon dioxide is essential to breathing, how can you retain it? Ms. Baglia's answer is to breathe only through the nose, all of the time, day and night, even during exercise. She goes on to ask, why is nose-breathing so important? The nose has bony ridges, and a warm, moist, filtered environment designed to retain the correct amount of carbon dioxide. So, how do we slow our breathing rate down and increase our carbon dioxide levels? According to Ms. Baglia, the Buteyko breathing techniques are designed to reset your body's natural breathing rate to accomplish this objective.

To learn more about this program, log on to [www.correctbreathing.com](http://www.correctbreathing.com). Many thanks to Carol Baglia for her interesting talk, the handouts, and for donating a book to our library entitled *The Carbon Dioxide Syndrome*, by Jennifer Stark and Russell Stark.

Cut here-----

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

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

Mail to: 22171 Harms Road, Euclid, OH 44143

## COMING MEETING

September 3

DAVID E. RILEY, MD

*"Parkinson's Disease – What  
have we learned?"*

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How to reach us  
Phone - 216-556-0607 - or  
[www.ohparkinson.org/ne](http://www.ohparkinson.org/ne)

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.

## A NOTE FROM STEVE DERMAN

I regret not being able to attend the August meeting and thank everyone in person for the enthusiastic support you've greeted my work as program coordinator.

As some of you may know, we have longed to return to our Boston roots but have waited until both sons completed college. With both sons now in Boston, the time was right for Ava and me to return as well. We will be moving on or about the 16<sup>th</sup> of July so I wanted to thank everyone for permitting me the opportunity to work on behalf of PD.

Time does not permit me to list everyone, but you know who you are. I cannot go without saying thank you to Marilyn Brandt, who is a pillar of strength and enthusiasm when it comes to PD and Lewy Body disease, and I am proud to have her as a mentor. The other person is Miriam Amster. The success of *PEP* News in no small part rests with her. Thanks Mim for all that you do.

Well, as that carton character says . . . "That's all folks."

Thanks again to everyone and may the search to find a cure for PD meet with success soon.

Steve Derman

### ***PEP NEWS***

Parkinson Education Program  
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## THE BACK PAGE

### *The Twenty-Third Pound*

My appetite is my shepherd.  
I always want.  
It maketh me to sit down and stuff  
myself.  
It leadeth me to my refrigerator  
repeatedly.  
It leadeth me in the path of  
Burger King for a Whopper.  
It destroyeth my shape.  
Yea, though I knoweth I gaineth,  
I will not stop eating,  
For the food tasteth so good.  
The ice cream and cookies, they  
comfort me  
When the table is spread before me,  
It exciteth me,  
For I knoweth that soon I shall dig in.  
As I filleth my plate continuously,  
My clothes runneth smaller.  
Surely bulges and excess weight  
shall  
Follow me all the days of my life  
And I will be fat forever.

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