

# PEP NEWS

Newsletter of the Parkinson Education Program of Greater Cleveland

JULY 2009

Marilyn Brandt, Editor

## JULY MEETING

### *DR. JEREMY RICH*

Chair, Department of Stem Cell Biology and Regenerative Medicine  
Lerner Research Institute of the Cleveland Clinic

### *“Potential Impact of Stem Cells on Parkinson’s Disease”*

Wednesday, July 1, 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.

### **Minneapolis Author Publishes *Life With a Battery-Operated Brain***

**A Unique New Step-by-Step Patient Guide to Deep Brain Stimulation for Parkinson’s Patients**

*By Jackie Christensen*

*(Jackie Hunt Christensen is also the author of The First Year: Parkinson’s Disease, An Essential Guide for the Newly Diagnosed and has published numerous articles and editorials regarding both Parkinson’s and environmental issues. In 2006, she won the Milly Kondracke Award for Outstanding Advocacy from the Parkinson’s Action Network in Washington, DC.)*

What would prompt someone to say “Let’s stick wires into someone’s brain, run voltage through them, and see what happens!”? So asks Minneapolis-based activist and author Jackie Hunt Christensen in her important new book, *Life With a Battery-Operated Brain: A Patient’s Guide to Deep Brain Stimulation Surgery for Parkinson’s Disease*. Beyond answering the “whys” that arise in considering Deep Brain Stimulation surgery, Jackie offers her unique perspective in this comprehensive book. This book ([www.lifewithbobb.com](http://www.lifewithbobb.com)) is designed to be a highly readable guide for people with PD, exploring the benefits of this particular surgery on many motor symptoms of the disease. “Deep Brain Stimulation is a process, not an event,” explains Jackie.

The author has firsthand knowledge of the procedure more commonly referred to as “DBS” and lived with PD for more than seven years before electing to be evaluated for DBS surgery. Ultimately, she was deemed a good candidate for the surgery, and DBS seemed like her only logical option—a choice that has been validated post-surgery, as Christensen now enjoys life with most of her motor symptoms well-controlled. PD, the author is quick to point out, does not end, but DBS is meant to be a long-term treatment.

Now Jackie Hunt Christensen offers readers a resource that was previously unavailable: a step-by-step look at her own journey, as well as information  
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on a typical evaluation process, medical statistics, questions to ask neurosurgeons, opinions from other DBS patients, the programming process for DBS, and much more.

“I wrote this book as a way of giving back to the community,” Jackie says. “DBS has given me back so much of my life! I want to share what I’ve learned from my own experience and others to help inform the decisions being made every day by others looking for those same results.”

The book is a must-read for those who are considering Deep Brain Stimulation—and for those who love them. Health professionals can also benefit from reading this book, as certain diagnostic tools and therapies may not be safe for use on DBS patients or require specific precautions.

## **THE LESSER-KNOWN TOLL PARKINSON’S TAKES**

*(By Maiken Scott-excerpted and modified)*

If you recently watched Michael J. Fox’s return to TV with his program “Adventures of an Incurable Optimist,” the toll that Parkinson’s disease has taken on the actor was clear. The tremor, stiffness, and effects on mobility are well-known, but Parkinson’s has another side that’s less recognized, and often catches caregivers off guard.

Lisa Wolper has witnessed many changes in her husband, Tim, since he was diagnosed with PD seven years ago: shaking limbs, a loss of balance, a weakening voice – these are all things the doctors told her would happen. “The one thing I was not prepared for was the psychosis.”

What is known as Parkinson’s Psychosis affects about 40 percent of patients, usually in the later stages of the illness. Wolper says her well-read and kind husband lately has had trouble concentrating. His short term memory is terrible, and he’s become suspicious. Wolper has discussed these behavioral changes with Tim, but says he’s very sensitive about the topic. A common problem, says Matthew Stern, professor neurology at the University of Pennsylvania. For example, many Parkinson’s patients become paranoid, and suspect a spouse of having an affair.

In some rare forms of Parkinson’s, the delusions and hallucinations are caused by the disease as it progresses. But, in the majority of patients, says Stern, the psychosis is a result of the many medications taken to control the physical symptoms.

Stern says: “If we think about what causes schizophrenia, one of the hypotheses is that there is too much influence of the chemical dopamine. And in

Parkinson’s disease we treat these patients by augmenting their dopamine system, by giving them drugs that stimulate their dopamine type receptor, so in a sense we are doing exactly the right thing to cause hallucinatory problems.”

As terrible as the physical effects of PD are, Stern says, the deterioration of the mind is the most devastating: “No matter how bad their tremor and stiffness and all the other motor symptoms of Parkinson’s disease, it’s those patients who have cognitive problems and particularly psychosis that become really disabled in terms of quality of life, and the burden to family; in fact the biggest risk factor of a patient with Parkinson’s entering a nursing home is really hallucinations and confusion.”

Stern describes the difficulties of treating Parkinson’s Psychosis: “If you reduce the medications that cause the psychosis, the physical symptoms get worse. And some of the drugs that could target psychosis have strong side effects.”

A new drug specifically designed to treat Parkinson’s Psychosis is being tested now. New Jersey neurologist Rocco DiPalla is one of the clinical investigators. DiPalla says: “In smaller trials, this drug has been promising as far as treating this condition; the larger study is to see if in broader scale there is still efficacy with this medication.”

If the drug proves to be successful, it will take several years before it is available to patients.

Matthew Stern says scientists keep searching for what he calls “the perfect Parkinson’s drug.” “We haven’t yet found the drug that can stimulate the right dopamine receptors, without stimulating the same receptors that can cause these adverse effects.”

For Lisa Wolper, Parkinson’s disease has changed her husband, her marriage, and her life, and she acknowledges the stress it has put on her as the primary caregiver. “It’s certainly challenged me to be more patient – it’s you know, at times you just want to scream.”

Wolper is hoping that new medications to deal with Parkinson’s Psychosis will come out in time to help her husband Tim.

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### *Beef up your brain – Mind benders*

*Give your brain a workout with brainteasers, crossword puzzles and memory games. Studies have shown that using these tools to stay mentally active can reduce the risks of developing dementia by building and maintaining a reserve of stimulation in your brain. Even following the current political scene can provide a boost to the systems that control attention and learning that are hard-wired into the brain.*

## EXERCISE STUDY TOPIC OF JUNE MEETING

Angela Ridgel, Ph.D., Assistant Professor, Department of Exercise Physiology, Kent State University, described the exercise study in detail, using slides. She explained that animal studies indicated that rapid forced-exercise improves motor function and has neuroprotective properties more than voluntary exercises. Human studies of physical and occupational therapies are shown to be of limited help. Rate of speed seems to be the important factor. The aim of the study is to evaluate upper body motor function before and after stationary motorized cycling and determine how exercise of the lower body affects motor function in the upper body.

A stationary tandem bike is used and set at 80 rpm (voluntary speed is usually 60 rpm). The goal is to find the optimal mode and intensity of exercise for PD. Scores show that mobility improves at the higher speed and this method can be used as an important adjunct to drug therapy. Another benefit of this program is that it will promote cardiovascular health.

As to how long the benefits of this therapy last, Dr. Ridgel said that tests are still under way.

Many thanks to Dr. Ridgel for an interesting and informative talk.

### Researchers believe they have found genetic cause for Parkinson's Disease

*Mainichi Daily News* – A team led by Shoji Tsuji of the University of Tokyo, and Tatsushi Toda of Kobe University discovered that those with a mutation in a gene called GBA are 28 times more likely to contract PD. They now hope to use their finding to explain exactly how the disease is caused, and develop a treatment.

There are an estimated 150,000 cases of PD in Japan. In 90 percent of the cases, however, they are the only members of the family to contract the condition, and the genetic component of the disease has never been identified. However, the team noticed that the GBA gene, which is responsible for causing an unusual condition called Gaucher's disease, also showed a mutation in those with Parkinson's disease.

They examined 534 PD patients and 544 healthy people, and found that 9.4 percent of those with the mutation suffered from the disease, and just 0.4 percent did not. They also discovered that those with the GBA mutation contracted the disease around six years earlier than those without.

"It's the first time that a risk factor has been this clearly identified," said Tsuji.

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Mail to: 22171 Harms Road, Euclid, OH 44143

**COMING MEETING**  
**August 5, 2009**  
**ANNUAL ICE CREAM**  
**SOCIAL!**  
**Join us for group**  
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**and more!**

### 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.

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June & Edward Gottschling  
Alan & Sally Tater

*For all who serve with valor and  
dignity—past and present*  
David W. Carter

### 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.*

## **AUSTRALIAN RESEARCHERS DEVELOP PARKINSON'S WRISTWATCH MONITOR**

**Webnewswire** – Scientists at the Melbourne-based Florey Neuroscience Institute, Australia's largest brain research institute, have developed a wristwatch device that continuously monitors the health status of Parkinson's disease sufferers.

The Victorian State Minister for innovation, Gavin Jennings, introduced the prototype wristwatch at the recent BIO2009 in Atlanta.

The new monitoring device will assist doctors treating Parkinson's patients by recording their symptoms throughout the day, and in the longer term, will assist researchers in developing new drugs for the disease.

"The right dosage and correct timing of dosing has an enormous impact on the wellbeing of a person with Parkinson's disease," said Mr. Jennings. "Currently, neurologists can only check dosage and timing by observing the patient during consultations, which may be at six to eight week intervals."

Some 80,000 people have PD in Australia, with one in five diagnosed before the age of 50. In the U.S., Parkinson's is the most common neurodegenerative movement disorder, affecting about two per cent of the population.

### ***PEP NEWS***

Parkinson Education Program  
of Greater Cleveland  
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## **VERY INTERESTING STUFF**

Each king in a deck of playing cards represents a great king from history:

Spades – King David

Hearts – Charlemagne

Clubs – Alexander the Great

Diamonds – Julius Caesar

The first novel ever written on a typewriter: Tom Sawyer

The state with the highest percentage of people who walk to work: Alaska

The average number of people airborne over the U.S. in any given hour: 61,000

Intelligent people have more zinc and copper in their hair.

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