

PEP NEWS

Newsletter of the Parkinson Education Program of Greater Cleveland

FEBRUARY 2017

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FEBRUARY MEETING

Wednesday, February 1, 2017 – 2 p.m. till 4 p.m.

Jessy Barron, MS, RD, LD from Fairhill Partners, a private non-profit organization, will speak on the Building Better Caregivers program that was piloted last year as well as a couple of similar programs they offer at the Cleveland Hts. Senior Center. This will be an interactive session which among other things will show ways caregivers can relax.

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

From David Brandt

Thank you to Dr. David Riley for speaking at our last meeting in early January. We had a large turnout listen as Dr. Riley commented on two recent developments regarding potential treatments for Parkinson's. He touched on a possible alternative to Deep Brain Surgery (DBS) which utilizes high intensity ultrasound and was recently tested at The Ohio State University. The benefit for this would be to avoid using a scalp incision or a hole in the head. This is not a cure for Parkinson's and is continuing to be studied.

The second development is what he described as a vaccine for Parkinson's which is being developed by AFFiRIS. The vaccine causes the body's immune system to create antibodies against alpha-synuclein, hopefully clearing out the clumps and protecting cells.

We have two articles in this newsletter that touch on both of these developments.

The 19th Annual Parkinson Symposium presented by the Ohio Parkinson Foundation North East Region will occur on April 22, 2017 from 10:00 a.m. to 2:30 p.m. Good news for most of our members is that it will

take place at the Hilton Garden Inn in Twinsburg – much closer to Greater Cleveland. The lead presenter will be Heather Zwickey, PhD National University of Natural Medicine, Dean of Research and Graduate Studies Director, and she will talk on Food as Medicine. She recently talked at the World Parkinson Congress last September. Make sure you attend this no cost event!

TRIBUTES

Beth Sersig and Christopher Brandt

**In Honor of Dr. Ben Walters
Judy Weidenthal**

**In memory of Dolores Colini
Judith Gluvna
Lisa and Scott Kulkin & Family**

Roy Miller & Paula Disabella

Dorothy Faust

David & Norma Harnick

David & Maxine Jacqmin

**In Honor of David Brandt
Right at Home**

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

Vaccine for Parkinson's Reports Positive Results from Boost Study

(Excerpt from www.michaeljfox.org)

New study results from Austrian biotech AFFiRiS support continued development of its vaccine against the key Parkinson's protein alpha-synuclein. Today the company announced its "boost" follow-up study – funded with a \$1.04 million grant from The Michael J. Fox Foundation – showed that an additional dose is safe and can elicit antibodies against alpha-synuclein.

Researchers believe that clumps of this protein (also called fibrils) are toxic and cause the cell death that leads to Parkinson's disease (PD) symptoms and progression.

AFFiRiS has developed a vaccine (called PD01A) to cause the body's immune system to create antibodies against alpha-synuclein, hopefully clearing out the clumps and protecting cells. The treatment works much like the flu vaccine, activating the body to create its own natural disease fighters.

The "boost" study builds on a first clinical trial, also funded by MJFF, where 24 participants with early-stage Parkinson's received four doses of PD01A. That trial proved the treatment was safe and showed that half of the participants created alpha-synuclein antibodies. Within a year; however, each of the "responders" saw their levels of alpha-synuclein antibodies decline.

This follow-up trial gave each participant one more dose a year later to see if a "boost" would be safe and would raise antibody levels again. AFFiRiS reported today that the trial was safe; all 28 participants (22 from the first trial and six other people with PD) completed the study. In addition, more volunteers (86%) saw an antibody response. All responders from the first trial responded again, and some who did not respond in the first trial produced antibodies with the boost.

Many questions remain about this therapy:

What about those 14% who didn't respond with antibodies in this trial? Dr. Dave says he's not surprised to see that not everyone responded because the treatment is relying on each person's immune system to create the antibodies and we just don't know enough about the protein or those individuals' Parkinson's or other biology.

Would the antibodies work against the type of alpha-synuclein that causes Parkinson's? Researchers don't know yet, but laboratory tests showed that PD01A-induced antibodies did bind to alpha-synuclein fibrils, the type thought to be toxic and associated with PD.

Can they keep the antibody levels up? That's the next step. A second follow-up study ("reboost") is ongoing, funded by MJFF, to monitor the participants and give another dose when their antibody levels start to fall.

Will PD01A slow or stop Parkinson's disease? The big question. Trials are still in the safety phase and not designed to test efficacy (there is no placebo, for example), but some preliminary observations are promising. Many (42%) of antibody responders from the first trial did not need to increase their dopamine medication over the study observation period (an average of three years).

In parallel, MJFF is leading efforts to validate measures of alpha-synuclein in living people so we can quickly and confidently assess the impact of therapies such as PD01A.

Parkinson's Disease Question Corner

Email barbaramarquardt@outlook.com with questions!

Question: Do you have any suggestions for eye and vision help that is affected by Parkinson's?

Answer: Yes, and great question!

I would highly suggest visiting a Neuro-Ophthalmologist.

A neuro-ophthalmologist is a doctor who specializes in visual problems that relate to the nervous system. This includes loss of sight due to injury to the brain or the optic nerve which transmits visual signals from the eyes to the brain. Many neuro-ophthalmologists are very familiar with Parkinson's, and could be more specific with treatment of eye issues related to Parkinson's.

You can visit the website: **North American Neuro-Ophthalmology Society** at www.nanosweb.org, or call 952-646-2037, or email: info@nanosweb.org to find a physician near you.

PEP March Meeting – Mar. 1, 2017

Kathy Stull and Faith Gilbert of the Amalia Foundation whose mission is to bring Delay the Disease Exercise program to those with Parkinson's to Northeast Ohio. They partner with Delay the Disease founded by David Zid and now have a number of classes including at the Cleveland Hts. Senior Center of which a number of our members attend.

Ohio State Trial Suggests Parkinson's Disease Can Be Treated with Ultrasound Waves

(Excerpt from The Columbus Dispatch)

Ron Nickelson practiced tongue twisters Friday from his hospital bed at Ohio State University's Wexner Medical Center.

"She sells seashells by the seashore," he told his neurosurgeon, Dr. Vibhor Krishna, with a smile. "Rubber baby buggy bumpers."

He wasn't just showing off. He was letting the doctor know that his speech had improved since he underwent experimental surgery the day before, when Krishna created a tiny lesion in Nickelson's brain to treat his Parkinson's disease and the side effects of the medication he takes to manage it.

Krishna used no scalpel. There was no drilling, either. Instead, Krishna's tool was a computer mouse that helped him deliver more than 1,000 high-intensity, focused ultrasound waves into Nickelson's brain.

The 61-year-old editor from Colorado was the second patient to undergo the treatment at Ohio State as part of a clinical research trial. The facility is one of three U.S. hospitals conducting the research involving patients who experience dyskinesia, which causes the involuntary movement associated with Parkinson's, as a result of taking medication used to treat the disease.

Currently, the "gold standard" treatment for Parkinson's and similar conditions is deep-brain stimulation, in which electrodes are placed in the brain and controlled by a pacemaker-like device, Krishna said.

Placing the electrodes involves drilling into the skull — something many patients decline. The therapy being tested at Ohio State and other sites provides a noninvasive way to target the part of the brain that sends abnormal signals.

"It's a paradigm shift. It's something that patients wanted for a long time," said Krishna, an assistant professor in Ohio State's neurosurgery department.

"The first time I sat through a procedure, it was transformational. You could control a patient's tremor without opening the skull, give them symptom control that's able to make an impact on their quality of life."

For his procedure, Nickelson's head was shaved and fitted into a halo frame to hold it steady for an MRI. His scalp was submerged in water that helped conduct the waves and keep the head cool.

For more than three hours, he lay there as doctors and technicians viewed his brain, found their target and delivered a dozen 10- to 13-second rounds of ultrasound from a neighboring room. While each single ray does not cause damage to the brain, 1,024 rays converging in a pinpoint spot creates a lesion.

In Nickelson's case, the lesion measures 6-by-4-by-5 milliliters and primarily treated the left side of his body by keeping those abnormal signals from being sent.

The team stopped several times during the treatment to determine if Nickelson's symptoms were improving. Dr. Barbara Changizi, a neurologist, ran him through a battery of tests.

Among other things, he was asked to open and close his fingers, twist his arm and tap his foot. She ranked the rigidity, tremor and slowness in his movements. Nickelson started with a score of 16, improving to 6 by the end of the treatments. Krishna expects he'll improve even more over the next week.

The procedure already has been approved by the U.S. Food and Drug Administration to treat essential tremor, which causes involuntary shaking. Researchers hope this study will bring FDA approval for the treatment of Parkinson's disease and medication side effects.

They eventually want to expand the technology to treat epilepsy, psychiatric disorders such as obsessive-compulsive disorder, brain tumors and neuropathic pain, Krishna said.

Dr. Ali Rezai, a neurosurgeon and director of the Neurological Institute at Ohio State, said that Wexner is the only Midwest hospital participating in the study. Ohio State, the University of Virginia and the University of Maryland plan to recruit a total of 20 patients.

"We're thrilled about it," he said. "This adds a whole new dimension in the way we can help people. We can perform brain surgery without ever cutting the skin."

Nickelson said his symptoms started about 14 years ago. When he isn't on his medication, he experiences a symptom called dystonia, which causes cramping and makes it difficult for him to move and articulate his thoughts.

(cont'd on last page)

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FIRST CLASS MAIL

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Ohio State Trial Suggests Parkinson's Disease Can Be Treated with Ultrasound Waves *(cont'd)*

"It feels like moving through the molasses," he said. "Your brain is telling your arms and legs to move, and you can't quite push through all this molasses."

When he takes too much medication, he experiences dyskinesia, which he describes as jerking, flopping, twitching or shaking.

To avoid too much or too little, Nickelson must carefully keep track of time, sometimes taking his medication as often as every two hours. He also has to make sure he isn't driving when a dose is about to wear off. Sometimes, it wears off at the office, meaning he has to take work home with him.

He said he hopes this experimental treatment brings back a better home-work balance.

Despite some discomfort during the procedure, Nickelson said he likely will opt to go through it again to improve his right side. So far, he's noticed improvement in his speech and other dystonia symptoms.

Nickelson knew about deep-brain stimulation, but didn't want wires put in his brain or the hassle of maintaining the pacemaker-like device.

"I've been following the progress of focused ultrasound for several years," he said the night before his surgery. "I've just been waiting for the chance to try it out."

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 checks payable to Parkinson Education Program and mail to 17930 Birch Hill Drive; Chagrin Falls, OH 44023

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