

PEP NEWS

Newsletter of the Parkinson Education Program of Greater Cleveland

OCTOBER 2016

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OCTOBER MEETING

Wednesday, October 5, 2016 – 2 p.m. till 4 p.m.

Please join us for a presentation and talk by Robert “Bob” Zimmerman, Ed.D, of Sydney, Ohio who has been living with Parkinson’s for 27 years. He recently published a book about his journey called, *Living With Parkinson’s*, the proceeds of which support Parkinson’s Disease Foundation (PDF) research programs. Bob is a continuing PDF Research Advocate.

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

(Last names N through Z, please bring light refreshments)

From David Brandt

I attended the 8th Annual Parkinson’s Boot Camp September 10, at the Convention Center in downtown Cleveland along with maybe another 800-1000 people – some of which included many members of *PEP*. As always, they put on a wonderful program, providing an update in PD research and inviting Greg Grindley, the DBS patient in the PBS live surgery last fall. Mr. Grindley spoke on how his life has changed. They had breakout sessions on yoga, boxing, and David Zid’s delay the disease exercises, as well as a care partner mini boot camp. Karen Jaffe was honored as the PD Champion Award recipient for all that she has done for the PD community. If you didn’t attend, please consider attending next year as there is so much to learn at these events, in a great environment, and with friends.

Once again, I want to give profound thanks to The Laretta K. Peters and Richard R. Peters Charitable Foundation for their generous grant to *PEP*. Mr. Peters was a victim of Parkinson’s Disease and through his foundation intended to further public awareness and provide support for those struggling with this disease. We at *PEP* do our best to fulfill Mr. Peters’ wishes.

Upcoming Events:

- Big Band Brunch is coming back! Sponsored by the Ohio Parkinson Foundation Northeast Region and Come Dance With Me will be held Sunday, November 6, 2016 at Executive Caterers. Once again, *PEP* will assist with the cost of the brunch.
- Save the Date: April 22, 2017 is the 19th Annual Parkinson Symposium being held at the Hilton Garden Inn in Twinsburg.

PEP November Meeting November 2, 2016

We welcome Barb Koeberle from Rock Steady Boxing who is bringing a program for Parkinson’s patients to a new Warrensville Hts. location that will open in October. She will present on how the Rock Steady Boxing Program has helped those with PD and also offer a demonstration. You may have been exposed to Rock Steady Boxing at the UH Parkinson’s Boot Camp. See why there are hundreds of Rock Steady sites across the country.

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.

LAST IN OUR 3-PART SERIES

Herbal Formula Treats Drug-Induced Parkinson's, Dementia and Schizophrenia

(Excerpt from www.realnatural.org)

Other mental conditions treated with Yigansan

Research has also found Yigansan to be helpful for other mental conditions. These include personality disorders, schizophrenia, twitches and other behavioral issues.

For example, in one study, 20 patients with borderline personality disorder were treated with Yigansan. After three months of treatment, the researchers found that Yigansan significantly improved the patients' test scores.

The patients were tested with the Global Assessment of Functioning (GAF), Clinical Global Impression Scale (CGI) and the Aggression Questionnaire (AQ). They scored better in all of these tests after being treated with Yigansan.

Specific improvements were seen in areas of anxiety, tension, depressive mood, hostility, suspiciousness, motor retardation and uncooperativeness.

The researchers concluded:

"The present findings suggest that Yigansan might be effective for the treatment of a number of borderline personality disorder symptoms, including low mood, impulsivity, and aggression."

A 2011 study from Japan's Shimane University School of Medicine studied 20 people who were diagnosed with visual hallucinations related to macular degeneration. This is also called Charles Bonnet syndrome.

The patients were given an average of 5.8 grams daily of Yigansan for four weeks. At week two and week four they were rested. Their hallucinations significantly decreased.

After Yigansan treatment, scores were significantly improved at both two and four weeks in the Neuropsychiatric Inventory, the hallucination subscale of the Positive and Negative Syndrome Scale, and the Clinical Global Impression test.

None of the patients experienced any serious adverse events.

In another study from the Shimane University School of Medicine, researchers tested 59 patients with schizophrenia. They gave 34 of the patients Yigansan doses of between 2.5 and 7.5 grams a day. Another 25 patients (controls) were not given the herbs.

The researchers found schizophrenia symptoms were reduced at two and four weeks with Yigansan treatment. Scores in the Positive and Negative Syndrome Scale for Schizophrenia were improved in the Yigansan group but not in the control group.

Kinder herbal medicines for developing minds

As I've mentioned in other articles, I am particularly disturbed at the massive over-prescribing of psychotropic and psychotic drugs to kids. As we can see with drug-induced Parkinson's, there are serious dangers to these drugs, especially in children whose neurological systems are still developing.

There are a number of safe herbs that can be used for children with neurological issues. As we can see with the Yigansan formula's successes, some of these herbs can have profound effects without the side effects.

In the case of Yigansan, we find this ancient formula not only helps mitigate the side effects of antipsychotic drugs that can cause Parkinson's, but also the research shows that the herbal formula can also be used to treat psychotic conditions, including dementia, schizophrenia and personality disorders.

Don't self-medicate, even with herbal medicines. And don't add herbs while taking medications. Talk to a doctor who is proficient in the use of these herbs before using them.

TRIBUTES

GE Foundation (matching gift)

**The Laretta K. Peters and Richard R. Peters
Charitable Foundation**

Arlene Vukcevic

**In Memory of Donald R. Wilham
Marianne R. Wilham**

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. AFFiRiS will present a poster on the study at the World Parkinson Congress in Portland, Oregon on Wednesday, September 21.

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 percent) 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.

"This showed that the body is not desensitized to the vaccine and can produce alpha-synuclein antibodies again," said Kuldip Dave, PhD, MJFF director of research programs who directs our alpha-synuclein portfolio. "And that you don't have only one opportunity for treatment – that if you don't produce antibodies with a first round of vaccine, you may with follow-up."

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. Future trials may explore those non-responders to determine who would be a good candidate for a therapy such as PD01A.

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 percent) 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). Future studies will be designed to assess efficacy.

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. Programs such as our Parkinson's Progression Markers Initiative and Alpha-synuclein Imaging Consortium are working toward such tools.

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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PEP NEWS

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FIRST CLASS MAIL

We try to keep our roster current. If you no longer wish to receive this bulletin or would like to receive it via email instead, notify Katherine.A.Kaminski@gmail.com or call 216-513-8990.

Parkinson's Disease Question Corner

Email barbaramarquardt@outlook.com with questions!

Question: Any recommendations for Parkinson's ease of use dinnerware?

Answer: Great question! It is the things we use daily that can help us with Parkinson's symptoms. I recommend the "Frank Dinner Plates" from CB2 (it is related to Crate & Barrel). The edge of this plate is curved up to allow you to guide your food on your utensil. The plates are glazed white porcelain, and are dishwasher, microwave, /oven-safe up to 350°. Contact www.cb2.com / 800-606-6252.

Also, to make eating easier GyroGear is coming out with a wearable technology called the GyroGlove. The GyroGlove has been developed with the intention of increasing hand stability. Mechanical gyroscopes within the glove are used to resist hand movements to allow for steady day-to-day activities to be carried out with ease and most importantly, confidence. Are you sitting down? The price will range \$550-\$850. GyroGear is looking to release product in 2017 – you may sign up for the GyroGlove's waiting list on the website, www.gyrogear.co (not .com) or google GyroGear.

As always, thank you for your question! Bon appetite!

Finding the Right Doctor or Motor Specialist

(Excerpt from www.michaeljfox.org)

What kind of doctor should I be seeing?

Many Parkinson's patients recommend working with a movement disorders specialist. This is a neurologist who has taken additional training in diseases that affect primarily physical movement, such as Parkinson's disease. Whereas a general neurologist may treat patients with any of more than 100 neurological conditions, a movement disorders specialist focuses on a handful of disorders. Specialists also often are affiliated with reputable universities or teaching hospitals.

How do I find a good movement disorders specialist?

It's a lot like hunting for a good dentist or a good mechanic: You need to ask around. Your primary care doctor may be able to give you a referral. If you attend a support group, ask other Parkinson's patients. Try contacting one of the national Parkinson's organizations. You can also post requests on Internet bulletin board sites. But remember that the Internet should only serve as a starting point for your research and education, not your only source of information, since it is so often difficult to source and verify the advice you find there.