

PEP NEWS

Newsletter of the Parkinson Education Program of Greater Cleveland

FEBRUARY 2018

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FEBRUARY MEETING

Wednesday, February 7, 2018 – 2 p.m. till 4 p.m.

We welcome back Fred and Dianne Discenzo from Come Dance With Me who will show beginners how dancing can improve the lives of those with Parkinson's. Come and enjoy good music and fellowship while benefitting from movement and dance.

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

(Last names A through M, please bring light refreshments)

From David Brandt

Pfizer, the world's third largest pharmaceutical company, recently announced that it would end all research and development efforts into new drugs and treatments for Alzheimer's and Parkinson's disease.

This surprise announcement resulted in a layoff of nearly 300 scientists. The company was heavily invested in research into the two diseases, but their efforts have been largely unsuccessful. Since the diseases develop uniquely from person to person, the clinical trials are usually complicated, lengthy, and costly. Some of these trials can cost \$1 billion. So even though the rewards of developing an FDA approved treatment would be tremendous, the near term costs are extremely high.

So who will step up in supporting new research? Will the government through NIH? Will the U.S. look at a change to patent laws which might offer a better return on investments? Or, will the Pfizer announcement spur other large pharmaceutical companies to also pull out which would be a big blow? Pfizer has said they will set up a venture fund to assist biotech companies that are conducting promising neuroscience research but the details are still unclear at this time. Let's hope they follow through.

Upcoming events on the schedule:

- **April 14** – OPFNE presents their 20th Annual Parkinson Symposium at the Hilton Garden Inn in Twinsburg. The program starts at 10 a.m. and runs through 2:30 p.m. This is an outstanding annual community program of sharing and learning. There is no charge for the event and door prizes and a free lunch are provided. Register by April 7, 2018 by calling 800-630-3193.
- **June 23** – Moving Day Cleveland will be held at Wade Oval in University Circle. PEP will be having a team. Stay tuned for more details.

PEP March Meeting – March 7, 2018

We welcome back Dr. James Leverenz, Director of the Lou Ruvo Center for Brain Health at the Cleveland Clinic Neurological Institute. He will discuss Parkinson's and Lewy Bodies.

TRIBUTES

Patrick and Marguerite Murphy

In Memory of Judith Weidenthal
Dr. Daniel Weidenthal

Greater Cleveland Cemetery Assn.

Parkinson's Disease Question Corner

Email barbaramarquardt@outlook.com with questions!

Question: What is helpful for swallowing issues and Parkinson's?

Answer: Dysphagia (dis-FAY-ja) is defined as a difficulty swallowing.

Dysphagia can range in severity from mild difficulty when swallowing to complete inability to eat or drink anything by mouth. Estimates conclude that as many as 15 million Americans suffer from some level of dysphagia, with an additional one million people receiving a new diagnosis every year.

VitalStim Therapy is a brand owned by DJO. It is a form of electrical stimulation used for the management of dysphagia.

The **VitalStim** Therapy System is an adjunctive modality to traditional exercise that unites the power of electrical stimulation with the benefits of swallowing exercises. Combining **VitalStim** and traditional therapy allows clinicians to help accelerate strengthening, restore function, and help the brain remap the swallow. Research supports the combination of these therapies to improve treatment outcomes.

The use of neuromuscular electrical stimulation in the treatment of dysphagia is one of the most researched dysphagia therapy interventions. **VitalStim** Therapy is supported by compelling clinical data published in peer-reviewed literature.

To learn more about **VitalStim** Therapy, please call 1-800-506-1130, or visit their website at <http://www.djoglobal.com/vitalstim> There are 42 facilities in the Cleveland, Ohio area offering the VitalStim Therapy, and all locations can be found online at <http://www.vitalstimregistry.com> or by calling their 800 number listed above.

Ref. <http://www.djoglobal.com/vitalstim>

Silverstein-backed startup will test gene therapy for Parkinson's

(Excerpt from www.fiercebiotech.com)

Regenxbio has joined forces with investment firm OrbiMed and a new nonprofit foundation to create Prevail Therapeutics, a startup focused on new biologics and gene therapies for Parkinson's disease (PD).

Prevail will draw on the expertise of the Silverstein Foundation for Parkinson's with GBA, which concentrates on a particular form of the disease caused by mutations in the glucocerebrosidase gene.

The foundation was set up this year by OrbiMed's co-head of private equity Jonathan Silverstein, who was diagnosed with GBA-linked PD in February and is mobilizing efforts to discover a cure for the disease. Silverstein backed the foundation with \$10 million of his own money, and is intent on accelerating research into PD with GBA as well as other forms of the disease.

Prevail says it will focus initially on research coming out of the lab of its co-founder and CEO Asa Abeliovich, M.D., Ph.D., who is on the faculty of Columbia University as well as being a scientific adviser to the Silverstein Foundation and co-founder of neurodegenerative disease biotech Alector.

By joining forces with Regenxbio, Prevail launches with an exclusive license to the gene therapy specialist's adeno-associated virus (AAV) based vector technology NAV AAV9 for PD and other neurodegenerative disorders.

Silverstein said that the NAV platform and Dr. Abeliovich's "deep expertise in the molecular mechanisms of neurodegeneration ... provides us with a promising opportunity to develop potential life-changing therapies for patients suffering from Parkinson's disease and other neurodegenerative diseases."

He told CNBC today that Prevail's board will also have some big names, including Leonard Bell, co-founder and former CEO of Alexion, OrbiMed venture partner and Alexion co-founder Steve Squinto and serial entrepreneur Peter Thompson of Silverback Therapeutics and Corvus Pharmaceuticals.

The new company will initially focus on GBA1, the most common of the PD mutations, which is estimated to be present in up to 10% of U.S. PD patients and perhaps 100,000 people worldwide. The disease mechanism linked to the mutation—an accumulation of alpha-synuclein in the brain—may have implications for the broader PD population and other neurodegenerative diseases.

"Many of the drugs we are trying for Parkinson's with GBA may work in the broader Parkinson's population," said Silverstein. The aim will be to get drugs approved for use in GBA patients first, and then expand their use into other patient groups.

The work of the foundation is attracting investment from companies who are not even active in PD, with cancer specialist Celgene today pledging a grant of \$5 million.

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.

Little-known chemical in Himalayan herb shows promise for preventing Parkinson's

(Excerpt from www.naturalnews.com)

Parkinson's disease, characterized by chronic rigidity, slowness of movement, impaired coordination, and tremors of the face, hands, and legs, is becoming a common, progressive, pervasive disease in today's world. As nerve cells die in the region of the brain called substantia nigra, Parkinson's disease begins to settle in. The dying neurons produce dopamine, a chemical messenger that controls coordination and movement. Over time, as the condition worsens, dopamine production decreases, leaving the patient unable to control movements in their face, hands, and legs.

Doctors predict Parkinson's to double between 2005 - 2030.

The Parkinson's Disease Foundation quotes that as many as "one million people in the US and an estimated seven to 10 million worldwide" live with Parkinson's disease. Dr. E. Ray Dorsey and his colleagues at the University of Rochester say that, "This is a chronic condition that will be claiming more and more people." The 4.1 million recorded cases of Parkinson's in 2005 is predicted to double in 25 years, according to Dorsey and his colleagues.

Dr. Warren Olanow, professor of neurology at Mount Sinai School of Medicine in Manhattan agrees. "They are absolutely on target. This will certainly be a bigger public health issue. Not only will more people develop Parkinson's but patients will have it longer and remain disabled by it."

But does this truly have to be the case?

The little known Himalayan herb that could change all that

As professors predict doom and gloom, with Parkinson's disease statistics skyrocketing, one little-known Himalayan herb is coming out of the shadows and showing positive signs of helping prevent Parkinson's disease.

That herb is picrorhiza kurroa and the compound inside it that's catching researcher's attention is known as *apocynin*. First used in 1883 by a German pharmacologist, apocynin was extracted from the Canadian hemp plant, (*apocynum cannabinum*) and used to treat heart problems and edema. Now, this little-known plant derivative is being isolated from the Himalayan herb picrorhiza kurroa, and is showing promise for prevention of Parkinson's.

Apocynin was first isolated from the Himalayan herb picrorhiza kurroa in 1971, where it immediately became useful for treating jaundice, asthma, and heart problems.

With strong anti-inflammatory properties, this herb prevents the formation of free radicals, oxygen ions, and peroxides in the body.

From herb, to compound, to specific neuroprotective molecule

To break it down further, Brian Dranka, Ph.D., of the Medical College of Wisconsin and his colleagues, Balaraman Kalyanaraman and Angeline E. Quadracci, have separated a specific molecule from apocynin called diapocynin. Using this molecule, Dranka has effectively treated a specific type of transgenic mouse called LRRK2R1441G. These mice are known to lose coordinated movements at around 10 months old, establishing Parkinson's-type symptoms. At three months old, the test mice were given diapocynin treatment. By the tenth month of the experiment, the loss of motor coordination had been prevented.

Dr. Kalyanaraman is pleased with the findings but says more research is to be done explaining how diapocynin's neuroprotective action works. "These early findings are encouraging, but in this model, we still do not know how this molecule exerts neuroprotective action. Further studies are necessary to discover the exact mode of action of the diapocynin and other molecules with a similar structure," he said.

Himalayan herb paints hope for future Parkinson's treatment

Doctors are expressing great need for new early detection methods for those who might suffer from Parkinson's disease. No causes have been isolated, but researchers are anxious to use this transgenic mouse study to help them identify early biomarkers in patients to help with early detection. By isolating picrorhiza kurroa's unique compound, apocynin, and furthermore, it's specific molecule diapocynin, doctors may have found the right natural medicine - a neuroprotective powerhouse capable of delaying or even preventing neuron death in the brain.

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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Five Ways to Make Cooking Easier with Parkinson's Disease

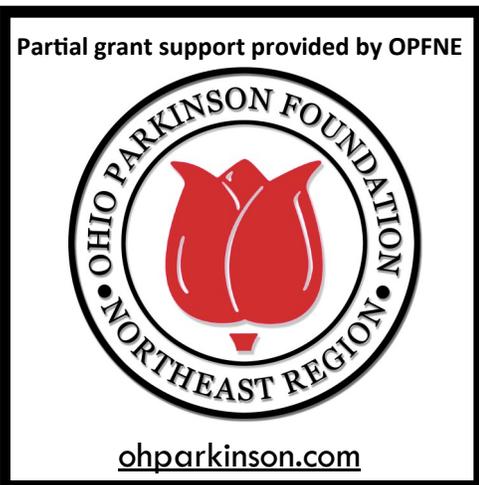
(Excerpt from www.michaeljfox.org)

In general, it's much easier to maintain a healthy diet when you cook at home. But Parkinson's disease symptoms can make meal prep challenging, and cooking can be exhausting.

Our community shared the tools and tricks they use to cook healthy, tasty meals safely and easily.

As for what to cook, our staff MD shares tips on planning meals around medications and other nutritional advice in a recent [Ask the MD video](#).

1. **Gather** everything you need and put it in one place before starting to cook. If it's more comfortable, sit in a chair that brings you to the height of your counter and prep food while sitting.
2. **Take safety precautions and organize your kitchen** so it's as accessible as possible. One commenter recommended [cut-resistant gloves](#). Make sure the equipment you need is on an easy-to-reach shelf.



3. **Use light-weight tools that are easy to grasp.** Lightweight pots and pans are easier to lift, and tools with thick handles can be more comfortable to hold.
4. **Choose recipes that don't need you to prepare two different parts at the same time.** Some people with Parkinson's have [trouble multitasking](#). If that sounds like you, try creating one-pot meals like salad or a stir fry. That way, you don't have to worry about checking the oven while you're in the middle of stirring a dish on the stove top.
5. **Freeze extra servings** to save for days when you're not feeling up to cooking. Parkinson's disease symptoms often vary from day to day, so it's handy to have quick meals on hand. Commenters also mentioned [taking a nap](#) before you cook to maximize your energy levels.