



PARKINSON News

PUBLISHED BY THE PARKINSON ASSOCIATION OF GREATER DAYTONA BEACH (PAGDB)

OCTOBER MEETINGS

We are excited to be hosting two unique webinars during the month of October!

Groundbreaking Technology in DBS Surgery

**Tuesday, October 13, 2020
11:00 AM**

For our first webinar we welcome back Neurosurgeon Dr. Grewal as he discusses Groundbreaking Technology in DBS Surgery.

SpeechVive: Leveraging the Lombard Effect in PWP

**Tuesday, October 20, 2020
11:00 AM**

Our second webinar will be presented by Jim Turnbach, Southeast U.S. Area Manager for SpeechVive, a wearable prosthetic device to assist PWP to speak louder.

Both of these wonderful webinars showcase some of the latest breakthroughs in technology to help people with Parkinson's.

To learn more and to register please see the next page of this newsletter where we go more in depth about each webinar and how to register.

FUN WALK POSTPONED

We are saddened to announce that due to the uncertainty surrounding the pandemic, our annual "Sole Support for Parkinson's Fun Walk" which was scheduled to take place on Saturday November 14th this year - is being postponed until further notice. Stay tuned to your newsletter for updated information on an alternate date for the return of the Fun Walk.

SEPTEMBER MEETING

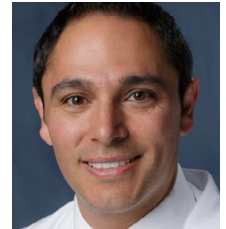
Tuesday, September 15, 2020

11:00 AM

Zoom Webinar

Management of PD Motor Symptoms: Emergent Treatment Strategies & Unmet Needs

Please join us as the PAGDB will be hosting Dr. Adolfo Ramirez-Zamora, he is the Associate Professor of Neurology, Associate Division Chief of Movement Disorders, and Director of Neurology Clinical Trials with the Center for Movement Disorders & Neurorestoration at the University of Florida in Gainesville. In his research clinic Dr. Ramirez-Zamora is on the forefront of the latest research and treatment strategies for PWP.



Dr. Ramirez-Zamora

Want to find out the latest goings on in the management of PD Motor Symptoms? If so - tune in and join us for this sure to be enlightening webinar.

Online registration for this webinar is required. To register click the button below or visit: www.parkinsondaytona.org/you-me-pd

RECENT GIFTS & GRANTS

- ♥ Gift from Deborah & Carmine Mannello – In Memory of Ida Mannello
- ♥ Gift from Diane Skelley to the PAGDB
- ♥ Grant from Volusia County

NOTE: The information in this newsletter and the information provided by our speakers is not intended as medical advice. Please consult your physician before trying anything new or different.

ZOOM SUPPORT GROUP

Nancy Dawson of Halifax Health-Hospice is facilitating a support group through Zoom. Nancy facilitates the Flagler Support Group, but since there is still so much uncertainty with meeting face to face she has been kind enough to offer anyone to join her support group in the Volusia/Flagler area. **If you would like to join or learn more please contact Nancy at: Nancy.Dawson@halifax.org or 386-425-3734.**

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GROUNDBREAKING TECHNOLOGY IN DBS SURGERY TUESDAY, OCTOBER 13, 2020 • 11:00 AM



Dr. Grewal

The PAGDB is pleased to welcome back Neurosurgeon Dr. Sanjeet Grewal. Part of a world class team of Neurosurgeons at the Mayo Clinic in Jacksonville Florida, where over 2000 DBS surgeries have been performed, Dr. Grewal will be discussing **break thru technology** in DBS surgery. He will be introducing Medtronic's new Dual Channel recharge free DBS Stimulator '**Percept**'. Medtronic's **Percept** is a DBS battery that is the first and only 3T MRI conditional battery with Brain Sensing Technology. Brain Sense Technology is designed to capture a patient's brain signals, providing clinicians unprecedented insight into their symptom state fluctuations and help deliver personalized, data driven treatment.

Join us in this fascinating presentation as Dr. Sanjeet Grewal explains how **Percept** technology can be used with Parkinson's disease, Epilepsy, and Essential Tremor DBS patients.

Online registration for this webinar is required. To register click the button below or visit: www.parkinsondaytona.org/you-me-pd

SPEECHVIVE: LEVERAGING THE LOMBARD EFFECT IN PWP TUESDAY, OCTOBER 20, 2020 • 11:00 AM



Jim Turnbach

Approximately 90% of PWP experience voice changes including low volume, slurred speech and reduced intelligibility. Traditional speech therapy for PWP requires intensive therapy sessions and a lifetime of daily practice to maintain your results.

We are excited to announce that we will be hosting Jim Turnbach, the Southeast U.S. Area Manager for **SpeechVive**, a wearable prosthetic device (like a hearing aid) that uses the "Lombard Effect" to assist PWP to speak louder. The

Lombard Effect is our natural response to speak louder and more clearly when communicating in a loud environment.

With SpeechVive 75% of patients experienced immediate increased loudness. Another 12% improved their speech in one or more areas, including vocal volume, clearer articulation and a more normal rate of speech after 8 weeks.

Participants in this webinar will learn the following:

- What is hypokinetic dysarthria?
- What are the current treatments?
- New technology
- Support research
- How **SpeechVive** Works

You'll not want to miss this webinar event!

Online registration for this webinar is required. To register click the button below or visit: www.parkinsondaytona.org/you-me-pd

To register for any of our webinars on our website please go to: www.parkinsondaytona.org and under the 'Events' tab click on the You, Me & PD tab to register. If you have any questions **please call Vince at 386-871-3879** or email parkinsondaytona@gmail.com. We are more than happy to help you register for these webinars.

In July Dr. Alaine Keebaugh presented 'The Genetics of PD: Progress & Implications' where she spoke on our current knowledge of the genetics of PD, and how this greater understanding is laying the groundwork for identifying new avenues toward finding a cure.

In her talk she covered how to get genetic testing for specific Parkinson's related genes and we wanted to share those resources.

She recommended:

- Talking to your physician
- [FoxInsight](#)
- [PD GENERation](#)
- Mayo Clinic
- UF Shands
- UF Jacksonville
- Talking with your local Movement Disorder Neurologist

NEED A STORY TO WARM YOUR HEART?

A nine-year-old's bake sales have raised \$3,500 for Parkinson's research.

Zoe Bernard started selling her homemade sweets in July as a fun way to pass the time during quarantine. Her speciality is banana bread which took three months to get right. She has made it her mission to raise \$10,000 for Parkinson's research. She is a one-girl show, donating 100% of her profits to PD Research. Her grandpa was diagnosed with the disease 3 years ago.

**To read the story, [click here](#).
To learn more about Zoe's Bakery [click here](#).**

Cognitive Deficits

REPRINTED FR: World Parkinson Congress (WPC) Email 8-7-2019 WPC Abstract Highlight



...process which is influenced by ageing and genetic variants promoting formation of protein aggregates in the brain; in contrast, executive problems reflect dysfunction in frontostriatal dopamine networks and are influenced by genetic variants affecting dopamine breakdown, and by dopaminergic medication.

Through better defining and understanding these separate cognitive syndromes, we can give more accurate prognostic information to patients, and target these different syndromes with more tailored therapies.

Caroline Williams-Gray University of Cambridge, Cambridge, United Kingdom

People with PD are around 2.5 times more likely to develop dementia than other people of a similar age, and nearly half will have developed dementia by 10 years into their illness. This has a major impact on quality of life, care requirements, and survival. Milder cognitive problems occur earlier in the disease, with one quarter to one third having 'mild cognitive impairment'. Subtle cognitive deficits have even been reported to occur in some 'prodromal' PD cases, before movement problems emerge.

Several different domains of cognitive function can be affected, including executive function (which includes planning and organizational abilities), memory, and visuospatial function. In more advanced PD, cognitive problems can be associated with behavioral changes and visual hallucinations. Diagnostic criteria for PD-Dementia have been established by the Movement Disorder Society, which are based on neuropsychological test scores, evidence of progressive decline, and impairment of day-to-day functioning due to cognitive deficits.

Diagnostic criteria have also been developed for PD-associated Mild Cognitive Impairment (PDMCI). However, there has been some debate about whether this is a useful diagnosis, as early cognitive impairment in PD is highly variable and not all patients with 'PD-MCI' will go on to develop a dementia.

Through studying a population-representative cohort of Parkinson's patients from diagnosis over time (the CamPaIGN study), we have demonstrated that there are distinct cognitive syndromes in PD which evolve differently. In particular, early problems with semantic memory and visuospatial function are predictive of developing a dementia, whereas problems with executive function are not necessarily predictive of dementia and can even improve over time.

We have used genetic and brain imaging studies to demonstrate that these syndromes have distinct underlying biological bases: Semantic/visuospatial problems reflect a posterior cortically-based...

Helping Parkinson's Patients Make the Most of Time at Home

by AdventHealth

Parkinson's Disease is a degenerative neurological disorder that causes decreased amplitude of movements and rigidity, both of which can impact a person's ability to walk. Usually, the symptoms of Parkinson's worsen over time, but with medication and exercise, those with Parkinson's can maintain or improve their quality of life.

"Not exercising consistently and at the right intensity can result in a decline in function," says Laura Patrick, PT, DPT, Board Certified Clinical Specialist of Neurologic Physical Therapy. If you are a caregiver for someone with Parkinson's Disease that's unable to make it to their regular therapy visits in person, here are some tips and tricks on how to maximize their daily exercise from home.

MAKING THE MOST OF WALKS

If you are caring for someone with Parkinson's Disease, there are certain things you can incorporate with daily walks to help your loved one maintain their function. At a minimum, specialists recommend Parkinson's patients take walks at a high intensity three times per week.

Instead of doing continuous walking for 30 minutes, Laura suggests doing interval training. "This could mean walking at a faster speed and exerting yourself more for about a minute, and then slowing down to walk at a comfortable speed for about a minute." Interval training could help increase heart rate, and as Laura explains, "Intensity is needed to cause neuroplastic changes that will help improve function with Parkinson's."

Rating of Perceived Exertion

6-11	Light Exertion	Like lying in bed or sitting relaxed
12-16	Medium Exertion	Like target-range exercise or activity
17-20	Max Exertion	Like the hardest workout ever

High intensity means reaching a 14-17 rating of perceived exertion (RPE) out of 20. To track this, utilize your loved one's RPE scale (a 6-20 scale with 6 being no exertion and 20 being maximum effort) by asking the patient how hard they are working. They should be responding at a level of "somewhat hard" to "hard."



For caregivers of patients with Bradykinesia, which means slow movement, you may be wondering how to help your loved one reach a higher intensity during their walks. Laura has a few suggestions for this:

Hold Their Hand

Swing your arm high forward and back, taking the hand of your loved one to encourage them to do the same right along with you.

Use Big, Exaggerated Movements

Swing your arms, take large steps, and encourage the patient to mimic your movements. You can then use the cue, "Walk like me."

Walk With Them to Music

Pick a song that has a beat that is faster than your loved one's usual pace, or a song they enjoy. Ask them to match the tempo.



The AdventHealth Sports Med & Rehab team is here for you, whether you're at home or with us in person. If you have any questions or would like to schedule an in-person appointment or video visit for your loved one, visit AHRehabEastFL.com, or call **833-787-6755**.

THE WELLNESS CORNER

Diet, Nutrition & PD

Diet and nutrition have been found to play a crucial role in Parkinson's.

Diet, is a hot topic in the field of Parkinson's. Diet and nutrition, like exercise may help to improve symptoms and possibly slow the progression of the disease.

Dr. Bloem and Dr. Ascherio praised the Mediterranean diet, for its potential to lower the risk of developing Parkinson's due to being rich in nutrients and antioxidants. The Mediterranean diet is generally high in vegetables, fruits, grains, healthy fats and fish, and is typically low in meat and dairy. A diet rich in nutrients and antioxidants is

On the other hand, Dr. Bloem theorised that "a lifetime of exposure to dairy" is associated with a higher risk of developing Parkinson's, likely due to the pesticides ingested by cattle from contaminated grass. Dr. Ascherio added that dairy also has other effects like reducing the level of uric acid in blood, which we found to be related to a risk of Parkinson's disease.

Deficiencies & Malnutrition

Dr. Bloem pointed out that a regular diet should offer all the necessary nutrients. Vitamin D and Vitamin C can be exceptions. "Many people, particularly when you age and particularly when you're a woman, are at risk of developing a vitamin D deficiency. There are fascinating anecdotal reports of people taking vitamin D and experiencing improved motor symptoms."

Vitamin C supplements can help to prevent bladder infections in Parkinson's patients by acidifying the urine. "Bladder infections can trigger a cascade that leads to worsening Parkinson's symptoms."

Bowel Problems

Bowel problems are common in Parkinson's patients, which Dr. Bloem said can be alleviated by drinking a lot of water and eating a diet rich in fiber. People with Parkinson's should see their general practitioner for laxatives only if all else fails.

"The rule is you need to have bowel movements at least once every other day."

Medication & Food Interference

As food can interfere with the efficacy of levodopa medication, Dr. Bloem recommended taking levodopa at least half an hour before or after a meal. In particular, he advised that protein intake be spread across the day.

"For most patients, taking your medication with a protein rich meal including dairy products and meat, can reduce gastrointestinal absorption of your levodopa you need the proteins in order to keep up your muscle strength and avoid weight loss, but try to spread the proteins over the day."

Thomas acknowledged that this can be hard to do. She said: "I have a struggle spreading my proteins with my levodopa because I can't take more than 15mg of levodopa at a time, so I'm taking it every two hours."

Dietitian?

Should a dietician be part of your standard Parkinson's care? Yes, said Dr. Bloem. "I think paying attention to the gut is part of routine clinical care at every consultation for people with Parkinson's. Parkinson's starts in the gut for many patients and slow bowel movements are very common, impacting the efficacy of your medication and appetite for food. It needs attention."

While a Parkinson's doctor or nurse can offer useful dietary advice, Dr. Bloem himself recommends that his patients see a dietician at least once.

<https://parkinsonslife.eu/diet-nutrition-parkinsons-webinar/>

To watch the full webinar: [click here](#)

Dr. Bastiaan Bloem is a professor of neurology and director of the Parkinson's Centre of Excellence at Radboud University Medical Centre, the Netherlands, and co-author of 'Ending Parkinson's Disease: A Prescription for Action', in which experts outline a bold plan to "prevent, advocate, care and treat" Parkinson's.

Dr. Alberto Ascherio is a professor of epidemiology and nutrition at the Harvard T. H. Chan School of Public Health.

Omotola Thomas was diagnosed with young-onset Parkinson's in 2016. She is a mother, blogger, Parkinson's campaigner and founder of ParkinStand - a platform designed to encourage people to fight Parkinson's

Exercises You Can Do at Home for Parkinson's

Wrist Stretch



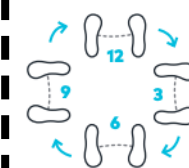
Position: Sit on the chair with back support.

Technique: Hold your hands in front of your chest and pull all fingers up toward you. Hold for 10 seconds. Repeat with the other hand.

Turning Tips

Individuals with PD must "tell" their feet how to move. By thinking about what you are doing, you use a different part of your brain than the part affected by PD. You re-route the message from the brain to the feet.

- When beginning a turn from a stopped position, lead with your foot, not your upper body. Planting your feet and turning your upper body frequently leads to a freezing episode.
- If you want to turn right, shift your weight to the left foot and step out with the right foot. To turn left, shift your weight to the right and step out with the left foot.
- Try not to pivot when you turn. Instead, focus on how you lift your feet.



To turn in a small area, or when you are stopped and must turn, try the "clock turn" technique: Start at 12:00, take two slow steps to 3:00, etc.

To turn in an open area, use large steps and make a U-turn.



Are you or a loved one diagnosed with Parkinson's disease and seeing or hearing things that aren't there?

We are currently enrolling into a research study of an investigational drug to treat these symptoms in Parkinson's disease.

This study is being conducted to see if the investigational drug might improve the activities of daily living in patients with hallucinations and delusions associated with Parkinson's disease psychosis.

To qualify, participants must:

- ✓ be 40 years of age or older with Parkinson's disease
- ✓ have one or both of these symptoms:
 - delusions (false or mistaken beliefs)
 - hallucinations (seeing or hearing things that are not really there)
- ✓ have a relative, housemate, or friend assist during the study and attend clinic visits

There are additional requirements for participation. The study staff will explain the complete list of requirements.

All qualified study participants will receive the investigational drug.

There is no cost to participate, and compensation for time and travel may be available.

To learn about joining our study, please contact us today.

Email
ewierzbicki@accelclinical.com
or call (386) 785-2400 for
more information.

WE WANT TO HEAR FROM YOU!

We love feedback on the content of our newsletters and any subject matter or content you'd like to see more of in future newsletters. We value your input on the webinars. Let us know anything you might be doing that is working well for you (or not), and to the degree that we can, we will publish your responses and input in future newsletter editions. Connect with us: parkinsondaytona@gmail.com

We're here for you and we want to help!

WEBINAR VIDEOS

All of our previous webinars in our You, Me & PD series are available on Youtube and our website! To visit our YouTube channel you can search for it by visiting www.youtube.com. In the search box search for: Parkinson Daytona. You will find our 'channel' and all of our uploads. You can subscribe to follow us and be shown future uploads. We also have all the webinar videos on our website under the 'Events' tab. Visit our website www.parkinsondaytona.org or [click here to visit our YouTube channel](#).

**"BELIEVE YOU CAN AND
YOU'RE HALFWAY THERE."**

DANCE *for* PD[®]

CLASSES | TRAINING | RESOURCES

For those that wish to continue to participate in a regular Dance for PD program with local Dance for PD instructor Gabriela Trotta – these classes are now **offered online every Monday at 1:30pm** – it's easy to register and participate and it's **FREE** to all PAGDB Members!

To find out how to connect with our live online Dance for PD program please contact **Gabriela at 386-405-6905 or email her at: gabriela59@aol.com or Nicole at nmante86@gmail.com.**

Gabriela & Nicole will be happy to help you get started.

SO GET OUT AND DANCE!



****Other than provide financial support for its members that wish to participate in this Dance for PD program, the PAGDB has no ownership stake nor controls any of the program content. PAGDB members that wish to participate do so at their own risk. Always consult with your doctor before you engage in any type of exercise program.**

PAGDB
PO Box 4193
Ormond Beach, FL 32175
386-871-3879
www.parkinsondaytona.org
parkinsondaytona@gmail.com

Board of Directors

Vince Kinsler
PAGDB Executive Director
yovinny57@aol.com

Akisia German
germanaahc@yahoo.com

Alaine Keebaugh
Boston Scientific
Alaine.Keebaugh@bsci.com

Bruce Popielarski
popiebp@yahoo.com

Christina Atanasoski
Newsletter & Web Designer

Ellen Lauturner
elauturn1@gmail.com

Gabriela Trotta
gabriela59@aol.com

Jennifer Harris
jharris1@5ssl.com

Ken Sipes, CPA
Treasurer

Marianne Chapin
Rock Steady Boxing
mchapin130@gmail.com

Matt O'Malia
O'Quinn All State Insurance

Nancy Dawson
Halifax Health Hospice
nancy.dawson@halifax.org

Sharon Estes, RN
386-252-3777

Ursula O'Leary
utrudeau@msn.com