



PARKINSON News

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



**Happiness is not
by chance,
but by choice.**

—
JIM ROHN



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Happy New Year

As we begin 2023, I'd like to take this time and space to express gratitude for life and send well wishes and blessings to all for the coming year!

2022 left us in a literal bang with two major storms that were, to say the least, disruptive. These late in the year storms caused our annual Fun Walk (scheduled for November 12) to be cancelled. In every storm cloud there is a silver lining; we were able to re-schedule the date of our walk within 48 hours of its cancellation! **Our Fun Walk event has been re-scheduled for Saturday Feb. 25, 2023.**

For all those that had registered for the November 12th walk (including online and paper/ mailed) – please know that all previous registrations have been recorded, are in our system, and are still good and active. If you or anyone you know that hadn't previously registered, and would like to attend the walk, there is a revised registration form reflecting the re-scheduled date that **can be copied/downloaded in this newsletter.** *Online registration is also open and active for those that would like to attend but have not previously registered.* **For more information – please visit our website at www.parkinsondaytona.org and click on the Fun Walk tab.**

So, let's keep in step and get our New Year off to a great start, and there's no better way than to attend our Fun Walk on Saturday February 25th. I look forward to seeing you all there!

Vince

RECENT GIFTS & GRANTS

- ♥ Robin Colborne – Gift to PAGDB in Honor of Teresa White
- ♥ Monica Gemperlein - Gift to PAGDB in Honor of Carol Croft
 - ♥ Diane Skelley via Thrivent Choice – Gift to PAGDB
- ♥ Gloria McCarthy – Gift to PAGDB in Memory of Bob McCarthy
 - ♥ Diane Castelli – Gift to PAGDB
 - ♥ F.O.E. Auxiliary 4435 Ormond Beach – Grant to PAGDB
 - ♥ Walt & Suzanne Steiner Foundation – Grant to PAGDB
 - ♥ Nancy Nix-Karnakis – Gift to PAGDB in Honor of Jeff Torborg
- ♥ Deborah & Carmine Mannello – Gift to PAGDB in Memory of Ida Mannello
 - ♥ Patricia Jones – Gift to PAGDB in Memory of Claude Begin
 - ♥ Robert McFarland – Gift to PAGDB in Memory of Claude Begin
- ♥ Donna & Bill Kisbany – Gift to PAGDB in Memory of Claude Begin
 - ♥ Brenda Hurley – Gift to PAGDB on Behalf of Carol Croft
 - ♥ Steve Unatin – – Gift to PAGDB

A huge debt of gratitude to all those that donate to our cause. Your gifts and grants go a long way in enabling us to carry on. Thank You!

To make a gift in honor or memory of a friend or loved one, to provide a grant, or to simply donate to the PAGDB cause: By mail, please make checks payable to Parkinson Association of Daytona and mail to P.O. Box 4193 Ormond Beach, FL 32175. To donate online, please go to our website at www.parkinsondaytona.org and click on the Donate link.

DONATE

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.

MANAGING OFF EPISODES IN PD

Tuesday, January 17, 2023 • 2:00–3:30pm

Bishops Glen Retirement Facility (Auditorium) 900 LPGA Blvd. Daytona Beach

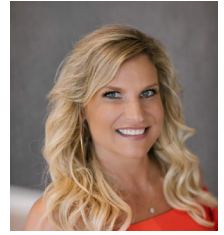
The PAGDB is pleased and excited to welcome back Dr. Zhigao Huang and his two patient ambassadors - Joe & Sarah Possenti. Dr. Huang is recognized as one of the top Neurologist/Movement Disorder Specialists in Florida. His areas of expertise include the diagnosis and management of complicated neurological conditions including Parkinson's disease, Tremors, Dementia and Memory disorders. In this program Dr. Huang will discuss "Off Episodes" and their impact on people with Parkinson's and how the injectable medication APOKYN cans assist with managing these off times episodes.



Dr. Zhigao Huang



Joe Possenti



Sarah Possenti

Dr. Huang will be accompanied by Joe & Sarah Possenti (husband and wife) who will share their personal (sometimes humorous) experiences of living with PD, what it means to be your own advocate, and how they became acquainted with APOKYN.

This was one of our most popular programs of 2022, and due to the tremendous feedback we received we decided to re-schedule it first up for our programs in 2023. If you missed it last time or wish to return for a worthy re-visit, we hope you plan on joining us for this valuable, educational, and entertaining program!

Reservations for this event are required, please register early for this event. To **register for this event in-person** please visit: www.parkinsondaytona.org/in-person-meetings, or **click the red button below**.

To register for online Zoom program please visit: www.parkinsondaytona.org/online-meetings or **click the green button below**.

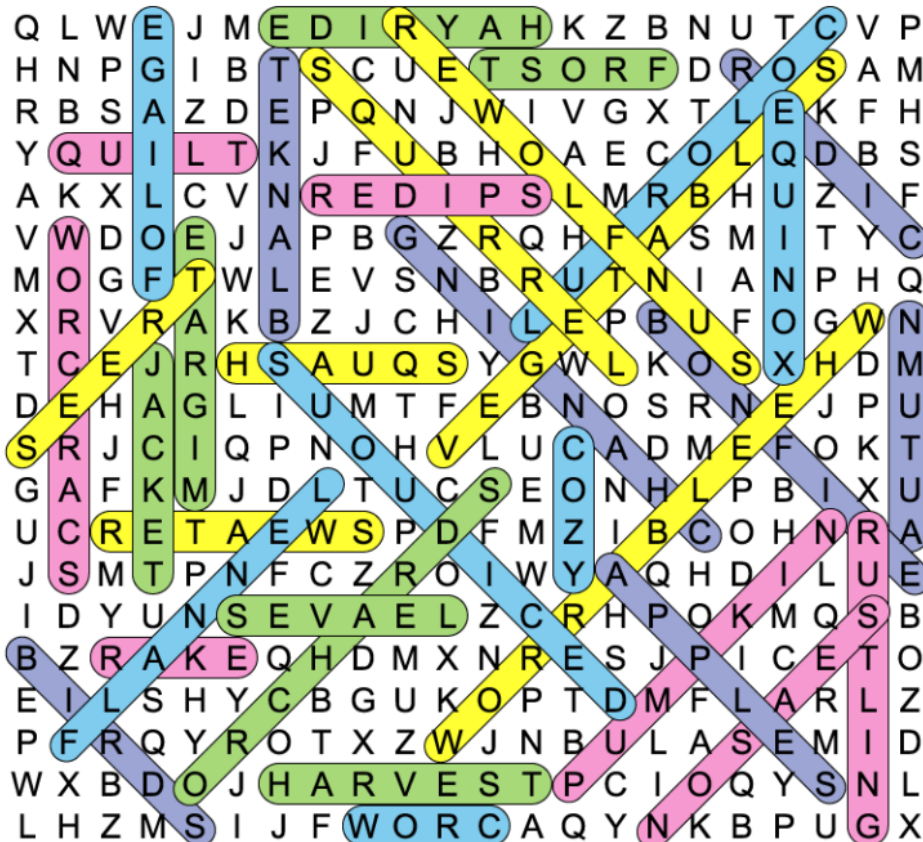
Register for In-Person Meeting

Register for Zoom Meeting

Fall Word Search Answers

See Page 9 in this newsletter for our Valentine's Day Word Search. Answers will be in the next newsletter edition.

Completing puzzles can strengthen the mind and help patients manage Parkinson's symptoms. Jigsaw puzzles, in particular, can increase skills of problem-solving, coordination, matching, and memory.



SPEAK OUT! SPECIFIC SPEECH THERAPY FOR PEOPLE WITH PARKINSON'S

Tuesday, February 21, 2023 • 2:00–3:30pm

Bishops Glen Retirement Facility (Auditorium) 900 LPGA Blvd. Daytona Beach

The PAGDB is pleased to welcome Emily Herndon, Speech Pathologist and Owner of Speak UP Virtual Speech Therapy, LLC, a telepractice that utilizes SPEAK OUT! the popular speech & cognitive training program that is designed specifically for People with Parkinson's disease.



Emily Herndon

Telemedicine is the practice of providing medical care virtually via your home computer, laptop, tablet, or smartphone. It can be a very effective method for receiving medical services because it provides convenient access to healthcare professionals, and rapidly advancing technology continues to improve the quality of virtual services. Speech Therapy is one of the more adaptable disciplines when it comes to different service delivery options. **During this program Emily will provide an informative presentation outlining the tremendous benefits that virtual speech therapy has to offer for individuals with Parkinson's disease.**

Emily received her Master's degree in Speech Pathology from the University of Florida and studied under some of the leading speech pathologists and researches specializing in Parkinson's disease. Starting her career at the VA Hospital in Gainesville and Lake City Florida, Emily ultimately decided to pursue her dream of owning her own telepractice.

Emily is certified in the popular speech therapy program SPEAK OUT! and she also leads her own weekly LOUD Crowd group for individuals looking to maintain the gains they've made during individual SPEAK OUT! therapy sessions.

Reservations for this event are required, please register early for this event. To **register for this event in-person** please visit: www.parkinsondaytona.org/in-person-meetings, or **click the red button below**.

To register for online Zoom program please visit: www.parkinsondaytona.org/online-meetings or **click the green button below**.

Register for In-Person Meeting

Register for Zoom Meeting

On Saturday, February 4, 2023, Jax Hope, Inc., will host a FREE Caregiver Symposium for People with Parkinson's and their Families. This is a FREE Event to allow Caregivers of those with Parkinson's to collaborate, connect and celebrate those who are caring for others on a day to day basis. There will be many vendors, workshops and chances for you to engage with others in the community. Lunch will be served. While this is a FREE event, registration is required. For more information, **see Page 14 of this Newsletter**.

JAX HOPE INC, originally Rock Steady Boxing Jacksonville, opened its doors on January 9, 2017, to 9 brave and hopeful people wanting to fight back against Parkinson's Disease. It's Vision is for A world in which all people with Parkinson's have a better quality of life.

PD HISTORY IN YOUR FAMILY? SHOWING SOME EARLY SYMPTOMS OF PD? WONDERING IF YOU HAVE PD? INTERESTED IN A SIMPLE DIAGNOSTIC SKIN TEST THAT HELPS DETERMINE IF YOU HAVE PD?

Since our March 2022 program featuring Kenny Buchanan with CND Life Science who gave a compelling presentation on how a new skin test (Syn-One Test) aids in determining the diagnosis of several diseases where abnormal alpha synuclein proteins are present (including Parkinson's disease), many people with PD, or PD in their family history have expressed interest in having this test conducted. The Syn-One Test can be done right in your doctor's/neurologist office.

CND is also a Medicare and Tricare participating provider and has in-network contracts with a growing list of commercial health plans and other insurance carriers. To learn more about CND Life Sciences and their Syn-One Test watch a 5-minute video by clicking on this link:

<https://vimeo.com/578086566/3a83361e8f>

Or to find out how you can go about arranging to have the Syn-One test done, you can contact Kenny Buchanan directly at 617-438-2582 or email at: kbuchanan@cndlifesciences.com

COMMUNITY CALENDAR & EVENTS

FLAGLER SUPPORT GROUP

PALM COAST COMMUNITY CENTER • 305 PALM COAST PARKWAY NE, PALM COAST

The Flagler/Palm Coast Support Group is hosting monthly meetings the **first Wednesday of each month** at the Palm Coast Community Center. For more information on this support group please contact Renee Shoner at 386-503-2239 or email at: Reneeshoner@gmail.com.

NEXT MEETING: Wednesday, February 1, 2023 • Wednesday, March 1, 2023

*SEE FLYERS IN THIS NEWSLETTER

EAST & WEST VOLUSIA SUPPORT GROUPS

The PAGDB in conjunction with Halifax Health is hosting PD Support Groups in both East Volusia and West Volusia. These programs are designed to provide a place for individuals with PD and their caregivers/loved one's to share their feelings, experiences, and resources with each other and to provide support and encouragement. These programs are offered free of charge to the community.

EAST VOLUSIA

WOODMARK (FORMERLY BISHOPS GLEN) • 900 LPGA BLVD. HOLLY HILL, FL

In East Volusia the support group program is being held on the **4th Tuesday of each month from 2pm-3pm** at Woodmark (formerly Bishops Glen Retirement Community).

NEXT MEETING: Tuesday, January 24, 2023 • Tuesday, February 28, 2023

WEST VOLUSIA

WOODLAND TOWERS • 113 CHIPOLA AVE. DELAND, FL

In West Volusia the support group program is being held on the **2nd Tuesday of each month from 2pm-3pm** at Woodland Towers.

NEXT MEETING: Tuesday, February 14, 2023 • Tuesday, March 14, 2023

These support groups are facilitated by Anne Tracy, RN Community Relations Coordinator with Halifax Health Continuing Care and Hospice. For more information please contact either Anne Tracy at 386-566-5728 Email: annette.tracy@halifax.org or Vince Kinsler at 386-871-3879 Email: yovinny57@aol.com

14TH ANNUAL "SOLE SUPPORT" FUN WALK

SATURDAY, FEBRUARY 25, 2023, 10AM-2PM • CITY OF PORT ORANGE LAKESIDE COMMUNITY CENTER & AMPHITHEATER

ROCK STEADY BOXING NSB

201 SOUTH RIDGEWOOD AVE. SUITE 13 EDGEWATER, FL

Monday, Wednesday and Friday morning you will find the music pumpin', the bags swinging and the Boxers punching at Rock Steady Boxing NSB. **Call to schedule an opportunity to observe a class. For more information on class times and how to get involved, www.inthiscorner.org | 386-314-6673**

BROOKS REHAB

Brooks Rehab is offering an **Adaptive Sports & Recreation Programs (& no you do not need to be athletic to participate!) they are in our community and provided FREE of charge!** Brooks also offers Exercise & Wellness Programs at several convenient YMCA locations throughout Volusia County. Cost for these programs is \$15.00 per month for YMCA members, and \$30.00 per month for non-YMCA members. **See flyers in this newsletter or our website for days, times and locations of these programs.**

Halifax Health | Brooks Rehabilitation

Adaptive Sports and Recreation - Daytona Beach

MONDAY	Tai Chi 3:00–4:00PM Pictona at Holly Hill 1060 Ridgewood Ave Holly Hill, FL 32117	
	TUESDAY	
WEDNESDAY	On-Water Rowing 8:00–10:00AM Halifax Rowing Boathouse 201 City Island Parkway Daytona Beach, FL 32114	Rec Game Night <small>[Rotating between Bocce Ball, Shuffle Board, Croquet and Horseshoes]</small> 4:15–5:15PM Pictona at Holly Hill 1060 Ridgewood Ave Holly Hill, FL 32117
	THURSDAY	
FRIDAY	ERG Rowing 3:00–5:00PM Halifax Rowing Boathouse 201 City Island Parkway Daytona Beach, FL 32114	Adaptive Yoga 1:30–2:30PM Port Orange Family YMCA 4701 City Center Parkway Port Orange, FL 32129
	ALTERNATES EVERY FRIDAY	
	Bowling 5:30–7:30PM Ormond Lanes 260 N US Highway 1 Ormond Beach, FL 32174	Billiards 4:30–6:30PM Uncle Waldo's Sports Pub 2454 Nova Road Daytona Beach, FL 32119

FOR MORE INFORMATION:

386.871.3024

Kristina.Seiple@Brooksrehab.org



CENTER FOR INPATIENT REHABILITATION

Halifax Health | Brooks Rehabilitation

Wellness Program Weekly Calendar

**MONDAY
WEDNESDAY
FRIDAY**

Wellness Program

DeLand Family YMCA
8:30-11:30am

Wellness Program

Ormond Beach Family YMCA
12:00-4:00pm

**TUESDAY
THURSDAY**

Wellness Program

Ormond Beach Family YMCA
12:00-4:00pm

Ormond Beach Family YMCA:

500 Sterthaus Dr, Ormond Beach, FL

DeLand Family YMCA:

761 E International Speedway Blvd, DeLand, FL

FOR MORE INFORMATION:

386.871.3024

sydney.olsen@brooksrehab.org





PARKINSON'S SUPPORT GROUP!

Flagler/ Palm Coast

*Join us for a meeting in
conjunction with the Nocatee
Support Group & Dr. Prosje*

› **Wednesday, February
1st @ 3:00pm**

› **Palm Coast Community
Center**

305 Palm Coast Pkwy NE,
Palm Coast, FL 32137

› **RSVP: Renee Shoner**
386-503-2239
Reneeshoner@gmail.com



Special Guest:

Michelle A. Prosje, Psy.D.
Licensed Psychologist/Neuropsychologist

Discussion: Mental & Cognitive Health

Dr. Prosje is the President of NeuroBehavioral Specialist of Jacksonville, Inc. (NBS-JAX). She has extensive training in education, clinical psychology, neuropsychology, and rehabilitation. Graduate training sites include Emory's Center for Rehabilitation and University of Alabama - Birmingham and following trained in neuropsychology at the University of Florida in Gainesville. She has experience working in hospitals, rehabilitation centers, colleges, and outpatient clinics with individuals ages 0-100 with various neurological and psychological disorders. Dr. Prosje's approach to patient care is to care for the whole person and raise awareness of the mind (brain), heart (emotion), and body (physical/medical issues) connection.

THE SWALLOWING ASSESSMENT - WHAT ARE WE LOOKING FOR?

Article Reprinted FR: WPC BLOG – Comprehensive Living – November 7, 2022

Swallowing is a neuromuscular coordinated activity that allows the uninterrupted passage of oral contents (food, liquid, saliva and secretions) into the stomach to pass from the mouth to the pharynx, to the esophagus and into the stomach. The swallowing process is divided into four phases:

1. The Pre-oral Phase begins with the anticipation of food being introduced into the mouth, salivation is triggered by the sight and smell of food.

2. The Oral Phase starts when the lips close and form a seal, chewing and manipulation of food begins, the food is mixed with saliva to form a bolus which is then transferred to the back of the mouth.

3. The Pharyngeal Phase is reflexive initiation of the swallow. The nasal cavity is sealed when the soft palate raises (to prevent food/fluid to go up to the nose). The larynx (voice box) moves upwards and forward, the vocal folds close, and then the epiglottis closes over the airway, to protect it, the pharynx pushes the bolus down (by contracting in a peristaltic motions) and the upper esophageal sphincter opens to allow the bolus through. Finally, the upper esophageal sphincter closes after the bolus has passed through in order to prevent the bolus moving back up.

4. The Esophageal Phase starts when the bolus is transported through the esophagus by peristaltic motions into the stomach. The lower esophageal sphincter opens to allow the bolus into the stomach and finally the lower esophageal sphincter closes after the bolus has passed through to prevent reflux.

Swallowing disturbances

Difficulty in swallowing known as dysphagia, can be described as any condition that weakens or damages the muscles, structures and nerves used for swallowing. Dysphagia can be categorized according to the swallowing phase that is affected. For example, oral phase dysfunction can occur when there are limited tongue movements, reduced coordination and tonus. Without proper tongue movements, the patient can have trouble forming and manipulating the bolus towards the back of the mouth and the pharynx.

When there is dysfunction in the pharyngeal phase such as insufficient closure of the airway while swallowing, food bolus or liquids could enter into the airway and may reach the lungs, a condition called aspiration.

This can cause coughing, a choking sensation, a change in voice quality, shortness of breath and can lead to aspiration pneumonia. Esophageal phase dysfunction can occur when there is a disturbance in the esophagus peristaltic motion or when the lower esophageal sphincter does not stay contracted, stomach contents can be regurgitated into the esophagus and even into the airway.

Swallowing disturbances in Parkinson's disease

Swallowing disorders is a common complication experienced by people with Parkinson's (up to 100%). The severity of dysphagia does not necessarily relate to the overall severity of the disease and it is documented in all phases of swallowing. Parkinsonian patients are "silent aspirators" with decreased cough reflexes, reduced clinical signs and lack of awareness. Silent aspiration occurs when food or liquid enters the airway (trachea) without any reflexive protective behavior such as coughing or choking. Aspiration is seen in more than half of the PD patients and aspiration pneumonia is one of the major causes of death.

Evaluation of swallowing disturbances

Dysphagia evaluation is performed by the speech language pathologist (SLP) in conjunction with other members of the multidisciplinary team. There are two questions to be answered:

1. What type of food is safe for the patient to swallow?
2. What are the therapy goals that should be included during the swallowing intervention program?

The goal of the swallowing evaluation is to examine the oral and pharyngeal phases of swallowing and to assess not only whether the patient is aspirating, but also the reason for aspiration, so appropriate treatment can be initiated.

There are three procedures for evaluation of patients with swallowing disorders:

- (1) the bed side evaluation or clinical swallowing evaluation that is performed by the speech language pathologist (SLP) and is performed at the clinic or at the patient's room.
- (2) The videofluoroscopy swallowing study (VFSS) and (3) the Fiberoptic Endoscopic Evaluation of Swallowing (FEES).

The VFSS and the FEES are instrumental evaluations and are considered to be the gold standard and procedures in swallowing evaluation.

All three methods of evaluation are used to make diagnosis of dysphagia and to guide management based on the findings. A high level of analysis of the swallowing assessment results requires a good understanding of normal swallowing and abnormal patterns to be expected with different underlying medical causes and conditions. A good understanding of swallowing at this level also will lead to significantly better rationales when recommending specific therapeutic intervention.

The importance of early detection of the swallowing disturbances in patients with PD.

Early detection and effective intervention can help prevent the serious consequences of dysphagia. It is known that patients' perceptions of their swallowing function are not always reliable, and that existing problems may be undetected if diagnosis relied solely on self-reporting, probably due to the decreased awareness and knowledge about what are the specific symptoms associated with swallowing problems.

Several questionnaires have been developed to use as a screening tool for detecting swallowing problems in PD including Swallowing Disturbances Questionnaire (SDQ) and Eat - 10. Its aim is to obtain information on their swallowing status and detect the swallowing disturbances as early as possible. The screening for swallowing disorders should be routinely administrated at PD centers and can be offered by any health care professionals. Evaluations and treatments of swallowing disturbances should be offered at early stages in order to prevent aspiration pneumonia and maintain the best possible quality of life.

Yael Manor PhD CCC-SLP is an Assistance Professor at Tel Aviv Medical Center, Movement Disorders unit, Tel Aviv, Israel. She has attended/presented at past WPC Congresses. Dr. Manor will be speaking at the WPC 2023 Congress in Barcelona. View the Scientific Program here.

Ideas and opinions expressed in this post reflect that of the author(s) solely. They do not necessarily reflect the opinions or positions of the World Parkinson Coalition®

Valentines Day Word Search

T V J H U G B V V X H L D B M R I O H A
R O T L R E R I M D A V C I B N A K P H
A U F B G N X K V V E O Z U G Y T L M J
E E P E N I T N E L A V V L W O I M Q O
H V O I V R R F R I E N D S H I P G X O
T X B E M I N E A T C O Z Z X H D Z P V
E Y Z J E R P H J R D F V L O O X O O M
E Q D I P W Z U A X L O Y Q R X U Y M E
W K K C N Z C P C O Y D B F G O Z I B Z
S H N P M P H M V L C V O N R X L S T V
Y E I J I Y S E K Q L L S F W H W K S Z
O A R M C U P I D S S H S L R E T M R C
V R E A X H G X C S R G I O K N I P V H
C T Y Z E B C C R U S H K W F S B S T O
O J P G B B B A L B N O M E Q S E M I C
K Q V D D F Y I Y K T O N R Z S H M P O
L B H Q P R K D U P I J M S O I W B L L
S L P X Q U L T D E D B T R X X A Z G A
K T U N P S X X C E C E H I J X D U X T
R G G W H G I T B E T D R D R J P O H E

ADMIRER
BE MINE
CHOCOLATE
CRUSH
CUPID
FLOWERS

FRIENDSHIP
HEART
HUG
KISS
LOVE
PINK

RED
ROSES
SWEETHEART
TEDDYBEAR
VALENTINE
XOXO



THE WELLNESS CORNER

This edition's Wellness Corner is a little different. The later half of the Wellness Corner is what you would traditionally find in this section. This edition is focused on Freezing of Gait and Balance - exercises and tips.

The beginning of the Wellness Corner for this edition is focused on new information from a clinical trial that was just completed about technology advancements/wearable devices in PD. This is really exciting and hopefully will be available to People with Parkinson's soon! There are vibrating devices available on the market currently, but none are FDA approved yet and it would be up to you and your care team to discuss trying out one of these devices. We will be keeping our eyes out and notify our members when the FDA approved devices are available.

At the end we link a YouTube video showing a PD patient using the device. It is beyond impressive and inspiring. We hope you take the time to watch the video. We are excited and hopeful to continue to see what is in the pipeline for PD and finding ways to manage the disease!

Good Vibrations

Can Parkinson's symptoms be stopped?

On June 17, 2018, Kanwarjit Bhutani stepped out of an elevator with his wife, unaware his life was about to change. A woman followed the couple from the elevator to the door of their condominium in New York City. Out of the blue, she recommended that Bhutani see Stanford Medicine researcher Peter Tass, MD, PhD, about his promising treatment for Parkinson's — a vibrating glove.

Bhutani was still processing what had happened when he realized the mystery woman was gone. He had been diagnosed with Parkinson's disease nearly a decade before, but only his close family and friends knew.

"I felt that Parkinson's was something old people had. I don't want to be associated with that. I'm not old, and I was very young — only 39 — when I got the disease," he said.

For years he'd been managing Parkinson's while juggling a career as president of several companies, including Tupperware U.S., Avon and Jeunesse. Then, the disease worsened without warning. "All of a sudden, I couldn't work," Bhutani said. "I basically went into hiding."

Bhutani scoured the internet for information on Tass' research and introduced himself over email. Within minutes, Tass replied. In August 2018 Bhutani and his wife flew to the Stanford campus in Palo Alto, California, to meet Tass, who assessed Bhutani's condition and explained the concept behind the glove.

"Most of it went over my head," Bhutani said. "It was all la la land, to be honest with you. I didn't understand much, but it's noninvasive." "It was noninvasive and it couldn't hurt him," added Bhutani's wife. "We had nothing to lose."

Parkinson's disease attacks brain cells that make dopamine, a chemical that is key to nerve communication for functions like movement, mood and behavior. Drugs that mimic dopamine are common treatments for the condition.

If the symptoms stop responding to drugs, deep brain stimulation is the gold standard treatment. The technique targets abnormal brain patterns with electrodes that are implanted into the brain and linked to a pacemaker-like device. Because of the risks of brain surgery, not all patients are eligible for or choose the treatment.

Yet, neither therapy is perfect. Drugs and deep brain stimulation are expensive and both can have serious side effects. They also don't always work and, even when they do, their benefits can wane. So it might be hard to imagine that a vibrating glove could be much help.

But a recent study of a small group of patients found that wearing the glove for two hours, twice a day does just that, alleviating the tremor, stiffness, abnormal walking, slow body movement and balance problems associated with Parkinson's.

Although the researchers didn't set out to study other symptoms, they were surprised to find patients reported the glove also alleviated mood swings, behavior changes, depression and the loss of smell and taste.

"It seemed like magic," said Stanford Medicine neurobiologist Bill Newsome, PhD, recalling the first time he saw videos showing improvements for Parkinson's patients before and after using the glove.

"But Tass' modeling studies suggest a plausible mechanism whereby fingertip stimulation could alter abnormally synchronous activity in the central nervous system."

Convincing the research community seemingly "magic" vibrating glove has real therapeutic effects will require further testing, explained Newsome, who holds the Harman Family Provostial Professorship and directs Stanford's Wu Tsai Neurosciences Institute.

An old idea refined

The idea of using vibrations to treat Parkinson's is not new, Tass explained. In the 19th century, neurologist Jean-Martin Charcot created a vibrating chair after learning that his patients' symptoms briefly improved after long, jostling carriage and horseback rides.

Charcot's vibrating chair, and the vibrating platforms and therapies developed by researchers who followed, alleviated some symptoms of Parkinson's, but the results were inconclusive and temporary.

When Tass was a medical student, he became intrigued with self-organization — the seemingly spontaneous assembly of patterns and structures, such as clouds and snowflakes. He went on to earn a doctorate in physics and a master's in mathematics for his research on self-organization, which revealed potential applications for neurological diseases, including Parkinson's.

"My goal is to create treatments that are more effective and less brutal on the body by simply utilizing the self-organization power within the body," Tass said.

How a buzzing glove could treat Parkinson's

The symptoms of Parkinson's arise when large groups of neurons abnormally fire in unison. Using computer simulations, Tass and his team discovered that a patterned stimulus that vibrates at a frequency of 100 to 300 hertz (cycles per second) can desynchronize neuron-firing. They called this coordinated reset stimulation.

Further, Tass discovered how to make the benefits of vibratory stimulus last, something that eluded Charcot and others who used vibrations to treat Parkinson's: Pauses are crucial between treatments and within stimulus patterns.

The body needs to unlearn abnormal neural connectivity patterns, Tass explained. Just as taking small breaks increases the effectiveness of study or exercise, pauses improve the treatment's effectiveness.

Tass explored possible therapeutic effects of the treatment by applying it directly to the brain with electrical stimuli via deep brain electrodes in studies in monkeys with Parkinson's symptoms (Annals of Neurology, 2012) and later in a study of six Parkinson's patients (Movement Disorders, 2014).

In the 2014 study in humans, coordinated reset stimulation was applied for three consecutive days in two daily sessions of up to two hours. The researchers found that the stimulation reduced the neural synchrony associated with Parkinson's and this correlated with improvement of motor function.

“My goal is to create treatments that are more effective and less brutal on the body by simply utilizing the self-organization power within the body.”

Peter Tass, MD, PhD, professor of neurosurgery

Next, Tass and his team set out to find a way to deliver the stimulation without implanting electrodes in the brain. The solution was to replace electrical bursts delivered through electrodes embedded in the brain with vibratory bursts delivered through mechanical stimulators to the fingertips.

Fingertips have many sensory neurons, which means a large portion of the sensory cortex of the brain is dedicated to receiving signals from them. This is important because a noninvasive therapy must act on a sufficiently large portion of the brain to have similar benefits as deep brain stimulation.

The outcome of this research is a strappy, skin-exposing glove that looks like something out of a sci-fi film. The glove is lightweight and can be worn while performing regular daily activities. It's attached to a device that delivers bursts of 250 hertz (a buzz slightly stronger than a cat's purr) through pin-sized openings on plastic pads strapped to the index, middle, ring and pinky fingertips.

Each glove collectively stimulates a patch of skin smaller than a dime.

What's next for the research?

In April 2021, Tass and his team published the results of pilot studies of patients — including Bhutani — with mild to moderate Parkinson's disease in *Frontiers in Physiology*. In these studies, eight Parkinson's patients received vibrotactile coordinated reset stimulation daily for at least three months (three of those patients received the therapy for six or more months).

The researchers assessed patients' motor function and obtained at-rest electroencephalographs before and after the three months of glove therapy using four subcategories — tremor, rigidity, bradykinesia (slow body movement) and axial (balance). They used EEGs, which measure brain activity, to investigate the therapy's possible effects on the abnormal, synchronous neural patterns associated with Parkinson's.

The researchers assessed the patients' movements and brain activity off medication at the start of the study, at three months, and during follow-up visits approximately every three months thereafter.

These pilot studies revealed that the vibrations were well-tolerated, produced no side effects, improved the patient's motor performance and reduced Parkinson-related neuronal synchrony in the brain.

“There's currently no middle ground between drugs and invasive treatments for Parkinson's patients,” said Leila Montaser Kouhsari, MD, PhD, a movement disorders neurologist at Stanford Medicine.

“Parkinson's patients are often really suffering, but symptoms, such as tremor, can vary with stress and medication fluctuations, so they may not be ready to go all in with invasive procedures. Or, because of other health problems, they may not be able to get surgery,” said Montaser Kouhsari, clinical assistant professor of neurology and neurological sciences.

“Depending on how the clinical trial goes, the glove could expand what we have to offer patients. It could be huge if it helps a lot of patients with no side effects.”

Tass is working with an industry partner to gain U.S. Food and Drug Administration clearance for the treatment, which he hopes to have by Summer 2023.

“Although much painstaking research remains to be done, this therapy is potentially game-changing because it is completely noninvasive,” Newsome said.

Before Bhutani used the glove as part of the study published this year in *Frontiers*, his Parkinson's symptoms included muscle contractions, loss of taste and smell, inability to speak above a whisper, mood swings, and obsessive-compulsive buying behaviors. Each day he took 25 medications — some to treat Parkinson's and others to alleviate the side effects of the other drugs.

At the beginning of his treatment, Bhutani wore the glove for two hours every morning, and two hours in the afternoon or evening.

Within three weeks, he said, his sense of taste and smell returned, and he was able to work in the garden again. Bhutani also reduced the drugs he was taking to 10 medications a day, and his muscles became less rigid and stiff, which restored his ability to show emotion with his face.

Bhutani still uses the vibrating glove, but not as often as he did initially because the benefits are lasting longer.

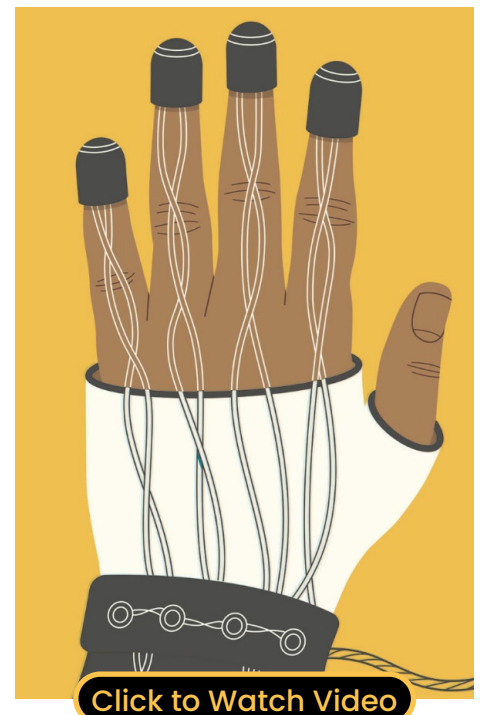
“In November 2018, I ran my first marathon,” Bhutani said. “It was a dream come true.”

His mood has also improved. “I feel my quality of life has come back. And I've got a very strong caregiver,” Bhutani said, smiling at his wife. “She has been by my side ... I'm grateful to her.”

He's also grateful to the mystery woman who suggested he contact Tass in the first place. Bhutani tried to discover her identity to thank her, but he never saw or heard from her again.

“I don't know who she was, but she changed my life,” Bhutani said.

<https://stanmed.stanford.edu/vibrating-glove-reorganize-neurons-parkinsons/>



If you would prefer to type in the web address: www.youtube.com/watch?v=YE.EwbxFT4Bc

You may have seen the TODAY show video which highlighted a fascinating device developed at Stanford University – a glove that imparts vibration to the fingertips in order to relieve Parkinson’s disease (PD) symptoms. In a small trial, participants wore the glove on each hand for several hours a day. The results showed that the device alleviated tremor, stiffness, and slowness in PD, even during the times of day when they were not wearing the device. Many people have seen this video clip and want to know how to get access to this technology.

It is important to note, that the concept of treating PD symptoms with vibration is not new. There have been multiple clinical trials performed to determine if either whole-body vibration or localized vibration can help symptoms with PD. A recent review analyzed the results of these trials and determined that whole body vibration was not better than standard physical therapy in improving gait and balance. No conclusion could be made regarding localized vibration as the results were too varied across different trials.

In addition to the Stanford research group, there have been other research teams that have worked on developing devices to utilize vibration as a means of easing PD symptoms. Researchers have worked on socks and shoe inserts that administer vibration to alleviate symptoms of freezing of gait. Neither of these devices are developed to the point that they have received FDA clearance for treatment of PD.

A larger placebo-controlled trial is now planned. This means that one group of people will receive the correct vibratory pattern using the glove and another group of people will receive an inactive vibratory pattern that is not thought to be beneficial. In this way, the research team is hoping to control for a possible placebo effect that can interfere in the researchers’ understanding of what the glove can and can’t do. You can find more details about the trial on clinicaltrials.gov. The glove is currently not available for purchase and obtaining access to the glove at this point is only possible through the clinical trial.

One of the most exciting aspects of this research is that vibration therapy has minimal to no side effects, which makes its potential introduction as a therapy much more straightforward. As the next clinical trial unfolds, it will also be interesting for the research team to note if there are certain people who have a more robust response to vibration therapy than others. The vibratory glove is part of a larger research effort to maximize the use of technology to help diagnose and treat neurological illness.

THE THERAPY TIPS TO PREVENT FALLS IN YOUR HOME

Postural instability is a common feature of Parkinson Disease. As a result of delayed reaction time, rigidity, bradykinesia, and poor control of the center of mass, falls occur. Falls are a leading cause of bone fractures, brain injuries, hospitalizations, and mortality of persons with Parkinson Disease. What can YOU do to protect yourself or your loved one from this downward spiral of events?

A great place to start is within your home and/or current living situation. Modifications to your environment can prevent falls with a few simple changes including:

- Installing nightlights to illuminate your path to the restroom at night
- Installing grab bars in your bathroom, in the shower and next to your toilet
- Remove throw rugs throughout your home
- Use NON-skid mats only in the kitchen and bathroom
- Apply NON-skid tape or mats inside of your shower or tub
- DO NOT wear slippery soled shoes, wear shoes with tread instead
- Remove clutter from the ground including magazines and electrical cords
- Rearrange the furniture to provide larger and wider walking paths
- Be sure to lock your walker or assistive device before and during transfers
- Keep your walker or cane parked near your bed if you use one to be available in the morning and at night
- Sit to dress instead of standing and trying to balance on one leg when applying your pants or shorts
- Stay well hydrated to decrease the incidence of postural hypotension
- Take your medications as prescribed by your doctor
- Place frequently used items in the kitchen on shelves that are within arms reach such as on the counter top vs. on a high shelf
- Avoid climbing on ladders or step stools
- Plan your errands and strenuous daily activities to occur when you feel best (earlier in the day vs. later in the day)
- Avoid multi-tasking and do ONE thing at a time such as attending to where your body is in space
- **Ask for help!**

BALANCE EXERCISES TO DO AT HOME

When practicing balance always be careful and safe by having a stabilizing object such as a counter or sturdy chair nearby or a partner.

Dual Tasking

One of the best balancing exercise for Parkinson’s disease.

Practice walking for 2 minutes while performing one of the following tasks:

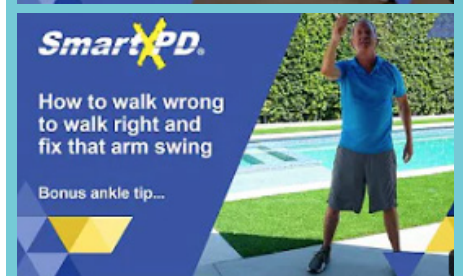
- Motor tasks, such as holding a cup of water
- Cognitive tasks, such as:
 - Subtracting a random number by 3.
 - Naming objects e.g. animals, colors.
 - Holding a conversation with another person.

For dual tasking, primary attention should be on balancing and walking, with all other activities as secondary tasks.

Tandem Standing

Stand with one foot ahead of the opposite, so your heel and toe are in line, keep your body upright and maintain your balance. Try to look straight ahead. Hold for thirty seconds. Repeat with the opposite foot ahead.

These are two great videos for balance & walking! Click the thumbnail to watch the video on YouTube.



You have questions about Deep Brain Stimulation (DBS) for Parkinson's Disease?



We have answers! Join us for an upcoming event.

Join Therapy Consultant at this Deep
Brain Stimulation (DBS) event.

Alaine Keebaugh, Ph.D.

February 08, 2023 - 11:00 am to 1:00 pm

Palm Coast Community Center
Room #112
305 Palm Coast Parkway NE
Palm Coast, FL 32137

770-356-6410

This is an In-Person event.
Join us by registering today!

To attend in person

register online at:
<https://LearnDBS.com/1496>

Or use your smartphone
camera to register.



We welcome family, friends and care providers to attend.



"DOCTORS DIAGNOSE, NURSES HEAL, AND CAREGIVERS MAKE SENSE OF IT ALL" - Brett H. Lewis

Serving People with Parkinson's and Their Families

CAREGIVER SYMPOSIUM

COLLABORATE, CONNECT & CELEBRATE:

Caring for the Caregiver



ALOFT JACKSONVILLE
TAPESTRY PARK HOTEL

FEBRUARY 4, 2023
9AM - 3PM

4812 West Deer Lake Drive,
Jacksonville, FL, 32246

Join us for our FREE event where you can connect with others in the community. We will have various activities, workshops, vendors, etc. Lunch will also be served. This event is free, but registration is required.

FOR MORE INFO -
Please visit
tinyurl.com/jaxhope2023



Speaker:
Michelle A. Prosjie, Psy.D.
Licensed Psychologist/Neuropsychologist



Speaker:
Toulia Wootan
Toulia's Tips for Caregivers

REGISTER FOR EVENT AND FIND MORE DETAILS BY SCANNING THE QR CODE WITH YOUR PHONE'S CAMERA



For any other questions please email or call Alaine Keebaugh: alaine@jaxhopeinc.org // 770-356-6410

[Click to Register for Symposium](#)

14th ANNUAL "SOLE SUPPORT" FOR PARKINSON'S FUN WALK

Port Orange Lakeside Community Ctr. – RESCHEDULED DATE: Saturday February 25, 2023 - 10:00am-2pm

****Registration Begins at 9:00am**

-REGISTRATION FORM-

IMPORTANT: This registration form must be filled out in its entirety, signed, and **mailed with your \$25.00 check made payable to the Parkinson Association of Daytona to P.O. Box 4193 Ormond Beach, FL 32175 and be postmarked no later than February 16, 2023.** Registration forms received after 2/16/23 cannot be guaranteed an event T-shirt/goody bag. **For children 12 & under the registration fee is \$15.00. For all registrants less than 18 years of age, a parent or responsible adult must designate as a minor child by checking here: _____ and fill out this form in the minor's name and sign on behalf of the minor child.**

PLEASE PRINT CLEARLY:

Last Name: _____ First Name: _____

Address/City/State/Zip: _____

Phone: (_____) _____ Email Address: _____

Age (if U-18): _____ T-Shirt Size: (circle one) S M L XL XXL

*****All registrants – MUST CHECK IN AT THE REGISTRATION TABLE PRIOR TO THE WALK – at check in you will receive a ticket for door prize drawings.***

Participation Release (PR)

By registering to participate in the Parkinson Fun Walk 2022/2023 (event); I understand and agree, that participating in this event may involve risk of personal injury which may result from not only my own actions, inactions, or negligence, but also from the actions, inactions, or negligence of others, the condition of the facilities, equipment, or areas where the event is taking place, and or the parameters associated with the event itself. Being in full knowledge to the foregoing, I hereby release, indemnify, and hold harmless the City of Port Orange and the Parkinson Association of Greater Daytona Beach (PAGDB), and all individuals, agents, employees, volunteers, representatives, officers, directors, and insurance companies associated with the PAGDB, of and from any and all liability, claims, demands or causes of action whatsoever arising out of or related to any loss, damage, injury (up to and including death) that may be sustained by me or any property of mine while participating in this event. I further agree, that by participating in this event, that if I suffer any injury or illness, I authorize the event facilitators to use their discretion to have me transported to a medical facility for treatment, and I assume full responsibility for this action. By signing below, I attest that I have read, understand, and agree to the entire content of this PR, that I am in good physical condition and have no medical condition that would be detrimental to my health or wellbeing by participating in this event. Further, I hereby grant full permission to the PAGDB, to use photos, videos, and any other record of me during this event for any purpose, and for which I agree to receive no compensation whatsoever in return. This PR shall be binding upon me, my heirs, my executors, legal representatives, and my assigns. This PR is construed to the laws of the state of Florida. **I agree that I am participating at my own risk.**

Signature of Registrant or Parent/Responsible Adult

Date

_____ X here if you cannot participate in the Parkinson's Fun Walk 2022/2023 but would like to help support our cause; all donations are gratefully accepted and much appreciated! Please make checks payable to the Parkinson Association of Daytona and mail to P.O. Box 4193 Ormond Beach, FL 32175. **Thank You!**

The Fun Walk Will Take Place Rain or Shine!

FW/2022-2023

ONLINE BRAIN & BODY TRAINING

Online Brain and Body Training for Alzheimer's, Parkinson's and Adults 50+

Total HealthWorks – an evidence-based virtual fitness platform created by the founders of Delay the Disease, the #1 Parkinson's group-exercise program in the country, is offering their Brain and Body Class **every Wednesday at 12:00 PM Noon EST via Zoom for FREE!**

Fill out the form on their website and receive a link in your email to join the online Brain and Body exercise class with Jackie Russell and David Zid. **Click the button to be taken to their registration page or visit their website to learn more:** <https://totalhealthworks.com/free-online-class/>

Don't worry, if you can't join the class at the scheduled time, **you will receive a link in your email to watch the class whenever you'd like!**

REGISTER

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

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386-871-3879

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WEBINAR VIDEOS

All of our previous webinars and monthly meetings 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](#).