



BRAIN N' MOTION

PARKINSON'S NEWS TO MOVE YOU FORWARD

4th Quarter 2021

CAREGIVING AND THANKFULNESS

BY JOHN GABRIEL
PACF PRESIDENT

“The unthankful heart discovers no mercies; but the thankful heart will find, in every hour, some heavenly blessings.” – Henry Ward Beecher

November, as you may know, is National Family Caregivers Month. It is a month to show our appreciation and support for the caregivers in our lives. And there are many. The National Alliance for Caregiving estimate that there are 44 million individuals in the U.S. who are caring for a family member, friend or neighbor.

For caregivers, the ongoing act of providing loving care for a family member can take an emotional and physical toll. No matter where you are on your care partner journey, know that you are not alone. Contact PACF to get answers to your caregiving questions and other helpful resources.

As we prepare to celebrate Thanksgiving, many families will say a prayer or a few words of thanks to the caregivers in their lives. A thanks that is certainly well deserved!

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LETTER FROM THE PRESIDENT

JOHN GABRIEL
PACF PRESIDENT

Dear Friends,

Having the opportunity to serve as the President of the PACF Board of Directors will go down for me as one of the most gratifying experiences of my life. I've decided not to run for a second term making it time for me to pass the gavel along to a person whom I highly respect. When thinking about the qualities this person should possess, Todd Stewart was foremost in my mind. Incoming President Stewart is resourceful, organized, passionate and he also has Parkinson's.

Todd was diagnosed with Young Onset Parkinson's Disease in 2013, he publicly shared his diagnosis in 2018 in the pages of the Orlando Sentinel newspaper and an accompanying video on OrlandoSentinel.com. He joined the PACF Board of Directors later that year and was elected President-elect of the group in 2019.

Like I did, Todd will have a gifted, dedicated board supporting him. I can't imagine a more diligent and compassionate team.

The newly elected Executive Board of the PACF:

- President: Todd Stewart, Envision Orlando
- President-elect: John Ashworth, Morgan Stanley
- Treasurer: Scott Herring, Chief Financial Officer at Florida Citrus Sports
- Secretary: Leslie Carney, IQvia
- General Counsel: G. Charles Wohlust

Our past president Marti Miller laid the groundwork for an easier transition for myself. For that I am grateful and hope to serve Todd in the same capacity.

I'd be remiss if I did not mention the amazement I still have for the Central Florida community. Through your generosity you aided the Parkinson's community with programs that have made a positive difference in the lives of those with PD and their caregivers. We are so appreciative and pray your generosity continues for these programs.

It is crucial, more than ever, that we keep the momentum going.

With the upmost gratitude, thank you.

A handwritten signature in black ink that reads "John Gabriel". The signature is written in a cursive, flowing style.

John Gabriel
PACF President



CAREGIVER THOUGHTS

CAROL RASKIN

Caregiver or care partner, which is it?


Our journey started almost 8 years ago and I find the answer to that question to be different every day. I remember when my daughter was born they said they had to observe me in the hospital doing certain things to be sure that I knew how to take care of my baby. I feel as a woman you're kind of nurtured into how to take care of a baby and people in general, however I in no way felt prepared for this journey. As a Caregiver or care partner you wear many hats. Firstly, I'm a wife, next a best friend who listens who cares who helps. There is also the role of nurse and nurses aide. Each day is a new challenge, with different things to deal with; some medical, some physical, some social, some psychological, and the list continues.

Relying on the many resources available to us for support has been a tremendous help. My husband found that pedaling with the Pedaling for Parkinson group helped him the first few years, but then it became too difficult. He has been doing Rock Steady Boxing for the past year and a half and still loves it. It has been via Zoom for the past 10 months, but it still works. During Covid one of the biggest challenges had been managing the social. We have found that the lack of socialization has been very taxing on both of us. Yes, we use Zoom and other technologies, but that in person contact is an important ingredient in keeping the brain active and alert. Covid has certainly made this aspect of caregiving even more of a challenge.

It's important to keep your sense of humor through all of this, because no one can say that this is dull. So you'll have to look at these challenges as learning experiences. Try to stay ahead of the game by learning how others have dealt with issues you are seeing. Although no two Parkinson patients are the same, most go through the same challenges at one time or another. To stay strong I always tell myself that there is someone out there dealing with something worse than us. We have to be strong, stay safe and be thankful that we wake up each day. So which are you today, caregiver or care partner?

“There are only four kinds of people in the world:
Those who have been caregivers.
Those who are currently caregivers.
Those who will be caregivers,
and those who will need a caregiver.”

- Rosalynn Carter



#NationalFamilyCaregiversMonth #NFCMonth

ROSALYNN FOR
CARTER CAREGIVERS
INSTITUTE

COMING OUT, WITH YOPD

TODD STEWART, PACF BOARD MEMBER

The most frightening days in my journey with Parkinson's Disease were not the days on which my diagnosis was confirmed, but instead every single day I shared this with another person in my life.

This is why I kept my diagnosis a secret for six long years.

It was never a case of being worried about how friends or family would respond, because I knew they'd be supportive. It was always more about not wanting people to treat me differently or to look at me like a "sick" person. (The fact that I believed a stigma surrounding Parkinson's existed is likely more a reflection on me than anything else, but nonetheless it was there in my head.) That's why it took so long for me to wrap my head around the diagnosis and work up the courage to openly live with the disease. At some point the physical and mental fight to keep the secret becomes counterproductive. And unhealthy. Whether it be hiding hand tremors in my pockets or eliminating meals to ensure the effectiveness of medications, at some point everyone breaks. My breaking point was six years in.

I started crafting a plan for sharing my diagnosis and I almost immediately decided the best route for me was to get it all over at once. Any apprehension I had over enduring such a public disclosure was minuscule compared to the way-more-uncomfortable prospect of having to share my story 25 separate times. Like a Band-Aid, I wanted to rip this moment right off and be done with it.

Everything was going to happen in two stages.

Stage one was to tell the friends and family who were still in the dark. Stage two was to tell the world.

So I went about gathering my favorite people for what my wife would later dub "The Parkinson's Brunch." Over the course of the meal — with mimosas supplying a bit of the courage — I shared my news. It wasn't easy, but the kind, generous support of the gathered loved ones soothed my soul. It was everything you could ever want from a moment like this.

Now it was time to tell the world.

As part of the senior editor management team at the Orlando Sentinel, I had access to digital and print platforms that provided a unique opportunity. Through a first-person story (and accompanying video) on my battle, I was able to release the burden I had been carrying for six years onto the

newspaper and website of the largest media company in the region.

It was freeing in almost every way I had hoped for and in many ways I could never have anticipated. Within minutes of my story landing online, the Parkinson Association of Central Florida reached out. That led to increased involvement in the region's Parkinson's community and a leadership position within the organization that has been one of the true blessings of my life.

I heard from so many people in the Young Onset Parkinson's disease community in Orlando — and across the country — who were struggling with how and when to share their diagnosis. Perhaps the most unexpected thing to come of my sharing was the revelation that two friends in my current friendship circles had also been diagnosed with Parkinson's. And neither had told a soul.

I was given the gift of an invaluable physical and virtual support system that powers me to this day.

Are there moments and days where I find myself slipping into anger, depression and frustration about this condition? Abso-freaking-lutely. It's a brutal, humbling and degenerative disease that's undefeated. It's always going to win. But I'm going to fight like hell. And I couldn't be better positioned to fight the fight than I am right now with so many more people in my corner.

Todd Stewart is the incoming President of the PACF Board of Directors, owner of Envision Orlando, proud husband and active member of the local PD community.





ASK THE DOCTOR

DR. RAMON RODRIGUEZ, NEUROLOGIST, MOVEMENT DISORDER SPECIALIST

Parkinson's disease vs. Parkinsonism?

Parkinson's disease is a complex neurodegenerative that is associated with a myriad of symptoms. Thus, sometimes the diagnosis can be difficult. It can be challenging to diagnose with certainty, even for the most experienced doctors. When your doctor is not entirely sure whether you have Parkinson's disease or not, a diagnosis of Parkinsonism is made. For others, it will be a diagnosis of secondary parkinsonism or atypical parkinsonism. Your doctor very likely refers to the same things. However, what is meant by those terms? To begin, let us define Parkinsonism. Parkinsonism is a very general term, meaning that a person has bradykinesia (slowness) associated with one of the following symptoms: stiffness (rigidity), resting tremors (tremors), and postural instability (balance problems). Those symptoms are called the cardinal symptoms of parkinsonian disorders. This is the criteria based on the UK PD Brain Bank Criteria. Everyone that is parkinsonian is slower than before and has at least one of the other three symptoms. However, those symptoms can be present in multiple neurological disorders. The challenge is to find out other associated symptoms that can help differentiate one condition from another. Let's jump into some of the most commonly diagnosed Parkinsonian syndromes.

Parkinson's disease: Parkinson's disease is the most frequently diagnosed parkinsonian syndrome. This is the one condition that is mostly associated with resting tremors. However, looking into the diagnostic criteria above, tremors are not a requirement to make a diagnosis of Parkinson's disease. Parkinson's disease is a slowly progressive neurodegenerative disorder associated with the deposition of an abnormal protein in the brain called alpha-synuclein. This condition is highly responsive to a medication called levodopa, which is the gold standard treatment for people with Parkinson's disease. Technically, every person with Parkinson's disease would be taking levodopa at some point in their condition. Parkinson's

disease is slowly progressive, and we measured disability in months to years. People typically will live a long life with Parkinson's disease, and they report obtaining good benefit from medications.

Lewy body disease: this is very likely the second most common parkinsonian disorder. Patients with Lewy body disease have symptoms similar to Parkinson's disease; however, the condition is complicated by hallucinations early in the disease and cognitive impairment. These patients might demonstrate some improvement to the typical medications used in people with Parkinson's disease during the first few years of the condition; however, after 4-5 years, they quit responding to the Parkinson's disease medications. They demonstrate more impairment in memory and have more hallucinations. They also lose the benefit they were showing previously to levodopa. This is a condition that typically progresses faster compared to Parkinson's disease. Interestingly, it is the same abnormal protein deposit, alpha-synuclein, in the brain of people with Lewy body disease.

Multiple systems atrophy: This is a condition that can present in different ways. Like Parkinson's disease and Lewy body disease, it is the same abnormal protein deposit in the brain of the people with this disorder. However, it has some marked differences that we will set it apart from Parkinson's disease and Lewy body disease. First, there may be three main clinical manifestations of multiple system atrophy: Some patients present with autonomic insufficiency, others present with a stiff parkinsonian manifestation, and others present with unsteadiness of gait and very poor balance. Patients with this type of condition might demonstrate some benefit to levodopa for a period between 3 and 5 years. However, after that, they begin to lose the robust benefit they were getting from the medication, resulting in more disability associated with their condition. Eventually, they will lose the medication's benefit. They have a predominance of dizziness when they are standing up (orthostatic hypotension), constipation, (Continued on page 7)

EARLY PARKINSON'S?

*We're working to
stop it in its tracks.*

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INSURANCE
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Experts are testing investigational medicines to learn if they may help delay disease progression. Join others in research studies today.

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*In a clinical research study, the participants may receive investigational study product or may receive an inactive substance, or placebo, depending on the study design. Participants receive study-related care from a doctor/research team for the duration of the study. Reasonable payments will be made for participation and the length of the study may vary.

ASK THE DOCTOR DR. RAMON RODRIGUEZ, NEUROLOGIST, MDS

(Continued from page 5)

urinary incontinence, and excessive sweating, among other symptoms. This condition also progresses faster compared to people with Parkinson's disease.

Corticobasal degeneration: This is a very complex disorder that is also frequently misdiagnosed as Parkinson's disease initially. The reason is that similar to Parkinson's disease, patients with these conditions tend to have a predominance of symptoms in 1 side of the body more so than the other. However, tremors are not a typical manifestation of this condition. They also seem to have a faster progression than Parkinson's disease. Patients with corticobasal degeneration eventually develop cognitive impairment. They develop a symptom called apraxia, which refers to the inability to coordinate movement. Many times, caregivers believe that the patient is showing weakness; however, in fact, what is happening is that patients are not able to coordinate complex movements in their brains. They can have some benefit to levodopa for the first five years. However, after that, that benefit is decimated, and they will develop more problems with her balance and eventually falls. The main protein deposit in people with this condition is called tau.

Progressive supranuclear palsy: This is another condition associated with the deposition of tau in the brain. The principal characteristic in progressive supranuclear palsy is that patients with this condition begin to fall very early

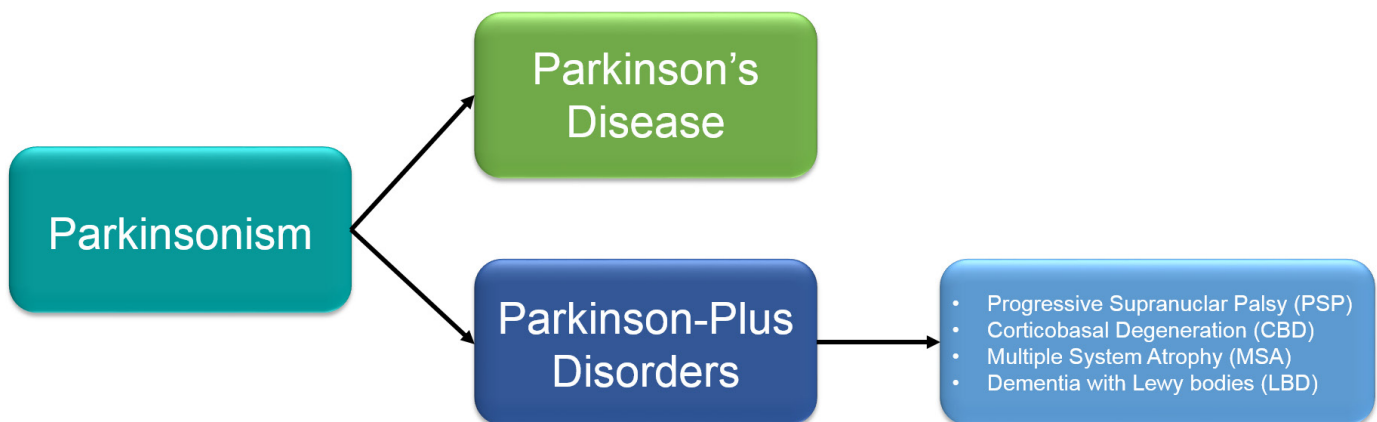
in their disease. Typically, people with this condition will fall backward, and they can fall multiple times per day. Also, they frequently complain of problems with her vision and difficulty speaking. Patients suffering from this condition also demonstrated a more rapid progression of their disease. They may require a walker or even a wheelchair because of the severity of the balance problems.

As you can see, these conditions may pose a diagnostic challenge, and sometimes it is not something that can be done in one visit. However, having someone experience evaluating this kind of condition can help identify those red flags that may differentiate one situation from the other. Having an experienced movement disorder specialist working along with your neurologist or primary care doctor might help diagnose and offer a potential therapeutic option or even participation in clinical research to improve the symptoms.

Dr. Rodriguez is a neurologist and movement disorder specialist in private practice in Orlando, FL, with a strong focus on improving the quality of life for patients with PD. He serves as an Advisory Board member for PACE.

Neurology One

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(407) 916-0304



LOCAL PARKINSON RESOURCES

The Parkinson Association of Central Florida raises money to fund local programs, support groups and educational initiatives that improve the quality of life for the local Parkinson community. www.parkinsoncf.org
Call 321-348-7223 or email info@parkinsoncf.org for more information or to have your PD group listed here.

The AdventHealth Parkinson's & Movement Disorder Outreach Program offers support groups, exercise and wellness programs virtually for people with Parkinson's disease and their loved ones. All meetings are FREE to attend! Call 407-303-5295 for more information or email ORL.Parkinson@AdventHealth.com

- Parkinson's Main Support Group: Virtually - Every Thursday, 12 - 1:00pm
- Carepartners and Caregiver Support Group: Virtually - Every Tuesday, 2:00 - 3:00 pm
- Young Onset Parkinson's Coffee Talk and Support Group: Virtually - Every Tuesday 2:00 - 3:00 pm
- Movement as Medicine: Virtually - 1st and 3rd Thursday of every month 1:30 - 2:30 pm
- Nova Southeastern University Treatment and Support Group: Virtually - Every Monday and Friday of the month 2:00 - 3:00 pm
- Rock Steady Boxing with Cynthia: Virtually - Every Tuesday 1:00 - 2:00 pm

Central Florida Lewy Body: Welcoming those diagnosed with Lewy Body Dementia and their care partners (families). For more information or to be placed on the email list(s), contact Sue Boudier Group Coordinator/Facilitator; FL certified Dementia Trainer at centralfloridalewybody@gmail.com Tel: 914-589-2004

- Education & Resource Group meetings: virtual 1st & 3rd Mondays/month, 4:30 - 6:00pm
- Care Partner's Only meeting: virtual 2nd & 4th Mondays/month, 4:30 - 6:00pm
- People with Lewy: virtual 2nd Wednesdays, 4:30 - 5:00pm
- "Art Friday" Zooms are held on the last Friday/month, 4:30 - 5:30pm

The Center for Health and Wellbeing offers exercise programs geared for people with Parkinson and their care partners. 2005 Mizell Ave #800, Winter Park, FL 32792 Call the Center for information and registration: 407-644-2492

- Pedaling for Parkinson's: in person, Mondays, Wednesdays and Fridays from 2:00 - 3:00pm
- Rock Steady Boxing: in person, Tuesday, Thursdays from 2:00- 3:00pm

Select Physical Therapy hosts a monthly support group on the second Thursday of every month in Osceola County. They lead discussions about available community resources for those with Parkinson's disease. Treatment options are offered at the Select Physical Therapy office located at 501 East Oak Street Kissimmee. For more information call 407-847-9110.



MARK YOUR CALENDARS!

2021/2022 EVENTS

11/18/2021

Live, Learn, Connect - PMD Alliance
Holy Trinity Greek Orthodox Church (outdoors),
Maitland 10am -12pm

12/8/2021

Getting Real - PMD Alliance
Holy Trinity Greek Orthodox Church (indoors),
Maitland 4pm – 6pm

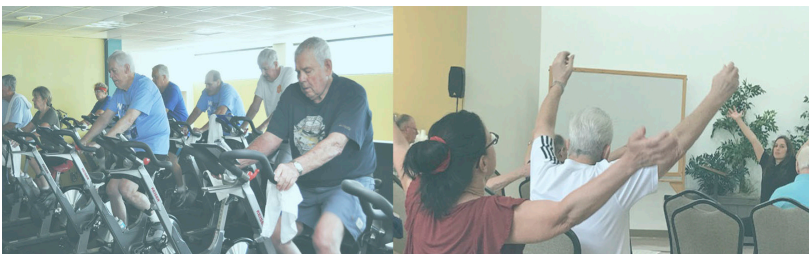
4/2/2022

Walk for Parkinson - PACF
Cranes Roost, Altamonte 9am - 12pm

4/8/2022

Dance for Parkinson - Lauren Carlsen, TeamFox,
Trinity Prep

Contact the Parkinson Association of Central Florida at 321-348-7223 for more information on these events



#GIVINGTUESDAY



#GivingTuesday is November 30th!

It is a day dedicated to giving – when people from all over come together to support those in need. This year, more than ever they need our support.

Thank you for choosing to support the Parkinson Association of Central Florida and positively impact people in our community with Parkinson's Disease.

Together, we can help those with Parkinson's live their best life now! Donate Today!



DONATE

HOW TO DONATE TO CHARITY FROM YOUR IRA

BY G. CHARLES WOHLUST, ESQ., PACF BOARD MEMBER

Required Minimum Distributions (RMDs) from your IRA can be a burden for many a taxpayer, uncomfortably boosting your income, sometimes even into a higher bracket. Did you know there is a way to do good with your RMD, both for others and for your own bottom line? It is called a Qualified Charitable Distribution (QCD).

The QCD rule allows traditional IRA owners to deduct their RMD on their tax returns if they give the money to charity. By lowering your adjusted gross income, the QCD rule can effectively reduce your income taxes. QCDs are capped at \$100,000 annually per person and must be made directly to the charity.





Any traditional IRA owner who is at least 70½ years old can use the QCD rule to exempt their RMD from taxation. Note that following the passage of the “Setting Every Community Up for Retirement Enhancement (SECURE) Act in December, 2019, the age to begin taking your RMD was raised to 72. The age limit here applies to the exact date on which the IRA owner turns 70 ½ or 72, as indicated above.

A charity must be a 501(c)(3) organization to receive tax-free IRA charitable distributions. The Parkinson

Association of Central Florida qualifies as a 501(c)(3) organization. <http://www.parkinsoncf.org/donate> Talk to your IRA custodian or call us about how to make it happen.

Chuck is a founding member of the PACF Board of Directors and serves as General Counsel. Chuck can be reached at the G. Charles Wohlust Law Offices (407) 644-3206

WHAT IT TAKES TO MAKE A QCD

-  The QCD must come from a Traditional or Inherited IRA.
-  Beneficiary must be at least 70 ½.
-  The distribution must go directly to a qualified charity.
-  You must receive a confirmation letter from the charity that states no goods or services were received in exchange for the contribution.

How to donate with amazon smile

- 1 Visit AmazonSmile**

smile.amazon.com
- 2 Choose Your Charity**

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- 3 Make a purchase**


AmazonSmile is a simple way for you to support your favorite charitable organization every time you shop, at no cost to you. When you shop at smile.amazon.com, you'll find the exact same low prices, vast selection and convenient shopping experience as Amazon.com, with the added benefit that Amazon will donate 0.5% of your eligible purchases to the charitable organization of your choice.

CONSIDERING DBS?

BY BARBARA WILLIAMS, THERAPY MANAGER, ABBOTT

How to have a discussion with your Doctor about DBS

Today, there is a lot of information about Deep Brain Stimulation (DBS) for the treatment of Parkinson's disease. You may have received literature, attended a webinar or even talked to another individual who may have had DBS surgery. DBS is an FDA approved therapy that has been used for over 20 years for the treatment of movement disorders. So how can you have this discussion with your physician?

DBS therapy can help you have better control of your

motor symptoms that are related to Parkinson's, such as tremor, rigidity and slowness of movement. It can also help give you more of the "on-time" during the course of your day.

This can help you get back to your daily activities and improve your overall sense of well-being.

Your doctor can help you decide whether DBS therapy is right for you.

You may be a good candidate for DBS therapy if:

- You have had Parkinson's disease for at least 5 years
- Medication that has helped your symptoms is less effective, or you are needing more of it.
- You are having troubling dyskinesias because of increasing medications.
- Your primary symptoms are tremors, rigidity and slowness of movement.

- You can be considered for surgery because you aren't suffering from other serious medical, cognitive or psychiatric conditions.

Your physician may also review your medications with the times of day you are taking your medications, along with times that you feel you are having "off-time" or dyskinesias. Keeping a log of these times and events will be very valuable in determining if DBS is right for you.

Having all this information will help in having the discussion if DBS is the treatment that will help your

Parkinson's symptoms. You may also ask for a referral to a Movement Disorder Neurologist to have an evaluation for DBS therapy. This specialist will do extensive testing to determine that you are at the right place in

your disease to have DBS therapy. Your Parkinson's Association can help you find a Movement Disorder Specialist in your area.

Hopefully this will give you the information you need to have that discussion about DBS therapy. Taking control of your Parkinson's disease may just be a few questions away!

To find a Neurologist who specializes in DBS therapy, visit: FindDBSclinic.com

Barbara Williams is a licensed DBS Therapy Manager with Abbott and an Advisory Board member for PACF.



GOOD VIBRATIONS, CAN PARKINSON'S SYMPTOMS BE STOPPED?

BY HOLLY MACCORMICK, OCTOBER 2021 - STANFORD MEDICAL

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 he said, 'It's noninvasive.'" "It was noninvasive and it couldn't hurt him," added Bhutani's wife, Suhkpreet Bhutani. "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 the 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.

"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." 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.

(CONT'D) GOOD VIBRATIONS, CAN PARKINSON'S SYMPTOMS BE STOPPED?

BY HOLLY MACKCORMICK, OCTOBER 2021 - STANFORD MEDICAL

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. (This is also why fingertips are ideal for Braille, but not tattoos.)

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." For now, the glove treatment is available only to Parkinson's patients participating in a clinical trial of the device that started Aug. 1. Tass is also 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.

Newsome said the new trial is one of many important next steps: "The therapeutic effects need to be documented in a larger group

of patients." More research will be needed to identify which Parkinson's patients are likely to benefit from the therapy, he said.

"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.

— For information about participating in a study of the glove's effects, contact the Tass lab (<https://med.stanford.edu/tass-lab.html>) at parkinsonsvcr@stanford.edu.

— Contact author Holly Alyssa MacCormick for media inquiries at hollymac@stanford.edu

— Artist's conception of a vibrating glove used to help relieve symptoms of Parkinson's. (Illustration by Harry Campbell)



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The Parkinson Association of Central Florida is **committed** to raising **awareness** of Parkinson's disease, supporting **programs** and providing **resources** for those living with the disease and furthering the research of **new treatments**. We believe that our efforts to deliver **important**, breaking news in the PD community will help us reach more people **impacted** in the Central Florida community.

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