



# PARKINSON News

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

## UPCOMING MEETINGS

### “Parkinson’s Disease and the Management of Off Episodes”

**Tuesday, January 19, 2021  
12:30 PM**

Please plan on joining us as we continue our webinar series You, Me, & PD. We kick off the new year hosting Dr. Tara Kimbason, a Neurologist and Movement Disorder Specialist with Tallahassee Memorial Hospital. Doctor Kimbason will discuss “off” episodes in PD, what causes them and available treatment options. Event will take place via Zoom.

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

**Register for Webinar**

### “Stronger Together” Thursday, January 21, 2021 1:00 - 6:00 PM EST

You’ll not want to miss this program as experts in the field of Parkinson’s disease from across the country and into Canada will be presenting in this online **Zoom Symposium** – Tune in for the whole program or come and go and choose which programs are of greatest interest to you! Either way this program has something of value to everyone! **Registration is required. See flyer in this newsletter for more information.** **\*\*Free CEU’s will be provided to CNA’s, OT’s, PT’s, SLP’s, and Social Workers that attend.\*\***

### “Moving Through Parkinson’s” Tuesday, February 16, 2021 Time TBD

We will be welcoming our friends from AdventHealth Rehab who will be presenting this program. Stay tuned to your upcoming E-Newsletters

## 2020 – Results of a Catastrophic Year

When I hear the term 2020, I most often relate it to vision, or specifically to hindsight. And that is exactly where I would like to put the year 2020 – in the rearview mirror!



Vince Kinsler

What is, however, worth talking about, is just how devastating the year 2020 has been, how quickly everything changed, and how dramatically people, organizations, businesses, education, and society have been affected.

The PAGDB has been no exception to this devastation. The greatest impact that 2020 has had on our association is that it immediately changed how we interacted with our members. Even though we are so fortunate to have a wonderfully produced online newsletter that helps us communicate to our members, for the year 2020 and the foreseeable future we are unable to congregate.

For the past 30 years, our monthly meetings delivered some of the most renowned speakers and experts in their fields, bringing highly relevant and up to date information, education, and resources directly to our member base – all in some way related to Parkinson’s.

One of the greatest benefits of our meeting programs is that they brought us together, the social aspect of congregating is in part what has made these meetings so special – we were all there together!

COVID put an abrupt halt to what we do best. We are currently in a world where contact between humans is now restricted in so many ways.

In addition to the current cessation of our monthly meetings, we had to make the difficult decision to cancel our annual Fun Walk; another beautiful social event that has so much value to our PD community. In addition to the loss of fun, friendship, and comradery that our Fun Walk provided, the inescapable burden is that the Fun Walk generates 65-70% of the funding needed for our annual operating budget.

We currently find ourselves in an unusual and most difficult position, one where we are now asking for some help. We are reaching out and asking our members to consider a gift to the PAGDB during this Holiday Season, either in the form of a donation in honor of a loved one, or in memory of a dear departed – or for any other reason. Any gift will be so appreciated and will help us sustain what we believe to be a short-lived downturn until such time that we can again return to some semblance of normalcy. We thank all those who have thought of us and donated to our organization.

Thank you for your consideration, and blessings to you and all yours for a Joyous Christmas, and a New Year filled with good health and prosperity.

*Vince*

**To donate 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](http://www.parkinsondaytona.org) and click on the Donate link or click the button below.**

**Donate to the PAGDB**

## RECENT GIFTS & GRANTS

- ♥ Caroline Boardley – Gift in Memory of Reginald Lyon Mercado
- ♥ Barbara & Steve Hart – Gift in Memory of Bill Mulvey
- ♥ Stephen Klinzman – Gift in Memory of Bill Mulvey
- ♥ Ellen Lauturner – Gift in Memory of Reginald Lyon Mercado
  - ♥ Ellen Lauturner – Gift to the PAGDB
  - ♥ Diana J. LeBrun – Gift in Memory of Bill Mulvey
  - ♥ Carlene LeCompte – Gift in Memory of Bill Mulvey
  - ♥ Becky Lester – Gift in Memory of Mary & Jim Nicholson
- ♥ The Walt & Suzanne Steiner Foundation – Grant to the PAGDB
  - ♥ Charles Weyant – Gift in Memory of Bill Mulvey
  - ♥ Diane Castelli – Gift to the PAGDB
- ♥ Nancy Nix-Karnakis – Gift in Honor of Jeff Torborg

## Condolences

Our heartfelt thoughts and prayers go out to the families of recently departed Association members:

- ♥ William "Bill" Mulvey
- ♥ Reginald Lyon Mercado
- ♥ Sal Ronci

## ZOOM SUPPORT GROUP ON HOLD!

The Zoom support group facilitated by Nancy Dawson of Halifax Health-Hospice is currently on hold. **If you have any questions you may contact Nancy at: [Nancy.Dawson@halifax.org](mailto:Nancy.Dawson@halifax.org) or 386-425-3734.**

## DANCE *for* PD<sup>®</sup>

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](mailto:gabriela59@aol.com) or Nicole at [nmante86@gmail.com](mailto: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.

## PD FRIENDLY GIFTS

Can't figure out what to add to your holiday gift list? Below is a list of gifts for people with Parkinson's so when the dreaded question of what do you want for the holidays arises, you have some inspiration.

- 1. Fitness Tracker/Smartwatch**  
For motivation on the days you don't feel like moving. Can track steps, movement and heart rate.
- 2. Coffee Accessories**  
Research shows that drinking caffeine in moderation can benefit the motor fluctuations of PD.
- 3. Slip-On Shoes**  
There are a variety of styles, but these make putting on shoes so much easier!
- 4. Sleep Accessories**  
We all know the benefits of sleep are so important for our health.
- 5. Exercise Accessories**  
Whether you want to do it or not, exercise and movement in general is so important for management of PD symptoms and slowing the progression of the disease. Seated exercise equipment is great too!
- 6. Books and E-Readers**  
Reading can help people with PD retain mental clarity and it is a great way to learn something new!
- 7. Cookbooks**  
Cookbooks are great to inspire yourself and try something new. Not big on cooking? Meal subscription services or giftcards to a local restaurant are a great gift.
- 8. Sunhat**  
PD is linked to an increased risk of developing melanoma. A stylish sun or sports hat can be worn to help protect people with PD, especially living in Florida.
- 9. Art Kits**  
Great for creativity, inspiration and reducing anxiety.
- 10. Silk & Sateen Sheets/PJ's**  
Not only comfortable and make sliding out of bed a bit easier.
- 11. Puzzles and Puzzle Books**  
Promotes mental stimulation and is all around fun!
- 12. Heavyweight Pens**  
Makes writing easier, improves legibility, builds strength, and decreases hand tremors.
- 13. Weighted Utensils**  
Makes it easier to keep food on the utensil and smoother from plate to mouth.

### DOES PD SMELL? - ODE TO JOY (AND ALISON)

REPRINTED FROM: World Parkinson's Congress (WPC)

The male silkworm moth has a sense of smell so acute that it can detect a single molecule of female moth pheromone from nearly 2 km away. This makes it the champion 'smeller' in the animal kingdom. But in second place, with her own specialised olfactory sensitivity must surely come the now legendary Joy Milne, a retired nurse from Perth (Scotland not Australia!).

You will have read her story, I'm sure. Joy has what is, by any standards, a remarkable sense of smell. She is able to detect a range of complex odours to a standard that would embarrass most professional sommeliers. It runs in the family – her grandmother was the same. But most remarkable of all is not her capacity to distinguish a 1961 Chateau Lafite from a 1959. It is her astonishing ability to identify people with Parkinson's from their smell.

Joy can tell if you have Parkinson's or not. And she can do this with astonishing accuracy. But that's not all - she can also detect people in the prodromal phase – that is those not yet diagnosed with Parkinson's. In other words, she could potentially tell if you are going to get Parkinson's. You have to be impressed. This, after all, is the holy Grail in terms of Parkinson's and neuroprotection. Early detection is the incentive to develop neuroprotective agents. And the development of neuroprotectants is the incentive for early detection. Joy Milne, with her astonishing olfactory powers, provides that link.

She first became aware of this gift with her husband, Les. Over the course of several years she noticed his scent changed, leading up to the point where he was diagnosed with Parkinson's. When she attended local Parkinson's UK meetings in Edinburgh, she noticed that this distinctive smell was common to all people with Parkinson's. One thing led to another and, in 2012, she found herself talking to Tilo Kunath, at Edinburgh University who was keen to investigate further.



Along with Perdita Barran, then in Edinburgh but subsequently in Manchester, the teams identified a number of volatile organic molecules associated with the Parkinson's 'scent', in essence its biochemical fingerprint. In February 2016, an editorial in the Lancet summarised the story to that point [1].

While the labs worked on the biochemistry, Joy continued to meet people with Parkinson's, keen to hear her story and share their own. One such encounter occurred in 2016, with Alison Williams a self-confessed "late-onset academic", based in Edinburgh and interested in ways of alleviating Parkinson's symptoms. Although the two hit it off instantly, they didn't meet again until the following year and when they next met, late in 2017, Joy was struck by how much less Alison smelled!

Now if it was you or I, we might make a comment to that effect. But Joy, now officially "honorary lecturer in analytical olfaction" in Manchester, could not do so. Her nose, now essentially a research instrument, was, in one sense "owned" by the University and governed by ethical committee constraints on disclosure.

But so substantial was the change she had detected in Alison – and so unexpected – that Joy quickly sought and obtained approval to tell Alison. "Whatever you're doing, keep on doing it" she said.

Alison went back over old diaries looking for clues. It soon turned out that the "whatever you're doing" was exercise, still the only freely available treatment for Parkinson's and certainly the only one widely accepted to be neuroprotective.

All well and good but Alison is not the ten-minutes-on-the-exercise-bike-should-just-about-do-it type. She focused not on exercise generally but upon those programs with a distinct cognitive dimension. She originally started with Tai Chi, before adding Pilates, Dance for Parkinson's, and the magnificently named "Mature Latin Movers". That's not all. Alison now does Tai Chi with weapons and, most recently, Taiko drumming!

***Continued on the following page...***



Has it benefited her? Well, the simple answer is yes. Nobody in her MLM or Taiko class knows that she has Parkinson's. And when I spoke to her recently by Skype, I was hard pressed to spot symptoms despite the fact she has been diagnosed more than seven years ago.

Alison's daily diary revealed what exercise she was undertaking, how much, how complex and how intensive (physically and cognitively) it was. Over the timeframe between the first and second time she met Joy, she noticed improvements in several motor and non-motor symptoms. Her sense of smell improved, along with gait, coordination and much else. What type of exercise is responsible? Alison's money is on the MLM class! And who would argue.

Joy also had the opportunity to smell Alison over this time period, confirming that the symptom benefits were matched by improvements in smell.

It wasn't long before they were thinking in terms of disseminating their results. The data was exciting – it needed somewhere where a poster would have a big impact. A big international meeting for instance, with a mix of patients, scientists and clinicians. And they settled on..... drum roll please..... WPC 2019 in Japan!

A big adventure – unfurling the poster [2] onto the board in Kyoto. And boy did it make an impression. At times you could not get near their poster at the meeting. It was like the first day of the Harrods sale! It felt as though everybody wanted to ask questions. Could this be a tool for assessing progression of Parkinson's? Or even the lack of progression? Some answers, many more questions, much input. All helpful.

So where do they go next? Joy and Alison have thought of that – a much more detailed study of whether exercise and subjective self-assessment of motor symptoms correlates with objective changes in smell. A win-win situation – good science and the embodiment of patient empowerment.

Were they happy they attended the WPC meeting? Absolutely. When I spoke to her, Alison was quick to point out how much she had learnt about ways of assessing her own illness from the insights of Tim Hague, Sara Riggare and others. "It's given me fantastic conversations, some very clear practical tools and terrific inspiration seeing how other people get on with it (Parkinson's)".

Yup, that's WPC.

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<https://www.worldpdcongress.org/working-parkinsons-connections/2020/1/22/ode-to-joy-and-alison>

1. Morgan J. Joy of super smeller: sebum clues for PD diagnostics. (2016) *Lancet neurology* 15, 138-9.
2. Williams A & Milne J. Parkinson's smell levels, symptom management and empowerment: when Joy met Alison. Poster at WPC Kyoto, June 2019.

# BRAIN GAMES ANYONE?

**Check out page 7 of this newsletter edition for a holiday themed crossword puzzle. Answers will be posted in the next newsletter edition. Happy searching! :)**

# Goodbye 2020. Hello 2021.

The holidays can be tough and this year has been quite a rollercoaster all on its own. I think we can all say we are ready for a new year and hopefully some much needed change back to the mundane. Adapting is something we all have had to do in 2020. And there was a lot of change to get used to all at once. While 2020 might be a large chapter in the history books (and maybe it will require its own book in history), it has brought a whole new meaning of gratitude for the small things, things we may have taken for granted and not placed much value on prior to this year. This was a year of change and unpredictability- but it was also a year of strength and realizing how important it is to have an attitude of gratitude for the things we already possess. A hug and gathering with friends and loved ones mean so much more now. Here is to hoping 2020 is a distant memory, but remember when moving forward to stay grateful.



# STRONGER TOGETHER

Free LIVE WEBINAR

Experts in the field of Parkinson’s disease from across the Country and into Canada are coming to you virtually

Register to automatically receive a Zoom link  
<https://dementiafamilypathways.com>

Thursday, January 21, 2021

12:00 – 5:00 pm CST

FREE CEUs for Nurses, CNAs, Social Workers, OTs, PTs, and SLPs  
Registration is required: <https://dementiafamilypathways.com/blank-page-3>



**Dr. Tara Kimbason, MD Tallahassee Memorial Healthcare**  
“Where are we Today with our Best PD Care?”



**John Zells, Parkinson’s Foundation Florida Chapter Advisory Board Member**  
“Living My Best Life with PD”



**Dr. Matt Davis, MD Tallahassee Memorial Healthcare**  
“A New Era for PD Care in Big Bend”



**Dr. Maya Katz, MD University of California San Francisco**  
“What should we be thinking about today to maintain our best PD selves?”



**Dr. Miyasaki Hayashi, MD University of Alberta**  
“CBD for PD: What do we know and where are we going?”



**Dr. Sanjeet Grewal MD Mayo Clinic**  
“Clinical Trials for Sleep in PD: Early data”



**Joohi Jimenez-Sahed, MD Mt. Sinai School of Medicine**  
“What does the Future look like for PD Treatment? - Clinical Trials”



**Alaine Keebaugh, PhD Boston Scientific**  
Moderator for Speaker Panel Discussion:  
Q&A PD Diagnosis, Treatment & the Future



# 299994598



**Register**

# THE WELLNESS CORNER

## The Possibilities That Arise From Adaptability

Celebrating the recent holiday here in the U.S. tested our ability to adapt. It has always been a time for the family to gather, but not this year. Our family members decided not to congregate in a physical space. Instead, we adapted, connected through video, spoke on the phone, and maintained a safe connection with loved ones.

In these times, I really rehabilitate my training to adapt. There are days when the disease invades every fiber of my existence, transforming me into something I do not recognize. Stress just makes everything worse. The disease never lets up, always presenting something that needs some new form of accommodation.

Adaptation can improve our mental health. While some of us manage to adapt to our physical disability's implications, others may fail to accept this new situation, manifesting depressive symptoms. I never let go of the possibilities that can come from adaptation and reasonable accommodations.

The spectrum stage theory for Parkinson's disease describes the importance of conductor/exercise training and of shifting perspective. Finding new ways to adapt and build creative accommodations to live better with a chronic illness is aided by shifting perspective.

Creative solutions to difficult problems often come from taking a step back, shifting to a new perspective, and discovering a new way of doing things. The spectrum stage theory is a shift in perspective from the classic view of Parkinson's disease. Within this shift in perspective of the disease are new possibilities for adaptation and lifestyle changes.

A study, published in the journal *Ecology and Society*, states:

"Transformation involves novelty and innovation. Transformational change at smaller scales enables resilience at larger scales, while the capacity to transform at smaller scales draws on resilience at other scales. Thus,

Humans have been blessed with a large prefrontal cortex. If you put headphones on, you can easily visualize your prefrontal cortex sitting in front of the headphones. Its main function is to help us adapt to our environment so that we may survive and thrive in even the harshest conditions, from the Arctic to the Amazon.

The gift of adaptability has given us tools, language, and cultural advancement, allowing us to specialize using our well-developed prefrontal cortex. Given the plastic nature of the human brain, we all have the potential to strengthen our adaptability through appropriate conductor/exercise training.

Dealing with chronic illness is difficult, but creative accommodations can make it easier. The next step with the spectrum stage theory of Parkinson's disease is to apply the information. You can design creative accommodations using the theory as a foundation. Each person with Parkinson's disease will need to be an active participant in the design of their own brain rehabilitation.

This is one of the reasons why conductor/exercise training is so important. The only person who really understands where you fall on the spectrum of the disease, and what your specific needs are due to the illness, is you, the person living with the illness.

How the human brain functions lies behind the conductor/exercise training. I propose to help people with Parkinson's learn creative accommodation design. When you are an integral part of rehabilitation design, a successful outcome is more likely.

We must be adaptable and flexible almost all the time, because we never know how bad Parkinson's will be on a given day. That's one accommodation. We must be willing to say, "I can't do that today. Maybe tomorrow."

Creative accommodations don't have to be huge. I have a small process when getting dressed. I lean against a wall on the opposite side of the leg that's going into the pants. This supports my body while freeing up my leg to navigate into one side of the pants.

Then, I shift to the other side and lean against the wall while putting on the other pant leg.

Sitting down to put on pants does not seem to work as well these days. Bending over off the bed tends to create a gravitational pull that throws me off balance. The wall is my accommodation for full-body support during this activity. It is a little thing, but it sure helps.

The spectrum stage theory of Parkinson's disease suggests that there is a wide range in the way the disease affects people. It is logical then to assume there will be a wide range of creative accommodations for each person.

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<https://parkinsonsnewstoday.com/2020/12/04/possibilities-adaptability>

# Crossword Puzzle

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

**BELLS**

**CANDLES**

**CANDY**

**CANES**

**CAROLS**

**DECORATIONS**

**EGGNOG**

**FAMILY**

**FRIENDS**

**FRUITCAKE**

**GIFTS**

**HOLLY**

**LIGHTS**

**MISTLETOE**

**ORNAMENTS**

**POINSETTIA**

**DECORATIONS**

**SINGING**

**SKATES**

**SLEIGH**

**SNOWFLAKES**

**SNOWMAN**

**SONGS**

**TREE**





**WISHING YOU  
& YOUR  
FAMILY A  
HAPPY, SAFE &  
HEALTHY  
HOLIDAY  
SEASON**

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**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](http://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](http://www.parkinsondaytona.org) or [click here to visit our YouTube channel](#).

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.