PARKINSON Pathfinder

SPRING 2021

This cover is a video still from coverage of our *Virtual* **Optimism Walk**!

View the whole video on YouTube at **bit.ly/2020nwWlk**

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apda AMERICAN PARKINSON DISEASE ASSOCIATION
NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

SPRING 2021

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OUR MISSION

Every day, we provide the support, education, and research that will help everyone impacted by Parkinson's disease live life to the fullest.

apda AMERICAN PARKINSON DISEASE ASSOCIATION
NORTHWEST CHAPTER
Strength in optimism. Hope in progress.

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COVER
Photo by Dale Cunning

Letter from the Executive Director:
April is Parkinson’s Awareness Month

Everyone has that special cause, the one that has hit close to home with a direct impact on you, a family member, friend, or colleague. For every cause the goal is to raise awareness, so that at least for a short moment, people pay attention. **For the PD community, April is our month.**

But for APDA, April really isn’t all that different. For us, every single month of the year is Parkinson’s Disease Awareness month. Every day, we’re working to improve the lives of people impacted by PD. **Today, regardless of what day finds you reading this, APDA is on the front lines**, helping people stay connected, informed, and moving. In our local community, we provide virtual support groups and online educational programs. We offer free exercise and movement classes, support people financially with our Patient Aid Scholarship program, and invest in promising research.

However, we still love April! Raising awareness remains critical so that Parkinson’s gets the attention it deserves in the research community, in the media, and in our own neighborhoods. PD impacts more than 1 million Americans and that number grows daily. **April offers a chance to take advantage of a special moment when there is extra focus on this disease as well as an opportunity to educate a broader audience about PD and about the support APDA can provide.**

HOW CAN YOU HELP SPREAD THE WORD?

- **Share your story!** Let people know how Parkinson’s impacts your life. Share APDA social media posts and/or host a Zoom party with PD awareness as the theme.
- **Learn something new about PD**: attend a live online APDA education program, such as Take Control, or check out our YouTube channel for more options. (youtube.com/APDAnorthwest)
- **Connect a community group, such as your church or Rotary club, with the APDA Speaker’s Bureau** and facilitate a learning opportunity (call 206-695-2905 or email apdanw@apdaparkinson.org for more info). Learn more about our Speaker's Bureau on page 13.
- **Stay connected with PD research!** Sign up for the Washington Parkinson’s Disease Registry www.registerparkinsons.org (NW residents outside of WA are welcome!) or follow up on an interesting study.
- Put together a team and sign up for the **APDA Northwest Virtual Optimism Walk on May 22**.
- Do you have a contact in the media? **Connect them with APDA and we will do the rest!**

Every 9 Minutes someone in the US is diagnosed with PD, thank you for helping raise awareness for this disease that impacts so many!

Photo by Keenan Barber on Unsplash

The ABC's of DBS

By Dr. Cong Zhi Zhao

Photo by Haroon Niaz on Unsplash

There is evidence that Deep Brain Stimulation (DBS) improves the quality of life for People with Parkinson's disease (PD). Proper timing, candidate selection, and realistic patient expectations lead to better DBS outcomes. DBS, alongside medications, should be considered another tool to combat the symptoms of PD. DBS is no longer considered to be a "novel" therapy or treatment of last resort.

What is Deep Brain Stimulation

DBS is a minimally invasive neurosurgical operation for treatment of certain neurologic and psychiatric disorders. DBS targets the deep nuclei of the brain that modulate movement. This operation has been approved by the FDA for over twenty years. It was initially approved for essential tremor in 1997, then Parkinson's disease in 2002. Since then, it has also been approved as a humanitarian device exemption for dystonia, obsessive compulsive disorder, and certain types of epilepsy. There is also ongoing exploration for its use in the treatment of Tourette's syndrome, chronic pain, depression, and memory dysfunction in Alzheimer's disease.

DBS surgery involves the placement of electrodes/leads (through a hole drilled in the skull) on the side opposite to the side of the body that is being treated. MRI or intraoperative monitoring (recording of electrical activity from the lead), help the surgeon place the leads in the optimal targets for the disease being treated. Once placed, the lead is secured to the skull and an extension wire is tunneled under the scalp and behind the ear. Finally, the lead is attached to a battery that is usually placed under the clavicle in the chest. The battery can then be turned on, and the signal to the leads can be adjusted by a physician to optimally treat the patient's symptoms.

The use of DBS in Parkinson's disease

Parkinson's disease is the second most common neurodegenerative disorder after Alzheimer's disease. PD has the following symptoms: resting tremor, bradykinesia, rigidity, and gait disturbance. It was not until the 1960s that the role of dopamine in PD was firmly established. Once the role of dopamine was established, the discovery of levodopa as a treatment for PD has been life changing for many.

After the initial excitement of levodopa therapy, it became clear that this was not a cure. As the disease progresses, motor fluctuations and non-motor symptoms become more troublesome and disabling for many. Levodopa alone was often inadequate to address those symptoms. Several years after

Personal Stories of DBS by Leah Frazier

DIANE

Diane's experience with Parkinson's was a slow, frustrating one. Symptoms began in 2003, and it took 8 years just to receive a diagnosis. In 2014, she began to notice the types of physical challenges common to those living with Parkinson's. She spent more and more time trying to manage her symptoms to keep them from affecting her work. The task became increasingly difficult. After a particularly memorable incident, Diane knew she could not continue as she was; "I was heading to dinner with my colleagues, and the twisting and cramping was so bad that I couldn't get across the street. I pretended that I had to stop and fix my shoelace. I was just trying to buy myself enough time to get control of my movements enough to make it across that street."

Once armed with her diagnosis, Diane began to educate herself on DBS. With increasing symptoms, and without the ability to leave work, Diane knew that she had no other choice. The screening process was both in depth and intense, but she moved quickly through the process. "I began the initial screening in mid-July and was scheduled for my first surgery in November." After the surgeries, Diane was scared that she was not seeing the results she'd hoped for. "It just wasn't delivering." Her symptoms even seemed to be getting worse, "I don't think I realized that the programming piece is as much an art as it is a science." She shared her concerns and went from working with a student programmer to an expert.

Not much more than a month after surgery, Diane was back at work and embarking on the busiest couple of years of her career. "DBS made it possible for me to continue working, and the work I did made a big difference in the lives of a lot of people. It allowed me to be a more valuable contributor in my field. I feel like I really made a difference."

A librarian, tasked with rebuilding things after the financial crisis blew up her entire department, Diane worked on an early literacy research project with the University of Washington, a project that would become the teaching methodology used throughout her field.

Diane attributes the ability to finish her career on a high note to DBS. She says, "I would do it again in a minute. The only regret I have is that I had my DBS 5 or 6 years before some of the newer technology which has emerged in such a relatively short period. I'm envious of people with new systems".

Now retired, Diane finds no surprise in being busier than ever.

Diane can be found continuing to "make a difference in the lives of others" as she forges forward as an advocate for Parkinson's.

initiating dopamine replacement therapy, many patients experience times where motor symptoms return as the medication wears off. This is generally described as "OFF time", meaning the return of motor symptoms in between doses of medication, leading to a loss of "ON time", which is the duration the medications are suppressing motor symptoms. Some patients began to experience drug induced dyskinesias, often described as "squirmy or fidgety" movements (typically at the peak of a medication dose). These dyskinesias can range from mild to severe movements and can lead to falls and injuries, as well as weight loss. As the disease progresses, the therapeutic window continues to narrow leading to less "ON time". These swings or motor fluctuations prompted a search for additional therapies for PD. While additional medications such as catechol-O-methyl transferase inhibitors, monoamine oxidase B inhibitors, amantadine, adenosine A2A antagonists, and dopamine agonists can decrease the off periods, there are still patients who are inadequately treated with only oral medications.

The use of surgery in the treatment of PD is not new and preceded the discovery of levodopa. Lesional surgeries were tried with some improvement of tremor and rigidity, but also caused motor weakness. It is now known that neuromodulation (in the form of electrical stimulation) can achieve the same tremor benefits without the unacceptable side effects.

There are generally three main targets in the brain used to manage DBS for movement disorders: STN, GPi, and VIM. For Parkinson's disease, STN and GPi are typically used with VIM playing a more minor role. For those with mainly tremors, STN and VIM, either unilateral or bilateral, may be the target. For motor fluctuations, rigidity, or intolerable dyskinesias, either STN or GPi are reasonable. The target chosen is based on patient's surgery goals, most bothersome symptoms, and other comorbidities.

What symptoms improve with DBS?

The general rule for DBS is that the specific motor symptoms that respond to dopaminergic therapy should also respond to DBS. In descending order of efficacy, resting tremor, rigidity, bradykinesia and some components of gait dysfunction, are improved with DBS. Extremity symptoms improve more than axial (midline body) symptoms. There is usually improvement in dyskinesia as well (both due to medication reduction and some potential direct anti-dyskinetic benefits from stimulation). The one symptom that may respond to DBS even better than levodopa/dopamine replacement therapy, is refractory tremor. While some patients do notice improvements in non-motor symptoms, such as sleep and mood, this is not typical or well-studied and may be a secondary rather than a primary response to stimulation.

Indications for DBS surgery are motor fluctuations, significant dyskinesia, medication refractory tremor, or medication intolerance.

What symptoms do not improve with DBS?

Some symptoms do not improve with DBS. Often the same non-motor symptoms that do not respond to dopamine therapy, will likewise not respond to DBS. These include speech dysfunction, gait freezing, orthostatic hypotension, cognitive impairment, dementia, hallucinations, urinary symptoms, constipation, and imbalance.

Both STN and Gpi DBS have been shown to improve the cardinal motor symptoms of PD as well as improving activities of daily living and quality of life. STN is associated with an up to 50% decrease in medication requirements.

Who is a good candidate for DBS?

The ideal candidate for DBS will be patients with idiopathic Parkinson’s disease who have a robust response to levodopa, and those who develop motor fluctuations or dyskinesias with minimal non-motor symptoms. Age plays a role. Younger patients are less likely to have other medical comorbidities that can complicate surgery or recovery. Operating too early in the course of the disease could lead to implantation in patients who may have an atypical parkinsonian disorder or may mean taking unnecessary risk in someone whose symptoms can be treated adequately with oral medications. However, waiting too long may lead to accumulation of comorbidities that increase surgical risk. While old age by itself is not an absolute contraindication, the risk of surgery goes up with age as does the relative risk to benefit ratio. However, ultimately it is the *physiological* age of the individual that is more relevant than the *chronological* age.

There is no absolute duration of disease needed to qualify for surgery, yet adequate time should elapse to rule out atypical symptoms or early onset of cognitive issues that could point to an alternate diagnosis. Time is also needed to establish levodopa response and to monitor for fluctuations.

Contraindications to DBS include other medical comorbidities such as significant cardiac or pulmonary disease. Significant cognitive impairment and severe, or refractory psychiatric disease are also contraindications. While many PD patients have some cognitive impairment, the need for informed consent is necessary in order to proceed with this elective surgery. Many PD patients have coexisting depression or anxiety. These comorbidities should be stable before proceeding with surgery and those with frank psychosis should show a long period of symptom control prior to being considered for DBS.

DBS is a brain surgery and comes with inherent risks (even minimal brain surgery can carry major complications). The risks to patients can come from the immediate issues surrounding the surgery, as well as long-term side effects. Perioperative risks include hemorrhage, ischemic stroke, or seizures Infection is the most common complication of surgery, and less common are hardware related issues such as lead erosion, lead fracture, or device malfunction.

Once the DBS surgery is completed, there are often several programming sessions needed to both optimize the stimulation efficacy as well as to avoid side effects. After the initial programming sessions, medications can often be tapered down. The goal is not to be medication free. The goal is to optimize the patient’s function and minimize the burden and side effects associated with medication. Long term follow-up to monitor battery status is important.

The duration of efficacy with DBS therapy in PD has been demonstrated in improved motor function that is durable. While initial quality of life measurements also show improvement, these may decrease with time, likely reflecting which likely reflects the progressive nature of PD.

Personal Stories of DBS by Leah Frazier

PETER

Because of his Parkinson's symptoms, Peter, a cartoonist, could no longer continue the work he loved. He was interested in DBS but was first turned away as a candidate for the procedure. The specialists believed that it was “too soon” in his disease progression to be considered. Approximately one year later Peter found himself in the position to be considered once again. He jumped at the chance. Peter explained that DBS consists of 3 main components, surgery, lead placement, and programming “The programming process was long. I had to do my part in keeping track of the medications and how effective they were throughout the day”. When asked about the changes DBS made in his daily life, “I absolutely noticed a difference in the amount of On-time I had.” Peter thinks that sometimes people make the mistake of thinking “that DBS is a cure-all or a one and done when in fact it’s something to be used in conjunction with medications and therapies.” Peter believes that his DBS made things easier on his wife, Pamela, as well. “I had great support from my wife. I underwent DBS to make life easier for her as well as myself. I wanted life to be easier for the both of us”. DBS allowed him to do more on his own, thus requiring less of Pam.

Peter understands the hesitation some have in considering DBS “It’s brain surgery after all. It’s scary”. Does Peter believe that DBS was the right choice for him? Without a doubt. “I feel so positive about my experience. It is wonderful and something that can help so much. I really think people owe it to themselves to look into it”. Peter shared that DBS had it given him back the time he didn’t know he had.

Today Peter and Pam split their time between WA and Alaska. Peter continues his work as a cartoonist. He told me that his work is not the same as it was before Parkinson’s, but he now sees the imperfections that Parkinson’s brings to his art “as a real-life visual example of the effect Parkinson’s can have on one’s life.”

Personal Stories of DBS by Leah Frazier

SUZANNE

Suzanne was diagnosed with Parkinson's in 2010. She explained that her disease progressed as expected, and with the help of medications, was managed well for the first five years. Then in 2015, Suzanne got her "wake-up call." She developed "nasty wicked dystonia on both sides." Her daily symptoms were "depressing as well as debilitating." She was no longer able to work and had to go out on disability.

When Suzanne's doctor at the University of WA suggested that DBS might be an option for her, she didn't hesitate. Suzanne had some familiarity with DBS. She had a brother-in-law who had been a recipient of the procedure. She says she embarked on her own DBS journey in "total peace" and "100% confidence that it would work for her". In January of 2016, on her 60th birthday, Suzanne had DBS surgery. She still sees it as the best gift she could have received.

Suzanne shared that the programming process was frustrating at times. "It's not an overnight process." She had the personal goal of reducing her medications and wanted to be an active part of the DBS process. She was anxious to put herself in the driver's seat again. In fact, one day, she showed up to her programming appointment in a wheelchair and left on her own two feet.

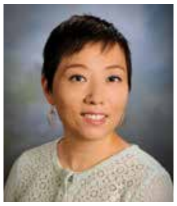
With her renewed abilities and motivation, Suzanne became a champion for the Parkinson's community in Snohomish County, where she lives. She soon discovered that there was little support or community resources available. With the help of local businesses and APDA NW, she developed a community, support resources, and exercise programs where there had been none.

Suzanne said that she would never have had the energy or motivation to advocate for Parkinson's had it not been for DBS. She has also reached her goal of reducing her medications by half, and along with exercise programs and support, has been able to slow the progression of her disease. To others considering the possibility of DBS for themselves, Suzanne suggests "be patient, work with your doctor, and be hands on throughout the process." Suzanne's advocacy work has extended the reach and benefits that DBS brought to her own life. Countless others have been able to benefit from her work on behalf of the Parkinson's community.

Summary

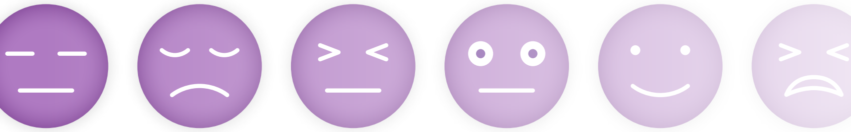
Parkinson's disease is a common neurodegenerative disorder that initially affects motor function. While medications are the first line treatment, over time many patients may develop motor fluctuations, disabling dyskinesias, or could have medication side effects that make DBS a reasonable adjunctive treatment. DBS is not a cure, but it has been shown to be a very effective treatment for tremors, rigidity, slowness, and some forms of gait dysfunction in the correctly selected patient. There is also evidence that DBS improves quality of life in PD patients.

Want to learn more? Join us on June 18th as a team of DBS experts discuss innovations and answer your questions.



Cong Zhi Zhao, MD *is a movement disorders neurologist at St. Luke's Regional Medical Center in Meridian, Idaho. She specializes in deep brain stimulation (DBS) therapy for conditions such as Parkinson's disease, essential tremor, dystonia, and other movement disorders and neurological conditions. In addition to her clinical practice, she evaluates patients as part of the multidisciplinary team at the St. Luke's Movement Disorders Clinic. She enjoys helping all of her patients live their fullest possible lives and encourages each one to work hard toward their goals.*

Dr. Zhao earned her bachelor's degree in bio-engineering from the University of California, Berkeley, and is a veteran of the U.S. Army.



Mood issues in Parkinson’s disease

By Kimmy G. Su, MD, PhD

Introduction:

While Parkinson’s disease (PD) is classically known by its motor symptoms of tremor, rigidity, slowness, and posture changes, it is often the underlying non-motor symptoms that cause even greater grief and frustration for patients and their families. Non-motor symptoms may include mood issues, cognitive impairment, poor sleep, blood pressure fluctuations, constipation and urinary problems.

Mood issues, in particular, can be quite debilitating for PD patients if they are not identified and treated. Studies have shown that they can worsen quality-of-life, contribute to physical and cognitive deterioration, and increase caregiver distress. This past year has likely been a further blow to mood in patients given the prolonged COVID-19 pandemic restrictions. Day-to-day activities essential to good mental health, such as regular exercise and socializing, have been impacted heavily. Thus, it is even more crucial to proactively address and intervene when mood issues develop.

The main mood issues present in PD include depression, anxiety, and apathy. These different aspects of mood will be discussed in detail, including both medication and non-medication treatment options.

Depression:

Depression in PD patients may present as poor sleep, loss of motivation, feelings of worthlessness, fatigue, poor concentration and cognition, decreased appetite, and slowness of movements. Sometimes it can be difficult to tease out if the symptoms are due to neurological changes caused by PD or due to depression itself. As such, the prevalence of depression in PD can be hard to pinpoint given the complexities with diagnosis of depression, ranging from 3% to more than 90% of Parkinson patients.

Assessment of depression will typically start with a clinic visit, during which the clinician will gather information from both the patient and family/caregivers and complete a physical examination. If there is concern for systemic abnormalities contributing to a patient’s symptoms (ex: thyroid or liver dysfunction, testosterone or vitamin deficiencies), further laboratory testing may be warranted. In addition, the clinician may investigate whether a patient’s depressive symptoms are associated with undermedicated periods. If the symptoms appear to correlate with feeling “OFF,” adjusting medication regimens to reduce motor fluctuations may improve mood in these patients.

Once depression has been diagnosed, management may include both medication and non-medication treatments. For medication treatments, different classes of anti-depressants may be used to increase serotonin levels in the brain. Serotonin is a chemical messenger (like dopamine) that is important for mood and emotional regulation. Medications typically used include selective serotonin reuptake inhibitors (SSRIs) such as sertraline and citalopram, serotonin norepinephrine reuptake inhibitors (SNRIs) such as venlafaxine, and tricyclic antidepressants such as amitriptyline. Dopamine agonists that mimic dopamine effects such as pramipexole can potentially improve depression as well. Overall, there is no clear consensus on what type of anti-depressant works the best in PD patients. There will need to be a discussion between the patient and clinician on which medications to consider, factoring in potential drug interactions and side effects.

For non-medication treatments, options may include cognitive behavioral therapy (CBT), which is a form of talking therapy that aims to help patients change negative thoughts, feelings, and behaviors that are causing them problems. For patients with severe, disabling depression, electroconvulsive therapy (ECT) may be considered. Support groups can also be a great resource for patients to connect emotionally, especially during COVID-19 social isolation. Lastly, the power of exercise on improving depression, mobility, and quality-of-life cannot be emphasized enough. Exercise regimens can be diverse and tailored to the individual patient, including biking, yoga, weight training, tai-chi, dance, and boxing. With COVID-19 limiting gym accessibility and in-person classes, online classes (often free through local and national PD associations) can be an effective alternative.

Anxiety:

Anxiety is another prominent mood issue that often coincides with depression in PD patients, with anxiety prevalence rates ranging from 20% to almost 50% in Parkinson patients. Patients may complain of nervousness, recurring thoughts of worry and fear, and feeling like they are losing control. Some patients may describe episodes suggestive of panic attacks with sudden severe physical and emotional distress accompanied by breathing difficulties, palpitations, and sweating. Reported anxiety may be constant (generalized anxiety disorder) or situational such as in public or in crowded places (social phobia, agoraphobia).

Like depression, initial assessment of anxiety may involve addressing potential systemic abnormalities and/or determining whether the anxious symptoms and panic attacks might be associated with undermedicated "OFF" periods. Patients may have restrictive breathing, freezing of gait, and increased tremors when they are "OFF," causing significant distress and anxiety that escalates to a panic attack as they feel that they are losing control of their mobility. Adjusting PD medications to reduce motor fluctuations or providing rescue options such as chewing an immediate release carbidopa/levodopa tablet, using inhaled levodopa, subcutaneous (under the skin) or sublingual (under the tongue) apomorphine can be helpful.

In terms of anti-anxiety medications, the same ones used to treat depression may also be helpful for anxiety management. SSRIs such as sertraline, fluoxetine, and citalopram are typically first-line treatments. Benzodiazepines, which enhance the activity of another chemical messenger called GABA (alcohol has the same target), can also be effective for anxiety. There are both short-acting (lorazepam) and long-acting (clonazepam) formulations of benzodiazepines. While effective, they do come with more side effects, including confusion, memory issues, balance problems, and sedation. Also, if stopped abruptly, they can potentially cause dangerous withdrawal symptoms such as seizures. Therefore, this class of medication must be used with caution, especially in older patients.

Non-medication treatments for anxiety should also be considered given the long-term potential benefits without drug side effects. CBT can be helpful for anxiety, in addition to mindfulness-based therapy, yoga, tai-chi, meditation, massage, music therapy, acupuncture, and aromatherapy. Exercise, again, can be quite helpful for managing anxiety symptoms, in particular regimens that incorporate sensory awareness and feedback.

Apathy:

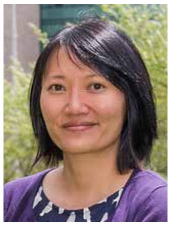
Apathy is defined as an increased lack of interest or motivation or a consistent feeling of indifference. On average, the prevalence of apathy in PD patients is around 30%. Apathy can have a significant impact on PD symptom control and quality-of-life, impairing motivation to keep up on medication schedules and participate in routine lifestyle activities such as exercising and socializing. For family and caregivers, apathy can cause frustration and lead to increases in caregiver burden.

Assessment of apathy may begin by clarifying whether the lack of motivation is associated with depression, impaired cognition or fatigue. If so, treatment of these symptoms may potentially help improve apathy. Depression treatments are discussed in detail above. In terms of cognition, medications that increase the chemical messenger acetylcholine (donepezil, rivastigmine) can be potentially beneficial. For fatigue, patients may be tried on the monoamine oxidase type B (MAO-B) inhibitor selegiline, which in addition to helping with PD motor symptoms, has a stimulant component.

Unfortunately, there is no known medication that directly improves apathy. Therefore, treatment is largely focused on non-medication management. This includes creating daily structured schedules for activities important to maintaining quality-of-life, such as exercising, socializing, engaging in hobbies, and sleep. Having patients set personal goals that are attainable, and provide rewarding completion, can also be an effective method to combat apathy.

Summary points:

- PD non-motor symptoms are often more troubling to patients and their family/caregivers then motor symptoms.
- Mood issues, which include depression, anxiety, and apathy, are prominent in PD.
- Initial assessment may involve ruling out systemic abnormalities with laboratory tests.
- Some mood issues are associated with undermedicated "OFF" periods and improve with PD medication adjustments that smooth out motor fluctuations.
- It is important to incorporate both medication and non-medication treatments when managing mood issues.



Dr. Kimmy Su is a movement disorders specialist who practices at both the Veterans Affairs Puget Sound Health Care System and at the University of Washington Medical Center. She is dedicated to the interdisciplinary team approach, working closely with the patient, family, caregivers, therapists (physical, speech, occupational), social worker and nurses to provide individualized and comprehensive care. She is actively involved in Parkinson's disease patient education and community outreach programs, as well as research through clinical trials.

FOR THE HEALTH OF IT: Tackling Apathy

By Dr. Kelsey Colpitts, PT DPT, The Parkinson's Fitness Project

The past year has led to changes in routine, a loss of in-person social interactions with our friends and family, a transition to online classes and activities, an increase in fatigue, and a loss of community. With more time at home and the loss of normal routines, many people have begun to feel stuck in place as well as experiencing something called apathy. Apathy is defined as a lack of motivation, reduced goal-oriented behavior, and reduced emotional expression. While everyone feels varying levels of apathy from time to time, **the rates of apathy amongst those with Parkinson's disease is higher than that of the general population**. Prior to the pandemic, apathy affected, on average, 30% of people with Parkinson's Disease. Given the reduction in social connections during the pandemic-induced quarantines of 2020 and 2021, the incidence of apathy has more than likely increased.

Apathy is caused by a decrease in dopamine and a rise in acetylcholine. Apathy can occur along with depression, (see pages 6-7) but it can also occur, on its own, without depression. Someone who is apathetic might not feel sad or despondent, but simply has no interest in doing the things that he/she used to find fulfilling. Feelings of apathy in people with Parkinson's have been shown to lead to a two-fold increase in screen time and couch time. This means that apathy significantly affects one's ability to perform activities of daily living which can lead to an accelerated deterioration in mobility. Furthermore, we know that couch time and screen time are not the behaviors that promote healthy living.

Higher levels of apathy make it hard to abide by the three main concepts that we promote as physical therapists for healthy living with Parkinson's. These concepts include: (1) strong social connections, (2) maintaining daily routines and (3) consistent exercise.

Here are four tips to help address apathy and help patients return to a lifestyle designed to help slow the progression of Parkinson's Disease.

Routine: Create a routine. It takes 20-60 days to build a routine. Routines can be built around anything like sleep, exercise, and eating. Once you have determined your routine, set reminders, tell your friends and family, and create a schedule that you can maintain. For instance, a routine to improve sleep could include setting an alarm to turn off all electronic devices 30 minutes before bed, turning off all the lights, and getting into bed every day at the same time. It would also include waking up at the same time every morning. Start to track your sleep routine and see how this impacts your levels of fatigue and apathy!

Accountability: Find a buddy to help build accountability. If apathy makes it difficult for you to keep yourself motivated to maintain your exercise routine, then adding an accountability buddy can help. Checking in regularly through texts, phone calls, or seeing them during live online workout classes can be inspiring. Your friends and family are there to support you through this process. You might be surprised at how many people are willing to go on a walk, a bike ride, or learn tai-chi with you. If you have a caregiver, work together to find activities that bring you both joy.

Setting Realistic Goals: Set realistic and achievable goals. Research has shown that 150 minutes/week of intensive exercise is key to slowing the progression of Parkinson's Disease. That breaks down to 20-25 minutes a day at a perceived effort of 6-7/10. If this goal is daunting, start small and build up to it over a couple of weeks. If you feel stuck in your routine, try a new series class or a new trainer to help you achieve your goals. When yo u achieve these goals, reward yourself!

Open Dialogue: Ask for help. Do not hold your feelings in, talk to someone. Utilize your physical therapist, trainers, family, and friends to help create goals and find ways that best suit you in overcoming these feelings of apathy. Seek out social workers, counselors and/or find a support group. Know that you are not alone.

As you start to apply these concepts to your life, check in with your levels of apathy. Are your routines getting easier? Do you feel more motivated to work out?

Need some help to apply these concepts?

Find Virtual Classes:
APDA Virtual Event Calendar: **apdaparkinson.org/events**

The Parkinson Fitness Project's online classes: **dailydose.com**

APDA Resources
APDA Resources below can be found on our website **www.apdaparkinson.org/Northwest**

Get the Book "Be Active & Beyond Book." You can call us at 206-695-2905 and we will mail it to you or you can **download** it from our website

Watch the Webinar
"Getting Motivated to Move"

Watch the Series:
"Let's Keep Moving"

Need some expert advice?
Call the APDA Exercise Help line! 888-606-1688 or email: rehab@bu.edu

Get the APDA Symptom Tracker: Version 2.0 is now available in both Spanish and English! Get it on Google Play or in the Apple App Store.

Photo by Benoit Vrins on Unsplash

MOVE & LIVE WITH OPTIMISM!

In the Virtual World...

As we continue to socially distance in order to stay healthy and safe, APDA remains focused on our mission of helping everyone impacted by Parkinson's disease live life to the fullest. As such, we remain committed to offering a slate of FREE virtual and print resources.

Visit the APDA Virtual Event Calendar!

Looking for something to do at home? You can easily view nationwide APDA events and programs in an easy to view format. You can filter by month and/or type of activity, with easy links to register. We will continue to keep you updated through our weekly "News You Can Use" email, but this is just one more tool to help you stay connected, educated and moving!

www.apdaparkinson.org/upcoming-events

Fri, Feb 19, 2021 | 10:00 am CT
Tai Chi – Beginner

Fri, Feb 19, 2021 | 10:00 am ET
Dance for PD®: Connecticut

APDA Northwest Chapter presents
TAKE CONTROL
PARKINSON'S EDUCATION SERIES
Fri, Feb 19, 2021 | 10:30 am PT
Important Topics to Discuss That May Not Come Up in Your Clinic Visit
Speaker: Dr. Laurie Mischley, ND, PhD, MPH
Naturopathic Physician & Researcher

Fri, Feb 19, 2021 | 11:15 am CT
Tai Chi – Advanced

PWR!
Parkinson Wellness Recovery
Fri, Feb 19, 2021 | 2:00 pm ET
Parkinson Wellness Recovery
Hosted by: Michelle Patterson, LPTA

Sat, Feb 20, 2021 | 8:30 am AK
Rock Steady Boxing

Sat, Feb 20, 2021 | 10:30 am AK
Body Moves
Increase your strength and balance, improve your posture, and engage your brain, with Dottie Harness-Foster, certified Feldenkrais instructor

Sun, Feb 21, 2021 | 12:00 pm PT
DANCE for the Body, Mind and Spirit

Mon, Feb 22, 2021 | 10:00 am CT
Standing Interval Training

Announcing APDA's Community Wellness Grant Recipients

For over a decade, APDA Northwest has funded community programs that are making a difference in the lives of those who live with Parkinson's Disease. **Through the APDA Community Grant program we partner with health and wellness programs to provide funding to make classes more accessible and affordable for Parkinson's patients and their care partners.**

Community programs can apply for 6 month grants which average $500-$2000 to help cover instructor, facility costs, and participant scholarships.

At the onset of the pandemic, we knew that the shift to online classes was critical and **revised our funding priority to partner with programs offering FREE online classes.**

Congratulations

to the following programs whose classes are now available to the public for free through July 2021.

DANCE for Body, Mind and Spirit

with Chris Daigre, Sundays at 12 pm PT

Chair Yoga

with Jenn Crawford, Wednesday at 1 pm PT

Yoga for PD

with Peter Lynch, Tuesdays & Thursdays at 2:30 pm PT

Body Moves

with Dotti Harness-Foster, Wednesdays & Saturdays at 10:30 am PT

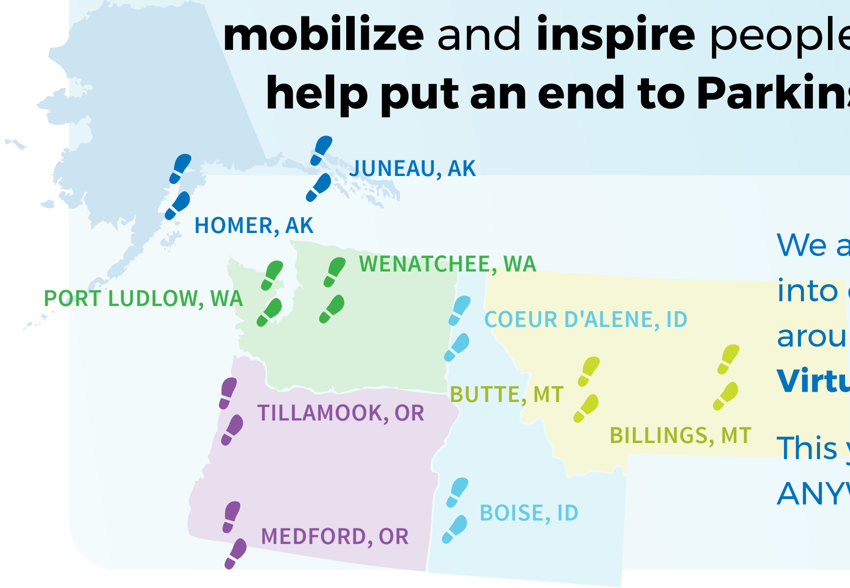
Rock Steady Boxing

with Pavitt Fitness, Saturdays at 9:30 am PT

OPTIMISM WALK
AMERICAN PARKINSON DISEASE ASSOCIATION

THE OPTIMISM WALK

is part of a nationwide movement to **mobilize** and **inspire** people to step up and **help put an end to Parkinson's disease**.



We are taking our optimism into our local neighborhoods around the Northwest with a **Virtual Optimism Walk**.

This year walkers will join us from ANYWHERE and EVERYWHERE.

Our opening ceremony will help kick things off live on Zoom on Saturday, May 22, 2021 at 9am PT.

This will be a fun event filled with strength and optimism. Our APDA Northwest Optimism Walk is one of our biggest outreach events and largest fundraisers of the year, and **our 2021 goal is to register more than 750 walkers and raise $200,000**. Proceeds from this event will keep people with Parkinson's connected, informed, and moving.

And YOU can help!

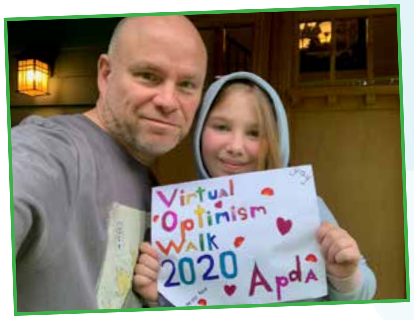
Register today as a Virtual Walker, fundraise online, and then on May 22:

WATCH the opening ceremony on Zoom

then WALK safely in your own neighborhood or wherever you are able!

As a Virtual Walker, you will help us celebrate our Parkinson's community as well as support our mission to provide the support, education, and research that will help everyone impacted by Parkinson's disease live life to the fullest. Covid-19 has hit people with Parkinson's especially hard, with isolation limiting their ability to socialize and exercise which are both vital to managing PD symptoms. APDA has responded with critical virtual programs to connect and support everyone impacted by PD during this trying time.

Photo by Brian Mann on Unsplash



THE DETAILS:

APDA Northwest *Virtual* OPTIMISM WALK

Saturday, May 22, 2021

Opening Ceremony live on Zoom 9am PT

SIGN UP TODAY!

bit.ly/Opt_Walk21

HOW CAN YOU GET INVOLVED?

WALK AS AN INDIVIDUAL, JOIN A TEAM,
OR FORM YOUR OWN TEAM!

Worried about fundraising or asking for money? DON'T BE! **Remember that you aren't asking for money for YOU, but rather for a worthy cause near and dear to your heart.** You will be surprised at how eager and willing people are to donate. Your personal story will tell people how Parkinson's has impacted your life and why you are walking. You can add photos and videos which will make your story even more inspirational. You can set up fundraising milestones and APDA will provide you with a fundraising guide and set you up for success, so you can meet your personal and team fundraising goals.

While walking in our Optimism Walk is important to raising awareness about Parkinson's disease, fundraising is also critical to help APDA meet our mission of providing the support, education and research. Our goal is to raise $200,000 to pay for local programs and services, connect people through virtual support groups, inform people with online education symposiums and free printed materials, keep people moving with free online exercise classes, provide patient aid scholarships to help people who are struggling to make ends meet, and invest in promising research.

JOIN OUR WALK COMMITTEE!

We are looking for volunteers from all over the Northwest who want to help grow this event to meet outreach, participation and fundraising goals. Join us every other week on Zoom to help plan fun activities, build team spirit, improve fundraising efforts, and generate enthusiasm across our five states leading up to this year's virtual Optimism Walk. If you are interested contact Kirsten Richards at 206-348-0213 or krichards@apdaparkinson.org.

WIN PRIZES!

Fundraising incentives:

$100 for an Optimism Walk t-shirt

$500 for an Optimism Walk hat

$1000 to join Circle of Optimism and earn a medal (and your name will be read during the Opening Ceremony on May 22!)

Prizes will be awarded for Top Fundraising Team, Largest Team, and Most Spirited

SHARE ON SOCIAL MEDIA!
Your walk page can link directly to your Facebook fundraiser, and after just a few clicks you can watch your donations grow.

New this year you can set up activity goals (think minutes, steps, miles per week) and let your friends and family see your progress while supporting your fundraising efforts.

Wonder Walkers

Movers and Shakers

Knock Out Parkinson's

CREATIVE TEAM NAMES
from previous years

Shaking, not Stirred

Team Bionic

Tremor-endous Trailblazers

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Celebrating our

2021 Magic of Hope Honorees

Honoring The Jones Family: Nancy, Dwight and Eric

ON FEBRUARY 26th WE HONORED THE JONES FAMILY for their leadership in supporting APDA. Inspired by the quest to know more about the challenges family patriarch David Jones bravely faced for 18 years, the Jones family demonstrates an energetic and unwavering dedication to raising awareness about Parkinson's disease (PD). The family has raised money to fund important research projects as well as contributing to support services for families just like theirs – families that live with the unique challenges of PD each day.

The Jones Family are inspirational, vibrant and productive members of the broader PD community, both in the greater Seattle area and on their beloved San Juan Island. Dwight, a non-stop fountain of ideas, joined the APDA Board in 2013 and has served as President for the past 4 years. Dwight's wife Amy also volunteers in the APDA office. Dwight helped create the "Paddle for PD" nonprofit. As head of Elliott Bay Marina Group, Dwight leads by example as a generous supporter and tireless ambassador for APDA. Nancy stepped up to fund the Parkinson's Registry several years ago when an unexpected need arose, and has selflessly opened her heart sharing her personal story at caregiver's conferences. Nancy has been a supporter of "PADS for PD" which teaches dogs to help identify people with Parkinson's by sense of smell, and she and David's dog Brenna was the first official PD-sniffing pup. Eric and wife Melissa, supported by his company Foushée Construction, have been major supporters of the APDA Northwest Optimism Walk and frequent contributors at numerous APDA events.

Please join APDA in thanking and celebrating the Jones Family for their devotion to supporting research, sparking new ventures, and raising awareness, optimism and hope for all those impacted by Parkinson's disease.

The Optimism Award Jeanne Kieffer

The first annual OPTIMISM AWARD recognizes those who have made a significant impact on the Parkinson's community by living the APDA credo of Strength in Optimism and Hope in Progress. Jeanne Kieffer was an easy choice as our first recipient.

Jeanne shared her story of progress:

"The world has changed since my diagnosis in 1992. I was 40 and the medical community dismissed Parkinson's as a diagnosis because of my age. Information on PD was outdated and movement disorder specialists difficult to find. I joined an early onset support group and found wonderful camaraderie in sharing personal experiences. I attended education programs sponsored by APDA which included the latest in Parkinson's research and other current topics. Today, I am thankful that information is available and readily attainable through computers, online sources, and organizations like APDA.

I've appreciated meeting new friends and trying out exercise programs geared to Parkinson's. Currently, I participate in boxing and bike riding, and am gratified that I have been able to push myself! Adhering to exercise programs can be tough but advantages are many. My balance is definitely improved with exercise. I also make it a priority to participate in research studies in our area, with a cure for PD always the ultimate goal."

Jeanne became involved with fundraising for APDA over 16 years ago, and has generously shared her infectious spirit and optimism. She served on the APDA Board for 8 years and was an active Magic of Hope committee member, where she was responsible for growing the Dessert Dash into an outstanding fundraiser.

Jeanne's years of experience living a wonderfully optimistic life have taught her that, "Parkinson's disease can be a full-time job but with the help and support of my family and friends as well as APDA, the future holds promise for people like me living daily with PD."

RAISING AWARENESS

APDA Speaker's Bureau

As a part of an initiative to increase public awareness about Parkinson's disease, APDA has recruited and trained a team of motivated individuals who are ready to speak to community groups like Rotary, book clubs, church groups, or your local Chamber of Commerce. The presentation aims to educate people about PD with the goal of expanding knowledge of the disease and raising awareness of the challenges faced by people impacted by PD.

The volunteer speakers include people living with Parkinson's, care partners, family members, and knowledgeable health professionals. We have a retired teacher, a sports radio personality, a native Chinese speaker, and more! We have developed a comprehensive and engaging presentation of easy-to-digest facts and stats about PD, and speakers will set a personal tone by sharing their connection to PD as well as how APDA is here to help.

Speakers gathered at a training session at our APDA office in February 2020 and were armed with the materials for in-person presentations, and then… Covid-19 hit. APDA turned this into an opportunity to equip our volunteers with the knowledge and tools they need to share the same information in a virtual format. Now that they are fully trained on Zoom, our speakers can reach your group no matter where you are located!

APDA has recruited and trained a team of motivated individuals who are ready to speak to community groups

With the myriad of health concerns our nation faces these days, not the least of which is coronavirus, a disease like Parkinson's can get lost in the mix. However, the fact remains that Every 9 Minutes someone is diagnosed with Parkinson's disease. With awareness comes knowledge, and with knowledge comes acknowledgment, empathy, hope and optimism. Ultimately, the goal of the Speakers Bureau is to engage our greater community to foster awareness that will drive support and fund research for solutions that will help everyone impacted by Parkinson's disease.

April is Parkinson's Awareness Month, and we can use your help spreading the word. If you know of a group who is interested in learning more about PD, we have speakers ready and waiting to help! Email us at apdanw@apdaparkinson.org to discuss further and set up a date.

MAGIC OF HOPE

On February 26 we gathered "virtually" for our Magic of Hope Gala & Auction held live on Zoom. Even though we were separated by distance and computer screens, the connection, community and celebration was incredible! More than 300 people registered to bid on auction items, and an estimated 400 guests from 20 different states and three countries logged in to watch the live show. Emcee Jake Whittenberg, KING5 Morning News, and Auctioneer Fred Granados led a spirited program, and we exceeded our fundraising goal! Proceeds from the event will fund local education programs, keep exercise classes offered for free, connect people with virtual support groups, provide financial support to people struggling, and invest in promising research.

Thank you to our sponsors

PREMIER

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Strength in optimism. Hope in progress.

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Seattle, WA 98109

SUBSCRIBE TO OUR NEWSLETTER!

Sign up for our newsletter by visiting our website **apdaparkinson.org/Northwest** or emailing **apdanw@apdaparkinson.org**

THANK YOU *for* CARING

about people impacted by Parkinson's disease

YOU *can keep people connected*

$100 supports **virtual meetings** for groups not able to meet in person during the pandemic

YOU *can provide financial support*

$300 provides a **full year Patient Aid scholarship** to someone struggling to make ends meet

YOU *can keep people informed*

$500 supports **online education programs**, increasing access to information and resources no matter where someone lives

YOU *can keep people moving*

$1,000 funds a **community grant** for an online exercise/ wellness class, offered free of charge to all attendees

Donate online at **apdaparkinson.org/Northwest**,
or mail a check to
APDA 180 Nickerson Street, Ste 108, Seattle WA 98109