

**Improving Disease** While Stuck at Home

Telemedicine and PD

# PARKINSON Pathana and a second second

### **BODDO AMERICAN** PARKINSON DISEASE ASSOCIATION NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

Go Green and Save Green!

Join us in our effort to cut back on physical mailings.

Simply contact APDA, apdanw@apdaparkinson.org or (206) 695-2905, to receive the Parkinson's Pathfinder via email in the future or to update your address.

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Strength in optimism. Hope in progress.

APDA Northwest 180 Nickerson Street, Suite 108 Seattle, WA 98109

Phone: 206.695.2905 Fax: 206.455.8980

apdanw@apdaparkinson.org apdaparkinson.org/Northwest

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COVER

"Porchtrait" with Bill Rasmussen's family (L to R starting in front row): granddaughters Sarah and Jessica, son-in-law Louis Van Hollenbeke, daughter Lynn, Bill Rasmussen Photo by Steven A. Schimmelman

#### 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. Nonprofits like APDA are feeling the financial impact of slowing donations in this time of uncertainty, but the reality is that Parkinson's disease (PD) isn't going anywhere.

Your ongoing financial support is needed, so that we can continue to provide vital services, including the

Patient Aid Scholarship Program









have all been touched by the pandemic in different ways: Everybody's reality has changed, and we are no different. Nonprofits like APDA are feeling the financial impact of slowing donations in this time of uncertainty, but the reality is that Parkinson's disease (PD) isn't going anywhere. The good news is, even small gifts from our

supporters can make a huge impact.

I'd like to explain why continuing financial support is so vital, by introducing you to just one of the many programs and services offered to people impacted by PD in our chapter, the **Patient Aid Scholarship Program**.

Even before the Covid-19 crisis, APDA recognized that for many people impacted by PD, daily expenses often exceeded the financial resources available. **The APDA Patient Aid Scholarship Program was designed to provide financial support to people with PD living in Alaska, Idaho, Montana, Oregon or Washington who are struggling to make ends meet**. Approved applicants will be granted up to \$300 once per calendar year, to pay for things like:

- Exercise/Wellness: for activities/classes such as boxing, dancing, yoga, PT, OT
- Medication not covered by insurance or other programs
- Respite Care or Adult Day Health
- Assistance at Home, for things like housework, yard maintenance, delivering groceries
- Adaptive Equipment such as grab bars, handrails, improvements for home safety and accessibility
- Transportation

The Patient Aid Scholarship program has helped our Northwest chapter to expand our mission to meet the needs of people impacted by PD across our region, no matter where they live. Consider a donation to APDA, even a small amount can have a huge impact on the lives of those we serve. Thank you for your support as we all navigate our new reality.

Sincerely,

ear Allebaut Jean Allenbach



# "Spread Sunshine All Over the Place!"

By **Mary Schimmelman,** APDA Northwest Board Member

APDA spoke with Bill Rasmussen, ESPN Founder and Entrepreneur, to hear his take on how the power of positive thinking and healthy habits play a pivotal role in shaping our lives with or without PD.

Ask Bill Rasmussen what goes through his mind when he first wakes and he may just start quoting Broadway musicals—not *Cats* or *The Lion King*. The good stuff! From Broadway's heyday—like *Funny Lady: "When you're down and out, Lift up your head and shout—There's gonna be a great day!"* 

When Bill first married, taking in a Broadway show was a favorite activity of he and his wife. They would cross the river from New Jersey to visit entertainment's then-epicenter. Those show tunes made a lasting impression on Bill, one that he still draws on and shares today.

*Mame* is another of Bill's favorites, the lyrics easily rolling off his tongue:

"Open a new window, Open a new door, Travel a new highway, That's never been tried before!"

Bill's lifelong trick? To always make his first thought in the morning a positive one, followed by another and then a third. It's a conscious decision he makes every day: *"Stay positive!"* 

Those upbeat show tunes help put Bill in the right frame of mind to meet what each day has in store. That lifelong habit has served him well, while navigating the many great—and maybe not so great days following his PD diagnosis in 2014. "Some days you realize it may not be such a great day, and you just readjust your plans and maybe sit and read a book instead."

Quotable luminaries are another mainstay of Bill's tactics to stay positive. One person who influenced Bill is longtime friend and legendary sports broadcast great Dick Vitale, who beseeches everyone to: "Greet life every day with energy, excitement and enthusiasm."

Another favorite rally cry for Bill, "Ya gotta believe!" was made famous by Tug McGraw, the talented NY Mets relief pitcher who carried the team through their 1973 season and propelled them to the World Series where they bucked the pundits and made it all the way to game seven. Despite the heartbreaking loss, Tug was a hero for his positive attitude.

It's likely then, that Bill was humming a show tune or revving himself up on "ya gotta believe" that morning in 1978 when meeting with one of seven potential investors for the fledgling cable venture, ESPN. Even though the answer from that one meeting was no, Bill was still thinking positive. After six no's he finally got his "yes."

As Bill explains, "All you need is one yes, and you're in business!"

#### Stay positive and seek the yes.

Bill's message to stay positive and keep seeking the yes is an important one.

Practicing positivity is second nature to the Rasmussen family. Decades later Bill's daughter accompanied her dad to his medical appointments and was there to hear the words "bad news" from his doctor. An oncology nurse, her thoughts jumped to cancer. When she heard the diagnosis of Parkinson's disease, her relief was immediate. This diagnosis was something she knew her optimistic dad and their close-knit family could handle. A challenge to be met, for sure, but with a "Yes, we got this."

"It may sound weird to say," Bill reflects, "but my Parkinson's diagnosis has actually turned out to be a positive thing too."

Owing to a stellar career filled with lifelong friendships, Bill is a champion of the moment. And Parkinson's disease is enjoying more awareness in this moment, due to his efforts.

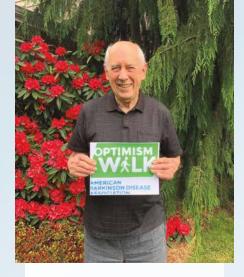
When Bill shared the news that he had Parkinson's with his extended ESPN family, they immediately got behind him with "total unbelievable support." A partnership began with a call to a longtime friend and colleague who had been with ESPN for decades since he was hired as a college intern. The now senior communications executive immediately said, "let's get your story out there!"

ESPN proceeded to send Bill on a somewhat strenuous 10-city media tour that coincided with the sports giant's 40th anniversary celebration. Aware of the potential health strains caused by PD, but knowing how important it was to Bill to get the word out, Bill traveled in style with a pro handler who he could lean on for support literally and physically—"he couldn't do enough for me! The left side is my weak side, and he was there." It was a whirlwind tour celebrating quite an accomplishment for ESPN and its founder.

### Shake off the stigma, shake off the shame.

Bill's mission to raise awareness for Parkinson's disease involves standing up loud and proud. He's observed that Parkinson's is a "quiet syndrome" that people may not know about or speak of, as if there's shame in having PD. Bill thinks the exact opposite and is proud to be vocal about his support for Parkinson's and APDA.

The estimate is that one million Americans are living with Parkinson's, and someone is diagnosed with the disease every 9 minutes. PD is the fastest growing neurological disorder in the world, with increasingly more young people living with early onset PD (diagnosed before age 50). While



#### Bill Rasmussen's 6 Top Tips for Staying Positive with PD:

1. Think Positive! Focus on songs, people, activities, memories, anything that make you happy and keeps you thinking positive. (Cue the show tunes!)

2. Always Seek the "Yes!" We often hear a lot of "no"s in life, don't be discouraged, accept each no and move on. Keep seeking the Yes, it only takes one!

**3. Exercise Your Brain!** Put your mind to work first thing each day, even before you rise. Keep your mind alert throughout the day puzzles, word games, read, meet new people, try new things.

**4. Keep Active!** Establish a daily routine and carry it out. Even if just 10 minutes, three times a day. Small strides go a long way when practiced regularly.

**5. Share Your PD story!** Raise awareness by telling people your Parkinson's story. The more people you tell, the more resources, programs, education and support APDA can provide to those impacted by PD and in turn, fewer individuals will feel alone in their diagnosis.

6. "Spread Sunshine All Over the Place!" Be a living example of APDA's credo: Strength in Optimism and Hope in Progress. unfortunate, this speaks to the growing need for Parkinson's awareness, and why the APDA Northwest Chapter is eternally grateful to Bill and so many others lending their voice to our cause.

On ESPN's 40th Anniversary tour, Bill addressed large crowds across the US, in cities such as New York, Charlotte, and Los Angeles, sharing his Parkinson's story and the reality that each person living with PD has a different path, a different experience. Bill noted the tour was timely, that in-person events like that won't happen again anytime soon due to Covid-19. Which is why he's all in on creative opportunities to get the Parkinson's message out there. Bill recently served as Honorary Chair of the 2020 APDA Virtual Optimism Walk, where he was able to utilize his celebrity status to raise awareness. ESPN has also awarded a grant to the APDA Northwest Chapter to develop opportunities for Bill to continue his outreach efforts and spread his message of positivity.

#### Exercise the body and mind.

While scientists are busy researching the brain, Bill is adamant that "Exercising your brain, every day!" is just as important as physical activity. The two go hand in hand.

The benefits of exercise of any kind are well documented—boxing, dancing, walking, sports, you name it. The important thing is to make up your mind to get up and move.

These days while 'stay home, stay healthy' is the dictate of an unprecedented time, Bill strolls the streets of his family's suburban Seattle neighborhood a few times a day (weather permitting!)

Join Bill

LIVE

on

August 10

Always on the lookout for positivity and the upside, Bill's latest friendship has been forged with one of the many neighborhood children he enthusiastically greets on his daily walks. "I met a two year old little girl who was doing a dance, so I said hello, watched and imitated her dance—that brought a big smile to her face," shares Bill.

"The next time I saw my new friend, she showed me a different dance that ended, I think, not as planned - with a plop onto the sidewalk. It wasn't far, she's only a couple feet tall after all! I smiled and told her that I was going to pass on trying that dance, so she wouldn't have to help me up. That got a good laugh from her mom! Now that was a positive experience right there," chuckles Bill.

Bill's Parkinson's brigade is expanding every day! His daughter and family who he lives with outside Seattle enjoyed the telling of that story over dinner. Bill's mission for positivity in life and awareness for Parkinson's are permanently intertwined with his entire support system—from ESPN execs and sports greats, to new neighborhood friends and his grandkids.

In the sporting way, Bill tosses out a challenge to keep positive: "I think we all have good days and bad days whether because of PD or not. It's the nature of life. It's easy to get down and this is why it's important to do all we can to help each other. Let's all get just one person feeling better with a positive outlook."

Bill's parting quote for positivity? It's a personal favorite from *Bye Bye Birdie*, "Spread sunshine all over the place!"

What's your favorite Broadway tune? Let's follow Bill's lead and all sing along.

for "Dr. Gilbert Hosts: Intentional Optimism— A Conversation with Bill Rasmussen" about optimism while meeting the challenges of Parkinson's disease.

To register for free go to: https://www.apdaparkinson.org/dr-gilbert-hosts/

**Bill Rasmussen** is a lifelong self-starter who in 1978 seized on an idea that brought sports to the masses with the founding of ESPN. The recently launched website www.ESPNfounder.com details Bill's career highlights and the myriad of people and organizations in the sports field that Bill has influenced in his stellar career. Bill lives in the Seattle Area and is an active supporter of APDA.

# Pain in Parkinson's Disease



#### By Pravin Khemani

Pain in Parkinson's disease (PD) has historically been an undertreated and underrecognized non-motor symptom of the disease that can greatly interfere with daily activities. Identifying whether the pain is associated with PD or some other condition can improve treatment options and improve quality of life.

The clinical definition of pain in the modern era of medicine is an "unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage," (IASP, 1979/2011). The key word here is 'experience' which is usually contextual. In the context of Parkinson disease (PD) and for the sake of this article, we will discuss chronic or recurrent pain or bodily discomfort expressed by a majority of people with PD and most commonly reported. (Sudden and acute pain, which always warrants emergent care, as well as headaches, chest pain, pelvic and abdominal pain are beyond the scope of the current discussion but should be promptly reported to the primary care physician.)

From the clinician's perspective, pain in PD can be broadly classified as *Pain from PD and its treatment* or *Pain in PD from other causes* (**see table**). However, from the patient's perspective pain is still pain and it needs to be addressed effectively regardless of the cause. This dichotomy of pain in PD informs treatment and also facilitates counseling of the patient and the caregiver and we will use it as a framework for this discussion.

Pain from PD and its treatment: Pain in PD has been historically undertreated and underrecognized as a legitimate non-motor symptom because of the overemphasis on treatment of the motor symptoms of PD. There is sufficient scientific evidence to explain abnormalities in pain processing in PD outside the dopamine circuits, but optimization of dopaminergic medications is the first step in the treatment of pain and discomfort in PD as the following scenarios illustrate:

**Wearing-off** is the period when dopamine levels fall below a therapeutic threshold in the brain leading to a return of parkinsonian symptoms. It is not uncommon for patients to experience generalized bodily discomfort or pain during *off*periods which can be mitigated by adjusting PD medications to last longer and eliminate *off*-time.

**Dystonia and Dyskinesias:** Dystonia is sustained abnormal twisting and turning of a body part (most commonly the neck, arm or leg) whereas dyskinesias are abnormal, rapid, repetitive movements that can occur anywhere in the body. Both dystonia

and dyskinesias can occur during *on* or *off* periods. While dystonia can be painful and limit mobility, dyskinesias are not typically painful but can be bothersome and intrusive. Effective approaches in the treatment of persistent dystonia include an adjustment of PD medications to reduce the frequency of *on/off* fluctuations, using dystonia-specific drugs, physical rehabilitation, botulinum toxin injections, and deep brain stimulation (DBS).

**Central pain, akathisia and restless legs syndrome (RLS)** are three phenomena which are not specific to PD but are commonly reported in PD due to the abnormal signaling of dopaminergic and nondopaminergic brain circuits. Central pain is variously described as generalized tingling, burning, or electric-like sensations; akathisia is a feeling of inner restlessness which makes one want to move or pace; and RLS is an uncomfortable and sometimes painful feeling in the legs, especially at night, interfering with falling asleep. If these sensations persist despite maximizing dopaminergic treatment, there are several classes of medications that can be used to treat these conditions effectively. Additionally, the PD doctor should be vigilant about eliminating certain medications and treating general medical conditions such as iron deficiency which can contribute to akathisia and RLS respectively.

**Depression, anxiety, sleep disorder, stress, constipation and deconditioning** from lack of movement: While these conditions do not all present as pain, they are very common in PD, significantly impair quality of life, and can consequently accentuate pain and discomfort. It is therefore critical to investigate for and treat these disorders in a multidisciplinary fashion when treating pain in PD to promote overall well-being of the patient.

**Pain in PD from other causes:** Unfortunately, having PD does not grant immunity from other conditions that cause pain, such as:

**Musculoskeletal (MSK) disorders:** This category encompasses conditions that are by far the most common causes of pain in PD. They include mechanical abnormalities of joints, bones, ligaments and muscles. In fact, shoulder pain and 'frozen shoulder' can be the initial symptoms of PD but they are not typically recognized as such because of their high prevalence in the general population. Osteoarthritis, osteopenia (thinning of the bones), and osteoporosis which can predispose one to fractures are very common in PD. Painful postural or spinal deformities presenting as "bent spine syndrome" or spinal scoliosis are also frequently observed. Why MSK disorders are highly prevalent in PD is not fully understood, but one theory is that lack of spontaneous movement could be a potential trigger for their occurrence. Pain from MSK disorders, most commonly described as a dull, deep, or throbbing ache, can be minimized by dopaminergic medications, especially if it's due to muscle stiffness and occurs only during *off*-periods. However, if pain persists, an evaluation by the general practitioner, rehabilitation specialist, pain specialist, and, if necessary, an orthopedic specialist is suggested. The importance of daily sensible exercise, avoidance of activities that predispose to injury, regular visits to the primary doctor for osteoporosis screening, and strategies to prevent falls and fractures cannot be overemphasized when treating MSK disorders in PD.

**Neuropathic pain** typically presents as numbness, tingling, burning, or a shooting shock-like sensation. The most common cause of neuropathic pain is peripheral neuropathy in feet and hands which can be due to a multitude of medical conditions. In the western world, painful neuropathy is most commonly observed in the setting of diabetes. In PD, vitamin B12 and folic acid deficiencies can cause painful neuropathy in the feet. Another very common neuropathic condition is carpal tunnel syndrome which causes wrist discomfort and numbness of the thumb, index, and middle fingers. When an electric or shock-like sensation radiates down an arm from the shoulder or neck, or down the buttocks or thighs from the hips or low back, the concern is a 'pinched nerve' or radiculopathy. The diagnosis and treatment of neuropathic pain is routinely done by neurologists or rehabilitation specialists. Oral medications and rehabilitation are first line treatments of neuropathic pain. Invasive procedures are reserved for cases where there is weakness or loss of feeling from imminent damage to the nerve or unrelenting discomfort and pain.

**Other neurological and general medical conditions** predisposing to pain can coexist with PD but their investigation and treatment must be tailored to each individual's complaint.

In summary, pain in Parkinson's disease is a very common non-motor symptom that can impair quality of life if it is not addressed. It is incumbent on the physicians taking care of the patient to elicit an appropriate narrative of pain from the patient and caregiver for its appropriate diagnosis and treatment. In addition to optimizing dopaminergic medications, multidisciplinary treatment through care coordination with the primary care doctor, rehabilitation specialists, and other specialists as needed is critical for effective treatment of pain in PD.

**Dr. Pravin Khemani** is fellowship trained in both neuromuscular disorders and movement disorders and practices at Swedish Medical Center in Seattle. Dr. Khemani's philosophy of care for movement disorders it to adopt multidisciplinary approach and closely collaborate with the patient, family and other caregivers. He is the author of a number of publications on Parkinson's disease and ataxia and is an investigator on several clinical trials. He is also a member of the APDA Northwest Board of Directors.

| Pain |    |
|------|----|
| from | PD |

| Symptom   | Treatment  |  |
|---|--|--|
| Wearing off   | Optimize PD medications  |  |
| Painful dystonia or dyskinesia  | <ul> <li>Optimize PD medications</li> <li>Medications for dystonia</li> <li>Botulinum toxin injections</li> <li>Rehabilitation</li> <li>Deep brain stimulation</li> </ul>  |  |
| Central pain, akathisia, RLS  | <ul> <li>Optimize PD medications</li> <li>Eliminate medications contributing to these disorders</li> <li>Screen and treat iron deficiency</li> <li>Medications for RLS</li> <li>Benzodiazepines, tricyclic agents, antidepressants,<br/>antiseizure medications</li> </ul> |  |
| Depression, anxiety, stress, sleep<br>disorder, constipation, sedentary state | <ul> <li>Screen for each of these conditions and treat<br/>in a multidisciplinary manner</li> </ul>  |  |
| Pain from other causes  |  |  |
| MSK disorders   | <ul> <li>Optimize PD medications</li> <li>Recruit assistance of general practitioner,<br/>rehabilitation experts and other specialists as needed</li> </ul>  |  |
| Neuropathic pain  | <ul> <li>Screening and treatment for common causes of neuropathy</li> <li>Rehabilitation and specialist referral for radiculopathy</li> <li>Neuropathic pain medications if pain is persistent</li> </ul>  |  |

### **Finding Empowerment in the Eye of the Storm** *Improving disease while stuck at home*

#### by Laurie K Mischley, ND PhD MPH

e are living in the middle of a global pandemic and our systems, patterns, and habits have been disrupted. We are finding new ways of living our daily lives, such as exercising at home and socializing with family and friends online. From here on out, we may have different relationships with our friends, families, providers, and ourselves. Although this disruption can be difficult, it also presents to us an opportunity, particularly for those living with Parkinson's disease. There is emerging evidence that the progression of Parkinson's disease (PD) can be reduced with lifestyle modification and there is no better time to build new routines than when your old ones have been interrupted.

#### IN DESPERATE NEED OF SOMETHING NEW

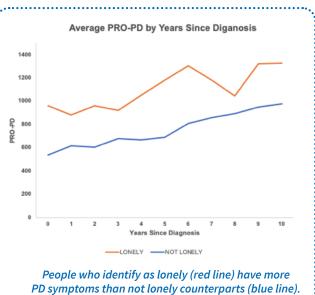
It's been two centuries, and there is not a single FDA-approved medicine to slow, stop, reverse, prevent, or cure PD. Dopamine-based medications work incredibly well to hide the motor symptoms of PD, but they're largely ineffective for nonmotor symptoms, such as constipation, apathy, muscle pain, fatigue, and impaired sleep. Much of the disease burden in PD is attributable to these unmanaged nonmotor aspects of the disease.

Since the conventional model has yet to be able to identify tools for slowing PD progression, a study was designed to permit a patient-centered definition of disease and ask a different set of questions.

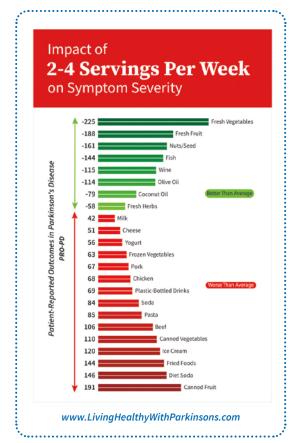
- Can we find the people doing exceptionally well over time with PD?
- Can we describe what they're doing differently than everyone else?
- Can we teach everyone to do what the successful people are doing?
- If people change their lifestyle, does it improve outcomes over time?

Over the past 7 years, within this study called CAM Care PD, over 2000 people with parkinsonism (PwP) have been interviewed. In this figure (below left), each of the 1600+ green dots represent the score of a person with Parkinson's disease. (The people with Parkinson-plus syndromes were removed from this analysis, but are included in the study.) Notice how some people have severe symptoms (red arrow) shortly after diagnosis, while others have relatively few symptoms (green arrow) for more than a decade. The blue line running across the chart is the average rate of PD progression over time. The goal of this study is to describe behaviors and lifestyle habits associated with PD symptoms over time and the results are shedding some light on lifestyle factors that contribute to disease progression.1





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#### FINANCIAL INSECURITY AND LONELINESS ARE MAJOR PREDICTORS OF PD PROGRESSION

The bad news first: Two of the strongest predictors of PD progression are the most difficult things to change—income and friendships. Both seem to be strong predictors of long-term health in PD, and yet we don't [yet] have a system in place to ensure that all PwP have financial security and a sense of community. For most, the COVID pandemic has further strained finances and social health. As a community, we need to come together and advocate for healthcare systems that remove the financial burden from patients and their families. We need to keep the

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politics out of public health and pass policies that meet the needs of PwP. In the meantime, through the generous support of donors, programs like APDA's Patient Aid Scholarship program aim to help by providing financial support for those with pressing needs.

If only it were as easy to pick up friends at the pharmacy as it is prescriptions! While COVID is keeping people isolated for now, social withdrawal has always been a problem for the PD community. Psychologically, some people feel insecure about their tremor or don't want their friends to have to wait for them. Nonmotor symptoms, such as apathy, anxiety, and fatigue make outings less enjoyable, while motor symptoms can occasionally make

them impossible. As part of the solution, the PD community has responded to these last few months of isolation by putting hundreds of programs online. A core component that contributes to the success of the Alcoholics Anonymous program has been to target social health as a therapeutic strategy and we need to follow suit. The APDA led the way with support groups and over the past decade there are now opportunities for PwPs to come together to work out, dance, sing, talk, hike, etc. Not everyone has the motivation or resources to attend these gatherings; and as a community, we need to continue to be creative in finding new ways to reach those that don't know what they're missing.

#### PHYSICAL ACTIVITY

Now for the [relatively] easy stuff: The people who exercise the most have the slowest accumulation of symptoms. According to the CAM Care PD data, the first two days of exercise each week don't do much to slow PD progression; The benefit becomes apparent at three days per week and increases in a dosedependent manner. In other words, people that exercise seven days per week have fewer symptoms than people who exercise six days per week. Numerous studies are currently underway to determine if one form of exercise is better than the others, with early studies suggesting high-intensity exercise offers the most benefit.

#### DOES IT MATTER WHAT I EAT?

In May of 2020, a study was published suggesting the more antioxidants a PwP consumed in their diet, the less their disease progressed over time.<sup>2</sup> This matches our own data (left) showing the more fresh vegetables and fruit, nuts and seeds, non-fried fish, wine, olive and coconut oil, and fresh herbs a person eats, the fewer symptoms they seem to accumulate. Conversely, the people who reported the greatest symptom severity the soonest were consuming canned fruits and canned vegetables, soda, fried foods, dairy, beef, chicken, pork, pasta, frozen vegetables, and drinking out of plastic bottles.

#### DISEASE-MODIFICATION IS HERE

We don't have a double-blind, placebocontrolled randomized multi-center clinical trial providing Level 1 evidence that if you make these changes you'll improve your disease. What we do have is a growing body of evidence *Continued on page 13* >

To join the CAM Care PD study: www.CAMCarePD.bastyr.edu For a updated study results: www.LivingHealthyWithParkinsons.com To learn more about PD School: https://pd-school.teachable.com To learn more about canine detection of Parkinson's: www.ParK-9.com For more information about Dr. Mischley: www.lauriemischley.com

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# MOVE & LIVE WITH OPTIMISM! At Home with APDA

#### EXERCISE YOUR VOICE!

Many people with Parkinson's disease (PD) experience changes in their ability to communicate. As you spend more time at home these days, you may find that you don't have the opportunity to speak to others as frequently and keep your speech flowing smoothly. You may notice that your voice is softer and breathy or hoarse, or that your speech is unclear and comes out too slowly or too fast. There are things you can do to strengthen and improve your voice and volume and much of it can be done in the comfort of your own home!

#### and and an and a second and a s

Make Your Voice Heard! Healthy Communication and Parkinson's Disease



#### Get the Booklet

Download it from the APDA website or call us at 206-695-2905 to order a copy

#### **Online Resources**

**APDA Webinar – "Living Well Every Day"** A speech language pathologist provides helpful information and advice regarding speech issues and PD, and a registered dietician and nutritionist offers recommendations about nutrition and other aspects of living well with PD.

**<u>APDA A Closer Look Blog:</u>** This Q&A explains what to expect from a speech evaluation and speech therapy, discusses singing as therapy, and gives some helpful tips.

<u>**Parkinson's Voice Project:**</u> Practice videos led by expert speech pathologists that you can do at home to strengthen your voice.

#### **EXERCISE YOUR BODY**

Exercise is a vital part of the treatment of PD, whether it is walking, boxing, yoga, etc. Although most in-person classes are on hold, you have many options to exercise at home.



#### **• Get the Booklet**

The APDA Be Active and Beyond Booklet has some great ideas, photos, and explanations of exercises you can do at home. Email or call us and we can send you the booklet or download it at apdaparkinson.org.

#### **Get Expert Advice**

Contact the APDA Exercise Helpline: 888-606-1688 or rehab@bu.edu The licensed physical therapists at the APDA National Rehabilitation Center at Boston University can answer your questions about PD-specific exercises.

#### **Online Resources**

Many exercise classes are meeting online and there are several archived educational programs available which will help you learn more about PD-specific exercise and why it is important.

#### **Virtual Exercise Programs**

APDA Northwest has compiled a list of online exercise programs. Find the link at apdaparkinson.org/Northwest

#### Let's Keep Moving Series

The APDA National Rehabilitation Center hosted a series of short (20 minutes) fitness-focused sessions on a variety of topics. You can find a link to those videos on our website.

#### **APDA Webinars**

*"Getting Motivated to Move"* and *"Staying Healthy, Keeping Fit"* are two great educational programs giving you tips and ideas about PD exercise.

#### **CONNECT WITH OTHERS**



#### Smart Patients

Join the **Smart Patients** online patient community! Members in this online discussion forum share help, advice and information about treatments, symptoms and side effects. Visit the support group page of our website to join.

### Upcoming Virtual Parkinson Education Programs

#### **APDA Parkinson's Good Start**

This 4-part educational program is designed specifically for those diagnosed with Parkinson's disease in the last 3 years. Learn from a team of esteemed experts and receive up to date information on diagnosis and treatment.

#### Wednesdays 5:30pm - 6:30pm PDT, June 24 - July 15

#### **APDA Take Control Series**

A monthly educational program giving those impacted by Parkinson's disease greater knowledge on a variety of subjects.

#### July Program - special 2-part series, sign up for one or both

Thursday, July 9 @ 10:30am Topic: The Gut Biome & PD Presented by: Dr. Kelly Condefer, Movement Disorders Neurologist, Confluence Health

Friday, July 10 @ 10:30am Topic: Unlock the Healing Power of Food Presented by: Wilma Shaw, Nutritional Therapy Practitioner & Board Certified in Holistic Nutrition, Embrace Nutrition Now

#### August

Friday, August 14 @ 10:30am Topic: Mind Over Parkinson's Presented by: Dr. Patrick Hogan, DO, Puget Sound Neurology

#### September

September 11 @ 10:30am Topic: Case Studies: Stories from the Examination Room Presented by: Pravin Khemani, MD, Swedish Medical Center

#### Find a Virtual support group.

Many local support groups have moved their meetings onto Zoom platforms. Contact the leader of a group in your community and join the conversation. Or call us to find out about joining a one of the newly formed all-virtual groups.

Need help with technologies like Zoom? Call us and we can help 206-695-2095



They are presented free of charge. **Registration** is required.

#### **Sing Loud for PD**

A chorus for people with PD and their carepartners. You may join for one or all sessions. No previous musical experience required.

#### Every Wednesday @ 12:30pm PD through July 29

#### **Caregiving During Quarantine**

An 8-session Support Program. Join a community of carepartners of people with PD for a weekly chance to talk and share. Facilitated by a licensed social worker.

#### Thursdays, 10:30-11:30am PDT July 2 - August 20

Space is limited

#### **DR. GILBERT HOSTS...**

A monthly series featuring expert discussion followed by Q & A from the audience.

#### 2nd Monday of every month @ 9:00 am PDT

Monday, July 13 Stem Cells & Parkinson's Disease with Dr. Evan Snyder

#### Monday, August 10 Intentional Optimism with ESPN Founder Bill Rasmussen

\*unfamiliar with Zoom but want to participate? Call or email us and we will help get you started.

#### For more information about any of these programs email, call or visit our website

# NUTRITION TIPS

### for the COVID 19 OUTBREAK

Even with our current isolation strategies, it is likely that COVID-19 will be with us for some time. While there is not currently a vaccine or a cure for COVID-19, self-care becomes ever more important and is likely our best defense. In addition to practicing social distancing and hand hygiene, NUTRITION is a key component of self-care. Here are a few nutrition tips to help boost your immune system and strengthen your defenses against any virus.

#### Stock up on fruits and vegetables

This is not a time to stock up on snack foods and sweets, but rather to increase your fruit and vegetables. Try to get a total of 5-9 fruit and vegetables in per day. Focus on eating at least one deep green vegetable per day, such as lettuce, kale, or collard greens. These can be added to smoothies, soups or scrambled eggs. Also aim to eat at least one high vitamin C food per day (such as an orange, berries or broccoli). If you are concerned about going out to shop, there are many home deliveries options for fresh produce such as: Imperfect Foods, Full Circle organics, Target, Costco, Whole Foods/Amazon Fresh, and other local grocery stores.

#### Stay Hydrated

Plain water is the best way to hydrate. Adequate hydration has many functions for protecting immunity. As we age, and with Parkinson's disease we lose our thirst mechanism which means you may not recognize your hydration needs. Aim for a minimum of 2 glasses of water between meals.

#### Use herbs for immunity

ER 2020

Immune boosting herbs include turmeric, garlic, ginger, astragalus (use as a tea or herb on food), and green tea.

#### If you are diabetic maintain tight blood sugar control

High blood sugars negatively impact the immune system, as does a diet that is high sugar or processed food diet.

#### Limit alcohol

This is not a time to throw caution to the wind. Alcohol suppresses the immune system. Limit alcohol to one drink per day or avoid it altogether.

#### **Consider supplements**

The following products (listed in order of potential effectiveness) are suggested:

- Vitamin D supports immune protection. Aim for 5000 IU per day
- Vitamin C helps in the production of white blood cells that help fight infections. For prevention, start with 500 mg/day and increase to1000 mg per day. If you have active disease, aim for up to 4000 mg per day. NOTE: DO NOT TAKE THIS IF YOU HAVE KIDNEY DISEASE OR A HISTORY OF KIDNEY STONES
- **Zinc** may be protective against respiratory infections. Aim for 15 mg/day.
- A multi vitamin: If concerned about the overall health of your diet.

#### Joan B. Hogan, RD, CD

www.food4lifecounseling.com, Specializing in Parkinson's disease and other neurological disorders, Author of Nutrition for the Ailing Brain

# **Telemedicine** & Parkinson's Disease

During the era of COVID-19, when social distancing is vital to ensure the safety of the Parkinson's disease (PD) community (and everyone else), getting to the doctor's office for management of PD has become a challenge. Because of this, many providers are now offering telemedicine visits which can be a great solution. For many, this is a brand-new way to interact with their doctors and many people with PD have had to learn about this new method of receiving care.

Dr. Jason Aldred is a Movement disorders specialist (MDS) who sees patients at his private practice Selkirk Neurology and at the clinical trials organization Inland Northwest Research, both based in Spokane, WA. He is on faculty at the University of Washington and Washington State University, and his practice sees patients from a wide geographic range, including eastern Washington, northern Idaho, and western Montana. His research and clinical care have involved many different telemedicine platforms over the last 10 years and telemedicine is often a part of the clinical care for PD in his practice. Here he shares his experiences with telemedicine and explains how it can benefit people with PD.

#### What is telemedicine?

Telemedicine is a general term that describes any type of electronic communication that provides healthcare without an in-person visit. Telemedicine has been used for decades, initially in areas with remote populations in need of medical care, using VCR-recorded exams that were then sent to a doctor who gave advice. Thankfully, technology improved over time, allowing videos to be transferred electronically to doctors who gave recommendations more quickly. Over the last few years, technology improved enough to allow high quality audio and video connection to create a medical visit that is much more like an in-person doctor's visit. Now cardiologists use remote stethoscopes, dermatologists use remote high definition cameras, and neurologists do examinations remotely for strokes presenting in the ER.

#### Why is telemedicine useful for people with PD?

In day-to-day practice, MDS neurologists examine people with PD by assessing speech, facial movement, upper and lower extremity movement, walking, and tremor. Because of the primarily audio and visual nature of the movement disorders examination that can be captured easily on video, telemedicine is uniquely suited for the evaluation of PD. In fact, as part of the training of MDS neurologists, trainees often watch videos of each other's patients to learn about details of the examination.

In addition, many people with PD live in areas with few or no Movement Disorders Specialty neurologists, or even Neurologists, therefore they either see no specialist or must drive hours to receive specialized care. As PD progresses, people may have more severe issues with cognition and movement or have a care partner who is older and has difficulty with mobility or driving. Winter weather can also limit their ability to get to their doctor's office. When people with advanced PD need care from their PD specialists the most, they may be at the highest risk for lack of access to specialty care because of difficulty leaving their home for a visit. For all of these reasons and more, telemedicine can be especially useful to evaluate and treat PD.

### \*

Because of the primarily audio and visual nature of the movement disorders examination that can be captured easily on video. telemedicine is uniquely suited for the evaluation of Parkinson's disease.

# Telemedicine 101 Toolkit

### Learn about the "platform" used for your upcoming telemedicine visit

FT.

- This is also called the "software" or "system" (Zoom is a common platform used for telemedicine)
- Ask your doctor's office for a demonstration video (or find one online) to familiarize yourself with how it should work

#### Ask how you will "link" to the visit

- This may involve clicking on a link in your email or text from your smartphone
- Smartphone connections may work with either regular cell phone signal or WiFi
- You may use your own computer, laptop, smartphone, or tablet or a family member, friend or neighbor's device. We recommend smart phones because they are the most readily available and usually connect easily.

#### Consider asking for a test appointment if you are worried you may not know how to connect at the time of your visit

• This may reassure you that everything is ready or give you an opportunity to fix any minor issues before your visit

#### **Connecting to the visit**

 When prompted on the screen, be sure to "Accept Video and Audio" connection for the visit

#### Tell your doctor during the visit "I agree to the use of telemedicine for this visit"

 Providers are being asked to get verbal consent for the visits by many insurers

#### **Camera best practices**

- Be your own camera person or have someone nearby to help.
- Sit with room light or daylight from windows shining on your face. Try to avoid windows and bright light behind you
- Set up the phone/camera approximately 3 feet away from you at eye level
- Have the camera aimed straight at you
- Rest the camera against a stack of books or edge of a counter or wall
- Look at the preview picture of yourself to make sure that your head is at the top of the screen and waist is at the bottom of the screen. This allows your doctor to see your movements, tremor, and other features of the examination
- Remember to speak loudly
- Modern technology is very good at picking up voice at a distance but be sure to speak up, especially if you have low voice volume
- Have a hallway cleared and either aim the camera in that direction or have someone else hold the camera to show your doctor how you walk up and down the hallway

#### Tips to make the best visit:

- Have your medications for PD on hand as you will likely need to refer to them
- Prepare a list of questions, concerns and/or goals for the visit so you're sure not to forget anything
- At the end of the visit, ask about a follow-up visit via telemedicine

#### Download the APDA Symptom Tracker App



Each person's Parkinson's disease symptoms are different. The more you and your care team know, the more personalized your care can be.

Easily track and share your symptoms, all from your mobile device.

Download the free APDA Symptom Tracker app today from the App Store or Google Play.



#### Although it remains unknown, our hope is that telemedicine continues to be covered by insurance after the pandemic is over.

Do you want to see Telemedicine continue to be covered by Medicare, Medicaid, and other insurances?

Email or call your legislator (Find yours at house.gov/representatives/ find-your-representative) and encourage them to allow continuing covering Telemedicine visits.

#### Is telemedicine covered by insurance?

Before the COVID-19 pandemic, Medicare and other insurers did not cover telemedicine as a benefit. Telemedicine was available but limited. According to the American Medical Association, before the COVID-19 pandemic, only 15% of healthcare providers had access to telemedicine at their practice. In remote areas referred to as Health Provider Shortage Areas (HPSA), patients had to go to specially designated telemedicine clinics to have this care covered as a benefit. At these clinics, the exam was performed, and then viewed remotely by a specialist. Even many HPSA areas had limited options due to the high cost of investing in and running telemedicine programs.

As of March 17, 2020, due to the COVID-19 pandemic, the Centers for Medicare and Medicaid Services declared a temporary allowance for in-home telemedicine to be covered on par with an in-clinic visit. Most Medicare recipients are older and have other medical conditions that place them at risk for serious illness due to COVID-19. Telemedicine has suddenly become vital during the pandemic, allowing those with chronic medical conditions to still receive medical care from the safety of their own home. Telemedicine reduces the risk of health issues going untended during the pandemic while maintaining social distancing. Many health care providers around the country are now offering telemedicine for the first time. Although it remains unknown, our hope is that telemedicine continues to be covered by insurance after the pandemic is over.

Having insurance coverage for telemedicine does not guarantee that a particular health system or medical practice will be able to deliver telehealth care. But many medical care practices and hospital systems have stepped up to the challenge due to COVID-19 with rapid transition to telemedicine platforms and a strong push to overcome any reluctance among their patients or providers in adopting this technology. Healthcare providers and patients have had to solve many problems regarding delivery of healthcare very quickly to keep patients healthy and out of Urgent Care and the Emergency Room.

The good news is that technology is much easier to use than at any other time in the past. For many people with PD, regardless of age and familiarity with technology, signing on to a telemedicine visit is straightforward and only requires a few clicks. One silver lining of this pandemic is that it accelerated our use of in-home telemedicine for medical care of PD and other conditions and encouraged doctors and patients who had never used telemedicine before to adopt it as a new tool to improve life for those with PD.

#### > Continued from page 7

that people who exercise daily, eat a plantbased diet, and have friends do better over time. These observational studies are the best we currently have, and they paint a consistent picture that one's lifestyle choices influence their health and disease severity.

Let's use this time in lock-down to take our own inventory. Let's study ourselves and our symptoms and be thoughtful about our strategy. The risks associated with making a few new friends, eating tapas, and increasing your physical activity are minimal, so why wait?

#### Dr. Laurie Mischley ND, MPH, PhD

studied naturopathic medicine (ND) at Bastyr University and Epidemiology (MPH) and Nutritional Sciences (PhD) at the University of Washington. Her work is focused on identifying the nutritional requirements unique to individuals with Parkinson's disease (PD). She has published on coenzyme Q10, lithium, and glutathione deficiency.

Dr. Mischley has academic appointments at the University of Washington and Bastyr University, where she conducts PD-related research. She has worked with the FDA, NIH, and the Michael J. Fox Foundation to administer intranasal glutathione, (in)GSH, to individuals with PD and is attempting to determine whether (in)GSH boosts brain glutathione and improves health.

She founded the Social Purpose Corporation, ParK-9, started Parkinson's School, and developed an outcome measure to assess PD severity (PRO-PD), and is author of the book Natural Therapies for Parkinson's Disease.

Dr. Mischley maintains a small clinical practice at Seattle Integrative Medicine focused on nutrition and neurological health.

#### **References:**

1. LK Mischley, RC Lau, R Bennett. Role of Diet and Nutritional Supplements in Parkinson's Disease Progression. Volume 2017 |Article ID 6405278 | https://doi.org/10.1155/2017/6405278

2. Puja Agarwal, Yamin Wang, Aron S. Buchman, Thomas M. Holland, David A. Bennett & Martha C. Morris (2020) Dietary antioxidants associated with slower progression of parkinsonian signs in older adults, Nutritional Neuroscience, DOI: 10.1080/1028415X.2020.1769411

# Finding Hope in Disease Modifying Research

#### by Melissa Bixby

The word "modify" means to make partial or minor changes, typically to improve something or to make it less extreme. In clinical research, to modify disease means much more than this simple definition. To modify, slow, lessen, or stop the course of disease can be life-changing, perhaps even lifesaving, and inspire hope for those suffering from disease. These possibilities are what have researchers and patients so excited about the future of this emerging category of research know as, "disease modifying" drugs or therapies.

Parkinson's disease research has experienced a sudden increase in new disease modifying trials over the past 5-10 years. While the design, length and study drug/device may differ, the goal is the same: to find a therapy to stop the progression of disease and improve quality of life for the patient. However, for the purpose of this discussion, the clumping spreads, the brain cells start to lose their ability to produce a very important chemical called dopamine. This loss or reduction of dopamine in the brain is what causes the typical symptoms of Parkinson's disease, i.e. slowness, stiffness, tremor as well as non-motor symptoms (depression, anxiety, sleep issues, and ability to think clearly). Many scientists believe that this continued build up of the alphasynuclein proteins is the root cause of Parkinson's disease. If this process can be interrupted, then perhaps it is possible to slow or stop PD progression.

The monoclonal antibody study drug contains a protein that recognizes the damaging forms of the alpha-synuclein that are clumping in the brain of PD patients. When the drug is given in regular intervals it may assist the body in slowing the progression of the disease. This has been a popular theory

## To modify, slow, lessen, or stop the course of disease, can be life changing, perhaps even lifesaving, and inspire hope for those suffering from disease.

focus will be on a topic that has received much attention, monoclonal antibody research trials. Monoclonal antibody is a mouthful, but in the most basic terms it is referring to a protein (made in a lab) used to bind to another protein or substance in the body (typically something that should not be there).

Monoclonal antibodies are also referred to as passive immunotherapy. In theory, these study drugs work similarly to the way we understand modern day vaccines. To help understand the mechanism by which this class of drug works, it is important to understand what creates Parkinson's disease (PD), in the brain. The brain typically creates good proteins needed for proper or correct function, not only in our physical body but in the way we think. One of these typical proteins is called alpha-synuclein, and in a normal functioning brain these alpha-synuclein proteins work as they should. However, for many reasons, including genetics, environmental toxins and reasons unknown, the brain sometimes produces dysfunctional or bad alpha-synuclein proteins, which then clump together throughout the healthy brain cells. As the and studied by numerous clinical labs and pharmaceutical companies. There are now several ongoing trials in phases ranging from preclinical to phase 2 and it is the hope of the entire scientific community that we will see great strides of these drugs in the next 2-3 years.

Another area that the scientific community is looking at is genetics. There has been a massive amount of support from the PD community at large in education and access surrounding the genetics of Parkinson's disease. Just two years ago there was not the ease of access for patients and their families to PD genetic testing. Initiatives like the Michael J Fox Foundation's Insight Study through a partnership with 23&Me, the Parkinson's Progression Markers Initiative, and the currently enrolling ROPAD, an international multicenter epidemiological observational study from Centogene, are all trying to accomplish a similar goal: what do the genetics of Parkinson's disease look like?

These trials amass a huge amount of information and help fuel our understanding of who and how many carry these

### There are many ways to get involved in PD Research.

Your neurologist can be a terrific resource about trials in your area. Or you can visit **www.clinicaltrials.gov** which is hosted by the National Institutes of Health (NIH) and lists all clinical trials past and present, for all conditions, and can be searched for trials that specifically address PD.

The following disease-modifying and genetics studies included in this article are being done right here in the Northwest! Please contact the study site to learn more.

#### **Disease Modifying Therapies**

#### M19-304: A Monoclonal Antibody study

Inland Northwest Research, Spokane, WA 509-960-2818; contact@inwresearch.com; www.inwresearch.com

**EvergreenHealth Research Services**, Kirkland, WA evergreenresearch@evergreenhealth.com; 425.899.5385; https://www.evergreenhealth.com/ parkinsons-disease-clinical-trials

#### PROSEEK: an Oral tyrosine kinase inhibitor study

**EvergreenHealth Research Services**, Kirkland, WA evergreenresearch@evergreenhealth.com; 425.899.5385; https://www.evergreenhealth.com/ parkinsons-disease-clinical-trials

#### **Genetic Studies**

#### **ROPAD: An LRRK2/Genetics study**

EvergreenHealth Research Services, Kirkland, WA evergreenresearch@evergreenhealth.com; 425.899.5385; https://www.evergreenhealth.com/ parkinsons-disease-clinical-trials Inland Northwest Research, Spokane, WA 509-960-2818; contact@inwresearch.com; www.inwresearch.com

#### **REASON: LRRK2 Study**

Inland Northwest Research, Spokane, WA 509-960-2818; contact@inwresearch.com; www.inwresearch.com Oregon Health Sciences University, Portland, OR 503-494-9531; allenjea@ohsu.edu

#### **Biomarker Studies**

#### Parkinson's Progression Markers Initiative (PPMI)

https://www.ppmi-info.org/ University of Washington/VA Puget Sound, Seattle, WA, kristasp@uw.edu Oregon Health Sciences University, Portland, OR 503-494-7230; bonnesu@ohsu.edu genetic markers and how can this information help create future therapies? Accompanying this newfound knowledge is another class of disease-modifying trials that use gene targeting. There are several trials, in various phases, which target patients who are positive carriers for the LRRK2 or GBA genetic variants. These two variants are the most prevalent in the PD community with 10-12% of the PD population testing positive for the GBA variant and 2-3% of the PD population testing positive for the LRRK2 variant. The theory is that these genetic variants may impair the ability of the brain to rid itself of harmful buildup of alpha synuclein. If a potential therapy could repair this process then we might be able to slow or affect the progression of the disease. This area of research is still looking for a connection between genetic PD (people who are carriers of one of the variants) and idiopathic PD (where the cause is unknown), and scientists are theorizing that a gene-targeting drug may interact with both types of patients.

Genetic testing is a personal and important decision for patients and their families. Speak to your neurologist to find out how to obtain access to genetic testing in your area.



Melissa Bixby is the Project Manager for Movement Disorders at Inland Northwest Research. She is a certified clinical research coordinator and clinical lab scientist with over 15 years of experience in the medical field. She has an undergraduate degree in biochemistry from Towson University and a graduate degree in biomedical science from Johns Hopkins University. She runs many of the large phase 1 and phase

2 interventional trials that include oral, infusion and intrathecal delivery routes. She is a credentialed coordinator with the Parkinson Study Group and Huntington Study Group where she is involved with other collaborative academic trials with sites around the world. She is heavily involved in several community support and outreach groups for Parkinson's Disease and Huntington's Disease and enjoys the time she gets to spend getting to know her patients and their families. Community support, education and access to clinical trials is one largest goals she has for the movement disorders portfolio.

#### Find out about Research Opportunities by joining the WPDR

The Washington State Parkinson's Disease Registry (WPDR), which is entirely funded by APDA, is a database of individuals interested and willing to participate in PD Research. Local researchers can apply to the registry to help find participants for their project. By connecting researchers to prospective study participants, we can help research happen faster.

You don't even have to live in Washington to join the WPDR!

To learn more about the WPDR please visit www.registerparkinsons.org or call 888-365-9901.

# PASS TO PASS

### Celebrates 5 YEARS of Hiking Adventures!



#### A.C. Woolnough

**Cour Summers Ogo** an event was created to demonstrate the invincibility of the human spirit, the need for unfiltered nature, and the determination to prove the Parkinson's community can achieve more than many believed possible. Pass to Pass was dreamt up by Bill Meyer and Ken Kisch, both avid hikers and outdoor enthusiasts who are living with Parkinson's disease.

The vision was to hike on the Pacific Crest Trail, doing different portions each year. Hikers with Parkinson's, support hikers, and pack animals were recruited and into the wilderness each year they go. The past four seasons have been successful in helping Parkies to achieve their dreams and overcome challenges through their trail experiences.

Below are words from some of the hikers. To read the full article about the hikers and their adventures visit **www.theoutdoorevolution.com**.

#### What did you get out of the experience?

I exercise every day and walk a lot to minimize my symptoms. I found a community of Parkies who enjoy the outdoors. We are willing to share our experiences. It is not just the hike experience, it is exercising to get ready, planning the hike, and talking together about the hikes.

#### What would you say to somebody considering Pass to Pass?

Go for it! This is a group of really good people, some with a great deal of experience, some not so much. However, everyone is willing to help each other, and I guarantee you will make life-long friends.

I promise you'll enjoy it, meet some good folks, have a sense of accomplishment—and forget you have PD for a while.

If all is deemed safe, Pass to Pass 2020 will take place in late summer. Visit **www.passtopass.org** to learn more!



**A.C. Woolnough**'s day job (37 years in public education as a teacher and principal) helped prepare him for his new job as a PD warrior. As a second generation Parky, he is now an advocate, educator, writer, speaker, research subject, grant reviewer, World Parkinson Congress ambassador, support group leader, and advisory council member. It's fair to say that he is "all in" for Parkinson's.











"I walk with the hope that we can stop the disease and offer treatments that allow people to maintain their dignity and independence. I walk with the hope that I can postpone the progression of this demoralizing disease. I walk with the hope that I can stay as mobile as possible and keep up with my husband and two kids. I walk with the hope that a cure for the disease is found before Parkinson's takes over my body and mind and I become a burden on my family."

> — Sue Bae Team SEAYOPD

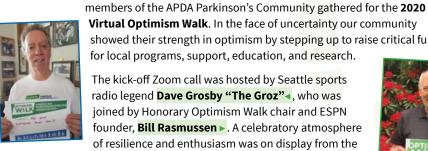


"I walk for my dad. He instilled in me a love of family and has always demonstrated endless kindness toward others. Through his actions, he taught me to support causes that I believe in. That is why I walk. His battle with Parkinson's has been rough and I walk to support him, as well as, to try to make the battle a little easier for others. Thank you, dad for being an amazing role model."

> Katie Zissermann Team Tom

#### OPTIMISM **AMERICAN PARKINSON DISEASE** ASSOCIATION

Sunday May 31st, separated by distance but united in common cause,



showed their strength in optimism by stepping up to raise critical funds for local programs, support, education, and research. The kick-off Zoom call was hosted by Seattle sports

Virtual Optimism Walk. In the face of uncertainty our community

radio legend **Dave Grosby "The Groz"**, who was joined by Honorary Optimism Walk chair and ESPN founder, **Bill Rasmussen** . A celebratory atmosphere of resilience and enthusiasm was on display from the start. Both are living with PD and have been graciously



and generously donating their time and talent to push out their message of hope and optimism.

The star power didn't stop there. GRAMMY® award winning artist Michael "Wanz" Wansley v made an appearance to introduce his original song promoting the APDA Virtual Optimism Walk, "APDA Comin at 'Cha (Strength In Optimism)." If you



haven't heard it yet, we encourage you to check it out on our APDA Northwest channel on YouTube - the photos will make you smile, and you likely will be singing the catchy chorus the rest of the day!

The festivities continued as participants safely walked around their neighborhood (or their living room!) and sent in photos and videos capturing their team spirit, smiling supporters, and overall OPTIMISM!

Thank you to everyone who joined us on this inspiring day. Even though most of us weren't able to walk together, our strength of community made sure that no one walked alone. Didn't get a chance to give? You can still donate at apdaparkinson.org/Northwest.

#### Thank you to our generous local sponsors:

#### **PLATINUM SPONSOR:**



#### **SILVER SPONSORS:**









Strength in optimism. Hope in progress.

180 Nickerson Street, Suite 108 Seattle, WA 98109

#### SUBSCRIBE TO OUR NEWSLETTER!

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

> The pandemic has changed how nonprofits can raise vital funds, and we need your help now more than ever.

> > Start small. Give monthly. Make a difference all year long.



helps cover the production costs of the *Parkinson Pathfinder*, filled with helpful articles written by experts and inspiring stories from people like you



contributes to community grant awards, which helps ensure exercise and wellness classes are offered in outlying areas and are affordable for all



provides Patient Aid Scholarship funds to people struggling to make ends meet, to help pay for expenses related to their Parkinson's disease

To set up a recurring donation, visit our website at **apdaparkinson.org/Northwest**, click **donate**, then **make my gift recurring.** Or give us a call at **(206) 695-2905.**