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Fundraising success!

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SUMMER 2022



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Strength in optimism. Hope in progress.

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A LETTER FROM BOARD MEMBER **BRIAN HARRIS**

A few months after being diagnosed at 48, in January of 2017, I sat with my 94-year-old grandmother trying to find the words that still sounded unfamiliar in my head: “I have Parkinson’s.”

Grandma was the matriarch of five generations and always had a ‘matter of fact’ way of looking at things. When the words finally crossed my lips, her immediate response was “So, this is what life has handed you. What are YOU going to do about it?” At that moment in time, I had no clue.

In the weeks that followed I pondered Grandma’s words of wisdom. I kept thinking, “What do I want most at this point in my life?” I attended a few PD support groups and didn’t connect with the others in attendance, because I didn’t see **me** reflected in their kind and welcoming faces. I was active, working full time, experiencing minimal symptoms that were outwardly apparent, and had plans for my future that just didn’t fit with my diagnosis. I realized I wanted – and needed – to see more people like **me** to help come to terms with my disease.

I have always been self-motivated and a planner while also enjoying the outdoors. So I thought, “If I build it, they will come.” And the idea of a Seattle-Area Young Onset PD activity group (SEAYOPD, pronounced **SEE** YOPD) was born. I reached out to the local support groups to find others with YOPD, and ten people attended the inaugural meeting in January 2018.

Our first outing was in February 2018, when seven of us took a snowshoe hike at Hyak Snow Park. Since then, we have hiked many trails in the Cascades and at urban parks. We have snowshoed and cross country skied at Snoqualmie Pass, have “rode the rails” on the Olympic Peninsula, kayaked around Elliott Bay, and whitewater rafted down the Wenatchee River. We’ve taken private tours of 3 cathedrals and enjoyed member-led concerts. While these outings provide great exercise, they are also an opportunity to ask questions, share our hopes and fears for what lies ahead, and offer camaraderie and community.

Now in our 5th year our members provide event ideas and feedback, assist with leading events, and offer website guidance. Our monthly hikes average 15-20 people and we’ve just begun our first spin off group called “Friends of SEAYOPD” where our loved ones come together - without their PWP - to share their thoughts and provide an understanding support system.

Sitting with my grandmother that day, I could never have imagined how her words and my ideas might play out. SEAYOPD is more than I ever envisioned. We are not the shaky, vulnerable, solitary people we felt like when diagnosed. We are here to support each other in the ON and OFF periods of our disease. No longer alone with our diagnosis, we now walk the path together.

Brian Harris

SEAYOPD

Seattle's Young Onset Parkinson's
Activity Group

www.SEAYOPD.com



SEAYOPD events take place all over the Puget Sound region and all are welcome! Check out our website at seayopd.com for upcoming events. Interested in starting your own activity group? Give APDA a call!

SEAYOPD does more than plan activities. Their team has been the top fundraiser in APDA Northwest’s annual Optimism Walk for the last 4 years! See page 12 for more information about this year’s Optimism Walk.



Travel

with PD

By Jill Ater



TRAVEL IS THE BEST EDUCATION!

My husband and I love to travel and are not about to let PD stop us. We've spent 9 of the last 12 months traveling in Europe! In doing so, we have discovered that by making some adjustments to our "pre-diagnosis" travel routines, we are able to continue to still enjoy our adventures. So, before you book those flights and run off to Ibiza, consider these suggestions.



Above, Jill with husband Alan, in Ronda, Spain



Ability Assessment - Be Honest with yourself and plan accordingly

- How are you physically? You may be prepared for some challenges, but no one can take a wheelchair up flights of stairs at a castle designed centuries ago nor up the steps of the Coliseum.
- Will you be with others who can help you, or will you need to skip out on some activities or sites (or parts of them)?
- How do you manage traveling on boats, airplanes, cars, trains?
- How will you manage your movement limitations when climbing stairs, walking on cobblestones/aged pathways, travers nature settings, hike, or while sitting for long periods of time?
- How about anxiety? If big cities and crowds increase your anxiety, plan accordingly. You can go to Portugal, see wonderful small towns, full of charm with great restaurants, museums and churches and skip the big cities like Lisbon and Porto.
- Do you feel too much pressure if others are waiting on you and you feel rushed? Consider this before joining a group tour. Remember anxiety can make physical symptoms like tremor worse.



Managing Time.

- Make sure to account for the extra time needed at airports, docks, train stations. Traveling can be stressful, so avoid getting yourself in a time crunch that can make it worse.
- You cannot see Rome in a day when you are able-bodied so do not expect that of yourself now. Remember to keep your expectations and plans realistic.
- Schedule in a rest day at least once a week. It will give you time to rest and recharge so you can continue to enjoy your time away.



Medications

- Bring more medication than you think you will need and make sure to place it in your carry-on luggage.
- Keep extra medication in a separate space in your luggage.
- **Always** carry a printed list/ spreadsheet listing all your medications. Include who prescribed them, when, and for what purpose. This is handy to have in general. I have never needed it when going through security, but I make sure I have it. This is handy to have in general (bring it to new doctor appointments and avoid filling forms).



DBS (if applicable)

- Will you have access to power to re-charge? Will your charger work with a basic travel power converter? Thinking of these things in advance will save you from getting in a bind.
- Programmer issues: Make sure to understand your personal programmer. Bring the phone number for a local tech support person.
- Airports: Remember to let security know you have a “medical device” and cannot go through metal detectors. Scanners are also used by many museums, arenas, and even unexpected locations. Be alert and prepared to tell people and remember that you also must avoid wands.



Physical Issues to think about

- **Beds:** Do you sleep okay in a full-sized bed? Many beds you will find in Europe are smaller than we are accustomed to.
- **Hotels or Air B&B's?** How important is a kitchen? Are there stairs or an elevator? In Europe, units are rarely on a ground floor and often do not have elevators
- **Bathrooms:** While access is improving, disabled bathroom stalls remain a very American thing. Are you able to

use a regular stall? In your pocket or purse bring your own toilet paper or tissue, as many are often out or not provided. Do not be surprised if there is no toilet seat. In the UK, there are some handicap public stalls, but they often require a special key. You can order them online in advance. (<https://www.disabilityrightsuk.org/shop/official-and-only-genuine-radar-key>). These are worth getting if you need a disability stall!

- **Grab bar:** I always travel with a suction shower grab bar. I also use it at home for added safety. Available at Lowe's or Amazon for less than \$20.
- I also travel with a **rubber non-slip shower mat**. Even the small European showers get slippery and a fall can quickly ruin a vacation.
- **Wheelchairs or Walkers:** If you use one, make sure you are comfortable on cobblestones and stair. What is your backup plan?
- **Walking Sticks:** I bring collapsible walking sticks for hiking. They are also helpful for managing cobblestone streets and other uneven walking paths.
- **Cane:** I bring a collapsible cane for the airport and mass transit. It is brightly colored and very noticeable. You want people to know you may be slower or need assistance. Europeans, in general, are very considerate of people with disabilities.

- **Suitcase:** Can you carry it? Are you certain it fits in the overhead? If you can't lift it yourself, consider checking it.
- **Shoes:** Remember, comfort comes first. We love the Keen brand, they offer great support and stability and the soles are designed for walking and hiking.
- **Clothing:** The key factors are washability, ease of on/off, and layers. I always bring something fancy and have never actually worn it!
- **Jewelry:** Never bring anything that you'd be upset losing. Remember, “Less = Easier”.



THINGS I NEVER TRAVEL WITHOUT:

- A cane and/or walking sticks.
- My MDS emergency number and email.
- A copy of all prescriptions including eyeglasses!
- A small cross body purse with extra pills and tissues.
- A water bottle.
- Medical Alert Bracelet. I am NEVER without it.

HAPPY TRAVELS!

Author **Jill Ater**
visiting South Stack
Lighthouse, near
Holyhead, Wales



Jill Ater was diagnosed with Parkinson's in 2005. She and her husband Alan are avid travelers and since June of 2021 they have visited 11 countries and been on 19 airplanes – Jill's advice is “always wear your mask, the last thing you want is to be sick on vacation”. You can follow their adventures, complete with amazing travel photos on both Facebook and Instagram, search for It's a Parkie World.

Helping Researchers Get to a Parkinson's Cure: Landmark Study Needs People with and without Parkinson's



By **Mary Dryland**
an interview with
Dr. Shu-Ching Hu

At APDA, we work tirelessly every day to support the Parkinson's disease (PD) community and to advance critical research.

One way we do that is to harness the power of our grassroots network to spread the word about important projects going on in the PD field. The Parkinson's Progression Markers Initiative (PPMI) is a landmark study that is currently underway that you and your loved ones (with and without PD) can participate in to support the advancement of PD research. To help you better understand PPMI and learn how you can get involved, we spoke to Dr. Shu-Ching Hu, neurologist at the University of Washington Medical Center, PPMI principal investigator at VA Puget Sound Health Care, and former medical director for APDA Northwest.

Today, PPMI is entering its most ambitious era yet. The study aims to enroll 4,000 volunteers at medical centers across the globe and as many as 100,000 online. We have two clinical sites in the Pacific Northwest region of the U.S., including the University of Washington/VA Puget Sound Health Care System in Seattle, Washington, and Oregon Health & Science University in Portland, Oregon. Additionally, since PPMI's inception, the Parkinson's Disease Registry – funded by APDA Northwest - has been instrumental in recruiting research participants.

Participants invited to join PPMI at a clinical site are asked to share biological samples like saliva and blood. They also complete assessments to help researchers better understand how disease starts and changes over time. That information may lead to insights and tools that can help better diagnose, treat, and even prevent brain disease.

What are biological markers and why are they so important?

A biological marker or “biomarker” is an objective measurement of disease. An example of a biomarker is cholesterol, which helps doctors diagnose and monitor the progression of heart disease. Unfortunately, to date, no practical, definitive biomarkers for Parkinson's have yet been identified, but they are a critically needed tool. They could help doctors better diagnose and treat Parkinson's and are also important for successful clinical trials testing treatments to slow or stop disease. Importantly, biomarkers also have the power to help identify people at risk for Parkinson's as well as establish strategies for prevention of the disease. Through PPMI, scientists are looking for physical and cellular characteristics from head to toe that show disease risk, presence or progression.



**Parkinson's
Progression
Markers
Initiative**

What is PPMI? Why is it so important?

Since PPMI first launched in 2010, it has enhanced how

Parkinson's research is done and what scientists know about the brain. Created by The Michael J. Fox Foundation (MJFF), the study is a collaboration of researchers, funders, and study participants working to better understand PD and advance new treatments. The study follows people – with and without PD – collecting data and biological samples over time to learn about how the disease starts and progresses.



Who should join the study that could change everything?

you!

People with and without Parkinson's can join PPMI. Anyone over age 18 in the United States can join the online part of the study. To enroll electronically visit michaeljfox.org/ppmi

Study sites in the U.S. and other countries are enrolling people diagnosed with Parkinson's in the past two years and not yet taking PD medication. In addition, sites are enrolling individuals without a Parkinson's diagnosis, but living with certain factors linked to increased risk of PD in individuals aged 60 and up:

- People who act out dreams while asleep (REM sleep behavior disorder)
- Parents, sisters, brothers and children of people with Parkinson's
- People with ongoing smell loss (hyposmia)
- People with a known genetic mutation linked to Parkinson's (GBA, LRRK2, SNCA, PRKN, PINK1)
- Control volunteers with no known connection to disease
- People of Ashkenazi Jewish descent are especially needed. This population may carry gene changes linked to Parkinson's. Veterans also have an important role to play in Parkinson's research. Military service can increase risk for PD through exposure to toxic chemicals or traumatic brain injury.

In the Northwest, PPMI has two clinical study sites – in Seattle at the University of Washington/VA Puget Sound and in Portland at Oregon Health Sciences University.

To find out if you are eligible to join PPMI at a medical center, please call:

877-525-PPMI

Or you can call the Seattle and Portland study staff:

Seattle: **206-277-6977** or **206-214-7786**
Portland: **503-494-8311**

View a complete list of recruiting sites at michaeljfox.org/ppmi-sites. (PPMI covers travel for potential volunteers and a study companion.)

The Parkinson's Progression Markers Initiative (PPMI) is a landmark study aiming to support PD researchers as they investigate physical and cellular characteristics that show PD risk, presence or progression.

How is PPMI data being used to speed drug development?

PPMI has developed the most robust PD data set and biosample library in the world. This unparalleled data and biosample library is open access, meaning that qualified scientists around the world can download study data in real time. Additionally, all data collected through PPMI is de-identified, meaning all demographic information (including your name and contact information) is removed, and the study has multiple safeguards in place to ensure that patient privacy is protected.

Today, scientists all over the world are downloading PPMI data on average 2,200 times per day. The dataset allows researchers to learn from a broad population of people and work toward our common goal, which is to better understand PD progression and prevent the onset of disease.

How has PPMI shaped the future of Parkinson's research and care so far? What are researchers hoping to learn as the study expands today?

Studies built on PPMI data have yielded significant findings. These include the use of sophisticated brain imaging to track early disease progression and tests of protein activity in spinal fluid to diagnose disease. Findings from PPMI have revolutionized the field's understanding of Parkinson's biology and design of over 20 human clinical trials testing potential new treatments, but there is much more to uncover.

What else has PPMI found? Newly identified genetic variants are linked to the disease. And PPMI data is helping scientists gain a better understanding of the relationship between motor and non-motor symptoms and how that may impact someone's course with disease. These results can point to new tests and therapies.



Shu-Ching Hu, MD, PhD, is a board certified neurologist at Harborview and UW Medical Center and a UW associate professor of Neurology.

Dr. Hu specializes in treating movement disorders such as Parkinson's disease, tremor and dystonia. He also conducts research on Parkinson's disease. What excites him the most is to see patients who are living life to the fullest, despite challenges caused by their illness.

GETTING SKIN DEEP

with PARKINSON'S DISEASE

By Dr. Kimmy Su, MD, PhD

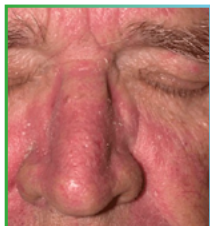
You may have heard of Parkinson's disease (PD) described as an iceberg, in which above the surface you see the motor symptoms of tremors, rigidity, slowness and posture changes, but below the surface there are many non-motor symptoms including blood pressure fluctuations, constipation and bladder issues. A lesser highlighted but equally relevant non-motor symptom are the skin changes that can occur with PD. We will review here commonly seen skin changes that impact PD patients, either associated with PD itself, or caused by PD treatments.

Skin changes due to PD

The most common skin changes due to PD include dermatitis, bullous pemphigoid, sweating issues, and melanoma. Generally speaking, it is unclear exactly why these skin changes tend to occur in PD patients.

Dermatitis

(aka irritation of the skin)



Seborrheic dermatitis – This is a skin condition that causes scaly, flaky patches, oily skin, and a red itchy rash. It can sometimes

look like eczema or psoriasis. Such dermatitis is seen in areas where there are sebaceous, oil-producing glands, including the scalp, face, ears, upper trunk and skin folds. It is not contagious and not due to the skin being unclean or infected. Treatment options include using over-the-counter products such as anti-dandruff shampoo, and topical ointments such as a mild corticosteroid cream, anti-fungal cream (ketoconazole) or keratolytic agent that breaks down the

outer skin layers (salicylic, glycolic acid). It is important to wash the skin regularly and avoid products containing alcohol as they can worsen the condition. For more resistant cases, oral anti-fungal medications (fluconazole) may be utilized.



Perioral dermatitis

– Skin irritation around the mouth can occur in patients with severe drooling issues. Treatment

of drooling may include using anti-cholinergic medications such as glycopyrrolate tablets or atropine drops administered under the tongue, or Botox injections into the salivary glands to reduce saliva production.

Sweating issues

PD patients may complain of either increased or decreased sweating due to dysfunction of the autonomic nervous system that controls the gut, bladder, blood vessels, and skin. Sometimes the sweating is associated with off-periods (when PD medications are less effective) or with dyskinesias (the

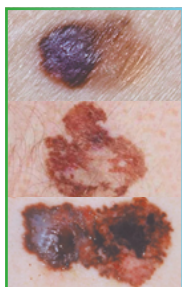
uncontrollable excessive movements). Thus, medication adjustments to lessen both may potentially reduce sweating. In some patients, anti-cholinergic medications may be utilized to reduce sweat production, though it is important to be aware that these medications can cause unwanted side effects such as constipation, urinary retention and confusion. For more targeted treatment, Botox injections into armpit sweat glands to reduce sweat production may be considered. Non-medication management options can also be helpful, including using an anti-perspirant (not just a deodorant that reduces odor) and wearing loose clothing made of breathable materials. For night sweating, bed sheets made of moisture-wicking material can be helpful. Lastly, try to avoid foods that can increase sweating such as alcohol, caffeine, and spicy foods.

Bullous Pemphigoid



Bullous pemphigoid is a rare skin condition that causes large, fluid-filled blisters due to the body's immune system attacking and destroying

healthy tissue by mistake (also known as autoimmune). The blisters mainly develop in areas of skin that are often flexed, such as the lower abdomen, upper thighs, armpits, but can also affect the mouth and throat as well. For milder and localized cases, topical corticosteroids may be adequately effective. For severe disease, more robust immune system suppression may be necessary via systemic corticosteroids or other immunosuppressing/modulating treatments.



Melanoma

Melanoma is a type of skin cancer involving melanocytes, which are cells that produce melanin or pigment. Studies have shown that

melanoma is more prevalent in PD patients compared to the general population. The underlying reason is not clear. In the past, it has been suggested that being on carbidopa levodopa increased the risk of melanoma, but more recent studies have been less convincing. Risk factors aside from PD to be aware of include ultraviolet (UV) light exposure, Caucasian race, older age, male gender, family history of melanoma, and personal history of melanoma or other skin cancers. Prevention is key, which includes using sunscreen and wearing UV protective clothing. Be on the lookout for unusual skin spots that fit with the ABCDEs of skin cancer (**A**symmetry, **B**order irregularity, **C**olor variability, **l**arge **D**iameter, **E**volution over time). Patients should see a dermatologist annually to do a skin cancer check. Localized melanoma can be treated with surgical excision, whereas widespread disease will need to be treated with surgery as well as chemotherapy.

Skin changes due to PD medications

It is important to be aware that certain PD medications can cause skin changes.



Amantadine — Livedo reticularis is a rare skin change caused by amantadine. This term, translated as “bluish” and “net-

like in appearance,” describes the lacy blue rash that can develop on the legs and arms due to increased blood in the veins. Livedo reticularis is not typically painful nor harmful, and some patients who find symptomatic benefit on amantadine may opt to continue taking it despite developing the rash. The rash usually occurs within weeks after starting

the medication, but rarely may appear years later. Once amantadine is stopped, the rash will gradually go away.



Dopamine agonists — Dopamine agonists include ropinirole, pramipexole, rotigotine and apomorphine. The oral formulations (ropinirole and pramipexole) can cause leg swelling or edema. Rotigotine, which is given in patch form, can cause local skin changes including redness, swelling, and itchiness. These changes are generally mild and tolerable, and resolve when the patch is removed. Thus, daily rotation of where the patch is applied can reduce skin irritation, and it is recommended that the same site not be used more than once every two weeks. In addition, after the patch is removed, the application site should be cleaned with soap and water to remove any residual medication or adhesive that can cause skin irritation. Lastly, apomorphine can be given under the skin (subcutaneous) as a rescue treatment when patients with motor fluctuations have an unexpected off-period. Occasional injected apomorphine does not typically cause skin changes, however, patients with an infusion pump may develop skin nodules over time. The nodules are usually mild in severity, but the more severe cases can become infected leading to abscesses. Ways to reduce nodule formation include rotating the infusion sites, using a lower concentration of medication, and massaging the infusion sites.

Skin changes as a potential PD biomarker?

A significant area of study in PD research is how to detect it earlier in the disease course. Given that 1) skin changes can potentially occur before the development of motor symptoms, and 2) it is relatively easy to get skin samples, identifying skin biomarkers is an area of great promise. Research is currently being done to

better understand how alpha-synuclein, the protein in Lewy bodies found in the brains of PD patients, accumulates in the skin. The big questions to be answered include when, where, and how skin biopsies should be obtained and how to process them afterwards to effectively diagnose PD.

Tips and Takeaways

- Non-motor symptoms are common in PD, including skin changes
- Skin changes in PD can be due to the disease itself, or due to treatments for PD
- Skin changes due to PD include dermatitis, bullous pemphigoid, sweating issues, and melanoma
- Treatment options can include both localized and systemic management depending on the severity of the skin condition
- PD patients have an increased risk for melanoma, so watch for skin changes and visit a dermatologist annually
- Amantadine and dopamine agonists can cause skin changes, which usually are not too troublesome and resolve once the medication is stopped
- Skin changes may be a potential biomarker for diagnosing early-stage PD before motor symptoms develop



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, community outreach programs, and research through clinical trials. Dr. Su serves as Medical Director of the APDA Northwest Chapter.

COULD THIS BE DUE TO PARKINSON'S DISEASE?

Uncommon non-motor symptoms
of Parkinson's Disease

By **Dr. Rebecca Gilbert, MD, PhD**
APDA Vice President and Chief Scientific Officer



It is common for a person with Parkinson's disease (PD) to attribute every new symptom that develops to PD. That is largely because the list of [non-motor symptoms](#) (symptoms that you can't see) commonly associated with PD is so varied, it can seem that almost anything is a symptom of PD! But if you take a closer look, there are some symptoms that are **very** commonly associated with PD, others that are virtually **never** associated with PD, and some in between.

Let's divide up non-motor symptoms into the following categories:

Symptoms that are commonly associated with PD

These symptoms include [sleep disorders](#), [abnormalities in blood pressure](#), [urinary problems](#), [constipation](#), [depression](#), and [anxiety](#). Even though these symptoms are so commonly seen in PD, they are also commonly associated with other issues that have nothing to do with PD, so it is vital to keep an open mind about their cause. If any symptom is new or worsening, it could be an indication of a new medical problem. For example, urinary problems are extremely common in PD, but may be a sign of an enlarged prostate, which can be treated in an entirely different way.

Symptoms that are unlikely to be related to PD

There are some symptoms that are typically *not* associated with PD. For example, chest pain, blood in the stool or blood in the urine should not be assumed to be PD-related and likely indicate another medical problem.

Symptoms that may be related to PD

These symptoms can be associated with PD, but are also commonly associated with other medical conditions, so more testing is necessary. For example, [weight loss](#) may be associated with PD but may also be a sign of a gastrointestinal problem or cancer. [Pain](#) may be associated with PD, but could be also due to arthritis, spinal stenosis, cancer, or a whole host of other causes.

There is a fourth category of non-motor symptoms that I would like to focus on now:

Symptoms that may be related to PD but that few people know about

People with PD and care partners may suspect that a particular symptom is related to PD, but they can't find information about it, so they are not sure. Two symptoms that pop up in this category are **runny nose** and **breathing problems**, which we'll focus on today. Of course, if these are new symptoms for you, they could be indicative of a new problem, including infection with COVID-19, so make sure to get yourself checked out by your doctor. However, if all else is ruled out, PD could be to blame. [Excessive sweating and specific skin disorders](#) are in this category as well and are addressed on page x of this publication.

Runny nose and Parkinson's disease

Runny nose, or *rhinorrhea* in medical jargon, is an annoying symptom that has been shown in a number of studies to be more common among people with PD than those without PD. The rhinorrhea of PD is not associated with a viral infection or environmental allergies, or any other common cause of runny nose.

Rhinorrhea can be an early feature of PD, sometimes present at the time of diagnosis. In fact, studies have shown that rhinorrhea is *not* correlated with disease duration, disease severity, or whether the PD is characterized more by tremor or gait difficulties. One study tested the smell of those with runny nose versus those without and determined that the presence of rhinorrhea did not correlate with deficits in the sense of smell.

There are no studies in the medical literature addressing how to treat the runny nose associated with PD. *Ipratropium bromide* is an anti-cholinergic medication that does not cross the blood-brain barrier and is available in two forms – an inhaled form to treat asthma, chronic bronchitis and emphysema; and a nasal spray that is used to treat allergic and non-allergic runny nose. The nasal spray may be worth a try in PD-related rhinorrhea.

Although ipratropium nasal spray is typically well-tolerated and is administered locally which limits side effects, it can have more widespread effects. Side effects of ipratropium that may be of particular concern for people with PD include low blood pressure, urinary retention and constipation. As always, discuss

any potential new medications with your physicians.

ClariFix Cryotherapy is a relatively new procedure for chronic runny nose. The procedure involves inserting a small device into the nose and freezing a small area at the back of the nasal cavity. It has not been tested specifically in runny nose associated with PD but may be an option to discuss with your physicians.

Breathing problems and Parkinson's disease

Usually, trouble breathing is not thought of as a symptom of PD. Those with PD who complain of this will typically have testing of their heart and lung function. This is necessary since, as we continue to emphasize, a person with PD can develop medical problems unrelated to PD and needs every new symptom evaluated like someone without PD. However, often the testing does not reveal a cardiac or pulmonary abnormality. Could difficulty breathing be a symptom of PD itself?

There are a number of ways in which difficulty breathing may be a symptom of PD:

Shortness of breath can be a wearing-OFF phenomenon

Some non-motor symptoms can fluctuate with brain dopamine levels, which means that they change as a function of time from the last levodopa dose. For some people, shortness of breath can be one of the non-motor symptoms that appears when medication levels are low. However, shortness of breath can be due to anxiety which can also be a wearing-OFF phenomenon. Sometimes it is not possible to determine whether the key symptom is anxiety or shortness of breath. Treatment involves changing medication dosing and timing so that OFF time is minimized. You can view on APDA's website a **webinar** which discusses the concept of wearing OFF and potential treatments.

Abnormal breathing can be a type of dyskinesia

Dyskinesias (the abnormal, involuntary movements that can be a side effect of levodopa) may manifest as an irregular and erratic breathing pattern. If this is the case, the treatment involves adjusting dosage and timing of levodopa so that dyskinesias are minimized, or adding amantadine or amantadine ER which can reduce dyskinesias. A [publication](#) on APDA's website addresses this topic in more details.

Restrictive lung disease

This refers to an inability of the lungs to fully expand with air. Restrictive lung disease can result in shortness of breath with exertion, and can worsen to cause shortness of breath at rest as well. Restrictive lung disease can occur in PD because of rigidity of the muscles of the chest wall as well as bradykinesia, or slowness of the muscles responsible for chest wall expansion and contraction. In addition, people with PD can have abnormalities in the posturing of their trunk including head drop, stooped posture, tilting of the trunk and bending at the waist. These postures can restrict the amount that the lungs can fill up. Treatment usually involves increasing the amount of levodopa.

Aspiration pneumonia

PD can predispose a person to [dysfunction of swallow](#) which can lead to aspiration, or foreign material (e.g. food) entering the airway. Aspiration can cause pneumonia which can

substantially impair a person's ability to breathe. Aspiration pneumonia is diagnosed on chest X-ray and is treated with antibiotics.

Sleep apnea (SA)

SA is a sleep disorder that can be associated with PD. In this disorder, breathing stops and starts throughout the night, leading to periods of low oxygenation in the blood and frequent awakenings. There are two main types of sleep apnea and both may play a role in PD:

Central – due to decreased drive to breathe in sleep due to brain stem lesion

Obstructive – due to abnormal function in the muscles of the upper airway

Diagnosis of SA is made via Sleep Study, a test which records activity of the brain and body during sleep including brain waves, oxygen levels in the blood, heart rate, breathing, eye movements and leg movements. It is important to note that untreated sleep apnea can raise the risk of heart disease and stroke, and can cause depression, poor memory, headaches, so it is very important to identify and treat it. Treatment of SA typically involves wearing a device during sleep that applies non-invasive ventilation through a nose or mouth mask, called a CPAP machine.

TIPS AND TAKEAWAYS

- It can be confusing to know which of your symptoms are connected to PD and which are not.
- There are some symptoms that are very commonly associated with PD, others that are virtually never associated with PD, and some that fall in between.
- Some non-motor symptoms that may be related to PD but that few people know about are runny nose, excessive sweating, specific skin disorders and breathing problems.
- People with PD can experience difficulty breathing for a number of reasons associated with PD, including wearing-OFF, dyskinesia, restrictive lung disease, aspiration pneumonia and sleep apnea.
- As always, discuss all your symptoms with your doctor so that he/she can assess the issue and decide how to best treat it so you can hopefully start to feel better.

THANK YOU TO THIS ISSUE'S BRONZE SPONSOR



TRACTOR TRIP for PARKINSON'S

An Epic Journey Across 5 States
to Raise Awareness – And Critical Funds –
For Parkinson's Disease

When Mike Adkinson's older brother Dan was diagnosed with Parkinson's last year, Mike and his family realized they didn't know much about this disease. They started doing research and learning as much as they could about PD. The also began talking about what they could do to help raise awareness.

Around that same time Mike's brother-in-law mentioned that he was interested in Mike's 2008 John Deere 3320 tractor. But how to get it to his brother-in-law's home in Perch Lake, Minnesota? Well, even at 76 years old, Mike is always up for a challenge, so why not drive? And this is how the idea for Mike's Tractor Trip for Parkinson's was born – an epic journey to drive a tractor and raise Parkinson's awareness along the way. And we don't use the term "epic journey" lightly.

Mike left Bellingham on Sunday May 15, driving his tractor on WA Hwy 20 and then along US Hwy 2 for the rest of his 1,700 mile journey, across Washington, Idaho, Montana, North Dakota, and Minnesota. He was pulling a small trailer which served as his fundraising billboard as well as a place to sleep if needed.

Driving a tractor leaves you exposed to the elements, and Mike was prepared for all weather conditions, even installing a windshield and a top to help with the expected rainstorms. However, encountering snow over Sherman Pass was still a hard day, but one which Mike met with his optimism:

"Today was one of the roughest days that I've had in a long time. It was cold, it was wet, and there were times where I wondered what the heck is wrong with me that I'm doing this. But then I started thinking about it, whatever I had to do today, was absolutely nothing compared to the stress that my brother and other people who have Parkinson's deal with every day."

At an average speed of 12 mph, he has chugged through rural areas and welcoming towns, making many stops along the way. Mike's wife Phyllis says that he has an ability to "collect friends," and his outgoing personality makes him a fantastic ambassador for Parkinson's disease and the perfect fit for this kind of adventure. Mike is gathering friends wherever he stops; listening to Parkinson's stories, discovering small world connections, sharing laughs – and a few tears –while everyone enjoys each other's company.

Mike waves at everyone who passes him on the highway. Sometimes people will pass his tractor only to wave him over a little further down the road, to express their thanks and encouragement. Often to hand him a donation, or in one case some freshly made brownies. Mike was met in Kalispell, MT by the local Parkinson's support group, who came with welcoming posters and balloons (despite a cold rainy day!), and in Cut Bank, MT he got a police and fire escort through town before having dinner with the mayor.



The tracks courtesy/Insanity100 on vecteezy

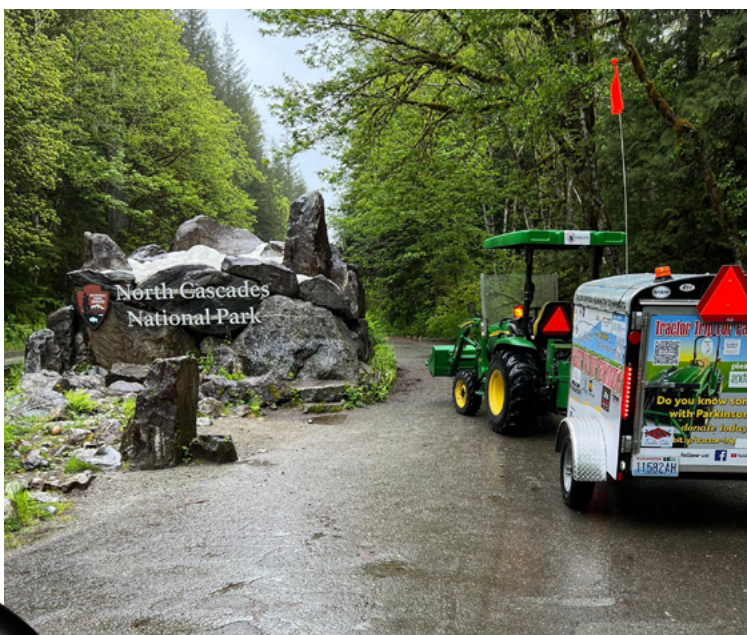


Mike's outgoing personality makes him a fantastic ambassador for Parkinson's disease and the perfect fit for this kind of adventure.

What is Mike thinking about on these long hours on the tractor? "I guess I would say I'm almost meditating, in that it is enjoyable and I lose myself. Every time I go up a hill or around a corner I'm anticipating, 'What is next? Who am I going to meet? What am I going to see?'" And of course, Mike has a few tractor jokes at the ready. Before heading into Glacier National Park, he was asked if he was afraid of bears, "No, and I have thought about that. I think I am safe because I'm pretty sure bears don't chase Deere."

Mike set a lofty fundraising goal of \$50,000. He has reached that goal and is dedicated to raising more! You can still support his efforts at bit.ly/tractor-trip.

Now THAT is an epic journey.



Have an idea for a DIY adventure of your own?

It can be as simple as a garage sale or birthday party, or as involved as driving a tractor across 5 states.

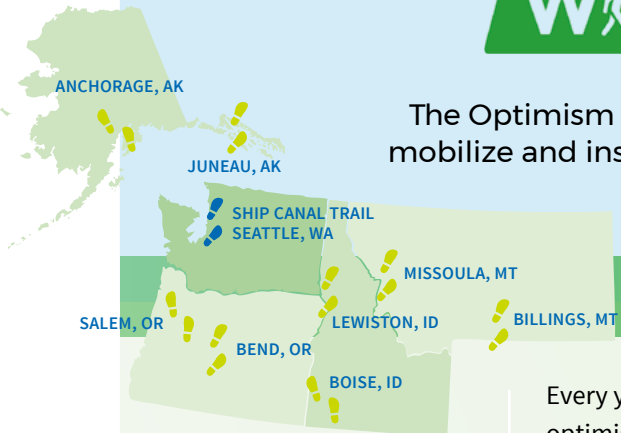
Contact us to start your own fundraising webpage!



**BACK
&
IN PERSON!**



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 WANT YOU TO JOIN IN THE FUN!

Every year our APDA Northwest Optimism Walk is filled with strength and optimism. It is one of our biggest outreach events and largest fundraisers of the year, and our 2022 goal is to register more than 750 walkers from all of our 5 states, and raise \$200,000! Everything will be outdoors and Covid protocols will be in place. Proceeds from this event will keep people with Parkinson's connected, informed, and moving. And YOU can help!

How will the funds be used?

APDA has responded to the demands of the past several years by expanding critical online support programs, educational offerings, and exercise & wellness classes that help connect and support everyone impacted by PD, even when meeting in person wasn't possible. APDA also offers financial assistance to people struggling to make ends meet, and invests in innovative research to find a cure.



Register today as a Team Captain, Team Member, or Individual Walker. Leading up to the event, you will reach out to your network and ask for their support – every \$25 / \$50 / \$100 gift makes a HUGE IMPACT in paying for Parkinson's support programs, exercise and wellness classes, resources, education programs, and research. As an Optimism Walk participant, you will help us celebrate our Parkinson's community as well as support APDA's mission to help

everyone impacted by Parkinson's disease live life to the fullest. You will find that fundraising is EASY when it is for such a great cause!

Team Captains will receive a Rally Pack in the mail that will help you grow your team, provide motivation to fundraise, and generate excitement for the event. Together we can make an impact!

On **October 1**, join us on the **Ship Canal Trail in Seattle**
– or – walk in your own town and/or neighborhood!

Don't live near Seattle but want to participate?
REACH OUT to Kirsten at krichards@apdaparkinson.org or 206-348-0213 and let's chat!

THE DETAILS



This year's Seattle Optimism Walk is an easy 1.5 mile down and back, starting and ending at our APDA parking lot. Walkers of all abilities are welcome and can turn around at any time!

It will be a carnival atmosphere, with poster making, face painting, games, and giveaways. Bring the whole family (friendly dogs welcome too)!



APDA Northwest OPTIMISM WALK

Saturday, October 1, 2022

Ship Canal Trail
180 Nickerson Street, Seattle

Opening Ceremony 11:00am

SIGN UP TODAY! bit.ly/NW2022Walk

WIN PRIZES!

Fundraising incentives:

Raise **\$100** for an **Optimism Walk t-shirt**

Raise **\$500** for an **Optimism Walk hat**

Raise **\$1000** to **join Circle of Optimism and earn a medal** (and your name will be read during the Opening Ceremony!)

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

WE WANT YOU ON 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. We truly want to make this year's Walk one where EVERYONE in our 5 state territory can participate! Our committee meets 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 Optimism Walk. *If you are interested contact Kirsten Richards at 206-348-0213 or krichards@apdaparkinson.org.*



GET CREATIVE!

Best team name wins a party package!

Creative team names from previous years: For Goodness Shake, Hike with Spike, Shake Rattle & Roll, Jan's Fans, Movers and Shakers, Dope-a-Team, Shaking not Stirred

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

**YES! I want to help provide the support, education, and research that will
help everyone impacted by Parkinson's disease live life to the fullest.**

Please clip and return with your check, made payable to: **APDA NORTHWEST**
and mail to us at **180 NICKERSON, SUITE 108, SEATTLE, WA 98109**

To donate by credit/debit card, please visit our website apdaparkinson.org/northwest or call **206.695.2905**

The Northwest Chapter of the American Parkinson Disease Association is a non-profit 501(c)3 organization. Our tax ID number is 13-1962771.



ENCLOSED IS MY TAX-DEDUCTIBLE GIFT OF: _____

My company _____ will match my gift. I will inform my employer that the
American Parkinson Disease Association, Northwest Chapter, is the match recipient.

Contact me with information on how wills and bequest can support the Northwest Chapter of APDA.

Donor's name _____ Donor's email address _____ Phone _____

Donor's address _____ City _____ State _____ Zip _____

This gift is given in honor of/in memory of _____ Please notify the above individual(s) of my gift

Honoree's address _____ City _____ State _____ Zip _____

***Thank you for
your generosity!***