

4 Get Outside!
Exercise Tips

6 Building
Care teams

8 Clinical Trials
in PD

PARKINSON *Pathfinder*

SPRING 2024

CELEBRATING **40** YEARS



**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.

SPRING 2024

TABLE OF CONTENTS

- 1 A Letter from the Executive Director
- 2 Looking for Ways to Improve Your Mental Health? VOLUNTEER!
Leah Frazier
- 4 Get Outside! Ideas to Safely Exercise Outdoors with Parkinson's Disease
Stephanie Babiarz, the Parkinson's Fitness Project
- 6 Building Bigger and Better Care Teams for People with Parkinson's: An Interview with Dr. Pravin Khemani
Lianna Marie
- 8 Clinical Trials in Parkinson's Disease: Who, What, Where & Why
Jen Gillick
- 10 Magic of Hope 2024: Raising Critical Funds to Support Our PD Community
- 13 Upcoming Events

Follow us on social media to stay connected!

 @apdanorthwest

 @apda_nw

www.apdaparkinson.org/Northwest

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.



NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

APDA Northwest
130 Nickerson Street, Suite 300
Seattle, WA 98109
Phone: 206.695.2905
apdanw@apdaparkinson.org
apdaparkinson.org/Northwest

APDA NORTHWEST
EXECUTIVE DIRECTOR
Kirsten Richards

PROGRAM DIRECTOR
Jen Gillick

MANAGER OF PROGRAM
AND COMMUNITY ENGAGEMENT
Katie Freeman, MSW

FUNDRAISING EVENTS MANAGER
Heidi Murdock

OFFICE COORDINATOR
Leah Frazier

REGIONAL DIRECTOR
Jean Allenbach

REGIONAL DIRECTOR OF
MARKETING & COMMUNICATIONS
Lianna Badran

BOARD OF DIRECTORS

PRESIDENT
Carl Carter-Schwendler

TREASURER
Sandra Ruedt

SECRETARY
Kathy Bray

MEDICAL DIRECTOR
Kimmy Su, MD, PhD

DIRECTORS
Suzanne Cameron
Leanne King Devitt
Cassidy Gannon
Brian Harris
Dwight Jones
Mary Schimmelman
Sreenivas Shetty
Takahiro Shigemitsu
Apurva Zawar



APDA Northwest is celebrating 40 years! Join me in reflecting on the past four decades.

1984

Pop music was in its heyday, and many of us were listening to new releases by Prince, Madonna, and Michael Jackson on cassette tapes and vinyl, although CDs were starting to gain traction. The top movie at the Box Office was Terminator, starring Arnold Schwarzenegger, imprinting "I'll be back" into our collective consciousness. Ronald Reagan was President. In local politics, Booth Gardner was elected governor of Washington a decade before he was diagnosed with Parkinson's disease.

In 1979, APDA laid the groundwork with a Parkinson's Information and Referral Coordinator housed at the University of Washington. Building on this foundation, a dedicated group of volunteers established a local chapter with the mission to raise funds, expand programs, and bolster support for the Parkinson's community. With an initial focus on Washington, services swiftly expanded to surrounding states. The chapter was run solely by volunteers until 2005, when the first paid Executive Director was hired.

2024

Presently, APDA Northwest operates with a team of five staff members spanning five states. Our commitment to addressing the increasing need remains unwavering. We still rely on our dedicated volunteers to provide essential support, education, and fundraising assistance.

In the past four decades, we have seen a surge in Parkinson's disease, now the fastest-growing neurological disorder, and the number of cases doubling since the mid-80s. Dopamine replacement therapy remains the mainstay treatment, but significant discoveries have been made in exercise, DBS surgery, focused ultrasound, gut microbiome, and gene therapy. Exciting research is underway, and APDA is proud to fund innovative and promising research into treatments and finding a cure.

Our mission remains clear as we look to the future: to provide unwavering support, education, and hope to everyone impacted by Parkinson's. Let's continue building bridges, cultivating connections, and igniting optimism for the road ahead.

Sincerely,

Kirsten Richards, Executive Director

PS: April is Parkinson's Awareness Month! APDA Northwest will be hitting the road to spread the word and educate the public about Parkinson's disease. Look for us at a retirement community near you. Want our Parkinson's Road Show to come to your community? Don't hesitate to give us a call and arrange a visit today!

Volunteering with APDA or the charity of your choice is a win-win since studies have shown that volunteerism reduces stress and increases positive, relaxed feelings by releasing – drum roll please – DOPAMINE!

To learn more about volunteering with APDA, read the article on page 2



Looking for Ways to Improve Your Mental Health? Volunteer!

By **Leah Frazier**,
APDA Northwest Office Coordinator

Heidi volunteering
at the Regatta



Pictured above (left to right): The check-in crew at the APDA Optimism Walk! Beth, Ann, Chuck, Mei, Alexa, and Amy.

HOW TO GET INVOLVED

Reach out and ask how you can join the ranks of APDA volunteers.

Contact Leah Frazier at **205-695-2905** or **lfrazier@apdaparkinson.org**

APDA Northwest would not be able to accomplish as much as we do without the many volunteers we are so fortunate to work with. The gift of their time, resources, and talents is immeasurable.

Here's a peek at some of our volunteers at work.

DID YOU KNOW THAT VOLUNTEERING has significant health benefits? Those who volunteer report an increase in both physical and mental health. Researchers have found that people who volunteer have lower rates of anxiety and depression. Additionally, these health benefits are felt even more by people over the age of 60.

Volunteering a few hours a week reduces stress, increases positivity, and leads to more relaxed feelings by **RELEASING DOPAMINE**. The National Library of Medicine has been studying the effects of volunteerism on a person's well-being. They go as far as to say that the physical health of people who volunteer is **"markedly"** better than their non-volunteering counterparts. Who knew?

Ask anyone who volunteers their time in the service of others, and they will give you the many reasons they choose to do so. You'll hear, "I love to give back" and "I like to make a difference."; those are universal. Since mental and physical health experts have been conducting extensive research on the benefits of volunteering, we can now understand the drive we often have to volunteer to help others. It's official: VOLUNTEERING IS GOOD FOR YOUR HEALTH.

Add the following benefits of volunteering to your own personal list:

- Your brain benefits from helping others (such as "helpers high," increased life satisfaction, slowing cognitive decline).
- Strengthens your connection with others (the physical and social health benefits of connecting with others are well documented).
- Provides a sense of purpose and meaning (puts life in perspective and builds empathy).
- Increases confidence (some volunteer activities require learning a new skill and provide a sense of pride and accomplishment).
- Increases employability (by gaining work experience, networking opportunities, and references).
- Combats depression (keeps you in regular contact with others and helps you develop a support system).
- Helps you stay physically healthy (it's estimated that volunteers have a lower mortality rate than those who don't).
- Prevents feelings of isolation (something we can all benefit from).
- Ignites your passions!

Volunteers from our Magic of Hope Gala, Kathy (left), and Linda



Ways To Volunteer at APDA

Did you know that you can volunteer as a family, team, or group? Whether it's two hours a month or three days a week, what you have to offer is needed by others!

Here are some of the ways you can volunteer at APDA:

- Event planning
- Board Member
- Leading volunteers
- Social media
- Writing publications
- Public relations
- Data entry
- Community outreach
- Leading a support group
- Grant writing
- Marketing
- Graphic design
- And more!

Don't see an area you'd like to help with on this list? Let us know, and we'll help you find an opportunity that matches your skills and passions with an area of need.



Clockwise from top left: Taylor, one of our college helpers offering much-needed admin support, volunteers helping prep for the Gala, and Thao and Karen

It's official:
Volunteering is Good for Your Health.

Get Outside!



Ideas to Safely Exercise Outdoors with Parkinson's Disease

By **Stephanie Babiarz, the Parkinson's Fitness Project**

With spring finally here, we are all eager to get back outside after being cooped up all winter. We already know all of the positive benefits of exercise for Parkinson's disease, so let's discuss how we can translate some of that exercise to the outdoors.

Living in the beautiful Pacific Northwest, our cities and surrounding areas have endless spots to get outdoors for a walk or hike. Doing so can be an excellent way to get some aerobic exercise and challenge your dynamic balance with varying surfaces, such as uneven sidewalks or trails.

A dynamic amplitude-based warm-up would be a great way to prime your body before getting outdoors. A simple routine of PWR! Moves (Parkinson Wellness Recovery) which includes weight shifting, big stepping, and active postural stretches may activate your body and make you ready to move BIG to optimize

your outdoor walk or workout. See image 1 for an example of a warm-up routine.

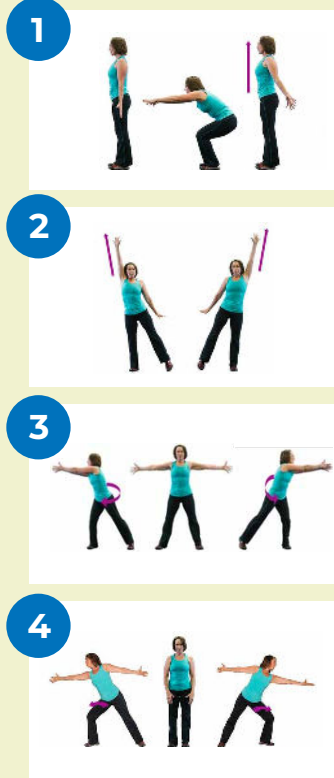
Another thing to consider is how to stay safe with different terrains. You may benefit from bringing along a set of trekking poles. Trekking poles have a variety of positive benefits beyond offering increased stability. Parkinson's can cause stooped posture and difficulty maintaining an upright posture for long periods, so actively using trekking poles will help you stay taller for longer!

Another symptom of PD is reduced or asymmetrical arm swing. Trekking poles will force you to continually move both arms by progressing the poles forward with each step. When performed correctly, they help you practice coordination with your opposite arm and leg moving simultaneously. Contact a physical therapist if you need guidance on how to fit or use your trekking poles properly while walking. They can help you learn how to use and fit all different types of assistive devices properly.

If you need more assistance to walk or have experienced falls in the past, then a paved path will be the best option for you. A great choice can be a local track if you live near a school. Often, the track is open to the public during certain times of the day, providing a great way to walk outside in a safer, more controlled environment. There are also ADA-approved trails throughout the Northwest.

Looking to do more than walk outdoors? Find an open space or a park bench, and you can do high-intensity

Dynamic amplitude-based warm-up:



training, including bodyweight strength push-ups, squats, hopping, and skipping for added amplitude! Other great activities you can do in an open field include tai chi or walking soccer to challenge your balance and coordination. See below for a list of more guided outdoor activities in the community that

cater to PWP or those with disabilities. Contact a physical therapist if you have more questions about appropriate outdoor exercises.

- 1. Outdoors for All Foundation.** Offer various outdoor recreational activities and events throughout the year for individuals with disabilities, including skiing, hiking, kayaking, cycling, and weekend trips.
Website: [outdoorsforall.org/programs/recreation-programs](https://www.outdoorsforall.org/programs/recreation-programs)
- 2. Pass to Pass - Adaptive Hiking.** Non-profit providing multi-day supported backpacking trips for individuals with PD all over the PNW region.
Website: [passtopass.org](https://www.passtopass.org)
- 3. Tandem Cycling class.** Weekly tandem cycling class that meets at Magnuson Park.
Phone: 206-461-5005
Email: customerservice@uwkc.org
- 4. Footloose Sailing Association.** Leschi harbor summertime adaptive sailing program
Website: [footloosedisabledsailing.org](https://www.footloosedisabledsailing.org)
- 5. The Parkinson's Fitness Project Field Day.** A fun summer outdoor event at Seattle U track with outdoor games and activities for PWP. Hosted by TFPF with PTs present to guide activities. Website: [theparkinsonsfitnessproject.com](https://www.theparkinsonsfitnessproject.com)
- 6. ADA Accessible Recreation:** At [Alltrails.com](https://www.alltrails.com) you can find an ADA accessible trail near you.
- 7. Walking Soccer Leagues:** Website: [wssa.org/League/WSASA/WalkSoccer](https://www.wssa.org/League/WSASA/WalkSoccer)

There are multiple ways to monitor your exercise to ensure you are putting forth the appropriate effort. A quick way to check in with yourself is to rate your effort with exercise on the Rate of Perceived Exertion chart (see above). Ideally, you are slightly breathless and working up a sweat (this would fall under

RPE Scale (Rate of Perceived Exertion)	
1	Very Light Activity Hardly any exertion, but more than sleeping, watching TV, etc.
2-3	Light Activity Feels like you can maintain for hours, easy to breathe and carry on a conversation
4-6	Moderate Activity Breathing heavily but you can still hold a short conversation. Still somewhat comfortable but becoming noticeably more challenging
7-8	Vigorous Activity Borderline uncomfortable, short of breath, can speak a sentence
9	Very Hard Activity Very difficult to maintain exercise intensity, can barely breathe and speak only a few words
10	Maximal Effort Feels almost impossible to keep going, completely out of breath, unable to talk, cannot maintain for more than a very short amount of time

the Moderate-Vigorous category on the RPE scale).

Another way people monitor their exercise progress is with an exercise diary that lists off the exercise, time, effort, and how they felt afterward; finally, some people like to monitor their heart rate (if not on a beta-blocker) and recovery using a smartwatch.

Hydration and sun protection are crucial non-exercise-focused things to consider when performing outdoor exercises. Make sure to bring along water to avoid dehydration and any symptoms associated with orthostatic hypotension, a common symptom of Parkinson's. People with PD also have a higher risk of skin cancer. Please wear either sunscreen or appropriate sun protective gear.

Are there increased benefits of exercising outdoors versus indoors? Research shows that outdoor activity, sometimes called "green exercise," improves feelings of revitalization and positive engagement. (1) All types of green exercise have also been shown to improve self-esteem and negative mood scales such as tension, anger, and depression. (2,3)

Apathy, defined as a lack of interest and enthusiasm, is a known symptom of Parkinson's. Thus, this positive effect on mood and motivation with outdoor exercise could be a great way to improve exercise compliance. In addition, simply being outdoors can boost your physical, psychological, and social health.

We look forward to seeing you outside!



Stephanie Babiarz, PT, DPT received her Doctor of Physical Therapy from Duke University in 2015. She has worked with people with Parkinson's Disease and other neurological diagnoses since beginning her career with Swedish Medical Center. Stephanie gained her PWR! certification in 2019 and has led PD group exercise classes as well as neurofitness and physical therapy sessions for PWP since then. She finds motivation from treating her clients daily and says, "My patients motivate me by the perseverance and strength they show every session."

Resources:

Thompson Coon J, Boddy K, Stein K, Whear R, Barton J, Depledge MH: Does participating in physical activity in outdoor natural environments have a greater effect on physical and mental wellbeing than physical activity indoors? A systematic review. *Environ Sci Technol.* 2011, 45 (5): 1761-1772.

Barton J, Hine R, Pretty J: The health benefits of walking in greenspaces of high natural and heritage value. *J Integr Environ Sci.* 2009, 6 (4): 261-278.

Pretty J, Peacock J, Hine R, Sellens M, South M, Griffin M: Green exercise in the UK countryside: effects on health and psychological wellbeing and implications for policy and planning. *J Environ Plan Manag.* 2007, 50 (2): 211-231.

Building Bigger and Better Care Teams for People with Parkinson's:

An Interview with **Dr. Pravin Khemani**

By **Lianna Marie**,
APDA Regional Director of Marketing and Communications

AS A CARE PARTNER FOR my mom, who had Parkinson's disease for 30 years, and a loved one of my uncle, who had PD for almost 20, I have been close to this disease for a long time. I've lived through the emotional roller coaster, witnessed the physical challenges, and seen firsthand the effects of many non-motor symptoms.

For those who are living with PD or caring for someone with this disease, you understand that every day with Parkinson's is different, and the longer you live with it, the more challenges you will face. Fortunately, with the right help and people around you, life with PD can be more manageable.

Over the past five years, I've been fortunate to get to know Movement Disorder Specialist Dr. Pravin Khemani, or "PK," as we call him. Every time I talk with him, I learn something new about Parkinson's. Last year, my uncle experienced Neurogenic Orthostatic Hypertension (nOH), which is low blood pressure upon standing. When he needed to be hospitalized for complications arising from nOH and a heart condition, PK was there to give me

some insight and guidance to help me and my family.

After my uncle's challenging ordeal, I learned about a talk that PK had done for APDA entitled "My Autopilot has Been Compromised: Understanding and Tackling Autonomic Dysfunction." In it, Dr. Khemani discusses dysautonomia, otherwise known as autonomic system dysfunction, and explains ways to manage nOH, constipation, lower urinary tract symptoms, and sexual dysfunction in PD. (If you haven't already watched this talk, I highly recommend you check it out at [YouTube.com/APDAnorthwest](https://www.youtube.com/APDAnorthwest).)

Many quotes from PK's talk stood out to me, but a key one was when he said, "*The autonomic nervous system is one of those very complex systems in the body that requires a team to come together to assist the patient and caregiver.*"

I wholeheartedly agree with the doctor, and this got me thinking about the often-understated importance of the Parkinson's care team. I asked Dr. PK if he'd answer some follow-up questions, and he kindly obliged.

Here is what the doctor had to say:

LM: In your clinic, what percentage of your patients have challenges with autonomic dysfunction? Generally, at what stage of PD are you noticing these challenges?

PK: Autonomic dysfunction is ubiquitous in Parkinson's. Typically, it worsens as the disease advances and occurs on a spectrum of mild to severe paralleling motor symptom progression. It becomes challenging to address autonomic dysfunction as pill burden increases and in the presence of other comorbidities such as cardiovascular disease, essential hypertension, and diabetes.

LM: You told me that you frequently see patients that have more than "just Parkinson's," meaning, as an example, they may have cancer in addition to PD. These two diseases (presumably) aren't related, but you have to treat PD in the context of having another

"This is very important to recognize: the neurologist cannot treat PD without effective collaboration with other doctors involved in the patient's care."

DR. PRAVIN KHEMANI

illness. I imagine that makes treatment challenging. Can you speak about that?

PK: Yes, *multimorbid PD*, a term for multiple disorders coexisting with PD, is more challenging to treat. For instance, if a patient has cardiovascular disease-causing blood pressure instability in addition to PD-causing neurogenic orthostatic hypotension, the movement disorders doctor has limited pharmacological treatment options as some medications used for the treatment of cardiovascular disease can worsen orthostatic hypotension.

LM: In your talk, you say to care for patients effectively, movement disorder specialists should have a list that includes a cardiologist, perhaps an autonomic expert, a gastroenterologist, and a urologist that they can refer patients to. Would you add any other specialists to that list? (ophthalmologist, etc.?)

"The fundamental role of the treatment of Parkinson's disease is to ensure that the patient and caregiver get all the support they need."

DR. PRAVIN KHEMANI

PK: This is very important to recognize: the neurologist cannot treat PD without effective collaboration with other doctors involved in the patient's care, especially in multimorbid PD, which we typically encounter in our clinics. In the above example, alerting the cardiovascular specialist or the primary care specialist about the patient's autonomic dysfunction would allow each provider to judiciously select medication that would address each disorder effectively without worsening the other.

Similarly, certain medications of the anticholinergic class can improve bladder symptoms but worsen cognition and autonomic dysfunction; therefore, communication with the urologist is essential.

LM: Of those specialists you mentioned, is there one you'd say should be at the top of the list? In other words, which one do you find is most often needed by PD patients?

PK: I believe a primary care physician knowledgeable about PD is the best ally a neurologist can have. Specifically, for autonomic dysfunction, collaborating with a cardiovascular and urological specialist aware of autonomic problems in PD can be helpful to the patient.

LM: Do you currently have a list (even if small) of specialists you refer your patients to in the Seattle area? If so, who does the list include?

PK: Fortunately, I work with the Swedish Medical Group, which has a network of stellar specialists who can collaborate with the neurologist to care for PD. We also have regular educational forums, such as the annual Neurology update and grand rounds, which are instrumental in spreading awareness of PD in the physician community.

Sometimes, we turn to APDA to look for community specialists closer to the patients, as traveling to Seattle is not feasible for all patients. However, unfortunately, the demand for specialists versed in the nuances of PD treatment far exceeds their supply. Therefore, continuous education is critical.

LM: Suppose a patient is in the hospital with complications from nOH (like my uncle with PD was). What is your advice to his family for him to get the best treatment possible?

PK: Caring for a hospitalized PD patient requires a special skill set, not only among nurses and other hospital staff but also the hospitalist providers.

The first step would be to engage a neurologist who knows PD management and advises the hospital team on which medications should be avoided. Metoclopramide for the gut, routine antipsychotics for psychosis, and other anticholinergics that are commonly prescribed in the hospital should be avoided in PD as they can worsen symptoms significantly.

The neurologist can also advise on pharmacological and nonpharmacological measures to treat nOH; the hope is the hospital providers will be open to these suggestions.

The caregivers can speak with the head nurse on the floor and give them educational materials designed by the APDA to treat nOH in the hospital. The nurses are the patients' best advocates; therefore, caregivers should not hesitate to communicate with them regularly.

The long-term goal is to have evidence-based training modules designed by organizations such as the APDA in collaboration with movement disorders specialists to be made available to all

hospital staff and providers caring for PD patients. Dr. Rebecca Gilbert (APDA Chief Mission Officer) and I are designing such a module for PD education in the community.

LM: What can APDA do to help fulfill its mission of making patients the center of care?

PK: APDA has been constantly engaged in forwarding care for PD through health literacy programs and publications such as the *Pathfinder*.

You have an excellent chapter in the northwest that has been tirelessly educating and advocating for patients and their caregivers for decades, which has helped us neurologists better care for our patients in the clinic. I am privileged to be involved with the APDA.

I hope we can design both live and virtual educational platforms for the non-neurologist providers taking care of PD patients because knowledge and collaborative care are essential for improving patients' and caregivers' quality of life.



Lianna Marie served as her mother's caregiver and advocate for over 20 years through the many stages of Parkinson's disease.

She serves as APDA's Regional Director of Marketing and Communications, and founded AllAboutParkinsons.com, an online community that has connected and helped thousands of people with the disease, their families, and their caregivers.



Dr. Pravin Khemani is a Movement Disorders Specialist at Swedish Medical Center in Seattle, WA and is fellowship trained in both Neuromuscular Disorders and Movement Disorders.

Dr. Khemani's philosophy of care for movement disorders it to adopt multidisciplinary approach and closely collaborate with the patient, family and other caregivers.

Clinical Trials in Parkinson's Disease:

Who, What, Where & Why

By Jen Gillick,
APDA Northwest
Program Director

If you live in the Northwest, you don't have to travel far (and sometimes not at all) to participate in Parkinson's disease (PD) research. Several research centers are conducting exciting, cutting-edge research and offer different ways in which you can get involved. Here's all the information you need to get started!



Why should I participate in a clinical trial?

Improving our treatment of Parkinson's depends on conducting clinical trials to collect information about PD patients and test potential new medications and procedures. Current treatment methods for PD are only available because of volunteer participants in clinical trials. Your participation will allow you to have firsthand experience with developing new medical treatments that may benefit others.

Who is eligible to participate in a clinical trial?

There are varying qualifications for any given trial. Some require participants to be of a certain age or stage of PD, while others require you to be experiencing specific symptoms of the disease. As all studies vary in qualification, you will have to refer to the trial conductor to participate. Some trials ask that you complete a survey, while others have you contact the trial conductor directly.

What types of clinical trials can I join?

There are many types of clinical trials, mainly divided into two large categories, with both types taking place at research institutions in the Northwest.

Observational Clinical Trials

In this type of trial, a new treatment is not tested. Instead, the trial carefully observes a particular aspect of the disease to learn more about it. These trials may require donating blood or other specimens, including spinal fluid, urine, or stool. Gene testing, imaging, neuropsychological testing, and questionnaires may all be components of an observational trial.

Interventional Clinical Trials

In this type of trial, a new treatment is tested to see if it either improves a particular symptom of PD or is neuroprotective and acts to slow down the course of PD. The intervention can be an exercise or therapy regimen, cognitive therapy, medication, surgery, or any other procedure. People without PD can often participate as well (e.g., family members), especially in observational trials, which typically collect the same information from both a PD population and a non-PD population to compare the results.

Where can I get involved in clinical trials?

Whether through national or regional organizations, many clinical trials are available for people with PD. Here's a list of trial opportunities and contact information to get you started.

Your neurologist can also be a great source of information regarding research projects near you.

What is the WPDR?

The Washington State Parkinson's Disease Registry (WPDR) – Washington State and Beyond

Funded entirely by APDA, this resource is unique to the Northwest and is helping research happen faster. Those people interested and willing to be involved in PD research answer some questions about themselves and get enrolled into a database. That database can then be queried by local PD researchers who are looking for participants in their research studies. Participant information is kept securely and updated annually, making it a valuable and easy to use resource to local researchers. Enrollees to the WPDR don't even have to live in Washington to join.

JOIN TODAY AT:
registerparkinsons.org
888-365-9901

National Websites:

clinicaltrials.gov

Hosted by the National Institutes of Health (NIH), this directory lists all clinical trials, past and present, for all conditions and can be searched for trials that specifically address PD.

clinicaltrials.gps.com

This National clinical trial guide allows you to search by zip code to find a study near you. Specific study and contact information are included.

michaeljfox.org/trial-finder

A resource run by the Michael J. Fox Foundation. Both people with PD and clinical trials can register on the site, and the Trial Finder matches willing participants and trials.

APDA as a resource

apdaparkinson.org/research/clinical-trials

Several nationwide studies are listed on the website, complete with detailed information on where and how to get involved. This page is also a great resource to learn more about getting involved in research, including some helpful webinars and interviews with research participants. You can also learn more about APDA-funded research projects and our Centers for Advanced Research.

Northwest Resources:

Evergreen Health

Kirkland, WA

As of printing, six different clinical trials were enrolled at EvergreenHealth.

evergreenhealth.com/health-services/clinical-trials/find-a-clinical-trial

✉ evergreenresearch@evergreenhealthcare.org

☎ 425.899.5385

Inland Northwest Research

Spokane, WA

As of printing, eight different clinical trials were enrolled at Inland Northwest.

■ inwresearch.com/parkinsons-disease

✉ contact@inwresearch.com

☎ 509-960-2818

Oregon Health Sciences University

Portland, OR

As of printing, seven different clinical trials were enrolled at OHSU.

■ ohsu.edu/brain-institute/patients-parkinsons-disease-research

✉ PDresearch@ohsu.edu

☎ 503-494-8881

University of Washington & VA Puget Sound

Seattle, WA

Both of these teaching hospitals have a variety of on-going research studies. The best way to get involved and notified about these opportunities is by joining the WPDR. (see sidebar, left)

Questions to Ask the Trial Coordinators

- What have previous studies shown about the safety and effectiveness of the new treatment?
- What are the most common adverse effects seen with use of this treatment?
- How will the treatment team monitor me for adverse effects?
- Is there anything in my medical history that puts me at higher-than-average risk in this trial?
- What will I need to do during the trial, and how long will the trial last?
- Will I have to travel to a different medical center for participation in the trial? Are those costs covered?
- What are the chances that I will receive a placebo in this trial?
- Who should I contact if my condition worsens during the trial?
- Will I be able to continue on the new medication (or begin it, if I received a placebo) after the trial is over?



The Magic of Hope Gala and Auction was held on Saturday, March 2nd, where over 300 guests mingled, celebrated, and gave generously!

This year's event raised \$595,000, which will pay for vital support, education, resources, and research.

HONOREE

Diane Bundrant and Trident Seafoods



At this year's event, we honored **Diane Bundrant and Trident Seafoods** for their longstanding and generous support of APDA, demonstrating a commitment to implementing creative solutions for the betterment of the Parkinson's community.

Diane, alongside her late husband Chuck Bundrant, founder of Trident Seafoods, has been a dedicated supporter of APDA for many years. Their introduction to APDA began when Trident fisherman and close friend Chris Jewell was diagnosed with Young Onset Parkinson's in 1998, and soon after, they began supporting APDA.

After Chuck was diagnosed with Parkinson's disease in 2006, a diagnosis later revised to Progressive Supranuclear Palsy, an atypical parkinsonism disorder, their involvement with the local Parkinson's community and APDA increased. Together,

Chuck and Diane inspired their Trident Seafoods family to give to philanthropic causes through their annual employee giving campaign, Adopt-a-Cause, and APDA was one of the beneficiaries.

Diane and Trident employees Jessica McNeil-Clapp and Jane Biel played pivotal roles on the Captains for a Cure fundraising committee in 2019. Their dedicated efforts included donating their time and well as leveraging extensive connections for sponsorship, VIP attendees, and auction items. The Trident Fish & Fin food truck even played a role in catering for the event.

Diane and Trident's big-heartedness extends far beyond, from again donating the salmon many enjoyed throughout the night to letting APDA use their property for Adventure Races and generously supporting APDA with annual contributions.

We are grateful to Diane Bundrant and Trident Seafoods for their exceptional support and contributions to APDA and our Parkinson's community.

OPTIMISM AWARD

Optimism Award winners exemplify the APDA tagline of "Strength in optimism, hope in progress" by having a meaningful impact on the Parkinson's community through support, education, wellness, and/or research. The Optimism Award celebrates people who are demonstrating optimism through their important contributions to the Parkinson's community, and providing inspiration and hope for all that can be achieved.

This year we had two categories: one for Community Members and one for Service Providers.

Deb Ivancovich

Optimism Award Winner - Community Member



For over 25 years, the Parkinson's disease community in Bellingham and Whatcom County has been privileged to know and learn from Deb Ivancovich.

Deb was introduced to her local PD community while working on her bachelor's degree in counseling. She learned about a small support group

for people with Parkinson's. The plan was to work with the group for six months as part of her degree work. Over two decades later, Deb has grown the group to a thriving monthly meeting that has supported hundreds of people with Parkinson's and their care partners.

As a respected private practice mental health counselor and adjunct faculty teacher for Trinity Western University in British Columbia, Deb brings her knowledge, positivity, and facilitating skills to serve the needs of those affected by PD. She devotes countless hours to making the group feel comfortable sharing their struggles and helping them feel empowered without taking the limelight herself.

In addition to facilitating this support group for over 25 years, Deb's compassion and concern for her PD community go above and beyond. One example is helping several members of the group over the years with transportation to the meetings after they lost the ability to drive.

Living with Parkinson's is a challenging road, but Deb's help and support have made life for those who are on it easier. Members of this thriving support group rave about Deb's optimism and genuine love for them.

"She is so refreshing that I forget I have Parkinson's disease when we are together."

"Deb's optimism has made the world of Parkinson's disease sufferers not one of adversity, but one of hope."

Bill and Nadean Meyer

Optimism Award Winner - Service Provider



Before his Parkinson's diagnosis, Bill Meyer had always been active outdoors, enjoying hiking, rafting, skiing, and fishing. As the disease progressed, his tremors and balance got worse, and hiking became increasingly difficult, especially carrying a heavy backpack over his Deep Brain Stimulation (DBS) batteries.

Determined to keep hiking and share his love for the outdoors, Bill took matters into his own hands and created a supportive hiking experience and founded an organization that he named PasstoPass. Since 2016, PasstoPass has provided multi-day supported backpacking trips for people with Parkinson's (PwP).

Trips are planned and led by PwPs or people with close connections to PD so that routes, trails, and distances are selected with the physical challenges of participants in mind. Support hikers help on the trails and in camp, and pack llamas carry gear so that Parkinson's hikers only have to carry a light day pack.

Nadean Meyer has been Bill's foundation and strength to achieve his goals with PasstoPass. She is always in the background doing paperwork, accounting, logistics, transportation, etc. Nadean's commitment, efforts, and labor of love have been pivotal in making PasstoPass so successful.

Since its inception, PasstoPass has offered 34 backpacking trips involving 174 Parkinson's hikers and 115 volunteer support hikers. In addition to logging over 10,000 cumulative miles, PasstoPass has helped PwPs in the Northwest and across the country experience the joy of being outdoors while challenging themselves, building confidence, and camaraderie with others. All experiences are free of charge.

"It's not only the trip itself, but meeting everyone else on our trips that has been wonderful. We have made friendships with other people impacted by Parkinson's from other parts of the country. And those relationships, too, have made our lives with Parkinson's easier."

Thank you to our generous sponsors

PREMIER:



SILVER:

Greg & Beverly DiMartino

Enviro-Tech Diving

Gobo Enterprises

Matson

Mirabella

University of Washington

PLATINUM:



GOLD:



More scenes from the party!



Resources for those New to PD.



PD Essentials is a program designed for anyone with little knowledge about PD (or those wanting a refresher). It is perfect for those new Parkinson's disease including friends, family and interested community members. The program is both a way to educate and a way to raise awareness about the fastest growing neurological disorder in the world.

APDA Northwest offers PD Essentials once per month. Join us virtually or in person for one of our upcoming sessions. <https://www.apdaparkinson.org/community/resources-support/newly-diagnosed-programs/>

Want to bring an in-person PD Essentials Course to your community?

Contact Jen to discuss 206-595-4478; jgillick@apdaparkinson.org



Spring Session of the popular PRESS program is now enrolling:

Virtual Program:
Tuesdays 12:00pm – 1:30pm PT
May 14 thru July 2, 2024
On Zoom

Designed for people diagnosed with Parkinson's disease within the past 5 years, this 8-week program will help you feel empowered, in control, and optimistic about your future with PD. Group size is limited. Care partners and family members encouraged to attend as well.

Save the Date!



Save the Date
A FUNDRAISING RACE
THURSDAY, JUNE 6, 2024
ELLIOTT BAY MARINA



RACE: 7:00 PM | PARTY: 7:00 - 10:00 PM
Online Silent + Live Auction Raffle Live Music Food & Drinks

benefitting: hosted by:



**SUBSCRIBE TO OUR
NEWSLETTER!**

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

April is Parkinson's Awareness Month



HELP SPREAD THE WORD!

Share your story. It is important to let people know how Parkinson's impacts your life. Discuss meaningful articles with friends and family, and share APDA social media posts.



ADVOCATE FOR PARKINSON'S.

Your voice is powerful, and it is important to urge your legislator to support the End Parkinson's Act. Learn more at michaeljfox.org/advocacy



CONNECT APDA TO A COMMUNITY GROUP.

Facilitate a learning opportunity by connecting us to your retirement community, or a leader at your church, Rotary, Elks, etc. (contact 206-695-2905 or apdanw@apdaparkinson.org to discuss).



STAY CONNECTED WITH PD RESEARCH.

Sign up for the Washington Parkinson's Disease Registry at registerparkinsons.org. Northwest residents outside of WA are welcome.



SUPPORT YOUR LOCAL PARKINSON'S COMMUNITY WITH A GIFT.

Make a donation at apdaparkinson.org/nw to help pay for support, education, and research.