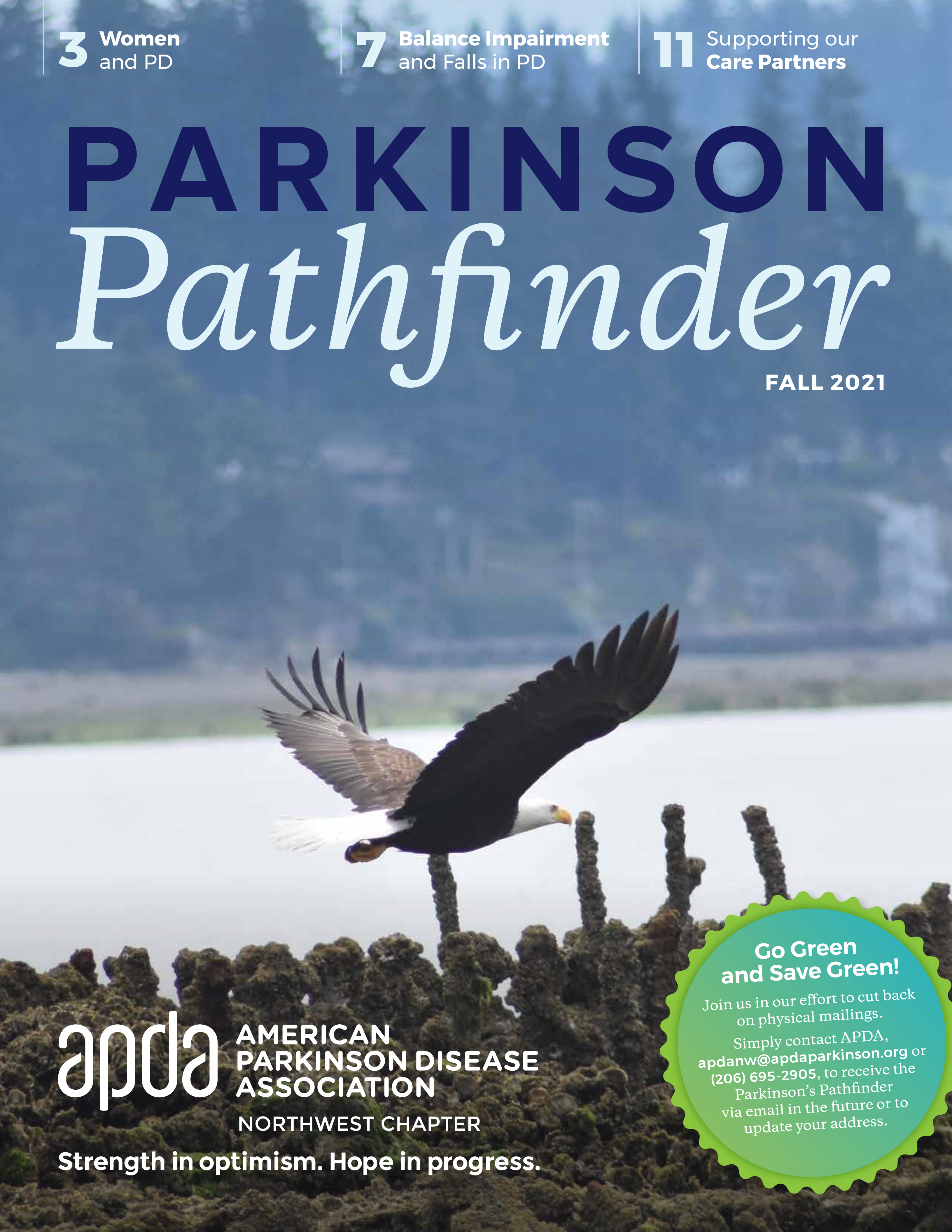

PARKINSON *Pathfinder*

FALL 2021

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.

apda AMERICAN PARKINSON DISEASE ASSOCIATION
NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

FALL 2021

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Strength in optimism. Hope in progress.

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PROGRAM DIRECTOR
Jen Gillick

DIRECTOR OF DEVELOPMENT
Kirsten Richards

COVER
Photo by Dustin Werner

APDA Northwest is run by hundreds of people. WHAT?! Yes, hundreds of people, but those people are not paid staff members, but volunteers. Volunteers are the visionaries in the community that make things happen: the leaders, the doers, the army of fundraisers, event planners, and mission delivery experts. This is how - with only a staff of three - APDA Northwest delivers vital services to people living in Alaska, Washington, Oregon, Idaho, and Montana.

We are always looking for community volunteers. If you would like to share your skills, know-how, and passion with us, we'd love to hear from you. Our needs are constantly changing! Here are just a few of the roles we are currently looking to fill:

- People with the expertise and connections to identify community needs and expand our services to meet those needs by serving on our Programs Committee
- Committee members for our Optimism Walk that can help grow the Walk in Seattle as well as people living in OR, ID, MT, AK and areas outside of Puget Sound to lead and recruit groups to participate throughout our five-state territory
- Magic of Hope Auction committee members to help with sponsorship, procurement and logistics
- Representatives to serve as APDA ambassadors in Alaska, Idaho, Montana, Oregon and Eastern Washington
- People who have the skills and relationships to help us diversify our income streams, such as grantwriting, estates and planned giving, and major gifts
- Tech/video experts that can help us with hybrid educational programs in 2022, so in-person programs can also have a live stream element

I'd like to introduce you to some of our amazing volunteer Board members!

On why they like volunteering...

Carl Carter-Schwendler

Roles: APDA Board President, Speakers Bureau

I like volunteering because it keeps me involved with the Parkinson's community. For several years after I was diagnosed with Parkinson's I largely faced it alone. My family was a great source of support, but I didn't really know anybody else with Parkinson's. Volunteering with APDA helped me connect with other people with Parkinson's and made me realize that we weren't powerless in the face of this disease.

Sandi Reudt

Role: APDA Board Treasurer

I like volunteering for APDA because the quality of the people (staff and volunteers) makes me happy to commit my own resources as well as to be comfortable encouraging others to contribute to this great organization.

Laurie Thompson

Role: APDA Board Secretary, Magic of Hope Committee Member

When it comes to volunteering with APDA, I've been really impressed by the passion for our mission and the strong desire to make a difference for individuals and families impacted by PD that I've seen from other volunteers, our staff and the Board. I also appreciate that APDA is always working to improve our programs, and especially in this time of quarantine and social distancing even expanding the number of individuals we are able to serve. As a donor and volunteer, I like the confidence I have that my giving is used very thoughtfully, and I see the staff work every day to keep costs down while funding more research and serving more individuals and families. Finally, everyone I've met and volunteered with has been fun and it really is a wonderful group of people working together!

Dwight Jones

Roles: APDA Board Member, Speakers Bureau

I enjoy being involved with APDA because of the great community they represent. The staff, board, and everyone associated with APDA are the most wonderful, giving, and positive people. Their infectious energy and bottomless optimism is invigorating to be a part of.

Brian Harris

Roles: APDA Board Member, Optimism Walk Committee Member, Office Volunteer, SEAYOPD (Seattle Young Onset PD) Activity group leader

Volunteering gives me strength to be doing something positive to improve the lives of people with Parkinson's.

Suzanne Cameron

Role: APDA Board Member, Magic of Hope Committee Member

After volunteering with APDA NW FOR 23 years, I am still inspired by the strength and resilience of the people with Parkinson's who we serve. I have seen how our efforts have resulted in improvement and hope for patients and families. I have also made deep and lasting friendships with other volunteers.

Mary Schimmelman

Role: APDA Board Member, Magic of Hope Committee Member

The Parkinson community is a group of smart, friendly, motivated personalities who each keep an individual passion for supporting and helping their loved ones living with Parkinson's. Everyone I have introduced to the APDA extended family comments on the warm and welcoming people they meet who really care about making a difference. And all of the events are really fun, even over zoom - it's a fun-loving group!

Traits they look for when recruiting new volunteers...

Steve Palmer *Role: APDA Board Member*

When recruiting new volunteers I look for a "whatever it takes" approach, from executive and leadership skills to a willingness to make donor appreciation calls.

Shaheen Kaplan

Roles: APDA Board Member, Speakers Bureau

When recruiting new volunteers I look for someone with passion, compassion, organization skills, networking skills, collaboration; being able to build partnerships and relationships.

Dr. Pravin Khamani, MD, Movement Disorders Specialist *Role: APDA Board Medical Director*

When recruiting for volunteers I look for communication, integrity, optimism, belief in and commitment to APDA's mission, individuals who are action oriented, responsive and connected with our community.

Takahiro Shigemitsu *Role: APDA Board Member*

The volunteer traits that I look when recruiting for are diversity (ethnicity, cultural background, gender, age, etc.), and connections to Parkinson's.

Leanne King-Devitt

Roles: APDA Board Member, Magic of Hope Committee Member, PD Support Group facilitator

The traits I look for in a volunteer really varies with the needs and the gifts different people have. I look toward diversity of experience and the ability to expand our outreach to the wonderful variety of cultures and communities we have here in the NW.

Ready to join this amazing group of volunteer leaders?

Contact Jean Allenbach at **jallenbach@apdaparkinson.org or call 206-550-0444.**

WOMEN & PD

I am a member of a group, a small select group. It's not a group you plan to join, you see I am a woman with Young Onset Parkinson's disease. Parkinson's disease (PD) has traditionally been viewed as an "old man's disease." Diagnosed with this disease at age 48 I did not fit the typical picture of PD and it has taken me some time to learn to negotiate this niche. Prior to my diagnosis I was working as a Nurse Midwife in a large urban hospital and had delivered over 800 babies.

My dad had PD and so did two of my uncles. All of them were diagnosed later in life. I knew a lot about the disease. What I did not know was that the disease might manifest differently for me, because I am female. I also learned that it might be different working with my health care team as a female and I might need to learn optimal communication strategies to best meet my needs.

Although we do not know the cause of PD, we have learned that it may present differently for men and women. Women report more non-motor symptoms and have more dyskinesias. We may have more fog brain and mood disorders. Our medications may not work as well the week before or during our menses. The gold standard medication for treating PD, carbidopa/levodopa, has been around for over 60 years and was only tested on male subjects in clinical trials. The dosing and effects have never been studied in women.

I have found that it helps me manage my experience to seek knowledge, communicate clearly, and keep up to date on what is happening in the PD community. As a health care provider, I have learned that many people do not report symptoms because they feel like they are complaining. They put their best foot forward when seeing their providers. If we, as people with Parkinson's, do not bring to the attention of our providers what is happening in our bodies we cannot expect them to read our minds. That includes discussing if our periods or fluctuating hormones during perimenopause are impacting the efficacy of our PD medications. We must start talking about it and providers must start asking about it.

There are many tools available if you need some guidance about what to discuss at your doctor visits. Maintaining an ongoing list of things that you want to discuss at appointments is important, you might consider printing a copy for your provider before your appointment to help them know what you want to discuss. You can encourage your care partner to also add to the list before your appointment.

Secondly, it is important that we be seen and treated as a whole person. For many, our PCP (primary care provider) can help to figure out the big picture and who may be best able to help with specific symptoms, and then make referrals or recommendations. For example, I have several challenges with my PD. My hand dystonia and tremors are treated best by my neurologist with botox injections and medication (Sinemet). For pain, I find that a massage therapist helps a great deal and occasionally I use a muscle relaxant medication prescribed by my primary care. Physical therapy and occupational therapy have been helpful at times. I also see a counselor for anxiety.

As consumers of healthcare, we employ our team to give us their expert advice. We pay them, or our insurance does, to guide us. Ultimately, however, the decision to take or not take the advice given lies solely with us. We take in all the information, and we have the absolute right and responsibility to ourselves to make the decision that feels right for our unique situation.

> Ultimately, I know it is my journey to navigate and I steer my ship. **I cannot control Parkinson's disease; I can only control my reaction to it.** I plan to live a long and engaged life and will focus on maximizing my health and well-being.

It is also OK to try new things and decide it is not the right fit. This includes the medications that we use. Medication can be a double edge sword. Sometimes, the benefit from a medication may be overpowered by its side effects. For me, this proved to be the case with a dopamine agonist. It worked great to help with stiffness but over time as I needed more medication to treat progressing symptoms, impulse control around food lead to weight gain and insomnia. I discussed the issue with my MDS (movement disorder specialist) and decided to taper off the medication and add more Sinemet. It was a tradeoff. I still have more stiffness than I'd like, but I sleep much better and have better impulse control.

I talk to many who feel that they can never stop something that they start. Sometimes it is important to give yourself permission to try new approaches if you are not feeling well or trying to treat a new symptom. Stopping some medications without a taper can be dangerous so it is important to always consult your provider.

Research is finding that individualized care is likely the best way to help us all feel better when navigating a chronic illness. In the center of this model is the patient. To make this model effective we must be aware of our own journey, speak up for ourselves at our appointments and be proactive. This means that it is not only all right but *expected* that you call, email or text your provider (or their nurse or assistant) if you are not getting relief with something new you are trying. Historically, women have been seen as less able to communicate rationally, especially around times of fluctuating hormones. The fact is that hormones do impact our bodies and therefore can also impact any treatments we are using for our PD. We are not being "hysterical;" reporting that our medicines don't work makes us strong.

It is not common practice for neurologists to discuss female hormones and therefore, it is important that we as women DO. Tracking your symptoms and your menstrual cycles is important and can be done digitally on your phone (there are multiple apps available). Having this information available for your neurologist and PCP can be useful to look at trends and perhaps even change dosing around hormonal events.

As a young woman with Parkinson's, I have learned to be the captain of my healthcare team. I own my healthcare decisions and I speak to both my primary care and my neurologist if I am finding new challenges. I look to my husband, providers, the YOPD (young onset PD) community, and PD organizations like APDA for information about new treatments and what is effective for me. Ultimately, I know it is my journey to navigate and I steer my ship. I cannot control Parkinson's disease; I can only control my reaction to it. I plan to live a long and engaged life and will focus on maximizing my health and well-being. I know that attitude is a huge factor in doing well, and I work daily to have a positive attitude with gratitude for being alive.

KAT HILL is from Portland, Oregon USA . She believes that we can choose joy in our lives no matter what we are faced with. Movement, mindfulness and gratitude help her navigate the challenges of living with Young Onset Parkinson's disease. After her diagnosis at age 48 she was forced to end her career as a nurse midwife after delivering over 800 babies.

Now she is an author and advocate for finding wellness despite a diagnosis. She speaks around the world literally and virtually for the World Parkinson Congress and The Davis Phinney Foundation and also is a co-founder of the Women's Parkinson's Project. Her co-authored book, currently titled *Being Well*, will be out in Summer of 2022 with Hatherleigh Press. She also hosts the podcast PD Lemonade on Apple iTunes and Spotify. You can find her at **www.kathill.org**

MENOPAUSE & PD:

An Interview with APDA Researcher Dr. Roberta Marongiu

DR. ROBERTA MARONGIU is an Assistant Professor of Neuroscience at Weill Cornell Medicine in New York City. Dr. Marongiu received an APDA research grant in 2018 to understand the brain mechanisms that influence the differences in the onset and course of Parkinson's disease (PD) between men and women. Pre-menopausal women have about a 2-fold reduced risk of developing PD as compared to men and post-menopausal women of similar age. Early menopause, either natural or surgical, is associated with an increased risk of PD. Menopausal women who had received estrogen are less likely to develop PD than those who had not. This suggests that gonadal hormones play an important role in protecting against PD. However, the mechanisms underlying the protective role of gonadal hormones, especially estrogen, against PD progression remain unclear.

Dr. Marongiu is using a mouse model of PD with high levels of alpha-synuclein in the substantia nigra, and characterizing the effects of inducing menopause on PD pathology and clinical manifestations. The proposed work will help to clarify the ways in which hormones influence PD onset and progression. A better understanding of these underlying molecular mechanisms can lead to better treatments and a cure for PD.

APDA is very selective and strategic in our research funding, and we are proud to support some of the brightest researchers who are at the forefront of this disease. We are excited about Dr. Marongiu's current work and have asked her some questions so you can learn more about the work APDA is making possible.

Q: What is the overarching goal of your research? What do you hope to find out?

A: The overall goal of my research is to understand the contribution of menopause transition (peri-menopause) on the onset and progression of PD in terms of pathology (alpha-synuclein accumulation, substantia nigra neurodegeneration, chronic inflammation) and motor dysfunction.

Our hypothesis is that peri-menopause accelerates the onset and progression of PD, and this should be reflected in early motor deficits and more severe pathology in our female mouse model of menopause compared to pre-menopausal females, and similar to what we would expect to observe in male mice.

With a novel multidisciplinary approach, our work is the first to study the influence of perimenopause on PD progression, and an important step in the identification of its underlying molecular mechanisms.

Q: Could you describe how you perform your studies?

A: I use two novel mouse models. The first one is the mouse model of PD generated by injecting the gene for human alpha-synuclein into the substantia nigra of the mouse - specifically in the dopaminergic cells that are usually lost in human PD. This leads to accumulation of alpha-synuclein in the substantia nigra which can cause neurodegeneration and motor deficits. The second one is the innovative model of accelerated ovarian failure (AOF), induced by injecting low doses of a toxin into the mice that can model the transitional process seen in human menopause.

After inducing AOF in our PD mice, we measure the extent of motor deficits over time in three tasks that measure spontaneous motor activity. At the conclusion of these tests, we study the mouse brains to measure the accumulation of alpha-synuclein, the extent of nigral neurodegeneration and the chronic inflammatory response. These measurements are correlated with the extent of motor symptoms observed in the mice.

Q: Can you tell us a little bit about what you have found out so far?

A: The first phase of our study was to develop our mouse model of PD by injecting alpha-synuclein into the substantia nigra. The generation of this model is an important step for our research as it allows us to study the effect of AOF on neuronal damage in the substantia nigra.

We use our PD mouse model in combination with AOF to quantify the influence of AOF on PD pathology and motor deficits. These data will allow us to better understand the role of menopause transition on the susceptibility of a female's brain to PD.

Our data shows that, similarly to male mice, menopausal female mice with PD develop early motor deficits compared to pre-menopausal females. Additionally, these findings correlate with increased dopamine neurons degeneration in menopausal females respect to non-menopausal female mice.

We are currently analyzing the brains of PDmice with menopause to quantify the degree of nigral alpha-synuclein accumulation and inflammatory response compared to male and pre-menopausal female mice with PD.

Q: What fuels your passion for research?

A: My passion for research was always driven by the desire to help people and find a cure for devastating brain disorders. Specifically, I dedicated my career to studying pathways and molecules involved in PD pathogenesis with the goal of identifying targets for the development of drug or gene therapies for the disease.

Moreover, the interaction with PD patients through my non-profit organization stopPD (Support and Training to Overcome Parkinson's Disease; www.stop-pd.org) inspires my research ideas and encourages me to keep my research focused on the issues that are most debilitating for patients.

Q: You also have a second calling as a PD Boxing coach. Can you tell us about that endeavor?

A: I co-founded the non-profit organization called stopPD with my husband, Alex Montaldo, with the mission to create and provide innovative complementary programs to improve the quality of life for people with PD. Our first program was focused on non-contact boxing and high intensity exercise. We are currently collaborating with the New York University Drama Therapy department, Fresco Institute for Parkinson's Disease, and a private company called Neurostorm Studios on a theater program toward the goal of improving speech, cognition, and spatial awareness in PD patients. It's important to me to help people who are currently dealing with PD, while we strive to find a cure for this devastating disorder.

Ways to Give:

Let's Talk Stock

	STOCK DONATION	CASH DONATION
Combined Fed + State income tax rate	40%	40%
Tax rate / tax amount for selling this stock	n/a	20% / $1,600 (0.2 x $8,000 gain)
Net amount to donate	$10,000	$8,400
Tax Savings	$4,000	$3,360

The stock market has been boasting record highs and an increase in capital gains tax rates may be coming. If you hold meaningful amounts of appreciated stock, itemize deductions on your tax return, and are charitably inclined, donating stock instead of cash can be a smart tax-planning move.

Here's why. Suppose you have the choice to 1) donate $10,000 in stock held for more than one year, or 2) sell the stock and donate the proceeds. You originally purchased the stock for $2,000, so you have a potential gain of $8,000. In this example, you have a 40% combined federal and state tax rate on your income, and a combined 20% tax rate on capital gains.

You see how you can make a bigger impact by donating stocks directly to a nonprofit (the same goes for donating other appreciated assets, like mutual funds or bonds). This donation not only allows you to be very tax-efficient with your charitable giving by potentially avoiding any capital gains tax, and the nonprofit organization also benefits by receiving a larger gift!

We have recently received stock donations of Apple, Starbucks, and Boeing shares. This was a win-win for both APDA and our generous (and tax-savvy) donors! If you are considering a gift of stock, please contact APDA and we will provide delivery instructions for your broker to make this a seamless transaction.

BALANCE IMPAIRMENT *and* FALLS *in* PARKINSON'S DISEASE

One of the most challenging symptoms of Parkinson's disease (PD) that fundamentally affects quality of life is balance impairment that can lead to falls.

Falls are one of the major causes of emergency room visits and hospitalizations for people with PD, so finding ways to prevent as many falls as possible is a high priority. Thankfully there are things you can do to improve your stability and decrease the likelihood of falling, and we'll share some helpful tips and advice below.

Causes of falls in people with Parkinson's

The most important first step to prevent falls is to identify the cause or causes of the falls. It may seem that everyone with PD falls for the same reason, but in fact, there are multiple factors that need to be assessed.

Postural instability is often referred to as one of the four cardinal features of PD (along with rest tremor, bradykinesia or slowness of movements, and rigidity or stiffness). Postural instability refers to the inability to right oneself after being thrown off balance. It is typically tested in the doctor's office when the neurologist tugs backward on your shoulders to see if you are able to prevent yourself from falling. A person with PD with postural instability may fall if they are jostled. This symptom is not typically present early in the disease and tends to develop as the disease progresses.

Freezing of gait is an abnormal gait pattern that can accompany PD (as well as other parkinsonian disorders) in which you experience sudden, short, and temporary episodes during which you cannot move your feet forward despite the intention to walk. In a sense, you're stuck. This results in the characteristic appearance of the feet making quick-stepping movements in place. However, while the feet remain in place, the torso still has forward momentum which makes falls common in the context of freezing of gait.

Festinating gait is another abnormal pattern of walking that can occur in some people with PD. In this gait, the person takes short steps which get smaller and faster, until it looks like they are almost running. The person may not be able to stop this pattern of walking and may end up hitting up against barriers in order to stop. Festination can lead to falls.

Dyskinesias are extra, involuntary movements that occur in some people as a side effect of Levodopa ingestion. When severe, dyskinesias can throw a person off-balance and cause falls.

Visuospatial dysfunction is one of the typical cognitive challenges that can affect people with PD. Deficits in this cognitive area lead to an inability to navigate oneself in three dimensions. A person may have difficulty maneuvering around obstacles in a room or backing up to sit down in a chair. This difficulty can also lead to falls.

Orthostatic hypotension is a drop in blood pressure upon changing head position, which is a common non-motor feature of PD. This can lead to dizziness and even passing out, which can be interpreted by the bystander as a fall.

Posture problems like stooped or tilted posture, often associated with PD, can contribute to imbalance.

Falls Prevention

Understanding which factors are contributing to falls is important since each is treated in a different way.

The postural instability of Parkinson's may be responsive to increases in PD medications.

Sometimes episodes of freezing of gait and gait festination can be reduced with increases in medication as well.

Bothersome dyskinesias can be treated by adjusting PD medications or initiating amantadine or amantadine ER.

A number of strategies can be used to manage orthostatic hypotension including increased fluids and dietary salt as well as compression stockings. If necessary, medications to increase blood pressure can also be considered.

Another important step in falls prevention – which is necessary to consider whatever the cause of falls – is modification of the home environment, such as:

Remove rugs and potential obstacles. Install grab bars in key areas in which falls are more likely, such as the bathroom.

Choose the right shoes for you: some like rubber soles and some do better with leather soles; check that shoes are not loose-fitting and provide support. Wear shoes with a slight heel to reduce falling in the backward direction, but no high heels.

Wear a medical alert bracelet or pendant in case a fall does occur. A very important part of managing someone who tends to fall which is often overlooked is assessing bone density. If thinning of the bones or osteoporosis is detected, medications can be prescribed to improve this, which can prevent a fracture should a fall occur. Your primary care physician can arrange for bone density testing, which is done via a quick and painless x-ray scan.

Why is fall prevention so important? Often a fall will cause no injury or a mild, easily reversible injury, however, sometimes a fall can cause moderate to significant injury.

In addition to the fall itself potentially causing a fracture or head injury, the fall could possibly result in an ER visit, hospital stay, or surgery, which can sometimes set off a series of events that has the possibility of worsening a person's PD even more substantially. Hospitalizations can interfere with medication timing, contribute to simultaneous infection, precipitate hallucinations, and increase confusion. Each of these setbacks can spawn additional setbacks which can contribute to the worsening of PD overall. In addition, immobilization after a fracture can interfere with exercise and physical therapy goals. For all of these reasons and more, it is important to do all that you can to reduce the chance of falls.

More Ways to Help Manage Balance for People with PD

Physical therapy Once medications are optimized and the home environment is as safe as possible, the next step in the treatment of falls in Parkinson's is a comprehensive rehabilitative assessment by a trained physical therapist. A physical therapist will then design a program that can address postural instability, freezing of gait, festination of gait, visuospatial dysfunction, and problems with posture, depending on the active problems that are identified.

Assistive devices Sometimes, the balance is affected to the point that an assistive device for walking becomes necessary.

The use of a cane is often discouraged by physical therapists who are experienced with Parkinson's. With only one side of the body using the cane, this creates an additional imbalance that is not present when using a walker. In addition, the cane itself can get caught up in furniture or other obstacles and contribute to falls.

Tips and Takeaways

There are many potential causes of falls in PD. Assessing why falls occur can inform the strategies used to prevent falls

Optimizing the home environment with de-cluttering and grab bars is an important part of falls prevention

Physical therapy is especially essential for those susceptible to falling

An assistive walking device may be necessary to maximize stability and quality of life.

Because of these concerns, walkers are often suggested as the assistive device of choice for people with PD. There are many types of walkers that are available for people with walking difficulties. Here is a simple guide:

Basic walker this is usually just a metal frame without wheels

Wheeled walker a metal frame with wheels. The wheels may be on two or four legs and the wheels may swivel or be fixed

Rollator a walker with swivel wheels on all four legs and hand brakes. The brakes typically need to be engaged for the walker to stop. Often the rollator has a seat and a basket for convenience.

U-step walker designed specifically with the concerns of people with PD in mind, particularly freezing of gait. The U-step walker has a reverse braking system which means that without engaging anything, the walker is in the braked position and the wheels will not turn. A lever must be gripped or pressed in order for the wheels to turn. Therefore, if freezing of gait occurs, the walker should stay stable. The walker can be ordered with a laser light and/or a sound cueing module which can be used to interrupt a freeze.

Your physical therapist can help you determine the walking aid that is best suited for your specific situation.

Should I be using a walker? This is a critical question that many people with Parkinson's grapple with and is best answered for each individual by their neurologist or physical therapist. I often hear the concern from people with PD that if they start to use a walker, they may become "dependent" on it, and they won't be able to walk without one in the future. If your balance is impaired and falling is a concern for you, talk with your neurologist about the potential steps that could improve your situation and prevent falls (as discussed above). If all adjustments have been made and poor balance is still present, the reality is that it will likely remain that way and will not be worsened or perpetuated unnecessarily by the use of a walker. At that point, a walker becomes essential for you to maintain your independence. Embracing its use is the best way to maximize your quality of life.

Additional resources on balance and falls prevention can be found on our website, such as our ***tips on overcoming a freezing gait****. In addition, APDA's Let's Keep Moving series shares expert physical therapy advice on a range of topics, including a three-part series dedicated to balance. This series can be found on* ***APDA's YouTube channel****.*

Research to prevent falls
APDA is proud to fund ***research*** *into fall prevention. Dr. Aasef Shaikh, recipient of the prestigious APDA George C. Cotzias Fellowship award for 2018-2021, is working to understand the different components that contribute to balance impairment in PD. By supporting our research efforts, you can help fund important work on critical topics like fall prevention.*

Thank you

for your generous donations

In the past year, we have received the following tribute donations:

IN HONOR

Biff Mautz
Bill Smersh
Brenda Lehman
Bryan Coluccio
Cal Severns
Chris Adams
Chris Daigre
Chris Jewell
Christine Engelhardt
Chuck Bundrant
Dave Grosby

In memory of
Dick Eller

Dennis & Candie Lambert
Dotti Harness-Foster
Jackson Wissing
Jeanne Kieffer
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EVERY
9
MINUTES

apda AMERICAN PARKINSON DISEASE ASSOCIATION
NORTHWEST CHAPTER

Every nine minutes someone in the US is diagnosed with Parkinson's.

YOU can make a difference

October 18–27

Support for **Care Partners**

The role of care partner can come about suddenly - without warning or permission – following a loved one's diagnosis with Parkinson's disease. There are no instructions, no rulebook, and no clear guidance for a future with PD.

And while a person diagnosed with PD has access to medical professionals, exercise programs, PT/OT, support groups, and more, often that same level of support for a care partner may be difficult to find. APDA wants to change that with an increased focus on programming and support specifically for care partners. With your help we can provide professionally-led educational support series, create targeted programming and expand our virtual caregiver support groups. Our goal is to provide connections and resources so that everyone looking for support can easily find it.

Show your love for the strong care partner in your life by **supporting our Every 9 Minutes fundraising campaign** in October. Proceeds from this fundraiser will pay for care partner support, education, and resources.

This is a peer-to-peer fundraiser which means we need your help ("many hands make light work")! It will only require a few minutes of your time, and for that small time investment you can make a huge impact. Here's how:

Point your phone camera at this QR code, it will automatically link you to our Every 9 Minutes website.

1. Register to be a fundraiser at **https://bit.ly/Every9Min**
2. During the nine days of the October 18-27 campaign, send a few emails to your family, friends, neighbors, colleagues and ask for support in honor of your #1 care partner, and all PD care partners.
3. If you are on social media, a few clicks and you can share a Facebook fundraiser (most FB fundraisers raise over $250!).

Not computer-savvy? Not a problem!
Give us a call at **206-348-0213** and **we can help set you up!**

Raising money for a worthy cause is easy. Our care partners spend so much time supporting their loved ones, now it is their turn!

Martin & Susan

"Martin, I don't have to turn around to know you will always have my back."

John & Christine

"Christine is the care partner that all of us with PD wish for. Her inherent concern for others, experienced ability to communicate clearly, and a constant commitment to sharing her research of PD subject matter genuinely serve the needs of many, not just me."

Dustin & Elizabeth

"My daughter carries things for me, helps me with tasks, and when my feet are not working properly she puts her foot out for me to step over so I can get going. She has really made life easier for me."

Parkinson's Care Partner

Can be sung to the tune of
On Top of Old Smokey

By: Forest Lane

I'm a person with Parkinson's, and I want you to know,
I cannot move real fast, But I sure can move slow!
In some situations, I need help with a task;
My faithful Care Partner, is the best one to ask!

You're my Parkinson's teammate, my partner who cares,
You're always on duty, everywhere.
When walking together, you slow down your pace,
Making sure that I do not, always come in last place!

Before diagnosis, you had plenty of chores,
But now you do twice as much, both mine and yours!
You have to decipher, notes written by hand,
You must reconsider, big travel you've planned.

You help me with balance, whenever I stand;
With manual dexterity and tremoring hands,
Your respectful assistance, we both have agreed,
That working together, we both can succeed.

The needs of your patient, can't be postponed;
They seem to take precedence, over your own.
So Parkinson's caregiver, give all you can;
But don't forget your own needs, cause you're not superman!

Your faithful assistance in all that I do;
Shows that [1 + 1], can be more than two.
So thanks for the care-giving and the great attitude;
You made my heart fill up, with gratitude!

Written to honor
our caregivers–
the unsung heroes
of the Parkinson's
landscape.

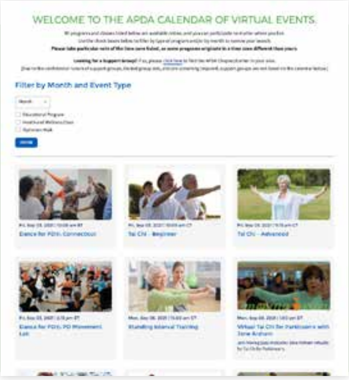
MOVE & LIVE WITH OPTIMISM!

Connect with others, build community, and be active!

In the Virtual World…

At the onset of the pandemic, APDA jumped into action to ensure that online exercise, educational programs, and support groups were there for everyone. As people consider resuming in-person gatherings, APDA will continue to remain focused on our mission of helping everyone impacted by Parkinson's disease live life to the fullest. As such, we remain committed to offering a slate of FREE virtual and print resources.

To reach APDA Northwest
call us at 206-695-2905 or email apdanw@apdaparkinson.org



WELCOME TO THE APDA CALENDAR OF VIRTUAL EVENTS

Filter by Month and Event Type

Dance for PD®: Connecticut

Tai Chi - Beginner

Tai Chi - Advanced

Dance for PD®: PD Movement Lab

Standing Interval Training

Visit the APDA Virtual Event Calendar!

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

apdaparkinson.org/upcoming-events/

Calling all care partners!

APDA will be offering several sessions of the Powerful Tools for Caregivers Series during the upcoming fiscal year. This 6-week evidence-based program helps caregivers take better care of themselves while caring for a loved one.

Each session will be led by certified, experienced class leaders. Space is limited.

If you are interested, please contact us to get on the list!

Smart Patients

▲ **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.

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

Free Virtual Fitness Programs continue!

Even as some PD Fitness programs return to in-person classes, APDA is committed to ensure that free virtual classes remain available. Perhaps it is difficult to leave your home, traffic is bad, you live in a town with no in person classes, or you just plain love logging in at home to workout with your online friends.

APDA has a host of classes listed on the **virtual calendar**.

Our Northwest chapter is proud to partner with local fitness instructors to offer you our most popular classes for free!

DANCE for Body, Mind and Spirit with Chris Daigre, Sundays at 12:30 pm

Yoga for PD with Peter Lynch, Tuesdays & Thursdays at 2:30 pm

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

A.M.P. with the Parkinson's Fitness Project, Mondays at 12:15pm

Newly diagnosed?

We will be holding several sessions of our signature PRESS (Parkinson's Roadmap for Education and Support Services) program this coming year. This program was designed for those diagnosed with PD within the last 5 years. The 8-week program is conducted in a support group format and was designed to provide emotional support, education and a safe place to share strategies to live your best life with PD.

Space is limited. If you are interested, please contact us to get on the list!

PRESS™
Parkinson's Roadmap for Education and Support Services™

Please help keep information accurate!

Are you part of a support group or PD exercise class?

We are trying our best to keep all the exercise and support group listings on our website up to date with the latest information, but as things change from virtual to in-person (and back again!) this has proved difficult. If you are leading or attending a support group or exercise class, please find the listing on our website and contact us if the information is inaccurate.

Thank you!

apda AMERICAN PARKINSON DISEASE ASSOCIATION
NORTHWEST CHAPTER

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**

What will your legacy be?

Legacy giving is a powerful way to support the people and causes you care about most. There are many ways to create a legacy, including giving through your donor-advised fund, stock donations, qualified charitable distributions, and more.

Deciding on the right way to give can be difficult, and APDA is here to help.

To discuss planned giving opportunities, contact us at **krichards@apdaparkinson.org** or **206-348-0213**.

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.