PARKINSON Pathfinder

WINTER 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.

AMERICAN PARKINSON DISEASE ASSOCIATION
NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

WINTER 2021

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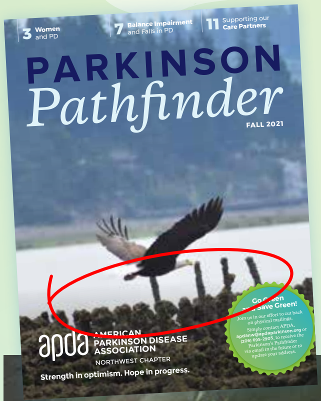

A note about the Fall 2021 issue of *Pathfinder*, from photographer **Dustin Werner:**

By selecting this photo, you unknowingly put a piece of WWI history on the cover of your magazine! All those things under the eagle (circled in red) are the remains of WWI warships scuttled on the beach.

Below, right: the warships as seen from the air; left: Another view of the ships;

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COVER
Photo by Dustin Werner

In early in 2013 I sat in a Bellevue neurologist office and a doctor I had just met a scant twenty minutes earlier informed me that I had Parkinson's disease. He gave me a book and told me I would probably have brain surgery in about seven years. (It was five.) He set me up with a blood draw and a referral to get an MRI and sent me on my way. **That day changed my life.**

I didn't really know much about Parkinson's disease. I knew it was a possibility going into my appointment, but I didn't look into it much. I knew that Michael J Fox and Mohammad Ali had it, but that was about all. I was thirsty for information. Unfortunately, the book my neurologist gave me probably hurt more than it helped. It was full of recommendations like 'use satin sheets so it's easier to turn over' and 'wrap rubber bands around your utensils so they are easier to grip.' Perhaps it was good advice for people at a certain stage of the disease, but it didn't address the concerns of a newly diagnosed forty-four-year-old in the middle of a high-pressure career in the tech industry with a wife and two twelve-year-old children. The Internet wasn't much help either.

This is where APDA comes in. APDA fills the gap between neurologist appointments. It provides essential, targeted information that goes beyond what a neurologist has time for. APDA supports research to find a cure. It connects people with Parkinson's disease and caregivers though exercise programs and support groups. After all, there are some questions that can only be answered by someone in the same situation.

That's why when I was approached in early 2019 to consider joining the board of directors, I was excited to give back and join. I was similarly honored to take the role of President when it became available early this year. My time on APDA's board has been a wild ride as we navigate what support looks like during a pandemic. But despite the challenges and the remote events, the events of the past couple of years has only strengthened my conviction that **APDA is an essential part of the Parkinson's community and each patient's care team**.

Carl Carter-Schwendler

Carl Carter-Schwendler
President, APDA Board of Directors

This is the second in a two-part series about Women & Parkinson disease.
The first can be found in the Fall 2021 Parkinson Pathfinder

WOMEN AS CARETAKERS

Kat Hill

Diagnosed with PD at age 48—at the peak of my career amid raising a family and caring for a parent with cancer—I learned quickly that I had limits. Physical and emotional limits. As a lifelong caretaker this was a difficult and eye-opening lesson. My experience is one that is all too common for many women in mid-life.

I hope to share a little about my experience in the hopes that it may help some of you to learn your own limitations of being a woman with PD and perhaps to encourage or nudge you towards your own self-care journey.

At the time of my diagnosis, I was the director of a large full-scope midwifery practice in an inner-city hospital in Portland, Oregon. My husband and I had our youngest child at home, a teenager, and two young adults in college. It was not the time to be thinking about leaving my job, taking a break and learning about my limits. I was ill-prepared for taking time out from my life to reflect and learn about how to care for my own health.

Historically, women have held the primary caretaker role in their families, which is still true today. This reality is a complex sociological legacy. Women are also most often the primary gatekeeper to accessing healthcare services for their families.

Serving others is an integral part of my identity and practice. Taking care of my family and a career as a midwife is my "calling." I am the oldest child in my family and the only female. From a very early age I felt responsible for my two younger brothers, a role that was further reinforced when my parents separated.

Later, I graduated as an "expert" caretaker. I developed my career as an educator and then a Nurse Practitioner and Nurse-Midwife. I married and had three children which further enriched my life and my expertise. My roles as wife and mother proved to be the most challenging AND fulfilling roles I have played. I have been married nearly 32 years.

In each of the roles I have played over the years, taking care of others has been at the core. I was not at all prepared for the change in identity when I was diagnosed with PD. I was not accustomed to being the patient. How was I to start to receive care?

In my early 30's I struggled with depression and anxiety. I often felt an internal 'shaking' that I could not explain. Not once did I question that I was "doing too much" or ignoring my own needs. I felt I was doing what I was born and raised to do, care for others. The symptoms, perhaps the earliest of my Parkinson's symptoms, led me to seek help. My primary care provider prescribed counseling, exercise and medication to mitigate some of the symptoms. Advice to find balance was ignored because I did not know HOW to practice self-care. Ultimately, my symptoms would not adequately be treated until after starting medications for PD and learning to be intentional about my limits.

I was squarely in the midst of the sandwich generation, with little time nor energy to address the nagging symptoms that were creeping in. Fatigue, brain fog, anxiety, twitchy hand… all explained away by the demands of a busy life.

I explained away symptoms to stress, perimenopause, and grief (prior to my diagnosis we lost my mother to cancer and then a few years later my father to Parkinson's-related complications). Then one morning I woke up feeling as if an elephant was sitting on my chest. It stopped me in my tracks and forced me to evaluate my situation. Several weeks later the right-hand tremor began, and the diagnosis came. Young Onset Parkinson's Disease. I left my career and started what I call my "Act 2.0."

First place the oxygen
mask over your face
before helping others.

Healer, heal thyself.

Easier said than done.

Kat's go-to "oxygen mask" tools:

Attitude of gratitude. When if find I am feeling low and getting lost in the "why me?" I list three things each day that I feel grateful for. For many years I kept a gratitude journal. I found this practice profoundly shifted my focus during my early years with PD helping me to focus on wellness and not illness.

Nutrition. Careful attention to diet. Avoiding too much sugar keeps me feeling my best and helps with perimenopausal symptoms. I also try hard to eat lots of fresh vegetables and some fruit each day. It helps keep my digestion regular.

Sleep. I try to follow a routine around sleep. Like so many of us, I have struggled with sleep for many years. If I have trouble falling asleep, I at least go to bed and "get flat." I may read or stretch for a while in bed even if I am unable to fall asleep right away. I find that often I am able to sleep and if not, my body has rested, and my mind has "unplugged" from screens and blue light for a while.

Movement. I try daily to get exercise. It is not always a high-intensity workout, but even taking the dog for a walk in the neighborhood provides a stretch, some fresh air, and change of environment.

Mind/Body/Spirit. Exercise and nutrition feed my body, and each day I try to find time to also "feed " other parts of me. I may sketch something in my sketchbook, paint, meditate, or find something inspiring to read. Wellness, for me, is a combination of caring for all the parts of me.

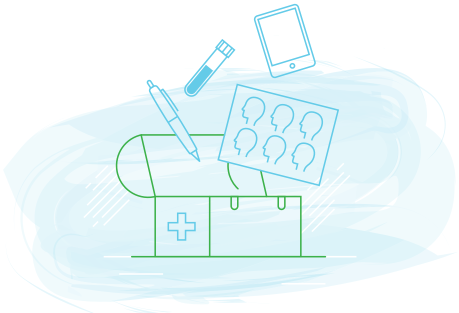
A watercolor by Kat Hill

I've been diagnosed now for over 6 years. I have found ways to take care of my health, making time for meditation and gratitude; prioritizing exercise; staying connected with others, and learning to rest when I need to. I am intentional about how I care for myself and how I make time to be of service to others. Continuing to seek counsel from my husband and therapist help me to keep balance and learn to say "no." I have finally learned how to practice self-care.

I wonder, at times, if my diagnosis and progression of disease might have been different had I learned to take care of myself earlier in my life? Did I delay my diagnosis by ignoring this advice? Have I learned these tools in time to model good self-care behaviors for my children?

I certainly do not claim to have the answers. I am just one woman with Parkinson's doing the best that I can each day, trusting it is enough, and hoping that my message might help a few others to pause to put on their oxygen mask before helping others.

KAT HILL is from Portland, Oregon. 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, *Being Well: A Guide to Joy and Resilience with Chronic Illness* is available for presale on Amazon. She also hosts the podcast PD Lemonade on Apple iTunes and Spotify. You can find her at www.kathill.org.



Diagnosing PARKINSON'S DISEASE

WHAT IS IN A NEUROLOGIST'S TOOLBOX

Pravin Khemani, MD

The definitive diagnosis of Parkinson's disease (PD) can be a challenge. Unlike other diseases such as diabetes, there is not one simple test which confirms a clinical diagnosis of PD. How do you know if your diagnosis is accurate? This article will review the variety of diagnostic tools that can help a neurologist accurately diagnose PD.

The neuropathological hallmarks of PD are the presence of Lewy bodies (microscopic bundles of abnormally folded proteins such as alpha-synuclein) in the brains of people affected by the disease, and neurodegeneration or progressive loss of brain cells in specific circuits or pathways of the brain. Unfortunately, this 'gold-standard' for definitive diagnosis of PD can only be established post-mortem and, thus, is not useful in determining a treatment plan. Instead, clinical diagnosis of PD is informed by the following *core* neurological signs:

BRADYKINESIA (slowness of movement)

Plus, ***one or more*** *of the following:*

ASYMMETRIC REST TREMOR

RIGIDITY

A precise clinical diagnosis of all neurodegenerative disorders, including PD, mandates that no other condition should be responsible for the clinical signs. Therefore, in addition to the above core neurological signs, 19 *exclusion* and 4 *supportive* diagnostic criteria are proposed to ensure a high level of diagnostic certainty. A primary drawback of using clinical criteria for diagnosing PD is their limited applicability in the early stages of PD. Another disadvantage of using these criteria is that they do not always reliably distinguish PD from its mimics which can cause *parkinsonism* - a combination of symptoms such as tremors, slowness, stiffness, shuffling, soft speech, and falls (**see Table**)[1,2].

An inaccurate diagnosis of a disease may result in unnecessary and incorrect treatment plus there is a huge emotional toll on patients and caregivers when the diagnosis is revised. We are in an era of cutting-edge research which is geared towards discovering disease-modifying therapy for treatment of PD in its earliest stages to slow down and even stop the disorder's progression. Therefore, early and very accurate diagnosis of PD becomes even more relevant when selecting subjects for clinical research. Recruiting patients who may have disorders that mimic PD would confound the outcome of research, an observation which has plagued clinical studies in neurodegenerative disorders for years.

For the reasons outlined above, clinical diagnosis of PD should be highly accurate, durable and, when necessary, supported by tests which confirm the presence of biomarkers (physiological clues) common in PD. Currently, we do not have a biomarker unique to PD and not present in any other disease, but there is significant ongoing research in this area and the outlook is quite promising. Until then, we have several tools which, when utilized and interpreted accurately, can diagnose PD with a high degree of precision (**see Table**). They include:

BRAIN MRI: is a commonly performed test, which is best used to exclude anatomical lesions that can cause *parkinsonism*. Strokes and normal pressure hydrocephalus (NPH) are two common causes of parkinsonism that can be revealed by an MRI of the brain. If an MRI is not obtainable, a CT scan of the brain is suggested, although the resolution of this test is poorer than an MRI.

BLOOD TESTS: become relevant in very young individuals (<35 years of age) with parkinsonism, in people with rapidly progressive parkinsonism, or someone who does not see a primary care doctor regularly. These blood tests are used to exclude metabolic disorders, autoimmune antibodies that can affect the nervous system, and other rare conditions that can result in parkinsonism.

PD mimics (diseases that resemble PD can cause parkinsonism)	Can coexist with PD	Clinical Tools				
		MRI brain	**DaTscan™ (false negative rate is up to 20-25 % and false positive up to 5-10 %)**	**Blood tests**	**Skin biopsy**	**Genetic tests (saliva or blood)**
Essential Tremor (ET)	Yes	Normal	Normal	Thyroid function should be checked	Normal	n/a
Normal Pressure Hydrocephalus (NPH)	Yes	Abnormal	Normal	n/a	Normal	n/a
Strokes (also called Vascular Parkinsonism)	Yes	Abnormal	Normal	Performed as part of routine screening	Normal	n/a
Drug induced Parkinsonism and Drug induced Tremors	Yes	Normal	Normal	Certain drug levels may be tested (such as Lithium)	Normal	n/a
Rapidly progressive Parkinsonism (many diseases can cause this condition including infections, cancers, immune, and rare genetic mutations)	Not typically	Nonspecific	Unknown	Abnormal in certain diseases	Unknown	Rare genetic mutations
Neurodegenerative diseases	**Can coexist with PD**	**MRI brain**	**DaTscan™**	**Blood tests**	**Skin biopsy**	**Genetic tests**
Lewy Body Dementia (LBD)	No	Nonspecific	Abnormal	Normal	Abnormal	GBA mutations
Multiple system atrophy (MSA)	No	Nonspecific	Abnormal	Normal	Abnormal	Rare genetic mutations
Progressive supranuclear palsy (PSP)	No	Nonspecific	Abnormal	Normal	Normal	Rare genetic mutations
Corticobasal degeneration (CBD)	No	Nonspecific	Abnormal	Normal	Normal	Rare genetic mutations

Nonspecific: *these tests have low sensitivity, meaning there is a high rate of 'false negative' results*
n/a: *not applicable, typically not ordered*

GENETIC TESTING: involves testing saliva or blood and is reserved for individuals suspected of young-onset PD (YOPD, age <50 years), when there is a convincing family history of parkinsonism, or when the clinical course is suggestive of genetic parkinsonism. Three genes are commonly associated with PD:

- *LRRK2* and *GBA* mutations are the most common genetic risk factors of PD
- *Parkin* mutations cause at least 25 % of YOPD

There is significant ongoing research for treatment of LRRK2-and-GBA-associated PD, therefore, tests for these mutations should be done when a genetic cause of PD is suspected.

SKIN-BIOPSY[3]: involves taking small samples of skin after it is anesthetized with lidocaine from three sites of the body and analyzing them for presence of abnormal alpha-synuclein-the protein present in PD brains. This simple, fast, relatively-painless outpatient test is commercially available and is gaining recognition as an invaluable tool to narrow the possible causes of parkinsonism. When the results are normal, at least three diseases. PD, MSA, LBD, can be excluded (**see table**). Application of clinical diagnostic criteria for these diseases in conjunction with skin biopsy results can further improve diagnostic accuracy. A large national trial is underway to discover the utility of the skin biopsy for diagnosis of PD and its mimics. Swedish Neuroscience Institute is one of the sites of this research study[4].

DATSCAN™ [5]: has been available for a long time in the US and was developed primarily to distinguish parkinsonism caused by Essential tremor (ET) from PD. However, over time, multiple studies have shown that it can be used for *clinically uncertain parkinsonism* (CUPS, a term commonly used when the cause of parkinsonism is unclear) to improve diagnostic accuracy of PD. The basic premise is that in neurodegenerative disorders that affect the dopamine pathways, this scan is abnormal. However, a DaTscan™ can be abnormal in several neurodegenerative disorders besides PD, hence, it must be interpreted in conjunction with the clinical exam and other tests.

When classical signs of PD, such as slowness, an asymmetric rest tremor, and stiffness are fully manifest, and when these motor symptoms are robustly responsive to an adequate dose of levodopa, there isn't any need for additional confirmation of the diagnosis. Currently, the sharpest tool in the toolbox of PD diagnostics is a well-done clinical evaluation followed by regular assessment by a neurologist who is familiar with and experienced in the treatment of PD and its mimics. However, even in the hands of a skilled neurologist, the diagnosis of PD can be challenging in the earliest stages or when clinical signs overlap with other disorders. Until one precise test for PD becomes available, we must judiciously utilize supportive tests to improve diagnostic precision for accurate recruitment into research trials and, most importantly, to effectively create a treatment plan which improves the quality of life for those affected by Parkinson's disease.

References:

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2. Tolosa, E., Garrido, A., Scholz, S. W., & Poewe, W. (2021). Challenges in the diagnosis of Parkinson's disease. *The Lancet Neurology*, *20*(5), 385–397. **https://doi.org/10.1016/S1474-4422(21)00030-2**
3. *https://cndlifesciences.com/patients/*
4. Contact **Nathan.Hansent@Swedish.org** or **Vanessa.Ochs@Swedish.org** for more information about this study
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Dr. Pravin Khemani is fellowship trained in both neuromuscular disorders and movement disorders. Dr. Khemani's philosophy of care for movement disorders is to adopt multidisciplinary approach and closely collaborate with the patient, family and other caregivers. He is the author of a number of publications on Parkinson's disease and ataxia and is an investigator on several clinical trials.

He is also a member of the APDA Northwest Board of Directors.

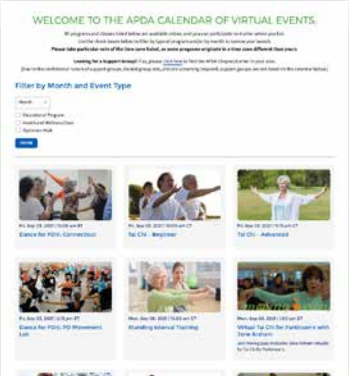
MOVE & LIVE WITH OPTIMISM!

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

Tai Chi - Beginner

Tai Chi - Advanced

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/

EXERCISE YOUR VOICE!

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

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

◂ Get the Booklet

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

Online Resources

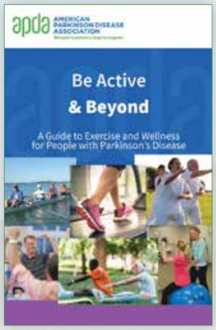
APDA Webinar – *"Living Well Every Day"* A speech-language pathologist provides helpful information and advice regarding speech issues and PD, and a registered dietician and nutritionist offers recommendations about nutrition and other aspects of living well with PD.

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

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

EXERCISE YOUR BODY

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



apda AMERICAN PARKINSON DISEASE ASSOCIATION

Be Active & Beyond

A Guide to Exercise and Wellness for People with Parkinson's Disease

◂ Get the Booklet

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

Get Expert Advice

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

Online Resources

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

Virtual Exercise Programs

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

Let's Keep Moving Series

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

APDA Webinars

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

CONNECT WITH OTHERS

Smart Patients

▴ 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

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!

PATIENT AID SCHOLARSHIP

We know the costs of living with Parkinson's disease can be a hardship for many. APDA is here to help through our Patient Aid Scholarship Program. The program was designed to provide financial support to people with PD in AK, ID, MT, OR and WA who are struggling to make ends meet.

This **annual $300 grant** can be used for a wide array of services/items. Funds are limited and are available on a first come basis until they run out.

—

Are you in a financial position to help someone else? Please consider donating to APDA so that we may award more grants to those who are struggling!

To apply for a scholarship or make a donation to the program please visit our website or give us a call.

Do you enjoy this publication?
Please consider making a gift to APDA to support the costs of producing the *Parkinson Pathfinder*.

join us

on **March 12, 2022**, at the **Seattle Design Center** for an evening of reconnecting and celebrating — in person — with an online viewing option for anyone who can't be there. Proceeds from Magic of Hope pay for our local education and support programs, research, and more!

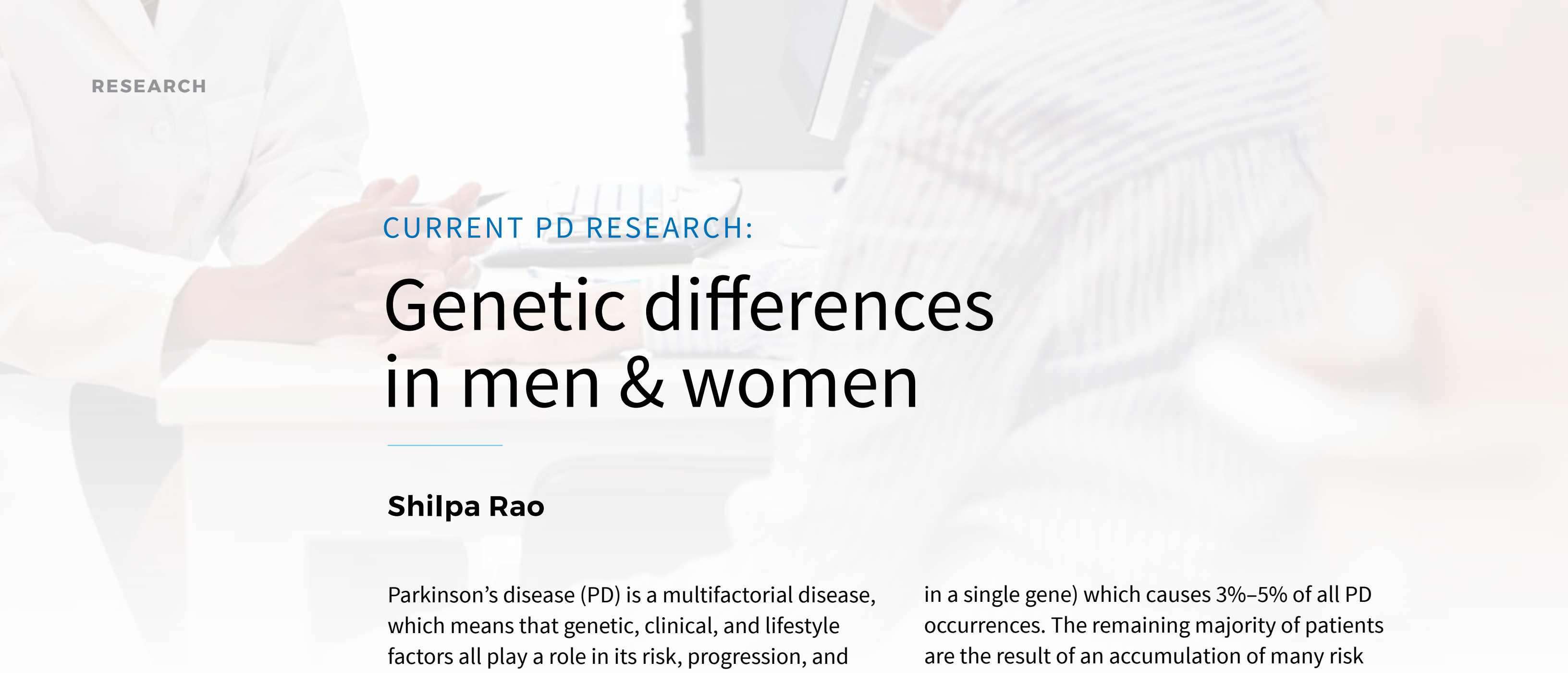
Check our website for more info and to purchase a ticket.

Committee members needed!
Help us plan our biggest fundraiser of the year. We need help with procurement, logistics, set-up, etc. Contact us at **jallenbach@apdaparkinson.org** to find out more.

SAVE THE DATE

March 12, 2022

Seattle Design Center



CURRENT PD RESEARCH:

Genetic differences in men & women

Shilpa Rao

Parkinson's disease (PD) is a multifactorial disease, which means that genetic, clinical, and lifestyle factors all play a role in its risk, progression, and treatment outcomes.

To date, there have been no studies that incorporate all these factors to predict the risk, progression, and severity of PD and that is the goal of Shilpa Rao's Ph.D. thesis at the Mata Lab. Dr. Ignacio Mata has been known to be the pioneer for performing genetic studies for under-represented PD populations, one of which has notably been non-European Latinos. He is currently funded by APDA with his study in "Next-Generation Sequencing of Parkinson's Genes in Understudied Latin American Populations". Now, the Mata Lab is also studying another under-represented group: *women*.

> "Men are about 1.5 times more likely to be diagnosed with PD than women, and the disease presents differently between them, not only in terms of risk but also with lifestyle, diagnosis, and treatment outcomes."

Age, gender, and ethnicity are commonly known to play a role in the risk of PD. Individuals over 60, men, and those of European descent are at a higher risk of PD. Specifically, men are about 1.5 times more likely to be diagnosed with PD than women, and the disease presents differently between them, not only in terms of risk but also with lifestyle, diagnosis, and treatment outcomes. The average age of diagnosis for both sexes is over 60. For women, many consider PD as a "post-menopausal" disease; however, there are those with young-onset Parkinson's disease (YOPD), but this group is smaller than typical Parkinson's disease patients and often stems from a genetic predisposition.

Genetics has been a large focus in the study of Parkinson's disease. Overall, about 10-15% of PD cases are caused by a genetic mutation. To date, there are 28 distinct chromosomal regions convincingly related to PD. Six of these specific regions contain genes with mutations that can cause monogenic PD (being determined by variant(s) in a single gene) which causes 3%–5% of all PD occurrences. The remaining majority of patients are the result of an accumulation of many risk variants and the interaction with the environment/lifestyle/life events. Most studies do not look at the combination of all these factors.

One factor often overlooked is gender-specific lifestyle experiences. Despite the consensus that PD is multifactorial, many studies and questionnaires done in research and are that are used clinically, focus on gender-neutral lifestyle experiences like alcohol, tobacco, smoking, and caffeine habits. But what about female-specific experiences such as menstruation, contraceptives, pregnancies, hormone-related disorders, and menopause?

A few studies have considered these female-specific lifestyle experiences, but the sample sizes were small and the results were contradictory. In the clinic, the surveys and questions asked by many neurologists never include female-specific factors. Thus, there must be a questionnaire that addresses these experiences to start raising awareness and allow the field to better consider if these factors play a role in the risk, progression, severity of PD, and treatment outcomes for PD.

With the help of neurologists, PD experts, and female-neurodegeneration experts, Shilpa has developed a questionnaire in order to gain more perspective about the clinical and lifestyle factors of women with PD. The questionnaire is about 20 questions long with an estimated completion time of 25 minutes. It addresses common female experiences, including menstruation, birth control, pregnancy/pregnancy-related issues, hormonal disorders, surgeries, and menopause. It also asks the responders how each of these experiences affected their PD, in terms of changes in symptoms and medications.

The goal of this study is to be more comprehensive about the lifestyle factors that women experience and determine the impact they have on the risk, progression, and severity of PD. The hope is that these questions will be the catalyst for mainstream discussion between women, their clinicians and the community. Women have often been overlooked and their experiences and physiological differences in aging have been ignored in relation to risk and clinical outcomes of multiple diseases, not just PD. This questionnaire sets the foundation to creating a template for PD and other diseases to begin examining the experience of women in association to their disease. This will ultimately lead to better treatment and care for women. For example, with better understanding of how hormones and menopause affect PD symptoms, clinicians can focus on utilizing hormone replacement therapy with or without deep brain stimulation. Additionally, advising women who have a family history or a genetic predisposition with female health concerns (such as family planning) can shift the current treatment and preventative care paradigm.

With these goals in mind, the Mata Lab questionnaire hopes to develop more accurate prediction models using all factors of PD, which has never been done before.

The goal of this study is to be more comprehensive about the lifestyle factors that women experience and determine the impact they have on the risk, progression, and severity of PD.

The "PD Womens Health Questionnaire" can be found via this link:

https://redcap.parkinson.org/surveys/?s=WPX84XW93L4PPHKC

Please note if you are a patient at the Cleveland Clinic or are already enrolled in PDGENEration or Fox Insight study, please contact them and inform them you'd like to take part in the survey.

To find our more information about the work being done at the Mata Lab, please visit their webpage:

https://www.lerner.ccf.org/gmi/mata/

Shilpa Rao is a PhD candidate in Molecular Medicine PhD Program at Cleveland Clinic & Case Western Reserve University in Cleveland, OH. She is currently studying the role a woman's lifestyle may play in the risk and progression of Parkinson's Disease in Dr. Ignacio Mata's lab at Cleveland Clinic Lerner Research Institute. Shilpa completed her BS in Molecular Biology at Loyola University Chicago.

APDA. Proudly funding research since 1961.

2021 marks the 60th Anniversary of APDA, which was founded in 1961. **One of the key pillars of APDA's mission is the support of research designed to unlock the mysteries of Parkinson's and ultimately put an end to this disease.**

APDA's research focus is unique, with the goal of finding and funding the best new talent in the field. APDA accomplishes this by giving post-doctoral fellowships to innovative and dedicated scientists and awarding research grants to the most promising scientific projects. Many APDA-funded researchers have successfully leveraged pilot data from their projects to secure multimillion-dollar grants through the National Institutes of Health and other grantors. Due to this methodology, APDA has been a funding partner in many major PD scientific breakthroughs, investing nearly $51 million in research since 1961. You can read more about APDA's Research Accomplishments on our website (hyperlink)

Additionally, APDA Northwest Chapter is committed to funding of the **Washington State Parkinsons Disease Registry**. In fact, the Registry is entirely funded by APDA! The Registry is a central database that connects the research community to people with Parkinson's who are interested in participating, which helps research happen faster.

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

To learn more please visit registerparkinsons.org or call 888-365-9901

Dr. Ariana Tart-Zelvin, PhD

BRAIN, MEET BODY

How to diminish the mental and emotional changes of Parkinson's Disease

Parkinson's disease (PD) manifests itself with a variety of physical signs and symptoms such as shuffling gait, stooped posture, and voice changes (i.e., hypophonia). However, less well known are subtle changes to mental and emotional well-being as the disease progresses. Although a patient's initial diagnosis is based on the clinical presentation of physical symptoms, cognitive changes may occur about a year or more later.

To help establish a baseline for a patient's mental and emotional abilities when first diagnosed, and to track changes over time, individuals with PD are often encouraged to undergo neuropsychological evaluations that entail a comprehensive assessment of an individual's neurocognitive domains including memory (visual and verbal), attention, visuospatial abilities, processing speed, language, and executive functioning.

Extensive research with PD patients has allowed for the identification of hallmark cognitive changes in individuals with PD. With disease progression, cognitive weaknesses usually include slowed thinking or decreased processing speed (bradyphrenia). Often, patients will report that they are "thinking slower" than they used to and that it takes them longer to grasp concepts or instructions during conversation. We also see memory problems, reduced psychomotor speed (bradykinesia), visuoperceptual/visuoconstructional difficulties, attention problems, executive functioning weaknesses, and changes to aspects of language.

Memory problems often present as forgetfulness initially but can become more profound over time. In addition, worsening attention and working memory often contribute to memory weaknesses. Language and communication are also affected, and individuals with PD tend to develop a softer voice when speaking (hypophonia), and small, and often illegible, handwriting (micrographia), although other language functions typically remain preserved. Visuospatial

IMPROVING Cognition, Emotional Well-Being, and Day-to-Day Functioning

Cognitive Rehabilitation – Cognitive rehabilitation refers to evidenced-based interventions that can improve an individual's ability to perform cognitive functions and everyday tasks by providing patients with compensatory strategy training. When appropriate, patients may also be retrained in previously learned skills. This service is typically provided via speech-language pathologists, psychologists, and neuropsychologists. Cognitive rehabilitation can be particularly helpful when individuals experience reduced attentional abilities and memory problems.

Exercise – Regular exercise (e.g., 30-45 minutes of exercise, five days a week) is highly beneficial for brain health. Specifically, aerobic exercise along with regular strength training workouts is recommended. Take a walk before breakfast or after dinner. Shoot a few hoops. Don't forget to include exercise as part of a PD-combating lifestyle! Consult your physician prior to starting a new exercise regimen.

Assistive Therapies – Individuals with PD often benefit from engaging in physical therapy (PT) and occupational therapy (OT) to assist with improving mobility and the ability to engage in everyday tasks safely and independently.

Psychotherapy – While it is not a foregone conclusion that individuals with PD will develop mood symptoms, about 80-90% of those with PD experience some degree of depression, anxiety, and/or apathy during disease progression. Thus, individual, couples or family therapy can often be helpful to target mood symptoms and to help patients adjust to and cope with physical, cognitive, and emotional changes associated with PD. For example, behavioral activation through increased engagement in enjoyed activities and social experiences can help to address apathy and depression.

THERE ARE WELL-RESEARCHED ACTIONS that individuals with PD and PDD can take to improve their cognition, emotional well-being, and day-to-day functioning, to a degree, in addition to pharmacological treatment or surgical intervention.

difficulties can make it difficult for individuals with PD to navigate while driving or traveling, arrange household items in a proper manner, and correctly perceive the orientation or motion of objects.

While it is not a given, individuals with PD can get diagnosed with Parkinson's Disease Dementia (PDD). The development of dementia depends on several factors such as how long a person has had PD and the stage of disease. Current estimates are that about one million individuals in the United States have Parkinson's disease and that over the course of their illness, approximately 50-80% of those individuals may experience PDD. The term dementia is an umbrella term that refers to a significant decline of cognitive functioning in one or more cognitive domains that negatively impacts one's overall ability to engage in everyday activities independently. Given the nature of neurodegenerative diseases and the fact that we do not have a cure at this time, symptoms worsen over time. That said, the rate of progression from one individual to the next can vary.

Importantly, there are well-researched actions that individuals with PD and PDD can take to improve their cognition, emotional well-being, and day-to-day functioning, to a degree, in addition to pharmacological treatment or surgical intervention. Refer to the table for some helpful suggestions.

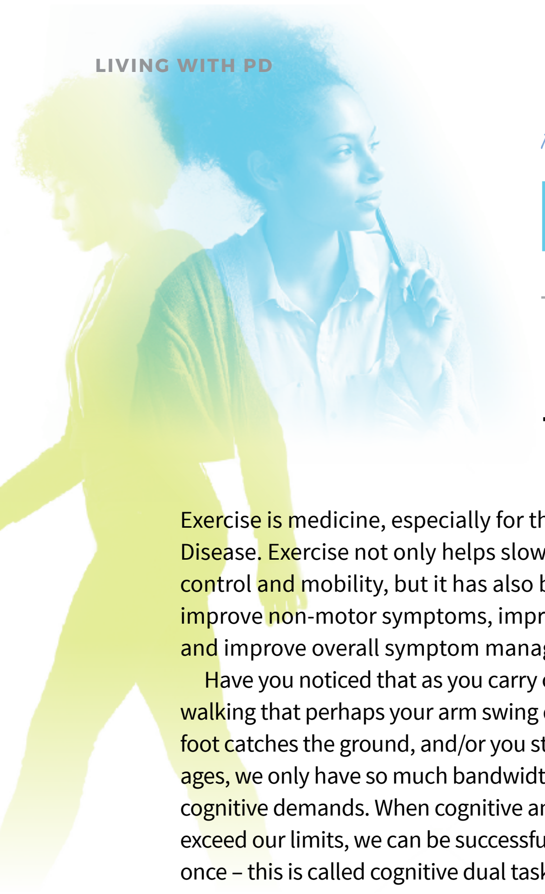
Educational and Social Support – APDA, as well as other PD nonprofits, provide excellent resources and social support for individuals with PD. They also provide helpful support for family, friends, and caregivers.

A Brain-Healthy Diet – Research suggests that following a Mediterranean style healthy diet (fruits, vegetables, lean proteins, complex carbohydrates, and nutritious fats) or the MIND diet is beneficial for brain health, including both cognitive and psychological functioning. Such diets have been shown to improve blood flow and can reduce a person's chances of vascular dementia and Alzheimer's disease.

Sleep and Sleep Hygiene – Sleep problems such as insomnia and sleep apnea, even mild sleep apnea, have been linked to dementia. Thus, it is important for individuals to focus on improving the quality, and at times, the quantity of their sleep (i.e., at least seven hours of uninterrupted sleep per night). To maximize the benefits of sleep, go to bed at the same time each night and wake up at the same time each day, minimize external stimulation prior to bed, limit caffeine use later in the day, and exercise, exercise, exercise!

Daily Functioning and Social Engagement – Individuals are encouraged to regularly engage in activities that keep them mentally, socially, and physically engaged. While the brain is not a muscle, it often acts like one. It is beneficial to use and challenge the brain by learning something new such as a new language, sport, game, art, or musical instrument. Additionally, socializing with others and connecting with one's community through volunteering can be beneficial for brain health, as social isolation and loneliness have been shown to increase one's risk of dementia.

Dr. Ariana Tart-Zelvin, PhD, is a Clinical Neuropsychologist with the Swedish Program for Healthy Aging, part of the Swedish Neuroscience Institute, in Seattle, WA. She has specialized training in in brain and behavior relationships and sees patients with Alzheimer's and Parkinson's disease, various dementias, multiple sclerosis, ALS, brain tumors and brain injuries.



For the Health of it

Brain & Brawn

The benefits of pairing cognitive exercises with physical movements

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

Exercise is medicine, especially for those with Parkinson's Disease. Exercise not only helps slow the decline of motor control and mobility, but it has also been shown to help improve non-motor symptoms, improve emotional well-being, and improve overall symptom management.

Have you noticed that as you carry on a conversation when walking that perhaps your arm swing disappears, your affected foot catches the ground, and/or you start to shuffle? As one ages, we only have so much bandwidth to devote to motor and cognitive demands. When cognitive and motor demands do not exceed our limits, we can be successful performing two things at once – this is called cognitive dual tasking. However, when the demands of a task exceed our mental capabilities, a sacrifice must be made in the performance of either the motor task, the cognitive task, or both. This sacrifice can lead to a loss of balance, falls, or difficulty carrying on conversations while walking.

The good news is that research shows that targeted and consistent exercises have lasting effects and can help improve and maintain the ability to perform cognitive dual tasks, improve the automaticity of motor movements, and have a positive impact on other areas of cognition which potentially reduces the risk of falls.

Here are some examples of cognitive-dual tasks that can be added to daily exercise routines to help mitigate cognitive decline and improve overall function. These can help maintain the size of your step length and arm swing while also carrying on a conversation or responding to the information around you.

Not all of these exercises mix cognition and physical movement but by practicing cognitive and physical context switching, you will find it easier to do this in everyday situations. This will help you reduce the risk of falls and improve your overall safety.

If you find that any of these traits apply to you or a loved one, please reach out to all members of your rehabilitation team (Physical, Speech, and Occupational Therapy) who are familiar with these concepts and can help you incorporate them into your daily exercise routines. Your mind and body will thank you for it!

Impact of PD on Cognition: **Set-switching**

The ability to shift between tasks or rules; and adapt to changes in the environment. This might show up as difficulty with walking and talking at the same time

Helpful Cognitive Exercise: **Set-switching**

—Lunges: Lunge left, name off a fruit; lunge right name off a vegetable

—Stroop Stepping: Say the color, not the direction.

Example: SAY "right green" DO: step forward with your right foot. (see stroop stepping grid, below)

RIGHT	Forward
LEFT	Back
LEFT	Forward
RIGHT	Side
LEFT	Forward
RIGHT	Side
RIGHT	Back

Impact of PD on Cognition: **Short term and procedural memory**

Difficulty tying your shoes or sequencing transitioning from sitting to standing.

Helpful Cognitive Exercise: **Visuo-spatial with set-switching**

Clock lunges with punches: Imagine standing in the middle of a clock. Practice stepping forward toward random hours and reaching with the opposite hand in the opposite direction of your foot.

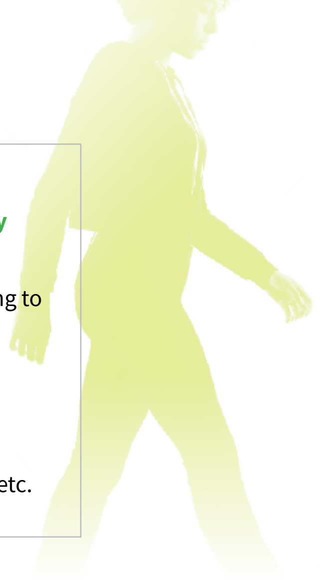
Impact of PD on Cognition: **Executive functioning**

Difficulty with working memory, flexible thinking, and self-control.

Helpful Cognitive Exercise: **Physical dual-tasking Drills**

— While performing high knees clap hands overhead, then behind your back.;

— Walk around the living room holding a cup of water without spilling any of the water



Impact of PD on Cognition: **Response inhibition**

Switching between tasks that require prioritization of the most important task. This might be seen as walking too quickly or a shuffling gait pattern.

Helpful Cognitive Exercise: **Inhibition Training**

Opposite Stepping--Say what it says, and step opposite. If it says right side, step left side; if it says step left forward, step right backwards (see stroop grid)

"Go and no-go" with boxing drills

Impact of PD on Cognition:
Short term and procedural memory

Difficulty tying your shoes or sequencing transitioning from sitting to standing.

Helpful Cognitive Exercise:
Attention Practice

While performing squats, count backwards from 100 by 3's, 4's, 7's, etc.

From left:
Chuck Bundrant;
Chuck and wife Diane
at Captains for a Cure;
Chuck in Alaska

THE PASSING OF AN ALASKA SEAFOOD LEGEND

CHUCK BUNDRANT

a true legend in the Alaska seafood industry, passed away October 17th at home in Edmonds, Washington, surrounded by his family and friends. He was 79.

He leaves behind his wife, Diane, son Joe (Mary), daughters Jill Dulcich (Frank) and Julie Bundrant Rhodes (Randy), 13 grandchildren, 5 great grandchildren, with two more on the way, his sister Linda Nelson (Doug), nieces and nephews and many others in his broader "Trident Family," all whom he loved dearly and touched with his passion, vision, generosity and unwavering determination to create opportunity for all of them despite monumental challenges at sea and ashore.

Chuck and his wife Diane were longtime supporters of APDA. First in support of a friend, and then later after Chuck was diagnosed himself with Parkinson's in 2006, a diagnosis later revised to Progressive Supranuclear Palsy, an atypical form of PD. APDA, along with Deadliest Catch Captains and the fishing community, celebrated Chuck in 2019 at Captains for a Cure, which raised $380,000 and funded a research grant in Chuck's honor. Friends and guests at the event were greeted with his warm smile and signature "thumbs up."

Chuck will be remembered for his genuine desire to forge a sustainable Alaska seafood industry that benefits all stakeholders. Chuck led and invested in a lasting future for North Pacific fisheries resources. His processing innovations will drive improvements for generations. He made many sacrifices to create opportunity for his family. He risked everything early on to nurture a stronger seafood industry in Alaska.

While Chuck is remembered for his shrewd business skills, toughness and determination, his generosity and belief in others were equally recognized and key to his success. Every business partner, fisherman, community leader, supplier, customer, employee and competitor were personally important to Chuck. His love for the State of Alaska, his loyal independent fishermen, his employees, and customers around the world was evident to all. To him, they were all extended family, and that spirit infuses the people of Trident who will carry on his legacy of servant leadership.

Chuck had a unique ability to motivate success with a combination of high support and high expectations. "I find I get a lot out of people when I push them," he used to say with a smile. But he was never immune to his own tough love. He pushed himself harder than anyone else and was always the first to show up if others needed help.

Chuck Bundrant leaves us with his great expectation and abiding challenge to achieve the impossible while looking out for one another along the way. He departs wrapped in the love of God and his family.

2021 Accomplishments

Take Control Education Programs

- **Sleep & Fatigue**
  Dr. Rebecca Gilbert
- **Neglected Clinic Topics**
  Dr. Laurie Mischley
- **Case Studies**
  Dr. Pravin Khemani
- **Homecare & Home Health**
  Shawn D'Amelio
- **Avoiding Apathy**
  Nate Coomer, DPT
- **Vision Issues**
  Dr. Steven Hamilton
- **Deep Brain Stimulation**
  OHSU DBS medical team
- **Dementia/Cognition**
  Dr. Nancy Isenberg

Passport to Research

- **Novel Trials**
  Dr. Jason Aldred
- **Disease Modifying Trials**
  Dr. Daniel Burdick
  Dr. Pinky Agarwal
- **Participate! PWP panel**
- **On a Molecular Level**
  Dr. Rebecca Gilbert
  Dr. Ian Martin
  Dr. Vivek Unni

Create Joy

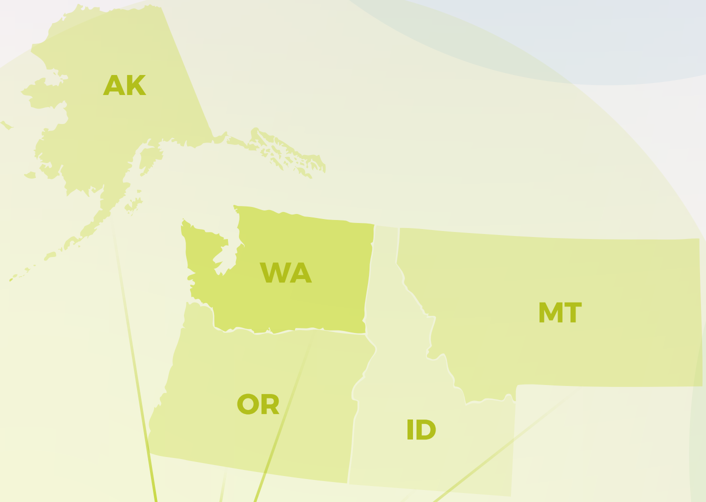
- **Puppetry**
- **Improv**
- **Poetry**
- **Laughter Yoga**
- **Pantomime**

Research

- **Washington PD Research Registry**
  - **APDA is sole funder**
- **Pathfinder Research Article**
- **$1.4 million awarded to researchers**

Programs for Newly Diagnosed

- **PRESS Support Series**
- **Parkinson's Good Start**



Patient Aid Scholarship Program

Professionally-led support groups
- General
- Atypical Parkinson's
- Care Partners
- Caregiving during Quarantine
- Flying Solo

2021 was a big year for APDA Northwest, we found new and innovative ways to virtually serve thousands across the Northwest and beyond!

Exercise Programs
- **Yoga for PD** Peter Lynch
- **Body Moves** Dotti Harness-Foster
- **Dance** Chris Daigre
- **Rock Steady Boxing** Pavitt Fitness

Resources
- Webinars
- Smart Patients online community
- Free publications
- Info & Referrals
- Quarterly Parkinson's Pathfinder
- A Closer Look blog
- Specialized Resources
  - Spanish Speakers
  - First Responders
  - Veterans
  - Young Onset
  - Fitness Professionals

AMERICAN PARKINSON DISEASE ASSOCIATION
NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

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Seattle, WA 98109

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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**

Send checks in the attached envelope, or in your own mailer to us at **180 NICKERSON, STE 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.

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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 ______

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Thank you for your generosity!