

2 Hiking with PD
an Essay

6 Tools and Tips
for Tremors

10 COVID-19 & PD
Q & A

PARKINSON *Pathfinder*

WINTER 2020

apda AMERICAN
PARKINSON DISEASE
ASSOCIATION
NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

**Go Green
and Save Green!**

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

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

WINTER 2020

TABLE OF CONTENTS

- 1 Letter from the Executive Director**
- 2 Lay Down the Backpack**
Laura Kennedy Gould
- 4 OHSU Researcher awarded a 2020 APDA Post-Doctoral Fellowship for the Study of Mutations in the LRRK2 Gene**
Nick Pernisco
- 6 Trouble with Tremors? Tips & Tools for Everyday Living**
Sumedha Kukreja, OT MBA & Jay Berger, PT CDB, certified in LSVT, Pulmonary Rehab and OTAGO
- 10 Answering your Questions about Parkinson's Disease and Coronavirus Disease**
Dr. Rebecca Gilbert
- 14 The Story of Ron & Stephanie: How a will can leave a legacy**
- 16 Life Happens: PD and Monthly Giving**
Bob Dixon
- 17 APDA 2020 Accomplishments**

apda AMERICAN
PARKINSON DISEASE
ASSOCIATION
NORTHWEST CHAPTER
Strength in optimism. Hope in progress.

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

Phone: 206.695.2905
Fax: 206.455.8980

apdanw@apdaparkinson.org
apdaparkinson.org/Northwest

APDA NORTHWEST

EXECUTIVE DIRECTOR
Jean Allenbach

PROGRAM DIRECTOR
Jen Gillick

DIRECTOR OF DEVELOPMENT
Kirsten Richards

BOARD OF DIRECTORS

PRESIDENT
Dwight Jones

TREASURER
Sandra Ruedt

SECRETARY
Laurie Thompson

MEDICAL DIRECTOR
Pravin Khemani, MD

DIRECTORS
**Suzanne Cameron
Carl Carter-Schwendler
Bryan Coluccio
Leanne King Devitt
Brian Harris
Shaheen Kaplan
Steve Palmer
Mary Schimmelman
Rene Spatz**

SUPPORT FOR THIS ISSUE PROVIDED BY

**Boston
Scientific**
Advancing science for life™

DBSandMe.com

Follow us
on social media:
stay connected!

 @apdanorthwest

 @apda_nw

 @apda_nw

www.apdaparkinson.org/Northwest

COVER

Randy Devitt

Photo by Leanne King Devitt



I hope this edition of the *Pathfinder* finds you and your loved ones settling in for a cozy and healthy holiday season. There is no way to sugarcoat it, 2020 has been an exceptionally difficult year. At APDA, we are acutely aware that social connection and exercise are key to living life to the fullest with PD (even during a pandemic!) and will continue to work hard so that everyone has access to the resources they need to stay healthy. **Take a look at our accomplishments on page 15**, we are proud of all that we've achieved so far!

As 2020 comes to a close (and thank goodness for that!), I've been reflecting on all that I am grateful for this year. **At the top of that gratitude list is YOU.** Whether it is your willingness to log in to a Zoom support group meeting, put in the effort to create a safe home workout space, watch an online education webinar, or generously offer financial support, **we appreciate YOU.** Your flexibility and resolve—in spite of numerous obstacles—are making it easier to keep people connected, informed, and exercising, as well as providing the financial support to anyone struggling to make ends meet.

As someone with a close connection to Parkinson's, you understand how difficult this disease can be. You also realize how important it is to support everyone impacted by PD, through patient service programs, education, and investing in promising research.

The upcoming year looks to be a challenging one for nonprofits like APDA, who rely on individual donors to keep our doors open. You can make an immediate impact by donating online at apdaparkinson.org/Northwest or tearing off the form below and mailing to APDA.

Your support matters now more than ever.

With gratitude,


Jean Allenbach



Thank you for mailing your gift to APDA 180 Nickerson Street, Ste 108, Seattle WA 98109

YES!

I want to help provide support, education and research for Parkinson's disease.

Enclosed is my gift of \$50 \$100 \$250 \$500 Other: _____

MY INFORMATION

NAME

MAILING ADDRESS

CITY

STATE

ZIP

EMAIL

PHONE

My gift In memory of In honor of: _____

For my tribute gift, please send acknowledgement to spouse/family at the address below:

NAME

ADDRESS

Lay Down the Backpack

By **Laura Kennedy Gould**



*Paul and Laura on 2019
backpack with Pass to Pass group.*

Carrying a 25-40 lb pack on your back—everything you need for a few days on the trail—was daunting for me even when I backpacked in my 30s. Now in my 60s the idea of wrestling with backpacking while also trying to manage Parkinson’s was even more intimidating. Back in my 30s, when I was courting a handsome outdoorsy man, I did more backpacking than I’ve ever done before or since. I had a great feeling of accomplishment and the backpacking enabled me to see beautiful mountain scenery I couldn’t see any other way. Oh yes! I also got the guy—we’ll be married 28 years in January.

After we got married, we continued to do the occasional backpack and I wanted to continue this activity even after I got the Parkinson’s diagnosis eight years ago. But eventually I needed to lay down the backpack, and focus instead on new ways to get out to the nature I love.

In 2016, I came across Bill Meyer’s Pass To Pass organization, a group of Parkies and others who backpack every summer to raise awareness and funds for PD. Llamas carry the heavy stuff. Hmmm... that sounded manageable and I thought I might backpack again “someday”.

Finally, “someday” arrived. In 2019, Bill asked me if my husband and I would like to be shadow hikers. We would meet the group

part way through their 5-day hike, provide a fresh lunch, and join them for the last three days. OK, sign me up.

I did two trials as preparation: I slept outside in tent and sleeping bag, and I day hiked a steep trail (7 miles round trip, 2100' gain) carrying the backpack with a half load of about 10 pounds. I passed both trials.

How did I fare on the trail? The first day I had the luxury of having the llamas carry my sleeping bag and food bag. I had the pleasure of meeting the intrepid Parkies and support hikers doing the full 5-day Pass to Pass trek. But after a sleepless night in a claustrophobic tent, I persuaded Paul that we should hike all the way out the next day. "I can do this," I thought, based on the information I had: 11 miles, all downhill.

Ha ha. Much to my surprise, there was plenty of elevation gain and almost equally taxing elevation loss. The "elevation loss" information I had was a net amount, and the true distance was more like 12 miles. And of course, since we had separated from the group, we could no longer make use of the llamas. Thankfully, my handsome sherpa came to the rescue. He was already carrying the tent, stove, fuel, cooking pot, and water purification. To that he added one of the backpacking chair pads, carried my sleeping bag in his hand for the last three miles, and then for the final mile he came back to carry my whole pack. What a guy!

You would have thought this would be the point where I would say "no more backpacking", but I wasn't quite ready. In January of 2020, I put out a blogpost inviting others to share the mule we had arranged for an August backpack in one of the Northwest's most beautiful spots: The Eagle Cap Wilderness in eastern Oregon.



Left: Still smiling—before Laura started on trial backpack, July 2020

Below: The best part of backpacking—the junk food afterwards. The legendary onion rings at Zeke's.

In this pandemic year, no takers on sharing the mule. Suddenly it was July and I needed to pay up the rest of the tab for the mule. Was I really going to be able to do this? Time for a trial backpack. With the usual summer construction delays, it took us some three hours to get to the trailhead. This is not an irrelevant comment. I found that, with Parkinson's, that long in a car (even with breaks) means I was already stiff and sore before I started down the trail.

We hoisted the packs on our backs and off we went. Immediately I turned into a zombie. Even though the trail had a very mild grade, e-v-e-r-y--s-t-e-p--w-a-s--a-g-o-n-y. The pack weighed a bit more than 22 pounds, not a lot for a backpack, and my Sherpa-For-Life was carrying our tent, water filter, cooking pot, stove, and fuel. But I felt like I was carrying a boulder which rested entirely on my right butt and right thigh. I would trudge 4 or 5 steps and then have to stop to rest. When I finally staggered into a clearing and had a little lunch, I was able to check my watch: it had taken me nearly an hour to go...about a half mile.

Pretty easy to make the call—neither this trial backpack nor the one in August were going to happen. Yes, I was disappointed, but frankly mostly I was relieved.

We still went to the Eagle Cap but the adventure turned out differently. Paul and I still hauled in our clothes and food for 8.5 rough rocky miles, but at the end was gourmet dining and fluffy beds at a lodge grandfathered into the wilderness. Later in the trip, we were joined by my fellow Parkie blogger Carol Clupny and her husband Charlie. Carol had suggested we car-camp and hike together while our husbands did the backpacking and this worked out beautifully. Our husbands were eager to tackle a more challenging backpack, while Carol and I day-hiked. She and I still got to explore the beautiful area and take in some fabulous mountain views, then return to our comfy campers for a glass of wine by the Wallowa River. It was a good lesson for me: If I stay flexible and positive, I can still enjoy my adventures in nature, even with Parkinson's.



Laura Kennedy Gould was diagnosed with Parkinson's disease in 2012. She writes about her experiences and Parkinson's research in her blog "The Magic Trick—Life with Parkinson's" at <http://magickrickparkinsons.wordpress.com/>. She and her husband Paul live in Burien, WA.

OHSU Researcher awarded a 2020 APDA Post-Doctoral Fellowship *for the Study of* Mutations in the LRRK2 Gene

By **Nick Pernisco**

DR. JUDIT PALLOS is a researcher at Oregon Health Sciences University (OHSU), and the recipient of a one-year \$50,000 APDA post-doctoral fellowship to conduct the study of mutations in the LRRK2 gene. Her work is under the supervision of world-renowned Parkinson's researcher Dr. Ian Martin.

Dr. Pallos is using fruit fly models to study the mutations in the LRRK2 gene and how this gene affects the onset and progression of Parkinson's disease. Fruit fly models (also called *Drosophila* models) are often used in studies of degenerative diseases because they generate a large amount of data in a small amount of time. *Drosophila* have a median lifespan of 35-45 days, so scientists use them to accelerate the discovery process in diseases like Parkinson's or Huntington's, which would take decades to study in humans.

The degeneration of the axon, the long, slender projection of a nerve cell used to communicate with other nerve cells, is observed in Parkinson's disease patients and in animal models of the disease. Since the mechanisms leading to this degeneration and their relationship to the death of neurons are not well understood, this is an excellent use of the fruit fly model to better understand the phenomenon.

A protein called prospero (corresponding with PROX1 in humans) has recently been identified as a modifier of motor deficits and neuronal loss in a mutant LRRK2 fly PD model. Since prospero is a transcription factor with an already established role in neuronal outgrowth and maintenance, the identification of other proteins that

interact with prospero and contribute to neuronal defects is an area of research ripe for further exploration.

Using the mutant LRRK2 fly across different ages, Dr. Pallos will measure



"Every little clue can contribute to understanding why the neurons die—and if we knew what exactly is happening, we could design interventions to **stop or prevent or maybe even cure those already suffering from this disease."**

DR. JUDIT PALLOS

levels of the cellular targets that prospero is involved in transcribing. She can then use a unique single dopamine neuron labeling approach to determine whether defects in nerve cell projections in the mutant LRRK2 nerve cells can be improved if these targets are altered.

The goal of this research is to determine how proteins in neurons play a role in cell degradation when the mutant LRRK2 gene is present. This may help us better understand how dopamine-producing cells die and could lead to improved therapies for human patients.

In Dr. Pallos's own words:

"One part of my project is to get a better understanding of how neuronal degeneration happens: we will look at single dopaminergic neurons in the PD fly brain, and study how it degenerates as the fly ages. What part of the neuron is affected? When does this happen? What is the timeline of the events leading to overt neuronal death? Understanding this is important for finding interventions that can help.

My goal is to add a grain of sand to the castle of knowledge. Sometimes I hope it will even be a pebble. I hope my results will give insights to others the same way I get ideas from work published by other researchers, and that step by tiny step we inch forward towards understanding the pathogenesis. It is like being a detective. Every little clue can contribute to understanding why the neurons die – and if we knew what exactly is happening, we could design interventions to stop or prevent or maybe even cure those already suffering from this disease.

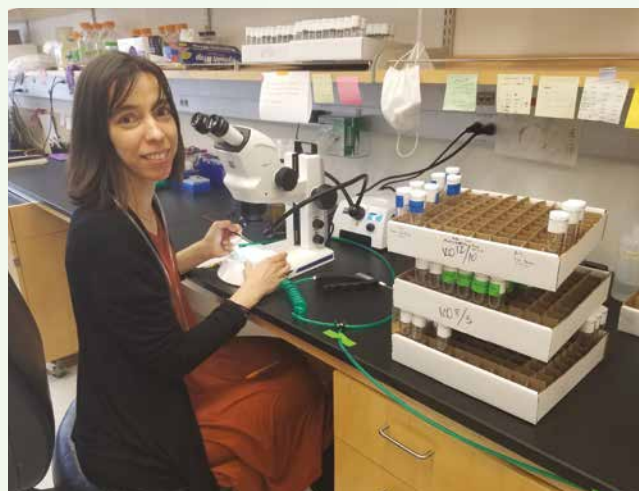
PD is a complex disease and elucidating any aspect of it can bring us closer to finding new treatments. My focus is on understanding the early events before overt neuronal loss, as I think we could have the biggest impact on changing the course of the disease if we identified the key early players."

Proudly investing in research since 1961

APDA is committed to investing in cutting edge research focused on discovering the causes, treatments, and finding the cure for Parkinson's 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 \$49 million in research since 1961. For the 2020-21 funding year APDA has awarded \$1.4 million in the form of three post-doctoral fellowships, five research grants, APDA's first-ever Diversity in Parkinson's Disease Research grant, and eight APDA Centers for Advanced Research.

All APDA grants are awarded through a competitive application process and reviewed by APDA's Scientific Advisory Board (SAB). "APDA is steadfast in our research focus - identifying and supporting researchers early in their careers to encourage them to either commence or continue dedicating themselves to PD research, as well as to help established investigators pursue new and novel ideas" states Rebecca Gilbert, MD, PhD, Vice President and Chief Scientific Officer, APDA. "We are excited for these researchers to commit themselves to their work and have hope for meaningful outcomes that can make a difference for people living with PD."

Additionally, APDA Northwest Chapter is committed to funding of the Washington State Parkinsons Disease Registry. 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. Find out more at registerparkinsons.org



MORE ABOUT

Dr. Judit Pallos and Her Work

Dr. Pallos received her PhD from the University of Szeged, Hungary, and studied Huntington's disease at UC Irvine in California. She is excited to conduct her study using a fly model to simulate Parkinson's in humans.

After earning her PhD, Dr. Pallos paused her career to raise her children, spending more than 9 years away from research. During that time she took care of her young children, served as a curriculum consultant for a Montessori and a volunteer science teacher at a public elementary school. She considered shifting to education entirely, but research kept beckoning to her.

Her first step was finding a university and an advisor who would oversee her work. Her husband started looking for a new job, and they focused their search in Oregon. Dr. Pallos said they chose this state based on "the (very) few things we knew about it: that it is very green, not too crowded, yet excitingly multicultural and interesting." The first time they visited was when they drove up to their new home with two cars, three kids, and three frogs. She knew within a few days that they had made the right choice. She researched her options at OHSU and learned that they had several labs with a focus on neurodegeneration, some of which even used *Drosophila* (the flies used in her study), which was a "dream fit" given her background of using flies to study Huntington's earlier in her career.

Now there was just the question of funding her research. Dr. Ian Martin already had a connection to APDA, and he suggested that Dr. Pallos apply for a fellowship. She found out in August that she was awarded the fellowship.

"It was very encouraging to me that APDA would support a candidate like me, someone who has taken a long career break. It is tricky for women to navigate the decision of whether and how long of a break they can take. You worry about closing too many doors. I am grateful to both Ian and APDA that they were able to look at my performance prior to taking time off, and invest in a person who has taken a break to raise a family."

Trouble WITH Tremors?

Tips & Tools for Everyday Living

Sumedha Kukreja, OT MBA

**Jay Berger, PT CDB, certified in LSVT,
Pulmonary Rehab and OTAGO**

A variety of adaptive devices are available that make life easier and more enjoyable by improving or minimizing tremors, and help with simple daily skills like eating, dressing, cooking and writing. They can reduce your effort and frustration, as well as increase independence, ability to remain in your home, and boost confidence. Many even look like common household items that people not dealing with tremors might use.

While there are some strategies to dampen the movement (covering liquids, only filling cups/bowls ½ to ¾ full, and keeping your elbow close to your body and your forearm on the table) they are often not sufficient. And voice to text can be annoyingly inaccurate.

Please note: The products listed here are suggestions. Listing these products does not constitute an endorsement. Neither APDA nor VirtualKare are receiving payment for including these items in this article. If the item is FDA approved, check to see if insurance will cover it before purchase.

Tremor dampening devices use several methods to achieve results:

- **Weight**
- **Silicone (or other non-slip) covering**
- **Widening or modifying the grip or item shape**
- **Two handles instead of one**
- **Suction bases and non-slip mats**
- **Straw or sipper-like piece options**
- **Electronic devices that counteract and dampen the tremor**



WRITING

◀ **HEAVY Super Big Fat Weighted Pen (Twin Pack) by CKW Ventures LLC**

Fat, heavy (3.5oz) pen with long-lasting metal ink cartridges to write smoothly and clearly. Set of 2.

<https://amzn.to/3lHgaMZ>

WEIGHTED DEVICES YOU WEAR



▲ **Men's Large Heavy Stainless Steel Bracelet**

Beautiful 303g (¾ lb) silver link wrist bracelet heavy enough to dampen tremors and still move arm easily.

Two sizes. www.wish.com

▲ **Silicone Adjustable Weight Bracelet by Prokth**

Fashionable, silicone bracelet with spaces to insert stainless steel cylinders to increase or decrease weight. Secures with stainless steel buckle. Comes in set of 2. <https://amzn.to/2FHanoA>



▲ **Parkinson's II Bracelet by AlexHealthJewelry**

Stylish, handmade crystal and amethyst bracelet that can be personalized, made to order. <https://www.etsy.com/shop/AlexHealthJewelry>

▲ **Parkinson's Essential Tremor Bracelet by AlexHealthJewelry**

Stylish, handmade, and made of natural stones. <https://www.etsy.com/shop/AlexHealthJewelry>

▲ **Maddak Ableware Steady Write Writing Instrument by SP Ableware**

Pen with wide triangular base with black ink for both right or left-hand use. Refills purchased separately.

<https://amzn.to/2GJgV9F>

EATING AND DRINKING



▲ Adaptive Utensils by Special Supplies

Dishwasher-safe, stainless-steel fork, knife, soup, and teaspoon with a wide, ribbed, weighted, food-grade silicone handle (it's also bendable)
<https://amzn.to/2FohJQx>

Liftware Steady Starter Kit by Liftware

An electronic device connects to the included soup spoon to counteract tremors (claims 70% more stabilization). Comes with a travel pouch, hand strap, and charger. Fork, spoon, and spork attachment sold separately.
<https://amzn.to/34LQGY0>

Gyenno Smart Portable Spoon by Gyenno

An electronic device attaches to utensils and counteracts hand movement (claims 85% less hand shaking). Comes with stabilizing handle, spoon attachment, fork, charging box and cable, and user manual. Fully charged, runs for 3 meals. Batteries are replaceable.
<https://amzn.to/3IS6ijN>

▼ Easy Grip Hand in Mug by Sammons Preston



16oz. polycarbonate cup with center opening to slide a hand through to hold the mug, instead of grasping the handle or cup. Rotating lid spins 360 degrees; easy open / close lever great for drinking on-the-go.

<https://amzn.to/3jTjWT1>

Kids (all ages really) Stainless Steel Cups by Soumou

Dishwasher safe, 16oz. stainless steel cup for hot and cold liquids. Thick, silicone sleeve protects hands from extreme liquid temperatures. Comes with 2 straws, silicone tips and cleaning brushes.
<https://amzn.to/3djUDXR>

Modaliv Scooper Bowl with Silicone Placemat Suction Base by Seyles

Dishwasher and microwave safe 36oz scooper bowl with high rim, contoured lip, suction cup and silicone placemat. Eat easily with one hand without the dish moving, tipping, or spilling.
<https://amzn.to/2SLaLYW>

Scoop Dish by Sammons Preston

Sturdy plastic, top dishwasher safe, 8" scooper bowl with non-skid rubber padded bottom. Contoured lip traps food to easily push onto cutlery.
<https://amzn.to/2Fm8pfQ>



MEMORY

◀ Pro Tracker With Replaceable Battery by Tile

Small bluetooth device works 400 ft to help you find any item you attach it to. Optional Alexa device for voice control.
<https://amzn.to/34avqfj>

GRIP AIDS

▼ EazyHold Silicone Adaptive Aid by EazyHold

Two dishwasher-safe stretchy silicone straps let you use the full hand around an item for better grip and sensory awareness. Comes in 8 sizes.
<https://amzn.to/3nlkb5C>



We know the costs of adaptive equipment can be a hardship for many.

APDA is here to help through our **Patient Aid Scholarship program.**

Apply for an annual **\$300 grant** through our **Patient Aid Scholarship program**, designed for individuals who are struggling to make ends meet.

Visit our website for more information and an application or give us a call.

OUTLETS AND LIGHTING

Smart Plug by Amazon

Plug in and talk through the Alexa app to turn on/off lights, fans, and appliances, schedule them to work automatically or control them while away. Alexa not included. <https://amzn.to/37qCrKW>

Smart Light Bulb by Treatlife

Voice or app controlled, dimmable, adjustable brightness, color (warm white to cool white) can also relax you. Works in any standard E26 light socket. Energy saving LED bulbs equivalent to 60W traditional incandescent bulbs. Saves up to 80% energy, longer life. Works with Alexa, Google Assistant. <https://amzn.to/31mvJ57>

SAFETY MANAGEMENT



Video Doorbell by Arlo

See (180 degree view, head to toe) and talk to visitors, even away from home. Motion detector sends notification if it detects movement. Has alerts, built-in

siren, night vision, can call your phone too. Easy installation. Waterproof. Alexa capable. <https://amzn.to/2HcDqUn>

3G WiFi Phone Call GPS Smart Watch, Real-time GPS Tracking, Touch Screen, Camera, Step Counter, SOS Alarm Anti-Lost GPS Watch by Laxcido

Real time tracker with 3 month store of data, free Android and IOS app software and web tracking platform, SOS one button emergency call, can work as cell phone (need SIM card), Electronic Geo-fence alerts when person leaves area, remote voice monitoring, step counter, alarm clock, voice chat. Note: Black version is for adults. <https://amzn.to/347CNUY>

SLEEP

360 c2 Smart Bed by Sleep Number

Temperature-balancing mattress responds automatically to your movements to adjust firmness for a good night's sleep. Assesses your sleep quality to help you improve your sleep. www.sleepnumber.com/360

Somneo Sleep and Wake Up Light by Phillips

Natural sunlight that simulates sunrise and sunset, and natural sound options to help regulate your sleep pattern and relax. Some units have FM radio. <https://amzn.to/35qzWz>

Alexa, Google Voice, and such Change the room temperature and turn on/off lights

Apple Health app can regulate your sleep wake cycle.



SleepPhones Wireless Headband Headphones by AcousticSheep

Bluetooth headphones encased in a soft headband (comes in 3 sizes). Easy to use to set up for a good night's sleep or simply relax. <https://amzn.to/359i0zI>

ThevoCalm Mattress

With their patented MiS Micro-Stimulation in the core of the ThevoCalm mattress, this mattress has been designed specifically for people with PD. <https://www.thomashilfen.us/thevocalm>

CLEANING

S5 Pure by Roborock

Auto charging, robotic mop and vacuum cleans and mops pet hair carpet and hard floor. Quiet operation, and cutting-edge room-mapping tech. Alexa option extra allows you to schedule, custom and spot clean, store "mapped areas" and more. <https://amzn.to/34a7rNI>



amazonsmile
You Shop. Amazon Gives.

Did you know that you can support APDA when you shop at Amazon?

Through AmazonSmile, a portion of your purchase is donated to APDA.

Go to <https://smile.amazon.com> and choose American Parkinson Disease Association as your charity of choice.

BATHING AND GROOMING



▲ Digital Shower Interface by Kohler

App controlled shower head can control shower outlets, has audio output, chromatherapy, steam and lighting. Stores 6 user-defined settings, two shower temperatures. Pre-programmed temperature and hydrotherapy programs for spa-like experience.

<https://amzn.to/3dFsgne>

Neo Non-Electric Bidet Toilet Attachment by Neo

Self-cleaning (front and back) Dual Nozzle attaches to any standard 2-piece toilet. Easy to assemble and adjust water pressure.

<https://amzn.to/35afZmT>

▶ Norelco Shaver by Phillips

Electric, cordless shaver with 4 flex heads that flex and float in 4 different directions.

Pop-up trimmer for mustache and sideburns. One-touch open for easy cleaning. 40 min /8 hour charge (about 13 shaves).

<https://amzn.to/34c7YP4>



◀ Electric Water Flosser by Waterpik

Removes up to 99.9% plaque and 50% more effective than floss for improving gum health

with on/off handle switch. Features massage mode, 10 pressure setting, built in time/pacer. Top dishwasher safe. 7 colors. <https://amzn.to/2H5wdpo>

DRESSING

Dressing Aid Pocket Dresser by Vive

All-in-one dressing tool with quick-release hand strap and pocket clip for pant and shirt buttons, zippers, shoe knots, and small buttons. Pocket-knife size.

<https://amzn.to/3o5DFkM>



▲ Maggie Snaps by Maggies

No-sew reusable magnetic fasteners replace buttons and snaps in silver, gold, and black 4 pack.

<https://amzn.to/3m2nmTU>

Magna Ready

Button down shirts and jackets with Magnet closures.

<https://magnaready.com/>

About the Authors



Jay Berger is a co-founder of *Virtual Kare* and a physical therapist for over 30 years, as well as a clinical educator and trainer to Physical Therapy students, clinicians, and laypersons. She has co-authored and presented clinical research and case studies, and training videos to help teach others of her unique skills. Jay is responsible for program development, content creation, and staff training.

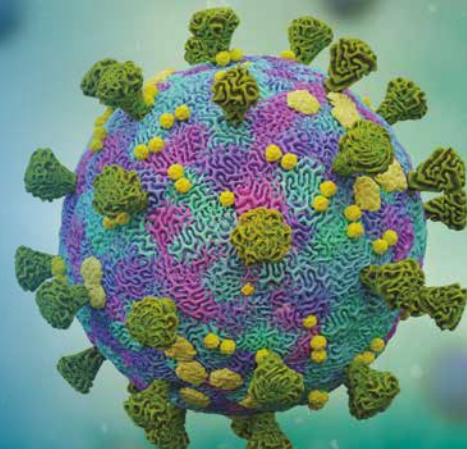


Sumedha Kukreja is co-founder of *Virtual Kare* and an Occupational Therapist with an MBA and 30 years of global healthcare experience as a clinician and in management. She brings strategic thinking and a strong understanding of policies and challenges in healthcare delivery. Sumedha is responsible for business development, operations, and marketing.

Visit us at: <https://www.virtualkare.com> Call us: +1 (866) 505-5518

Answering your Questions about Parkinson's Disease and Coronavirus Disease 2019

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



With the continued spread of Coronavirus Disease 2019, also known as COVID-19, in the United States and throughout the world, Parkinson's disease patients have been reaching out and asking questions through APDA's Ask A Doctor website portal. Dr. Rebecca Gilbert, APDA VP and Chief Scientific Officer, has been answering these questions and keeping the information about PD and COVID found on our website as up to date as possible.

Here are some of the latest answers to submitted questions.

Additionally, for the most accurate information about the virus, please focus on reliable websites such as the Centers for Disease Control & Prevention (CDC) or information from your local health department.

—

Q: My husband has PD with moderate symptoms. Normally, he is independent with all his activities, although he walks slowly. One day, his symptoms worsened dramatically, and he was not able to walk. I took him to the ER where he tested positive for COVID-19. His recovery has been very slow and he is now in rehab. Is this normal? Will he recover?

A: In general, people with PD and other brain illnesses often have 1) worsening of their PD symptoms in the face of inter-current illnesses such as COVID-19, and 2) have a slower recovery to their baseline once they have recovered from the inter-current illness. It sounds like both of these have happened to your husband. However, with proper rehab and some perseverance, there is hope that he will slowly return to his baseline.

Q: I have PD. Now that the country is "opening up", what should I do? Should I start to venture out or continue my current practices of staying at home and only going out for walks if I can safely stay six feet away from others?

A: Various states are creating plans to "reopen" if/when the rate of new cases of COVID-19 slows down. (It should be noted that in many places in the US, new cases are not slowing, yet reopening is taking place anyway.) It is important to reiterate

that the risk of a complicated course of COVID-19 is not the same for everyone. People who are over 65 and have underlying medical conditions will continue to need to be careful even though their city is opening up. Small studies from around the world are examining whether PD is an underlying medical condition that increases the risk factor for worsened COVID-19. For those with advanced symptoms, the answer seems to be yes. For those with mild symptoms, the jury is still out. The PD community will therefore have to be more careful than the general population as we ease back into "normal" life. If you must be in a situation in which there are other people around, wearing masks and staying more than six feet away are important, and don't forget to wash your hands frequently. These measures reduce (but do not eliminate) the risk of transmission and should continue even if others around you are not complying.

Q: I have multiple home health aides who come into my home to help in the care of my husband with very advanced PD. Should I eliminate this care because of the concern that these aides will inadvertently infect him?

A: I have been getting a variation of this question from many people. There are no easy answers. It does not seem realistic to make you the sole caretaker of your husband who typically needs multiple people in addition to you to help him over the course of the week. It does not seem that this would be a good solution for him or you. Of course every time someone comes into your house they could be bringing the virus in, even if they are asymptomatic, but he would be at increased risk of falling for example, if you were solely responsible for all his care. So there are risks in both directions, but in this case it is likely that the benefits outweigh the risks and you should continue to have at least some of the aides continue to come to your house.

I would make sure the aides are scrupulous about their hand hygiene throughout the day and remind them to avoid touching their face, nose, and eyes. Frequently-touched surfaces should be cleaned often and disinfected. Of course, if any of the aides are not feeling well, they should NOT come to the house.

Q: Can the stress of the COVID-19 situation make Parkinson's symptoms worse?

A: Stress can definitely increase PD symptoms. I have discussed the relationship between stress, anxiety and PD in general before and COVID-19 has certainly created a very stressful environment for everyone right now. It is being felt much

more acutely by older adults and those with chronic medical issues, members of the population who have an increased risk of complications from COVID-19 infection. Many people with PD experience anxiety as a non-motor feature of their PD, and many are reporting that anxiety has increased during this very tense time. To help minimize stress and normalize the current situation, be sure to establish daily routines, continue to exercise at home, and stay connected with family and friends online or on the phone. Also, take a break from the non-stop news coverage of the pandemic and enjoy a good book or fun TV show.

In addition to a potential worsening of PD symptoms from the overall stress of the COVID-19 situation, people with PD should also be aware that PD symptoms would also be expected to worsen if they were to contract the COVID-19 virus. In general, it is very common for PD symptoms to get worse when there is any inter-current illness. In the pre-COVID era, if PD symptoms worsened suddenly, a clinician would be suspicious that an infection was brewing such as a UTI, the flu or bacterial pneumonia. So there is every reason to believe that symptom worsening would also occur with a COVID-19 infection as well.

Q: Who is more at risk from coronavirus: a person with PD and no other health issues, or someone with diabetes, heart disease or lung problems?

A: Without more specific information about PD and COVID-19, it is difficult to evaluate this question. It is very clear from the data emerging from the ongoing pandemic that the risk of complications from COVID-19 rises steeply with age and with co-morbid medical conditions such as diabetes, heart disease and lung problems. We do not have similar data yet for people with PD.

PD is a very variable disease. Some people who are young and have very mild PD may not have any increased risk from coronavirus. However, we don't know that for sure.

What features of PD could increase complications from coronavirus?

Although we do not have enough data regarding COVID-19 and PD specifically, we can extrapolate from experiences of people with PD and other viral respiratory illnesses

PD and other viral respiratory illnesses

PD motor- and non-motor symptoms can be exacerbated by any medical illness, including a viral respiratory illness. This means that in addition to the respiratory symptoms of the virus, people with PD may feel that they are slower and stiffer than usual and that their medications don't seem to be working as well. Hallucinations may start in a person who never experienced that symptom before. Recovery from the illness can be more drawn out. Since COVID-19 is a viral respiratory illness, it would be reasonable to assume that someone with PD who contracts COVID-19 could experience these complications as well.

In addition, people with PD may have restrictive lung disease which refers to an inability of the lungs to fully expand with air. Restrictive lung disease can occur in PD because of rigidity of the muscles of the chest wall as well as bradykinesia, or slowness of the muscles responsible for chest wall expansion and contraction. People with PD may also have abnormalities in the posturing of their trunk including head drop, stooped posture, tilting of the trunk and bending at the waist. These postures can restrict the amount that the lungs can fill up. PD can also predispose a person to dysfunction of swallow and difficulty clearing secretions from their airway. These issues could contribute to development of complications during a respiratory illness.

Because of these reasons, people with PD are always strongly encouraged to protect themselves from any infection as much as possible. Vaccines such as the flu vaccine and the Pneumovax vaccine (for bacterial pneumonia) are strongly recommended. (COVID-19 does not yet have a vaccine, but one is already in clinical trial).

People with more moderate PD also may start to experience decreased mobility, with more risk of falls. As PD advances it can cause additional problems including urinary dysfunction and weight loss. All of these elements can contribute to general frailty and increased risk of infection, including increased risk from COVID-19.

All things considered, it is good practice for those with PD, because of age and because of their underlying PD, to consider themselves at increased risk from COVID-19.

Tips and Takeaways

COVID-19 is a novel virus and **information on how it behaves is continuously evolving.**

Most people who are infected with COVID-19 will recover completely. However, **older adults and those with underlying medical issues are at an increased risk** of developing serious outcomes from COVID-19

as compared to those who are younger and healthier.

It is incredibly important for everyone, especially the PD community, to **follow all recommended risk-reduction guidelines and adhere to local regulations.**

PD symptoms such as balance problems/falls, swallowing difficulties, urinary dysfunction and weight loss **contribute to general frailty and increased risk of infection**, including increased risk from COVID-19.

Talk with your doctor about any concerns you have about COVID-19.



The story of Ron & Stephanie

How a will can leave a legacy

Ronald Miller and Stephanie Harris lived simply and cared deeply, creating a warm, inviting home out of a modest house in Indianola on the Kitsap Peninsula in Washington state. The couple met in 1970 and had what they joked as a “30-year engagement” before getting married in 2000 and honeymooning in a teepee on a friend’s property in Idaho. They never thought much about leaving a legacy.

Ron often lamented that he was not born a century earlier. The couple ate healthy “real” food, often from their garden, and cooked their meals on a wood stove. They didn’t add a telephone until the 1990’s (and Stephanie had to lobby for it!). Ron’s mother also lived in the neighborhood and if she needed Ron for anything, she called him by using a cowbell from her front porch. Ron worked for many years at the local transfer station, and often brought home a truckload of recycled metal, antiques, and vintage tools that he intended to repurpose for other uses; recycling and reusing was a valued lifestyle choice.

Ron and Stephanie lived active lives. They had a sailboat and loved to sail. Ron also loved to bike, and in his early 70’s, shortly before he was diagnosed with Parkinson’s in 2013, he biked the full length of Vancouver Island. Stephanie loved to travel, with one of her most memorable trips being to the Republic of Georgia with a friend from the Peace Corps. Ron’s favorite pastime was always splitting and chopping wood, which he did almost every day, up until he physically couldn’t.

Neighbors remember Ron for his signature beard, and picture him wearing those work coveralls and wearing a hat, and always working on a project. Stephanie was a tireless, devoted caregiver when Ron’s Parkinson’s disease symptoms started to slow him down. She sought out services to make life with PD a bit easier, and contacted APDA regularly for information and support.

They never would have referred to their property as an “estate.” But after Stephanie unexpectedly passed away in September 2019, a neighbor

*A gift that will make an impact
for hundreds of people
living with Parkinson's in the Northwest.*

Now that is a legacy.



suggested to Ron that he make a will. Even though he didn't think he had much to give, he followed his friend's advice. Ron passed away this past spring, leaving 25.5% to APDA, 25.5% to the Kitsap Rescue Mission, and the rest going to friends and neighbors. Turns out that Ron and Stephanie owned their home and after the estate was settled, that 25.5% turned into \$57,097 for APDA. What a tremendous gift from a couple who lived life somewhat on the margins... a gift that will make an impact for hundreds of people living with Parkinson's in the Northwest. Now that is a legacy.

*With special thanks to Beth Nichols for sharing
Ron and Stephanie's story*

FREEWILL

What will your legacy be?

Creating a will is a powerful way to support the people and causes you care about most. Get peace of mind and in just 20 minutes create or update your legally-binding will, free of charge. Have a lasting impact on the future of Parkinson's disease.

Secure your legacy for the people and causes you love today.

Find it online at:

www.freewill.com/APDAParkinson

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.

LIFE HAPPENS:

PD and monthly giving



By **Bob Dixon**

Life happens. Be it Parkinson's, COVID-19, or any other of life's challenges, I know that I need to adapt and adjust my lifestyle accordingly. This life. My life. Proper amounts of exercise, a good diet, and enough sleep all need my attention. It is not a crime to rest, renew, and refresh. It is, however, a crime to quit! I will never, ever quit. I know that I will not win my battle with PD, but I will give it one hell of a fight.

My PD is directly attributable to exposure to agent orange while in Vietnam in 1970-1971. I have a 100% PD service-connected disability due to that exposure, and because of that I get a monthly check from Dept of Veterans Affairs. At times this makes me feel guilty when talking with others who have PD, because I get a check and you don't, and we have the same condition. So while I take care of Bob, I also donate most of that check to worthy causes. I give to APDA and am interested in funding PD research. My wife Becky died in 2014 after two lengthy battles with breast cancer, so the American Cancer Society gets a donation. Becky and I both served as board members of two different chapters of the American Red Cross, and ARC gets a donation. We have both been active members of our church communities over the years, and I continue to increase those pledges.

I wish that, from my standpoint, I could make a larger contribution to APDA. I really do enjoy the Take Control presentations very much, and the Dr. Gilbert Hosts webinars, she does a great job leading those events. My takeaways from APDA presentations and publications are always very positive and thought provoking, even when the subject matter can be challenging.

Life happens. So get out and live it!

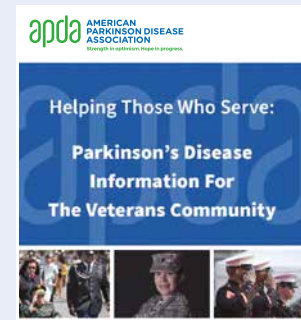


Above: **Bob Dixon lost his wife Becky in 2014, and then was diagnosed with Parkinson's disease 4 years later at age 71**

Top: **Bob Dixon's 2019 father's day skydiving adventure. Proving wrong the basic training drill sergeant who told Bob in the summer of 1970: "the only two things that fall out of the sky are bird sh*t and a damned fool."**

APDA Serves the needs of the Veteran's Community.

If you are a veteran and have been diagnosed with Parkinson disease, APDA is here to help. Veterans may be at an increased risk of PD because of their service particularly those who served in Vietnam because of exposures to pesticides and herbicides. In 2010, the Department of Veterans' Affairs (VA) added PD to the list of diseases with a presumptive service connection, based on the time and location of service.



Download APDA's booklet on our website or contact us to request a copy

APDA's *Helping Those Who Serve Handbook* is a publication available to veterans of the United States Armed Services. In this booklet you will learn about Parkinson disease, its symptoms, treatment, and the benefits available to you as a veteran. You will also learn about the six Parkinson's Disease Research, Education, and Clinical Centers or "PADRECCs". Each PADRECC delivers state-of-the-art clinical care, conducts innovative research, and offers outreach and educational programs to all veterans currently enrolled in the VA Healthcare System. **Two of these PADRECC's are located right here in the northwest—in Portland and Seattle.** For more information, call the PADRECC/Consortium Hotline at 800-949-1001, x5769 or visit their website www.parkinsons.va.gov.



Supporting groups on Zoom

helping hundreds see friends and maintain support networks

Personal phone calls

to check in on people with Parkinson's during stay at home orders

Invested in local wellness classes

in order to offer them free of charge for people with Parkinson's



Keeping people connected
RELATIONSHIPS

Individualized technology support

to support group leaders, wellness professionals and hundreds of others living with PD



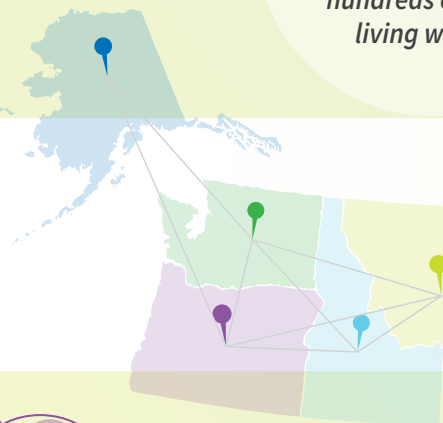
Keeping people moving
EXERCISE

Increased access

to a wide variety of the best free classes around the country



Yoga for PD
Dance
Boxing
Body Moves
Singing...
and more



APDA 2020

RESPONDING TO THE NEEDS OF OUR COMMUNITY



Keeping people informed
EDUCATION

44 downloadable booklets, educational supplements, and fact sheets

including 14 in Spanish (mailed versions available at no cost!)

Innovative Virtual Education Programs

watched live and on YouTube by thousands of people impacted by PD

Information packets and resources

sent to hundreds of newly diagnosed individuals across the NW

Providing financial support
PATIENT AID SCHOLARSHIP

Assisted Struggling Families

Provided \$300 scholarships to help families make ends meet



\$50,000 research grant

awarded in honor of Chuck Bundrant, Founder and Chairman of Trident Seafoods



Helping Research Happen Faster

Fully funded the local Parkinson's Disease Registry connecting NW researchers to study participants

Awarded \$1.4 million

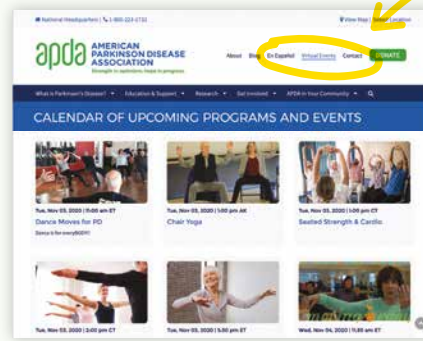
to the most promising clinicians and innovative research, including APDA's first-ever Diversity in PD Research award

Providing Hope for Tomorrow
RESEARCH

MOVE & LIVE WITH OPTIMISM!

In the Virtual World...

During this health crisis, APDA remains focused on our mission of helping everyone impacted by Parkinson's disease live life to the fullest. As such, we have developed new programs and are offering a slate of FREE virtual and print resources.

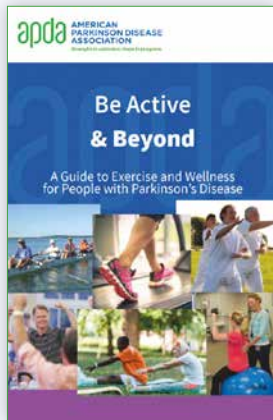


Introducing the APDA Virtual Event Calendar!

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

Check out the virtual calendar at apdaparkinson.org/events

KEEP MOVING!



Get the Booklet

This 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/download-exercise-guide/

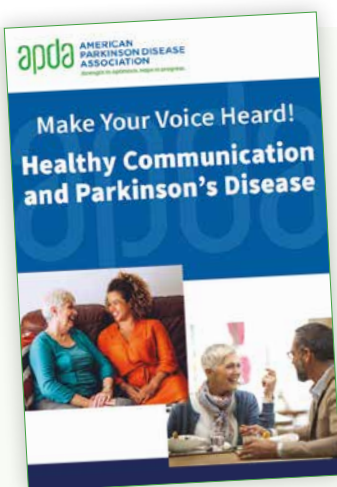


PARTICIPATE in a virtual class

We know that most of you can't participate in your regular fitness routines, so APDA is proud to sponsor free community programs that bring opportunities to you!

All classes are offered on Zoom and registration is required. All times noted are Pacific Time.

- DANCE for Body, Mind and Spirit, Sundays at 12 pm
- Music Therapy, Mondays at 10 am
- Dance for PD, Tuesdays at 8 am
- Chair Yoga, Tuesdays at 1 pm
- Yoga for PD with Peter Lynch, Tuesdays & Thursdays at 2:30 pm
- Body Moves, Wednesdays & Saturdays at 10:30 am
- Laughter Yoga, Thursdays at 7 am
- Rock Steady Boxing, Saturdays at 9:30 am



Get the Booklet

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!

PARTICIPATE in a virtual class

- Sing Loud, Wednesdays at 12:30 pm pt

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 join one of our newly formed groups.

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

CONNECT WITH OTHERS!



Upcoming Educational Programs

We have a variety of virtual education programs happening in the coming months. From programs like about disease-state issues, to inspirational conversations, to research updates there is something for everyone.

Are you getting the *News You Can Use* weekly email?
This is a weekly email to keep you informed of upcoming programs that may be of interest. If you are reading this and not receiving that email, please email us at apdanw@apdaparkinson.org or call us 206-695-2905

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

THANK YOU *for* **CARING**
about people impacted by Parkinson's disease

YOU
can
Keep people
connected

\$100 supports **virtual meetings** for groups not able to meet in person during the pandemic

YOU
can provide
financial
support

\$300 provides a **full year Patient Aid scholarship** to someone struggling to make ends meet

YOU
can
Keep people
informed

\$500 supports **online education programs**, increasing access to information and resources no matter where someone lives

YOU
can
Keep people
moving

\$1,000 funds a **community grant** for an online exercise/wellness class, offered free of charge to all attendees

Donate online at apdaparkinson.org/Northwest,
or fill out the form on page 1 and mail a check to
APDA 180 Nickerson Street, Ste 108, Seattle WA 98109