

2 40 Years of **Medical Breakthroughs**

4 **Sunny Days**
Tips for sun safety

8 **Optimism Walks**
are coming up!

PARKINSON

Pathfinder

SUMMER 2024

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NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

SUMMER 2024

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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.

apda AMERICAN
PARKINSON DISEASE
ASSOCIATION
NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

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

APDA NORTHWEST

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AND COMMUNITY ENGAGEMENT

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Kerry Howard



I hope this issue inspires you to find new ways to live well with your Parkinson's diagnosis, or maybe it serves to provide new energy to keep going with what is already working for you.

As we celebrate 40 years of APDA serving the Northwest, we thought it would be fun to revisit some of our favorite Pathfinder articles from the past decade. We had a blast reading through old issues and picking our top stories. Whether it was learning circus stunts, having a loyal Great Dane by your side, finding humor and happiness while living with Parkinson's, or going on a backpacking adventure, we noticed a common theme. Each of our picks was about people living well with Parkinson's and finding their strength through optimism. We hope these stories bring a smile to your face, just like they did for us.

There are so many other inspirational stories that you won't find republished in this issue. I've had the privilege of interviewing and writing about some unforgettable people. There's Ade Eitner, who passed away in October 2022, but who in 2019 invited me into his Everett home and shared his generous philosophy on charitable giving and how Rock Steady Boxing was keeping him going late into his 80s (Fall 2019 issue). Then there's the story of Ronald Miller and Stephanie Harris, both now deceased. Ron biked the length of Vancouver Island in his 70s, likely experiencing Parkinson's symptoms as his diagnosis came shortly after this trip (Summer 2022 issue). They left an unforgettable legacy by naming APDA in their will.

These stories resonate with us because they embody our mission statement: **to help everyone impacted by Parkinson's disease live life to the fullest.** It's the **PEOPLE** in these stories – people just like you - who are at the heart of our work. Your experiences, resilience, and strength keep us striving to provide valuable support, connections, education, and funding for research.

Remember, APDA is here for you. We are committed to supporting, educating, and connecting you to our vast library of resources available online and in print, in-person education programs like Live Well and PD Essentials, virtual exercise and wellness classes, personalized resources from our on-staff social worker, training for volunteer group leaders, and celebratory events like our Optimism Walk. You are not alone in this journey.

I hope this issue inspires you to find new ways to live well with your Parkinson's diagnosis, or maybe it serves to provide new energy to keep going with what is already working for you.

Sincerely,

Kirsten Richards



Join us as we commemorate 40 years of serving the Northwest with a “\$40 for Forty” fundraising campaign to pay for vital support, education, and resources.

Donate online at bit.ly/APDA40 or see the back cover for a donation form.



Medical Breakthroughs in the Past 40 Years

1980s

Genetic Discoveries - APDA funds Dr. Roger Duvoisin, who studies the roles of heredity and environment in PD



Until the late 1980s, PD was understood to be caused mostly by environmental factors, *not* faulty genes. **Dr. Roger Duvoisin** was a prolific PD researcher and one of the earliest chairmen of APDA's Scientific Advisory Board (SAB). At the time,

he worked at Robert Wood Johnson School of Medicine in New Jersey, which was and continues to be an APDA Center for Advanced Research.

Duvoisin firmly believed that genetics were not significant in the development of PD. In the 1980s, he was involved in epidemiologic studies that attempted to show that genetic factors did not play a major role in this process.

What changed his thinking and led to a revolution in PD research that continues today was the discovery in 1990 of the Contursi family, a large family in Italy that had what appeared to be autosomal dominant PD. This meant that PD was found generation after generation, and children with a parent with PD had a 50% chance of developing the disease.

Exploring Neuroprotection beginning in the late 1980's

DATATOP (Deprenyl and Tocopherol antioxidative therapy of Parkinsonism). This was the first trial, conducted in the late 1980s and early 1990s, to find a neuroprotective agent for Parkinson's disease.

1990s

Discovery of alpha-synuclein

Above: Excerpt from *Ann Neurol.* 1996. PMID: 8957018 showing APDA's support for Dr. Duvoisin's pivotal work.

By 1997, researchers including Duvoisin discovered that the Contursi family harbored a mutation in alpha-synuclein, now known to be the fundamental component of the Lewy body, the pathologic hallmark of Parkinson's.

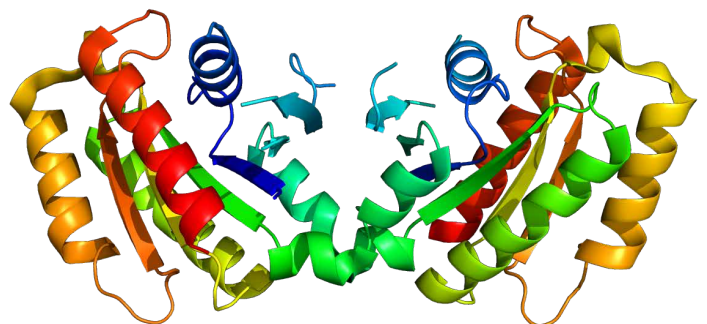
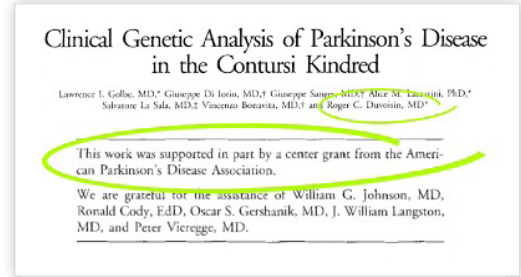
It is hard to overstate the importance of this discovery in our understanding of PD. Since 1997, a tremendous amount has been learned about alpha-synuclein and its role in PD. This knowledge has been transformed into potential therapies for PD. Today, multiple clinical trials are focused on manipulating alpha-synuclein pathology to treat PD and hopefully slow down the disease.

2000s

Additional Genetic links

Researchers found several additional genes linked to Parkinson's, including LRRK2.

The discovery of LRRK2 launched a thriving research field around this gene and the desire to discover more. This is leading to new improvements in diagnosis and the potential of individualized therapies for PD.





New FDA Approved Treatment Medications

Several new medications were approved for PD in this decade for the treatment of motor fluctuations, dyskinesias, and PD psychosis. These new medications for treating the symptoms of PD add more options for patients to get better control of their PD symptoms leading to better quality of life.

2010s

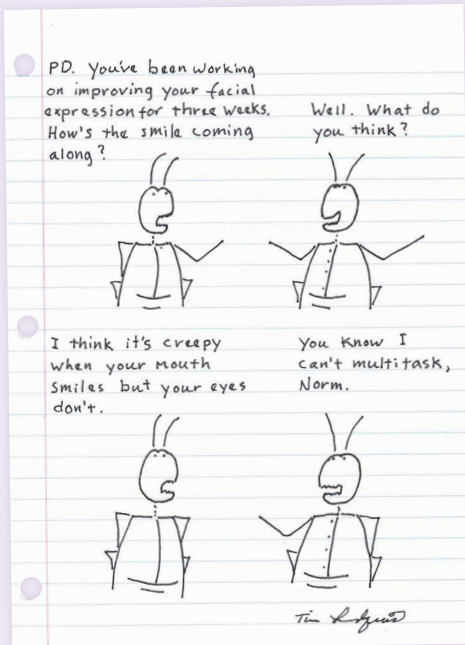
There is much hope for the future!

Amazing scientists and researchers are working on finding better treatments and, ultimately, a cure for Parkinson's disease.

As of March 2024, there are nearly 400 ongoing Parkinson's research projects, 163 of which are clinical trials in various stages.

2020s
and
beyond

SMILING!



Facial expressions are like the outward expression of self-talk. If the talk is negative the effect is deprecating. Not smiling is like that except that the deprecation is expressed openly, for all to see. It's not that I don't smile. If I'm engaged in conversation I can be outwardly animated, but at rest I look serious, even mad. The condition is called hypomimia—the mask of Parkinson's—the blank or angry expression that comes with the disease. My PD fitness class instructor tells us to smile in our workouts. Then says, not creepy, though. And we all laugh because we get it. Because we've got it. Hypomimia.

So, what about facial fitness?

I'm not a doctor, or a scientist, or a fitness instructor, but I do know that the more I exercise my face the more in control I am of my expression.

Like working out to improve my balance and strength and flexibility and stamina, I do a facial toning routine in the morning. Face exercises. I sit in front of a mirror and do ten minutes of cheekbones up and down. Corners of my mouth up and down. Nasal folds in a sneer. Face pressed

to the left. To the right. Happy. Sad. Surprised. Frightened. Winking. Everything up. Everything down. Twenty repetitions for each.

Now, when I feel myself flustered or stone-faced I'll force a smile. It's better than no smile, I think. And I believe it tells my body to relax, be uplifted. When I enter a room I stand straight and smile. When I make eye contact with others I start with a smile. I bet research on smiling and chronic disease shows there are no negative effects of smiling. Probably increases dopamine in the brain. People will see your smile and mirror it back. Another shot of dopamine.

We know exercise is key to keeping mobile, especially with PD.

So exercise your best smile!

Tim Lundquist has a Master's Degree in Education and Bachelor of Arts in Drama. He has enjoyed careers in the performing arts, standup comedy, and public education. He was diagnosed with Parkinson's disease in July of 2015.



Originally featured in the Summer 2018 Parkinson Pathfinder

SUNNY DAYS AHEAD

Leah Frazier

Few things are better than feeling the sun on your face.

It's a feeling so cherished that many of us plan our vacations, important events, and even where we choose to live around our ability to access more of it. The sun's warmth brings us joy and serves a vital purpose for our bodies. Vitamin D is one of the main benefits we receive from those soothing rays. Countless studies have shown the mental and physical health benefits of vitamin D:

- Regulates blood sugar
- Improves mood and reduces depression
- Strengthens our immune system
- Helps maintain healthy blood vessels
- Supports bone and muscle health
- Has anti-inflammatory properties
- Helps in regulating our sleep patterns

I wish I could stop here and leave you with feelings of vacation days wrapped in the sun's embrace. However, as much as we love the sun, it can be our skin's enemy. Our risk of skin cancer grows with age, and those living with Parkinson's Disease have an even greater risk of developing skin cancer. It hasn't been determined why this is, but it warrants your increased attention to any skin changes and seeing a dermatologist at least once a year.

More than 90% of skin cancers are caused by sun exposure. The good news is that the National Institute of Health and the Skin Cancer Foundation tell us that sunscreen has little effect on our vitamin D levels. In essence, wearing sunscreen outside will not cause a vitamin D deficiency. Experts are unanimous

in their warnings about protecting your skin and utilizing the many other ways to elevate your vitamin D levels if needed. Please check out the list at the end of this article.

The medical community is united in its advice on how to enjoy the sun while safeguarding your skin. It's important to remember that no sunscreen can completely block UV radiation. However, it can provide a shield that allows you to spend time outdoors while minimizing the harmful effects of the sun's rays.

- Wear a broad-spectrum sunscreen (protection against UVA and UVB rays) with a minimum SPF factor of 15.
- Apply sunscreen to all skin not covered by clothing.
- Use at least 1 ounce of sunscreen (enough to fill a shot glass) to cover exposed areas. An ounce should cover the whole body, but you might need to adjust the amount depending on your body size and body hair.
- Apply sunscreen to dry skin about 15 to 30 minutes before going outdoors. Try to get out of the habit of applying sunscreen at the beach or while already outside. You are not protected by the sunscreen until your skin has absorbed it.
- Reapply sunscreen at least every 2 hours or more often after swimming or sweating. Plan on applying every 1.5 hours to limit your exposure past the 2-hour mark, when protection wanes.
- Protect your lips by applying a lip balm that contains sunscreen with an SPF of 30 or higher. Reapply frequently and after eating and drinking.
- Limit your sun exposure between 10 a.m. and 4 p.m., when UV rays are the strongest. Check the UV levels (you can do this on most smartphones!) and minimize your time outdoors when it reaches 7 or higher.

- Wear a wide brim hat.
- Wear tightly woven clothing on as much exposed skin as possible. You can find clothing designed with an SPF factor. This allows you to enjoy your favorite activities while also helping to keep your body temperature down.
- Throw away sunscreen after 1–2 years. Sunscreen loses potency. Make a habit of going through your sunscreen at a certain time each year and dispose of any expired sunscreen.
- Don't forget to apply sunscreen to your ears, scalp, lips, neck, tops of feet, and backs of hands.
- Take regular breaks in shaded areas.
- Wear sunglasses with maximum UV protection.

How to get more vitamin D:

- **Mushrooms:** Mushrooms are the only completely plant-based source of vitamin D. Shiitake mushrooms are particularly recommended for their vitamin D content.
- **Egg yolks:** Egg yolks are a common source of vitamin D.

- **Fortified foods:** Vitamin D may be added to certain foods to increase their nutritive value. This process is called fortification. Some common vitamin D-fortified foods are milk, orange juice, ready-to-eat cereals, certain types of yogurts, and tofu.
- **Dairy foods:** Dairy products like Swiss cheese, cow milk, curds, and cottage cheese are also good sources of Vitamin D.
- A tablespoon of **cod liver oil** contains 1360 international units of vitamin D.
- **Supplements:** For many people, taking a vitamin D supplement may be the best way to ensure adequate intake.

A blood test is the only way to determine your vitamin D serum levels.

Ask your doctor if you should have your vitamin D levels checked.

Regatta for APDA



Top Fundraiser Bill Hedges raised \$5,630!



Captain Keith McKenzie on Race Day

The 3rd Annual APDA Regatta on June 6 was a gorgeous day on the water hosted by Elliott Bay Marina. We had a record turnout with 35 teams. The sailing community and friends of APDA enjoyed a spectacular evening to raise funds for a great cause.

Thanks to the generosity of the sailing community, **we raised over \$50,000** in critical funds for local support, education, and research.

Thank you to our Regatta sponsors

ADMIRAL



SKIPPER



CREW



Marina Management,
Fisheries Supply,
Ballard Landmark
Elliott Bay Yacht Sales

LAUGHTER
is the **BEST**
MEDICINE!

*(BUT ALSO GIVE
 REAL MEDICINE
 A SHOT)*

Eric Lundquist



Tim, France and Eric beam their way through Ballard during APDA's Adventure Race.

WHEN MY DAD STARTED SHOWING symptoms, it was tremendously difficult to bring it up without offending his sense of pride. However, we were able to approach the subject through humor, which has been invaluable in the process of letting us talk.

It started when my mom told my brother and I “Max, Eric, have you noticed that your father has been keeping his right hand in his pocket more often? And he looks more gaunt than usual and he speaks less. His face shows less expression. It’s called masking. I think he has Parkinson’s disease.”

We responded the only way we knew how. I said “Damn, I thought Dad was just stoic and handsome.”

We didn’t believe Mom at first. We didn’t want to. See, my mom has the tendency to always imagine the worst case scenario. In our experience, you don’t want Mom to be right about anything. If Mom has any prediction of hers come true, you’re up a creek. This time she seemed right. She had put in a lot of hours on Google and had compiled a case more airtight than the space shuttle. But in her fear of a worst case scenario, she had actually caught it before it would become that. In order to capitalize on my mom’s prediction, we had to act quickly.

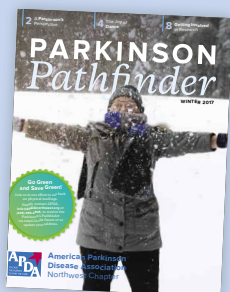
A note about my dad: my dad has a tremendous amount of ingenuity when it comes to

solving a problem without actually fixing it properly. For example, all of our cars have “a trick” to starting them. He fancies himself a modern day caveman: curious, imaginative, and full of a primordial resourcefulness. In addressing a problem though, you’ve got to acknowledge it first.

It was hard to get my dad to see a doctor to diagnose him, but no matter how tempting, you can’t ignore a progressive disease. Parkinson’s is like being pregnant. Even if you ignore it, you’re eventually gonna have a whole new set of obligations. We had to approach the issue and get it into the light in a way that was acceptable.

In our family, we pride ourselves on our sense of humor. My dad and I slam down zingers non-stop and my mom and brother end up taking those jokes as admirably as Rocky takes punches to the face.

Humor would be the key to talking about my dad’s Parkinson’s. Deciding to take one out of his book, we had to get creative. Seeing my dad find unorthodox solutions to everyday problems all my life, I knew that by working our way around the problem, we could address it. In this scenario, my dad’s pride was the temperamental Subaru Justy, and jokes



Originally featured
in the Winter 2017
Parkinson Pathfinder



IN OUR EXPERIENCE, TALKING ABOUT
MY DAD'S PARKINSON'S AND
MAKING JOKES OFFERS
A SENSE
OF CONTROL
OVER THE SITUATION.

were my vice grips and tin foil. So I tactfully used my nuanced, razor sharp wit to “encourage” my father to seek a medical professional.

“Hey Kevin Shakin’! Is your Foot Loose? Go see a doctor!”

That did the trick. As much as I hate bullying, you can’t deny its effectiveness. Hey, all care groups function differently.

I know that my dad would rather not talk about his Parkinson’s. It must be excruciating for a father to look weak in front of his kids. On the flip side, there is value in talking about it. By putting our heads together and pooling our knowledge, my dad is getting better insight for making his Parkinson’s work in his life.

In our experience, talking about it and making jokes offers a sense of control over the situation. I do stand-up comedy in Seattle, so of course I took this premise to the stage. Like this one: “I wanna write jokes about my dad’s Parkinson’s that he likes. But it’s hard to write something that’s good. You see my dad knows jokes like he knows the back and front and back and front of his hand.”

And my dad wrote some jokes too. His joke, which I like a lot: “Now that I’m in the Parkinson’s club, do you want to see my secret handshake?” Now he relates his story of his diagnosis, the doctor exclaiming “Yup! You got Parkinson’s!” like she was Oprah giving an audience member a new car. Addressing the issue of course isn’t the only thing you have to do. Treatment is next.

Luckily my mom is a fitness instructor, so she’s making sure he’s working out. He’s doing LSVT Big and Loud. We all read Hal Newsom’s book HOPE

and in a week, he’s seeing his neurologist to see if a particular drug cocktail tickles his fancy. I even got an internship at APDA Northwest, so we have even more resources to make this work.

We were invited to the APDA’s last fundraising event, The Adventure Race. My parents still talk about how fun it was. Costumes were encouraged, and we went a little overboard. The residents of Ballard must have been shocked to see the crew of the U.S.S. Enterprise from Star Trek walking their streets, looking for clues. I remember fondly when we walked up to the sign-in booth and they asked who the team captain was. I got to say, doing my best Shatner, “I...am the Captain.” Going to that event was encouraging for all of us because we got to see so many people committed to the cause.

You can’t cure Parkinson’s right now. But you can sure as heck try to delay its progress and maintain your health. And my dad, the genius caveman, has a lot of experience with finding solutions to things that can’t be fixed outright. He has creativity, resourcefulness, and a family to multiply those benefits. Our sense of humor lets us be more open and work together to map out a better plan for managing Parkinson’s.

Oh and if you want to follow my dad’s own humorous writing on hiking and life with Parkinson’s, his blog is timlundquistwrites.com.

Tim Lundquist takes a selfie before one of his trips into the backcountry.

UPDATE: Eric and his family are still joking around today, with the added help of his parents' extremely anxious and loving terrier-something mix, Beau.



2024 OPTIMISM WALKS



The Optimism Walk is part of a nationwide movement to mobilize and inspire people to step up and help put an end to Parkinson's disease.



WIN PRIZES!

Fundraising incentives:

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

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

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

Special recognition will be given for **Top Fundraising Team, Largest Team, Top Fundraising Individual, and Most Team Spirit**

Every year our APDA Northwest Optimism Walk is filled with strength and optimism. Again this year, there will be two walk locations. The Seattle Optimism Walk is one of our biggest outreach events and largest fundraisers of the year. If you live south of Seattle, you can opt to join the Olympia Optimism Walk. Our combined goal for the Northwest Optimism Walks for 2024 is to raise \$245,000! Proceeds from the walks will keep people with Parkinson's connected, informed, and moving. And YOU can help!

Register today as a Team Captain, Team Member, or Individual Walker. Leading up to the walks, you will reach out to your network and ask for their support – every \$25 / \$50 / \$100 gift makes a HUGE IMPACT in paying for Parkinson's support programs, exercise and wellness classes, resources, education programs, and research. As an Optimism Walk participant, you will help us celebrate our Parkinson's community as well as support APDA's mission to help everyone impacted by Parkinson's disease live life to the fullest. You will find that fundraising is FUN & EASY when it is for such a great cause!

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



APDA Northwest OPTIMISM WALKS

The Northwest Optimism Walks are an easy 1.5 mile walk.

Walkers of all abilities are welcome and can turn around at any time!

Bring the whole family!



SEATTLE

Saturday, September 21, 2024

Ship Canal Trail
130 Nickerson Street, Seattle
Festivities begin at 9:30am
Opening Ceremony 11:00am

SIGN UP TODAY to walk in Seattle!
<https://bit.ly/SEATTLEWALK2024>

OLYMPIA

Saturday, September 28, 2024

Marathon Park at Capitol Lake
1011 Deschutes Parkway SW, Olympia
Festivities begin at 11:30am
Walk begins 1:00 pm

SIGN UP TODAY to walk in Olympia!
<https://bit.ly/OLYWALK2024>

Not in Washington? Organize a Community Walk

Recruit your family, friends, neighbors, support group and more and JOIN US on September 21 from where YOU live!

PICK A LOCATION for a short, non-competitive family-friendly walk, such as a park with a flat, accessible walking path. If your location is a public park with picnic tables and/or covered area, consider reserving for your event.

PICK A TIME You will want to allow 30 minutes for check-in, e.g. check-in at 9:30 and Walk begins at 10am.

REGISTER A TEAM at <https://bit.ly/SEATTLEWALK2024> - Include the city/town name in your team name (e.g. Striders - Wenatchee).

CONTACT APDA with your Walk details and we will help by sending targeted emails and provide you with a flyer customized for your community Optimism Walk.

GET THE WORD OUT!

Let's STEP UP to help put an end to Parkinson's disease!

From your team page you can easily invite others to join you.

Encourage Walkers to form their own friends/family teams! The more the merrier.

Please include the city/town in their team name so APDA can clearly identify them and get any incentive prizes to you in time for your Walk!



Contact us with any questions!
hmurdock@apdaparkinson.org
 (206) 798-3205

Service Dogs for Parkinsons

Renee Le Verrier

I tried enhancing my Parkinson's balance with a cane, figuring that it would help me navigate through crowds and narrow walkways. The Great Cane Incident, however, convinced me otherwise. I was walking through the airport with my cane. When I stopped at my gate, dyskinesia set in and it was as though I had a giant pointer in my hand. It swung and dipped and waved. I nearly scalped a queue of passengers.

That was when I decided to trade my cane for a Great Dane.

Sir Thomas and I have been a team for six years. He has held me steady through dyskinesia, kept me moving forward during freezes, and balanced my gait when my meds were "off." He has gotten me out of places where I'd still be stuck if he hadn't been there. Actually, the fear of falling that had oozed into my reasons to venture out less and less frequently had disappeared once I ventured out with my service dog by my side.

“ I decided to trade my cane for a Great Dane.

Service Dog Definition

The Americans with Disabilities Act (ADA) specifies that a service dog is "individually trained to do work or perform tasks for a person with a disability. Service dogs are working animals, not pets and the work or task the dog provides must be directly related to the person's disability. Dogs whose sole function is to provide comfort or emotional support do not qualify as service animals."

For more information, visit the ADA at: www.ada.gov/service_animals_2010.htm

What Makes a Dog a Service Dog?

Highly trained, service dogs must also have certain traits and behaviors to qualify as an assistant to a person with a disability.

TEMPERAMENT: Service dog raisers and trainers will disqualify pups early on if they show any sign of aggression, from dominance play to snagging food from other pup's bowls. Ditto with excessive fear or timidity. These dogs must be calm and confident enough to withstand crowds, loud music, hours lying still on the floor at a restaurant, elevators, buses, and so on.

BREED: The breeding and the breed can be important. A toy breed is not likely to be a mobility dog. Large, calm breeds tend to be better matches to pull a wheelchair or support a person's weight while bracing.



Considerations

CARE AND COSTS: *Service dogs need exercise, feeding, grooming, vet care, ongoing training, harnesses, bed, treats toys and lots of love and praise.*

SCHEDULE AND PLANNING: *A service dog team is together 24/7; wherever you go, there you both are. Schedule accordingly and always carry extra plastic bags and wipes.*

ATTENTION: *If you're shy about your diagnosis, be aware that a service dog, in my experience, is a social magnet. I haven't completed a shopping list since Sir Thomas came home because I get stopped in the aisle so many times with compliments, questions, coos, questions and more questions.*

Resources for Further Information

SERVICE DOGS

International Association of Assistance Dog Partners, c/o IAADP, P.O. Box 638, Sterling Heights, MI 48311, 1-888-544-2237, www.iaadp.org

Assistance Dogs International: ADI www.assistedogsinternational.org

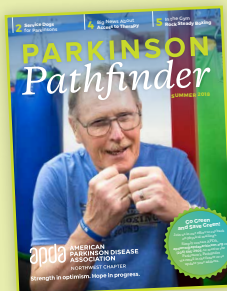
REGULATIONS

www.ADA.gov or call 800-514-0301

GENERAL INFORMATION

www.servicedogsociety.com

<https://leverrier.com/service-dogs/>



Originally featured
in the Summer 2018
Parkinson Pathfinder

TRAINING: Service dogs hold the PhD's of dog training. They pass the socialization, basic commands, canine good citizen tests with flying colors before they even start training for the work and tasks they'll provide. Service dogs are required to be "individually trained." This is somewhat confusing as it doesn't mean the dog must be trained by an individual. It means that the dog is trained for an individual. No two service dogs are interchangeable.

WORKER: No matter how adorable Fluffy is, the family pet is not a service dog. Sir Thomas is part of the family but he's not a pet. He was bred, raised and trained as a working animal. He certainly gets his down time when he gets to roll in the grass and race around the garden. But as soon as his vest goes on, he switches to work mode.

How a Service Dog Can Help

A service dog and its handler are often referred to as a team or as

partners. I've found that a cane adds one level of support while a service dog adds four legs that can step in. More than a walking aid, service dogs can ease the everyday movement challenges posed by Parkinson's. The wagging tail is a bonus.

Mobility

Even when other assistive devices such as a wheelchair or walker are being used, service dogs can do tasks that can otherwise sap the human's energy, such as:

- Pull a wheelchair; guide a walker.
- Open doors.
- Pick up dropped items.
- Turn on lights, press buttons.
- Assist with dressing.

Balance

When walking unassisted, a dog can do tasks that aid movement and provide support, including:

- Stabilize gait.
- Steady a person when on uneven ground.
- Propel from a freeze.
- Brace for weight shifting, turning, or rising from a chair.

In addition to all of the above, a service dog can make a big difference in maintaining independence. If the fear of falling or crashing into something—or someone—in public makes going out in public a non-option, it may be time to consider some balance assistance. In particular, consider one that has four feet for stability and a built-in personality that wants to—and can—help in so many ways.

Renee Le Verrier, E-RYT, teaches yoga for Parkinson's. She also trains yoga teachers how to design specialized classes for people living with Parkinson's. The author of *Travels with Tommy: Stories of Life with a Service Dog*, Renee has lived with Parkinson's for twenty years. For the past twelve years, Renee has had a service dog by her side. Riker, her third after Tommy and Brycen, stabilizes her walking, helps her move out of a freeze, and braces her when she rises from a chair or the floor after yoga. "With my service dog by my side, I have less fear of falling and can be more independent than without. My Dane is better than a cane."

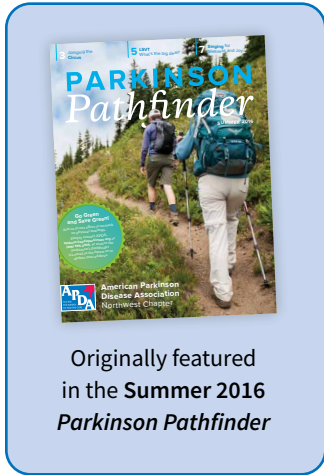
To read her Service Dog blog, visit Renee at www.leverrier.com

Running Away to JOIN *the* CIRCUS

John Cornicello

It all started a few years ago. I was working for a well-known software company. My job had me at a computer, typing, most of the day. I started noticing some “issues.” My left hand was becoming less accurate. Double-caps, repeating letters, things like that. I also noticed that my left arm was pulling in towards my body when at rest and it didn’t move/swing as I walked. My piano playing had actually been getting better for a few years, then all of a sudden started taking a dive, too.

My first thought was that I suffered some sort of mild stroke or something like that. I got a referral to a neurologist and an MRI and things looked good. He had me do some basic movements as he observed me and he suggested that I might have Parkinson’s. I had no tremors or anything like that. Just the stiff left arm and some cogwheel type of movement in my left wrist.



Originally featured in the **Summer 2016 Parkinson Pathfinder**

I had already been taking Ropinerole for restless leg, so we didn’t change anything there. My diet has never been that great, so my wife and I tried to go radical (for me) for a few months with no sugar, carbs, or gluten. I did lose about 20lbs very quickly. But I was now starting to get some tremors in my left hand. After 3 months, I went back to dairy and gluten, but have managed to keep away from sugared soft drinks.

Concurrently with all of this I had been photographing for a circus school here in Seattle. SANCA is the School

of Acrobatics and New Circus Arts, one of the largest such schools in the world. I became friends with the owners and at the end of a benefit show in February 2015 I casually mentioned that I had Parkinson’s and asked Jo Montgomery if she had ever worked with Parkinson’s patients. She said she had not, but that I should stop in at the school the following Monday. And I’ve been there just about every Monday since.



I was 57 and pretty sedentary. Jo started slowly with stretching exercises and then gradually asked me to try more activities. My initial reaction to most of these was, “you want me to do what??” OK, I can bounce on a trampoline and do some jumping jack type of movements. But now you want me to do a seat drop? And then come back to a standing position? I dreaded the trampoline for about 2 weeks. Then it clicked and has become a favorite part of our routine. Next came walking on a balance beam. About 3” wide and 6” off the ground. More difficult than expected, but not so bad. I could do that one. Until one day she suggested a tight wire instead. A steel cable about 1/2” or so wide. Barefoot. Jo would be holding one wrist as I walked back and forth across the wire. I never measured it, but I’m guessing it is a 12 foot distance. Amazingly I did it. And I enjoyed it.

All of this has built good core strength and improved my confidence. So next came juggling. I've never been able to juggle. Maybe it is from lack of discipline and practice. But I try. Balls, clubs, rings. On my own, I'm really bad. But I found that I can toss 2, 3, or even 5 rings with another person. I believe that this is helping make new brain connections that might help with Parkinson's.

Then back to stretching. When I first started I couldn't move my left shoulder. I would hold my left arm out to the side and grab a bar and tell it to move up/down and forward/back. And nothing would happen. I could tell my right shoulder to make all sorts of movements and it would. But the left shoulder would just sit there, completely ignoring my commands. I don't know if it is the medications (I started seeing a movement specialist in June, 2015, and started Carbo/Leva in September), or all the other exercises, or a combination, but my left shoulder is finally starting to follow instructions and move around in circles when I want it to.

We also do some strength training by doing pull-ups on a trapeze bar and an exercise where I grab a bar above my head against a wall and pull my knees up to my chest 20 times.

Outside of circus school I have set up my home "triathlon" routine. I do a 30 minute routine that consists of a mile on a treadmill, then spinning at 80-90 rpm on a stationary bicycle, and then I take a shower.

All of this has helped me maintain a healthy and positive attitude. I consider myself lucky that my tremors are mostly mild and confined to my left hand so they don't affect my photography. Yes, I've started using a tripod



more often, but not all the time. I do worry that my left hand tremor might be a distraction to my subjects (I'm a portrait and headshot photographer) if my hand starts banging against my tripod. But I do explain the situation if that happens and all seems good.

Recently I found out that one of the members of SANCA's board of directors has been diagnosed with Parkinson's and she has joined in on the Monday class. Our first try at juggling rings with each other went remarkably well.

Some days I wonder if I should be more concerned with my Parkinson's. But so far I have managed to maintain a very upbeat attitude. I really look forward to both the SANCA and the home workouts. And I am somewhat amazed as I learn about more and more friends and colleagues who have some sort of tremors, be they essential tremors or Parkinson's. This makes me have hope that more people will be learning about these issues leading to more research and the possibility of cures and even prevention.



Update from John: The Parkinson's group still meets at SANCA, but I no longer attend. My disease is still pretty well controlled, though; these days, I am concentrating on my stationary bicycle at home, walking and stretching, and working with stretch bands. My balance is still pretty good. My big concerns are fine motor skills such as typing, piano, handwriting, etc.

I closed my photography business during COVID, but I continue shooting for myself and for APDA events. PD has not affected my photography except at the end of a session when I need to pack up equipment (the bending, rising, bending, and standing wipes me out). I still encourage people to go out and try some circus training.

Happiness

Even with Parkinson's

Approaching Parkinson's with a positive attitude is the most important thing you can do when seeking happiness.

As the founder of Parkinson's Warrior (the book, the Facebook group, the website), I'm often asked how to find happiness in life while living with Parkinson's. I believe happiness is possible, and that your life could be much more than just struggling with a disease. Here are 5 steps to happiness that I've found while living with Parkinson's.

Step 1: Find your why

The first step in finding happiness that is long-lasting is to find out why you want to be happy. Finding your "why" has been a concept for a very long time – why do you want to live? why do you want to feel well? why do you hope for a cure? – these are very old philosophical questions. Recently, asking "why" came back into vogue thanks to a book by speaker, Simon Sinek.

Ask yourself why you want to be happy. Is it to be at peace with your life? Is it because you hope for a cure with optimism that can't be beaten? Or maybe it's a selfless act to ease the burden on a loved one. Why do you want to be happy? Keep that in mind...

Step 2: Check your attitude

Attitude is everything. Approaching Parkinson's with a positive attitude is the most important thing you can do when seeking happiness. Yes, it's true that you are afflicted with an incurable illness. Yes, it's true that you have your good days and bad days. But guess what? Despite all of this, you can still choose to have a positive attitude. That's right, you can CHOOSE to be positive instead of expressing yourself negatively.

An infamous example is when I had DBS surgery in 2018. I call this infamous because I've told this story many times to many different groups of people, and many have recounted this story to others. When I went in for my deep brain stimulation surgery, I was prepped and rolled into the operating room. It was a scary and sterile place, with a dozen people standing around ready to do their thing. I certainly had to draw up some courage for that situation. After all, this was brain surgery. The surgeon looked at

me as I laid on the gurney, and asked, for verification purposes I suppose, what I was here for. My response: "You're going to put a couple of holes into my head!" In the scariest moment of my life, I chose to say something funny. I CHOSE it. The surgery went well, and I was glad I had chosen positivity in that moment as it helped set the stage for my recovery.

Step 3: Start self-healing

Since Parkinson's currently has no cure, self-healing means being at your best, physically, cognitively, and emotionally. Eating well (no fad diets for us, we have particular needs that require certain levels of proteins and carbs), exercising (again, no fad fitness machines – walking, weights, yoga, and specialty boxing are best), playing games (crosswords, sudoku), reading and writing (help ease anxiety and depression), and reducing as much stress as possible, will all help with being at your best.

These activities will not only make you feel better in body and spirit, but they'll also give you a rush of dopamine, serotonin, and endorphins, which will make you feel happier.

Step 4: Find your community

Whether you're an introvert or an extrovert, being out among people is essential to your health. At the most basic level, going to your local Parkinson's support group could improve your mood and make you happier. From there, the sky's the limit. Depending on how you feel, you can join meet-ups with people practicing your favorite hobby, you can go to family events (an important link to your past), and perhaps other Parkinson's events. Even sitting alone in a crowded cafe can make you feel happier and more connected to the world.

Be sure you don't let the disease stop you from doing what you love. Perhaps you need to do things a little differently, but you can still find some aspect to be engaged in. Find people who will support you



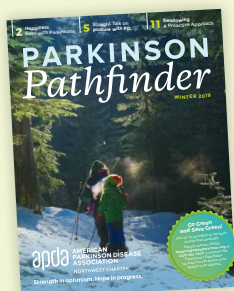
Nick Pernisco
 founded Parkinson's Warrior as a way to connect people with Parkinson's, and to act as a ray of positivity and inspiration to all those dealing with this illness.

After going through his own struggles when he was 33, Nick decided he would not let this disease defeat him. He decided to change his life by learning everything possible about Parkinson's. He began seeing Parkinson's as an enemy to be destroyed, or at least kept at bay, rather than simply as a disease.

Nick wrote the book, *Parkinson's Warrior*, and maintains a growing community of Warriors on Facebook. He also created the popular disease tracking app, Parkinson's LifeKit.

Nick is a proud alumnus of the APDA board and actively works as an online Film and Media professor. These days, he finds happiness in spending his time with his kittens, Beverly and Deanna, his senior cat, Sashimi, and his wife of 18 years, Rosaline.

Find out more about Nick and Parkinson's Warrior at www.parkinsonswarrior.com



Originally featured in the Winter 2019 Parkinson Pathfinder

and lift you up. Finding and maintaining a strong community is important for your long-term health, as well as for your long-term happiness.

Step 5: Prepare for setbacks

Always remember that happiness is not a moment in time, it's a long-term feeling that keeps you optimistic in hard times, hopeful when things look hopeless, and open when all you really want to do is curl up in bed and shut out the world. You have Parkinson's – life won't be a series of upbeat moments, puppy dogs, and ice cream. You will have setbacks. There will be days you don't want to get out of bed. That's ok – you should expect these things. But staying upbeat will help you get through trying times.

There are so many variables to finding happiness, and it's tough enough for people without Parkinson's. For us Parkies it is a little bit tougher, but it can be done! Go out there and be a Parkinson's Warrior. Figure out why you want happiness, be positive, exercise and eat well, go out and find people to share your life with, and don't be discouraged by setbacks. You can do it, I believe in you!

Keep fighting and never give up!

Congratulations to Suzanne Cameron!

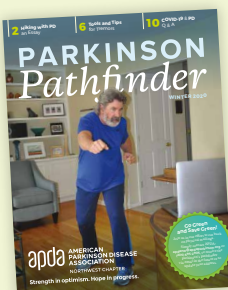


At the APDA Leadership Conference held in Denver in late July, **Suzanne Cameron** was awarded with the prestigious **Salvatore J. Esposito, Sr. Award** which is given in memory of APDA's second president and in recognition of distinguished service.

Awardees are recognized for exemplifying commitment, creativity, service, and leadership in the execution of APDA's mission in the local community. Suzanne has been involved with the NW chapter since her husband Chris was diagnosed with PD in 1998 at the age of 39. Suzanne's "can-do" attitude and passion to help people with PD – along with her determination to fund a cure - has led to her having a hand in raising an estimated \$7 million! Join us in congratulating Suzanne Cameron on this well-deserved honor.

Lay Down the Backpack

By Laura Kennedy Gould



Originally featured in the **Winter 2020 Parkinson Pathfinder**



Paul and Laura in 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. Hmm... 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 and her husband, Paul, live in Burien, WA. Laura writes about her experiences and Parkinson's research in her blog "The Magic Trick - Life with Parkinson's" at <http://magicktrickparkinsons.wordpress.com/>. She is currently working on updating the format of that blog, so if you are a "WordPress Wizard" and would like to help her with the update, please reach out to Laura.

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