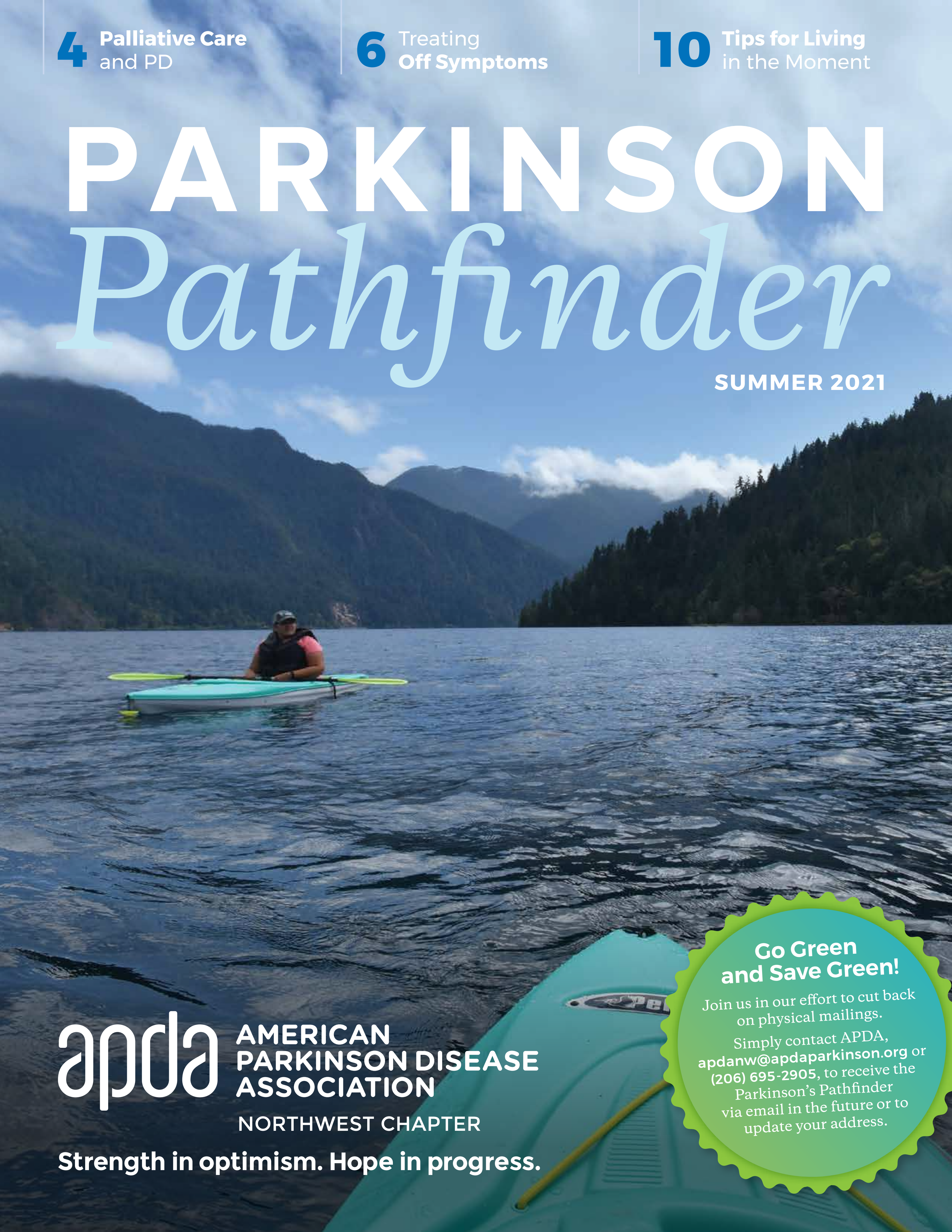
PARKINSON *Pathfinder*

SUMMER 2021



Go Green and Save Green!

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

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

apda AMERICAN PARKINSON DISEASE ASSOCIATION
NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

SUMMER 2021

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

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COVER
Photo by Dustin Werner
Lake Crescent, WA

Letter from the
EXECUTIVE DIRECTOR

When Jen came to me with the idea of a Create Joy series (see page 13) - which will feature activities nurturing creativity and joy – it started me thinking. **What can any of us do to create joy, so desperately needed after the past year?** I get a lot of my energy from personal interactions, so finding positive energy was sometimes a challenge. There are many things out of our control, like a Parkinson's diagnosis or a pandemic but there are many things we can do to increase joy:

Undertake a challenging new activity or project with a commitment to mastering it. Set a goal, learn the steps, and master it.

Get inspired. Find activities that take you out of the ordinary day-to-day life, like meditating or being alone in nature.

Engage in an activity that feels like play. Do something uplifting and enjoyable that is just plain fun.

Deal with any sadness that blocks your joy. Allow yourself to cry, acknowledge the hurt and losses and tell yourself, "It is okay to feel sad." Let it out so you can feel washed clean.

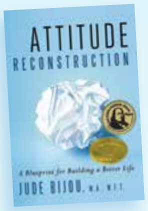
Honor yourself consciously and frequently. Interrupt negative thoughts and replace them with statements such as, "I'm fine the way I am. I did my best!" Focus on the good and what you did well.

Give yourself a break from the day-to-day world. Nurture yourself. Set up a time just for you, disconnect from daily. **Remind yourself: My job is to take care of myself.**

Say the word JOY often. Repeating and contemplating the word joy can create that emotion. More joy will rise if you simply invite it to do so.

When we feel joy, we feel more positive about ourselves. We feel confident, powerful, capable, lovable and fulfilled. Join me in participating in the six-week *Create Joy* series (page 13) and also challenge yourself to *Live in the Moment* (pages 9-10).

Joy,



Excerpts from Jude Bijou, M.A., MFT, is a respected psychotherapist, professional educator, and workshop leader. Her award-winning book is *Attitude Reconstruction: A Blueprint for Building a Better Life*.

The Advocacy is Just Beginning

By
Wendy Ann Miller

David Kovalenko via Unsplash

An alarming number of people diagnosed with Parkinson's disease—10 to 12%—are veterans. The Department of Defense Neurotoxin Exposure Treatment Parkinson's Research Program (PRP) is devoted to research to discover why a significantly higher percentage of veterans are diagnosed with Parkinson's disease. These discoveries could lead to a cure.

The PRP budget has been flatlined at $16 million since FY 2012. In an effort to increase that budget, people gathered in March 2021 to make their voices heard. The American Parkinson Disease Association, Michael J. Fox Foundation and Parkinson's Foundation teamed up for the annual Parkinson's Policy Forum. It was an opportunity (albeit virtually) for advocates to ask state legislators to support increasing the PRP budget by $9 million to $25 million. Advocates represented all five states covered by the APDA Northwest Chapter.

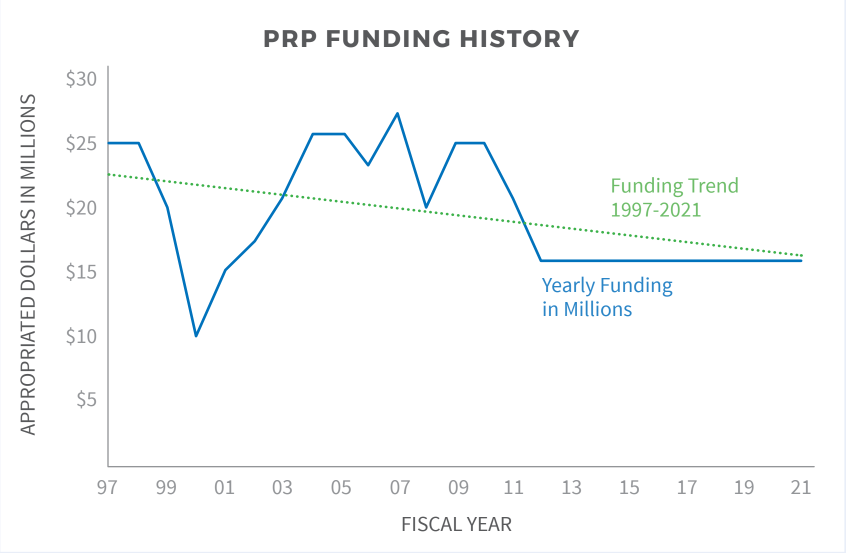
Washington State's team consisted of five passionate advocates: Jean Allenbach, Diane Hutchins, Lise Husted, Glenn Kasman, and Wendy Miller. We met with the aides to Senators Patty Murray and Maria Cantwell, and Representatives Rick Larsen, Pramila Jayapal, Marilyn Strickland, and Suzan DelBene—all of whom were knowledgeable, warm, and receptive.

If you don't like numbers, skip the next few paragraphs. Otherwise, read on for the justifications for our ask.

According to a study commissioned by the Michael J. Fox Foundation, and financially supported by APDA:

- Approximately 1 million people in the U.S. have Parkinson's, which costs the nation $52 billion each year. This includes a direct medical cost of $25.4 billion, with additional indirect and non-medical costs of $26.5 billion. It is estimated that more than 1.6 million people in the United States will be impacted by Parkinson's disease by 2037, at an estimated economic burden of $79 billion.
- $23 billion of the direct cost to the federal government is shouldered by Medicare, with an additional $2 billion attributable to SSI/SSDI.
- Medicare insures 90% of people with Parkinson's. In 2017, only 7% of direct medical care costs were attributable to private insurance. The excess medical cost of PD for patients on Medicare is $24,811 every year.
- APDA Northwest covers, WA, OR, ID, MT & AK with a total population of 15,084,633 people; it is estimated that 48,620 have Parkinson's. The direct and indirect costs to care for people with Parkinson's in this area is $2.451 billion.
- The federal government spends $25 billion every year to care for people with Parkinson's disease, and only $234 million researching the disease.

Veterans dedicated their lives to protecting and serving us, it's time for the government to invest more to find a cure for Parkinson's!



Next Steps: Building a Compelling Case for Funding

Our advocacy group was so energized and encouraged after the Policy Forum we were eager to do more. We added two veterans living with PD to our group, Bill Rasmussen and Bob Dixon, and began emailing, zooming, and brainstorming. We decided that we might be able to make a more compelling case for funding the PRP by making a video of veterans with PD who would share their personal stories. The video could be sent to members of Congress as further encouragement to support increased funding for the PRP as well as shared via email, on social media, and other avenues to help increase awareness.

The first step is to recruit the story tellers. We are looking for:

- Veterans who are willing to share their Parkinson’s story.
- Female veterans with PD.
- Veterans diagnosed with PD who did not serve in Vietnam or were not exposed to Agent Orange but may have experienced traumatic brain injuries, sleep disruptions, and/or cognitive and psychiatric symptoms, all of which are suspected triggers for PD in military personnel.

We would be happy to attend any virtual PD support group meetings to discuss this project.

If interested in recording a roughly 3-minute story of your journey with PD as a vet, please reach out to Jean Allenbach at **jallenbach@apdaparkinson.org** or **206-550-0444**.

If you are a veteran, APDA has a free handbook ***Helping Those Who Serve: Parkinson’s Disease Information For The Veterans Community*** that can be found on our website or we can mail it to you.

COST AND PREVALENCE IN THE NORTHWEST

48,620

Northwest population is **15,084,633** people; **48,620** have Parkinson's

The direct and indirect costs to care for people with Parkinson's in the Northwest is

$2.451 BILLION

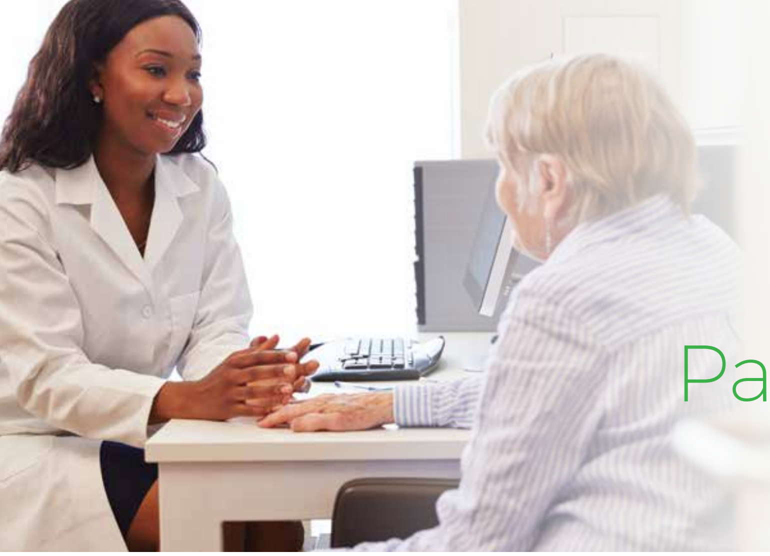
PD PREVALENCE IN THE NORTHWEST

3.22

PER 1,000 PEOPLE

The federal government spends $25 billion every year to care for people with Parkinson's disease, and only $234 million researching the disease.

It's time for the government to invest more to find a cure for Parkinson's.

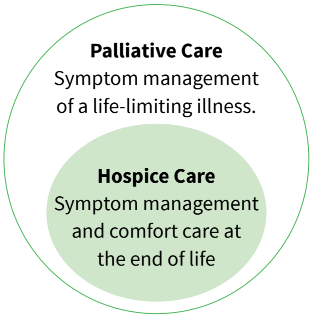


Palliative Care AND Parkinson’s Disease

What is Palliative Care?

Palliative Care is a medical specialty that is centered around the specific needs of people living with a chronic serious illness, with ultimate focus on optimizing the quality of life. The World Health Organization describes Palliative Care as “an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness and aims to prevent and relieve suffering through the early identification, assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual” (World Health Organization, 2021).

In 2006 the specialty of Palliative Care was first recognized by the American Board of Medical Specialties. It originally grew out of the hospice movement, seeing a need to provide nuanced care from the first weeks of a new diagnosis through the end of life. As expected, there was resistance to utilizing hospice as it was associated with death and dying. Palliative Care was intended to reframe living with life-limiting condition from a painful time of suffering, to a time where it is possible to live more comfortably when a serious illness is unavoidable.



As treatments to prolong life become less effective, treatments for symptom management/comfort increase.

When is the right time to access Palliative Care?

Palliative care referral is appropriate for people living with serious chronic illness at any stage of disease and can be accessed in many ways. The important thing to understand is that (unlike hospice) appropriateness for Palliative Care is based more on needs than prognosis.

Many people are referred to specialist palliative care during a time of disease progression when they are experiencing complex pain or symptoms (for PD, these are often non-motor symptoms such as insomnia, appetite, or mood). When palliative care was first introduced, people were referred in the later stages of their disease. However, it has been shown that earlier integration with palliative care provides a more gradual transition from primarily neurological-focused care to more symptomatic support. A recent investigation of the impact of early palliative care integration suggests patients receiving palliative care jointly with their routine neurology care may benefit from enhanced symptom control and quality of life (Kluger et al., 2020). An additional important finding was a reduction in caregiver stress over time.

How would I access Palliative Care?

- — General Palliative Care Outpatient Clinic, referred by Primary Care Provider or Parkinson’s Disease Clinic
- — Neuro-Palliative Care Specialist, embedded in a Parkinson’s Disease Clinic
- — Inpatient Specialist Team, referred by hospital medical team. This hospital team can also provide a layer of consistency and familiarity through prolonged hospital stays when other staffing regularly rotates and sometimes remain trusted care providers over the course of recurrent hospitalizations.
- — Home-Visit Palliative Care Programs or through telemedicine, when a patient may find it difficult to travel to clinic appointments.

How is Palliative Care different from Hospice?

The main difference between hospice and palliative care is most apparent when considering the goals of the person receiving medical care.

Palliative Care ideally begins first, and teams collaborate with disease management teams when the goal is to optimize health and well-being *while* living with chronic serious disease. Palliative Care can begin at the time of a new diagnosis and if not then, can be engaged as symptoms are more complicated, or conversation about heroic life-prolonging measures arise, like CPR, Intubation, Tube Feeding, and Antibiotics. The hope is to match the care a patient receives with their personal preferences, which are unique to each person. Palliative care is ideally involved far earlier than the last 6 months of life, so when difficult conversations are needed, a trusted

> The hope of palliative care is to match the care a patient receives with their personal preferences, which are unique to each person.

relationship is ready and available to patients and families.

Hospice is an insurance benefit provided to patients when life expectancy is expected to be six months or less and the patient is no longer seeking life-prolonging treatments. While some communities have a local hospice facility, more commonly patients prefer to remain at home with loved ones and/or privately paid caregivers for support. Hospice provides supportive care (medical advisor, visiting nurses, social work, spiritual care, nursing assistants, volunteers), comfort-focused medications, and medical equipment for the home. Hospice also provides bereavement support extended to loved ones in their grief.

How does Palliative Care differ from routine care for Parkinson's Disease?

Palliative Care specialists sometimes compare the specialty to taking the local train. While routine care for Parkinson's management provides direct train service with an experienced conductor safely taking you as expected from point A to point B, Palliative Care provides periodic stops to hop off the train to check the map and clarify where you're going, ask the conductor for recommendations on the route, tend to unexpected bumps on the ride, and regroup with a plan for the next leg of the trip.

Routine care is usually driven by collaboration between specialist and patient, and often includes physical and occupational therapy to optimize function. Because Parkinson's disease specialists know what to expect, they often address common disease-related symptoms or concerns that impact quality of life, such as motor symptoms including tremor, balance impairment, and rigidity.

Specialty Palliative Care services can be consulted alongside a primary specialist to look at the larger picture, provide guidance, help with transitions and additional symptom and/or emotional support. Specialty teams usually include a medical provider, social services provider, and spiritual care provider, but also sometimes include psychologists, art and music therapists, physical or occupational therapists, dietitians, pharmacists and more. The team-based approach also layers different lenses of expertise that take more time, face-to face, to improve helpful coping skills while addressing grief, existential distress, and family stress.

Advanced Care Planning (ACP)

Parkinson's disease is a progressive, incurable disease, and the preparation for living life through adversity can greatly comfort all touched by the illness. Many families struggle to know what their loved one would want when decisions must be made about medical care, such as Cardio-Pulmonary Resuscitation (CPR), intubation/life support, tube feeding, antibiotic treatment, and when to start focusing primarily on comfort-focused care. The Advanced Care Planning (ACP) process helps address these concerns, and palliative care teams frequently assist patients and families through these complex discussions. Making these hardest decisions for yourself, before your family must wonder what you would prefer, is a tremendous gift.

The ACP discussion assists patients as they complete written documentation of their preferences, such as an Advanced Directive, Durable Power of Attorney for Healthcare or a Living Will. The Advanced Directive is a guidance document that represents a conversation between a patient and their healthcare decision-makers and speaks for the patient when the patient cannot speak for themselves. Palliative Care Specialists get to know their patients and families over time and can be an important resource to help navigate uncertainties through an evolving medical landscape.

Palliative Care teams honor patients and families exactly where they are during difficult times. The only agenda they carry with them is to help make a patient's preferences known and to advocate for the best outcomes given the patient's preferences in each setting. The relationships that these difficult conversations foster often become the intervention that patients and families wish they would've been introduced to earlier in their disease process. If you're unsure if palliative care is right for you, ask your medical provider for their recommendation. Providers will often be pleased to extend an extra layer of support for you at any time.

For more information:
www.getpalliativecare.org

https://www.swedish.org/services/palliative-care-and-symptom-management

Susan Franke, MDiv, BCC
Spiritual Care Provider at Swedish Palliative Care - First Hill Campus

Jormain Cady, ARNP, DNP
Nurse Practitioner at Swedish Palliative Care - First Hill Campus

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Concurrent/integrative model of palliative care. A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report. Chapter 1. Framework. National Quality Forum. Washington, DC, 2006, p. 3.

World Health Organization. Palliative Care. https://www.who.int/news-room/fact-sheets/detail/palliative-care (8/5/2020). Accessed on July 27, 2021.

From OFF to ON

Treating Off Symptoms

Dr. Pravin Khemani,
Movement Disorders Neurologist, Swedish Neurosciences

Meet Mrs. Smith,

a 63-year-old woman who was diagnosed with Parkinson's disease 10 years ago. Her Parkinson's disease has been pretty well-managed through her carbidopa/levodopa medication which she takes four times a day, four hours apart. However, since her last visit with her neurologist she has noticed that about one hour before her next dose of medication she would have bothersome hand tremors, stiffness and was imbalanced. She was also having some non-motor symptoms of dizziness, anxiety, and 'brain fog' about thirty minutes before each dose of medication and waking up in the middle of the night with tremors and uncomfortable stiffness. She started to keep a symptom diary and at her next visit she reviewed it with her neurologist. They explained to her that what she is experiencing is called Off symptoms or wearing off and that it is not uncommon.

Off symptoms occur in Parkinson's disease (PD) primarily due to undertreatment with levodopa as the disease progresses. Ineffective distribution of doses and poor absorption of drugs exacerbate Off symptoms. (For the purpose of this article, PD medications imply those formulations that contain levodopa taken multiple times a day). Although not everyone with PD experiences Off periods in the early stages, they are almost universally present at some point as the disease progresses. Off symptoms in PD can vary in character, frequency, severity, duration, and timing over the course of the disease. Additionally, not everyone's Off symptoms are comparable. Recognition of the Off state by the patient and physician is the first step in addressing it as untreated Off symptoms can significantly impair quality of life.

Both motor and non-motor symptoms can occur during Off, either together or separately. Motor Off symptoms are reminiscent of the untreated state in PD: tremor, stiffness, slowness, freezing, festination (shuffling), drooling, swallowing difficulty, softer speech, dystonia and even dyskinesia can occur in the Off-state. Less commonly, changes in breathing pattern have been reported during the Off period. Of all these symptoms, Off-dyskinesia (abnormal writhing, bobbing, twisting, turning of any part of the body) is the most challenging to recognize as an Off symptom, since dyskinesia is typically an On symptom occurring shortly after taking PD medications or mid-cycle between doses. One clue to recognizing Off-dyskinesia is its occurrence shortly before the next dose of medication is due.

Non-motor Off symptoms may escape detection by the physician if they are not paying attention to the patient or caregiver's narrative and if a pattern is not identified vis a vis timing of medications. They include pain, brain fog, fear, anxiety, restlessness, depressed mood, grogginess, cognitive impairment, difficulty with language, nausea, numbness, tingling, feeling too hot or too cold, dizziness, light-headedness, sleepiness or insomnia, gastrointestinal distress, urinary complaints, blurred vision-you name it; any bodily discomfort can be a non-motor Off-symptom. An uncomfortable sensory experience that occurs shortly before it is time to take the next dose of levodopa and persists for a while until the medication takes effect is likely a non-motor Off symptom. It is common for non-motor and motor Off symptoms to occur simultaneously.

It is not possible to effectively discuss or treat Off symptoms without discussing the On-state, which is the period when PD symptoms are well treated and mobility is at its peak. The ideal goal of PD treatment is to minimize and eliminate Off symptoms while maximally prolonging the On state without dyskinesia. Unfortunately, as the disease progresses, the On-state can be disrupted by dyskinesia. At best, dyskinesia can be ignored and is often preferred over the Off-state; at worst, it can actually hinder mobility and cause significant discomfort by repetitive, uncontrolled movement of the body. [It is important to recognize that fear of potential dyskinesia is not a rationale to undertreat PD or delay treatment with levodopa. We have ample scientific evidence that early and effective medical treatment of PD ensures a more salutary course than undertreatment].

Motor fluctuation is used to describe disruptive On-Off periods during the day. "Common Patterns of Off", above right, describes common patterns of On and Off periods versus the timing of medications. When Off symptoms occur in isolation from dyskinesia, strategic medical interventions can be implemented depending on the wearing off characteristics (see Table 1, opposite). The basic strategy is to ensure a steady and adequate level of levodopa in the blood and brain despite its short half-life (a measure of blood concentration) between doses. Table 2, opposite, illustrates the minimization of On-Off fluctuations via surgical interventions.

The mechanism causing Off symptoms is complex and the significant variability between individuals is not fully understood. Internal factors causing Off symptoms include biochemical changes in the movement circuits due to a progressive loss of dopamine producing cells coupled with the short half-life of oral levodopa. External factors that are potentially modifiable are related to medication regimen and drug absorption which can be maximized by taking

Photo by Isabella and Zsa Fischer on Unsplash

Common Patterns of Off

Wearing off of PD medications leading to Off symptoms can be observed:

- **Early morning Off (AM)** before the first dose of medication is taken
- **Middle of the night Off (MON)** causes sleep disruption or difficulty getting to the restroom
- **End of dose Off (EOD)** occurs shortly before the next dose
- **Random Off (R)** can happen at any time of the day during waking hours regardless of medicine timing
- **Prolonged Off (P)** has an extended duration, even after taking medications
- **Sudden Off (S)** occurs without any warning, even mid-cycle between doses (similar to random Off but has the additional characteristic of being rather abrupt).

Table 1: **Currently Available Treatments for Off**

Off Symptoms						Medication Strategy
AM	MON	EOD	R	P	S	
X	X	X				Rasagiline (Azilect®) (taken at night as an adjunct to carbidopa/levodopa doses taken during the day)
X		X		X		Carbidopa/levodopa (fractionation-or small doses taken multiple times a day)
X	X	X		X		Carbidopa/levodopa CR (controlled release) or ER(extended release)
X	X	X		X		Carbidopa/levodopa ER (Rytary®)
		X		X		Entacapone (COMTAN®) (taken with each dose of carbidopa/levodopa)
X	X	X		X		Opicapone (Ongentys®) (taken at night in addition to steady doses of carbidopa/levodopa taken during the day)
		X		X		Carbidopa/levodopa/Entacapone (Stalevo®)
X	X	X		X		Dopaminergic agonists • Ropinrole (Requip®, Requip® XL) • Pramipexole (Mirapex®, Mirapex® ER) • Rotigotine patch (Neupro®) (Relatively long-acting medications taken with levodopa formulations.)
X	X	X			X	• Istradefylline (Nourianz®) • Safinamide (Xadago®) • Amantadine ER (Gocovri®) (Once-daily long acting medications taken in addition to levodopa formulations.) • Osmolex®ER (amantadine extended release) • Amantadine
X	X	X	X	X	X	• Levodopa Inhaler* (Inbrija®) • Apomorphine HCL sublingual film* (KynmobiTM) • Apomorphine HCL injection* (Apokyn®) Short, quick-acting medications taken 'on-demand' for isolated Off episodes.

levodopa as prescribed on an empty stomach with a full glass of water, treating constipation effectively, and exercising daily and sensibly to ensure optimum blood flow to the digestive system and the brain. However, the first and most critical step in treating Off periods in PD is identifying them and discussing their impact on your quality of life at every visit with your neurologist.

For Mrs. Smith, her neurologist first prescribed risagiline to mitigate the Off symptoms but that only partially helped. It was then recommended that she take the carbidopa/levodopa five times a day, three hours apart but due to her busy schedule, she found this option quite burdensome. Rytary® was suggested in lieu of carbidopa/levodopa but it was denied by her insurance company. The solution for Mrs. Smith came by adding opicapone at night. It successfully eliminated all motor and non-motor Off symptoms and significantly improved her quality of her life.

Table 2: **Surgical Strategies**

Surgical Strategy	Considered when wearing off (or motor fluctuation) persists despite optimization of above medications
Levodopa/carbidopa intestinal gel (DuopaTM)	• All patterns of wearing off and motor fluctuation (Not for persistent or breakthrough tremor which does not respond to levodopa)
Deep Brain Stimulation (DBS)	• All patterns of wearing off and motor fluctuation • Persistent or breakthrough severe tremor
Focused Ultrasound (FUS)	• Persistent or breakthrough severe (one-sided) tremor

Reference: Vijiaratnam, N., Foltynie, T. Therapeutic Strategies to Treat or Prevent Off Episodes in Adults with Parkinson's Disease. Drugs 80, 775–796 (2020). https://doi.org/10.1007/s40265-020-01310-2

FOR THE HEALTH OF IT: Getting Unstuck

Kelsey Colpitts, PT DPT
The Parkinson's Fitness Project

Do you ever find your feet frozen or glued in place? Do you ever feel stuck? Freezing of gait (FOG) affects 50-80% of people with Parkinson's disease. It is defined as a brief, episodic absence or marked reduction of forward progression of the feet despite the intention to walk. These episodes typically last a few seconds and can be experienced as a brief trembling in space followed by short, small steps but it can occasionally exceed more than 30 seconds to even minutes. It is a frustrating motor symptom that increases the risk of falls, decreases quality of life, and can lead to a loss of independence. In this article, we will discuss what FOG is and provide five steps to help address it.

What is FOG?

Freezing of gait typically occurs when your visual stimuli are challenged or when you are emotionally stressed or rushed. Visual stimuli can include doorways, thresholds, cracks in the sidewalk, curbs, patterned carpets, tight spaces such as bathrooms, or when turning. Emotional stimuli include stress, anxiety, and time sensitive situations such as crossing the street.

What is the biological basis behind freezing of gait? Walking or forward locomotion requires our brains and body to coordinate multiple circuits and feedback loops that facilitate balance, posture, and ambulation. While most of us take the ease of walking for granted, Parkinson's disease can disrupt these circuits and challenge the initiation and continuation of smooth and automatic movements such as walking.

Do you ever find your feet frozen or glued in place? Do you ever feel stuck? Freezing of gait (FOG) affects 50-80% of people with Parkinson's disease.

Getting Unstuck

If you find yourself experiencing trouble initiating movement, or find yourself stuck in place, below are several steps that can help get you moving:

Stop and breathe. Fight the urge to continue forward as this shifts your weight onto your forefoot and contributes to an increased difficulty of safely completing the next forward step. Instead, take a moment and take a soft breath in and a full exhalation out, releasing tension from your shoulders and your body.

Stand tall and shift back onto your heels. By shifting your weight back onto your heels, you should feel more stable and comfortable. It increases your base of support and allows you to shift your weight more easily.

Shift your weight, shift your eyes. Try rhythmically shifting your weight from your left leg to your right leg. Or, sometimes people find that taking a backwards step and then a forward step helps them re-initiate walking. To shift your eyes, find a target in the distance that you want to walk to or past. For instance, if you are frozen before a doorway, look beyond the doorway and walk to the chair in the next room.

Step big. After you stop, breathe, adjust your posture, and shift your weight, try to take a large step through the doorway and to your chair, or over the cracked sidewalk and to the next tree.

Sing! Try audible cueing. Sing your favorite song with a good rhythm that helps you sway or shift your weight to the music or try counting 1, 2, 3, 4. If this does not work, have a companion help by saying, "step big".

If you experience symptoms of FOG, please work with your neurologist or movement specialist to optimize your medications.

Physical therapist are also instrumental in helping you free your feet. They can expand upon the techniques outlined here as well as introduce you to new ways of moving. It is also important to mention additional components that may contribute to FOG such as visual spatial awareness, the ability to set-switch effectively (or move from one task to the other), and some postural components. Physical therapists can help address these areas to help improve your quality of life and manage your motor-related symptoms.

5 tips to help get unstuck

Stop and breathe

Stand tall and feel your heels

Shift your weight, shift your eyes

Step big

Sing or count it out

STEPS TO *Living in the Moment*

"Live in the moment!"

What does that mean, exactly?

We know what it means; we just have a hard time doing it!

We are all so distracted with our multiple responsibilities it is hard to live in the present. But fitting little things into your busy schedule can be more beneficial than you might think. Many of these activities will not only help improve your mental health, but also positively alter things in your body.

Challenge

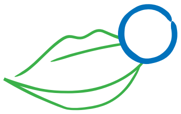
Take a moment to try one of these activities every day this week.

Track your progress by pinning this page on your wall or fridge. After you complete an activity, mark it off! By the end of the week take a moment and reflect to see which one of these things worked for **you** to center yourself. Be mindful of what is successful and how it helped your overall mindset throughout the day. After your "living in the moment" week is complete, try to implement these small rituals into your day-to-day life. Have fun on your adventure!

Read Fiction

Find a good book and get lost in the story. It's best if your book transports you into the body and mind of the protagonist. Let me suggest reading a good fictional thriller!

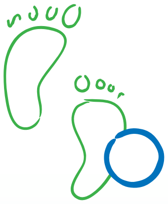
It turns out reading a thrilling fiction novel is not only fun, but it can improve our brains! Researchers at Emory University found that people who read an assigned novel affected not only the area of the brain associated with language, but also in the primary sensory motor region of the brain. So when the hero runs, your brain thinks you're running, too! Brain benefits without putting on your running shoes!



Watch Comedy

When has a good laugh not transported you into a different mindset? There are so many kinds of humor, from wordplay and self-deprecation, to slapstick and dark humor. Search for comedies on tv, Netflix, or your favorite streaming service and you are sure to find one that tickles your funny bone.

In addition, there are benefits! Media psychologist Dr. Pamela B. Rutledge, director of the Media Psychology Research Center in California explains: "Humor, when it's actually funny, has social and physical benefits: laughter releases neurotransmitters responsible for your happiness, such as dopamine, serotonin, oxytocin, and endorphins." Furthermore, "the release of these chemicals in response to humor decreases stress, diminishes pain and in the process strengthens the immune system."



Walk on Grass

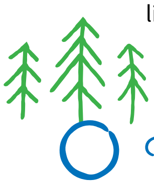
Barefoot, that is! Walking barefoot on grass is also called "earthing" or "grounding." This may be one of the easiest ways of focusing on the here-and-now. As you walk barefoot on grass, watch where you place your feet! You don't want to hurt yourself while practicing this activity. In addition to watching where your feet land, notice how the grass feels on your skin, and conversely, how the earth feels under you. This simple activity can be an all-consuming way to focus and center yourself.

The health benefits are many! The most recent scientific research has explored grounding for inflammation, cardiovascular disease, muscle damage, chronic pain, and mood.

Try New Food

While you could try eating a familiar food mindfully, a new food may force you to pay attention to every detail. How does it look? What does it smell like? How about the texture on your teeth? And, of course, what about the flavor?

In addition to the benefits to your taste buds, trying new foods can increase your health, too! Variation in your diet is very important, by trying new, healthy food you'll introduce more positive nutrition to your body. With plenty of variety, you will get everything from vitamin C to iron to linoleic acid without even having to think.



Forest Bathing

Forest *what*? It's originally a Japanese thing. The term Shinrin-yoku (forest bathing, or immersing yourself in the forest environment) was coined by the Japanese Ministry of Agriculture, Forestry, and Fisheries in 1982, and can be defined as connecting with and taking in the forest: a process intended to improve one's mental state and provide physical relaxation.

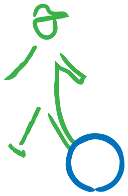
Try forest bathing: find a secluded place to sit in a wooded area and focus on the subtle sounds around you, the warmth of the sun or chill of the wind. The goal is to focus on the little nuances of the environment around you that you might not notice day-to-day.

Studies show that forest bathing could lower concentrations of cortisol, lower pulse rate, lower blood pressure, increase parasympathetic nerve activity (the "rest and digest" side of your nervous system, and lower sympathetic nerve activity, the "fight or flight" side).

Smell the Coffee

Make the most of every moment with coffee! There are numerous health benefits to drinking coffee: from caffeine to antioxidants and other active substances that may reduce internal inflammation and protect against disease. But did you know that just **smelling coffee** can increase your performance? Believe it and it will happen.

An American study done in 2018 found that people in a coffee-scented environment performed better on an analytical reasoning task due to heightened performance expectations. This occurred even though the coffee-like scent actually contained no caffeine! So in other words, people thought they would do better because they expected to do better… the coffee-like smell made it so! Enjoy that cup of coffee if you brew it or buy it from your local shop.



Take a Brisk Walk

Get outside in the sun this summer with a brisk walk around your neighborhood. Researchers found, in a study of people with Parkinson's, that by walking three times a week, participants saw improvements that positively affected their daily lives. They saw a 15% improvement in motor function and mood, 14% improvement of attention/response control, 11% reduction of tiredness, and 7% increase in aerobic fitness and gait speed.

Trying to motivate yourself to get out the door? Try to find objects of one certain color, find out how many birdhouses your neighborhood has, or count the number of times you see an animal. Make walking enjoyable!

Mei Hanway is a high school senior at Seattle Lutheran. Her grandfathers on both sides of her family are living with Parkinson's. Mei first got involved with APDA her freshman year by volunteering at the Optimism Walk. Like everyone else during this time of COVID Mei has been looking for a way to get away from her computer screen and find positive light to focus on. She has achieved that through focusing on the little things that she can control and have fun doing. By sharing these activities with you she hopes that you can find a little light in your day as well. This project is part of her overall 'senior project' that she is working on this year with APDA and her school. She plans to study Business at the University of Washington, Bothell next year.

The year 2021 marks the 60th Anniversary of APDA, which was founded in 1961. This milestone has given us the chance to look back at our accomplishments over the past 60 years and reflect on what we have achieved—and also what we have yet to achieve. One of the key pillars of APDA's mission is the support of research designed to unlock the mysteries of Parkinson's and ultimately put an end to this disease. APDA has been a funding partner in many major Parkinson's disease (PD) scientific breakthroughs, investing more than $51 million in research since its inception.

Today, we will look at two of these major PD scientific breakthroughs that are part of APDA's legacy.

APDA Turns 60!

Our Research Highlights

Supporting the work of
George C. Cotzias, MD

In 1957, Dr. Arvid Carlsson demonstrated that dopamine was a neurotransmitter, or brain chemical, that was important in movement. After these observations, doctors tried to treat people with PD with levodopa, a precursor of dopamine, that unlike dopamine was able to cross the blood brain barrier. These efforts were not successful, mostly because people could not tolerate the doses of levodopa required to improve movement. Doctors may have given up at that point if not for the crucial work of Dr. George C. Cotzias, who gave people small doses of levodopa every two hours, building up to the doses that were beneficial for movement. In this way, Dr. Cotzias demonstrated that levodopa was an effective and feasible treatment for Parkinson's disease.

Dr. Cotzias worked on many crucial elements of levodopa treatment. In this paper shown below, he made the critical observation of what is now called the levodopa "protein effect", that in some people, diets high in protein can interfere with levodopa absorption and decrease the efficacy of the medication.

Although levodopa remains the most effective treatment for Parkinson's, research scientists have built upon the discoveries of Dr. Cotzias to devise a whole variety of new ways to deliver levodopa to the brains of people with PD.

APDA is proud to have supported the pioneering work of Dr. Cotzias, and in 1979, APDA's George C. Cotzias Memorial Fellowship was created in his memory. This award supports a promising physician-scientist over a three-year period, allowing for early-career development in research and patient care of PD. It has been awarded to 30 individuals since it was established, six of whom became department heads (or higher) at major academic medical centers.

Protein Intake and Treatment of Parkinson's Disease with Levodopa

Ismael Mena, M.D., and George C. Cotzias, M.D.

January 23, 1975
N Engl J Med 1975; 292:181-184
DOI: 10.1056/NEJM197501232920404

Supported primarily by the U.S. Atomic Energy Commission, the National Institutes of Health (Project NS 11131-01) and the National Institute for Occupational Safety and Health, Public Service, U.S. Department of Health, Education, and Welfare (Grant OH 00313-10), co-ordinated by the American Health Organization (Project AMRO-4618); it was supported in part by The Charles E. Merrill Trust and the American Parkinson's Disease Association. A preliminary report was given at the Princeton Conference on Parkinson's Disease, April 11-13,1973.

Excerpt from study published in the *New England Journal of Medicine*, 1975, showing APDA's support for Dr. Cotzias' breakthrough research.

George C. Cotzias Fellowship Recipients

Here are the accomplishments of just a few of the past recipients of the George C. Cotzias Memorial Fellowship. (The year in which they won the Cotzias Fellowship is in parenthesis next to their name):

Dr. David Eidelberg (1995) – is the Susan and Leonard Feinstein Professor of Neurology and Neuroscience and has served as director of the Center for Neurosciences at the Feinstein Institutes for Medical Research in Manhasset, NY since its founding in 2001. His research focuses on characterizing the brain networks in PD and related disorders using imaging techniques, such as PET scanning and functional MRI.

Dr. David Standaert (1996) – is the John N Whitaker Professor and Chair of Neurology at University of Alabama School of Medicine at Birmingham. His research focuses on understanding the molecular causes of PD including the role of inflammation in the development of PD. Dr. Standaert serves as the Chairman of APDA's Scientific Advisory Board.

Dr. Talene Yacoubian (2007) is an Associate Professor of Neurology at University of Alabama School of Medicine at Birmingham. Her research focuses on understanding the mechanisms that contribute to development of PD including the mechanisms by which abnormal alpha-synuclein propagates in the brain.

Dr. Vivek Unni (2016) is an Associate Professor of Neurology at Oregon Health & Science University in Portland, OR and a member of APDA's Scientific Advisory Board. His research focuses on understanding the role of alpha-synuclein in the development of PD using advanced imaging techniques in the live mouse brain.

Discovery of alpha-synuclein

APDA also played a pivotal role in another major breakthrough in our understanding of PD – the discovery of alpha-synuclein as a key factor in development of Parkinson's.

Up until the late 1980s, PD was understood to be caused mostly by environmental factors and not faulty genes. Dr. Roger Duvoisin was one of the earliest chairmen of APDA's Scientific Advisory Board (SAB), and a prolific PD researcher. 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 was a firm believer that genetics were not significant in the development of PD and in the 1980's, he was involved in epidemiologic studies which attempted to show that genetic factors did not play a major role in the development of PD.

What changed this 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 who had, what appeared to be, autosomal dominant PD, which meant that PD was found generation after generation, and children with a parent with PD had a 50% chance of developing the disease.

Dr. Lawrence Golbe, also at Robert Wood Johnson School of Medicine, spearheaded this effort, partially funded by APDA, to study this family.

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

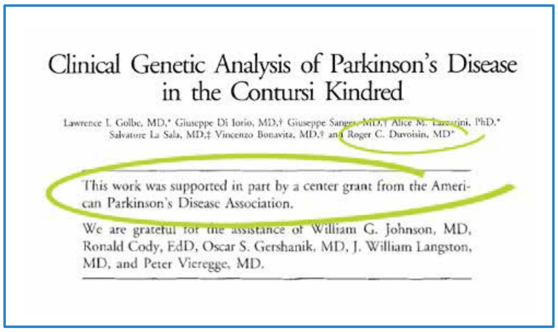
It is hard to overstate how important this discovery was in our understanding of PD. Since 1997, a tremendous amount has been learned about alpha-synuclein and its role in PD. This knowledge has been transformed into potential therapies for PD and today, multiple clinical trials are focused on manipulating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

APDA continues to fund cutting edge research to help advance our understanding of PD and help bring us closer to more effective treatments, and eventually, a cure. Learn about what we are currently funding at **apdaparkinson.org/research**.

Tips and Takeaways

- APDA has been a funding partner in many major Parkinson's disease (PD) scientific breakthroughs since its inception in 1961
- APDA helped fund work that led to the use of levodopa for treating PD and for identifying alpha-synuclein as a key molecular player in the pathogenesis of PD
- APDA continues to fund some of the brightest minds in PD research – awarding grants every year to fund promising research projects that have met the stringent criteria of our Scientific Advisory Board
- To join us in our research efforts, please consider donating to APDA

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



Clinical Genetic Analysis of Parkinson's Disease in the Contursi Kindred

Lawrence I. Golbe, MD,* Giuseppe Di Iorio, MD,† Giuseppe Sanges, MD,† Alice M. Lazzarini, PhD,*
Salvatore La Sala, MD,‡ Vincenzo Bonavita, MD,† and Roger C. Duvoisin, MD*

This work was supported in part by a center grant from the American Parkinson's Disease Association.

We are grateful for the assistance of William G. Johnson, MD, Ronald Cody, EdD, Oscar S. Gershanik, MD, J. William Langston, MD, and Peter Vieregge, MD.

APDA Northwest committed to helping local research happen faster!

APDA Northwest Chapter is the sole funder of the Washington Parkinson Disease Registry. (WPDR). **The Registry is a database made up of individuals who are interested and willing to participate in Parkinson's research and contrary to its name you DON'T have to be a Washington State resident to join the registry!**

Local researchers apply to the Registry to find participants for specific research projects. The Registry recruits for a wide range of studies including drug trials, exercise and therapy studies, studies involving technology, genetics, and more. APDA fully funds the registry, as it is crucial to support the connection of researchers and participants so we can better understand disease progression, possible therapies and an eventual cure.

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

DR. REBECCA GILBERT *APDA Vice President and Chief Scientific Officer*

Dr. Gilbert received her MD degree at Weill Medical College of Cornell University in New York and her PhD in Cell Biology and Genetics at the Weill Graduate School of Medical Sciences. She then pursued Neurology Residency training as well as Movement Disorders Fellowship training at Columbia Presbyterian Medical Center. Prior to coming to APDA, she was an Associate Professor of Neurology at NYU Langone Medical Center. In this role, she saw movement disorder patients, initiated and directed the NYU Movement Disorders Fellowship, participated in clinical trials and other research initiatives for PD and lectured widely on the disease.

Join Us this summer
for the APDA's

Create Joy Series

Create and be joyful this summer! Join us for a series of interactive workshops designed to spark joy and creativity. Try something new or revisit a previous passion while you enjoy the documented benefits of improved mood and better quality of life.

All workshops presented on Zoom, registration is required, space is limited. Visit our website for more information.

July 8 Parkinson's Pantomime

Join mime – pantomime, extraordinaire Tim Lundquist in this interactive demonstration. Exercise your face to unmask masking, learn basic mime technique, express ideas with movement and play

July 15 Laughter Yoga

Combine unconditional laughter with yogic breathing. Join the Funny Yogi, Jessica Brustad to move, stretch, breath, play, and embrace your inner child. Fun, joyful and cathartic. No yoga mat needed!

July 22 Invisible Beauties ~ A poetry class

Use poetry to bring the beauty inside you to light. Vicky Edmonds will share easy ways to deepen your relationship with yourself through writing.

July 29 Improv & Imagination

Improv is all about saying, YES, to whatever happens IN THE MOMENT. Join Taproot Theater's professional actors for laughter, fun and inspired creativity.

August 5 Parkinson's Puppetry

Explore movement and creativity with puppets. Join the "Puppeteer with PD", Rob D'Arc, in making simple newsprint and masking tape puppets that you can bring to life with your own hands!

August 12 Connecting through Art

Relax and play with watercolors. Wendy Gottlieb, Art Educator from the Parrish Art Museum will guide you through a step-by-step watercolor painting activity.

▲ Team SEAYOPD was the top fundraising team, raising over $22,000!

OPTIMISM WALK
AMERICAN PARKINSON DISEASE ASSOCIATION

**The 2021 Optimism Walk was held on May 22.
Walkers from all over the Northwest worked to raise awareness and critical funds to support local education programs and materials, free exercise and wellness classes, patient support services, research, and more.**

A huge thank you to our sponsors:

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

What will your legacy be?

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

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

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

OUR MISSION

Every day, we provide the support, education, and research that will help everyone impacted by Parkinson's disease live life to the fullest.