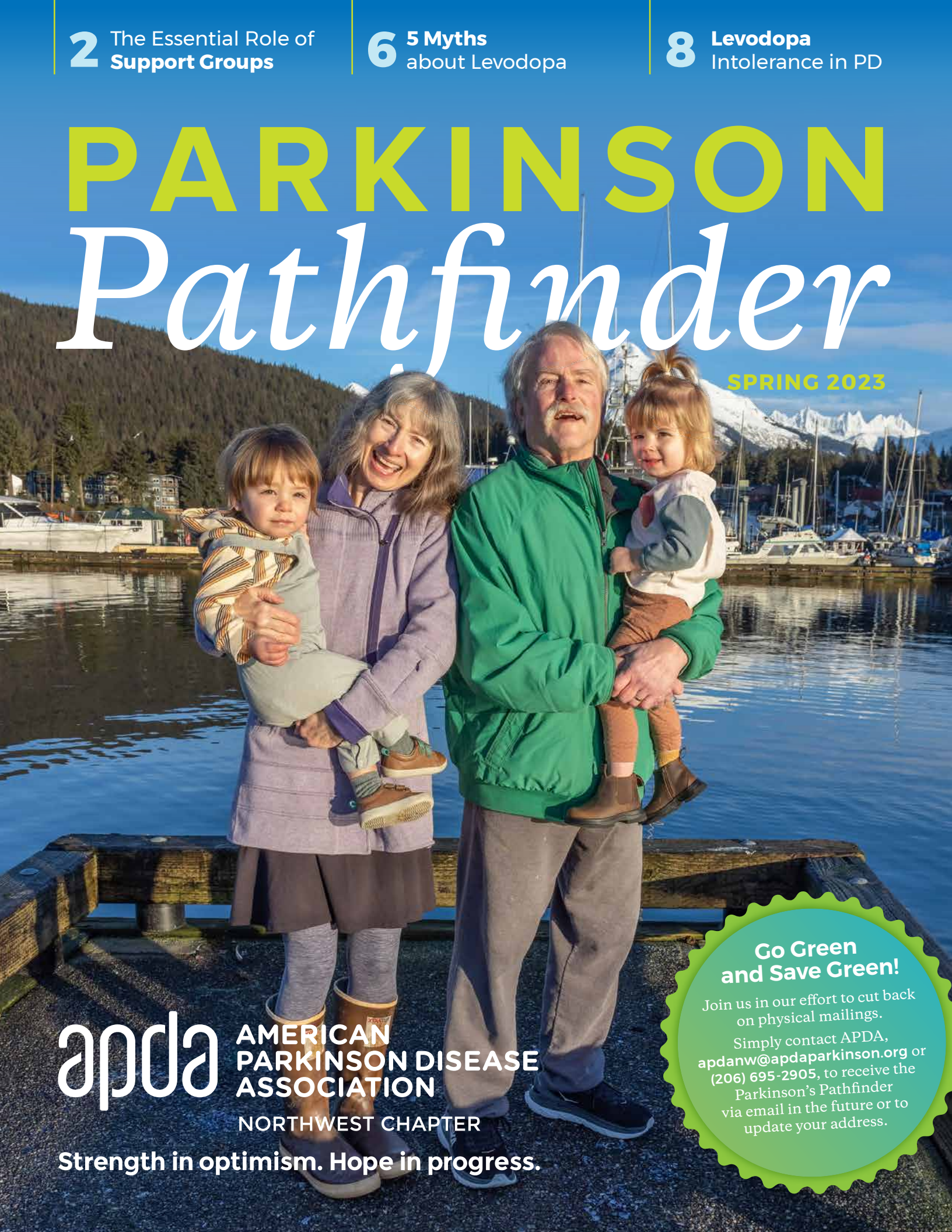
# PARKINSON *Pathfinder*

SPRING 2023



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NORTHWEST CHAPTER

**Strength in optimism. Hope in progress.**

SPRING 2023

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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.


AMERICAN PARKINSON DISEASE ASSOCIATION
NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

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COVER

**Kerry Howard**, *Juneau, AK*
Richard and Luann with their grandkids at the harbor. Richard has Parkinson's and boxes with the Rock Steady Boxing Juneau group.

## Help spread the word!

**Share your story.** It is important to let people know how Parkinson's impacts your life. Incorporate it into your conversations, share APDA social media posts, and/or host a gathering with PD awareness as the theme.

**Advocate for Parkinson's.** Your voice is powerful, and it is important to urge your legislator to support the End Parkinson's Act. Learn more at michaeljfox.org/advocacy

**Connect APDA to a community group.** Facilitate a learning opportunity by connecting us to a leader at your church, Rotary, Elks, etc. (contact 206-695-2905 or email apdanw@apdaparkinson.org to discuss).

**Stay connected with PD research.** Sign up for the Washington Parkinson's Disease Registry www.registerparkinsons.org (NW residents outside of WA are welcome) or follow up on an interesting study.

*A letter from the*
**EXECUTIVE DIRECTOR**

**April is Parkinson's Awareness Month.** It is our objective that for at least 30 days, Parkinson's disease will stand out amongst all the other daily clamor and our message will be heard. We hope people will not only pay attention, but be motivated to ask questions, explore resources, reach out to ask for help if they are experiencing symptoms or challenges, and be inspired to get involved in some way.

For APDA, April really isn't all that different than any other month. Every day, we're working to improve the lives of people impacted by PD. Every month of the year APDA is on the front lines, helping people stay connected, informed, and moving. To our Northwest community we offer numerous support series focused on the newly diagnosed and also care partners, hold innovative education classes (both online and in person) that address identified needs and knowledge gaps, and provide a wide variety of online exercise classes, wellness workshops, and helpful free resources, such as this Parkinson's Pathfinder. We help people struggling to make ends meet with our Financial Support program. And importantly, we invest in promising research.

But we still want to take advantage of April! Parkinson's disease is the fastest growing neurological disorder, impacting more than 1 million Americans, and growing daily. A recent study determined that PD is 50% more prevalent than previously thought – which means every 6 minutes someone in the US will be diagnosed with PD. Raising awareness remains critical, so that Parkinson's gets the attention it deserves in the research community, in the media, and in our own neighborhoods.

April offers a chance to take advantage of a special moment when there is extra focus on this disease. We have listed a few simple outreach ideas to the left. Together we can take this opportunity to educate a broader audience about PD and about the support APDA can provide.

Sincerely,

Kirsten Richards, Executive Director

# Don't Go It Alone

## The Essential Role of Support Groups

By **Nicole Hill**

**Do you remember what it was like when you or your loved one was diagnosed with PD? What was that experience like? Did you feel fear? Dread? Confusion?**

Lynn Woods of the Flathead Valley, MT group has seen firsthand when people "come in so scared, with questions like, what's going to happen? What am I going to face? What does the future bring?"

Without a doubt, the diagnosis of PD is life-changing and likely overwhelming. There is a barrage of both emotion and information—too much for any one person to handle by themselves. Thankfully, you don't have to. Support groups offer tremendous and often vital resources, connections, and encouragement. They function as places to learn, share, socialize, and help others.

Two important functions of support groups are education and knowledge sharing. The beauty of a support group is that while all members have different experiences, the group together has a common goal—to feel better. This means members can bring their unique ideas, challenges, and successes to the table to share with everyone. Marjory McClaren of the Flathead Valley group reports that she gets more information here than in any other place. She says, "having other people with Parkinson's is just so important. You can't get the same kind of therapy from those who don't have it." When you consider the collective number of years a group has in dealing with PD it becomes clear that there is a wealth of knowledge found there.

Meeting together at regular intervals is also an excellent way to keep up on research and resources. This happens naturally between group members, but inviting guest speakers is a wonderful way to stay up-to-date in the PD world. Plus, it can provide a meeting focus and helps keep the conversations going.

But even more important than information are the connections found in a support group. Unfortunately, isolation is a common theme for a Person with Parkinson's (PWP). Diane Hutchins of the Olympia, WA group points out that "with the progression of PD, there may be a loss of friends or communities" due to mobility challenges, decreased energy, or even transportation issues. All the facilitators agree—with PD, socialization is one of the most important things a support group provides. As Phil of the Poulsbo, WA group put it, "everyone needs social air."

Support groups become even more critical for those who live alone or have few local family or friends and for whom isolation is an even bigger risk. Phil states that for them, a support group is "like they've found a life raft on a sea of overwhelming thoughts."

The most successful support groups have a strong feeling of community where people care about each other and want to work and grow together. The members are truly friends. Lynn says that when people are, "not alone, they have confidence they wouldn't have otherwise."

Setting the tone for meetings is an important role of the facilitator and each of these leaders stressed the need for positivity.

Diane emphasizes that PD doesn't have to be as dire a prognosis as many initially think. Participating in a support group makes the disease less scary, gives a lot of confidence, and pulls "people out of the initial shock and depression." She suggests, "try to have a sense of humor and don't take things too seriously." With all the research and support going on in the community, she reminds us that PWP are in a good position and that those in a support group are much more informed patients.

Marjory and Lynn like to remember that everyone in the group has an interesting life outside of PD. They want their members to realize that PD doesn't define them. Marjory wants her meetings to be a place for learning and laughter. "I want them to walk away with information they can use as well as the hope that there's something more for us." And Lynn, who leads the carepartner group, reports that their meetings have an open feel and that when people leave, it's with a feeling of release, "like they can handle it."

Phil's group starts the meeting with a "tremor safe zone" pledge and light exercise. His philosophy is "to not let Parkinson's drive your life. Put yourself in front of Parkinson's." He advises to not get so consumed that you lose sight of the good things in life. The pledge that starts the meetings reminds the members that as a group they are made stronger and wiser, they inspire each other, and they are not alone, but in this together.

The diagnosis of PD is indeed life-changing. But having a support group can also be life-changing. Everyone needs support, and providing support to others is equally rewarding. "I don't know if there are words to describe how rewarding it is," says Phil. Marjory agrees, stating that the people "make it easy to do the work. I get rewards every day." Diane loves knowing that she has made a difference in the lives of others, and Lynn says, "even if one person shows up, it is worthwhile."

**Nicole Hill** is a freelance health content writer. She has over 20 years of nursing experience in a variety of settings including hospital, community, school, and camp. ER has been her main area of expertise, but she loves that nursing affords many opportunities in different areas. Now she is excited to expand into writing.

*This article was produced with insight from interviews with the following support group facilitators:*

**Diane Hutchins** *of the Olympia, WA-based group;* **Phil Segadelli** *of the Poulsbo, WA-based group;* **Marjory McClaren** *and* **Lynn Woods** *of the Flathead Valley, MT-based group*

**If you are thinking of starting and facilitating a support group in your area, take a page from those who've done it. Here are some suggestions for getting started.**

- **Don't do it alone** — if you can recruit another person or two, you can work together to brainstorm ideas and divide up tasks
- **Contact the APDA** office for support
- **Distribute information** about the group where it makes the most sense such as neurology clinics and PT/OT/SLP offices
- Ask the local newspaper about free **advertising**
- **Consider working with local clergy** — they are usually tapped into local resources
- **Be grateful for every person in the group** — it's perfectly fine to start out with 2 or 3 people. It's still valuable and can make a difference.
- **Delegating tasks** will strengthen the entire group as others invest their time, and it prevents personal burnout.

### It takes work to run a support group.

Some of the challenges one might face include:

- Group participation
- Setting a day and time that works for the group
- Transportation issues for members
- Keeping fresh with relevant topics
- Coordinating guest speakers

But the challenges can be offset with a positive attitude, some preparation, and help from others. Over time, some of the challenges work themselves out as you learn from your mistakes and tweak things to work for your group. Support groups settle into what works for them.

### Phil's group:

- Supplies a weekly email newsletter
- Has a theme or subject matter for every meeting – often using David Phinney's book, *Every Victory Counts* as source material
- Has started spotlighting members during meetings

### Diane's group:

- Has a show-and-tell with books members have read
- Has a trifold of resources for members
- Puts effort into helping those with transportation issues
- Is a mix of PWP and caretakers

### Marjory's group (PWP) and Lynn's group (carepartners only):

- Has a well-designed website
- Has a Facebook page
- Connects in multiple exercise classes
- Has a very strong sense of community

## Q&A WITH

# APDA Researcher **Stephan Grimaldi**

By **Nicole Hill**

**Stephan Grimaldi** is a post-doctoral fellow at Massachusetts General Hospital and recipient of a 2023 Post-Doctoral fellowship from APDA. He is currently researching ways to use cutting-edge technology of a 7-Tesla MRI scanner to evaluate brain biomarkers of neurodegeneration in the stage prior to the development of Parkinson's disease (PD). Through his research he aims to identify biomarkers of neurodegeneration with the goal of making early diagnosis a reality.

**Q: Could you describe your research?**

**A:** I'm very interested in finding out what's happening in the brain of people who get PD. A lot of studies and research focus on people who already have the symptoms of PD. By that time, over 50% of the dopamine neurons are dead. So we have to focus on the 10-15 years before symptoms of the disease appear. But how do we identify which people are going to develop PD in the future? We know that REM sleep behavior disorder (RBD), a sleep disturbance in which people act out their dreams, can occur in people prior to a diagnosis of PD. Over 70% of people with RBD will go on to develop PD. We would therefore like to know what is going on in the brains of people with RBD and potentially find biomarkers of neural degeneration. If we can do this, we can propose new treatments and then follow the effect of the treatments by looking at those biomarkers. Since these individuals do not have symptoms of PD, we cannot follow their clinical state, so biomarkers that can be followed over time are very critical for this population.

**Q: What methods do you use to conduct your research?**

**A:** We first have to identify people with RBD and without PD. Those people are actually hard to find for our research because patients who have those symptoms do not generally see a doctor. Some of them sleep alone so they do not even know they are acting our their dreams, and some of them are told by their spouse that they are active sleepers, but they do not go to see a doctor. When we do identify such a patient, they are seen by a neurologist at the sleep clinic and then can be referred for the study.

During the study, we perform several clinical scales for PD even if they do not have the symptoms. After that, they go into the 7-Tesla MRI scanner (a standard MRI is 3-Tesla), which produces images of the brain that are very precise and can discern microstructure, anatomy and connectivity from one part of the brain to another. My project is to analyze both baseline MRI and follow-up MRI to see the changes concerning microstructure, anatomic changes, and connectivity changes in the part of the brain where we know there are nuclei that are involved in the sleep process. We hypothesize that those nuclei in the brain stem and the connectivity between them are damaged.





> I really want to be part of what we can discover early in Parkinson's disease to change people's lives.

**Q: What do you hope to accomplish with your research?**

**A:** We are hoping to be able to identify an early change that can serve as a biomarker for neuronal loss. The biomarker could then be monitored. For example, if we give a treatment, we will be able to see if this treatment is effective or not by following what happens to the biomarker. There are a number of treatments in clinical trial that target the alpha-synuclein protein which aggregates in PD. Currently, these clinical trials are recruiting people with PD and not RBD alone, but in the future, clinical trials might expand to include people with RBD to see if onset of PD might be delayed or even prevented, The goal would therefore be to monitor the brain changes in the MRI biomarkers we develop as the treatment is given.

**Q: What's the advantage of an earlier diagnosis?**

**A:** Knowing that you have PD, or that you are at very high risk of developing PD, will potentially allow you access to clinical trials that aim to delay or prevent disease progression. In addition, knowing your PD diagnosis can be motivating to make healthy lifestyle changes such as increased exercise and improved diet which can have a substantial impact on brain health.

**Q: How might your research benefit people who already have PD?**

**A:** There are other reasons to conduct research into the microstructure, anatomy, and connectivity of the brain besides the identification of an early biomarker of neurodegeneration. For example, in people who already have PD, this knowledge can more precisely guide electrode placement during a Deep Brain Stimulation (DBS) surgery. Understanding these structural changes in someone who has PD can even help in the design of new DBS strategies.

**Q: Why did you choose to study PD?**

**A:** I chose PD because I'm very interested in the multiple symptoms of PD; the motor symptoms and the non-motor symptoms — particularly the neuropsychiatric symptoms — throughout the course of the disease. My research is motivated by the idea that we can do something — we can find a way to stop the evolution of the disease. I really want to be part of what we can discover early in the disease to change people's lives.

# 5 Myths ABOUT Levodopa

By **Dr. Rebecca Gilbert,**
APDA Chief Scientific Officer

When prescribed, levodopa is extremely effective in treating the motor symptoms of Parkinson's disease (PD) and is embraced by many with PD. Many individuals see using Levodopa as a vital ingredient in maintaining movement and quality of life. It is the most prescribed medication for PD and has been the mainstay of PD treatment for decades. APDA research support played a role in the discovery of levodopa for PD treatment when we funded the work of Dr. George C. Cotzias back in the 1960s.

Despite the research and general support from the Parkinson's community, there are many myths that surround the use of levodopa that make many people hesitant to start taking it even after their doctor recommends it. To clarify some of the confusion and misinformation, APDA presents five myths that often circulate in the PD community about levodopa and tries to explain the reality behind them.

*Note: In the US, the combination of carbidopa/levodopa is used in order for the levodopa to make its way to the brain before it breaks down, so you may often see the medication referred to in this way. Dosages appear as two numbers like 10/100, 25/100, and 25/250 — the first number refers to the milligrams of carbidopa in the pill. The second number refers to the milligrams of levodopa in the pill.*

## 1 MYTH #1: It is important to delay starting levodopa for as long as possible to delay the onset of motor fluctuations and dyskinesias

**FACTS:** Early on in PD, a dose of levodopa can last six hours or longer, but often, as PD progresses, a levodopa dose tends to relieve symptoms for shorter amounts of time. A person may take a dose of levodopa and have good symptom relief for a period that is referred to as ON time. After this period is over, the effects of levodopa may start to wear off and symptoms of PD return for a different period referred to as OFF time. This phenomenon of alternating between ON and OFF time is known as motor fluctuations. In addition, dyskinesias or involuntary movements can occur, typically at the time of peak brain dopamine levels or when brain dopamine levels are changing. There are many strategies that your doctor can try to smooth out your response to medication throughout the day to help with motor fluctuations and dyskinesias.

The development of motor fluctuations and dyskinesias typically occurs after being on levodopa for many years. This has led some people to infer that the amount of time on levodopa influences the development of motor fluctuations and dyskinesias. If this were truly the case, it would make sense to delay taking levodopa for as long as possible.

However, it has been shown in many clinical trials that the onset of motor fluctuations and dyskinesias has to do with how long you've had the disease and not with how long you have been taking levodopa. If you wait until your disease has progressed before you start taking levodopa then motor fluctuations may start sooner after levodopa is started (because your disease is more advanced), as compared to when levodopa is started earlier in the disease progression (when symptoms are typically milder). Therefore, the development of motor fluctuations and dyskinesias is a function of the stage of Parkinson's disease you are in and not the length of time you are on levodopa.

**On the flipside:** Levodopa does not have to be started as soon as you are diagnosed with PD. In general, there is no downside to postponing levodopa treatment if your PD symptoms are not affecting your daily function. However, please discuss with your neurologist or physical therapist to determine if you can exercise effectively and up to your maximal capabilities in your current state. Because exercise is potentially neuroprotective, you do not want to unnecessarily accelerate your PD progression by remaining off levodopa and not being able to exercise maximally.

## 2 MYTH #2: Levodopa loses effectiveness over time

**FACTS:** It is true that over time, people with PD tend to need to take more levodopa. As the progression of PD takes place, there are fewer dopaminergic neurons in the brain that can produce their own dopamine. A person with PD tends to need more medication containing dopamine to compensate for these changes. Therefore, a higher dosage of levodopa over time does not mean that the medication is no longer working; it means that the disease is changing.

In addition, as PD progresses, a person may start to develop more symptoms that are not responsive to levodopa. Levodopa best treats the motor symptoms of PD such as slowness, stiffness, and tremor. Some motor symptoms, including balance problems, do not respond as well to levodopa regardless of when the medication is started.

Non-motor symptoms that do not respond well to Levodopa, include:

- fatigue
- depression
- sleep problems
- cognitive difficulties
- variations in blood pressure
- urinary problems
- constipation

These symptoms do not typically respond to levodopa and may cause more disability over time than motor problems. The perception may be that over time, levodopa is not effective, when in fact there are new symptoms that develop that levodopa cannot treat.

## 3 MYTH #3: Taking levodopa should be avoided if possible. Taking a natural medication, like Mucuna, is better

**FACTS:** Levodopa can be life-altering for people with PD, helping them move more naturally and restoring quality of life. Mucuna (also known as the velvet bean), contains 6-9% levodopa on average by weight, so taking Mucuna is a method of ingesting the same compound, levodopa. However, Mucuna has several limitations which make it difficult to be the sole medication used for PD symptoms without any pharmaceutical-grade levodopa. Most importantly, it does not contain carbidopa, an enzyme inhibitor that is incorporated into the pharmaceutical form of levodopa, which stops the breakdown of levodopa in the bloodstream. Adding carbidopa or an equivalent compound to levodopa was a major scientific breakthrough, allowing for much less levodopa to be ingested, since more passes into the brain where it is converted into dopamine. With lower doses of levodopa ingested, the side effect profile of levodopa, especially nausea, is substantially improved. Mucuna does not contain carbidopa, so the amount of levodopa that can be ingested without side effects is limited. In addition, Mucuna is not regulated by the Food and Drug Administration, so the amount of levodopa in a supply of Mucuna is unreliable leading to doses becoming unpredictable.

**On the flipside:** There are people with PD who have successfully incorporated Mucuna into their standard levodopa regimen with good effect. If you are having trouble with your levodopa regimen, and you are interested in trying Mucuna, speak with your neurologist about the best way forward.

## 4 MYTH #4: Levodopa causes intolerable side effects for many people

**FACTS:** Levodopa can have an array of side effects such as nausea, fatigue, dizziness, and hallucinations. However, with patience, you and your neurologist will likely be able to find a formulation and dose of levodopa that you will be able to tolerate and can help treat your PD symptoms successfully. Occasionally, your neurologist will need to prescribe an additional medication to treat a side effect from levodopa. Sometimes, anxiety over a possible inability to tolerate levodopa interferes with being able to tolerate the medication. In these cases, treating the underlying anxiety can be helpful.

Dyskinesias are a common side effect of levodopa. Like any side effect of a medication, dyskinesias exist on a spectrum. Sometimes dyskinesias are very mild and can be barely noticed by the person with PD. Other times, dyskinesias are severe and can cause imbalance or social embarrassment. In most cases, dyskinesias are in the middle of the spectrum. Your neurologist will work together with you to find the formulation and dosing schedule of levodopa that minimizes dyskinesias. If this is not sufficient, medications to decrease dyskinesias can be prescribed as well.

On the flipside: A small number of people have significant side effects from one or more formulations of levodopa to the point that taking the medication reduces their quality of life. This occurs most commonly with the immediate-release version, also known as Sinemet. If this occurs, talk with your doctor about what can be done. As mentioned above, there are ways to considerably improve the tolerance of levodopa, such as by slowly titrating the medication up over time or taking the medication with certain foods. Changing the formulation to a longer-acting version can substantially improve the situation as well. With these changes, those affected can obtain the benefits of levodopa without having distressing side effects. Nevertheless, most movement disorders neurologists have encountered a small number of patients who seem unable to tolerate any formulation of levodopa regardless of what is tried. This is a rare, but difficult problem to face because levodopa is the most effective medication for the motor symptoms of PD. If it can't be tolerated, other medications for PD can be tried in its place, but they are unlikely to give as robust relief of PD motor symptoms as levodopa provides.

## 5 MYTH #5: Levodopa is toxic to neurons and contributes to disease progression

**FACTS:** The question of whether levodopa is toxic to neurons and accelerates disease progression has been studied in numerous ways over the past three decades, without conclusive evidence that it does so. In fact, levodopa has been shown to increase life expectancy in people with PD, which strongly argues that levodopa does not accelerate the disease. In addition, levodopa has been shown in clinical trials to improve quality of life for people with PD.

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# Levodopa Intolerance in PD

By **Dr. Pravin Khemani**

Levodopa is the gold standard for the treatment of Parkinson's disease (PD) for the simple reason that it provides the essential neurotransmitter dopamine. This chemical is deficient in people with PD and causes its cardinal motor symptoms. Other medicines might mimic or increase the effect of levodopa, but none come close to the robust and sustained improvement in mobility that levodopa provides.

Dopamine acts in the brain to improve motor symptoms of PD but it is not able to get past the blood-brain barrier, a defensive line of very selective cells. However, levodopa, which is eventually converted to dopamine, can enter the brain.

Like all medicines, levodopa has side effects that can make it difficult to take as prescribed. The most common levodopa-related complaints are due to its premature conversion to dopamine in the body before the drug enters the brain. For this reason, it is combined with carbidopa—a compound that prevents its breakdown into dopamine (Fig 2). Carbidopa/levodopa, also known as Sinemet, is the most commonly prescribed drug formulation for PD. There are other medications that may be combined with carbidopa/levodopa (C/L) to improve its efficacy if necessary.

Fluctuating brain levels of dopamine are associated with poor outcomes. Therefore, the primary goal of levodopa treatment is to improve motor symptoms by maintaining a consistent concentration of the medicine in the blood and ensuring a steady supply of dopamine to the brain, while minimizing side effects.

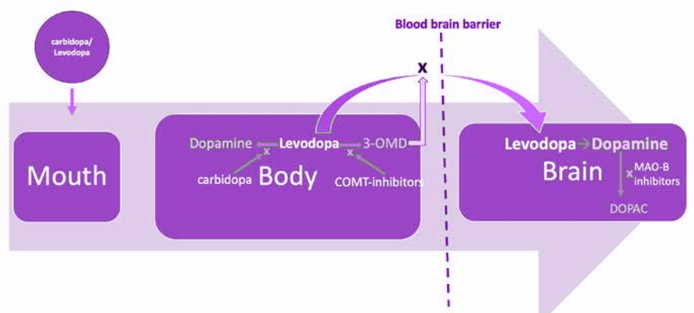


Figure 1

Before we discuss various tips and tricks to improve levodopa tolerance, it is important to emphasize that levodopa is not toxic in any way. Delaying treatment or 'saving' it for later is not justified in current clinical practice. Several scientific studies have demonstrated that quality of life and longevity in PD are much improved in the post-levodopa era compared to when patients were untreated. Therefore, levodopa-phobia has no scientific basis and might be the first hurdle to overcome in PD management. (see previous page for more information) .

The 'start low and go slow' method is a good first strategy to improve levodopa tolerance. This is done by taking half or sometimes quarter tablets and gradually increasing the total dose. The optimal combination of carbidopa: levodopa is 1:4 (e.g., Sinemet 25/100) to prevent the conversion of levodopa to dopamine before it enters the brain (Fig 1).

For the purpose of troubleshooting, adverse effects from levodopa can be divided into **1.) Non-motor and 2.) Motor symptoms**.

## 1. Non-motor side-effects of levodopa: (see Table)

**a. Gastrointestinal (GI):** The most common complaint related to Levodopa is nausea, which diminishes over time. It is recommended that the medicine be taken at least a half-hour before meals. If nausea is persistent, the medicine can be taken with no or low-protein foods, as protein competes with the passage of levodopa into the brain. Ginger formulations, including candied ginger or ginger tea have helped some patients. For severe nausea, extra carbidopa, or anti-nausea medications can be prescribed.

PD causes the entire gut to slow down causing constipation, bloating, symptoms of irritable bowel syndrome, early satiety, and decreased appetite *(APDA has webinars on this topic, learn more at YouTube.com/APDAnorthwest)*. Levodopa can worsen these symptoms. A slow gut reduces the absorption of levodopa which in turn causes motor complications. Constipation is first addressed with dietary modifications—increasing hydration and intake of fruits, vegetables, and fermented foods, and reducing or eliminating meat and dairy. If these changes fail, over-the-counter (OTC) products, such as probiotics and polyethylene glycol (Miralax), are recommended. Different products work for different people so a 'trial-and-error,' strategy is typically used until a steady bowel regimen (at least 5 bowel movements per week) is achieved. Prescription drugs may be needed if constipation doesn't improve with non-medical remedies.

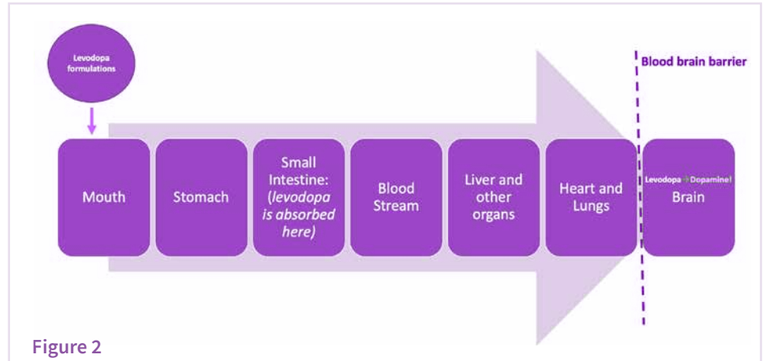


Figure 2

Regular checkups with a primary care provider are critical to ensure good gut health. They can help determine if other medicines are aggravating GI symptoms and see if there are ways to cut the medications out. Consultations by a nutritionist or GI specialist are standard of care for persistent and bothersome GI issues.

**b. Orthostatic hypotension (OH)**: This is a sudden drop in blood pressure (BP) upon standing. OH is common in PD and can be intensified by levodopa. Additionally, supine hypertension (high BP when laying down) can coexist with OH. The first line of treatment for OH is increasing fluid and salt intake, avoiding hot environments, small frequent meals, fall precautions, and compression garments. If these measures fail, medications can be used for low BP while being careful about supine hypertension. Fortunately, OH does not occur until later in PD and is not a very common side effect of levodopa. Early and severe OH should prompt an investigation for diseases other than PD.

Levodopa can reportedly exacerbate unstable cardiac arrhythmias; therefore, if present, treatment of abnormal heart rhythms is recommended before initiating the medicine.

**c. Psychiatric symptoms:** Unfortunately, psychiatric symptoms are common in PD and levodopa can make them worse. However, these occur in advanced stages and on larger doses of the medicine. Higher doses of levodopa can occasionally cause dopamine dysregulation syndrome (DDS) and impulse control disorders (ICD), especially in people predisposed to addictive behaviors. DDS is a result of taking too much levodopa and causes motor and psychiatric complications. ICD manifests as impulsive behaviors such as

*Continued on page 10 >*

| Non-motor side-effects | Nonpharmacological Management | Pharmacological Treatment: |
|---|---|---|
| **Gastrointestinal** | • Dietary modification<br>• Ginger products<br>• Taking levodopa with non-proteinaceous food | • Start low and go slow<br>• Primary care, nutritionist, and GI evaluation<br>• OTC products to treat constipation, bloating, including probiotics<br>• Carbidopa, COMT-inhibitors, ondansetron, domperidone, pyridostigmine, linaclotide, lubiprostone |
| **Orthostatic hypotension** | • Hydration and salting<br>• Compression garments<br>• Avoiding hot environments<br>• Small frequent meals<br>• Fall precautions | • Safely eliminating other medicines that can cause OH<br>• Pyridostigmine, droxidopa, fludrocortisone, midodrine<br>• Cardiovascular consultation for persistent OH |
| **Psychiatric and cognitive** | • Patient and caregiver safety | • Elimination of medications that exacerbate psychosis<br>• Adjustment of levodopa dose<br>• Psychiatric and psychological consultation<br>• Pimavaserin, quetiapine, rivastigmine, donepezil, clozapine |
| **Sleep** | • Increase daily physical activity<br>• CBT-I for insomnia | • Safely eliminate other medications contributing to EDS<br>• Adjust levodopa timing<br>• Sleep consultation to evaluate OSA and improve sleep hygiene<br>• Armodafinil, modafinil |

> 5 Myths, continued from page 7

In summary, the effectiveness of levodopa is unparalleled for people with PD, and as such, it is important to understand the facts about the medication and not get confused or deterred by common myths that could keep you from benefitting from this treatment. Always talk to your doctor openly about any concerns or questions you have so together you can make an informed decision that best suits your personal situation.

### Tips and Takeaways

- Levodopa is the mainstay medication of PD treatment, yet there are many misperceptions and myths surrounding this medication.
- Development of motor fluctuations and dyskinesias are a function of the stage of Parkinson's disease you are in and not the length of time you are on levodopa.
- Needing more levodopa over time does not mean that the medication is no longer working; it means that the disease is changing.
- With patience, you and your neurologist will likely be able to find a formulation and dose of levodopa that you will be able to tolerate and will treat your PD symptoms successfully.
- Levodopa has been shown to increase life expectancy in people with PD, which strongly argues that levodopa does not accelerate the disease.
- As always, be sure to talk with your doctor about any medication questions or concerns, or any side effects you are experiencing.

> Levodopa Intolerance, continued from page 9

over-shopping, overeating, hoarding, excessive hobbyism, repetitive useless motor activity (also known as punding), and hypersexuality. A movement disorder specialist can identify and reverse DDS and ICD by adjusting the dose of levodopa or with psychiatric intervention when necessary.

Psychosis (delusions, hallucinations, or paranoia) is uncommon in early PD, but it can be magnified by levodopa in advanced stages. Levodopa-induced psychosis early in the disease should alert the physician to the diagnosis of possible Lewy body dementia. Levodopa-related psychosis is treated by changing the dose or starting antipsychotic medications. Drugs used for dementia are effective in managing mild psychosis.

**d. Sleep disorders**: Excessive daytime sleepiness (EDS), insomnia, and vivid dreams are not uncommon with levodopa, especially in people with an underlying sleep disorder. The first step in handling levodopa-related sleep disorders is to evaluate and address other conditions such as obstructive sleep apnea (OSA). There are several medications other than levodopa that worsen EDS; safely eliminating them under the guidance of the prescribing physician is suggested. Undiagnosed OSA and poor sleep hygiene are two of the most common treatable causes of EDS. Taking the last dose of levodopa a few hours before bedtime may improve insomnia and vivid dreaming. Additional measures include increasing physical activity during the day, prescribing medications for EDS when appropriate, and cognitive behavioral therapy for insomnia (CBT-I). A sleep study and referral to a sleep specialist are recommended when excessive sleepiness is reported.

## 2. Motor side-effects of levodopa:

a. Motor fluctuations occur as PD progresses to the mid and late stages. Levodopa-induced dyskinesia (LID), involuntary writhing movements, and the return of motor symptoms when levodopa wears off are examples of motor fluctuations. Young-onset PD patients are more prone to earlier motor fluctuations than older PD patients. There are several strategies that can be employed to manage motor fluctuations just search "**Motor Fluctuations**" on the APDA website and you will find some great resources. Rarely, freezing of gait (FoG) can occur with high doses of levodopa; it is improved by reducing the total dose while being vigilant about deterioration in overall mobility.

## Case:

Mr. HW is a 58-year-old man with progressive tremors, stiffness, and slowness which interfere with his occupation as a painter. His examination and testing confirm the diagnosis of PD. However, he is unable to take carbidopa/levodopa (Sinemet 25/100) due to severe nausea. The dose is very gently increased in increments of quarter tablets, but nausea persists. With additional carbidopa and COMT-inhibitors (Fig 1), and taking the medication with non-proteinaceous food, his tolerance for the medication improves to the point where he is able to take an adequate amount of levodopa resulting in significant improvement in PD symptoms and his ability to paint again.

In summary, while levodopa can cause bothersome side effects, those can be managed effectively by a movement disorders neurologist. Levodopa, marketed as carbidopa/levodopa in the US, remains the most effective treatment for PD and is appropriate for any age of patient and stage of disease when used judiciously.

**Dr. Pravin Khemani** is a Movement Disorders Specialist at Swedish Medical Center in Seattle, WA and is fellowship trained in both Neuromuscular Disorders and Movement Disorders. Dr. Khemani's philosophy of care for movement disorders it to adopt multidisciplinary approach and closely collaborate with the patient, family and other caregivers.

**Reference:** 1. Abhishek Lenka, Gianluca Di Maria, Guillaume Lamotte, Laxman Bahroo & Joseph Jankovic (2022) Practical pearls to improve the efficacy and tolerability of levodopa in Parkinson's disease, Expert Review of Neurotherapeutics, 22:6, 489-498, DOI: 10.1080/14737175.2022.2091436





# The Magic of Hope

GALA & AUCTION BENEFITTING APDA

# CELEBRATING 20 YEARS!

**We were also thrilled to honor and celebrate our 2023 Optimism Award Recipient Brian Harris**

Brian was diagnosed with Parkinson's disease (PD) in 2017 at the age of 48 and has been supporting the Young Onset community and APDA ever since - with boundless energy, dedication, and optimism. Brian founded the Seattle-area Young Onset PD activity group (SEAYOPD) to provide a way to stay active and engaged with the outdoors, and in the process created critical connections and a vibrant community. Brian has been on the APDA Board of Directors since 2019 and an important contributor to annual Optimism Walks, support group outreach, Magic of Hope Gala & Auction, and much more. Brian is the first to volunteer and the first to follow-up with an email saying, "Now that I've finished this project, what is next?" He also meets regularly one-on-one with people newly diagnosed with young onset Parkinson's disease, offering guidance, resources, and calming reassurance.

**The Magic of Hope Gala and Auction was held on Saturday, March 11 and was back in person for the first time since 2019. Guests were excited to reconnect and to celebrate, and also gave generously! This year's event raised over $550,000, which will pay for vital support, education, resources, and research.**

At this year's event we honored the founders of Magic of Hope: Suzanne Cameron, Chris Jewell, and Dianne and René Spatz. When Chris Jewell was diagnosed with Parkinson's at the age of 39, his wife Suzanne Cameron immediately knew she wanted to get involved with the Parkinson's community, it is in her nature to "DO something!" She connected with APDA, and then soon after in 2003 started planning a gala and auction to raise funds for local Parkinson's education and support programs. Chris can be credited with coming up with the inventive name Magic of Hope. Their best friends Dianne and René Spatz jumped in to help, and this superhero team all worked tirelessly that first year - and for many years after – to pull off successful events. These four have had a hand in raising over $4 million since that first event in 2003!

And they had lots of help to pull off fabulous events year after year! Many guests at this year's event were the same volunteers that have helped at so many previous Magic of Hope events, and the recognition and celebration of their outsized impact continued throughout the evening.

**Thank you to our generous sponsors of the 2023 Magic of Hope Gala & Auction!**

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Aegis Living, Medtronic, University of Washington, Virginia Mason Franciscan Health

# Newly Diagnosed with PD?
# APDA is here to help!

The four simple words, "You have Parkinson's disease," is life changing. For the approximately 90,000 people who are diagnosed each year, the quantity of information and the uniqueness of each person's experience with Parkinson's can be overwhelming. You are not alone! APDA is here to help you begin your journey with Parkinson's with specialized programs and services for the newly diagnosed. We will connect you to a vast and supportive community of people, resources, and education, to give you the best start.

Here are some of the unique ways APDA is here to help those who are new to living with Parkinson's disease.

### PRESS™ Program: APDA's Parkinson Roadmap for Education & Support Services™

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

PRESS is an 8-week program that provides an opportunity for those impacted by PD to meet others facing a similar experience. Led by a licensed healthcare profession, the program is designed to provide emotional support, education, and coping strategies to live your best life with PD.

APDA NW has hosted over 200 participants in the program and the feedback has been glowing.

*I feel that the interaction and personal sharing among the participants was key to the success of this program. We had excellent attendance and motivation within our group. Our facilitator brought exceptional knowledge and group skills to our group*

*Excellent! The companionship, information, and education is so valuable in dealing with the "overwhelm"*

Several PRESS programs will be held in the upcoming year, to learn more about the next session please contact us.

### Education

APDA offers a vast array of print materials as well as live and virtual education programs, all with the goal of educating and empowering people impacted by PD.

Choose from Good Start for those newly diagnosed, Take Control with timely and timeless topics, or our traveling in-person Live Well symposiums. APDA also offers specialized programs throughout the year on subjects such as Deep Brain Stimulation and Research. Many of these programs are archived on our YouTube channel for later viewing.

In addition to this quarterly magazine published by APDA NW, we offer more than 40 free informational booklets and fact sheets available for download or in print, including unique resources for specialized patient populations like Spanish or Chinese speakers, care partners, veterans, and Young Onset PD.

### Support Groups

Connecting people through support groups is one of the foundational principles of APDA and it continues to be at the heart of our mission. On our website, we list over 100 support groups in our 5-state region and we provide training, logistical support, and educational materials to these groups. In addition, APDA Northwest runs 11 professionally-led support groups, including groups for care partners, people living alone with PD, and those diagnosed with Atypical Parkinson's disease.

### Information & Referrals

Looking for a Parkinson's Specialist? Want to find a wellness class in your area? Need some educational booklets? Interested in being involved in research? We can help through our information and referral hotline 206-695-2905.



OPTIMISM WALK AMERICAN PARKINSON DISEASE ASSOCIATION

# APDA Optimism Walk: A Community Success Story

### Want to plan an Optimism Walk in your neighborhood?

**Reach out to APDA and we can help! Contact Heidi Murdock, Fundraising Events Manager, at hmurdock@apdaparkinson.org or 206-798-3205**

### Plan a walk in 5 easy steps:

1. **Pick a Location**
2. **Pick a time**
3. **Contact APDA**
4. **Register a Team**
5. **Get the word out!**

SAVE THE DATE!
APDA NORTHWEST
**Optimism Walk**
**Sept 30**

Over the summer, Olympia resident Sue Forson was reading the *Parkinson Pathfinder* which encouraged people to think about holding a community-building Optimism Walk in their neighborhood Sue was part of a walking group organized by Thrive Community Fitness personal trainer Christie Agtarap that was meeting weekly, so with that foundation already in place she thought this might be a perfect fit. She presented the idea to the Thrive walking group, contacted APDA, and the group was off to planning their first event.

The first step was to form a committee and share responsibilities. They started with 6 volunteers: Sue, Christie, Nancy, Steve, and two other Susie's. Christie demystified the technology and helped the team register participants. Nancy, a former financial planner, handled the money, and Steve handled all of the event day logistics, things like the tents, tables and chairs. The rest of the committee filled in the gaps, and worked on recruiting and building enthusiasm. APDA helped by creating a press release and Olympia-specific posters that their group hung around the community.

**"Everyone on the committee is directly affected by Parkinson's so this was an easy sell for us because of all the wonderful things that APDA does to support the PD community here in Olympia. When you get people involved who really want to do it, it isn't that hard. For us, everyone did their bit and it came together beautifully."**

What was the secret to their success? Sue credits Christie and the committee with being proactive and reaching out to their Parkinson's community. The planning process wasn't as challenging as they anticipated, and they accomplished most of it during the month leading up to their Walk. The fundraising piece was also surprisingly easy. Their initial goal was to have 20 walkers and to bring in $2,000, and on Walk day they had over 60 people and raised over $8,000!

**"Everyone had a really good time and enjoyed getting out, bringing awareness to PD, walking with one another and having fun. Tons of people (visiting the park) stopped to ask what the walk was for and if they could get more information about PD."**

apda AMERICAN PARKINSON DISEASE ASSOCIATION
NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

130 Nickerson Street, Suite 300
Seattle, WA 98109

**SUBSCRIBE TO OUR NEWSLETTER!**

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

## YES! I want to help provide the support, education, and research that will help everyone impacted by Parkinson's disease live life to the fullest.

Please clip and return with your check in the envelope provided in the center of this magazine, or mail to us at **130 Nickerson St, Suite 300, Seattle WA 98109**

To donate by credit/debit card, please visit our website **apdaparkinson.org/northwest** or call **206.695.2905**

The Northwest Chapter of the American Parkinson Disease Association is a non-profit 501(c)3 organization. Our tax ID number is 13-1962771.

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