

2 Happiness
Even with Parkinsons

5 Straight Talk on
Posture with PD

11 Swallowing
A Proactive Approach

PARKINSON *Pathfinder*

WINTER 2019

apda

AMERICAN
PARKINSON DISEASE
ASSOCIATION

NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

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WINTER 2019

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COVER

The Werner family snowshoeing at Snoqualmie Pass.

Photo by Dustin Werner

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PARKINSON DISEASE
ASSOCIATION
NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

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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.

Throughout the year, we hear thank you from the people who continually inspire us to do more, and these stories motivate us to stretch each donation as far as we can. I want to share a few of the thank you's from the past year, because truly they aren't just showing appreciation for APDA, they are expressing gratitude to our generous donors who make the work we do possible!

THE LINK BETWEEN EXERCISE AND MENTAL/PHYSICAL WELLNESS

My neurologist has noticed my physical improvements as the result of participating in Rock Steady Boxing. What I noticed is the immediate emotional uplift following the class! Thank you APDA for the financial grant that supports this program!

A donation of \$500-\$2000 helps get an exercise/wellness program off the ground while keeping the class fee low for people impacted by PD.

SUPPORTING CAREGIVERS

I wanted to thank the facilitators and APDA for the opportunity to attend the Powerful Tools for Caregiving Series. I was very proud of myself today and thanks goes to what I learned in this class. Today I consciously utilized one of the communication techniques I learned in this classes and it worked. I have also taken a stand for my own self-care. So, thank you again from the bottom of my heart!

Because of the generosity of sponsors, we can provide connections, education and resources to everyone impacted by PD.

INFORMATION & REFERRAL

I just want to thank you again for all your help, your list of resources, and your *Pathfinder* newsletter. I called your contact and I truly think she is our angel who is going to come beside us and help find the best place for my dad, when that day comes. I'm thankful that there are people in the world like you, who want to help people who are trying to navigate through this hideous illness of Parkinson's.

We appreciate all of you who donate your money and your time to help us put together newly diagnosed packets, education mailings, or write/edit Pathfinder articles!

PATIENT SUPPORT

I would like to thank you for financial assistance. It enabled us to travel during times when every penny was watched because of the large medical needs that PD creates. Also, the materials that the APDA sends are helpful for both the person with PD and the caregiver. We are so grateful for your help.

Every \$300 you donate provides a patient aid scholarship to someone in need.

EDUCATION PROGRAMS

Thank you for the Take Control Series. It has helped me round out my understanding of Parkinson's. I have to say today's event was great! The only way I think it could have gone better is if an announcement was made that Parkinson's has been cured. Everything went so well, the turnout was fantastic, and everyone seemed to be enjoying themselves.

Generous donors / sponsors have enabled us to hold more education programs than ever before, empowering people with knowledge to help live life to the fullest.



You can support APDA's mission by donating online at apdaparkinson.org/Northwest or sending a check in the envelope found in the middle of this magazine. Your gift helps us meet the needs of a growing Parkinson's community as well as invest in promising research, and will provide support, education and resources to the 60,000 people living with PD in the Northwest. Refer to the back cover if you are curious what your donation might pay for.

Sincerely,

Jean Allenbach, Executive Director

PS: Check out our 2019 accomplishments on page 8.
Thank you for inspiring APDA to do more!

Happiness

Even with Parkinson's

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

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

Step 1: Find your why

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

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

Step 2: Check your attitude

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

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

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

Step 3: Start self-healing

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

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

Step 4: Find your community

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



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

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

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

Nick is the newest member of the APDA Northwest Board of Directors, joining a community of incredible people who are working tirelessly to provide help and hope to those impacted by Parkinson's disease.

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

Be sure you don't let the disease stop you from doing what you love. Perhaps you need to do things a little differently, but you can still find some aspect to be engaged in. Find people who will support you and lift you up. Finding and maintaining a strong community is important for your long-term health, as well as for your long-term happiness.

Step 5: Prepare for setbacks

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

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

Keep fighting and never give up!



Have some Poetic Talent? Share it with us!

There are many talented writers within the Parkinson's community. To celebrate Parkinson's Awareness Month in April (which also happens to be National Poetry month!) we want to feature your work in the spring issue of our *Parkinson's Pathfinder*.

Please submit your poem by February 1st via email to apdanw@apdaparkinson.org. Selected works will be shared on APDA social media or printed in the *Pathfinder*.

We look forward to reading your poems!

MOVE & LIVE WITH OPTIMISM!

The APDA website: www.apdaparkinson.org/Northwest

is a clearinghouse for Support Groups and Wellness Programs throughout our 5 state region

(Washington, Oregon, Idaho, Alaska, and Montana).

Select your state and find a group active in your community!

No group in your community? APDA can help! We provide technical assistance, training, and expertise in how to get a group started in your area. Call 206-695-2905 to learn more.

Check back often as new programs are added regularly!

No access to the Web? Call us!

We will help you find a group that is right for you or we can send you a complete list.

*Connect with others,
build community,
and be active!*

Featured Wellness Programs:

EUGENE, OR Rowdy Readers

**supported by an APDA community grant*

**A six-week vocal program that
connects pwp & children**

Sierra Corbin | 541-600-2028

sierra@eugenespeechtherapy.com

www.eugenespeechtherapy.com/rowdyreaders

LAKEWOOD, WA Rock Steady Boxing

**Blackbelt USA - Battleground MMA
Tue & Fridays @ 10am**

Karen Burns | 253-584-5966

lakewood@rsbaffiliate.com

BILLINGS, MT Move Free with Parkinson's

**Westpark Village Senior Residence
Thursdays at 2:00pm**

Sharon Forman | 406-690-2989

slforman7@yahoo.com

Featured Support Groups

SEATTLE, WA Flying Solo with PD A new group for singles living with PD

2nd Saturday of the month @ 10am

Leanne King-Devitt, MA, LMHC | (206) 794-1094

leanne@seattleelderconnections.com

WEST SEATTLE, WA General

**Quail Park - West Seattle
1st Monday of the month @ 2:30 pm**

Joan Kelly, MSW | 206-612-8571

joankellymsw@gmail.com

LYNNWOOD, WA General

**Verdant Community Health Center
1st Monday of the Month at 10:30am**

Carol Aguayo | 425-743-6029

agua549@frontier.com

ANCHORAGE, AK General

**Anchorage Pioneer Home
3rd Saturday of the month at 3:30 pm**

Paula Williams | (907) 231-3231

appylucy55@gmail.com

Straight talk on Posture with Parkinson's Disease



DR. NATE COOMER is a Physical Therapist who has been working with neurologic diagnoses for over ten years. He received his certification as a Neurological Specialist in 2010 by the American Board of Physical Therapy Specialties and has centered most of his work in the past four years to treating Parkinson's disease. He is the founder of the Parkinson's Fitness Project whose mission is to develop physical and online training centers to promote ongoing neurological health in those with PD. Dr. Coomer is a great friend to APDA and has shared his enthusiasm, knowledge and talent with hundreds of attendees at APDA educational events throughout the Northwest. Outside of his career you can usually find him running frantically after his two small children throughout the streets of Seattle.

“Sit up straight”, your parents always told you when you were young.

This phrase is also heard all too often by people dealing with postural impairments due to Parkinson's disease. Postural changes are one of the hallmarks of the disease. Improving posture isn't as easy as putting a book on your head. In this article we will try to help you understand why these changes occur and what you can do to keep yourself on the straight and narrow.

Studies have shown that people with Parkinson's can have an altered sense of true vertical position when standing and this causes some to lean to one side or stoop forward. Abnormal muscle tone can also alter their posture. Muscle tightness and rigidity in the abdominals and hip flexors can pull the torso into a slumped position while weakness in muscles that hold our torso and head upright make it hard to overcome. ON/OFF times with medications can also lead to changes in posture.

There are even names given to specific postural abnormalities when it comes to Parkinson's disease. Pisa Syndrome is the name given when someone is leaning significantly to one side. Camptocormia is a big word that means a person is leaning forward from the waist due to uncontrollable muscle contractions, known as dystonia, in the abdominals. As you can see, difficulty standing upright can be due to many different reasons. However, managing these issues is imperative for healthy living.

Although postural changes are a difficult part of the disease, it is important to attend to these issues as many negative side effects can result from a stooped position including:

- Neck and back pain from poor alignment of the spine.
- Difficulty with taking deep breaths and talking loudly as expansion of the lungs diminishes.
- Stiffness and reduced range of motion in the spine which causes difficulty with daily tasks like reaching into overhead cabinets and putting on clothes.
- Difficulty with walking and risk for falls due to asymmetrical alignment causing increased demand on our musculoskeletal and balance systems.
- Difficulty swallowing due to narrow poor head and neck positions. This can also create an increased risk for choking and pneumonia.
- Development of scoliosis.

These changes are often subtle and happen slowly over time. Many times a person may not even realize their posture is slipping. That is why the importance of regular checkups with a Physical Therapist to assess posture and overall mobility can have huge benefit of keeping posture on track. Physical Therapists can determine the reason behind postural changes and prescribe strengthening and stretching exercises to balance out muscle tension that may be causing an imbalance. They can also educate in creative ways to retrain your posture at home and how to monitor progress over time. Here are some simple tips to help keep you moving in the right direction.

Tips for improving posture

- Take standing breaks every 30-45 minutes when sitting at a chair for extended lengths of time to avoid stiffness.
- Pick a consistent background and have family members take pictures of your standing posture every 3-6 months. The pictures will help you compare your standing position to landmarks in the background over time. This will help

you realize if changes are taking place even when you may not notice it.

- Use mirrors to check your posture regularly at home. If you have difficulty with side leaning you may consider using a piece of vertical tape on a mirror to help remind you of upright.
- Try a Tai Chi or Yoga class to improve postural alignment and flexibility
- Are you a techie? Try using wearable devices to give you feedback throughout the day. Devices like the “Upright Go” work to train your posture to the optimal level.

Postural impairments are a challenging part of Parkinson’s disease.

A worsening posture can have serious consequences on many areas of our overall health. It’s very important to work with your health care providers, including Physical Therapists, to address these issues early on and come up with a proactive plan to address the disease through exercise and training to keep you moving in a straight line.

Here are a few easy exercises to perform from home to maintain an upright posture in either sitting or standing.

Use a broomstick at home to perform these easy stretching exercises to strengthen and stretch your postural muscles.



- 1 Standing or Seated Scapular Retraction**
Holding broomstick in both hands, squeeze your shoulder together while pulling the hands back. Hold 3 seconds. Repeat 3 sets of 10 repetitions



- 2 Standing or Seated Side Bends**
Holding broomstick overhead, lean to the side until you feel a stretch in the flank, hold 30 sec. Repeat 3 times to each side.



- 3 Standing or Seated Overhead Reach**
Holding broomstick in both hands, reach overhead and elongate the spine. Hold 5 seconds. Repeat 10 times.

“My goal with my monthly giving is simply to carry on the work and mission that the APDA has around providing care and education.”



Above: Wendy Holman

Left: Wendy's mom, Eloise

WENDY HOLMAN

Why I Give

Wendy Holman has been giving to APDA through her employee giving plan for many years, as well as donating during Giving Tuesday and Give Big donation days. Her recurring gifts have been modest, but still total over \$2,100 in just the past 5 years!

We recently spoke to Wendy about her history with Parkinson's disease and why she chooses to give to APDA. In her own words:

My mother was diagnosed with Parkinson's disease in the 1980's, and her approach to this diagnosis was always to learn as much as she could about the disease and incorporate that learning into her life. **The APDA newsletter was a significant source of information for her and she greatly valued the support and encouragement of the APDA I&R Coordinator.**

As my mother's disease progressed and I became more of a caregiver, I participated in a support group for adults with parents who had PD, and eventually became the volunteer leader of that group. **I met other people in my PD support group who became lifelong friends.**

I really like the fact that the education programs and patient services provide the opportunity for individuals with PD and their families to develop a network of support that works for them. I like the approach of providing both education and activities. Many of the activities (boxing, dancing, cycling, singing, etc.) provide a way for a person with changing physical abilities to continue being active as long as possible—and even extending that time because of their participation. APDA provided me with valuable resources, a community of others who understood the challenges, and encouragement to become an advocate for my mother and others with Parkinson's.

My goal with my monthly giving is simply to carry on the work and mission that the APDA has around providing care and education. I have been excited to see that APDA has been growing! I remain interested and committed to APDA and am glad to support their efforts.

Join Our

MONTHLY GIVING TEAM!

Our **Monthly Giving Team** is a special group of donors who make a difference through recurring donations. Monthly gifts from team members help pay for education, support and research that enriches lives while providing hope and optimism. A small monthly amount can have a huge impact!

\$10
/MONTH

can provide essential financial assistance by covering the costs of transportation, respite care, exercise classes, and more. Just FIVE team members giving for one year can cover two annual Patient Aid scholarships.

\$15
/MONTH

can motivate people with Parkinson's to get up and MOVE; just THREE team members giving for one year can cover one exercise community grant award, making classes more affordable and accessible for all.

\$25
/MONTH

can connect researchers to local study participants and help research happen faster; just TEN team members giving for one year will provide one month of essential funding to the Washington Parkinson's Disease Registry.

Every day, APDA provides



Developed new and unique programs fostering connections and community like Sidekicks, Improv, PRESS for newly diagnosed, Flying Solo support group, and Powerful Tools for Caregivers.



PATIENT AID

Over 500 participants are currently enrolled in APDA programs providing transportation and respite care.



THE SUPPORT



REFERRALS & RESOURCES

Referred callers to support groups and wellness programs, and provided instructors with materials, helping improve the lives of more than 3,500 people/month who attend these programs.



EXERCISE & WELLNESS

Funded \$15,000 in community grants to classes in ID, OR, WA & AK.



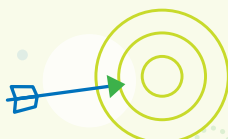
>150 VOLUNTEERS helped with education programs, patient services, fundraisers and office support.

EDUCATION

WELCOME!

CONNECTING PEOPLE

We spoke with 475 people with Parkinson's who were new to APDA, over 200 who were newly diagnosed, and ALL of whom now have access to APDA educational materials and resources.



TARGETED UNDERSERVED COMMUNITIES

like Anchorage AK, Wenatchee WA and Fife WA for our Live Well, Education is Empowerment and Good Start education programs.

IN PERSON & ONLINE EDUCATION

More than 1,000 people attended APDA education programs, and thousands more accessed webinars and downloadable education materials.



Fully funded a research grant to study the VPS35 protein, in honor of Chuck Bundrant, Founder & Chairman of Trident Seafoods.

RESEARCH

Held our first ever **INNOVATIVE RESEARCH SYMPOSIUM**

attended by 300 people impacted by PD, medical professionals and researchers.



LOCAL RESEARCH STUDIES

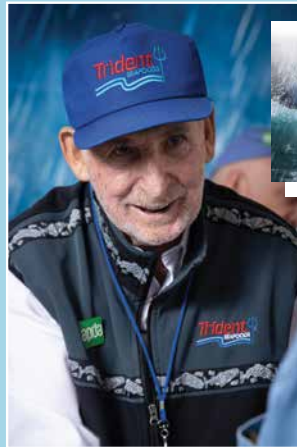
APDA fully funded the Washington Parkinson's Disease Registry, connecting researchers to local study participants so that research happens faster.

That will help everyone impacted by Parkinson's disease
live life to the fullest.

APDA Funds Research Grant IN HONOR OF CHUCK BUNDRANT

APDA is committed to investing in promising research to find a cure, and thanks to the generous outpouring of support at the recent Captain's for a Cure event, we are able to fully fund a research grant to Dr. Dorian Sargent.

Four captains from the Discovery Channel's "The Deadliest Catch"* series, along with fans and many friends from the fishing community, gathered on September 14 at Fremont Mischief Distillery to celebrate Chuck Bundrant, Founder & Chairman of Trident Seafoods. Competitive bidding for silent auction items set the tone for a boisterous live auction and generous "raise the paddle," which combined to raise over \$380,000.



Chuck Bundrant holding an Alaskan King Crab, surrounded by his "fishing family" and APDA.

Dr. Dorian Sargent, a post-doctoral fellow at the Van Andel Research Institute, studies proteins that are mutated in genetic forms of PD.

Dr. Sargent's research focuses on the underlying causes of Parkinson's disease (PD) by studying proteins that are mutated in familial cases of PD. His project aims to identify the mechanisms by which a mutation of a gene called VPS35 which is implicated in some familial cases of PD, induces neuronal death and protein accumulation in a

genetic mouse model of PD. He will also study the potential role of another protein, LRRK2 in these processes.

By understanding how these mutations contribute to the development of PD, Dr. Sargent hopes to better understand the molecular mechanisms that lead to PD, which is fundamental to the development of new therapeutics.

The APDA Northwest chose to fund this particular study in honor of Chuck Bundrant because VPS35 may also be related to PSP (Progressive Supra Nuclear

Palsy), an atypical form of Parkinson's disease. Chuck is living with PSP so funding this research grant through the Captains for a Cure event was a wonderful way to honor him.

Dr. Sargent is very grateful for his funding and says "As a postdoctoral fellow, this first grant is a very important step in the development of my career and encourages me to pursue the study of genes related to Parkinson's disease and other parkinsonian disorders."

Thank you to our Captains for a Cure Sponsors:

HIGHLINER:



KING COILER:

DiMartino Family Foundation | LFS Marine | Matson Navigation Co.

Swallowing in PD: *A Proactive Approach*

I meet a lot of people with Parkinson's, many of whom have been diagnosed for a long time. Yet as a Speech-Language Pathologist (SLP) who helps those with PD, I have found that many people with the disease don't know what we do and how we can help. It is my mission to change that and to educate all people with Parkinson's about the benefits of working with an SLP.

SLPs work on issues with speech, language, swallowing, cognition, voice, and breathing (among others). I'm an SLP who specializes in Parkinson's and in this article I will focus on swallowing troubles.

PARKINSON'S AND SWALLOWING

How do you know if you are having trouble with swallowing, a condition called dysphagia? Take a moment to take the swallow disturbance questionnaire at the bottom of this page.

If you answered yes to any of these questions, it may mean you are having trouble and should reach out to your neurologist or primary care physician, who can refer you to a Speech-Language Pathologist. Multiple evaluations by an SLP are sometimes necessary throughout the course of the disease, since they specialize in evaluating dysphagia and recommending treatment options.

SWALLOW DISTURBANCE QUESTIONNAIRE

	0 Never	1 Seldom (Once a month or less)	2 Frequently (1-7 times a week)	3 Very frequently (more than 7 times a week)
1. Do you experience difficulty chewing solid food like an apple, cookie or a cracker?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Are there any food residues in your mouth, cheeks, under your tongue or stuck to your palate after swallowing?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Does food or liquid come out of your nose when you eat or drink?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Does chewed up food dribble from your mouth?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Do you feel you have too much saliva in your mouth; do you drool or have difficulty swallowing your saliva?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Do you swallow chewed up food several times before it goes down your throat?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Do you experience difficulty in swallowing solid food (i.e. do apples or crackers get stuck in your throat)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Do you experience difficulty in swallowing pureed food?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. While eating, do you feel as if a lump of food is stuck in your throat?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Do you cough while swallowing liquids?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Do you cough while swallowing foods?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Immediately after eating or drinking, do you experience a change in your voice, such as hoarseness or reduced?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Other than during meals, do you experience coughing or difficulty breathing as a result of saliva entering your windpipe?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Do you experience difficulty in breathing during meals?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Have you suffered from a respiratory infection (pneumonia, bronchitis) during the last year?	<input type="radio"/> Yes	<input type="radio"/> No		

Research shows anywhere from 40% to 95% of people with Parkinson's will develop dysphagia. Not only can this impact quality of life, it can also lead to aspiration pneumonia, which is the leading cause of death in Parkinson's disease.

Even if you are not actively experiencing trouble swallowing, seeking out a speech pathologist can help you maintain your current level of swallowing ability as long as possible. We know how helpful exercise is in helping to maintain physical function, the same is true for swallowing. SLPs can prescribe exercises to improve and preserve good swallowing habits so that, hopefully, major problems like aspiration pneumonia can be avoided in the future.

Recently, researchers have suggested utilizing respiratory muscle strength training, such as expiratory muscle strength training (EMST) to help maintain swallow function and control coughs. This involves purchasing a \$50 device that will remain with you for the course of your disease. EMST is a

daily exercise program for your lungs that helps improve your cough and the musculature involved in swallowing. This exercise program is set up and monitored by a trained Speech-Language Pathologist and can be started at any time.

What else do you need to do? Have an instrumental swallow study done! This is a video x-ray (MBS) or a tube going down your nose (FEES) to visualize your swallow function. Since SLPs don't have x-ray glasses and can't see inside your

throat, these types of tests give us an insider's view of your swallowing function. This is a highly recommended study, especially since people with Parkinson's may experience sensory deficits and could have an impaired cough or silent aspiration. This means that when food or liquid go down the

wrong pipe, no coughing occurs. You may have trouble swallowing and not even know!

Drooling (sialorrhea) is another issue that can develop and is something to be aware of. This happens because swallowing is not as frequent as it used to be, leading to an accumulation of saliva in the mouth. If you notice this symptom, mention it to your neurologist or speech pathologist. Some possible ways to treat drooling include atropine, a drug used to reduce saliva, botox injections to tighten the saliva glands, and chewing sugar-free gum. More research is needed on drooling as a symptom of PD, so finding and participating in research about this issue could be helpful to you and to others.

If you have trouble eating and it is not related to swallowing this is where another allied health professional can help. An Occupational Therapist can address eating challenges if tremors are impacting your ability to get your fork to your mouth. Being fed by others is a leading cause of aspiration pneumonia so if you are having troubles, a doctor can give you a referral to an OT who can find adaptive equipment to help.

Also related to swallowing is oral health. How often do you get your teeth cleaned? Oral health is extremely important if you have difficulty swallowing. Rotten teeth are also associated with aspiration pneumonia. Keep up those cleanings and follow your dentist's recommendations!

Dysphagia can be problematic for anyone with Parkinson's, so getting ahead of any issues is the best way to maintain your swallowing function. Monitor your symptoms (your care partner can help here as well), and request a referral to a Speech-Language Pathologist at any time to learn more about this condition, for an evaluation of your own swallowing, to seek treatment, and to find longer-term strategies that will help reduce the possibility of complications due to this condition.

Even if you are not actively experiencing trouble swallowing, seeking out a speech pathologist can help you maintain your current level of swallowing ability as long as possible.



Julie Fechter, MS, CCC-SLP is a speech-language pathologist who specializes in Parkinson's and owns a private practice, Sound Speech and Swallow. She offers LSVT Loud, McNeill Dysphagia Therapy Program, SPEAK OUT!, and EMST for people with Parkinson's. If you have any questions, or have a referral to an SLP? She'd love to be part of your team. soundspeechandswallow.com | 206-427-7019



WHAT WILL YOUR LEGACY BE?

For many of us, there is a compelling need to make a difference—to leave a lasting impact on our friends and family, and the world in which we live. At APDA, we are dedicated to helping people impacted by Parkinson's live life to the fullest. **A legacy gift to APDA in your estate plan is a powerful way to ensure continued outstanding patient services and education programs, elevate public awareness, and support research designed to ultimately put an end to Parkinson's disease.**

WHY DO ESTATE PLANNING?

- Ensure the wealth you have accumulated over your lifetime goes exactly where you want it to go and when.
- Give directions to be followed in case you can't make decisions for yourself.
- Organize your affairs and designate who will handle them when you are gone.
- Appoint a guardian for minor-aged children and provide for special needs of your loved ones.
- Minimize possible estate taxes and probate fees.
- Remember and provide for family, friends and organizations you care about.

Estate planning can mean making some difficult and uncomfortable decisions, but once your plan is in place you'll have peace of mind that you have done your best to plan and provide for yourself and for loved ones, as well as for the causes you've cared about during your lifetime. Remember that it's never too early—or too late—to do retirement planning.

FREEWILL

To make this planning process less stressful, APDA has partnered with FreeWill to provide you with a free and easy way to write your legally-valid will.

Visit freewill.com/APDAParkinson to get started.

When you share your commitment to APDA in your estate or financial plan, you become an honored member of our APDA Legacy Society. Members help ensure that APDA's work continues until our mission—to help everyone impacted by Parkinson's disease live life to the fullest—is accomplished. Contact us for the bequest language to use in your estate plans or to discuss planned giving options.

Deciding on the right gift for the charitable causes you care about can be difficult. It is important to think about issues ranging from maximizing tax benefits, and producing income, to preserving assets for your loved ones.

SOME POSSIBLE GIFT OPTIONS:

- **A gift of CASH** could be right for you if you want to make a gift that has the greatest immediate impact. Writing a check or donating online is the easiest way to give to APDA.
- **Giving STOCKS & BONDS** that you have owned for more than one year is a way to reduce your capital gains tax while supporting APDA.
- **A gift of your RETIREMENT ASSETS** can shield you or your heirs from taxes while funding APDA's future. If you are age 70-1/2 you can make a qualified charitable distribution (QCD) from your traditional IRA, which will count towards your required minimum distribution but is not included in taxable income.
- **A gift of LIFE INSURANCE** that you no longer need can provide generous support to APDA, and the death benefit of your policy will not be included in your estate.

To learn more about legacy giving, contact APDA Northwest at 206-695-2905 or krichards@apdaparkinson.org.

Save the Date!

Upcoming Events

Stay Tuned to our website & your inbox for further information about these 2020 Programs & Events.

Website: apdaparkinson.org/Northwest

Email: apdanw@apdaparkinson.org

Phone: 206.695.2905

APDA Take Control Series

2020 Series: 1/10, 3/13, 5/8, 7/10, and 9/11
Second Friday of the Month
Mercer Island Community Center

The series will be presented the second Friday of every other month at Mercer Island Community Center. Each session will have two speakers and topics will rotate.



Jan 9 – Feb 27, 2020
Thursdays 11:30am – 1:30pm
Valley Medical Center

April 1 – May 20, 2020
Wednesdays 6:00pm – 8:00pm
APDA Northwest Office

The popular PRESS™ Program: APDA's Parkinson Roadmap for Education & Support Services™ will be held at least 2 more times in 2020. This 8-week series designed for individuals diagnosed with PD in the last 5 years.



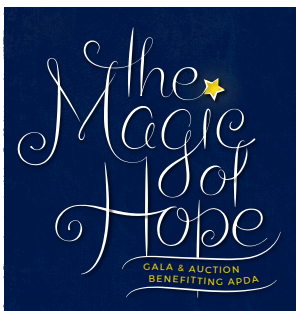
Friday, April 24th, 2020
10:00am – 3:30pm
University Place Presbyterian Church

APDA & the Pierce County Healthcare Providers Council team up for this one day event. This conference is focused on health, wellness, movement, and research. Featuring Dr. Rebecca Gilbert, APDA Vice President & Chief Scientific Officer.

Parkinson's Good Start

Parkinson's Good Start is a two-day educational program for those diagnosed with Parkinson's in the past 3 years. Learn from a team of esteemed experts and receive up-to-date information on diagnosis, treatment and wellness options.

Next Parkinson's Good Start will be in March 2020.



Saturday, March 13, 2020
Seattle Design Center
apdaparkinson.org/magicofohope



Join APDA Northwest and over 700 walkers at the **Annual Optimism Walk on Saturday, June 6.**

It is never too early to start building your team!

Visit our website at apdaparkinson.org/events/optimism-walk-4/ for more information!

**SUBSCRIBE TO OUR
NEWSLETTER!**

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

*Thank
You*

FOR SUPPORTING OUR MISSION!

What your donation can pay for:



\$100

Covers the cost for 100 people to receive the quarterly *Parkinson Pathfinder*—highlighting Northwest stories, resources, and PD research.



\$300

Pays for a one year scholarship of Patient Aid, for support services like transportation and respite care.



\$500

Funds a community grant to an exercise/wellness program, which increases access and keeps costs low for all attendees.



\$1000

Helps expand education programs to underserved areas and communities within our Northwest region of AK, WA, ID, MT and OR.