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and PD

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Clinical Trials

PARKINSON

Pathfinder

SPRING 2022

apda AMERICAN
PARKINSON DISEASE
ASSOCIATION
NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

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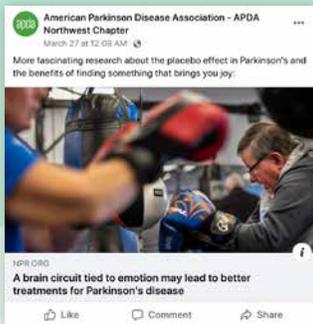
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SPRING 2022

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 APDA Northwest Chapter @APDA_NW - Jan 25
Today is National Plan for Vacation Day! Since many of us haven't traveled in a while, find some refresher travel tips at apdaparkinson.org/article/dd-su2... To ensure a successful trip remember to plan ahead, take care of yourself, and know your limits!

 **AMERICAN
PARKINSON DISEASE
ASSOCIATION**
NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

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COVER

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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.



*I listened as the doctor
told my mother,
"You have
Parkinson Disease".*

I have dedicated nearly seven years to the mission of APDA. I have poured my heart into doing all I can to ensure everyone impacted by PD has the support, education, and services they need to live life to the fullest. As the Executive Director of APDA NW, I work alongside you as we fight to bring awareness to PD and strive to support Care Partners in their vital roles.

Then, just a few months ago in November, I found myself sitting in the doctor's office with my mom. I heard the words I already knew to be true, but that were no less benign. I listened as the doctor told my mother, "You have Parkinson Disease". I had already noticed the tremors happening at rest, the shuffling gate, rigidity, and the many other non-motor symptoms commonly associated with PD. Even so, a lump formed in my throat. I was feeling the associated emotions well known to so many who hear a doctor confirm a diagnosis for themselves or a loved one. I also realized how frightening it must feel to hear such a diagnosis and feel alone. Many people walk out of this appointment without the understanding and resources that I have, thanks to my connection with APDA.

My mom and I are lucky. We have each other, our family, friends, and an incredible and supportive community. We know how to get the help we need. We know where to turn. As with all things PD, my heart is always with our mission at APDA. Yet, this time with the kind of understanding that can only come from the very personal experience of which I am embarking on. The question remains, how do we help those who have not

yet found their way to the connections and resources of APDA? How do we reach those that do not realize this isn't a journey they must take alone?

As Parkinson's Awareness Month comes and goes each April, I and APDA work to raise awareness of PD. I undertake our mission with the same fervor I always have. This year, I am not only doing so as the Executive Director of APDA NW, I do so as a care partner. I am not only working alongside and for you. I am you.

Please encourage everyone impacted by PD to connect with APDA Northwest, so they have the same support, understanding, and resources that helped my mother and I when we heard those words no one can ever forget, "You have Parkinson Disease".

Get connected. Stay connected. Connect others.


Jean Allenbach
Executive Director & Care Partner

Hard to Swallow: Dysphagia in Parkinson's Disease

Sarah Awde, SLP

Most people are aware of the communication difficulties that occur in Parkinson's disease (PD), but many are surprised to learn that swallowing issues are common as well, especially in the later stages of the disease.

Swallowing is one of those bodily processes that we often don't give a second thought to... until it becomes a problem.

As a speech language pathologist (SLP), my job is to evaluate and manage *both* communication and swallowing impairment. The reason that swallowing issues (referred to medically as *dysphagia*) came under the purview of SLPs is because the process of swallowing involves much of the same anatomy and physiology involved in speaking. Speech pathologists have specialized training in head and neck anatomy and physiology. We take courses in voice, articulation, respiration, resonance, and motor speech. We have extensive training in dysphagia and complete clinical practicums to assess and manage all manners of swallowing disorders.

This leads us to the obvious question... WHY do swallowing issues occur in people with Parkinson's? What exactly is happening here?

Along with the hallmark feature of difficulty initiating movement, Parkinson's is known for making movements *smaller*, and is often referred to as the *disease of low amplitude*. We often think of these smaller movements as they refer to gross motor movements such as having a shuffling gait pattern or reduced arm swing when walking.

Now think of it in terms of communication. Vocal projection

becomes reduced resulting in a soft, difficult to hear voice. Articulation and facial movements become reduced resulting in less precise speech and masked facial expression. Even intonation and prosody in the voice can be affected, resulting in flat robotic sounding speech.

With respect to swallowing function, the jaw, lip, tongue, and throat movements can become reduced in range resulting in difficulty chewing food, controlling liquid in the mouth, and triggering a strong, timely swallow.

So, does PD directly cause weakness in the face, mouth, and throat muscles like, let's say, a stroke? Not really. There is a two-fold effect happening here. The dopamine deficiency results in a *perceptual* impairment, a "faulty feedback loop" if you will. Your brain gives you incorrect information about the size of the movements you are making. You may THINK that you are speaking loudly or smiling widely because your brain tells you that you have put sufficient effort into these movements. But this is often false information. Your voice may in fact be too quiet and your smile minimal. Because of this perceptual issue, you don't adjust the movement to make it bigger. And as the old saying goes... *if you don't use it, you lose it*. Over time, reduced movement and range result in the eventual weakening of those muscles and systems.

It's also important to know that there are three distinct phases of the swallow, and any or all of these can be impacted in Parkinson's disease. The first phase of the swallow is the mouth or *oral* phase. During this part of the swallow, food or liquid must be prepared, controlled, and

transferred to the back of the mouth. The second phase of the swallow is the throat or *pharyngeal* phase. This is where the brain takes over and completes a complex set of movements to safely transport the food or liquid into the food tube. An important part of the pharyngeal phase is ensuring that the airway is sufficiently closed to prevent food or liquid from "going down the wrong pipe." This is referred to as *aspiration*. Aspiration events can lead to aspiration pneumonia which can be deadly if left untreated. The third phase of the swallow is the food tube or *esophageal* phase. This is where the food is transported to the stomach. Speech pathologists primarily manage the first two phases of the swallow as the third phase is largely treated and managed with medication and/or surgical intervention.

So, what are some of the typical swallowing difficulties in Parkinson's disease?

- Spillage from the lips or prematurely into the throat due to difficulty controlling food/liquid/medication
- Difficulty initiating the transfer of food from the front to the back of the mouth
- Difficulty initiating the pharyngeal phase of the swallow
- Inadequate range of movement of the laryngeal structure resulting in reduced closure of the airway during the swallow
- Food residue in the throat after the swallow
- Reduced sensation of food/liquid entering the airway resulting in absent or ineffective cough response to clear



Some of the Signs/ Indicators of Swallowing Issues

Drooling

Trouble controlling
food/liquid in the
mouth

Trouble moving food/
liquid to the back of
the mouth

Sensation of food
sticking in the throat

Coughing, choking or
wet sounding voice
during or after a meal

Increased length of
time to finish a meal

Difficulty
swallowing pills

If you are experiencing any difficulty swallowing, it is important to seek out a clinical swallowing evaluation with an experienced speech language pathologist to best determine an individualized treatment plan.

So, what exactly does a swallowing assessment entail? The first part of a swallowing evaluation is the clinical assessment. The speech pathologist will take a detailed medical history and ask you about the swallowing issues you are experiencing. Next is the oral motor exam. This is a test that looks at how the muscles in your face, mouth, and throat are functioning. The SLP may ask you to smile widely, press your tongue against a tongue depressor, wiggle it side to side, cough, wrinkle your brow, puff your cheeks with air, or voice different sounds. They are assessing your cranial nerves.

The next part involves having you swallow different textures of food: liquid, puree, mixed textures, harder solids etc. They are watching for many things. How are you able to chew, prepare, control, and transfer various food textures? How long does it take? Is there any spillage from the lips? How well are you able to clear food from your mouth? Are you aware when food spills out? Next, they will likely feel or palpate your throat when you swallow. They are feeling for how quickly and briskly your throat rises when you swallow. This will indicate how well you are closing off your airway when you swallow and how well you are opening your food tube to allow food to pass through to the stomach. Next, they are watching for what happens after the swallow. Is there coughing or throat clearing? Is there a change in voice quality? A wet or bubbly sounding voice can indicate that something has gone down the wrong way as food and liquid that passes over the vocal fold will

change the sound of the voice.

If your speech pathologist feels it is indicated, they may book you for a swallow x-ray. This could be referred to as an MBS (Modified Barium Swallow) or a VFSS (Video-Fluoroscopic Swallowing Study). This test is performed in an x-ray department. The therapist will mix different food textures with barium - a chalky white mineral that shows up on an x-ray. They will ask you to swallow these items while you are being x-rayed. This test allows the SLP to see exactly what is happening during the swallow and the results will guide the swallow treatment plan.

During the test they may have you do special positions or manoeuvres to see if there are any strategies that improve swallow efficiency and airway protection.

After the test, the SLP will meet with you to review the results and discuss the treatment plan. Treatment may involve any of the following:

- Food texture modification
- Positioning strategies or specific swallowing tips/manoeuvres during meals
- Specific swallowing exercises
- Speech/voice therapy or exercise program

Speech therapy for swallowing issues? Yes! Parkinson specific speech & voice exercises can help with strengthening the respiratory, articulatory and phonatory systems. Remember that SLPs manage both communication and swallowing issues because of the similarities in anatomy and physiology. When you regularly engage in Parkinson specific voice and speech exercises you are also targeting swallowing function!

How's that for a two for one deal?



SARAH AWDE is a Canadian registered speech language pathologist currently living with her family in the south of France. She is passionate about helping individuals with Parkinson's disease optimise their speech and swallowing function through regular adherence to voice exercise.

With her team of 6 therapists, Sarah runs a global online Parkinson specific speech and voice exercise program called Get LOUD Stay LOUD.

GetLoudStayLoud.com

WRITING BIG!

Andie Hill, OTS

Writing and typing is a basic skill that we use every single day. We use it in minuscule tasks from making grocery lists and sending emails, to journaling, or communicating with loved ones. Many of us take this skill for granted, until it becomes challenging, or we are unable to write or type altogether. In occupational therapy, we refer to writing and typing as an Instrumental Activity of Daily Living, or an IADL. When this IADL becomes challenging, it can have a big impact on an individual's quality of life (QoL). Writing and typing can become ever more challenging for certain populations, such as those that experience movement disorders like Parkinson's disease (PD), and as a result, can significantly affect their QoL.

People with PD often experience a variety of motor symptoms which can include challenges with handwriting, known as micrographia. Micrographia is a reduction in writing amplitude, stroke duration, fluency, and duration, which can result in small, cramped, and

illegible handwriting (Nackaerts et al., 2017). Current research shows the cause of micrographia to be unclear, however there may be a correlation to damage of the basal ganglia motor circuit in the brain. This section of the brain is linked to movement and motor planning, which are both impacted in people with PD (Kanno et al., 2020). Gross motor and fine motor movements become slower, which is referred to as bradykinesia. Motor planning becomes slower, which is the ability to remember the correct steps and produce the desired movement without having to think about it, such as writing your name. In addition to handwriting difficulties, these symptoms also impact a person's ability to type on a keyboard or use a mouse.

So, how do people with PD improve their handwriting and typing skills? There are multiple strategies to improve micrographia and typing, including adaptive equipment, exercises, and positioning.

WRITING EXERCISES

A study by Vorazoo et al. (2019) showed improvements in fine motor skills and handwriting speed for people with PD after completing a handwriting exercise program.

The handwriting exercises in this program consisted of writing the alphabet five times per day for four weeks using ½ inch graph paper. Participants that completed the exercises demonstrated increased writing speed and satisfaction compared to the control group.

OT Tips:

- Practice lower-case letters and upper-case letters
- Practice with different adaptive writing utensils and wrist weights
- Practice writing in different sizes
 - Practice BIG!
 - Write one letter using the whole page of a notebook
 - Write one letter per 3x5 index card or sticky note
 - ½ inch graph paper should be the smallest size you practice
- Practice writing ABCs on a white board – BIG!
- Practice writing ABCs with your eyes closed
 - Decreasing visual input can improve micrographia (Kanno et al., 2020)
- Utilize external cues
 - Use lined or graph paper
 - Write along to the beat of music to keep a steady pace

ADAPTIVE EQUIPMENT

If you are experiencing tremors, dystonia, or dyskinesia, then you might also be experiencing challenges with writing. A simple adaptation of adding weight to either your writing implement or your wrist can help decrease the amplitude of these unwanted movements (Mo & Priefer, 2021). In addition to weighted utensils, there are also writing utensils specially designed for people with PD, such as the PenAgain.

Another adaptation that can improve handwriting skills is a slant board. Slant boards create the optimal writing angle of 20-30 degrees, which assists in forearm stabilization and a slight bend of the wrist to provide a functional writing position (Beck, 2016).



Weighted pens

2-pack = \$18



Pencil weights

6-pack = \$20



available in several weight options

TheraBand wrist cuff

2-pack = \$15



PenAgain

3-pack = \$8



Do-It-Yourself: Pencil weight

Pencil, hexagon nuts,
rubber bands = \$3)



Adjustable slant board \$24

**Before purchasing, use a 3-ring binder to see if writing on a slant works for you.*

STRENGTHENING EXERCISES

Strengthening the hands can help maintain independence with activities of daily living (ADL) by reducing tremors, rigidity, and bradykinesia (Wang et al., 2020). It is important to work the small muscles of the hands and fingers to improve fine motor control and hand dexterity, which directly correlates to writing and typing.

OT Tips:

In-Hand Manipulation:

- Hold an object in the palm of your hand, move it to your fingertips and back to your palm, repeat
- Hold a round object in your hand and rotate it clockwise and counterclockwise

Finger Isolation:

- Place your palm and fingers flat on a table, lift one finger up at a time, repeat with all fingers
- Make an "O" by touching your thumb to each of your fingers

- Pick up coins from the table using your thumb and one finger to pinch, repeat using each finger

Strengthening:

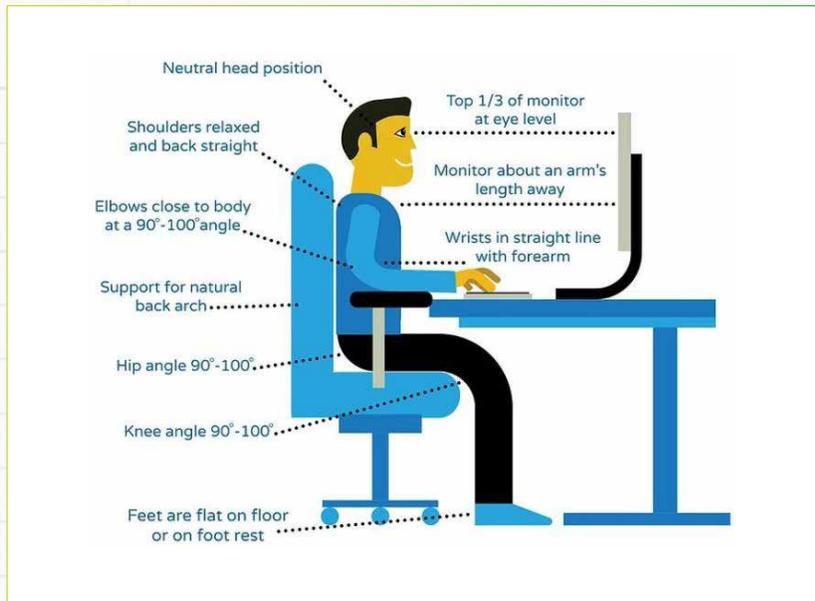
- Squeeze an object that has resistance in the palm of your hand
 - Theraputty:
 - Start with one strength and build your way up as you get stronger
 - Stress ball or rolled-up socks can work as well
- Place a small rubber band around two fingers at a time and stretch the band
- Finger Exercizer:
 - Start with one strength and build your way up as you get stronger
- Frequency of exercises
 - Repeat these exercises 1-3 times per day for 10-12 repetitions or 3-5 minutes to see results



TheraPutty 3-pack = \$8



Finger Exerciser \$10



POSITIONING

Proper body positioning and seating ergonomics can help improve writing and typing. When sitting at a table to either work on the computer or write, keep in mind the 90-90-90 rule. Your elbows should be bent at 90 degrees and at the same height as the working surface, hips should be at a 90 degree angle with your bottom against the back of the chair, knees should be at a 90 degree angle with space between the chair and the back of your knees, and your feet should be flat on the floor.



Lumbar Support Pillow (\$34)

OT Tips:

Make sure your chair is comfortable and has proper low back support

- Lumbar Support Pillow (\$34)
 - Supports upper, middle, and lower back depending on placement
 - Improves posture
 - Can be placed on office chair, car seat, couch, etc.
- Take frequent movement breaks (every 20-30 minutes)
- OT's like to say, "Proximal stability for distal mobility"
- Make sure your back and trunk are well supported so your arms and hands can complete tasks
- The picture above represents proper seating ergonomics while working on a computer

ADAPTIVE EQUIPMENT/ TECHNOLOGY

OT Tips:

- Adaptive keyboards with enlarged keys help minimize mistakes while typing
- Ergonomic keyboards help with hand and finger positioning to increase function
- Computer features, such as "Dictate", performs speech-to-text which reduces the need to physically type
- Computer apps:
 - WordQ – performs word prediction to limit the amount of key strokes
 - SteadyMouse – removes shaking motion of cursor and decreases accidental clicks to make using a mouse more functional



ABOUT THE AUTHOR:

Andie Hill is an occupational therapy doctoral student at the University of Mary in Bismarck, North Dakota. She just

completed a 14 week capstone project with APDA Northwest where she created a program focused on improving fine motor skills in those with PD. She is from Boise, ID but currently lives in Seattle, WA where she enjoys hiking, mountain biking and playing board games with friends.

Andie will graduate in April 2022 and we will proudly get to call her Dr. Andie Hill.

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Recursos en español de la APDA

Con la mayor red de base en todo el país, la Asociación Americana de Enfermedad de Parkinson (APDA), se dedica a combatir y apoyar a cada persona y familiar afectado por esta enfermedad.

Proporcionar información educativa y programación en español es parte de este esfuerzo.

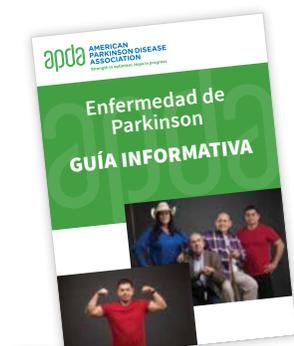
Los siguientes recursos están disponibles para la comunidad de habla hispana:

Línea de ayuda gratuita: llamar al 800-223-2732 para recibir ayuda en español

En el sitio web: Visitar la sección En Español en el sitio web de la ADPA para más información y para pedir folletos y publicaciones en español:

<https://www.apdaparkinson.org/resources-support/en-espanol/>

PUBLICACIONES EN ESPAÑOL



[Como vivir con la enfermedad de Parkinson](#)

[Constipación y enfermedad de Parkinson](#)

[La Fatiga en la enfermedad de Parkinson](#)

[Cambios cognitivos en la enfermedad de Parkinson](#)

[La depresión y la enfermedad de Parkinson](#)

[Síntomas Urinarios en la Enfermedad de Parkinson](#)

[Tarjeta de emergencia](#)

[Lista de Medicamentos Aprobados en Estados Unidos](#)

[Medicamentos que se deben evitar o usar con precaución en la Enfermedad de Parkinson](#)

[La Enfermedad de Parkinson y la Salud Bucal](#)

[Síntomas Urinarios en la Enfermedad de Parkinson](#)

[Mi Mami Tiene EP Fluctuaciones motoras en enfermedad de Parkinson](#)



INFORMACIÓN
Y RECURSOS
EN ESPAÑOL

Grupo de Apoyo para Cuidadora

Acompáñenos a una conversación sobre cómo ayudar a un ser querido a manejar los síntomas de la enfermedad de Parkinson para tener la mejor calidad de vida posible. El programa está diseñado para ayudar a los familiares y cuidadores de personas con la enfermedad de Parkinson. Comenzaremos con la serie en español y luego el próximo mes en inglés. Cada mes cambiará entre el inglés y el español.

Para participar: llamar al 800-223-2732 o mandar un mensaje electrónico a Rosa Peña rpena@apdaparkinson.org

Create Joy Series

It's a Wrap!

The 2022 Create Joy was full of such fun and creativity we had to share some of the results, and thank our facilitators!



Therapeutic Painting

Instructor: **Georgetta Gancarz**

"It was a little out of my comfort zone but I really liked the exercises that Olivia introduced to us. I am using some of the exercises currently! I think it has helped with the volume of my voice. Olivia has such a wonderful, bubbly personality. Very likable!"

— Harriet F.



Laughter Yoga

Instructor: **Jessica Brustad**
www.thefunnyyogi.com

If I were a stream,
 sometimes rushing happily,
 sometimes still, sometimes
 clear and clean and
 sometimes sluggish and
 dark. You would be a flitting
 Dragonfly with iridescent
 powers. Laughing, smiling,
 lovingly leaving your
 reflection on my water

— Carol

"Parkinson's is not a very bright disease, so I just choose colors I like to brighten my day"

— H. Black



Poetry

Instructor: **Vicky Edmonds**

"I was having a very bad morning. After Laughter Yoga I felt great. Thank you!"

— Ginny R.



Body & Beats

Instructor: **Megumi Azekawa**
www.pugetsoundmusictherapy.com



They say it's good to meditate to relieve stress. I found this class very meditative. Not only did I participate in class, I also painted between the classes. It's a little addictive!

— Marsha



All the World's a Stage

Instructor: **Olivia Mann**
www.getloudstayloud.com

"Informative and a blast of fun!"

— Kathleen D.

"I've had so much fun and I can't tell you how grateful I am to have had this opportunity."

— Jennifer W.



We'd like to thank and recognize our series sponsor who made this series possible:
Supernus Pharmaceuticals

My Parkinson's Story

Peter K. Bruck



I got my first drum set when I was 14. It was the 1960's in the San Francisco Bay Area. Rock and Roll was everywhere, and I wanted to be a part of all that was going on. Some friends and I started our own rock group, which became quite the money-maker from playing weekend gigs. I enjoyed playing so much that I went on to study music in college, and then set out to make a career of it. This was the life for me. I was going to be a professional musician.

Transforming dreams into reality is not easy, and for me, it was a very rude awakening. I tried my best, but I just couldn't bring all the right pieces together at the same time. The bills stacked up and my dreams faded away. At the age of 25, I threw in the towel and put my drums (and dreams) into storage. I was to become a carpenter. This was the beginning of a long, interesting, and for the most part, satisfying career. I was a general contractor, and that kept me gainfully employed for many years. It was after suffering a back injury, that I left the private sector and ended up working in government. However, a small flame would continue to burn inside me all these years and I hoped that in retirement, I could start thinking about bringing my drums out of storage and pursue that dream of becoming a professional drummer.

I officially retired in 2015. There was a wonderful party for me and when anyone asked what I was going to do in retirement it was always the same answer – I'm going to spend time with the love of my life, Rebecca, and play my drums. Everything was going great. I was retired and my drums were at home! I was playing in three different jazz bands, teaching drums to school-age kids at a local music store, and I had plenty of time on my hands to practice and make up for all those years without my drums. Life couldn't have been better.

Shortly after retirement, I began to notice stiffness and slowness of movement on my right side when playing. My left hand couldn't play nearly as fast or as under control as in the past. Initially, I chalked it up to not practicing enough so I practiced harder. I found that with a lot of practice, I could compensate for much of the

decline in my playing, but not all of it. I made an appointment with Dr. K., a movement disorder specialist. I brought a small drum practice pad with me to the appointment. I was able to show Dr. K. what I was experiencing. I also had him listen to my past recordings and compare them to more recent ones. There was a clear decline in my drum skills. It was at this appointment with Dr. K. that he diagnosed me with having Parkinson's Disease (PD).

Over a period of months, Dr. K. increased dosages, added new meds to counteract side effects from the other meds, and told me I had neurogenic orthostatic hypotension (lower than normal blood pressure). I was generally feeling worse than when I was originally diagnosed. I was fatigued and had "brain fog". Things were not going well. Something needed to change, so together Dr. K. and I worked out a plan. We made some adjustments to my medications and I focused on making some lifestyle changes. As much as possible, I was taking more control of my health and care. I felt empowered.

I have learned how to incorporate common-sense lifestyle habits into my everyday routines. It's not without sacrifice and it took time and commitment each day. I now incorporate four main activities into my life every day: moving my body, exercise, sleep, and mindfulness. If I don't do them, any other strategies that I've incorporated into my PD lifestyle approach seem to be far less effective. By embracing these activities each day, I am building a solid foundation upon which my passion for drumming is integrated into a personalized "PD minimal-progression regimen." Drumming has once again filled an important part of my life.



PD has forced me to make changes that have improved the quality of my life far beyond their impact on my PD alone.

I have learned to combine my PD drum exercises with conventional drum practice. Unlike some drummers that minimize their range of motion, I incorporate large movements of the arms. I regularly push the envelope, which is important for maintaining progress. Over time, the trendlines show that I'm able to play faster and better than three years ago. I like to think that seeing improvement in my drumming is also an indicator of how much I'm able to keep my PD in check. And my drumming really does continue to get better!

Being mindful of how I am playing the drums is another critical element of my drumming regimen. I'm not just hitting the drum heads with a stick; I'm listening to the sounds I make, feeling the rebound of the sticks, sensing the pressure of the stick against my fingers, subtly changing the dynamics, providing accents, reading the written musical notation and turning it into sounds on the drums, and coordinating the four limbs to produce multiple rhythms. Being mindful of these things helps to keep one in the present. It is also believed by some researchers that these types of activities can also lead to the generation of new neuro-pathways.

I find that developing this type of mindful behavior within the realm of playing drums, helps me to apply mindfulness in other aspects of my life. When I walk mindfully down the street, my gait becomes more even (as in a marching band), my arms swing in unison with my step, and I consciously lift my feet to keep them from dragging. I often take music with me when I do my walks and find

myself walking and tapping my fingers in time with the music. As much as I can, I consciously make my body to do those things it's supposed to do on its own. Over time, people with Parkinson's (PWP) unconsciously shorten their steps and constrict their movements. I believe that the more we are mindful of what we are doing, the better the chances are that the progression of Parkinson's can be slowed.

The last piece of my "drumming regimen for Parkinson's", which is also the first thing I do when I sit at the drums, is to *smile*. People used to always tell me that I seemed to lack expression and emotion when I played the drums. PWP tend to have a "mask", which reinforces this wall between drummer and audience. To work on this, I have put up a mirror in my drum practice space and consciously smile. I even have a reminder sign that says "SMILE"! At first it felt strange to do that, but over time, I have learned to smile more. It really does seem to bring everything in my drumming regimen together.

I'm only 2½ years into my diagnosis. I don't know what my future has in store for me. There have been a few refinements but my medication level has stayed pretty much the same for the last 1½ years and I don't see any other signs of progression. In fact, my drumming is better than it was when I was much younger. Is that any indication that I'm keeping PD at bay? I don't know. What I do know is that PD has forced me to make changes that have improved the quality of my life far beyond their impact on my PD alone.

Although the symptoms of PD vary widely, I can't worry about which ones may show up in my life. I love playing my drums and with the fortitude, persistence, and help and support of others, I have found a way to continue playing. My playing the drums may have started with that 13-year-old boy who was determined to buy his first drum set so many years ago, yet the impact and joy drums have had on my life has evolved to encompass far more than I could have imagined.





2022 OPTIMISM AWARD WINNER:
KERRY HOWARD



“Living with PD is a challenge, but it is a disease you can live with, and for that I am grateful.

No one knows what the future holds but I believe in being kind, brave, and grateful.

Pessimists may be right more often, but optimists have more friends and more fun.”

KERRY HOWARD

Kerry Howard grew up in a family that ascribed to the philosophy of “Whether you think you can, or you think you can’t—you’re right,” and from a young age she was taught to look at the bright side. Born and raised in Colorado, Kerry learned to love nature, animals, and photography. She slowly moved north and west, landing in Juneau, Alaska in 1981 where she had a successful 30-year career in natural resources.

In 2015, Kerry developed a tremor in her hand, and was ultimately diagnosed with Parkinson’s disease (PD) in 2016. After getting over the initial shock of this diagnosis and a period of adjustment, Kerry chose to approach the disease like she approached other challenges in her life, as realistic and positive as possible. She quickly discovered that she was not alone—and made connections through PD support groups and exercise classes. Kerry found readily available resources through organizations like APDA which have helped her navigate this disease, including the APDA PRESS™ program (Parkinson’s Roadmap for Education and Support Services) which Kerry attended remotely during 2020.

Among Kerry’s many accomplishments that led to her selection as this year’s Optimism Award winner includes advocating for her Parkinson’s community by being a Davis Phinney Foundation Ambassador, an NWPFF Community Advocate volunteer, and a MJF Foundation Policy Ambassador, as well as lobbying Alaska’s congressional delegation about Parkinson’s issues since 2018. Kerry also helped establish the first Rock Steady Boxing program in Juneau, Alaska, and procured funding for this program to go virtual during the pandemic so that people from all over the Northwest could participate. And her friends and PD peers will tell you, she is an optimistic force to be reckoned with!

Join APDA in congratulating Kerry Howard and celebrating her strength in optimism!

MAGIC OF HOPE OPTIMISM AWARD

At our annual Magic of Hope Gala and Auction, APDA Northwest recognizes a worthy individual in our Parkinson’s community who has made a significant impact by living the APDA credo of “Strength in optimism. Hope in progress.”

Thank you for the generous support of our Magic of Hope sponsors!

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Understanding Clinical Trials: What You Need to Know

Improving our treatment of Parkinson's disease (PD) is dependent on conducting clinical trials to collect information about PD patients and to test potential new medications and procedures. All of the advances in treating people with PD have come about through clinical trials and clinical trials are dependent on participation by those with a PD diagnosis to be successful.

But what is a clinical trial and what do you need to know about participating in one?

Types of Clinical Trials

There are many types of clinical trials, mostly divided into two large categories.

Observational Clinical Trials

In this type of trial, a new treatment is not tested. Rather, the trial carefully observes a particular aspect of the disease to learn more about it. These trials may require you to donate blood or other specimens including spinal fluid, urine or stool. Gene testing, imaging, neuropsychological testing, and questionnaires may all be components of an observational trial.

Both types of clinical trials are crucial for advancing the treatment and ultimately finding a cure for PD. When a new treatment for PD is developed, it must go through several stages of testing before the United States Food and Drug Administration (FDA) considers it for approval.

Interventional Clinical Trials

In this type of trial, a new treatment is tested to see if it either improves a particular symptom of PD or is neuroprotective and acts to slow down the course of PD. The intervention can be a type of exercise or therapy regimen, Cognitive therapy, Medication, Surgery, or any other type of procedure.

Participating in a Clinical Trial

Participation in a clinical trial is voluntary, and you have the right to withdraw from the trial at any time. Participating in an interventional clinical trial may offer you the chance to try a new treatment that may benefit you more than currently available treatments. Depending on the details of the trial, you may also have the opportunity to receive types of interventions you would not otherwise receive, such as physical therapy or dietary advice. However, participation may also expose you to some risks you would not otherwise be exposed to if you were not in the trial. Additionally, before you begin any trial you will go through a process of *Informed Consent* which is the process of learning about all of the possible risks and benefits of a clinical trial.

How do I Find Out about Trials?

Your neurologist can be a terrific resource about trials in your area. Or you can visit

www.clinicaltrials.gov

It is hosted by the National Institutes of Health (NIH), it lists all clinical trials past and present, for all conditions, and can be searched for trials that specifically address PD.

Questions to Ask About Clinical Trials

- What have previous studies shown about the safety and effectiveness of the new treatment?
- What are the most common adverse effects seen with use of this treatment?
- How will the treatment team monitor me for adverse effects?
- Is there anything in my medical history that puts me at higher-than-average risk in this trial?
- What will I need to do during the trial, and how long will it last?
- Will I have to travel to a different medical center for any of my visits?
- What are the chances I will receive a placebo in this trial?
- Who should I contact if my condition worsens during the trial?
- Will I be able to continue on the new medication (or begin it, if I received a placebo) after the trial is over?
- What will it cost me to participate in the trial?

What Is in the Pipeline Here in the Northwest?

Join us online to learn more about some promising clinical trials taking place in the Northwest



Connecting people with Parkinson's to the scientists who are working towards better understanding and one day, a cure for Parkinson's disease.

Join us for a series of live conversations between ESPN talk show emeritus Dave "The Groz" Grosby, local Parkinson's Researchers, and YOU the audience.

Live on Zoom, Summer 2022

Find Out about Research Opportunities by Joining the WPDR

The **Washington State Parkinson's Disease Registry (WPDR)**, which is entirely funded by APDA, is a database of individuals interested and willing to participate in PD Research. Local researchers can apply to the registry to help find participants for their project. **By connecting researchers to prospective study participants, we can help research happen faster.**

You don't even have to live in Washington to join the WPDR!

To learn more about the WPDR please visit www.registerparkinsons.org or call 888-365-9901.



SATURDAY
October 1st



SATURDAY
June 11th



Upcoming Education & Support Series

Series are held on zoom, space is limited

For the Newly Diagnosed: Next session of our popular 8-week program for newly diagnosed will be held in September of 2022.

For Care Partners: There are two more classes scheduled in 2022 for the 6-week Powerful Tools for Caregivers series.

Contact us to learn more and register.

Looking for a life-changing adventure?

Join our friends with Pass to Pass in a Pacific Crest hiking adventure this summer.

PASS TO PASS

This summer Pass to Pass, is planning 8 new multi-night hikes in WA, OR and CA along the Pacific Crest Trail.

www.passtopass.org | spokanebill@gmail.com

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**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, made payable to: **APDA NORTHWEST**

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

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