

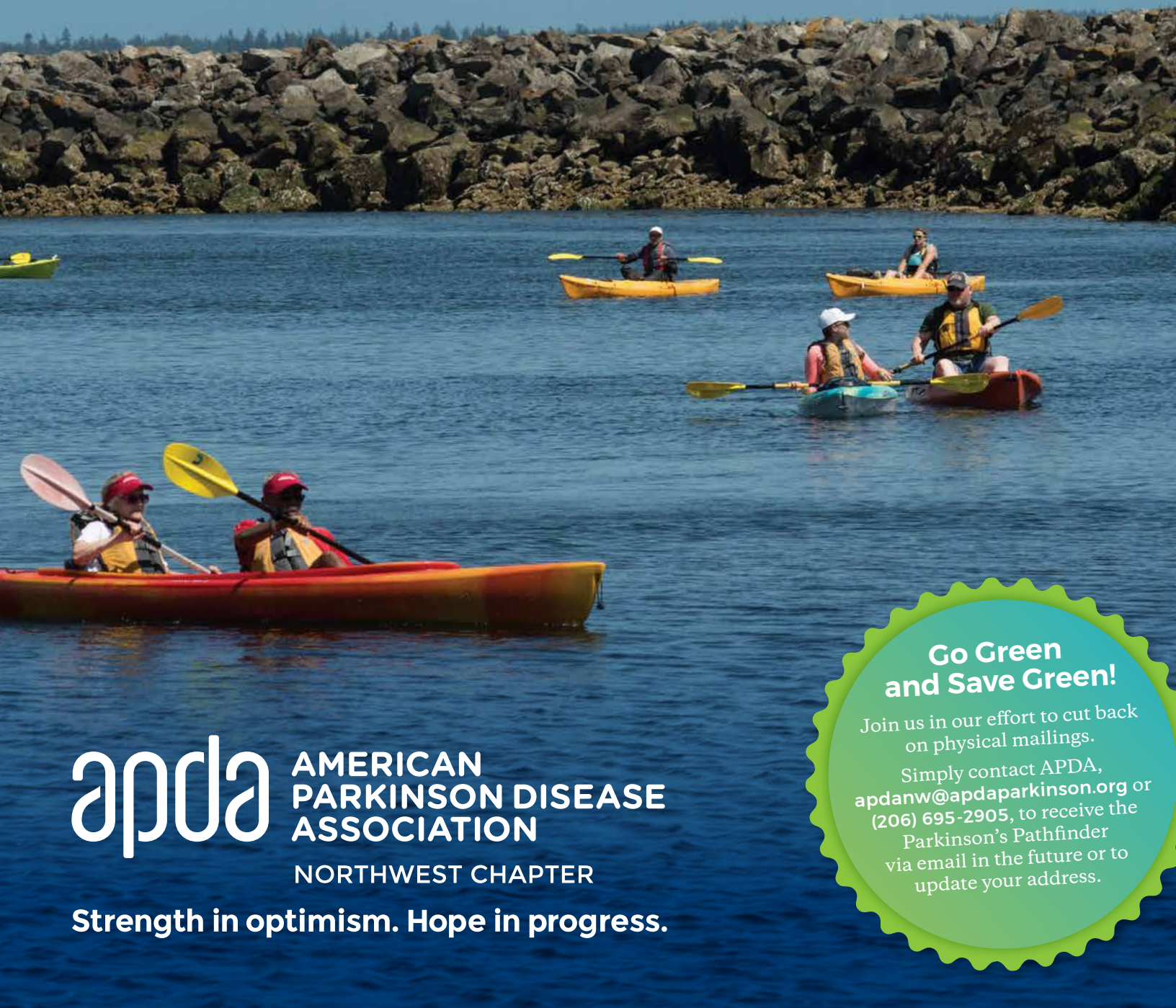
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Chuck Bundrant

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PD Psychosis

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Around the World

PARKINSON *Pathfinder*

FALL 2019



apda AMERICAN
PARKINSON DISEASE
ASSOCIATION
NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

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(206) 695-2905, to receive the
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update your address.

FALL 2019

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COVER

Second annual Paddling for Parkinson's in Elliott Bay, July 2019

Photo by Ken Kisch

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PARKINSON DISEASE
ASSOCIATION
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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.



From left to right, Carl, Brian, and Steve

We are excited to introduce the newest additions to our APDA Board of Directors:

Carl Carter-Schwendler, Brian Harris, and Steve Palmer!

They recently answered some "get to know you" questions.

CARL CARTER-SCHWENDLER

I was diagnosed with Parkinson's disease in 2013 when I was 44 years old. I didn't really know anything about Parkinson's, the only people I was aware of who had Parkinson's were Michael J Fox and Mohammed Ali. I had a busy life, working at Amazon and raising my two children. I didn't have time to think much about my PD.

Through a boxing program, I met several people with PD, both young onset and older, as well as people from APDA Northwest. I decided it was time to get more involved, which is my way of 'paying it forward.' I would like to serve as a bridge between APDA and the technology industry, and also bring a perspective of the working young onset population.

I live my life to the fullest by practicing strategic denial. I don't think much about the future or worry about what Parkinson's will eventually take away from me. I also don't let Parkinson's stop me from doing what I want to do. And I try not to mourn those things it has already taken from me.

If I could pick a superpower, I would definitely choose time travel. I would go to the future and bring back the cure for Parkinson's, well before I was diagnosed. There may be unintended consequences to the time-space continuum, but I'm willing to take that risk.

BRIAN HARRIS

I was diagnosed in 2017 just after turning 48. It was shocking and a relief at the same time. Like many with PD, I went through several other possible ailments before finding a Movement Disorder Specialist who quickly identified my symptoms.

In the next few months as I grappled with my situation, I attended a few traditional support groups, not quite finding the connection I desired. **I had an idea to create a circle of friends with PD that were working full time, active, and in need of conversations with others that truly understand what I was dealing with; Seattle Young Onset PD (SEAYOPD) was born in January 2018.**

It's my hope that I can bring a perspective to the APDA Board that is fresh and energetic, and assist them in making the PD community a better place for all. I plan to create a series of mini research seminars that connect scientists trying to find the hidden clues of PD to the people holding the secrets.

I live my truth by showing people that you can live, love and laugh with PD. My husband, Damion and I enjoy road trips, hiking, camping, exploring new restaurants, and entertaining our friends.



STEVE PALMER

I was diagnosed with PD in 2016, but looking back (like many PWP's) there were some noticeable symptoms much earlier. My right arm was weak, my handwriting was cramped, and I was having speech problems. To combat the disease I enrolled in the Loud Crowd program to help with my speech, started Rock Steady Boxing in August, and am exercising more than ever.

My connection to APDA began with my participation in the PRESS program in 2018. The 8 sessions were beneficial from an educational standpoint, helping me gain a better understanding of PD and how to cope with it, and our group also became good friends. After the program ended, I was intrigued by the idea of joining the APDA Board to stay involved and give back to the PD community, and look forward to helping with the fundraising effort.

I recently retired after 42 years in the surety bond business. I have two adult children and four grandkids, all of whom live nearby. I also love to golf and travel, and have been fortunate to combine those activities in recent years, making trips to Ireland, Scotland and France to golf on world-ranked courses and attend the Open Championship and the Ryder Cup.

I found this quote recently from Teddy Roosevelt, and it's become my mantra: "Do what you can, with what you have, where you are."

MEET CHUCK BUNDRANT

*Adventurer, Innovator,
Supporter, Friend*

Meet Chuck Bundrant.



Chuck Bundrant is the owner, founder and chairman of Trident Seafoods, the largest vertically integrated seafood company in North America. Chuck has made a significant impact in the Northwest, the fishing industry, and the local Parkinson's community. The Bundrant family has been a longtime supporter of APDA, even before Chuck was diagnosed with Parkinson's disease (PD) in 2006, a diagnosis later revised to Progressive Supranuclear Palsy (PSP), an atypical form of PD. Today, Chuck lives an active life full of hope and optimism despite the challenges PSP presents.

The following article contains material adapted from the book *Catching A Deckload of Dreams*, Chuck Bundrant and the Story of Trident Seafoods, in addition to Trident Seafoods' website and personal interviews.

In the winter of 1961, 19 year old Chuck Bundrant got into his 1952 Ford and drove from Tennessee to Seattle, in search of a great adventure at sea. And what an adventure it was, stretching into a 12-year journey across Alaska, aboard any ship he could find, discovering everything there is to know about fishing and crabbing along the way. Then in the early 1970's, Chuck met two other like-minded crab fishermen, Kaare Ness and Mike Jacobson, and together they pooled their money and built the Billikin – an innovative 135-foot boat that changed the course of the entire seafood industry.

The Billikin was the first vessel of its kind. It featured crab cookers and freezing equipment on board making it possible to process the fish right away. It also marked the beginning of Trident Seafoods. However, the story of Chuck Bundrant is not just about a successful company, it is about his commitment to and support of the people that make up the fishing community, the Trident family. Chris Jewell, friend, fisherman and APDA community member recalls how he considers himself lucky to be part of this family. "Chuck's commitment and support on the fishing grounds were his stock and trade. I realized very quickly how valuable this support was one year when my boat's transmission burned out, and I was dead in the water with 40 miles of ocean between me and any type of mechanic's shop. I put a radio call into Trident. Within 2 hours Chopper Chuck was above my deck in the Trident chopper, picking up my transmission and headed back to South Naknek where his mechanics completely rebuilt it. By the next morning

Chopper Chuck was back and lowering it onto my deck and we were back fishing in 2 days instead of 2 weeks. This meant the difference between a profitable season and going home broke. I was just one boat out of hundreds that fished for Chuck, and if you were lucky you were part of the Trident Family!"

Joe Bundrant, Chuck's son, also refers to this commitment to the Trident family: "When people ask about Trident Seafoods, many of them wonder how many millions of metric tons of fish we catch each year or how many millions of dollars we post in sales. Those are the numbers, but the real story of Trident is the story of the Trident people. It's the story of their hard work and the adventures they've shared with my father over these past 40 years. You might call him lucky, but my dad considers himself "blessed" - blessed to have kept company with the very best people in the industry. He truly cherishes his people. He listens to their dreams, motivates them by example, and rewards their hard work and loyalty."

Chuck's support of the fishing community and his love for adventure are shared with his beloved wife Diane who describes their life: "Every day is, and has been, an adventure and thrill with him. You just never know... and you never forget."

Many local fishermen have a story to tell about how Chuck helped them get started in the fishing industry or provided aid at a crucial time, helping them out of a precarious situation or providing support to a family when a fisherman was injured or ill. Chuck is known as an adventurer, an innovator, a supporter, and a friend to so many.





On Saturday, September 14th Captains for a CURE auction and fundraiser will be hosted at Fremont Mischief Distillery with Trident Seafoods and Cameron Catering, featuring four generous captains of Discovery Channel's* Deadliest Catch show: Captain Casey McManus and Captain Josh Harris of the F/V Cornelia Marie, Captain Sean Dwyer of F/V Brenna A, and Captain Keith Colburn of the F/V Wizard. As a tribute, fishermen and fans will gather to raise funds for APDA in honor of Chuck Bundrant.

The event was the brainchild of Mike and Patti Sherlock, owners of Fremont Mischief Distillery. They started their partnership with the "Catch" captains in 2013, when they began aging Mischief's Storm Tossed Rye aboard each of these

captain's fishing vessels. As part of Captains for a CURE, guests will blind taste and vote for their favorite whiskey, as the flavor profile is impacted by differences in storms, temperature and barometric pressure. Guests will join the captains in raising money for APDA and Parkinson's disease, by bidding on exciting auction items like the Captain's chair from the Cornelia Marie wheelhouse and one really stinky pair of greenhorn baiting gloves, and raising their paddle to Fund-A-Cure.

APDA is committed to find a cure, and guests will be invited to "Fund-A-Cure" by fully funding a research grant in honor of Chuck Bundrant. APDA has awarded

Van Andel Institute a research grant to study a mutation in a protein called VPS35 that is known to cause Parkinson's disease in some families, and a recent study also found that people with PSP-P had a mutation in this protein. APDA feels that further studying this protein can have ramifications for PSP, and funding this research grant is a wonderful way to honor Chuck.

Donations made to Captains for a CURE will also enable APDA to continue providing information, education, and support to all those impacted by Parkinson's. We are grateful for the generous support from our sponsors, committee members, donors, and Captains, who donated their time, talent and treasure to make this fundraiser possible.

Thanks to our Captains for a CURE Highliner Sponsors!



Footnotes:

*"Deadliest Catch" is a registered trademark of DISCOVERY COMMUNICATIONS, LLC LIMITED and is not affiliated with Storm Tossed Rye Whiskey, Fremont Mischief Distillery or the fundraiser for American Parkinson Disease Association (APDA); 1. Trident's Our Story: <https://www.tridentseafoods.com/Our-Story>; 2. Catching A Deckload of Dreams, Chuck Bundrant and the Story of Trident Seafoods. John van Amerongen. Documentary Media LLC; First edition, 2013.



SAVE THE DATE!

On Saturday, March 14th, 2020, the 18th annual Magic of Hope Gala & Auction will be held in Seattle. While it may be many months away, the planning for another successful event has already begun! If you are interested in joining the committee, please reach out to APDA at apdanw@apdaparkinson.org or call 206-695-2905. We would love to add a few new dedicated members to our team!

How to Bring Light to the Darker Side of Parkinson's:

A Primer on Hallucinations and Delusions and How to Manage Them



When most people think of Parkinson's, they think of the motor symptoms that often come with it: tremor, rigidity, slowness, and shuffling. However, they are often unaware that Parkinson's comes with a wide variety of non-motor symptoms that can affect thinking, mood and behavior as well.

Parkinson disease psychosis (PDP) is a non-motor symptom of Parkinson's that causes people to experience hallucinations and/or delusions. Approximately 50% of all people living with Parkinson's will experience some form of hallucinations or delusions, and the longer one lives with Parkinson disease, the greater the likelihood they'll experience them.

What causes Parkinson disease psychosis?

Parkinson's is a brain disorder associated with a loss of dopamine-producing nerve cells (neurons) deep inside the brain. Dopamine is a neurotransmitter (a chemical substance) that helps regulate the body's movement, and it also allows us to think clearly and regulate our emotions. When you try to replace the dopamine that's been lost in a person with Parkinson's, it can disrupt the system, which can impact thinking, visual processing and more. PDP can therefore be a symptom of the disease itself or a side effect of the medications used to manage it.

As a result, it's an ongoing balancing act for doctors treating Parkinson's to prescribe enough dopamine to control a person's motor symptoms, but not so much that the person experiences hallucinations and/or delusions.

What makes some people with Parkinson's more susceptible to PDP?

Not everyone living with Parkinson's will experience hallucinations and/or delusions, but there are several things that can increase your risk. Here are a few to look out for. Be sure to speak to your doctors and care partners if you notice any changes.

- Decline in memory
- Increased cognitive impairment
- Increased motor symptoms and disabilities unrelated to Parkinson's
- History of depression
- Increased sleep disturbances such as REM Sleep Behavior Disorder, sleep apnea, vivid dreaming and sleep interruptions
- Vision problems such as blurry or double vision
- Hearing problems
- Aging (it's common for people to experience vision and hearing problems as they age so the older one gets, the more likely they will be affected by hallucinations)
- Medication changes such as new medications, dosage changes and drug interactions
- Disease progression (70% of people who have been living with Parkinson's for over 20 years will experience PDP)

What are hallucinations?

A hallucination is something someone sees, hears, smells, tastes or feels that's not actually there. Essentially, they are tricks that the brain plays on the senses. It's estimated that about 50% of people with Parkinson's experience some type of hallucination over the course of having the disease. Most of the time these hallucinations are visual in nature.

For example, one person reported that he often sees tiny people along the floorboards in his kitchen. Another one said he sees people who aren't there when he walks into a certain room of

his house. One doctor shared that a patient regularly mistook her laundry piles for a person.

These visions appear clear as day to the person with Parkinson's but cannot be seen by anyone else. In some cases, the visions may be disturbing and cause emotional distress, but that's not always the case. They may be friendly and not bothersome at all.

When people with Parkinson's first start experiencing hallucinations, they typically experience them with insight. This means that they know what they are seeing isn't real, and they're able to recognize it as a symptom of living with Parkinson's.

On the other hand, when people lose insight, they begin to believe that the hallucinations are real. They may start talking to them, interacting with them and even try to draw their care partner into the scene with them. When their hallucinations reach this stage, they can go on for a very long time and cause hyper-agitation and aggressiveness, which can be very difficult for the care partner to witness and manage.

In addition, whether the hallucinations are distressing or not, just interacting with them can pose a potential risk of harm to the person with Parkinson's or anyone else in the room.

What are delusions?

Delusions are specific and fixed beliefs that are very real and true to the person experiencing them. They can contradict all semblance of reality and rational thought, but no amount of convincing can change what the person believes is true. Additionally, if you try to convince someone experiencing a delusion that it's not true, they can become suspicious and doubt you which makes an already difficult situation even worse.

Delusions happen much less frequently than hallucinations. Only about 10% of people with Parkinson's experience them, but because they're often ongoing, involuntary and feel very real to the person, they can be much more difficult to manage and treat.

The most common delusions people with Parkinson's experience are:

- The belief that their spouse is being unfaithful
- The belief that their care partner is poisoning them with their medications
- The belief that people are stealing from them

Fortunately, many people with Parkinson's have found ways to treat and manage the symptoms of Parkinson disease psychosis.

What's the treatment for Parkinson disease psychosis?

The single most important thing to do when it comes to PDP is to tell your care providers and partners the minute you notice changes in your vision, hearing, thinking and behavior. The earlier they know what's going on, the sooner they can begin interventions to help you feel better.

Once you bring your concerns up to your doctor, he or she will typically do a clinical evaluation, review your medications

and dosage, assess your lifestyle and determine the severity of your symptoms. Depending upon what he/she finds, your doctor may refer you to counseling or therapy, adjust your medication, change your medication, eliminate medication or do all of the above. If none of those strategies work, your doctor may try antipsychotic drug therapy to see if he/she can adjust chemical levels in the brain. This can bring with it an entirely different set of problems, so it's important to be invested every step along the way and be sure you're well-informed before you move in that direction.

How to care for someone who experiences hallucinations

If the person you care for experiences a hallucination, there are a few things you'll want to do in the moment and others you'll want to do when the moment passes.

The most important thing to remember is to never try and talk the person with Parkinson's out of their hallucination. They are actively experiencing it and by trying to talk them out of it, they may either feel like they aren't being heard or that their experience is being diminished.

What matters in the moment is their safety and your reassurance that they're going to be okay. You might calmly say, "I understand that you're seeing X. I'm not having that experience, and I just want you to know that everything is going to be okay, there's nothing dangerous happening here, and you're safe."

Other strategies are to:

1. Turn on all the lights to make the room as bright as possible, as hallucinations often happen in low lighting.
2. Have the person look closely at what they're seeing as that can help reset the brain and make the hallucination end.
3. If the person does not have insight, give them reassurance, provide a distraction, or move into a different room or suggest a new activity.

Here are a few actions you can take once the hallucination has passed:

- Talk to the person about it. Most of the time, even if the person does not have insight, they will remember when it's over.
- Tell their doctor and offer as much detail about the episodes as you can remember, including time of day, location and anything else that may have had an impact on the situation (i.e. the person's fatigue, hunger levels, etc.).
- Be sure to keep light switches in convenient locations. Since waking up and going to bed are the most prevalent times for people with Parkinson's to have hallucinations, turn lights on as soon as you wake up and make sure they're bright.
- Eliminate/reduce shadows in the house and be careful where you place mirrors and reflective surfaces as they can play games with the mind.
- Investigate any environmental triggers that could be causing hallucinations with more frequency or regularity.

Continued on page 11 >>

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!*

MOSCOW, ID

Parkinsinger's: A vocal exercise and music group

No Musical Experience Needed

Mondays, 11am

Contact: Christy Pansegrau | 406-950-0233
cpansegrau.mtbc@gmail.com
www.soundharmonymusictherapy.com

SEATTLE, WA

Two Weekend Yoga Options

Sundays 4:30 – 6:00pm

Northgate - UW Northwest Hospital

Contact: Peter Lynch | 206-719-8007
thagrdnr@yahoo.com

**funded by an APDA Community Grant*

Sundays 1:00pm

The Parkinson Fitness Project, 106 Lakeside Ave

Contact TFPF | 304-506-3876
nate@theparkinsonfitnessproject.com



Support Groups WE WANT YOUR FEEDBACK!

New Group
King County Group:

Flying Solo with PD

Do you have PD and are single, spouseless, uncoupled? We are starting a new group just for you. No, this isn't a dating club and we won't be speed dating, but we will meet together, get to know one another and bring in guest speakers to discuss topics of interest to you. We want to hear your ideas and gauge your interest. Please visit our website and take a [quick survey](#) or call us to learn more.

Stay Tuned for the inaugural gathering in mid October.

No group in your community?

Or is there a specific type of group (e.g. for care partners or young onset) you'd like to see?

We'd like to hear from you. Take a brief survey and give us your ideas! [Survey](#) can be found on our home page in the APDA Northwest Quick-Links

Clinical Trials in Parkinson's Disease:

Participation Opportunities Abound in the Northwest

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. However, lack of participants in clinical trials is the number one obstacle to success of a clinical trial. If you live in the Northwest you don't have to travel far (and in some cases not at all) to participate in PD research. There are several research centers conducting exciting cutting edge research plus you can join The Washington State Parkinson's Disease Registry (WPDR) (even if you live elsewhere) and learn about trials that way.

Types of clinical trials

There are many types of clinical trials, mostly divided into two large categories, with both types taking place at Northwest research institutions.

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.

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.

People without PD can often participate as well (e.g. care partners), especially in observational trials which typically collect the same information from both a PD population and a non-PD population in order to compare the results.

How to get involved in clinical trials

National/International Websites:

Clinicaltrials.gov 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.

clinicaltrials.gps.com You can search by location. Specific study and contact information is easily found.

Fox Trial Finder www.michaeljfox.org A resource run by the Michael J. Fox Foundation. Both people with PD and clinical trials can register on the site and the Trial Finder matches up willing participants and trials.

The Washington State Parkinson's Disease Registry (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. This makes research happen faster by connecting researchers to willing study participants.

You don't even have to live in Washington to join the WPDR! To learn more about the WPDR please visit www.registerparkinson.org or call 888-365-9901

Local Northwest Resources:

Your neurologist can be a great source of information regarding clinical trials in your area, and may even want to refer you to a clinical trial being conducted at the medical center at which you seek care.

Evergreen Health, Kirkland, WA As of print date, 13 different clinical trials were enrolling at EvergreenHealth. www.evergreenhealth.com/parkinsons-disease-clinical-trials | 425.899.5385 | EvergreenResearch@evergreenhealth.com.

Inland Northwest Research, Spokane, WA As of print date, 18 different clinical trials were enrolling at Inland Northwest. www.inwresearch.com/research-studies | 509-960-2818 | contact@inwresearch.com

Oregon Health Sciences University Portland, OR As of print date, 13 different clinical trials were enrolling at OHSU. | www.ohsu.edu/brain-institute/patients-parkinsons-disease-research | 503-346-3540

Swedish Medical Center Seattle, WA www.swedish.org/services/neuroscience-institute/research | 206-215-3565

University of Washington & Puget Sound VA Seattle, WA These large institutions have a number of ongoing trials and although there is not one centralized listing several studies can be found at: www.iths.org/participate/depts.washington.edu/neurolog/divisions/movement-disorders/research-opportunities.html

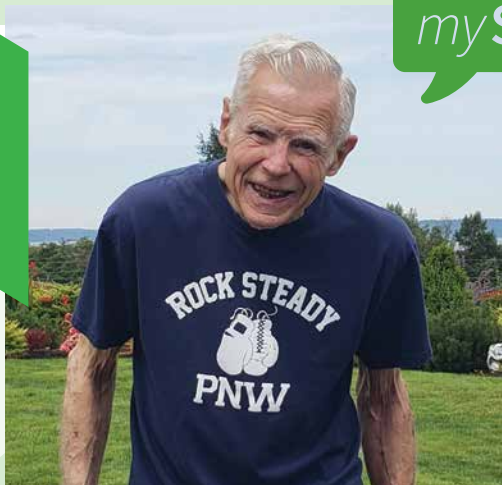
Online ONLY Studies

CamCare: www.CAMcarePD.bastyr.edu neuroresearch@bastyr.edu | 425-602-3306 | This is a long-running prospective, observational study designed to describe disease progression, symptom change, quality of life, diet and lifestyle habits among PD patients.

MPower: www.parkinsonmpower.org/your-story

The purpose of this study is to understand variation in the symptoms of PD. This study uses an iPhone app to record these symptoms through questionnaires and sensors.

mySTORY



“Giving to charitable causes has always just seemed like the right thing to do.”

— ADE EITNER

THE GLOVES ARE OFF: **ADE EITNER**

A Donor's Story

Ade Eitner is a good supporter to have in your corner. He remembers giving to charitable causes almost immediately after beginning his engineering career. He started small, giving through workplace programs like the United Way and donating to other causes that he cared about, such as Catholic charities and his alma mater, Santa Clara University. He makes a point to support local nonprofits that are making a positive impact in his community and on the lives of his friends and loved ones; when his wife passed away from cancer 11 years ago he added that cause to his list. Ade estimates that he has given to well over 50 charities over his many years of giving.

Ade was diagnosed with Parkinson's disease in 2016 at age 83. He began attending APDA education programs where he first heard local PD experts speak about the importance of exercise and nutrition. He now pays closer attention to what he eats, and works to keep his symptoms under control by attending Rock Steady Boxing classes three times weekly, as well as physical therapy and adding in some exercise sessions at home.

Ade chooses to give to APDA because he likes the focus on education and patient support, in addition to investing in research. He has recently started consolidating the number of charities he gives to, looking to provide more dollars to causes where his gift can have the most impact and organizations like APDA that keep administrative and overhead costs low. He enjoys seeing his dollars at work in the local programming that APDA brings to his Parkinson's community. Ade says it best:

“Giving to charitable causes has always just seemed like the right thing to do.”

Thank you Ade, for putting Parkinson's disease on the ropes!

WAYS to GIVE

Make a Qualified Charitable Distribution

Are you age 70-1/2 or older? A charitable IRA rollover allows you to transfer funds directly to APDA without having to recognize the distribution as income.

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 enrich lives. A small monthly amount can have a huge impact!

Include APDA in your Will

Secure your legacy for the people and causes you love. Create your will for free today, in less than 25 minutes, with a new tool available at www.freewill.com/APDAParkinson

Honor a Loved One with a Tribute Gift

In lieu of a birthday or holiday gift, make a donation to APDA in honor of a beloved friend or family member. Or throw a party to honor someone impacted by PD, and ask guests to make a charitable gift.

THANK YOU FOR SUPPORTING OUR MISSION!
Contact APDA at 206-695-2905 for more information.

It was lovely to see the many ways the conference incorporated the unique culture and traditions of Kyoto into the experience. Here I am among a massive display of 15,000 folded paper cranes!
 – Leslie Chambers

FIGHTING PARKINSON'S DISEASE AROUND THE WORLD

Highlights From The World Parkinson Congress

This piece was written by
 APDA President and CEO, Leslie A. Chambers,
 a guest blogger for APDA's *A Closer Look* blog.

SAVE THE DATE

The next WPC will be
 held in Barcelona,
 Spain in 2022!

APDA was in Kyoto, Japan for the 5th World Parkinson Congress (WPC) — an international forum for dialogue on the latest scientific discoveries, medical practices, and caregiver initiatives related to Parkinson's disease (PD). WPC takes place every three years, and a very unique aspect of the conference is that it brings together physicians, neuroscientists, clinicians and health professionals from many fields of expertise, as well as people living with PD and care partners for a well-rounded and inspiring experience. At WPC, it was thrilling to meet so many people from around the world who agree wholeheartedly with our mission and are living and breathing it every day in their own local communities.

STRONGER TOGETHER

Several themes repeated themselves throughout the conversations we had at the APDA booth in the WPC exhibit hall. Whether speaking with people living with Parkinson's (PD) and their care partners or with our colleagues and counterparts from medical institutions and PD organizations around the world, there was much talk about idea sharing and collaboration. There were many conversations about how we can work together, ideas for staying connected, and questions about how to maximize the learnings that we have collectively amassed. We look forward to staying in touch with the many new friends we made and seeing how we can support each other from afar. Despite

geographic distance, cultural differences and language barriers, we had many meaningful and insightful discussions.

RESEARCH HIGHLIGHTS

A big part of WPC is centered about sharing the latest in PD research. Experts from around the world shared their research results and insights on many topics – a sampling is listed below (many of which have been past topics in the *Closer Look* blog):

- Personalized medicine for PD – and the development of different therapies for different types of PD that may start outside the brain
- The biology of Alpha synuclein
- The importance of participation in clinical trials, and the challenges of recruiting patients
- Advances in stem cell therapy for PD
- Discovering new PD genes and risk factors
- Wearable devices to monitor PD
- New exercise approaches to optimize PD symptoms

While we all may get frustrated at times with the pace of research and medical progress, I am always encouraged when I hear renowned doctors talking passionately about their dedication to PD and the latest work they are doing, as I did at WPC.

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POSTER SESSIONS: APDA'S WORK ON DISPLAY

We were proud to have several posters on display throughout the conference. Rosa Peña, MSW, APDA's Senior Director of Programs and Services Field Operations, presented a poster entitled Parkinson's Roadmap for Education and Support Services (PRESS)™ – A How-to for Developing Early Coping Skills that highlighted the success of our signature PRESS program – an eight week in-person support series to address the psychosocial needs of those who have been diagnosed within the last five years. Cathi Thomas, MS, RN, CNRN, from our APDA Massachusetts Chapter and Information & Referral Center presented two posters, along with her colleagues from Boston University School of Medicine, on Service-learning as an introduction to Parkinson's disease for pre-clinical medical students and Providing education and support for newly diagnosed patients and families in the community.

Unique collaboration and perspectives

Doctors and researchers from all over the globe discussed trends in research, advancements in care, and problems still

to solve. Patients got to hear firsthand about the work being done to help understand this disease. Some inspiring people presented about life with PD, addressing the surprising benefits as well as the frustrating losses. Whenever you bring together the brightest scientists and most determined advocates, no matter where they are from, you're going to have an incredible sharing of ideas and a collective energy that can only help move things forward for the PD community. And to have all of the key players in the fight against PD – the physicians, researchers, advocates and the people living with the disease together in the same space, talking, sharing, and collaborating is an incredible opportunity and something that really stands out about this conference in particular. (Most conferences are geared either for the medical community or the patients, but not both.)

The most meaningful exchanges for me are always the ones I have with people living with PD. The people who face the challenges PD brings them every day, but who are determined not to give up. The care partners who no matter how exhausted or scared, remain the biggest cheerleaders and fiercest advocates. It is those moments that remind us so clearly why our work is so important.

We return home more committed than ever to our mission.



To subscribe to *A Closer Look* blog and to continue to hear about both timely and timeless topics related to Parkinson's disease visit <https://www.apdaparkinson.org/doctor-blogs/a-closer-look/>

APDA Community Grants: Increasing Access to Wellness Classes

Because of our generous donors, APDA Northwest is able to fund community programs that are making a difference in the lives of those living with Parkinson's disease. Through our Community Grant program APDA is increasing accessibility and affordability of programs by awarding grants of \$500-\$2000 to help pay for instructor fees, facility costs, and participant scholarships.



In 2019 APDA was proud to support a diverse group of programs:

Yoga for PD
Seattle, WA

Body Moves
Homer, AK

Singing for Wellness & Joy
Coeur D'Alene, ID

Music Therapy for PD
Renton, WA

Yoga for PD
Bothell, WA

Rowdy Readers
Eugene, OR

Yoga for PD
Renton, WA

Yoga for PD
Leavenworth, WA

Dance for People with Parkinson's
Bellingham, WA

Artist in Residence Program
Boise, ID

Next grant application deadline is December 31, 2019. Successful applicants will be able to demonstrate a viable wellness program that provides a valuable benefit to members of the Parkinson's community. For more information about the APDA Community Grant program and to find an application please visit our [website](#).

"This program has challenged me and helped me grow in many different ways. It helps me realize I am not alone. It teaches me mindfulness that enriches my life and see beauty in the world, even when I am struggling. It helps me manage my emotions around my disease, that are sometimes overwhelming. Trying these new things that I never thought I could do is so positive, it makes me feel positively healthy!"

—Program Participant at the Artist in Residence Program.




The 2019 APDA Northwest Optimism Walk was our largest and most successful walk yet!

A total of 750 participants came together as a TEAM and raised \$170,000 for the Parkinson's community! Wow!

The day was like one big HUG, filled with community, hope, love, and optimism. Many thanks to our sponsors for making this nationwide event possible for the Northwest Chapter of APDA.

PLATINUM



GOLD



SILVER

Abbott Labs, Acorda Therapeutics, Boston Scientific, C. Don Filer Insurance, CarePartners Senior Living, Cameron Catering, Foushée Construction, and GE Healthcare.

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How to care for someone who experiences delusions

If the person you're caring for experiences delusions, here's what you can do in the moment:

- Stay as calm and as patient as you can and remember that this belief has nothing to do with you and only with what is going on in your loved one's mind.
- Remove any objects in the room that could pose a danger to them or to anyone else.
- Clear space so there are no tripping hazards and it's easy for the person to move around.
- Do not try to reason with the person or convince them why their belief is false.
- Reassure them that everything is going to be okay.
- If the person becomes aggressive, minimize your movements and remain calm.
- Ask the person to talk to you about what they are feeling and really listen to them so they don't feel threatened.
- If you feel like you or they are in danger, call 911.

Here are a few actions you can take once the delusion has passed:

- Inform the doctor immediately.
- Educate others who may care for the person how to handle the situation if it happens.
- If the person is open to it, discuss it with them and ask them to explain what the experience is like for them and if there's

anything different you could do next time.

- Seek expert advice if you feel like you need support in managing these episodes.

Bringing light to the darker side of Parkinson's

If you or a loved one is living with PDP, please work closely with your Parkinson's doctors to assess your unique situation and create a treatment plan that's right for you. No two people experience PDP in the same way, so it's critical to understand and evaluate all of your potential options. Throughout the process, be sure to make note of how you feel, how you behave and how medications or therapies are impacting you on a regular basis so your doctors and care partners can keep an up-to-date record of your experience.

Often the hardest part of PDP is the fear of the unknown. As a person with Parkinson's, you may worry about having hallucinations and/or delusions and not being able to do anything about it. As a care partner, you may worry that you won't be able to help the person with Parkinson's feel safe if something does happen.

The good news is you now have information on what Parkinson disease psychosis is, the risk factors, biological and environmental triggers that can bring them on, and how to manage a psychotic episode if it occurs.

Adapted from an article appearing in the APDA, St. Louis Chapter May/August newsletters, written by the Davis Phinney Foundation and published on their blog.

Newly Diagnosed with PD?

APDA is here to help!

The four simple words, "You have Parkinson's disease," are life changing. For the approximately 60,000 people who are diagnosed each year, the quantity of information and the uniqueness of each person's experience with Parkinson's can be overwhelming, but you are not alone. APDA is here to help with specialized programs and services for the newly diagnosed. We are here with you on your journey with Parkinson's and will connect you to a vast and supportive community of people, resources, and education.

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 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 professional, the program is designed to provide emotional support, education, and coping strategies to live your best life with PD.

Nearly 50 individuals have participated in the APDA PRESS 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.

APDA Parkinson's Good Start

This two-part educational program is presented by a team of Parkinson's disease specialists. The goal of the program is to provide up-to-date information on diagnosis, medication management and treatment options. Designed for persons who have been diagnosed with PD in the last 3 years. This program is held several times throughout the year.

Support Groups

Connecting people through support groups is one of the foundational principals of APDA and it continues to be at the heart of our mission. On our website, we list over 200 support groups in our 5 state region and we provide training, logistical support, and educational materials to these groups. Additionally, APDA runs eight professionally led support groups, including one for those 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.

Save the Date!

Upcoming Events

To register for these and other programs, please contact us:

Website: apdaparkinson.org/Northwest

Email: apdanw@apdaparkinson.org

Phone: 206-695-2905

APDA Take Control Series



**Join us for the final session of our
2019 Take Control educational series**

Monday, September 9th

1:00 – 3:00pm

Mercer Island Community Center

Neurorehabilitation in Parkinson's disease

Dr. Karen Torres, Neuropsychologist, UW & Harborview Medical Center

Staying Safe In & Outside the Home

Jen Fox, Physical Therapist, CHCS Services

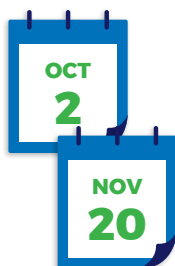


Saturday, September 14th

10:30am – 3:30pm

Anchorage Senior Center

Spend the day with APDA and a slate of PD experts. It is a day designed to educate, inspire, and empower those impacted by Parkinson's disease.



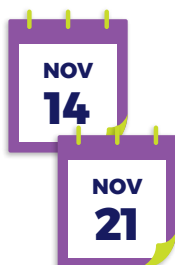
October 2nd–November 20th

10:30am–12:30pm

Aegis Living of Kirkland

This 8-week program is open to those diagnosed with PD in the last 5 years. Led by a licensed healthcare professional, the program is designed to provide emotional support, education and coping strategies to live your best life with PD.

Parkinson's Good Start



Thursday, November 14th & Thursday, November 21th

1:30 – 3:30pm

Fife Library

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 PD experts and receive up-to-date information on diagnosis, treatment and wellness options.



180 Nickerson Street, Suite 108
Seattle, WA 98109

SUBSCRIBE TO OUR NEWSLETTER!

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

APDA SYMPTOM TRACKER

Introducing an easier way to track your symptoms and manage your care

Download the free **APDA Symptom Tracker** mobile app today.

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.