

2 Walking
to the Beat

4 Medical Marijuana
and Parkinson's

10 Cutting-Edge PD
Research in the PNW

PARKINSON *Pathfinder*

FALL 2018

apda AMERICAN
PARKINSON DISEASE
ASSOCIATION
NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

Go Green and Save Green!

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

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

FALL 2018

TABLE OF CONTENTS

- 1 Letter from the APDA Board President**
- 2 Walking to the Beat**
Chris Altwegg
- 3 Remembering Don Covey**
Community Grants
Veterans
- 4 Medical Marijuana & Parkinson's Disease**
Rebecca Gilbert, MD, PhD
- 6 My Story**
Bryan Coluccio
- 7 Putting Your Donations to Work**
- 8 Thank You to our Donors!**
- 9 Move and Live with Optimism!**
- 10 Cutting Edge Research in the PNW**
Get to Know Dr. Vivek Unni
- 12 Recent Events**
- 13 Upcoming Events**



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Strength in optimism. Hope in progress.

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COVER

Fall Leaves with Ken & Linda Kisch, APDA Community Members

Photo by Ken Kisch

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.

EVERY



MINUTES

apda AMERICAN
PARKINSON DISEASE
ASSOCIATION
NORTHWEST CHAPTER

Yes, you read that correctly. EVERY 9 MINUTES someone in the US is diagnosed with Parkinson's disease.

That is 6 new people every hour, 160 new people every day. These are real people, not just numbers. I can speak from experience, as my dad was diagnosed with Parkinson's in 1999, and he lost his battle this past May.

Parkinson's disease is now the fastest growing neurological disorder in the world. Researchers and neurologists have even started using the word *pandemic*. The time to act is now, and your donation can make a difference! *See how we are putting your dollars to work on page 7.*

Parkinson's has not had the same attention or funding support as other neurological disorders and high profile diseases. As more and more families are impacted by Parkinson's, we can no longer be quiet. Your financial support is needed so that we can continue to fund promising research and provide the support and education to help the thousands of people impacted by Parkinson's in the Northwest. *Read why donor Bryan Coluccio gives to APDA on page 6.*

With your help, APDA will continue to innovate by introducing new patient services and education programs to meet the changing needs of our Parkinson's community and empower those impacted by the disease. *Programs like the ones found on pages 9 and 13 are helping families learn, connect and live better, and live life to the fullest!*

APDA has positioned itself to invest in the most promising clinicians and scientific projects, with the goal of attracting researchers who want to make a commitment to building a lifelong career in the field of Parkinson's. *Hear from APDA funded researcher Dr. Vivek Unni on page 11.* **With your help, we can make great strides towards our goal of discovering the cause and finding a cure for Parkinson's disease.**

There is a Chinese proverb that says the best time to plant a tree was 20 years ago. But the second best time is now.

**Every 9 minutes.
The time to act is now.**

Sincerely,

Dwight Jones
Board President, APDA Northwest



My father and I enjoying a laugh.

Walking to the BEAT

Chris Altwegg

In July of 2010, at age 57, I was diagnosed with Parkinson's disease. The first year after a PD diagnosis is really tough. Your world has taken a dramatic turn. Life as you've known it is not to be the same. There are so many questions to answer. But wherever you go, you hear the same thing: Exercise! Exercise! I personally hate exercise. But I can walk. And that's exercise, so I started walking. But it can be boring, and I needed something to entertain me. I found Michael J. Fox's three books on tape, each read by Michael himself. I walked and walked and walked, listening to all of them. In particular, the first book, *Lucky Man: A Memoir*, gave me a lot of hope and calm. I had a lot of worry and fear to walk off, and this really helped.

When I finished listening to them, I was still walking but I needed something else. Not news or talk radio. The classical music station just put me to sleep. So I flipped on a local rock station. They played tunes I loved, and I found myself walking in step with the beat. In fact, I couldn't not walk in step.

I looked up a couple of the tunes that had pushed me to walk faster than I normally would have. They had beats in the range of 115 to 125 beats per minute (BPM). So I gathered a playlist of my favorite music with a strong, fast beat. The personal enjoyment actually made the walks fun. Over time, I found I could go farther and faster. So, with my stride and a smartphone application tracking my mileage, I discovered I was walking in the range of 3.8 to 4.2 miles per hour. (Your mileage may differ. You are your only competitor.)



Chris Altwegg walking to the beat near his home in North Seattle

I discovered that a strenuous walk was an excellent remedy for the afternoon fatigue I had been suffering. Afternoons around 2:00 or 3:00 PM, I would start feeling severely fatigued. But if I made myself go for a walk, the fatigue became much more manageable and far less debilitating.

There have been numerous studies on what is being called "inspired exercise." Pushing yourself harder than you're inclined to move, may really be beneficial both short-term and long-term. Try it for yourself!

So how
can
YOU
do this?

HERE ARE THE STEPS I RECOMMEND:

- ▶ Discuss this with your doctor to be sure it's right for you.
- ▶ Using a timer, walk at a normal pace for two minutes, counting your steps. Divide by 2 to find your BPM (beats/steps-per-minute).
- ▶ Google 'Fixed Beat Walking Music' for some tunes. Or MixMeister.com has a BPM analyzer program to measure your own music.
- ▶ Load the music to your phone or other device.
- ▶ Using the headphones of your choice, turn on the music and head out to walk for 10 to 15 minutes or more, in pace with your BPM music.
- ▶ Walk 4 or 5 times per week, increasing your time and distance as you can and adding music at a faster BPM. (Don't push yourself in the beginning. Think time and distance, rather than speed. Don't wear yourself out and quit too soon.)
- ▶ Keep a record of your accomplishments. There are apps for both the iPhone or Android phones which can track your walk route, measuring distance, time, and speed. The cumulative list is inspiring and something to be proud of. It will also really impress your doctor on your next visit.
- ▶ A more detailed explanation of the process, along with Android and iPhone software titles and sources of music, can be found at <http://bit.ly/walk-to-the-beat>



APDA Northwest's Community Grant Program:

APDA Northwest funds 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.

Next grant application deadline is December 31, 2018. 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.

In 2018 APDA was proud to support the following programs:

Yoga for PD

Seattle, WA; Renton, WA
Bothell, WA

Singing for Wellness & Joy

Coeur D'Alene, ID

Rock Steady Boxing

Bothell, WA

Dance for Parkinson's

Port Townsend, WA

Body Moves

Homer, AK



APDA serves the needs of the Veterans Community

Are you a Veteran?

If you are a Veteran and have been diagnosed with Parkinson's disease (PD), APDA is here to help. Veterans may be at an increased risk of PD because of their service particularly those who served in Vietnam because of exposures to pesticides and herbicides. In 2010, the VA added PD to the list of diseases with a presumptive service connection, based on the time and location of service.

APDA's **Helping Those Who Serve Handbook** is a publication available to veterans of the United States armed services. In this booklet you will learn about Parkinson's disease, its symptoms, treatment, and the benefits available to you as a veteran. You will also learn about the Parkinson's Disease Research, Education and Clinical Centers (PADRECCs) created by the Department of Veterans Affairs as centers of excellence for PD treatment, as well as the national consortium of regional treatment centers. Two of these PADRECC'S are located right here in the northwest – in Seattle and Portland.

Helping those who serve



IN MEMORIAM DONALD "DON" COVEY

DONALD "DON" COVEY died on October 22 at the age of 90 due to complications from Parkinson's disease. He had a storied career with Unico Properties, serving for nearly 40 years in various executive roles, and was influential in the revitalization of downtown Seattle

in the 1980's. One of Don's many accomplishments included saving the 5th Avenue Theatre from demolition, and overseeing its restoration and reopening. He was involved with numerous organizations and held top leadership positions on the Greater Seattle Chamber of Commerce, University of Washington Alumni Association, Downtown Seattle Association, Municipal League of Seattle/King County, the Rainier Club, the Washington Athletic Club, and more.

His diagnosis with Parkinson's disease at age 79 offered a new challenge, and Don immediately got involved with APDA in a leadership capacity and was an advocate for everyone with Parkinson's disease. "I had the privilege of serving on the Board with Don. He had a consistent yet

soft-spoken leadership style; he was a man of few yet wise words. At our APDA Board meetings, Don was an ambassador of the human side of people living with Parkinson's," said Wendell Matas, former APDA Board President.

Don handled Parkinson's disease with dignity, and remained as active as he could after his diagnosis. He maintained his positive attitude, saying "I don't want people feeling sorry for me because I don't feel sorry for myself." He took Parkinson's one step at a time, realizing not only that people may have to be a little more patient with him, but that he had to be patient with himself.

Donations in the memory of Don Covey can be made to the American Parkinson Disease Association, Northwest Chapter.

Medical Marijuana & Parkinson's Disease

Rebecca Gilbert, MD, PhD

Medical Cannabis as a treatment for Parkinson's disease is gaining wide attention. We'll help you understand the science, controversies and current research involving the use CBD and THC in treating the symptoms of Parkinson's disease.

Parkinson's disease (PD) can be very challenging to cope with, causing a mixture of motor and non-motor symptoms that affect nearly every aspect of daily living. Although the medications that doctors prescribe can be helpful, there remain gaps in what the medications can treat. Understandably, people with PD are eager to find alternative methods to help their symptoms, leading many of these patients to look into whether other therapies, such as medical marijuana, also known as medical cannabis, can be useful.

Cannabis and the brain

Through natural curiosity, humans have discovered numerous medicinal uses for products extracted from plants over the years. Digoxin, a medication for heart disease, was derived from the foxglove plant and Paclitaxel, a medication used to treat certain cancers, was discovered through the Taxus species of plants.

Similarly, medical properties have been discovered in Cannabis, a genus of plant that, when ingested, can exert numerous effects on the brain and body.

With further scientific investigation, it was discovered that the effects of the cannabis plant occur through the binding of certain chemicals in cannabis to a system of receptors in the human brain, named the endocannabinoid system (ECS). Cannabis contains more than 60 of these chemicals.

Marijuana and public health

Cannabis is a substance that can be abused—that is, taken for non-medical reasons in a manner that can be harmful. Cannabis can stimulate the reward system of the brain and cause a pleasurable “high”, which can then be sought after by the user, leading to further use. Cannabis can change how a person perceives their surroundings and affect memory, reaction time, judgement, and ability to learn. Despite this, it was noted anecdotally by users that certain medical problems, such as chronic pain for example, were improved with marijuana. This led to efforts to create medical marijuana - purified chemicals from the cannabis plant, used at the doses that produce the desired result without harmful effects.

THC and CBD

The two primary chemicals that are isolated from the cannabis plant are Delta-9-tetrahydrocannabinol (THC) and Cannabidiol (CBD). THC exerts the mind-altering effects that recreational marijuana is known for, whereas CBD does not. For the most part, medical marijuana consists of purified combinations of these two chemicals in varying ratios. The combination can be dispensed as a liquid, pill or nasal spray. Both THC and CBD interact with the ECS.

Medical marijuana and Parkinson's disease

Since CBD and THC are chemicals that occur naturally in a plant, they were by definition not designed to combat any of the symptoms of PD. It is unreasonable therefore to expect that they will be a solution to all that ails a person with Parkinson's. More research needs to be done, but based on what is known about the biology of cannabis, one could hypothesize that THC and/or CBD may be helpful for aspects of PD such as tremor, stiffness, insomnia, dystonia, pain, dyskinesias or weight loss. However, clinical trials are needed to prove:

- Which of these specific symptoms are helped?
- What ratios of THC and CBD work for a particular symptom?
- What doses of THC and CBD work for a particular symptom?

APDA LAUNCHES NEW BLOG,

A Closer Look

APDA is excited to offer a new blog featuring Dr. Rebecca Gilbert, APDA's Vice President and Chief Scientific Officer. Dr. Gilbert is talking straight to readers three times per month, breaking down the latest news and topics surrounding Parkinson's disease.

With so much information available today, it can be hard to sort through it all. The new blog, called "A Closer Look," will make sense of all the science in a way that is easy to understand, and include practical, take-home tips that can help everyone impacted by Parkinson's live life to the fullest.

Dr. Gilbert wants to hear from you! Subscribe to the blog and suggest topics at www.apdaparkinson.org/doctor-blogs/a-closer-look/.



DR. REBECCA GILBERT

*APDA Vice President and
Chief Scientific Officer*

Dr. Gilbert received her MD degree at Weill Medical College of

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

Because the history and politics of marijuana trigger such strong emotions, it is understandable that the public has begun to think of THC and CBD as unique substances with their own rules. But they should not be viewed this way. They are chemicals found in plants that have effects on the human brain and body and may help humans cope with some difficult medical symptoms. And if they are used by humans to cope with a medical symptom, then they are medications. To that end, we need to treat THC and CBD as the medications that they are and subject them to the same standards that we do any medication. Clinical trials can help us understand what symptoms they treat and what doses are needed. A major limitation to performing clinical trials with medical marijuana is that the federal government continues to consider marijuana an illegal substance and will not fund research involving marijuana. There are various efforts to try to change this¹, with the hope of opening up medical marijuana to further study.

One must also consider that just like any medication, medical marijuana can interact with other prescription medications such as those that cause sleepiness or thin the blood. In addition, medical marijuana can have side effects. And just like any medication, the side effects will vary depending on the person taking it. Elderly patients are typically more susceptible to side effects, for example. Some side effects that might occur include sleepiness, confusion, difficulty concentrating, apathy, mood changes and gait imbalance. Therefore, before even considering medical marijuana, especially in the elderly, patients need to discuss how marijuana interacts with their other medications and weigh all the risks and benefits with their doctor.

Clinical trials in Parkinson's disease with CBD and THC

A few clinical trials have been conducted

investigating the role of CBD and THC in PD. In one^{2,3}, an open label study of CBD (in which doctor and patient were both aware that the patient was receiving treatment and there was no control group) was conducted on six patients with psychosis. Psychotic symptoms decreased. In a second trial, an open label study of CBD was conducted on four patients with REM behavior sleep disorder. Symptoms decreased. In a third, a double blinded trial of 21 patients were treated with CBD. Motor scores did not improve, but quality of life scores did. In another, patients at a movement disorders center were asked to fill out an anonymous questionnaire about their experience with cannabis. Of the 84 patients who admitted to using cannabis, 39 described mild or substantial improvement of PD symptoms including tremor and dyskinesias.

In 2017, the National Academies of Science, Engineering and Medicine released a report based on a review of 10,000 scientific abstracts concerning research into marijuana's effects on all aspects of health and disease. They published their conclusions⁴. They concluded that there was not enough evidence in the literature to currently support the use of medical marijuana in PD—as opposed to conditions such as chronic pain, chemotherapy-induced nausea, and multiple sclerosis among others, for which supportive evidence is available. This means that more studies need to be done in PD. One study⁵ is currently underway at University of Colorado.

Despite this lack of data, PD is typically one of the diseases for which a patient can obtain medical marijuana in the states in which it is available. Now the medical community needs to play catch up – and after the fact, provide the data to decide whether these medications are safe and truly work for symptoms of PD.

SOURCES:

1. LA Times Article: <http://www.latimes.com/opinion/editorials/la-ed-marijuana-public-health-20171227-story.html>
2. Clinical studies of cannabinoids for movement disorders: Article: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4357541>
3. Clinical studies of cannabinoids for movement disorders: Table <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4357541/table/T4/?report=objectonly>
4. National Academy article: http://nationalacademies.org/hmd/~media/Files/Report%20Files/2017/Cannabis-Health-Effects/cannabis-conclusions.pdf?_ga=1.153874296.1929557111.1484251916
5. Cannabis clinical trial: <https://clinicaltrials.gov/ct2/show/NCT02818777?term=cannabis&cond=parkinson%27s+disease&rank=3>



Teresa and Bryan Coluccio at the 2017 Magic of Hope Gala & Auction

Bryan Coluccio is an APDA Board member, long time volunteer, and a financial contributor to our mission. He was diagnosed with Parkinson's at age 41. We recently asked him to answer the question "Why do you give?" and these are his words.

mySTORY

BRYAN COLUCCIO

Philanthropy, from my perspective, is a vocation. A person can be philanthropic in three different ways: by sharing your time, talents and treasure.

In my view, all of us can be a philanthropist by volunteering and investing time and energy into those causes that are important to us. My spouse Teresa and I have made monetary donations to support causes important to us over the years. But for the most part, our primary contributions have been volunteering our time and lending our skills.

This past year, the company I work for was sold to a Fortune 500 company. As a result of the sale, I received a significant financial award for my 30 years of service. Teresa and I, without any afterthought or hesitation, knew exactly what we wanted to do with a significant portion of that financial award – to share our good fortune by donating to our favorite charities, one of which is the Northwest Chapter of the APDA.

I have early onset PD. I am fortunate to manage my symptoms fairly well, through meds, bilateral DBS, and exercise. **I give to APDA because of its two-prong approach to PD: supporting research and offering programs that enable those with PD to live better lives.**

Funding is of great importance in several ways: it helps to create awareness of PD, and awareness leads others to contribute. Funding supports research, and I am optimistic that a cure is around the corner. More dollars for research will get us around that corner more quickly. And funding supports programs that help those with PD live better lives as we await that cure.

The impact of these donations has been profound for both Teresa and me. Writing out the checks and notes to each of the recipients brought on a few tears, truly tears of joy. Teresa and I were able to hit the "trifecta:" we had long provided time and talent to support our favorite charities, and now we were able to share our treasure as well.

WAYS to GIVE

SUPPORT OUR MISSION

Planned Giving

Create your legacy:
Include APDA in your will

Give retirement assets
such as Qualified IRA Distribution
or stocks/bonds

For more information call our Office of
Planned Giving 347-329-1408

Memorials and Tributes to honor family and friends

In lieu of a holiday gift

Do-it-yourself Fundraising

Throw a party to honor a loved one
impacted by Parkinson's

Plan a bake sale,
chili cook-off or yard sale

Ask friends to support an adventure
such as a running or bike race

Online shopping

Give a portion of sales to APDA
while you do your shopping on
EBay, Amazon and more!
See list of retailers at shopAPDA.org

Make an [online donation](http://apdaparkinson.org/Northwest)
at apdaparkinson.org/Northwest

**Or use the donation envelope
in this issue to mail in a check**

EVERY
9
MINUTES

Every 9 minutes someone in the US is diagnosed with Parkinson's disease. 6 per hour. 160 per day.

What **DONATIONS** to **APDA** **HELPED FUND** last year:



30%

Education outreach to 30% more attendees (nearly 1,000 people!)



13 different education programs serving all stages of Parkinson's



Over half of attendees lived **outside the Greater Seattle area**, including Everett, Port Angeles and the Tri-Cities. Next year we plan to bring education programs to Idaho and Alaska!

Increased access to information, support and resources to **7,000 subscribers** of our quarterly *Parkinson's Pathfinder*.



Empowered people newly diagnosed by providing **education, resources and psycho-social support:**

* 8 week PRESS (Parkinson's Roadmap for Education and Support Services) Programs in a support group format

* 2-day Good Start education programs



Offered resources to 165 support groups, representing the states of WA, OR, ID, AK, MT, helping support an estimated 2,000 people impacted by PD

\$1.7 million awarded to support cutting edge research grants



\$12,500 in community grants to support exercise and wellness programs such as yoga, boxing & dance.



Grew APDA Ride Repay by 29% and Caregiver's Day Off by 21%, increasing access to transportation and respite care to promote independence and well-being.

What your **DONATION** to **APDA** can **PAY FOR** next year:



\$100

One month of transportation expenses for an APDA Ride Repay participant.



\$250

Covers costs for 10 individuals including those newly diagnosed and their spouses to attend a 2 day Parkinson's Good Start program.



\$500

Funds a community grant to a wellness program. Increasing access and keeping costs low for all.



\$1000

Helps expand education programs in under served areas and beyond Washington State.

Thank you

for your generous donations

Donations from mid-June to October 2018

\$10,000+

Anonymous
Glaser Foundation

\$2,500 +

Aegis Living
Costco Wholesale
Executive Match
Crowley Cares
Foundation
EvergreenHealth
Paddle for Parkinson's
Swedish Neuroscience
Institute
Trident Seafoods

\$1,000-\$2,499

Acadia Pharmaceuticals
Adamas Pharmaceuticals
Beret Kline & Steve Talt
Bill & Melinda Gates
Foundation
Catherine Lancaster
David Klotz
Jennifer Calloway
Kathleen Cummins
Kevin Pfau
Leonora Cabrera
Michael & Catherine
Amiss
Microsoft Giving
Campaign
Starbucks Coffee
Company
T-Mobile USA

\$500-\$999

Adams Coeur d'Alene
Tractor Company
Alaska Boat Company
Allergan
Amy Barnes
Anders Svensson
B&N Fisheries Company

Bill & Melinda Gates
Foundation
David Warren & Valerie
Motley
Elliott Bay Marina
Jang & Mei Wu
John & Elsie Crossman
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Steffen-Westerbeck
Martin Harsin
Medtronic DBS (WA)
Nordstrom
Paul Harvey
Ringler Associates
Sandra Ruedt
US WorldMeds

\$250-\$499

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Retirement Connection
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Ron Vandenberg
The Parkinson's
Fitness Project

\$100-\$249

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Toshi Moriguchi
Wally & Pamela Adams
Wayne Holt
Wendy Graves
Zach Vall-Spinosa

TRIBUTE GIFTS WERE RECEIVED IN LOVING MEMORY OF:

Beverly Hinkle
Brian Rawson
David Jones
George Petrovich
Gerald Heimann
Howard "Don" Skelton
Jan Newman
Janet Zema
Larry Newman
Robert Wade
Virginia Vernard
William Tozer

TRIBUTES GIFTS WERE RECEIVED IN HONOR OF:

Bryan Coluccio
Norman Ruedt

Start small
\$ give monthly.

Make a difference all year long.

To set up a recurring donation,
visit our website at
apdaparkinson.org/Northwest, click
donate, then make my gift recurring.
Or give us a call at (206) 695-2905.

\$10
PER
MONTH

can fund **scholarships**
to APDA educational
symposiums, so that
everyone can access
timely and relevant
information about how
to live well with
Parkinson's disease

\$25
PER
MONTH

can fund **transportation**
to exercise classes and
support groups through
APDA Ride Repay, giving
independence to
someone who can no
longer drive due to their
Parkinson's disease

\$50
PER
MONTH

can fund **20 hours of
respite care** through
the APDA Caregiver's
Day Off Program,
offering a breather to
a partner caring for
someone with
Parkinson's disease

MOVE & LIVE WITH OPTIMISM!

*Connect with others,
build community,
learn, and be well!*

The APDA website: 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!

Featured Support Groups

SEATTLE & TACOMA, WA

Veteran's Support Groups

2nd Friday of the month
11am–12:30 pm

2 LOCATIONS

Puget Sound VA

1660 S. Columbian Way

American Lake VA

9600 Veterans Drive

Contact: Annie Gellenbeck
253-583-1015, ann.gellenbeck@va.gov

McCALL, ID

APDA General

4th Thursday of the month at 5:30pm

St. Luke's McCall Medical Center

Contact: Carrie Kyrias, MS, CCC-SLP
(208) 630-2379, kyriasc@slhs.org

SITKA, AK

General

2nd & 4th Thursday
of every month, 6pm

Pioneer Home - Chapel

Contact: Chelsea Phelps, 586-215-6644
chelsphelps@gmail.com

Featured Wellness Programs



PORT TOWNSEND, WA

Dance for Parkinson's

Thursdays begins January 2019

Contact: Rae Stier
rstier@jeffersonhealthcare.org

SEATTLE, WA

Yoga for Young Onset PD

Thursdays 5:45pm – 7:00pm

Phinney Community Center
8 week series starts February 2019

More information & pre-registration
Sam Poyta, MSW, CYT
571-377-9384
Samantha.poyta@gmail.com

WENATCHEE, WA

Rock Steady Boxing

Tues, Thurs, & Sat at 11am

Contact: Rich Pratt, (509) 795-0831
wenatchee@rsbaffiliate.com

The American Parkinson Disease Association Awards More Than \$1.7 Million in Cutting-Edge Research Grants

From Biomarkers to the Microbiome, Some of the Smartest Parkinson's Research to be Funded in 2018-2019

THE AMERICAN PARKINSON DISEASE ASSOCIATION (APDA) has been a funding partner in many major Parkinson's disease scientific breakthroughs over the last 50 years, investing more than \$47 million in research grants since 1961. APDA maintains 8 Centers for Advanced Research and individual research grants and fellowships are awarded annually for promising research by experienced and young scientists.

This fall, APDA awarded more than \$1.7 million to support cutting-edge Parkinson's disease (PD) research in the form of: a prestigious George C. Cotzias Fellowship, two Post-Doctoral Fellowships, 11 Research Grants, and eight APDA Centers for Advanced Research. "APDA is funding an exciting array of projects this year", said Rebecca Gilbert, MD, PhD, Vice President and Chief Scientific Officer, APDA. "Our funding support will help investigate new biomarkers of Parkinson's disease, examine the scientific basis for gender differences in PD, and probe the differences in PD among people of varying ethnicities, among many other worthy projects that will have an impact on the future of PD research".

One such APDA research award recipient is located right here in the Northwest. Dr. Vivek Unni is a research-physician at Oregon Health Sciences University in Portland, OR and recipient of the 2016 George C. Cotzias Fellowship. This \$240,000 three-year fellowship is named in honor of the scientist who had a critical role in developing Levodopa as a treatment for Parkinson's disease, and is awarded to a young physician-scientist with exceptional promise in the Parkinson's field. APDA recently interviewed Dr. Unni, see page 11 to read about his exciting research.

Learn more about all the 2018 grantees, including the 11 investigators performing innovative PD research at major academic institutions across the United States and the exciting work they are doing by visiting

www.apdaparkinson.org/research/what-we-fund/

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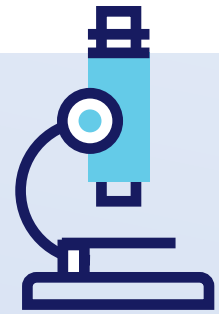
Make Research Happen Faster!

Join the Washington State Parkinson Disease Registry (WPDR)

The WPDR is a database made up of individuals who are interested and willing to participate in Parkinson's research. Local researchers apply to the Registry to find participants for specific research projects. APDA fully funds

the registry, as it is crucial to support the connection of researchers and participants so we can better understand disease progression, possible therapies and an eventual cure.

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



APDA Parkinson's Research Symposium

Did you know the Northwest is a hotbed of PD research and clinical trials?

Come Learn More!

This one day conference is all about Parkinson's research and will bring together local researchers and those impacted by Parkinson's disease. Attendees will learn about the latest in Parkinson's research, local projects and trials, and what it's like to be a research participant.

This event gives people impacted by Parkinson's an opportunity to meet the scientists, researchers, and clinicians who are working towards better understanding and one day, a cure for PD.

Researchers and physicians from Evergreen Health, University of Washington, Swedish Medical Center, the Seattle Veterans Administration, Inland Northwest Research, Bastyr University and others will all be involved in this first-time event.

Registration opens in January so look for an email or give us a call to make sure you are on our list.

**Save the Date for
Saturday,
March 30, 2019
at Bellevue College**

About Dr. Unni's Research:

Research Objective:

To utilize powerful, new imaging approaches to study molecular mechanisms of Lewy body pathology-associated cell death in PD.

Background:

Lewy bodies are associated with the cell death of neurons in Parkinson's patients, but little is known about what Lewy bodies actually do. Do they cause cells to die, or are they a defensive reaction that protects them, or are they neutral — just a marker that the cell is sick? This is a big, overarching question in the field.

Methods/Design:

By monitoring the living brains of PD mouse models, Dr. Unni's team is able to test what happens to neurons that develop Lewy bodies and how this influences cell survival. His recent work shows that neurons that develop Lewy bodies are destined to die within a few months. Dr. Unni's group is now focusing on understanding why this cell death occurs and what it is about forming a Lewy body that makes cells vulnerable to degeneration.

Relevance to Diagnosis/Treatment of Parkinson's disease:

If we learn more about why neurons with Lewy bodies die, we could develop treatments that stop this process and potentially slow or halt the progression of PD.



Get to Know DR. VIVEK UNNI

Dr. Unni is an associate professor in the Parkinson Center, the Department of Neurology and the Jungers Center for Neurosciences Research at Oregon Health and Science University (OHSU) in Portland.

How did you get into Parkinson's research? What first interested you?

I first started working on Parkinson's when I was a neurology resident at Harvard. I was drawn clinically to patients with PD because I thought that diagnosing PD was interesting intellectually. I was encouraged that there were some good treatments that we could offer patients for their symptoms, and there were plenty of important research questions left unanswered about how we could develop new treatments that could stop the disease from beginning or getting worse.

Congratulations on winning the Cotzias Award! What was your initial reaction to receiving the grant?

Gratitude and excitement! Funding for new investigators entering the PD field has been particularly tight the last several years, since research funding at the NIH has been particularly short since the financial crisis of 2008. Many young investigators, like myself, have found it harder than in the past to get funding to do the work they love.

What challenges do you face in research?

I face many of the same challenges that others in the field face at this moment. Trying to get more funding to do the work we believe in is hard for many people in the field. But in many ways the biggest challenge is not just getting funding, but also being able to develop new ideas. Science thrives on the unexpected - finding that clue that was missed or never seen before in order to make

a great, new discovery. This is actually what I spend most of my professional life trying to do and it is in many ways the hardest thing to do, but it is also the most satisfying part of being a scientist, and fundamentally what drives most of us.

Where do you see Parkinson's disease research going in the future?

I think the next several years will be focused on using the clues we have developed from human genetic studies of PD to try to answer what really causes PD, how does it spread, and how can we stop it. Many exciting proteins like LRRK2, Parkin, PINK1, DJ1, and the one we study, alpha-synuclein, and many others, have already been discovered that are involved in PD. I think the near future will be dominated by trying to figure out what all these proteins do, how they inter-relate, and why they all intersect to cause PD.

What is your advice for young scientists pursuing Parkinson's research?

PD research has lead the field of neurodegeneration in many ways over the years in terms of its contributions. I think that the first treatments that slow or halt the progression of a neurodegenerative disease are likely going to come from PD research. So I would tell young scientists that you are entering the PD field at a potentially golden moment, and to take advantage of what is in front of you to push our knowledge forward in new ways and build on the great work that has been done by those who came before us.

APDA prides itself in funding the brightest and most innovative scientific talent in the Parkinson's field. Want to help fund research?

Donate online at apdaparkinson.org/northwest

Adventure Race ^{was a} **HUGE SUCCESS** for Parkinson's



Team spirit, clever costumes, great scavenger hunt, and fun at the post-race celebration was experienced by all. **Together, we raised awareness and over \$55,000 to support APDA Northwest's efforts to provide support, education, and research to everyone impacted by Parkinson's disease.** The

Adventure Race for Parkinson's is possible because of the dedication of volunteers, sponsors and supporters. Thank you!

To see more pictures of the many creative team costumes, silly race challenges and smiling faces at the post-race celebration visit APDA's Facebook page @APDAnorthwest.

THANK YOU TO OUR GENEROUS SPONSORS:

Presenting Sponsor:

Niagara Bottling

Silver Level:

Trident Seafoods, US World Meds & Crowley Cares



SCARVES UP!!!

On Saturday, October 13th Seattle University hosted its Inaugural Parkinson Disease Awareness Men's Soccer Game in partnership with APDA Northwest. Soccer fans learned a little more about Parkinson disease by hearing statistics throughout the game, speaking to staff at the APDA booth, connecting with the PD community in the crowd, and observing our friends at Arcaro Boxing perform a PD boxing demonstration. Seattle University donated a portion of every advance ticket sold to APDA, and we received 100% of the funds from the specially designed Seattle U Soccer/APDA Northwest rally scarf! Thanks to Bryan and Sarah Coluccio, Coach Fewing and the Seattle U staff for making this event possible.



Former Seattle U Soccer Players Sarah Coluccio (2012-15) and her dad Bryan Coluccio (1975-78, co-captain '78), diagnosed with young onset Parkinson's at age 41. Bryan is an APDA Northwest Board Member and champion for all impacted by Parkinson's disease.



There was truly the Magic of Hope in the air during last year's gala & auction, with a **sold-out crowd of 500 people raising over \$500,000 for**

people impacted by Parkinson disease in the Northwest! Now officially the largest fundraiser for APDA in the country, we are ready to break records again. Join us on Saturday, March 16, 2019 at the Seattle Design Center for the 17th Annual Magic of Hope Gala & Auction. Sign up today to take advantage of early bird pricing... and before we sell out again!

To learn more visit www.apdaparkinson.org/magicofhope or contact APDA.

2019 Educational Programs

At APDA Northwest we believe that **education and learning are critical components in your journey with Parkinson's disease.** That is why APDA Northwest offers an array of in-person educational programs designed to inform and empower those living with Parkinson's and provide opportunities to connect with experts in the field. All programs are open to everyone impacted by Parkinson's.

Stay tuned to our website and your inbox for the official announcement of dates!

APDA Take Control Series

Parkinson's disease is a complex disorder with new challenges to face as the disease progresses. The more educated a patient and family becomes the more they are able to Take Control of their disease. Experts in the field will educate and prepare you to recognize these challenges and learn how to manage them with practical tools and greater knowledge so that you can live life to the fullest.

In this new format for 2019, the series will be presented every other month beginning in January, with rotating topics of interest. Stay tuned, we are working on plans to live broadcast these programs for those who cannot join us in person.

APDA 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 2019.

Powerful Tools for Caregiving Series

Powerful Tools for Caregivers is a series of 6 classes that teaches family caregivers how to take better care of themselves while caring for a family member or friend. The series has been taught worldwide since 1998 and APDA Northwest is excited to be able to offer it in 2019 to those who are caregivers to someone with Parkinson's disease.

We will be offering this class starting in late March of 2019.

PRESS program

The popular PRESS™ Program: APDA's Parkinson Roadmap for Education & Support Services™ will be back again in 2019. This 8 week program is designed for individuals diagnosed with PD in the last 5 years and 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.

Two PRESS programs will be held in 2019, one beginning mid-January and the other in May.



**OPTIMISM
WALK**

**AMERICAN
PARKINSON DISEASE
ASSOCIATION**

WALK WITH US!

Join APDA Northwest and
OVER 600 walkers for the

**6th Annual Optimism Walk
in Seattle
on Sunday, June 2, 2019**

Visit our website and
register your team now—
it's never too early to start building
your team and raising funds!

**SUBSCRIBE TO OUR
NEWSLETTER!**

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

*Get Involved
with*
APDA!

As a chapter, we are growing fast and have **BIG PLANS** to
do more to support the local Parkinson's community—
so we need **YOUR** help!
Here are some ways you can get involved.

**Join, Learn &
Build Community**

- Attend an APDA Educational Program
- Participate in a community support group or wellness class
- Stay informed about local PD research initiatives by registering with the Washington State PD Registry (pg 10)
- Create your 2019 Optimism Walk team of family, friends or colleagues

**Donate your
Time & Talent**

- Serve as an APDA Ambassador at speaking engagements or information fairs
- Join an event planning committee or volunteer at our events
- Volunteer in the APDA office Monday-Friday

