

WINTER 2017

TABLE OF CONTENTS

- Our Successful 2016

 Letter from the Executive Director
- Laughter is the Best Medicine! (But Also Give Real Medicine a Shot)
 Eric Lundquist
- Spotlight on an APDA Community Grant: The Joy of Dance Jen Gillick
- 6 Live with Optimism
- Move with Optimism
- Getting Involved in Research: A Look into the WPDR Jen Pate
- 10 Recent Donations
- 12 Live Well Event
- 13 Upcoming Events



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As we prepare for 2017, I would like to take a moment to share some exciting 2016 successes of the American Parkinson Disease Association, Northwest Chapter and thank you for being a part of it all! Our dual mission is unique in the northwest, as we work to provide help for today through direct services, support and education, and also hope for tomorrow through funding research.

Because of our volunteers, supporters and sponsors we were able to make a significant impact and help more people than ever before, by...

- Growing our APDA Ride Repay & APDA Caregivers Day programs by 19%, providing vital services directly to Parkinson's patients and their families
- Promoting 286 movement classes and support groups on our newly designed website, so that dates, times and locations are easily accessible
- Awarding community grants to yoga, dance and singing programs, ensuring that the cost to participate in these activities remains affordable
- Providing in-person education programs to more than 700 people, making information and resources available to help everyone impacted by Parkinson's live life to the fullest
- Funding two additional APDA professionally led support groups and strengthening this network where people find solace, comradery, understanding and optimism

Fostering Optimism through supporting Parkinson's disease research...

- Increased local fundraising led to more funding for national research projects
- Two research breakthroughs during 2016 were funded by APDA
- APDA Northwest gave \$25k to the Washington State Parkinson's Disease Registry, the only disease registry of its kind in the U.S. with a research focus
- Working with the PD Canine Detection Project to determine if Parkinson's disease can be detected by dogs
- · ...and much more!

In addition, our Optimism Walk, Magic of Hope Gala and Adventure Race events were all huge successes! We had a 54% increase in attendance over prior year, and a 39% increase in revenue, but we are far from done.

Parkinson's disease is a growing problem. It affects millions of people and is the second most common neurological disease, having an estimated combined direct and indirect cost of nearly \$25 billion. The American Parkinson Disease Association has vowed to continue the fight against Parkinson's disease until there is a cure, and we hope you will join us in that commitment as well!

Sincerely.

Jean Allenbach
Executive Director



WHEN MY DAD STARTED SHOWING symptoms, it was tremendously difficult to bring it up without offending his sense of pride. However, we were able to approach the subject through humor, which has been invaluable in the process of letting us talk.

It started when my mom told my brother and I "Max, Eric, have you noticed that your father has been keeping his right hand in his pocket more often? And he looks more gaunt than usual and he speaks less. His face shows less expression. It's called masking. I think he has Parkinson's disease."

We responded the only way we knew how. I said "Damn, I thought Dad was just stoic and handsome."

We didn't believe Mom at first. We didn't want to. See, my mom has the tendency to always imagine the worst case scenario. In our experience, you don't want Mom to be right about anything. If Mom has any prediction of hers come true, you're up a creek. This time she seemed right. She had put in

a lot of hours on Google and had compiled a case more airtight than the space shuttle. But in her fear of a worst case scenario, she had actually caught it before it would become that. In order to capitalize on my mom's prediction, we had to act quickly.

A note about my dad: my dad has a tremendous amount of ingenuity when it comes to solving a problem without actually fixing it properly. For example, all of our cars have "a trick" to starting them. He fancies himself a modern day caveman: curious, imaginative, and full of a primordial resourcefulness. In addressing a problem though, you've got to acknowledge it first.

It was hard to get my dad to see a doctor to diagnose him, but no matter how tempting, you can't ignore a progressive disease. Parkinson's is like being pregnant. Even if you ignore it, you're eventually gonna have a whole new set of obligations. We had to approach the issue and get it into the light in a way that was acceptable.

In our family, we pride ourselves on our sense of humor. My dad and I slam down zingers non-stop and my mom and brother end up taking those jokes as admirably as Rocky takes punches to the face.

Humor would be the key to talking about my dad's Parkinson's. Deciding to take one out of his book, we had to get creative.

Seeing my dad find unorthodox solutions to everyday problems all my life, I knew that by working our way around the problem, we could address it. In this scenario, my dad's pride was the temperamental Subaru Justy, and jokes were my vice grips and tin foil. So I tactfully used my nuanced, razor sharp wit to "encourage" my father to seek a medical professional.

"Hey Kevin Shakin'! Is your Foot Loose? Go see a doctor!"

That did the trick. As much as I hate bullying, you can't deny its effectiveness. Hey, all care groups function differently.

I know that my dad would rather not talk about his Parkinson's. It must be excruciating for a father to look weak in front of his kids. On the flip side, there is value in talking about it. By putting our heads together and pooling our knowledge, my dad is getting better insight for making his Parkinson's work in his life.

In our experience, talking about it and making jokes offers a sense of control over the situation. I do stand-up comedy in Seattle, so of course I took this premise to the stage. Like this one: "I wanna write jokes about my dad's Parkinson's that he likes. But it's hard to write something that's good. You see my dad knows jokes like he knows the back and front and back and front of his hand."

And my dad wrote some jokes too. His joke, which I like a lot: "Now that I'm in the Parkinson's club, do you want to see my secret handshake?" Now he relates his story of his diagnosis, the doctor exclaiming "Yup! You got Parkinson's!" like she was Oprah giving an audience member a new car. Addressing the issue of course isn't the only thing you have to do. Treatment is next.

Luckily my mom is a fitness instructor, so she's making sure he's working out. He's doing LSVT Big and Loud. We all read Hal Newsom's book HOPE and in a week, he's



seeing his neurologist to see if a particular drug cocktail tickles his fancy. I even got an internship at APDA Northwest, so we have even more resources to make this work.

We were invited to the APDA's last fundraising event, The Adventure Race. My parents still talk about how fun it was. Costumes were encouraged, and we went a little overboard. The residents of Ballard must have been shocked to see the crew of the U.S.S. Enterprise from Star Trek walking their streets, looking for clues. I remember fondly when we walked up to the sign-in booth and they asked who the team captain was. I got to say, doing my best Shatner, "I... am the Captain." Going to that event was encouraging for all of us because we got to see so many people committed to the cause.

You can't cure Parkinson's right now. But you can sure as heck try to delay its progress and maintain your health. And my dad, the genius caveman, has a lot of experience with finding solutions to things that can't be fixed outright. He has creativity, resourcefulness, and a family to multiply those benefits. Our sense of humor lets us be more open and work together to map out a better plan for managing Parkinson's.

Oh and if you want to follow my dad's own humorous writing on hiking and life with Parkinson's, his blog is timlundquistwrites. com.

Tim Lundquist takes a selfie before one of his trips into the backcountry.



IMAGINE A ROOM: MIRRORS ON one wall, a wooden bar running the length of the other wall, soft music in the background, 20 men and women seated in chairs. There is tremor visible in the arms of a few and there is a quiet anticipation of what is to come. The music gets a little louder and the dance instructor, Pam Kuntz, begins class. This is "Dance for People with Parkinson's Disease and Other Neurological Disorders," held every Friday at Ballet Bellingham in Whatcom County. The class is free for participant's thanks in part to a community grant provided by APDA's Northwest Chapter.

In 2010 Choreographer and teacher Pam Kuntz created a dance/theatre performance piece called "Stories from Jim and Jo," a moving performance about living with disabilities featuring Jo, a woman living with MS and Jim, a man living with Parkinson's disease. During a post-performance discussion Pam met Rick Hermann, a Bellingham resident also living with Parkinson's disease. Their friendship developed and not too long after that first encounter the two decided to create a dance class for people with PD and other neurological disorders.

Pam began by researching how she might go about creating and teaching this class, which included research on PD. And Rick was the promotions guy, in charge of creating the flyer, spreading the word, and finding participants. During her research phase, Pam armed herself with as much information as possible about PD. She found many resources about exercise programs for people with PD and discovered David Leventhal's "Dance for PD" program. She knew she would be teaching a modern dance class, a technique class that trains dancers to communicate ideas through movement. "I just needed to find out how to be smart about teaching people with neurological disorders, and how to create a successful experience for the participants that both taught the art of dance and brought JOY to their lives."

Dancing is emerging in scientific literature as an effective approach to managing some of the symptoms of Parkinson's disease. More research needs to be done and is currently in progress, but the results from a number of preliminary peer-reviewed studies and meta-analyses conclude that this



We just have a hoot,

> it's so much fun. We laugh and we just enjoy each other's company more than I can begin to say."

form of activity shows some therapeutic benefit in gait, balance, and increased fluidity of motion. Plus it is socially engaging and fun!

"We just have a hoot, it's so much fun. We laugh and we just enjoy each other's company more than I can begin to say." Each class is an hour in length and is a combination of dance technique done seated, at a ballet barre, and in the center, standing if the participants so choose. It is a whole body workout that incorporates flexibility, strength, balance, coordination, and joy. "We dance hard. Folks are exhausted by the end of the hour."

Additionally, Kuntz says that a unique community has been built as a result of this dance class, "our community is based on the principals of mutual support and that of joy in sharing an hour of movement with those who understand the challenges faced when living with PD or other neurological disorders." This year, that community has

nearly doubled in size thanks in part to an APDA Community Grant.

The goal of the APDA Community Grant program is to help make health and wellness programs more accessible and affordable for people with Parkinson's disease and their care partners by financially supporting these types of beneficial programs. Each grant averages about \$1,000, allowing community partners such as Pam to offer classes at free or reduced cost.

Christine has been participating in the class for six years and loves the opportunity to move—really move. "This class is like a lot of other things in life, you get out of it many things but you don't realize what you are getting until many months have passed and you realize that experience. One of those things is socializing with people from a variety of backgrounds and a variety of skills. That's helped me a lot. This day is my best day."



LIVE WITH OPTIMISM! Support Groups

Attending a Support Group is a great way to connect with others, build community and learn.

Support Groups vary greatly from place to place and from group to group. There can be guest speakers or exercise demonstrations and some cover specific topics or are for a particular group.

On APDANorthwest.org you will find:

Over 200 support groups in our 5 state region (Washington, Oregon, Idaho, Alaska, and Montana). Select your state and you can see if there is a group active in your community!

There are groups designed specifically for:

- Young Onset
- Men's Groups
- Carepartners
- · Atypical Parkinsons
- General PD
- Veterans
- Women's Groups
- And more

Want to start a group in your area?
Call us, we can help!
Know of a group in your area that is not listed?
Let us know!



No access to the web?

Call us and we will help you find a group that is right for you or we can send you a complete list. 206-695-2905

Brand New Program Seeks Participants!

WERE YOU DIAGNOSED WITH PD in the last 5 years? Then the PRESS (Parkinson's Roadmap for Education and Support Services) program is for you!

We are currently seeking 15-20 participants for an exciting new program designed to give you a roadmap on your journey with Parkinson's disease.

This 8 week program conducted in a support group format will help you feel empowered, in control, and optimistic. The program is designed to provide emotional support and a safe place to share coping strategies to live your best life with PD.

Topics covered will be:

- · What's next after diagnosis?
- How to best manage your medications
- · Building your healthcare team

- Dealing with physical symptoms and emotional stress
- The impact of PD on daily coping & relationships
- · Tips for daily living
- · And More!

The first session will be held in King County beginning in February. This is a free APDA program, built specifically to empower those newly coping with PD. It will be evaluated for its effectiveness and benefit to you at the completion of the 8 weeks.

If you are interested in participating or just want to learn more, please call Jen: 206-695-2905 or email: info@apdanorthwest.org.

Be Active. Exercise is now recognized as a vital part of the treatment of PD. There is a growing body of literature describing the hander of for people with DD.

strengthening, balance, and stretching exercises to optimize function and enhance quality of life.

Find an activity you will enjoy in the Health and Wellness section of APDAnorthwest.org. New Opportunities are being added on a regular basis! So check back often.

Here are a few featured new programs!

Rock Steady Boxing

Rock Steady Boxing is now in Southern Oregon! The Rock Steady Boxing Program was designed specifically for people with PD. You will move your body through all planes of motion so you can feel and function better.

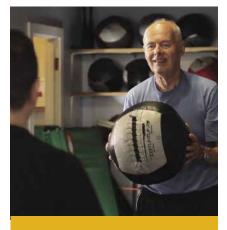
> Classes held at Higs Gym, 2744 Taylor Road, Central Point, OR 97502; Contact: Kim Adams, 541-301-8935



Summers Parkinson's Fight Club

Fight PD with a seasoned champion in your corner. Bret Summers brings over 40 years of boxing experience to your fight against Parkinson's Disease. Classes held weekly.

Contact: summersboxing29@gmail.com or call 425-740-0742



The Parkinson's **Fitness Project**

Offering classes, on-line videos, and PD-specific physical therapy, A.M.P. (Amplitude + Mental Agility + Power) Classes Combining PWR!, BIG, yoga, boxing, cognitive training. The best methods in PD training to give you the best results!

Group classes held Tuesdays and Thursdays at 1:30 and 2:30 pm in Seattle's Leschi neighborhood

Visit: theparkinsonsfitnessproject.com or call 304-506-3876 for more information.

Power Forward Boot Camp for PD

Developed by the Brian Grant Foundation, this high intensity fitness class has an emphasis on total body movements and is designed for those in the early stages of Parkinson's.

Come try it for FREE on January 7th, at the Phinney Neighborhood Association, Seattle

8-class series January 11th-February 4th, 2017; Wednesdays 6-7pm and Saturdays 1-2pm

Visit: www.remixworkouts.com/ parkinsons.html or call France at (206) 367-4896

Stay tuned!

New programs are in the works beginning in 2017!

Check APDAnorthwest.org for the latest updates.

Getting involved in Research:

A look into the WPDR

Jen Pate

Research Coordinator WPDR

OUR TEAM AT THE WASHINGTON Parkinson Disease Registry (WPDR) has been thrilled by the response we have received from the Parkinson disease (PD) community. Over 2,000 PD patients have joined the WPDR and many have later participated in research studies.

Founded in 2007, the WPDR is a nonprofit project that has been supported by Northwest Chapter of the APDA since its inception.

Enrollment in the WPDR starts with a 10 minute phone interview. The information collected allows our

team to determine eligibility for the PD studies that are currently recruiting new participants. Assuming that an individual meets the eligibility criteria for a study, we send them a research flyer by mail. The flyer contains the contact information of the study, allowing potential participants the opportunity to ask questions and enroll.

WPDR serves a dual purpose. It expedites the recruitment process for researchers,

allowing studies to use the time and money that would be spent recruiting to actually make progress with the science. At the same time, the WPDR allows those interested in PD research to stay involved and become aware of the different PD research opportunities



While I can't write a multi-million dollar check to fund research,
I can participate in research studies.

—Suzie Schofield

around them.
Suzie Schofield,
who is an APDA
Board Member and a
participant in multiple
PD research studies

provides her insight

that are taking place

on her experience with the WPDR.

"My husband was diagnosed at age 33 and has been living with

Parkinson's for 20+ years. While I can't write a multi-million dollar check to fund research, I can participate as a "control" in research studies. (That's right - you don't have to have Parkinson's to participate in a Parkinson's research study!) Some important work currently being done looks at whether there are genetic markers tied to Parkinson's. With the WPDR sponsored by APDA, local researchers can easily access individuals and families, who

can provide something as simple as a saliva or blood sample, to help take part in essential research. I hear a lot of people ask: What can I do to make a difference? My answer is: Get involved. Be part of the APDA community. Attend a fund-raiser. Stay informed. And become part of the Washington Parkinson's Disease Registry to take part in local research. It's easy, free, non-invasive and most importantly, it's essential to fuel progress and bring us closer to a cure."

With the help of individuals like Suzie Schofield, Researchers have been able to recruit for their studies which will benefit people with PD all over the world. Neurologist and research staff from around the Puget Sound area have offered their insight about how the WPDR has impacted their research.

"I have utilized the WPDR to reach out to patients who may benefit from our PD trials and to help increase the chances that a trial will be a good fit for a participant. It has been particularly helpful for recruiting for PD trials addressing non-motor PD symptoms such as overactive bladder, sleep disturbances and drooling."

Pinky Agarwal, MD, MDS Evergreen Neuroscience Institute Booth Gardener Parkinson Care Center

"I've used the WPDR for three clinical trials of intranasal glutathione, one on Cannabis and PD tremor, and 'CAM Care in PD, which is looking at diet & lifestyle choices that affect rate of disease progression. The WA State PD Registry recruitment efforts

If you would like to advance PD Research in Washington State please sign up with the Registry.

To learn more visit:
https://depts.washington.edu/wpdr/
or call 888-365-9901





Did you know that APDA contributed \$25,000 to the WPDR and is currently its sole funder?

account for over 30% of all our clinical trial participants. You've accelerated recruitment, saved us money, and given people access to studies they might not have otherwise known about. Thank you for all you do, you are an invaluable resource to the Pacific NW PD community!"

Laurie Mischley, ND, PhD, MPH Bastyr University

The WPDR recruits for a wide variety of studies that range from drug-trials, to exercise and therapy studies, to studies involving new technology aimed to alleviate Parkinson's symptoms. There are even studies that can be done from home on the computer or phone. Regardless of your ability or desired level of involvement, the WPDR will be recruiting for a study fit for you.

With the help of the WPDR, patients and their loved ones can be proactive in working to conquer PD, rather than being left to feel that the disease is conquering them. It has been such a powerful experience to see the WPDR in action and how useful it has been for over 49 research studies in the past 10 years.

YOUR DONATION HELPS ANGELIQUE

HER DOCTOR SAID SHE WAS TOO YOUNG TO HAVE PARKINSON'S, SO SHE WENT UNTREATED FOR YEARS.

Angelique is 52 years young. She estimates she has been living with PD for about 10 years. She was having trouble walking, talking and driving before she received an official diagnosis just last summer. Soon after, she attended the APDA Optimism Retreat where she met a lot of people and tried boxing, dancing and yoga. "I'm doing much better now," says Angelique. "The support helps me stay positive and hopeful."





YOUR GIFT GIVES JOE FREEDOM

PARKINSON'S HAS COMPROMISED HIS MOBILITY, BUT JOE IS STILL MOVING AND SHAKING.

People with Parkinson's say it's the disease that "keeps on taking" the ability to do daily tasks. Joe loves art, but at age 92, he cannot work a camera. So he sketches his subjects in ink on paper. Joe and his wife Estelle no longer drive. They use the APDA Ride Repay program to cover the cost of Uber rides – to get to the doctor, an occasional social outing or an APDA support group. Estelle says they have met several qualified caregivers through the APDA Caregiver's Day Off program.

YOUR SUPPORT IMPACTS SUZANNE

THIS YEAR, SUZANNE'S BIRTHDAY GIFT TO HERSELF WAS ELECTIVE BRAIN SURGERY.

Diagnosed with PD in 2010, Suzanne's symptoms progressed over five years, affecting both sides of her body, including "a really wicked dystonia" in her right foot. When medications failed, she said DBS (deep brain stimulation) surgery was "not a question of if, but when." Suzanne turned 60 in January and had surgery weeks later. At a recent DBS Happy Hour, hosted by APDA, Suzanne and others visited about the importance of staying active, utilizing all of their resources and remaining optimistic.





PLEASE GIVE TO APDA – NORTHWEST

USE THE ENCLOSED ENVELOPE OR DONATE ONLINE AT: APDAnorthwest.org/GIVE

AMERICAN PARKINSON DISEASE ASSOCIATION



Thank you

for your generous donations

Donations from July-November 2016

\$2500 AND GREATER

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Crowley Cares Foundation

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\$500-\$999

Barb Kittell

Chris Morris

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Jason Viydo

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\$250-\$499

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A one day conference of learning, movement, and optimism. Featuring wellness classes and information sessions designed to educate and empower those impacted by Parkinson's disease.

SUNDAY, JANUARY 29th, 2017 10am-3:30pm

STAR Center, 3873 S 66th Street, Tacoma WA 98409

For more information please visit our website at www.APDAnorthwest.org or call us: (206) 695-2905 ext. 1

Event Schedule 12:30 Lunch 9:30am **Registration Open** Where are the PD Success Stories? 10:00 Welcome Remarks and Talk Dr. Laurie Mischley presents her study Nan Little, author of: "If I can Climb Mt. into what choices are being made by Kilamanjaro, why can't I brush my Teeth." those with the most benign disease. 10:15 **General Session** 1:55 **General Session** Movement IS Medicine, Nate Coomer, A Multidisciplinary Approach to PD Physical Therapist Treatment Dr. Katelan Longfellow, 10:50 **Breakout Session 1** Movement Disorder Neurologist We will be offering a variety of Wellness 2:40 General Session: Your Brain on PD activities for you to choose. Dr. Jeff Shaw, Neuropsychologist 11:35 **Breakout Session 2** 3:15 Q & A Panel We will be offering a variety of Wellness activities for you to choose.

To register, please fill out and return the form below, or register online at www.APDAnorthwest.org

Attendee 1:		Attendee 2:
State:	Zip:	State: Zip:
Dietary Restrictions?		Dietary Restrictions?
onference fee 525 per person. LY BIRD SPECIAL! 0—if you register efore Jan 5, 2017 Scholarships are	Relationship to PD:	Relationship to PD:
	\square I am a person with Parkinson's	☐ I am a person with Parkinson's
	\square I am a caregiver to someone with PD	$\ \square$ I am a caregiver to someone with PD
	☐ Other	☐ Other

To pay by check, mail this registration form with a check made payable to: APDA Northwest, 150 Nickerson Street, Suite 100, Seattle, WA 98109

MARK your CALENDARS!

Good Start Program

Have you been diagnosed with Parkinson's in the last three years? Join us for an education program designed specifically for you.

Tuesday, January 10th, 6–8pm Bellevue Regional Library

**Next Good Start will be Thursday, March 16th in Lynnwood

DBS Meetup & Happy Hour

Do you have DBS and want to meet others who have undergone the procedure?

Are you curious about DBS and want to meet DBS graduates?

Please join us for our second meet up!

Wednesday, Jan 18th, 2017, 4–6pm

Bonefish Grill 22616 Bothell Everett Highway Bothell, WA

Take Control Program

An educational program designed specifically for people in the later stages of Parkinson's and their caregivers.

Wednesday February 15th, 2017 Seattle location to be announced soon

**Next Take Control is May 18th in South Seattle

Go to APDAnorthwest.org to register for one of these free programs or call 206-695-2905

the Dates

APDA Magic of Hope Gala

April 29, 2017 at Seattle Design Center

Sign up TODAY as last year was a sell out! Visit www.APDAnorthwest.org/magicofhope to take advantage of the early bird ticket and table pricing, become a sponsor, join our committee or make a donation!



Upcoming Fundraising Events



Join APDA Northwest and Walk Chair Matt Wood for the

4th Annual APDA Optimism Walk

scheduled for June 2017.

Last year more than 300 people attended the walk, raised funds and had a ball getting to know each other!

To make sure to get on the list or to help on the planning committee contact Jean Allenbach at 206-695-2905 or jallenbach@apdaparkinson.org



APDA Northwest 150 Nickerson St, Suite 100 Seattle, WA 98109

SUBSCRIBE TO OUR NEWSLETTER!

Sign up for our newsletter by visiting our website www.APDAnorthwest.org or emailing info@APDAnorthwest.org

Get Involved with APDA!









Volunteer your TIME AND TALENT

Help out in the office

Attend an event

Host a donor dinner & ask guests to donate to APDA

Join the Board or committee

Share your skills as a grant writer, editor, fundraiser, IT professional, graphic designer and more!

Give

FINANCIALLY

Write a check

Donate on-line

Set up a monthly recurring gift

Ask for donations to APDA in lieu of gifts

Donate stock

Include APDA Northwest

in your will

Sponsor an event

Make your

VOICE HEARD



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