

New Funding inPD Research

How to Choose a Home Care Agency

# PARKINSON Pathfinder

# **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.

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#### COVER

It's almost time for winter activities! Joann. Cal and Linda snowshoeing last winter in the mountains near Seattle.

Photo by Ken Kisch



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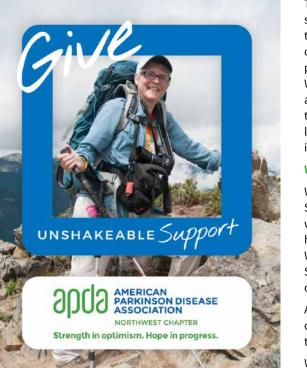
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We're moving!

Our new address: 180 Nickerson, Ste 108 Seattle, WA 98109





APDA Northwest is the sole funder of the Washington State Parkinson's Disease Registry, which connects researchers to people with Parkinson's so that research can happen faster. Nationally, APDA awarded \$1.5 million in research grants, each one holding the promise of improved quality of life for people with Parkinson's.

Delivering all these programs and services, while making an investment in research, costs money. Please consider making a contribution which will help us maintain critical programs and expand new ones to meet the needs of our growing Parkinson community. It will enable us to support the research being conducted into finding the causes and ultimately a cure for Parkinson disease.

As you read through this issue, keep in mind the three words from above. **Optimistic. Caring.** Tireless. We hope that you can join APDA in our mission to help everyone impacted by Parkinson's live life to the fullest by making a donation to APDA.

lear Allebach Jean Allenbach

Executive Director

Three words that can stand alone, but together offer a powerful statement of how we see ourselves at APDA Northwest. Employing those three qualities, the three of us-along with an army of outstanding volunteers - have accomplished more than we dreamed possible. And the reward for all this hard work? Hearing from you. We are fueled by the stories of how attending an education program, a support group, or an exercise class, were "life changing." Or how the answer to a question on our resource line made your day just a little bit easier. And so we keep going, because our mission is too important to slow down.

#### What did APDA Northwest accomplish in 2017?

We added **new education programs**, such as Live Well South Sound in Tacoma, and Live Well Tri-Cities. These symposiums were developed to provide timely and valuable information about health, wellness and research to these underserved communities. We piloted an 8 session Parkinson's Roadmap for Support Services (PRESS) group for people newly diagnosed, which was overwhelmingly successful.

APDA helped launch 12 new exercise programs, and consulted on countless others. An estimated 3,000 people benefit every week from the exercise programs listed on our website.

We have increased direct services, growing our APDA Ride Repay by 11% and Caregiver's Day Off by 19%. We held a support group training for our volunteer leaders across the region, so that they can be armed with the tools and resources to benefit their members in the best way possible.

Jennifer E. Gillick

Jen Gillick Program Director

K-Richards

**Kirsten Richards** Finance & Development Director

# **SELF-ASSESSMENT**\* Track your Function and Gain Control

As a Physical Therapist, countless Parkinson's patients have told me how unnerving and frustrating it is to feel like you are no longer in control of your body. One of my goals is to teach people how to take some control back from their disease. We know that exercise is one way that people can help slow the progression of Parkinson's disease and fight against the symptoms, but how can you tell if you're operating at your best?

Tracking yourself over time is a terrific way to know whether the steps you are taking to manage your disease are helping. Your neurologist tests you every few months, but having some way to measure your function easily and frequently while at home can be a valuable way to evaluate your function and give you a little more information and control. It's also a great way to compare your symptoms before and after you have started a new medication, changed your diet,

adjusted your sleeping habits or jumped into a new exercise program. Seeing positive results can be empowering and motivating, making it likely that you will continue to do those beneficial things in your daily routine.

With new technology, there are many ways that people can assess their function throughout the day. Mainstream devices such as Fitbits and other pedometer apps now track steps per day, distance walked, and other valuable data. Apple's Health app is available on iPhones and also tracks steps per day, minutes spent on exercise, and sleep patterns. These are all focused on the general population but could be easily applied to give you data on how much you're moving each day. I tell my clients to log their step count every day for a week in order to calculate the daily average and then to repeat this process again at least every 3 months. This easy task alone gives you something to compare to over time to ensure you are keeping up with the same amount of activity day in and day out.



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The Daily Dose App

60 0 For an option specific to Parkinson's disease, the Parkinson's Fitness Project has developed the Daily Dose App to track steps and many other PD symptoms. This app couples weekly PD- specific exercise videos with simple tests to track neurologic status, cognitive function, vocal volume, steps/day and emotional state. These results are graphed over time so that you can see how you're doing.

At APDAparkinson.org you can also find a new tool to help track your symptoms. The APDA Healthcare Communication Graph allows you to rate how you feel in several specific areas. Your results are then generated and graphed on a report which can be printed and shared with your healthcare team. Done weekly, it can be used as a valuable tool to track how you are feeling and recognize any patterns.

There are also new tools in development. Investigations into the use of accelerometers on Smartwatches and smartphones are now being used in research to gather data

and analyze movement throughout the day in people with Parkinson's disease. Accelerometers are analyzing functions such as walking mechanics and arm movement when trialing different medications and procedures to see if there is improvement in function. Though much of this technology is still in the research phase, investment in this area by companies such as Intel and Apple signal there may be more to come.

Whether you are a techie or are computer illiterate, tracking your symptoms has become not only possible, but easy and accessible, and can be extremely valuable in gaining some control over your disease. Find a method that works for you to monitor your function over time. It will give you motivation, keep you on the right track with your home program, and help you take back ownership over your Parkinson's disease. Start tracking yourself today!

## **Simple and** safe home tests to help monitor physical function





I try to give everyone who works with me some simple ways to monitor their function through tests called "outcome measures". These tests have all been proven to monitor physical function in different ways and can be conducted within most home environments to give individuals an awareness of how they are moving over time.

Use these tests at any time but I always encourage clients to test themselves at least every few months and keep a log. It can be useful to share the data with your health care providers in order to keep them informed.

Follow the instructions below for each test. As you follow the instructions for each test it is helpful to have someone else time you. The numbers in bold lettering will help you compare and see when you have made significant improvements and whether you are at risk for falls.

#### **1. TIMED UP AND GO**

Assesses your mobility, balance, walking ability and fall risk

#### INSTRUCTIONS:

- safely as possible
- the chair.

Risk for Falls increases: >11.5 sec Signifiant Change: 4.85 sec

2.5X SIT TO STAND Assesses your leg strength and speed of

INSTRUCTIONS:

transfers

- 5th repetition.

Risk for Falls (age dependent) 60-69 y/o **> 11.4 sec** 70-79 y/o > **12.6 sec** 80-89 y/o **> 14.8 sec** 

Significant Change: 2.3 seconds or greater

Dr. Nate Coomer is the owner of The Parkinson's Fitness Project in Seattle, which offers Physical Therapy, Personal Training, Group Classes and Online Exercise Training. Nate is a Doctor of Physical Therapy who has been working with neurologic diagnoses as a physical therapist for over ten years. He received his certification as a Neurologic Specialist in 2010 by the American Board of Physical Therapy Specialties and has centered his career to treating Parkinson's. He has certifications in LSVT BIG, Parkinson Wellness Recovery (PWR!), and as a Brian Grant Foundation Bootcamp Instructor. He serves on the APDA Program Committee, and regularly participates in community events and educational opportunities for the PD community.

• Begin in sitting position on a kitchen chair. Stand, walk 10 feet, turn around, walk back and sit down as quickly and

· Timing begins when you start to stand and ends when you sit completely into

· Sit with arms folded across chest and with back against a kitchen chair. Stand and sit 5 times as quickly as you can.

• Timing begins at "Go" and ends when the buttocks touches the chair after the

#### **3.10 METER WALKING** SPEED

Assesses your normal walking speed

#### INSTRUCTIONS:

- Walk without assistance 10 meters (32.8 feet) at a comfortable speed. The time is measured for the intermediate 6 meters (19.7 feet) to allow for acceleration and deceleration
- Start timing when the toes of the leading foot crosses the 2-meter mark.
- · Stop timing when the toes of the leading foot crosses the 8-meter mark.
- Assistive devices can be used but should be kept consistent and documented from test to test
- Calculate your speed in total meters (6m) divided by time in seconds (m/s)

Significant Change: 0.18 m/s (0.6 ft/sec)

#### **4. SINGLE LEG STANCE TIME**

Assesses your overall standing balance

**INSTRUCTIONS:** 

• Stand on one leg with a timer starting when the opposite foot leaves the ground and ending when that foot returns to the ground.

Risk For Falls: **<10 sec** 

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# LIVE WITH Support OPTIMISM! Groups



Support groups are 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 apdaparkinson.org/Northwest 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!

<ul> <li>Young Onset</li> </ul>	• Men's Groups
Carepartners	<ul> <li>Atypical Parkinsons</li> </ul>
• 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

# **MOVE WITH OPTIMISM!**



Exercise is now recognized as a vital part of the treatment of PD, and there is a growing body of literature describing the benefits of exercise for people with PD. The research reveals the importance of endurance, strengthening, balance, and stretching exercises to optimize function and enhance quality of life.

Find an activity you will enjoy in the Local Resources and Support section of apdaparkinson.org/Northwest.

Check back often as new opportunities are being added on a regular basis!





#### **New Support Groups** in Lynnwood, WA

Held the 1st Monday of the month Verdant Community Health

#### Working and Living with PD:

A unique support group designed for those who live with PD and are employed 6:30pm – 8pm

**General PD Support Group** Come get to know others impacted by PD. 10:30am - 12:00pm





#### **APDA Launches Online Support Site**

In collaboration with Smart Patients, APDA has launched an online support forum, through which people with Parkinson's, their care partners and families can interact and learn from each other in a safe, supportive environment.

smartpatients.com/partners/apda

#### GIG HARBOR, WA **Rock Steady Boxing**

#### Tue, Thurs, Sat, 3:30-4:30pm **Gig Harbor YMCA**

Contact: J.J. Hudson, Head Coach (253) 678-0927 jj@global.t-bird.edu

Want to strap on some gloves? You can find classes in Arlington, Covington, Ferndale, Kirkland, Kirkland, Seattle, & Wenatchee.

#### **ANYWHERE! Neurofitness Training from your** own home!

Online Training Videos created by experts in Parkinsons Disease. New videos added weekly.

Find out more: www.theparkinsonfitnessproject.com

#### BAINBRIDGE ISLAND, WA **Boxing for Life**

Bainbridge Island Athletic Club Weds & Fri

Contact: Shayne Turgeon 206-842-5661 Shayne@bainbridgeac.com

#### SAMMAMISH. WA

#### **Pedaling for Parkinson's**

Sammamish Community YMCA Tues & Thurs

**Begins January 2018** 

Contact: Katie Fraser 425-395-7626 kfraser@seattleymca.org

#### SPOKANE, WA

**Boxing for Parkinson's** 

The Legacy Boxing Club Mon & Thursdays @2:30

Contact: Shad at 509-270-8731 thelegacyboxingclub@gmail.com

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# Washington State Researcher is awarded Competitive APDA Research Grant

ope in progress isn't just a tagline in our mission, but a commitment to invest in the most promising clinicians and scientific projects that will eventually lead to a cure for Parkinson's disease.

One of those promising scientists is Ignacio F. Mata, PhD, Assistant Professor, University of Washington, Department of Neurology and Researcher at the VA Puget Sound Health Care System in Seattle. In March, he was awarded a \$50,000 APDA research grant for his work on genetics in the area of Parkinson's disease (PD) in Latinos. This funding will have great impact on understanding genetic variants that most commonly cause PD in the Latino population. I recently spent the day with Dr. Mata, to learn more about his research.

To date, variants in almost a dozen genes have been clearly shown to cause PD, with most studies including only individuals of European origin. Latinos have largely been excluded from genetic research in general, including Parkinson's research. Interestingly, Dr. Mata has found that many of these variants common in European derived populations appear to be rare in Latino populations who have low European ancestry. This Euro-Centric research has widened the disparities in research and health for this group which will comprise 22% of the US population before 2050. Dr. Mata aims to change this research disparity.

#### LARGE - PD

To solve this problem and shed some light about the genetics of PD in Latinos, Dr. Mata has been building a consortium of clinicians and researchers in Latin America to recruit and study PD patients. Over the past 10 years, he has been building the Latin American Research Consortium on the Genetics of Parkinson's Disease (LARGE-PD), which is comprised of 9 institutions in 7 different countries, and has recruited over 4,000 individuals, including healthy controls.

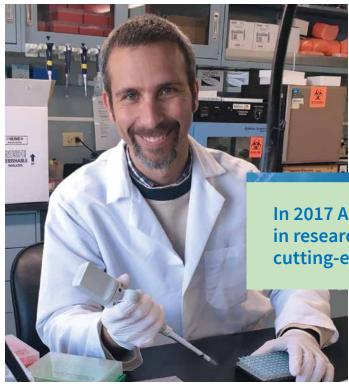
Dr. Mata is a man on a mission. He often travels to Latin America to speak about his work, train scientists, find personnel for research sites and identify local neurological resources for genetic collection protocols.

The APDA research grant will allow Dr. Mata to select 350 subjects from LARGE-PD who have reported a family history of PD. He will use a recently designed neurodegeneration sequencing panel to sequence all known PD genes in these individuals to identify those variants likely to be pathogenic. The results of this study will help evaluate the frequency

#### \* LARGE - PD

stands for the Latin American Research Consortium on the Genetics of Parkinson's Disease; its mission is to investigate the genetics of PD in Latinos.

photo: Jen Gillick; Author photo: Randy DeMoss/DeMoss Photog



of known variants in Latinos, as well as help identify novel variants that may be specific to these populations.

The LARGE-PD team wants to give people in the Latino community, both globally and in the US, the possibility of benefitting from emerging knowledge and therapies that could improve their lives.

The morning I met Dr. Mata (or Nacho, as prefers), he had just returned from a nine day visit to three countries in South America where he was continuing work on the LARGE-PD project. I accompanied him to a Parkinson's support group meeting where he spoke about long-term goals and the hope that through his work Latinos will be included when developing and trying new therapies for the disease. Especially any therapies based on genetic profiles.

As we drove back from the Parkinson's meeting we had a lively question and answer session, and then he talked about how essential early detection was in PD. He spoke of the promise of neuroprotective drugs, biomarkers, and his early research days at Mayo Clinic in Jacksonville, Florida. He talked about his wife and two sons, and the importance of securing funding for the important work he was doing. Meandering his way through 5 o'clock traffic he said in passing what might best sum up this brilliant young man.

In 2017 APDA awarded \$1.5 million in research grant funding to support cutting-edge PD research

> "One of my life skills is how to connect people with one another and with resources. I really like helping people."

He does that. He's a man with a mission.

Since 1961, APDA has invested more than \$46 million in research and have been a funding partner in most major Parkinson's disease (PD) scientific breakthroughs. Dr. Ignacio Mata is just one of sixteen promising scientists to receive funding from APDA in 2017.

There is still much to learn about Parkinson's disease. Continued research is essential to a better understanding of the disease progression, continued therapies, and ultimately a cure. APDA has been committed to this since 1961 and will continue to invest in promising clinicians and projects like that of Dr. Ignacio Mata. There is *Hope in progress*.



Ronda Clark is a writer, software business entrepreneur and successful avionics software recruiter. Today she is a PD care giver. EXPERT ADVICE

# HOW TO CHOOSE A **Home Care Agency**

Home care typically refers to nonmedical services that help an adult live and thrive at home. In its simplest terms, home care means assistance with activities of daily living and household tasks. Ideally, home care also provides meaningful companionship for older adults and peace of mind for their families.

There are currently over 70 million family caregivers who provide in home care, but there are times and circumstances where hiring a professional caregiver to provide some of this care is a good choice. Setting up a relationship with a home care agency, before a high-pressure or emergent situation arises, can be a wise decision. Most home care agencies work hard to ensure their clients live as independently as possible while receiving the care they need to maintain a high quality of life.

#### **Paying for Home care**

Home care is not a service covered by Medicare but it is sometimes covered by Medicaid and Veterans benefits. Long Term Care insurance covers home care services, typically once you need assistance with at least 3 ADLs (activities of daily living). There are a few public benefit programs, including APDA's Caregivers Day off program that cover respite care services but otherwise, home care is a self-pay service.

The cost varies, depending on the degree of care you need and where you live. You can expect hourly rates to range from \$25-\$35/hour. "Live-in care" is another option where one caregiver stays with you in the home for 24 hours at a time; each state has different regulations for this type of service.

**Nicey Hilton** is a Seattle Home Care Liaison for Home Care Assistance, which employs more than 6,000 team members across 160 markets and has been recognized in the New York Times and on CNBC for their innovations in home care.

Visit home careassistance.com/seattle and hospitaltohome care.com for informative, educational resources.

### Tools for choosing the right agency

#### 1. Determine your needs

Doing a self-assessment of care needs is a valuable way to start in order to communicate to an agency what type of home care services are needed. Activities for Daily Living (ADL's) are the basic tasks involved in personal care and household work.

Care Needs	Independent	Stand-By Assistance	Physical Assistance	Totally Dependent
Eating				
Bathing				
Dressing				
Toileting				
Transferring				
Continence				
Ambulating				
Medication Reminders				
Meal Preparation				
Light Housekeeping				
Transporation				

#### 2. Evaluate the agencies

Once you have determined the services needed, you are ready to compare the quality and costs. Feel free to voice any concerns and ask any questions you may have—a top agency should be accustomed to answering these questions and be committed to ensuring that you are comfortable.

Is the agency licensed by the sta What are their Yelp and Google Has the company been respons How does the agency choose ca insured and background checke Does the company employ its ca ing and workers' compensation? Does the company conduct careg procedure for newly hired caregiv How do they match caregivers t What happens if a client wants a the same caregiver each time or Does the company offer back-up Is the Care Manager available on What kind of service agreement to charge? Does the company perform regu tion reviews and caregiver evalu Does the company require a sati contract or deposits?

#### 3. Connect with the right caregiver

Once you find an agency that best suits your needs, the next task will be ensuring that the caregiver is a good match. The agency's Care Manager will assess your needs, especially focusing on your unique interests and personality, to match you with the best person. If for any reason you feel the caregiver is not a good fit for you, they can have some-

one else work with you. The following are questions you can ask the Care Manager regarding your caregiver:

share with me? • What's their personality style? or prefer quiet time?

What is their pressure of the second s

history?

1	2	3

evious	emp	lovme	nt
	••••P		

- Do they have any credentials, training, education history, awards you can
- Do they like to engage in conversation
- Welcoming someone new into your home is a change. On the first day, asking your caregiver a few questions can be a great way to understand them and build commonality:
- · What is the most rewarding aspect of your job?
- What is the most frustrating aspect of your job?
- What special skills do you have that you think will be useful in working with me? • How do you respond to stressful
- situations?
- Do you have any hobbies or interests?
- I enjoy [activity, food, hobby]. Is this something you could help me to continue?



Donations from July 11th–October 23rd

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# **ADVENTURE RACE** for **PARKINSONS 2017**



Over 220 racers braved the sun, wind and rain to participate in the Adventure Race for Parkinson's on Sept. 30 raising \$75,000 for Parkinson's research! The outpouring of support makes an enormous impact and it's incredible to see what can be achieved when the community rallies together.

Racers and donors alike may wonder where their donations go after the big day. Here's what we were able to do with your generous contributions:

• Fully fund the Washington State Parkinson's Disease Registry, which gives researchers access to pre-screened study participants.

- Provide a national APDA research grant to local PD researcher Ignacio Mata, PhD for his groundbreaking research on next generation sequencing of Parkinson's genes.
- Help fund the \$1.5 Million in research grants approved last month.

Our

BEST

year

vet!!

This event raises valuable funds but also brings together a motivated, inspiring group of people together. Teams had fun, laughed a lot and maybe shed a few tears – especially when they couldn't get those stretchy nylons to cooperate!

Many thanks to top sponsors, Niagara Bottling, Carter Subaru, Lundbeck, Trident, Home Care Assistance, Medtronic, Cameron Catering, Elliott Bay Marina and UW Medicine as well as all participants, donors, sponsors and volunteers - we wouldn't be here without you!

#### **DIY FUNDRAISING**

Want to make an impact on people living with Parkinson's disease in the northwest? Organize a fundraiser at your home, work or in the community and donate the funds to APDA. From Chili Cook-Off's to Dinner Parties, Garage Sales to Jean's Days at the office, there are lots of easy and fun ways to make a difference. Contact APDA or go to apdaparkinson.org/Northwest, click on get involved, then organize an event for our online DIY tools set up an easy and meaningful fundraising campaign. Here is a highlight of a few recent ones...



#### **Fit for the Fourth OrangeTheory Fitness, Ballard** \$2,025 Raised for APDA

In June, OrangeTheory Fitness, Ballard, ran an event called Fit for the Fourth. Teams competed for points, prizes and glory by completing various challenges, from positive self-talk videos, dancing, meeting new people in class, and other healthy habits. Their goal was to help raise awareness about Parkinson's disease, while also raising money for APDA. We are so thankful to OrangeTheory and their members who participated!



#### **Pass to Pass Hike** \$1,876 Raised for APDA

There are several common threads among the hikers on the Pass to Pass hikes over the past two years; Parkinson's disease, love for the outdoors, willingness to improve one's symptoms and accepting challenges. Seven people with Parkinson's, support hikers and pack animals travel 60 miles in 9 days on the Pacific Crest Trail with the mission to increase awareness and demonstrate that activity can relieve symptoms all while fundraising for Parkinson's research. For information or to participate in 2018 visit passtopass.org.



#### **STP Bike Ride** \$5.700 Raised for APDA

Chris Jewell has been living with Parkinson's disease for 19 years. He made a decision to challenge himself 15 years ago, and with a love of cycling he rode his first Seattle to Portland Bike Ride. 15 years later, he is still peddling the 202 miles now with friends and family by his side. Chris wants to give hope to others struggling with Parkinson's disease by raising funds for APDA research, so they too can find strength in optimism too.











**APDA** Take Control



**Parkinson's Education** Program





APDA Live Well South Sound



JUNE





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

Phone: (206) 695-2905 Email: apdanw@apdaparkinson.org Website: apdaparkinson.org/Northwest

An educational program designed for individuals in the mid to later stages of Parkinson's and their carepartners.

December 7th, 2017, 1:30 – 3:30pm

Aegis Living on Madison

2200 E Madison Street, Seattle, WA 98112

#### **PD Educational Program** Port Angeles

Featuring: Dr. Pinky Agarwal, Movement Disorders Neurologist and Dr. Nate Coomer, Physical Therapist Registration opens mid-December.

Please join us for a day of moving, learning, and optimism. Featuring wellness classes and information sessions designed to educate and empower.

Sunday, February 25, 2018, 10:30 – 3:30 pm Star Center, Tacoma, WA

#### The Magic of Hope at the Seattle Design Center

A magical night of cocktails, dinner, merriment and more at our largest fundraiser of the year. the APDA Magic of Hope Gala & Auction. Join us for a spirited gathering of guests who are all passionate about APDA's mission to help everyone impacted by Parkinson's disease live life to the fullest!

Please join us for a fun-filled fundraising walk for all ages and abilities! Mobilize your friends, family and co-workers and help us in putting an end to Parkinson's disease.

Seattle, WA



Strength in optimism. Hope in progress.

180 Nickerson, Ste 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

# Start small and give monthly.



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



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



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

# 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.