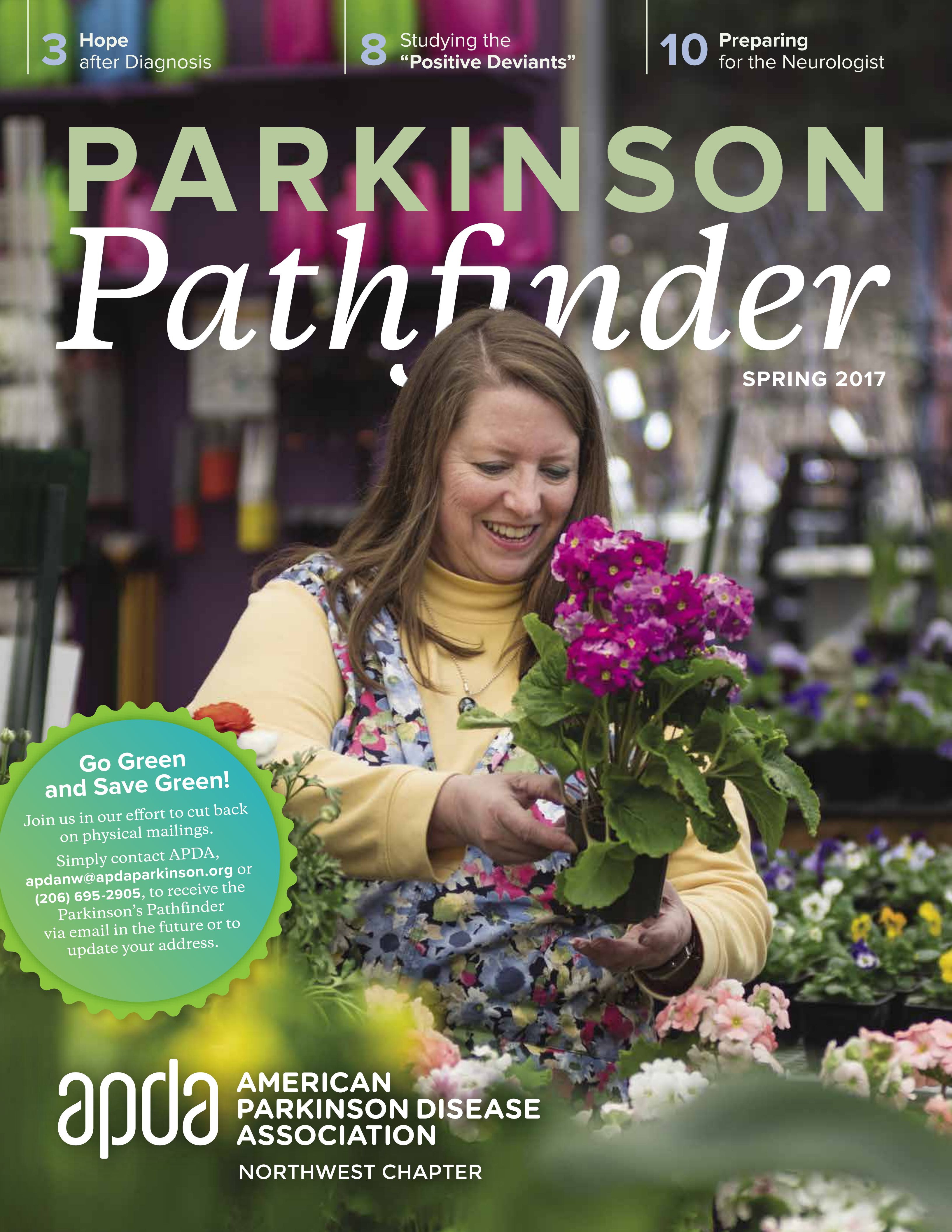
PARKINSON *Pathfinder*

SPRING 2017



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.

apda
AMERICAN
PARKINSON DISEASE
ASSOCIATION
NORTHWEST CHAPTER

SPRING 2017

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COVER
Alice Cleeton kicks off her spring gardening by shopping for some color for her home.
Photo by Ken Kisch

AMERICAN PARKINSON DISEASE ASSOCIATION
NORTHWEST CHAPTER

APDA Northwest
150 Nickerson St, Suite 100
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Phone: 206.695.2905
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Hours: Monday–Friday 8:00AM–4:00PM

apdanw@apdaparkinson.org
apdaparkinson.org/northwest

We are so excited to share with you— **the new brand identity and strategic direction for the American Parkinson Disease Association!**

A new logo brings the APDA brand into more modern times with a clean, contemporary look that is much easier to read, and a tagline that celebrates hope and optimism. The new marketing materials are fresh, friendly and truly focused on our mission.

APDA has a rich history helping thousands of people living with Parkinson's disease, and their care partners. For more than 55 years, the organization has grown and contributed millions to important education information, fitness and wellness programs, and essential research in the fight for the cure.

The new materials better reflect who we are, what we do, and our optimistic outlook for the future.

Unlike other organizations that may do one or the other—APDA's purpose is two-fold: to provide programs to improve quality of life for those facing PD; and to unravel the scientific mysteries of this disease through outstanding science. We are also unique in that we are the largest grass-roots network with APDA Chapters and Information & Referral (I&R) Centers across the country.

Every day, we provide the support, education, and research that will help everyone impacted by Parkinson's disease live life to the fullest.

Research is part of our DNA. While many know us for our programs and services in the community, APDA Northwest is also the sole funder of the WA State Parkinson's Disease Registry; and we support a host of national research efforts. In fact, APDA has been a funding partner in most of the major Parkinson's scientific breakthroughs over the past 50 years.

To see more of the new APDA brand, visit **APDAparkinson.org** or our Chapter website at: **APDAparkinson.org/northwest**. A full transition to the new brand, across our nationwide network, is expected to be complete by December 2017.

apda AMERICAN PARKINSON DISEASE ASSOCIATION
Strength in optimism. Hope in progress.

Our new logo (above) and website (left) are emblematic of our optimistic outlook for the future

April is Parkinson's Awareness Month!

We invite you to join APDA Northwest this April in raising awareness about Parkinson's Disease.

Make your VOICE heard: Help the public and those in your life better understand the disease

- Tell others your personal story
- Follow us on Twitter @APDA_NW
- Like us on Facebook @APDAwashington
- Visit us on Instagram @APDA_NW
- Retweet & share posts
- Call the APDA office and ask how you can help

Help advance PD Research. Whether you have PD or not, your participation in research is critical!

- Join the Washington State Parkinson's Disease Registry www.registerparkinsons.org
- Find a clinical trial near you https://clinicaltrials.gov

Get involved with APDA and the greater PD community:

- Put together an Optimism Walk Team (June 4th)
- Attend the Magic of Hope Gala (April 29th)
- Attend an APDA Educational Program
- Share your time and talent by volunteering at the APDA office or at an event
- Participate in a community support group or wellness program
- Donate to APDA financially

glassybaby

Share our message of Strength in Optimism!

During the month of April, 10% of the sale of each STRENGTH glassybaby will be donated to APDA Northwest. Additionally, enter the giving code "apda" at checkout April 1-30, and 10% of your entire purchase will be donated to APDA.

STRENGTH—every human bears a burden, to test the muscles in your soul.
In love and kindness we find our STRENGTH to overcome life's heaviest times.

www.glassybaby.com

LIVING WITH PD:
hope after diagnosis

MY LATE HUSBAND HAL WAS diagnosed with Parkinson's in 1994 at the age of 65. At the time, we didn't even know what Parkinson's was! With no encouragement from the diagnosing doctor, we were told only that it was a progressive and degenerative disease with no cure. That news came as quite a shock so we set out to learn everything we could about this disease.

Hal had been an upbeat, optimistic and active person all his life. After the Parkinson's diagnosis, he told me how he wanted our partnership to work, and I think we became a real team.

He suggested some partnership rules for us:

1) He would continue managing his life as before, and I was not to help unless he asked me
2) He would deal with his medications himself without reminders from me
3) He would be honest with me about how he was feeling, if I asked
4) I could coach and make suggestions, but he reserved the right to say he'd had enough
5) He would speak for himself and I would not be a spouse who did all the speaking for him.

He wrote a letter to our children, explaining what we knew about the disease and encouraged them to talk about it with him whenever they wanted. He kept the communication open with other family and friends as well.

We joined a Support Group early on, where we always came home with a new idea or some new information about medications. We went to conferences and heard great speakers. We met with excellent doctors —and these Movement Disorder Specialists became friends as well as experts in his care.

I did my part by joining the APDA board and serving as their secretary for 12 years. During that time, the organization became much more visible and active. We hired an Executive Director, started the Magic of Hope Gala, created new programs and support groups, garnered much more publicity, and raised more money for research.

Peggy Newsom at the 2016 Magic of Hope Gala

Hal, always a writer, wrote a book he named HOPE, written especially for those newly diagnosed. At least 15,000 books are in circulation. We were often asked to speak to other groups or to talk to someone who had been newly diagnosed with Parkinson's.

When Hal found he could no longer ski, he wrote an article entitled "It's Not Giving Up, It's Replacing", to emphasize that finding a new activity could still be enjoyable when the previously loved activity was no longer an option. His daily mantra was "Get Up, Get Dressed, Get Going" and he did it to the last.

A few years before Hal passed he told me that having Parkinson's was important in his development of compassion. He could always find something positive in his attitude, and it showed in the way he interacted with others.

I have seen many positive changes over the last 20 years. There is much more awareness of and publicity about the disease. There are many excellent Movement Disorder Specialists in the Pacific Northwest, unheard of 25 years ago. There are treatments for formerly unknown manifestations of the disease. There are new and effective medications available, to help a variety of symptoms. There is advancement in therapies to treat patients. There is growth in support groups, dance and exercise classes. There is strength in optimism, there is hope in progress.

Preparing for the Future

Outlining your care and housing options

WHILE PARKINSON'S DISEASE IS NOT life threatening, it is life altering. It can be unpredictable and the rate of progression varies from person to person. For this reason, people with Parkinson's are often advised to "plan for the worst and hope for the best". This philosophy helps us to be prepared for difficulties before they happen, if they happen.

There are many elements in planning ahead for your future with PD. Knowing what housing and care option is right for you is just one. This article describes and outlines the varied options available so that you can begin to evaluate what might be the right option for you.

This article was submitted by MARLA BECK, founder and president of Andelcare Inc., which provides in-home elder, Parkinson's disease and Alzheimer's care. www.andelcare.com; 425-283-0408.

At Andelcare we spend a lot of time counseling individuals with Parkinson's Disease (PD) about their care options. I like to gather the whole family around so they can all hear the same information and everyone can feel comfortable asking questions.

Author, Marla Beck with her mom.

Although I don't have a crystal ball, after 15 years leading an award-winning, in-home care agency I am familiar with the basic care options and their costs.

Just let me say that which option is most appropriate depends on an individual's health, mobility, mental acuity, financial resources and wishes. The most important issue for the family is safety and security. Keeping these goals in mind, let's look at options and prices (Seattle Metro area).

Aging in place allows one to remain in a familiar community. As an individual's Parkinson's disease progresses one may need what we call custodial care or assistance with activities of daily living (ADLs) such as eating, showering and toileting. These are often provided by a family member but can also be fulfilled by home-care agencies. Additionally, many of today's home modifications and technological advances like life alert buttons and medication reminder systems have helped individuals to remain at home longer.

Adult day programs offer structured social activities at community centers or area churches that provides a safe and enriching environment for an individual while also offering respite opportunities for family caregivers.

Some offer basic medical and therapy services. Participants usually need their own transportation to and from or can get help from Access or Senior Services. Rates run about $15 per hour and hours vary as to availability.

A home-care agency can provide customized, in-home elder care, companionship, homemaking, personal care and nursing services. In consultation with his or her family, the PD person chooses the services. Services can include bathing, dressing, meals and other daily-living activities, including transportation. Services can range from one hour a day to 24/7 live-in care. Home care provides the opportunity for an individual to remain in their home and is a good solution to give respite to the main family caregiver. Costs can be covered by long-term care insurance, but not Medicare. Services of a Certified Nursing Assistant (CNA) from a good agency cost about $27-35 per hour.

People with Parkinson's are often advised to "plan for the worst and hope for the best". This philosophy helps us to be prepared for difficulties before they happen, if they happen.

Independent-living facilities are either rented apartments or purchased condos that often offer limited recreational and social activities, meals, housekeeping and some transportation. No special health-care services or assistance is offered. A one bedroom apartment can be anywhere from $2000-4000 per month.

Assisted-living facilities vary in what care they offer. Some offer care a la carte where you pay for what help you need and some are all inclusive. Some offer care similar to nursing home level and some are minimal assistance like once a week shower help and medication management. Costs can run from $3,000 to $7,000 a month. If you need heavy-duty memory care the base cost can double to $6,000 to $14,000 per month.

A continuing-care retirement community (CCRC) charges residents a lump-sum entrance fee, as well as monthly rent. Care ranges from independent-living apartments to assisted-living apartments and nursing home rooms all on one central campus. As your level of care needs change, you may change residences within that campus, moving from an independent apartment to an assisted living apartment. Depending on contract terms, buy-ins vary greatly as you are buying pre-paid services and they can range from $100,000 to $1 million. In addition, monthly fees range from $2,500 to $4,000. A portion of the buy-in fee is refunded to your estate.

Adult family homes (AFH) provide an array of services that range from offering assistance with ADLs to specialized capabilities in dealing with acute medical concerns. They generally offer the same level of care as a nursing home, but in a smaller setting. AFH can accommodate two to six residents. Rooms are either private or shared, depending on the home. Social activities vary. These homes are licensed by the state, and some homes have their own area of specialization such as Parkinson's or Alzheimer's. AFH range in cost from $5,000 to $10,000 or more per month.

No matter which housing option you choose, the key to receiving the best care is to have friends and family visit often. These visits provide an incentive to staff to treat you or your loved one with the utmost care because they know they are being observed. With that in mind, it is important to choose a location that friends and family can easily visit. And most importantly, you should always feel safe and respected in any level of care you choose.

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, from group to group, and even from month to month. There might be guest speakers or exercise demonstrations or a presentation and discussion about a "hot topic."

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!

There are groups designed specifically for:

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

APDA's Seattle Mindfulness Gathering has MOVED!

Our mindfulness-based support group is now in the BALLARD neighborhood of Seattle.

This group, dedicated to supporting hope and well-being through the practice of formal and informal meditation is open to those living with PD and their families.

Please join us in this beautiful new location!

Merrill Gardens of Ballard
2418 NW 56th Street, Seattle, WA 98107

6:30pm - 7:30pm
4th Wednesday of every month

Led by Bartja Wachtel, LICSW, MHP
emfmbartja@gmail.com, 206-250-9166

Thank you Merrill Gardens for your sponsorship!

MOVE WITH OPTIMISM!

Be Active!

Exercise is now recognized as a vital part of the treatment of Parkinson's. 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 Health and Wellness section of APDAparkinson.org/northwest. New opportunities are being added on a regular basis, so check back often!

Here are a few featured new programs!

TACOMA, WA

Music Therapy for Parkinson's

Fridays: 1:30pm - 3:30pm
Tacoma Lutheran Home
$8/session

Contact: Megumi Azekawa
253-448-1400

www.pugetsoundmusictherapy.com/mtxpd/

MONROE, WA

Wellness Yoga

Wednesdays: 10:45-Noon
Monroe YMCA, grp room 2
$5/class

Contact: Tawnya Axelson
425-422-8078
tawnyaa@frontier.com

ARLINGTON, WA

Yoga for PD

Mondays: 9am
Stillaguamish Senior Center
$5/class

Contact: Kathleen
info@kathleenbuchanan.com
206-699-4605

NORTH SEATTLE AND REDMOND AND SURREY, BC

Rock Steady Boxing has more offerings!

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.

North Seattle @ MKG Seattle
Contact:
Jodi or Donovan Loomis
206-291-3149
rsboxingseattlenorth.com
seattlenorth@rsbaffiliate.com

Kirkland @ Northwest Fighting Academy
Contact: Carol, 425-508-1696
pugetsound@rsbaffiliate.com

Surrey, BC
Contact: Frankie LaSasso
Box2fitsurrey@rsb-affiliate.com
778-384-6284

SEATTLE, WA

Talk Loud, Talk Proud

A conversation group for people with PD for those who want to converse with others and practice strategies and exercises to increase vocal volume, improve voice quality and speaking rate. Led by a licensed speech language pathologist.

Contact: Julie Trautmann
206-368-1092
jtrautmann@nwhsea.org

MARYSVILLE, WA

Pedaling for PD

Marysville YMCA
Begins: May 1st

Contact: Carrol Bailey
360-651-1605

Check APDAparkinson.com/northwest for the most up to date wellness listings!

If you are involved in a program that is not listed, please let us know!

Unusual Parkinson's Study Learning from "Positive Deviants"

Laurie Mischley, ND, MPH, PhD

Bastyr researchers gather data from patients around the world in search of a recipe for success.

RESEARCHER LAURIE MISCHLEY, ND, MPH, PhD(c) designed a trial based on real-world conditions for Parkinson's patients.

What if researchers of a destructive disease focused not on sickness but on wellness? What if they sought those who managed the disease most successfully and learned what they had in common?

That's the approach behind an ongoing Bastyr University investigation of Parkinson's disease. The project, led by Laurie Mischley, ND, MPH, PhD(c), of the Bastyr University Research Institute, employs an unusual method. The study uses an online survey to collect a broad range of data from patients with Parkinson's and related diseases from all over the world. Participants complete a survey every six months, answering questions about medications, diet, herbal supplements, exercise, meditation and an array of other factors.

This approach is enabling Dr. Mischley's team to build an ever-growing data set to analyze, searching for common traits among those who maintain their health despite the disease. Their discoveries could lead to new clinical trials on Parkinson's therapies.

"It's just taking advantage of what we can now do with statistics," says Dr. Mischley, who is leading a similar study on multiple sclerosis.

"We're taking a step back to ask a common-sense question: 'Among those with Parkinson's who are doing unusually well, what are they doing differently?'"

To find out, the study continues to need participants from anywhere in the world at all stages of Parkinson's, regardless of whether they use alternative therapies. Participants take the survey online twice a year for five years. The data becomes especially powerful once researchers have tracked people for two years or longer, Dr. Mischley says.

Researcher Laurie Mischley, ND, MPH, PhD(c) designed a trial based on real-world conditions for Parkinson's patients.

Already, the results are extremely interesting. "We are beginning to find new ways to describe this disease and track progression, and it's becoming obvious that choices we make really do correlate with outcomes," says Dr. Mischley.

Bastyr student clinicians discuss a case.

Positive Deviance

The study uses the "positive deviance" model of focusing on those who deviate from the norm in their success. Rather than investigating one variable at a time through double-blind placebo-controlled trials — the gold standard of mainstream medical research — Dr. Mischley's project will seek to uncover all significant traits of the successful (and unsuccessful) outliers. It may turn out that they eat a lot of carrots, drink ginger tea, practice meditation daily, and live in tropical climates (to give a purely imaginary example).

For a complex disease like Parkinson's, an unconventional approach makes sense, says Dr. Mischley.

"We have this really diverse disease in Parkinson's, and it's just not likely we're going to come up with one single agent that's going to stop the whole thing," she says. "Funders invest millions of dollars in double-blind placebo-controlled trials, and they're not bearing fruit."

Five credible studies have linked eating dairy with Parkinson's, but no one has studied how dairy affects progression rates for those who already have the disease, partially because of a lack of funding, Dr. Mischley says. To her, that shows the limits of conventional research methods.

She says positive deviance has gained more attention in international research and nutrition research (because you can't design a placebo for, say, eating a banana).

"Positive deviance seems to be getting a lot of good attention," she says. "People really like the term. It also fits the naturopathic philosophy, because rather than studying disease, we're studying health."

Student-Faculty Collaboration

Funding for the study comes in part from the National Center for Complementary and Integrative Health (NCCIH), a part of the National Institutes of Health that helps Complementary and Alternative Medicine Care (CAM) practitioners conduct scientifically rigorous studies that can advance public health. Bastyr students are also helping with study design and data collection, developing research skills along with their medical training.

"Anyone with a diagnosis of Parkinson's disease can participate," says Dr. Mischley. "Individuals don't need to use complementary and alternative medicine. Our goal is to enroll a diverse cohort of participants so that the results reflect individuals in good and poor health, from urban and rural environments, who treat their disease in very different ways. The more people that participate, the more accurate the findings!"

To learn more about the study or find out if you are eligible to participate, please visit: www.camcarepd.bastyr.edu

Preparing for your neurology appointment:
Helping your neurologist to help YOU!

ON YOUR MARK!

AN APPOINTMENT WITH YOUR NEUROLOGIST will be most productive if you are prepared to share your information and concerns. Here is a checklist to help you get organized.

GET READY!

IF THIS IS YOUR FIRST appointment, ask the neurologist's office what types of information you should bring. These may include office notes from other doctors, MRI or CT images of your brain, and lab reports.

- ☐ **Medication list** Document all prescription medications (including non-Parkinson's drugs), over-the-counter medications, vitamins, and supplements; dosages; when medications are taken; and when you first started taking each. Are there any medications that you were on in the past that were discontinued? Have you experienced any side effects?
- ☐ **List of Parkinson's symptoms you are experiencing** Which are new? Which are most troublesome?
- ☐ **Movement symptoms** (walking, getting out of chair, moving in bed etc)
- ☐ **Fluctuations in your symptoms** (typically correlated with medication cycle, eating, sleeping, and exercise)
- ☐ **Dyskinesias** (involuntary movements caused by Parkinson's medications)
- ☐ **Non-movement symptoms** (swallowing, speech, nausea, constipation, urinary frequency and/or urgency, drooling, excessive sweating, dizziness upon standing, swollen ankles, sleep disorders, restless legs, and more)
- ☐ **Changes in mental status** (depression, anxiety, cognition, ability to make plans, hallucinations, compulsive or excessive behaviors such as shopping, gambling, or sex)
- ☐ **List three items that you most want to discuss with the neurologist** (There may not be time to address everything during your appointment, so it is important to prioritize your needs.)

GO!

Arrive early to allow time for parking, using the restroom, getting to the appropriate reception desk, checking in, and filling out paperwork.

Bring along water, a snack, and any medications you might need in case your appointment is delayed.

Ask a family member or friend to accompany you, to take notes and remind you of anything that seems important that has not been discussed.

At your neurology appointment: You did your homework, so you are prepared when your neurologist asks about your symptoms and medications!

Special requests Ask early in the appointment about prescription refills, disability forms, handicapped parking permits, etc; often a nurse or secretary is available to work on these during your appointment.

Address those three major concerns on your list of priorities.

Ask for a referral to a physical therapist for help with balance, gait, strength, pain, and flexibility issues.

Ask for a referral to an occupational therapist for help with handwriting, home modifications, driver evaluations, computer modifications, and adaptations to make dressing, grooming, cooking, and eating easier.

Ask for a referral to a speech language pathologist for help with speech and communication problems (including vocal volume, clarity of speech, and increasing facial expressivity) and swallowing.

Ask for recommendations regarding exercise and nutrition.

Ask about participation in clinical research trials.

Ask about the best way to get in touch with the neurologist in between appointments: Contact with a nurse or secretary, by phone or email?

Ask where you can get more information about Parkinson's disease.

Prepared by Diane L. Church, PhD
Courtesy of the APDA Parkinson's Center at Dartmouth-Hitchcock Medical Center, Lebanon, NH

OPTIMISM WALK

AMERICAN PARKINSON DISEASE ASSOCIATION

Ship Canal Trail Seattle

June 4, 2017

Start/Finish at
Nickerson Street Saloon
318 Nickerson Street
Seattle, WA 98109

Check-in/Activities: 9:30 am
Walk: 10:30 am
Post-Walk Celebration: 11:00 am

Register online today!
APDAnorthwest.org/optimismwalk

apda AMERICAN PARKINSON DISEASE ASSOCIATION
NORTHWEST CHAPTER
ph 206-695-2905
info@apdanorthwest.org

What is an Optimism Walk?

- A fun-filled fundraising event!
- A short non-competitive walk with family-friendly activities!

Raise $100 or more and get a free Optimism Walk T-shirt!

Why Walk?

- Every nine minutes someone is diagnosed with Parkinson's disease.
- Funds raised provide local support, education and research.
- **The more we raise, the more people we can help.**

Walk with us and help put an end to Parkinson's disease!

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TASTE THE PURE DIFFERENCE!

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Thank you

for your generous donations

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The Puyallup Tribe
of Indians

Thank you Puyallup Tribe for awarding APDA Northwest an educational grant in support of the Live Well program.

Photo courtesy Carl-Evert Kangas on Flickr

MARK *your* CALENDARS!

APDA Webinar

May 11, 2017, 10am–11am PST

Spotlight on Movement Functions:
Coping with On/Off Periods

Register on-line: www.apdaparkinson.org

Good Start Program

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

Thursday, May 18th, 5:30–7:30pm

2100 Building, 2100 24th Ave S., Seattle, WA 98144

SAVE THE DATE:

Parkinson's Disease Educational Symposium

Tuesday June 27th, 2017, Seattle

Support Group Leader Training

Designed for new or seasoned support group leaders. Connect with others and share ideas in facilitating a successful support group.

Tuesday June 27th, 2017, Seattle

3rd Annual Optimism Retreat!

A one-day conference focusing on movement and well-being for people with Parkinson's disease, their families, and care partners.

Sunday, August 27th, 2017, Mercer Island

Go to **apdaparkinson.org/northwest** to register for one of these programs or call **206-695-2905**

The Magic of Hope

GALA & AUCTION BENEFITTING APDA

Since 2003, the Magic of Hope Auction & Gala has made a positive difference in the lives of the thousands of people living with Parkinson's disease in the Pacific Northwest.

Our 15th Annual Auction & Gala will be held on April 29, 2017 at the Seattle Design Center.

We are expecting 400 guests and have the goal of raising $300,000 to be used towards our mission of providing support, education and research to help everyone impacted by Parkinson's live life to the fullest.

This year we will be honoring John, Suzie and Buckley Schofield for their outstanding commitment to APDA. The Schofield family's energy, along with their unwavering support and dedication, have provided strength and hope to countless people impacted by Parkinson's disease.

Thank you to our sponsors:

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TASTE THE PURE DIFFERENCE!

GOLD

Cameron Catering
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Aegis Living
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apdanorthwest.org/magicofhope

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