PARKINSON *Pathfinder*

SPRING 2020

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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

Strength in optimism. Hope in progress.

SPRING 2020

TABLE OF CONTENTS

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OUR MISSION

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

AMERICAN PARKINSON DISEASE ASSOCIATION
NORTHWEST CHAPTER
Strength in optimism. Hope in progress.

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COVER
"Shaking not Stirred" Optimism Walk team captained by Dustin Werner.
Photo by Karen Carter-Schwendler

As we finalize this edition of the Parkinson's Pathfinder we find ourselves navigating an unprecedented time as together we face the worldwide outbreak of COVID-19. For the safety of all employees, patients, volunteers, and attendees, we cancelled all of our in-person patient education events in March and April as well as our largest fundraiser of the year—the Magic of Hope Gala.

At APDA, we are proud of our credo "Strength in optimism. Hope in progress." **Because the gala makes up 50% of our budget to pay for programs and services for individuals and families impacted by Parkinson's, we couldn't just cancel it. So we moved the auction online!** We had tremendous support from our Magic of Hope sponsors (see below), and our wonderful vendors Cameron Catering, Fred Granados Auctioneer, PTNA and Seattle Design Center, who did not charge cancellation fees.

It is during trying times when people pull together (even when we have to remain 6 feet apart!) and our communities become stronger. At APDA we are here for you, and continue to take calls from families and individuals impacted by Parkinson's and provide them with high quality support, education, and services. Education is empowerment, so we are selecting new dates for in-person education programs, moving many of the support groups to teleconferencing, and are working on recruiting teams and individuals for the annual Optimism Walk on June 6th.

April is Parkinson's Awareness month. A period when we take time to raise awareness about PD and honor and celebrate those impacted by the disease. In this issue we learn about the life of James Parkinson, feature poetry written by individuals living with the disease, and educate you about emerging research in the gut biome and freezing of gait. We hope that you enjoy reading it!

Jean Allenbach
Jean Allenbach
Executive Director

Thank you to our Magic of Hope sponsors for helping make this event a HUGE success!

A Special THANK YOU to our Premier Sponsors

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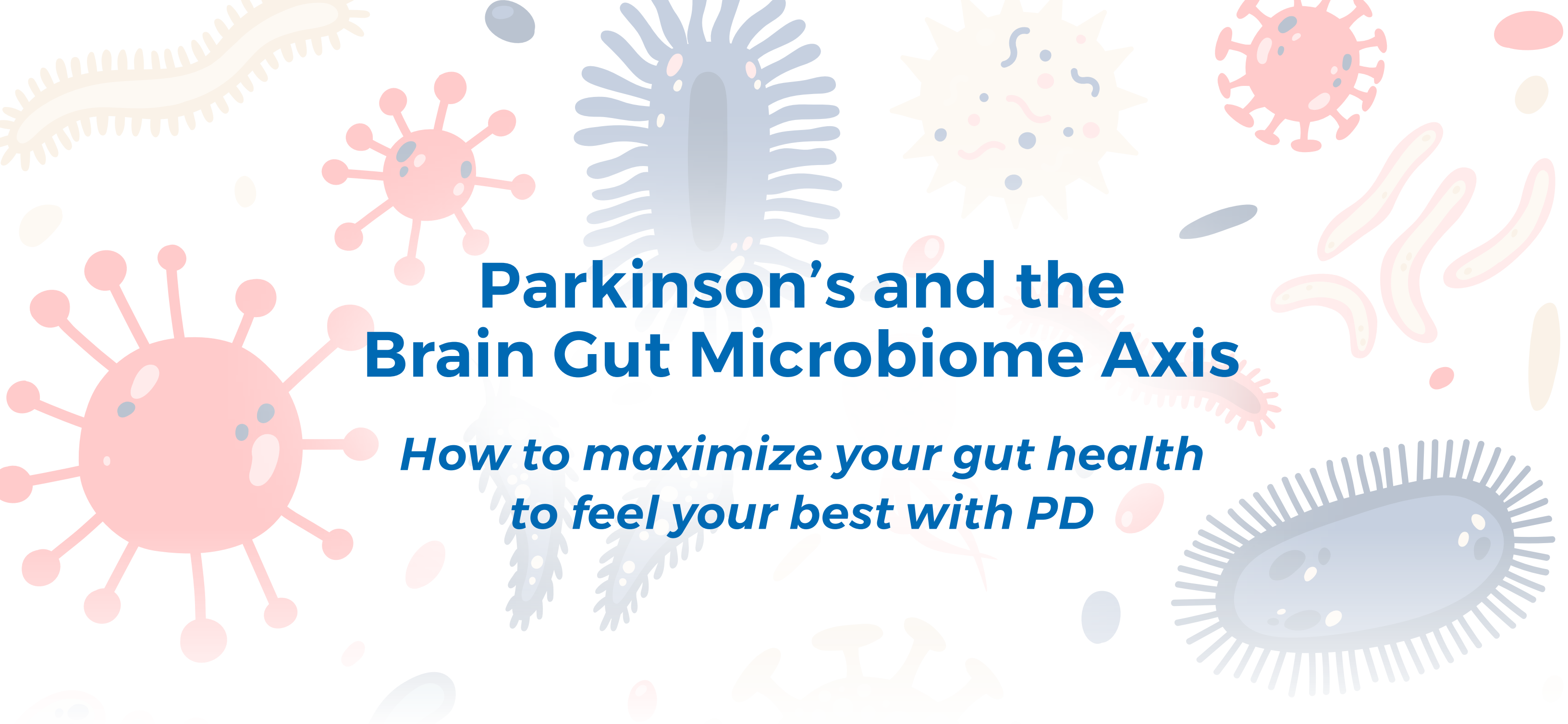


Parkinson's and the Brain Gut Microbiome Axis

How to maximize your gut health to feel your best with PD

PD and your gut

It's no secret that Parkinson's disease (PD) affects the digestive system. Anyone who has experienced the relentless constipation that can accompany PD can attest to this. Lewy Bodies, the protein inclusions seen under the microscope in brain neurons affected by PD, were discovered in nerves in the colon back in the 1980s. A vast new field of research is unraveling a much more intriguing story. In some, if not all, people who develop PD, the disease not only involves the gut, but it may actually originate there.

In the past decade there has been an explosion of research into the human microbiome, most of which is located in the gut. The microbiome is the vast population of bacteria, viruses, and fungi that inhabit our bodies throughout our life. We have a respiratory microbiome and a skin microbiome, but the gut microbiome outweighs the rest. Five pounds of friendly bacteria live in our GI tract, mostly in our large intestine. These organisms help control several processes going on in our bodies and our brains. Research is showing that when we lack a diversity of types of good bacteria in the gut, we not only become susceptible to infections, but we also can become prone to a myriad of chronic conditions from obesity to heart disease.

The gut microbiome plays an important role in the communication between our "big brain" and the "little brain" in our digestive tracts. There is constant signaling between our gut and our brain, in both directions, along a superhighway called the vagus nerve. In PD, the vagus nerve transmission between brain and gut does not work properly, and peristalsis, the muscular movement that pushes food through our digestive tract, slows down, resulting in severe constipation, bloating and abdominal discomfort. The constipation issue can start many years before the actual motor symptoms of PD develop. This may lead some to develop a condition called small intestine bacterial overgrowth (SIBO), which occurs more often in people with PD. SIBO can cause bloating, pain, nausea, and if left unchecked, malabsorption of vitamins and nutrients. It is very possible that SIBO can affect absorption and metabolism of Parkinson's drugs in the intestine. SIBO has also been associated with motor impairment in PD, and eradicating it resulted in improvement in motor fluctuations in a couple of small studies.

It has only recently been discovered that many of the beneficial gut bacteria we harbor are actually miniature factories producing neurotransmitters such as serotonin, GABA, and dopamine. These bacteria are like an inner pharmacy within our bodies. Neurotransmitters produced in the gut are sent directly to the brain via cells in your gut lining called neuroendocrine cells, which connect directly to the vagus nerve. This means that the health and integrity of our gut function not only influences digestion, but it also has a direct influence on brain function.

In Parkinson's we recognize that the brain loses the neurons that manufacture dopamine in the substantia nigra. What if we could populate our bodies with beneficial bacteria that could produce more dopamine within our gut instead? Certain species of Bacillus have been shown to manufacture dopamine in our guts. It is still not clear if this is a viable treatment for Parkinson's, but bolstering our own bacteria's dopamine production might solve the common issue of poor absorption of carbidopa/

levodopa in the pill form, by instead activating our inner pharmacy. There is yet another type of bacteria, a type of enterococcus, which has been found to essentially “eat” levodopa in the digestive tract, before your body can absorb it! So it is clear that from the Parkinson’s perspective, there are both beneficial and harmful bacteria we may harbor in our microbiomes. How we can manipulate this system to treat PD is still being actively researched.

How to maintain gut health for optimal brain health

The good news is that we do not need to wait for the full story to unfold of the Gut-Brain-Microbiome axis and connection with PD before we start making healthy changes in our own lives to improve gut and brain function. There are many simple steps that everyone can take now.

The key factors leading to overall gut wellness include: 1) diversity of microbiome, i.e. having lots of different types of friendly bacteria, 2) normal immunologic function of the gut lining and intact tight junctions, 3) lack of dysbiosis, or an overgrowth of less beneficial organisms.

We can support the diversity of our microbiome in a variety of ways, some of which are summarized in the side bar. In many ways if we could pick up some of the habits that our grandparents had during their lives, we would be off to a good start. It is also helpful to avoid toxins that can destroy the gut lining. One such substance is glyphosate, known popularly as RoundUp. Glyphosate is becoming ever more present in our food supply, and research is linking it to diseases as diverse as lymphoma to autism. Educate yourself on glyphosate at www.detoxproject.org. Alcohol is also toxic to our gut lining. However, some studies have linked “moderate” alcohol consumption, equivalent to 1 drink per day, to some health benefits. It is safe to say that avoiding alcohol completely is the safest bet for your gut. If you do like to consume alcohol, stick to 3 per week for optimal gut health.

Another interesting factor that determines our gut barrier integrity is our mental health. Remember that I mentioned the gut brain communication is bidirectional earlier? The brain instructs the gut, just as the gut instructs our brain. Our emotional state also influences the function of our gut. If we do not control our reaction to external stress, if we harbor anger and resentment, and allow our minds to control us rather than us controlling our minds, our gut function gets disrupted. Simple things like learning positive coping mechanisms and seeking mental health counseling when we feel overwhelmed can minimize destructive stressors on our brain and gut. A healthy mental state promotes a healthy gut, and vice versa.

This is an exciting time. Researchers are actively exploring the effect of the Gut-Brain-Microbiome axis on Parkinson and vice versa. I am very hopeful that this area of research will unlock some mysteries of PD which have not been fully revealed by decades of brain-focused research. It is now clear that in order for Parkinson’s research to advance towards a cure, we need to learn as much as possible about our microbiome and gut health. While researchers are busy unraveling the mysteries of the brain-digestive tract's connection in PD, let’s do our part by improving our gut health now!

ABOUT THE AUTHOR

Dr. Kelly Condefer is a practicing neurologist and fellowship trained movement disorders specialist in Wenatchee, WA.

TIPS FOR
PRIME GUT HEALTH

- **Eat a wide variety of plant based foods, colorful vegetables, organic when possible.**
- Limit your intake of dairy products, and meats including chicken. Especially avoid processed meats like deli meats.
- Practice good oral health! Use a metal tongue scraper, see the dentist, and brush and floss twice daily.
- **Go outside regularly, into the woods, and breathe deeply.**

- Limit alcohol intake to 2-3 drinks per week.
- Do not use sprays like Round Up in or around your home and try to limit your exposure where it is used.
- Plant a vegetable garden.
- Avoid antibiotics unless absolutely necessary.

- **Eat fermented foods like sauerkraut, kimchi, kombucha, and Bragg’s apple cider vinegar.**
- Take a high quality probiotic supplement, preferably one that has been studied in clinical trials. I recommend: www.microbiomelabs.com MegaSpore biotic for the best source of bacillus species.
- Obtain a reverse osmosis water filter for your home to reduce the amount of glyphosate and other toxins in your water.

Poetry from the APDA Community

BUTTONS

Rick Hermann
Living with Parkinson's since 1998

An embroidery of fingers and buttons
clumsily engage, one button at a time,
climbing up the front of my shirt
to the bony pocket
beneath my Adam's apple.
Not wanting too much
of your help, I try to find the
jacket sleeve
with my flapping arm,
performing a twirl,
a dervish following the leading hand
to Paradise, a kitten
chasing it's tail. We laugh.
Downstairs, the other spouses wait,
leaning on palmate canes like strange birds.
My second arm finds its place in the world,
a red bow tie clips onto the white dry leaves
of my Oxford button-down collar.
I lace my shoes with strings
of worry beads, a shimmering hope
banked against my next breath.
I try not to shuffle as we make for the door.

Making Peace

M.J. Franich
Living with Parkinson's since 2018

My left hand is different now,
as it always was, the writing hand,
the one that grips a metal barreled
ball point pen because it takes more
effort now, to form the letters and the words.

The neurologist explained, I had
two things in common with
Michael J. Fox. Our initials obviously,
and Parkinsons. Holding the prescription
slip, confused, I did not smile.

I have relearned how to swing
my left arm again, in time
with the opposite foot. Piles
of pill supplements wait each morning,
fish oil mixed with liquid CoQ10.

In grocery stores and public spaces,
when syndromes suddenly surface
others sometimes notice. At home,
in the gym, walking on a trail they often
are set aside, like taking off a coat.

Emotion makes the left hand shake
a little, or a lot, sometimes calmed with a
slow breath, a deep, focused moment.
Every minute of every day, all the small steps
forward whisper thoughts about tomorrow.

My journey with PD, my companion,
has only just begun. I cannot stop or wait,
there is this work to do and so together now
we press on, a hand that holds and moves
the pen, word by word, a story to be told.

To celebrate the many talented writers within our Parkinson's community during National Poetry month, we are featuring some selected works on these pages. Follow us on Facebook (@APDAnorthwest) to see more examples during the month of April!

Now That You're A Senior

Frederick McMullin
Living with Parkinson's since 2009

Now that you're a Senior
You are the proper age
To take on your new status
As an honored sage
Children will adore you
Teens will think you're cool
Men will ask for your advice
And dogs will follow you

Now that you're a Senior
A venerable old man
You have responsibilities
We're sure you understand
We need all the wisdom
You've gathered over years
Your common sense and judgement
Will fall on eager ears

Now that you're a Senior
We hope you will agree
To take on your new role
And aid society
Our culture would just crumble
And we would not survive
Without the help of Seniors
And all the old and wise

Dear Body

Doris Martin
Living with Parkinson's since 2011

Imagine my surprise
When I no longer felt at ease within you, dear body.
When you began to make movements I did not request,
Left hand keeping time to music I do not hear.
Fingers on keyboard go from rapid accuracy to jerky hit-n-miss,

Imagine my surprise
When I request "left foot out" during exercise class – and get nothing.
When shoulders hunch forward as if to protect a precious jewel in my
chest When handwriting becomes *oh, so small…*
When even the little pinkie hurts!

Imagine my surprise
Dear body, when all you want to do is lie perfectly still on the couch – for hours!
When Velcro sheets make turning over in bed an acrobatic feat.
When high anxiety turns a drive to the store into an Indy 500 event.

Imagine my surprise
When rigidity replaces fluidity,
When the fog of fatigue morphs into dyskinesia,
Conjuring up frightening "spastic" images.

Imagine my surprise
When medication is AN answer, but not THE answer.
When exercise takes on a quality of life importance.

Where is the hope?
I'm dancing as fast as I can…

STATISTICS

Pat Erickson
Living with Parkinson's since 2002

Statistics flow
Oh no
Filling my day with tales of woe
Predictions of this
Chances of that
Telling me I will no longer be Pat
Now what's up with that!

I am not a number to be placed on a chart
I'm a woman, mother, friend with a really big heart
If you look at a number, that's all you'll see
When there really is so much more to me

Statistics don't show what will be
They show only the past and they don't define me

Daily life Measures of Freezing of Gait: Potential for Rehabilitation

Dr. Martina Mancini

Walking problems, such as slow, shuffling, and short steps and particularly freezing of gait (FoG) are common and highly disabling in Parkinson's disease (PD). During an episode of FoG, patients experience a feeling as if their feet are glued to the floor. FoG affects up to 80% of patients after 10 years of disease, it remains a treatment challenge in clinical practice, and it affects quality of life, often causing falls.

Figure 1. Example of a person walking while wearing wearable sensors to characterize walking objectively.

Despite its common and disabling features in everyday life, FoG is surprisingly difficult to assess in daily clinical practice. In fact, walking improves when patients consciously focus on walking, and this is what typically happens when examined by a clinician. Additionally, the typically well-lit and broad hospital corridors without obstacles, where patients are often assessed, do not provoke FoG, as the phenomenon is commonly provoked in narrow spaces and while turning.

These difficulties assessing FoG are problematic as optimal management depends on objective assessment. Assessment involves both identification of FoG (i.e. the presence or absence of FoG) and also aims to map its' frequency and severity. A robust, objective assessment of FoG is needed to initiate or change treatment (e.g., to start or increase the dosage of levodopa or to initiate a referral to a specialised physiotherapist) and to evaluate the effects of treatment.

The possibility of detecting subtle changes in walking just prior to FoG and assessing FoG severity with wearable sensors (example in Figure 1) has emerged as a useful tool in the laboratory but has not yet been realized for everyday life. Objective measures of leg coordination during walking and FoG during daily life typically use 1-3 sensors.

Our measures of average and variability of time spent freezing at home are associated with the patients' perception of freezing. After developing a 1-minute turning-in-place test to objectively measure the severity of FoG in the clinic, using three wearable sensors attached to both feet (or shins) and the lumbar region, we asked our study participants to wear the same wearable sensors for a week of continuous monitoring. Our novel method first identifies a period of walking and turning during daily life activities and then identifies signs of freezing, averaged across the 7 days. Freezing is identified based on high frequencies of feet/leg acceleration and low correlation between the right and left foot angular velocities (example in Figure 2). We showed that the measures of freezing in daily life, average time spent freezing and variability of FoG episodes were significantly associated to perceived FoG severity. Balance perception, measured by a clinical scale, was also significantly associated with the time spent freezing and its variability across the hours of the week.

What's next? Our laboratory studies are showing that a vibration cue about each foot contact with the ground can significantly reduce the frequency and severity of FoG in some people with PD. This may mean that a portion of people with PD could benefit from tactile feedback, i.e. less freezing, during everyday life.

The unique characteristic of our system is that it can reduce FoG while turning, while other feedback systems are limited only to gait. In fact, FoG is much more common during turning than during straight walking and freezing during turning often leads to injurious falls. In the near future, we will investigate the efficacy of tactile gait feedback during daily life with these novel, objective FoG measures.

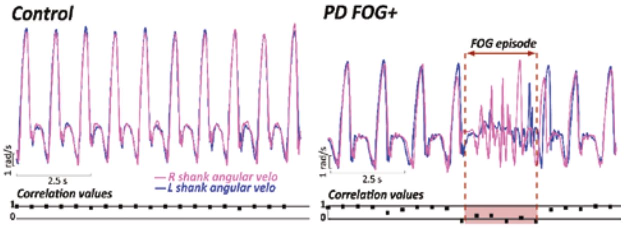


Figure 2. Example of right (pink) and left (blue) shank angular velocities, measured with wearable sensors, during walking and their correlation values (below) in a healthy control subject and a participant with PD before and right after a FoG episode.

Dr. Martina Mancini is a researcher at Oregon Health Sciences University. The goal of her research is to improve everyday functional mobility and prevent falls in individuals with Parkinson's disease by investigating the pathophysiology of motor impairments and objectively characterizing them with new technologies. She is nearing the end of a five-year Early Career Award from the National Institute of Health that focused on characterizing gait disturbances in people with Parkinson's disease and developing a prototype tactile feedback system to improve turning and FoG. She hopes to translate her research into effective strategies that can be used by clinicians, physical therapists and patients.

MOVE & LIVE WITH OPTIMISM!

Connect with others, build community, and be active!

The APDA website: www.apdaparkinson.org/Northwest
is a clearinghouse for Support Groups and Wellness Programs throughout our 5 state region
(Washington, Oregon, Idaho, Alaska, and Montana). Select your state and find a group active in your community!

No group in your community? APDA can help! We provide technical assistance, training, and expertise in how to get a group started in your area. Call 206-695-2905 to learn more. Check back often as new programs are added regularly!

No access to the Web? Call us! We will help you find a group that is right for you or we can send you a complete list.

APDA 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, or participant scholarships.

In 2019 APDA was proud to support the following programs.

Yoga for PD:
Seattle, WA
Renton, WA
Bothell, WA
Leavenworth, WA

Rowdy Readers
Eugene, OR

Body Moves
Homer, AK

Undefeated Boxers
Salem, OR

Next Grant Application deadline is June 30, 2020.

Successful applicants will be able to demonstrate a valuable benefit to members of the Parkinson community.

For more information visit our website.

Need Some Home Fitness Ideas?

DAILYDOSEPD

Our friends at the Parkinson Fitness Project have some amazing online classes.

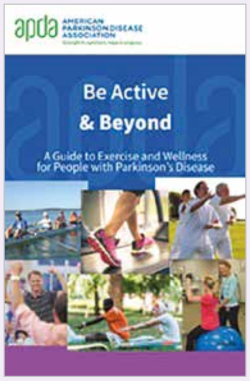
You can sign up for a FREE 30 DAY TRIAL and then if you like what you see, use the promo code MOVE when signing up to get the next 3 months at 50% off. They also have some free classes available, do live online classes, and if you are in the greater Seattle area you can join them in person.

www.dailydosepd.com

Workouts from APDA St Louis

The APDA Greater St. Louis Chapter holds fitness classes for PD in their office. They live stream the classes and then make them available on their YouTube channel.

Visit **youtube.com** and search "APDA St. Louis" to find all their recorded classes.



< APDA Be Active and Beyond Booklet

The APDA Be Active and Beyond Booklet has some great ideas, photos, and explanations of exercises you can do at home. Email or call us and we can send you the booklet or download it at **apdaparkinson.org**.

OPTIMISM WALK
AMERICAN PARKINSON DISEASE ASSOCIATION

The Optimism Walk is part of a nationwide movement to mobilize and inspire people to step up and help put an end to Parkinson's disease.

Join us on Saturday, June 6 at the APDA office in Seattle. This is a family friendly event with festivities such as poster making, face painting, pop-a-shot with Sonic legend Slick Watts, and an award ceremony emceed by radio personality Dave Grosby ("the Groz"). Meet ESPN founder Bill Rasmussen, our Honorary Optimism Walk Chair who has lived with Parkinson's since 2014. After a short 2 mile walk along the scenic Ship Canal Trail you can enjoy a delicious lunch, live music by the Kennedy Brothers, and an opportunity to connect and celebrate with our Parkinson's community.

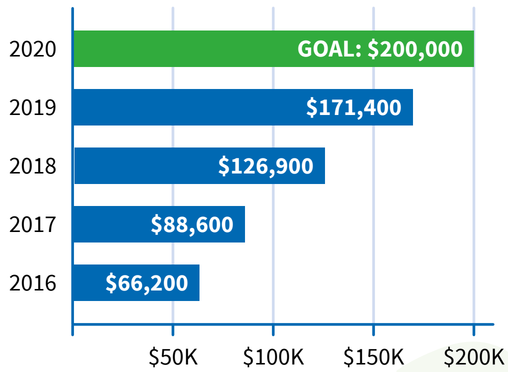
THE DETAILS

APDA Northwest OPTIMISM WALK
Saturday, June 6

Walk starts and ends at the APDA office
180 Nickerson Street, Seattle

9:30	Check-in
10:30	Walk Begins
11am-1pm	Post walk festivities!

Optimism Walk Fundraising
MOBILIZE, INSPIRE, MOVE!



HOW CAN YOU GET INVOLVED?

Walk as an individual, join a team, or form your own team!

In 2019 our smallest teams were dynamic duos while the largest team was made up of 56 enthusiastic walkers! We had lots of individual walkers and teams of all sizes, made up of family, friends, co-workers, support groups, exercise classes, and more! Ask a few friends and grow your team from there.

Worried about fundraising or asking for money? DON'T BE! Remember that you aren't asking for money for YOU, but rather for a worthy cause near and dear to your heart. You will be surprised at how eager and willing people are to donate – all you have to do is ask. People want to help, they just don't know what to do. Give them the joy of feeling a part of something big, by inviting them to donate and/or join your team! Your personal story will let people know why you are walking and how Parkinson's has impacted you, and why you are passionate about supporting APDA. You can add photos and videos which will make your story even more inspirational. APDA will provide you with a fundraising guide and set you up for success, so you can meet your personal and team fundraising goals. Last year, walk teams exceeded their goals by an average of 87%!

Can't make it to Seattle on June 6? Set up a team in your community, register online, and do a fun walk around your neighborhood on June 6. APDA Northwest chapter covers Washington, Alaska, Oregon, Montana and Idaho so money raised from our Northwest Optimism Walk will benefit thousands of people living throughout our region.

While walking in our Optimism Walk is important to raising awareness about Parkinson's disease, fundraising is also critical to help APDA meet our mission of providing the support, education and research. Our goal is to raise $200,000 to pay for local education programs, patient aid scholarships, printed and online resources, and invest in promising research.

EARN PRIZES!

Fundraising incentives:
$100 for an Optimism Walk T-Shirt
$500 for an Optimism Walk Hat
$1000 for an Optimism Medal

Prizes will be awarded for Top Fundraising Team, Largest Team, and Most Spirited.

SHARE ON SOCIAL MEDIA!

This year will be easier than ever for your friends to donate – you can link your donation page directly to a Facebook fundraiser, and watch your donations grow.

SIGN UP TODAY!
apdaparkinson.org/Northwest

We are excited to introduce the newest member of our team: **Cody Olsen**! Stepping into the role of Fundraising Events Manager for APDA, he is in charge of this year's Optimism Walk. He's excited to be an ally to this cause, and get to know the community around it. Outside of work Cody enjoys scuba diving and making short films. He looks forward to meeting you!

Who Was James Parkinson?

by Peter G. Beidler

Parkinson's disease has long been known by the name of an eighteenth-century British medical doctor named James Parkinson. He did not have, nor did he discover a cure for, the nasty disease that bears his name. Who was James Parkinson and how did "his" disease come to be named for him?

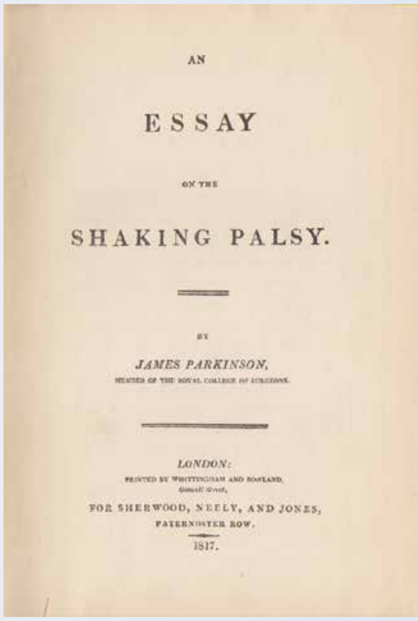
James Parkinson was born in 1755 in the town of Hoxton just north of London. Not long after he got his medical degree, his father, also a doctor, died unexpectedly, and James took over his father's medical practice. He worked as a practicing physician all his life.

James Parkinson was well-known in his own time, but not for his pioneering work on the disease that bears his name. He was best known for disseminating medical information and for his geological work.In a time when only the rich could afford to consult medical doctors, James Parkinson worked hard to make basic information about medical care available to anyone who could read. He gained fame as the author of a large number of medical articles, pamphlets, and books. He wrote about topics like the care and feeding of children, how to recognize and treat rabies and epilepsy, how to treat intestinal worms, the nutritional importance of breast-feeding, the dangers of quack medicines, the health benefits of personal hygiene, and the value of inoculation in preventing smallpox.

James Parkinson's medical advice was brought together in 1799 in his medical magnum opus, a two-volume encyclopedia with this imposing title: *Medical Admonitions Addressed to Families; Directions for the treatment of the sick on the first appearance of the disease; by which its progress may be stopped, and a fatal termination prevented from taking place, through NEGLECT OR IMPROPER INTERFERENCE*. This family encyclopedia made widely accessible the most up-to-date information about sanitation, prevention of diseases, and treatments for common illnesses. Due to its comprehensive, detailed, and easy-to-understand discussion of a wide range of diseases and medical conditions, Parkinson's Medical Admonitions found its way into many British and American households.

James Parkinson's fame for his medical writings was soon eclipsed by his fame as a collector and interpreter of fossils. One of Europe's earliest paleontologists, James Parkinson helped to establish the first geological society and was an early leader in the new science. He spent his most productive years writing about the history of the earth, the geological strata of England, and the principles of oryctology (the study of fossils). His monumental, illustrated, three-volume *Organic Remains of a Former World* (published between 1804 and 1811), was at the time viewed as his most important and influential work. No one—certainly not Parkinson himself—could have predicted that two centuries after his death he would be remembered not for these large accomplishments but for a much narrower one.

James Parkinson was a busy and energetic man. He worked full days as a physician and apothecary, traveling out almost every day to visit sick patients in their homes and almshouses. Most nights, he read widely and wrote voluminously. Perhaps what



AN

ESSAY

ON THE

SHAKING PALSY.

BY

JAMES PARKINSON,

MEMBER OF THE ROYAL COLLEGE OF SURGEONS.

LONDON:

PRINTED BY WHITTINGHAM AND ROWLAND,

Goswell Street,

FOR SHERWOOD, NEELY, AND JONES,

PATERNOSTER ROW.

1817.

> Perhaps what was most distinctive about James Parkinson was his ability to observe carefully and to draw fresh inferences from what he observed.

was most distinctive about James Parkinson was his ability to observe carefully and to draw fresh inferences from what he observed. His work on what he called the shaking palsy originated not in observing his own patients but in noticing the strangely tortured movements of three elderly men, strangers to him and to each other, as they moved awkwardly through the crowded streets of Hoxton. He noticed that they walked hunched over, leaning forward as they shuffled and stumbled along the busy streets. He introduced himself to each of them and asked them a series of questions.

How long had they had that arm tremor? Did their arm shake like that when they were sleeping? What had triggered the condition? When had they started speaking with such difficulty—so softly and indistinctly? Was it painful to walk hunched forward like that? Did the tremors hurt? What other symptoms did they complain of? Slowness? Stiffness? Drooling? Did anyone else in their families share these symptoms? Were symptoms better or worse if they drank a pint or two of beer? Did anything—fresh air, certain medicines, certain foods, certain kinds of exercise—improve or worsen their symptoms? Did they ever feel constipated? Why did they not step down heel-first as other men did? Why did their arms not swing as they walked? Did they fall often? Did they ever contemplate ending their own lives?

Through careful observation, asking questions, and paying close attention to the answers of those three men, and later three more men who exhibited a similar range of symptoms, James Parkinson was able to draw amazingly accurate profiles of the people who suffered from the shaking palsy. Other medical people had noticed patients with some of the symptoms that James Parkinson described, but treated them as isolated symptoms and individual medical phenomena. James Parkinson's genius lay in his hunch that these and other symptoms might exemplify progressive stages of the same slow-moving disease.

In 1817, when he was sixty-two, James Parkinson published a substantial pamphlet that he called *An Essay on the Shaking Palsy*. He was surely aware of the inadequacy of the term "shaking palsy" since he knew that the tremors were not always present in the six men he observed, and he knew that as the disease progressed many other symptoms presented themselves.

James Parkinson never attached his name to the disease. In 1872, nearly a half-century after his death, a French neurologist named Jean-Martin Charcot found and read the essay and understood its importance. He referred to the disease as le malalie de Parkinson, and the name stuck.

James Parkinson never found a cure for the disease that bears his name. By observing, asking lots of questions, and listening carefully to the answers, he showed subsequent medical researchers more precisely the nature of the disease that required their attention—and that still does.

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Note: My main sources for this article were Cherry Lewis, The Enlightened Mr. Parkinson (New York: Pegasus Books, 2017), and Dr. James Parkinson, An Essay on the Shaking Palsy (1817).

Pete Beidler *Pete Beidler was diagnosed in 2006, about the time he retired after teaching English for forty years at Lehigh University in Pennsylvania. Pete's new book* Living and Dying with Parkinson's Disease *will be published in May 2020. He and his wife Anne live in Seattle.*

Continued from page 4

Caring

by Peter and Anne Beidler

Dear Anne:

Sixty years ago you and I dreamed that we would work and save money together, build a home together, raise our children in it, and then when we got old we would take care of each other until we died.

We've done pretty well with the early parts of our dream, but now we are both seventy-nine. We are unequivocally old. It is the time of life when we dreamed that we would take care of each other until we died. But my Parkinson's is pretty rapidly entering its last stages. That means that what is left for me is to get more and more dependent on you, and what is left for you is to be my caregiver until I die.

It troubles me to realize that I will not be able to carry out my part of our dream in the months to come. You will be taking care of me way more than I will be taking care of you.

As I enter the difficult end stages of Parkinson's disease, I will be more and more of a bothersome burden for you. I cannot drive anywhere, or walk to the bus stop, or get on the bus. I freeze and fall trying to walk across the kitchen to get a glass of water to wash down my thirty-odd daily assortment of pills.

It seems that everything I do makes more work for you. I spill chili on the fresh table cloth, so you wash it. I get hungry, so you run to the Ballard Market. When you get back, I cannot even help you carry the groceries in. I need stool softener, so you run to Walgreens. I dribble drops on the bathroom floor. If I don't notice them and wipe them up, you do.

What is your reward for for all this work you do because of me? Nothing but the knowledge that as I grow weaker and more helpless, your job will only get worse. So much for the dream of taking care of each other until we die. The reality is that you will be taking care of me until I die.

I'm so sorry. You deserve better. It can't much fun being my caregiver.

Love,
Pete

Dear Peter:

Being your caregiver smears me all over
With lonely juice and
Angry juice and
Self-pity juice and
Resentment juice and
Very, very much sadness juice.
Caregiving almost swallows me up.
But wait a minute.
Time to wash my face and
Take a nap and
Muster up a smile and
Let myself remember how
I really love you: the
Way you try so hard to walk, the
Way you make things with your hands, the
Way you sing old silly song sometimes, the
Way you dash off goofy limericks, the
Way you sweetly put up with me.
And I begin to make
Some grateful juice.

I love you.
Anne

Dear Anne:

I know a young beauty, so fine,
That it's hard to think—seventy-nine?
She's a goddess for real
So this love that I feel
Is a true adoration divine.

I love you, too.

Pete

Pete and Anne Beidler have been living with Parkinson's disease since Pete was diagnosed in 2006.

Save the Date!

Upcoming Events

Stay Tuned to our website & your inbox for further information about these 2020 Programs & Events.

Website: **apdaparkinson.org/Northwest**
Email: **apdanw@apdaparkinson.org**
Phone: **206.695.2905**

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.

Second Friday of every other month: May 8, July 10, September 11
Join us in person at Mercer Island Community and Event Center,
or watch the live or recorded broadcast on YouTube.

PRESS™
Parkinson's Roadmap for Education and Support Services™

May 5–June 23, 2020
Tuesdays 6:00pm – 8:00pm
APDA Northwest Office

The popular PRESS™ Program: APDA's Parkinson Roadmap for Education & Support Services™ will be held at least 2 more times in 2020. This 8-week series designed for individuals diagnosed with PD in the last 5 years.

PARKINSON'S Live Well SOUTH SOUND

Postponed: New Date TBD
University Place Presbyterian Church

APDA and the Pierce County Healthcare Providers Council team up for this one day event. This conference is focused on health, wellness, movement, and research. Featuring Dr. Rebecca Gilbert, APDA Vice President & Chief Scientific Officer.

SEATTLE STORM

APDA Night at the Seattle Storm

Wednesday May 27th 7pm
vs Connecticut Sun

Help us spread Parkinson's awareness at this family friendly event.

Call APDA at 206-695-2905 for ticket information.

PARKINSON'S Live Well MONTANA

Saturday June 27th, 2020
Montana State University
BOZEMAN, MT

Spend the day with APDA and a slate of national and local Parkinson disease experts. This conference is focused on health, wellness, movement, and research. Featuring movement disorders neurologist, Dr. Pravin Khemani.

PARKINSON'S Live Well PUGET SOUND

Saturday, August 28, 2020
Bellevue College – BELLEVUE, WA

Explore various activities developed for people with PD such as Boot Camp, yoga, and dance. Strap on some gloves for boxing or try your hand at juggling. This year we are also excited to offer a special workshop designed specifically for care partners. It will be a day filled with movement, optimism and fun designed to help you live your best life.

Lunchtime keynote address from Dr. Laurie Mischley, renowned Naturopathic Physician and Researcher

AMERICAN PARKINSON DISEASE ASSOCIATION
NORTHWEST CHAPTER

Strength in optimism. Hope in progress.

180 Nickerson Street, Suite 108
Seattle, WA 98109

SUBSCRIBE TO OUR NEWSLETTER!

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

PARKINSON'S AWARENESS MONTH IS APRIL!

What can YOU do to spread awareness?

Speak Up!

Invite someone from our APDA Speaker's Bureau to speak at your company or at an event, or get trained to be a speaker (206-695-2905 for more info).

Social Media

Share APDA posts and tell your personal story and connection to PD

Stay connected with PD research!

Sign up for the Washington Parkinson's Disease Registry www.registerparkinsons.org (NW residents outside of WA are welcome!) or follow up about an interesting study.

Learn something new about PD

Attend an APDA education program such as Live Well South Sound, watch an APDA online webinar, or download education materials.