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and Brain Health**

PARKINSON *Pathfinder*

WINTER 2023

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PARKINSON DISEASE
ASSOCIATION
NORTHWEST CHAPTER

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WINTER 2023

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COVER

The Matanuska Glacier, Alaska
Dustin Werner

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.



As the dark and rainy days settle in here in the PNW, I take comfort in the friendships and social connections I've cultivated through work, family, and my community. My book club recently finished a compelling read, *The Good Life: Life-Changing Lessons from the World's Longest Scientific Study on Happiness* which reaffirmed something that seems like common sense yet can prove challenging for so many of us: relationships are the cornerstone of a happy, meaningful, and fulfilled life. **And research shows that the stronger our connections, the healthier our mind and body.**

Read about
**Social Connection
and Brain Health
on page 8.**

It is no secret that we are experiencing an epidemic of loneliness and isolation. Our Surgeon General recently highlighted the staggering toll it is taking on individuals and our society. Within our Parkinson's community, we witness poignant tales of isolation, from those recently diagnosed to people bravely navigating advancing stages of PD.

At APDA we are committed to combatting the loneliness problem by fostering connections in our community.

This giving season, I invite you to partner with APDA in our efforts to eradicate isolation and loneliness from our Parkinson's community. Positive change is on the horizon, and you can help us meet the challenge.

Here's how APDA will be working to ignite change:

- **Fostering Connection through Support Groups** such as PRESS for newly diagnosed, Powerful Tools for Caregivers, and specialized groups for Veterans, Spanish speakers, Young-Onset PD, and more
- **Cultivating Community via Interactive Events** both in-person and online, including Live Well Symposiums, YOPD-CON, and Take Control
- **Elevating Wellness with Personalized Programs** like our Beyond Medication: Wellness Workshops series and free specialized exercise classes

Take a moment to explore the progress we've already made in our infographic on page 7, showcasing the impact of APDA's crucial support and education. In 2024 we are committed to expanding this essential work and making a tangible difference in the lives of those impacted by Parkinson's.

This holiday season let's stand united in our resolve: no one should face the challenges of Parkinson's alone. It is never too late to strengthen your existing relationships, as well as build new ones within your PD community.

Sincerely,

Kirsten Richards
Executive Director

PS: Thank you for considering APDA in your annual giving. **Together let's be the change that our community needs.** Use the envelope in the middle of this issue to return a gift to APDA or donate online at adaparkinson.org/Northwest.

World Parkinson Congress: *The Road to Barcelona*



By **Bill Clugston**

A diagnosis of Parkinson's Disease (PD) is the beginning of a new and unexpected journey. Life plans vanish, and new roads appear. For myself and many of my fellow Parkies diagnosed with PD, the road led to Barcelona, Spain, and the World Parkinson's Congress for 2023.

The World Parkinson's Congress (WPC) was established in 2004 as an international forum for dialogue on scientific discoveries, medical practices, and care for Parkinson's disease. Anyone involved in the PD community is welcome and encouraged to attend. The World Parkinson Coalition Inc., a US-based nonprofit organization dedicated to bringing the global Parkinson's community together, organizes and runs the congress.

I attended my first WPC event in 2016 with my wife Sandy in Portland, OR. We were both overwhelmed by the number of programs available to Persons with Parkinson's (PWP) and the access we had to the researchers and clinicians working to cure PD. It was at the 2016 event that we both decided to be more active participants at a future WPC. We set sights on the 2022 WPC in Barcelona, Spain. That was the plan until the COVID-19 pandemic moved the date to 2023. Fortunately, if you have PD, you learn to deal with twists and turns in your journey! And sometimes, a detour can add new insights to your trip.

By late 2022, COVID-19 was fading from the world stage, and the Coalition finalized its plans for the Congress. I dusted off my Duolingo app and continued to learn Spanish. Nobody told me the primary language for Barcelona is Catalan – another twist in the road! Sandy and I joined the WPC choir, directed by Judi Spencer of Victory Drumming. The chosen song for the opening ceremony was named "The Road," composed by Charlotte Daniel and the members of the "Parky Players," a theatre group whose members have PD. Determined to help however we could, Sandy and I also joined the WPC volunteers.

A primary purpose of the Congress is to share knowledge and research on Parkinson's Disease. The plenary and focus group sessions are one of many information-sharing methods. Another method, one where persons with Parkinson's talk one-on-one with researchers and PD specialists, is the round table discussions. A third way of information sharing is the Abstract Sessions. Abstract presentations allow the discussion and sharing of new research, ideas, and methods that may slow or cure Parkinson's Disease. I was honored to present an abstract on using music playing to slow PD.

We arrived a few days before the Congress to get our bearings and get past the jet lag. Barcelona is a beautiful and welcoming city with many parks and



an excellent transportation system. The first WPC activity on our schedule was a volunteer event to fill attendee bags. It was a great way to get to know the other volunteers and to build cohesion within the volunteers! The next day brought another pre-congress event – the arrival of the Tour de Parkinson cyclists! Some of the cyclists came from as far away as the British Isles, and many of the cyclists were also PWPs. The arriving cyclists were met by a music celebration that included a drum circle, local Catalan singers, and music from around the world.

The day before the main congress is a day of pre-congress tracks focusing on advances in research and treatment, interprofessional care, our Parkinson's journey, advocacy, and young onset PD. For the people involved in the opening ceremony,



Barcelona skyline: Alessio Rinella

it was an afternoon of rehearsals and work! The choir rehearsed into the early afternoon and was released to rest our voices. The opening ceremony was only hours away!

The WPC choir was first up during the opening ceremony, and we climbed up onto the stage with a massive screen behind us, illustrating the hand-off from the 2019 Kyoto WPC to the 2023 Barcelona WPC. It was “performance time” for the choir! There is a particular adrenaline rush with being on a large stage with 2600 people in front of you! Singing “The Road” passed in what seemed like an instant, but the choir received a standing ovation — our months of hard work had paid off!

The opening ceremonies continued with Pamela Quinn’s dance group, a masterful saxophone performance by Tomas Gisbys, who was diagnosed with YOPD, and several WPC 2023 video entries. The real surprise was a video address by Sir Paul McCartney! Paul had a dear friend who had Parkinson’s Disease and wanted to speak on his behalf. The opening ceremonies came to a close, but now the actual business of the Congress was just beginning! It would be all hands on deck for the volunteers on the first official day of the Congress!

Soon it was time for my WPC abstract presentation. The abstract sessions are used by researchers, medical professionals, and persons living with Parkinson’s to communicate research findings, PD caregiving, and how PWPs live with PD in their daily lives. My abstract suggested that playing the Native American Style Flute is beneficial in slowing the progress of the disease. I was one of many with an alternative therapy abstract. During the two days of



abstract presentations, many discussed the benefits of music, singing, acting, and comedy improv for persons with PD. Having PD doesn’t require dropping out of life! Learning new skills can slow the disease.

The second full day of the Congress was filled with more volunteer duties. I had a Coffee Break concert with some of my friends from the WPC Choir in the afternoon. I was first up with a flute performance. By far, it was my largest venue to date!

On the third and final day of the Congress, Sandy was working the Renewal Room, and I spent a lot of time with the WPC Help Desk. After our volunteer shifts, it was time for the WPC closing ceremonies and another music session – this time, a drum circle led by Judi and Warren Spencer. The WPC main stage was becoming a familiar location for Sandy and me! One surprising note from the closing ceremony – there was no announcement of a venue for the next World’s Parkinson’s Congress! Parkie, the Parkinson’s Racon, was shown in a

video with his bags packed, heading out to evaluate more sites for the next WPC.

With the completion of the closing ceremony, the volunteers formed a corridor thanking the attendees for their attendance. The attendees were equally

grateful for the hard work of the volunteers!

I returned to my post at the WPC Help Desk for the final minutes of the Congress — and one closing example of the selflessness of the volunteer corp.

My sidekick at the help desk was Sam, a young man from Great Britain. Sam is on his way to his first year of college and does not

have PD, but his mother has young-onset Parkinson’s. Many young men his age would probably have a “blowout” summer before college, yet he chose to anchor the help desk for the three days of the congress. With his kind of selfless help, I can only believe that a cure for PD will come sooner rather than later! Consider attending the WPC no matter when or where the new location is! The memories and knowledge will stay with you forever on your Parkinson’s journey.



Bill and Sandy Clugston, enjoying the beauty at a park in Barcelona.



We are excited to introduce our newest staff member, **Katie Freeman, MSW**. As the Manager of Programs and Community Engagement, Katie will expand our resources and programming for caregivers and people with advanced Parkinson's, including those with Parkinson's disease dementia (PDD). They will also manage our network of support groups and facilitate two groups personally: one for spouses of people with advanced Parkinson's, and one for people with Atypical Parkinson's.

Before joining APDA Northwest, Katie spent seven years working with the memory loss community, providing programming and services to people with dementia along with their family and loved ones. Katie graduated from the University of Washington with a master's degree in Social Work, where they focused their studies on elder and disability care, health equity, and community organizing. Katie is eager to apply their experiences to a new community and contribute to APDA's mission of helping everyone impacted by Parkinson's disease access the care and support that they need.

Having Katie on the APDA Northwest team means that we can now offer much needed social work services. Social workers are valuable members of your care team who can connect you to resources, education, and community, all with the goal of reaching your best quality of life.

*Join us in welcoming
Katie Freeman to APDA!*

INTRODUCING OFFICE HOURS

Katie will start offering Office Hours beginning in January 2024! Community members and their families can sign up for 45-minute sessions, either in-person or on Zoom, to consult with Katie on their personal journeys with Parkinson's Disease.

Why sign up for a session?

For Newly Diagnosed:

- Receive a Newly Diagnosed Kit, including our Parkinson's Disease Handbook, Exercise Guide, and other personalized resources
- Learn about APDA Northwest's educational programs, like PD Essentials, where you can learn more about Parkinson's disease and the best ways to manage your health and wellbeing
- Get connected to local support groups, exercise classes, and more
- Develop tools for managing the emotions that come with a new diagnosis

For Caregivers:

- Sign up for the next session of Powerful Tools for Caregivers, a 6-week program all about caring for yourself while caring for a loved one with Parkinson's
- Find local caregiver specific support groups
- Get referrals to Parkinson's professionals, including caregivers, home health agencies, and more
- Learn about financial options for funding your loved one's care
- Discuss strategies for ensuring the safety of your loved one at home, in the community, and while travelling

For PDD

- Talk about your unique experiences and needs with an expert in neurodivergent communication
- Find dementia-friendly recreation, enrichment, and support programs in your area
- Learn about cognitive fitness and ways to keep your brain healthy and active

For Young-Onset Parkinson's Disease

- Discuss challenges in the workplace and learn more about workplace rights and ADA accommodations
- Get advice for talking about your condition with your kids and find age-appropriate resources for all members of your family
- Learn about ParkinSex and other tools to encourage intimacy and healthy relationships with your partners

For Community Members:

- Find out how to start a Parkinson's support group or exercise class in your community
- Learn the best ways to support your friends and neighbors with Parkinson's
- Get involved with Parkinson's advocacy on the community, state, and national level

For Parkinson's Professionals:

- Chat with Katie about the services you offer and join our referral network

For everyone in our community, Katie's Office Hours are an opportunity to be seen and heard by a compassionate social worker who can offer advice, reassurance, and connections to community.

Be Your Own Executive: Executive Functioning in Parkinson's Disease

By **Ariana Tart-Zelvin, PhD**
and **Nicholas Ensroth, B.Sc**
Swedish Center for Healthy Aging



Executive functioning is an umbrella term for higher level cognitive functions involved in planning, organizing information, inhibiting inappropriate behavior, prioritizing tasks, initiating appropriate behavior, and utilizing mental flexibility. These functions allow us to engage in goal-driven decisions and be able to seamlessly switch between multiple tasks. These “top-down” processes also include multi-step sequences, which allow us to successfully engage in more complex tasks of daily living such as cooking a meal, planning a grocery store run, or driving a car. Managing your finances, maintaining your home, meal planning and transportation all require executive functioning.

Several regions of and networks within the brain are associated with executive functioning such as the prefrontal cortex, anterior cingulate cortex, hippocampus, thalamus, posterior parietal cortex, basal ganglia, and the frontal-parietal network. For example, the dorsolateral prefrontal cortex is involved in planning, working memory, and cognitive flexibility whereas the ventromedial prefrontal cortex assists with emotion regulation and decision-making.

Learn More about Executive Function and PD!

Join Dr. Tart-Zelvin in a discussion at the APDA Northwest Take Control Program on December 15th at 1:00pm PT.

Live on Zoom. Register at www.apdaparkinson.org/events or watch the recording on the [APDA Northwest Youtube Channel](#)

Executive functioning can be just as susceptible to decline as other cognitive abilities such as memory or language in the context of a neurodegenerative process. Many people are quick to notice memory and language issues in themselves or their loved ones but declines in executive functioning may be more difficult to detect initially. In clinical evaluations, executive functioning may be measured with a variety of tests. For example, the patient might be required to remember specific rules and when to apply them. These tests translate to reality in situations such as driving a car, multi-tasking, and following sets of instructions.

Knowledge of what executive functioning is and the degree to which it is integral to one's daily life is important for anyone at risk of cognitive decline, but particularly those diagnosed with Parkinson's Disease (PD) or Parkinson's Disease Dementia (PDD), as studies have shown their executive functioning may be affected more than those diagnosed with Alzheimer's Disease (AD), for example.

On a simplified level, Parkinson's Disease (PD) is characterized by a lack of/loss of dopamine (dopaminergic neurons). While the physical symptoms will be quite salient for many people with PD, the neurocognitive symptoms of dopamine depletion can also greatly impact daily life. Declines in executive functioning can result in difficulties driving, keeping track of appointments and special events, and engaging in more complex activities such as cooking or managing finances or medications. While studies have shown that dopamine-replacement medications can be helpful to improve functioning to a degree, there are also several cognitive and behavioral strategies that PD patients can utilize. For example, to address changes in executive functioning, individuals can:

- **External Compensatory Aids** - The use of compensatory aids, such as planners, checklists, alarms, or written

reminders are typically helpful. Checklists can be particularly helpful when completing a multi-step task such as cooking a meal or packing for a trip. When possible, the individual is encouraged to set alarms on a phone or smart home device to remind the person to check said aids regularly. Events, appointments, and important information should be immediately written down or entered into a phone or planner. The person should keep this information in visible, easy to find places.

- **Simplify Tasks** – It is recommended that the person engage in one activity or task at a time, rather than trying to balance multiple tasks (i.e., multi-task) or projects at once, reduce distractions as much as possible and that the person allows more time to complete tasks.
- **Meditation and Mindfulness** – Research shows that practicing meditation and/or mindfulness can help to improve attention, emotional regulation, and overall executive functioning.
- **Medication Management** – It is important for individuals with PD to closely monitor their medication regimen. Assistance from a trusted individual as well as a regularly utilized pillbox can be incredibly beneficial. **Extra tip** – use a smart pillbox or an app on your smartphone that will notify you or a support individual if you forget to take your medication! The APDA Symptom Tracker app (www.apdaparkinson.org/apda-symptom-tracker/) can be used to track medications.

Employing these strategies above can help you keep doing the things that you love to do and live your best life with Parkinson's disease.

- **Social and Cognitive Engagement** – Regular engagement with others or in an activity helps to stimulate the brain, improve problem-solving, and reduce stress which can negatively affect cognitive functioning.

- **Cognitive Rehabilitation** – Cognitive rehabilitation refers to evidenced-based interventions that can improve an individual's ability to perform cognitive functions and everyday tasks by providing patients with compensatory strategy training. When appropriate, patients may also be retrained in previously learned skills. This service is typically provided via speech language pathologists, psychologists, and neuropsychologists.

Parkinson's disease causes numerous physical and cognitive changes that can make accomplishing everyday tasks challenging, including changes in executive functioning. But, just like there are ways to adapt to the physical changes of Parkinson's through exercise and rehabilitation therapies, you can find

ways to adapt to the cognitive changes as well. Employing the strategies above can help you keep doing the things that you love to do and live your best life with Parkinson's disease.



Dr. Ariana Tart-Zelvin, PhD, is a Clinical Neuropsychologist with the Swedish Program for Healthy Aging, part of the Swedish Neuroscience Institute. She has specialized training in in brain and behavior relationships and sees patients with Alzheimer's and Parkinson's disease, various dementias, multiple sclerosis, ALS, brain tumors and brain injuries.

EVERY



MINUTES

Every 6 minutes someone in the US is diagnosed with Parkinson's disease. 10 per hour. 240 per day.

How your **DONATIONS** to **APDA** are making an impact:



Empowering thousands of people living with PD through education, support, connections, and resources.



Informing through our virtual education series, which offers timely and timeless topics presented by local experts helpful for all states of PD.



STRENGTH IN OPTIMISM

Promoting hope and optimism to the newly diagnosed with education, resources, and support:

- 8 week PRESS support series (Parkinson's Roadmap for Education and Support Services)
- PD Essentials: a 75 minute introduction to Parkinson's. Offered monthly, in-person and virtually
- Good Start education programs

Hosting opportunities to connect and learn with in-person education conferences, such as Live Well South Sound and YOPD-CON.



Publishing our quarterly *Parkinson's Pathfinder* — with a distribution list of more than 15,000 — featuring insightful and inspiring articles written by experts and people living with PD.

HOPE IN PROGRESS

Extending our presence into under-resourced and underserved areas with our new Manager of Programs and Community Engagement, who is also increasing the assistance and resources available to the nearly 200 support groups across our 5-state region.



Investing in cutting edge research with nearly \$2 Million awarded in 2023-2024. We also fully fund the local Parkinson's Research Registry, connecting researchers to study participants which helps research happen faster.



Keeping everyone active and engaged with our free virtual exercise and wellness programs, catering to a wide range of interests including yoga, dance, tai chi, singing, and more.



Providing reliable and vital education and information through our online Parkinson's Resource Library. Find publications, blog posts, webinars, and more. Print versions are also available free of charge.



Offering essential resources, valuable information, and a compassionate ear to those who reach out to our local helpline.

YOU CAN HELP! What your gift to APDA can pay for:

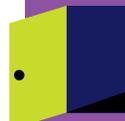
\$100

Funds one **virtual exercise class**, keeping wellness accessible and free.



\$250

Covers the cost of one **virtual PD Essentials**. Double your gift to bring an in-person PD Essentials to your town!



\$500

Enables our **on-staff Social Worker** to offer **individual appointments** providing 1:1 support and resource guidance.

\$1000

Brings a 4-week online **Beyond Medication: Wellness Workshop** to life





Social Connection *and* Brain Health

by **Katie Freeman, MSW**

An epidemic of loneliness and isolation is affecting Americans' health and well-being.

In May 2023, the U.S. Surgeon General, Dr. Vivek H. Murthy, released an advisory report¹ identifying a surprising epidemic sweeping the nation. It's not a virus or a disease, but rather an epidemic of loneliness and isolation affecting Americans' health and well-being. This is especially evident among those with Parkinson's Disease (PD).

Recent trends in the United States indicate a change in our social connections. Our social networks are shrinking, and fewer people are engaging in social activities. More people are living alone instead of with family or roommates. Between 2003 and 2020, the time we spent alone increased by an average of 24 hours a month. Growing political polarization has eroded our trust in each other. The COVID-19 pandemic and related restrictions exacerbated these trends in the U.S. and worldwide², and they will likely have long-standing impacts on our physical, psychological, and cognitive health.

Social connection encompasses our interactions, relationships, roles in our communities, and the sense of belonging we feel. These connections are as vital to our survival as food, water, and shelter. Humans are inherently social beings, relying on each other for survival, just as we did thousands of years ago. Our bodies and brains have evolved

to depend on these connections for optimal health. We are biologically wired for social connection; our brains have adapted to expect proximity to others.

People who are more socially connected live longer and have better physical, mental, and cognitive health outcomes. Social isolation, on the other hand, can lead to poorer health outcomes and shorter lifespans. Chronic social isolation can increase the risk of premature death as much as smoking up to 15 cigarettes a day.

Social connection affects our health through three main pathways: biological, psychological, and behavioral. Numerous studies have demonstrated its impact on our cardiovascular and neuroendocrine systems, immune functions, and gut-microbiome interactions, all crucial for good health.

Additionally, social isolation can increase inflammation, similar to physical inactivity. In contrast, social connection has been shown to improve blood pressure and cardiovascular responses and reduce oxidative stress. It aids in regulating our neuroendocrine system and gives us meaning, purpose, and stress relief. Social connections can also serve as a buffer against harmful coping mechanisms and the negative health effects of stress. Furthermore, our social ties influence health-related



TIPS FOR INCREASING SOCIAL CONNECTION:

PARTICIPATE in a group exercise class instead of working out alone.

JOIN a book club or discussion group. Libraries, community centers, and spiritual/cultural communities often offer these for free.

VOLUNTEER for a cause that you're passionate about. Help school kids with their homework, pack lunches at a foodbank, or clean up your favorite hiking trail.

INVEST time in your existing relationships. Pick up the phone, meet up for coffee, or go for a walk together.

ASK for help from family, friends, or professionals if you're struggling.

behaviors like diet, sleep, exercise, and medication and treatment adherence.

Various factors affect our ability to connect with others. On an individual level, these include socioeconomic status, race, gender, class, health, disability, and life stage. Structural factors are also at play. Availability of socializing places in the community, workplace policies that promote work-life balance versus long hours, access to transportation, and housing affordability all matter. On a broader level, cultural norms, values, public policies, civic engagement, and historical inequalities impact our ability to connect.

Due to these individual and structural factors, many people with Parkinson's (PWP) face barriers to social connection. The condition is stigmatized, leading to judgment, ostracization, and discrimination. PWP may isolate themselves due to embarrassment about symptoms like tremors, gait problems, or drooling³. Parkinson's is also associated with depression, which can lead to social withdrawal.

Due to a lack of accessible transportation and programs and services for people with Parkinson's in their communities, many become isolated at home. This isolation poses a significant problem for those with PD because social connection is vital for brain health. In addition, chronic loneliness and social isolation can increase the risk of developing dementia by approximately 50% in older adults.

Social connection has proven to be an important protective factor against neurodegeneration due to the way it increases cognitive reserve⁴.

Cognitive reserve is, in essence, the brain's ability to deal with damage or pathology⁵, a concept identified in research since the late 1980s. In studies of people with Alzheimer's disease, researchers observed differences between the physical damage in the brain (neuropathology) and the expected cognitive and behavioral symptoms. This discrepancy highlighted cognitive reserve as an additional protective factor, representing the brain's resilience in the face of disease.

Cognitive reserve shows up through two modes in the brain. The first is Neural Reserve, where neural networks become more efficient, flexible, and capable of handling disruptions caused by brain damage. The second is Neural Compensation, where the brain starts using different structures and networks not typically utilized by individuals without these diseases, compensating for pathology. Numerous factors influence our brain's capacity for cognitive reserve, including education, socioeconomic status, and social connection. **For people with Parkinson's, social connections can enhance cognitive reserve and bolster brain resilience.**

As a community, we can collaborate to create more opportunities for social connection among PWP. Here at APDA Northwest, we provide support groups, community events, art and exercise classes, and many more opportunities to connect with others.

Want to get something started in your neighborhood? Let us know, and we can offer guidance on starting a Parkinson's support group, social club, or fitness class!

Endnotes

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APDA Proudly Supports New 2023-2024 Parkinson's Research: Exciting New Parkinson's Research is Underway

On September 7, 2023, APDA announced 20 new Parkinson's disease (PD) research grants, for a total of \$1.975 million in funding for the year ahead.

Our grant recipients are working tirelessly to understand the complexities of Parkinson's disease and to develop new treatments and eventually, a cure. We are honored to support these researchers and their innovative and inspiring work.

The 2023-2024 APDA Parkinson's Disease Research Grants and Fellowships:

THE GEORGE C. COTZIAS FELLOWSHIP

The George C. Cotzias Fellowship is APDA's most prestigious award and is granted to a young physician-scientist with exceptional promise who is establishing a career in research, teaching, and clinical services relevant to PD. The award spans three years and is designed to fund a long-range project focused on PD.

THIS YEAR'S AWARDEE IS:



KRITHI IRMADY, MD, PHD

RNA regulation in Parkinson's disease

and levodopa-induced dyskinesia
Rockefeller University, New York, NY

Major question to be answered: How do changes in RNA and RNA-binding proteins contribute to the development and progression of Parkinson's disease (PD) and levodopa-induced dyskinesia (LID) in the dopamine-dependent regions of the brain?

Why is this important? This research will analyze the changes in RNA and RNA-binding proteins that occur in people with PD and specifically those with LIDs. LIDs are poorly understood and are a difficult to treat side effect of levodopa. By understanding these RNA changes that occur in those with LIDs, new paradigms of treatment can be designed to address LIDs.

DIVERSITY IN PARKINSON'S DISEASE RESEARCH GRANTS

This grant supports the study of the health inequities and/or differences among under-studied PD communities, across the spectrum of ethnicity, ancestry, geography, socioeconomic conditions, and gender.

THIS YEAR'S AWARDEES ARE:



KAREN HEGLAND, PHD

Low utilization of deep brain stimulation (DBS) therapy among minoritized individuals with Parkinson disease
University of Florida, Gainesville, FL

Major questions to be answered: What are the patient characteristics that can predict the suitability of Deep Brain Stimulation (DBS) surgery?

How do patients perceive the key factors influencing their acceptance of DBS?
Are there ethnic disparities in the quality of life experienced by individuals who have undergone DBS surgery?

Why is this important? By utilizing a mixed methods approach, the study aims to uncover patient predictors for DBS surgery, explore patient perspectives on DBS acceptance factors, and analyze potential ethnic differences in the quality of life among DBS recipients. This knowledge could empower healthcare providers to remove barriers and ensure equitable access to advanced care options, ultimately enhancing the well-being of all PD patients.



LAURA ANDREA PRIETO, PHD

Physical Activity Among Latino/a People with

Parkinson Disease and their Care Partners
University of Wisconsin Madison, Madison, WI

Major question to be answered: How do individual and community-based factors impact the engagement of physical activity, encompassing motivation, access, and participation, among Latino/a individuals with PD and their care partners?

Why is this important? This research aims to uncover the intricate influences on physical activity engagement within the Latino/a PD community and among their care partners. By exploring the factors that affect physical activity access and participation, the research strives to enhance the well-being of Latino/a individuals with PD. Furthermore, insights into care partners' roles and the potential for broader applications to other under-represented groups could lead to more inclusive physical activity programs.

POST-DOCTORAL FELLOWSHIPS

This two-year fellowship is awarded to support post-doctoral scientists, who recently completed their graduate degree work, and whose research holds promise to provide new insights into the pathophysiology, etiology, and treatment of PD.

THIS YEAR'S AWARDEES ARE:



ABDULMUNAIM EID, MD

The Neurobiological Basis of Parkinson's

Disease Clinical Subtypes
Washington University, St. Louis, MO

Major question to be answered: What are the biological differences between distinct clinical subtypes of PD such as 'motor only' 'cognitive & motor' and 'psychiatric & motor' using advanced neuroimaging methods?

Why is this important? This research addresses the complexity of PD which encompasses motor, cognitive, and psychiatric issues. Identifying

and understanding clinical subtypes is pivotal for predicting disease progression accurately and tailoring treatments for individual patients. By revealing the underlying biological differences using advanced neuroimaging techniques such as magnetic resonance imaging (MRI) and positron emission tomography (PET), this study contributes to a deeper understanding of PD subtypes.



NAEMEH POURSHAFIE, PHD

Enhancing neuronal resilience to neurode-

generation via the epigenetic-metabolic axis *University of Pennsylvania, Philadelphia, PA*

Major question to be answered: What is the intricate interplay between the proteins α -synuclein and tau, and how do they collectively contribute to cognitive decline in PD and related conditions?

Why is this important? In many people, abnormalities of both α -synuclein and tau are responsible for cognitive difficulties in PD dementia and Dementia with Lewy bodies. This research will investigate the complex relationship between these two proteins and how their gene expressions are modulated, with the goal of uncovering potential avenues for protecting neurons from their damaging effects.

RESEARCH GRANTS

The APDA Research Grant is awarded to investigators performing innovative PD research.

THIS YEAR'S AWARDEES ARE:



ANDREW ARRANT, PHD

Investigating the Role of Progranulin in

Synucleinopathy *University of Alabama at Birmingham, Birmingham, AL*

Major questions to be answered: What is the relationship between progranulin and α -synuclein aggregation? Does this relationship worsen neuronal loss, inflammation, lysosomal dysfunction, and behavioral deficits associated with α -synuclein aggregation?

Why is this important? This research will investigate whether low progranulin levels contribute to α -synuclein aggregation. Understanding this relationship could provide crucial knowledge for potential treatments addressing neurodegeneration in PD. Progranulin-boosting treatments are already in clinical trial for other conditions, and these potential treatments could also be tested in people with PD.



BRIANA DE MIRANDA, PHD

Cdk5 inhibition as a protective mechanism

against environmental toxicant induced Parkinson's disease *University of Alabama at Birmingham, Birmingham, AL*

Major question to be answered: Does inhibiting cyclin dependent kinase 5 (Cdk5) offer protection against PD pathology that is triggered by trichloroethylene (TCE) exposure?

Why is this important? Exposure to TCE has been linked to an increased risk of PD, but it is not understood how this happens. This study will investigate whether increased Cdk5 activity is involved. By understanding how TCE increases PD risk, then steps could be taken, such as decreasing Cdk5 activity, to mitigate this risk. Of note, there are ongoing clinical trials of cyclin dependent kinase inhibitors in certain cancers and these potential treatments could be tested in people with PD as well.



JEFF EELLS, PHD

Mechanisms of SARS-CoV-2 infection induced dopamine neuron damage

East Carolina University, Greenville, NC

Major question to be answered: Does SARS-CoV-2 infection harm dopamine neurons?

Why is this important? The potential relationship between SARS-CoV-2 infection and PD risk has been incompletely explored. This study will increase our understanding of how the virus might damage dopamine neurons or influence the accumulation of the PD-related protein α -synuclein.



ENRICO OPRI, PHD

Stimulation induced evoked potentials for guided intra and post-

operative functional mapping. *The Regents of the University of Michigan, Ann Arbor, MI*

Major question to be answered: Can deep brain stimulation (DBS) local evoked potentials (DLEP) effectively enhance the precision of anatomic targeting during asleep DBS surgery, providing improved mapping information for clinical targeting?

Why is this important? Using DLEPs to target the precise brain location for electrode placement during asleep DBS surgeries offers a potential alternative to doing awake surgeries. Furthermore, the study will test the predictive power of the intraoperative DLEP-based localization in informing which DBS contacts provide the patient with the best motor therapeutic benefit post-operatively. Successful integration of DLEP-based mapping could enhance targeting and programming accuracy and thereby improve treatment outcomes.



NIKHIL PANICKER, PHD

Using iPSC models to interrogate

Inflammasome-mediated pathogenesis in Parkinson's Disease *Cleveland Clinic Foundation, Cleveland, OH*

Major question to be answered: How does the immune response contribute to the spread of α -synuclein in PD?

Why is this important? Recent studies suggest that the body's immune system may play a role in PD pathology. Excessive inflammation in the brain, caused by immune cells known as microglia, has been linked to PD progression. The NLRP3 inflammasome, a complex of proteins, appears to be overactivated in microglia in PD. This study will explore whether reducing inflammation within microglia can protect neurons from accumulating α -synuclein. This approach can open new avenues of PD treatment.



SATYA SURABHI, PHD

The role of Lamp1 in age-related neurodegenerative diseases *Albert Einstein College of Medicine, Bronx, NY*

Major question to be answered: How does fruit fly Lamp1 impact the mechanism of a-synuclein clearance in the brain?

Why is this important? Lamp1 is responsible for clearance of proteins in the fruit fly and may resemble the PD genetic risk

factor GBA1. This research will use the fruit fly model to understand Lamp1's role in a-synuclein clearance thereby furthering our understanding of PD neurodegeneration.



WILLIAM ZEIGER, MD, PHD

Mechanisms of posterior cortical circuit dysfunction and cognitive impairment in a mouse model of PD *University of California, Los Angeles, Los Angeles, CA*

Major questions to be answered: How does the accumulation of a-synuclein in the brain contribute to the dysfunction of brain cells responsible for thinking and memory problems in PD?

Why is this important? Cognitive dysfunction in PD has a major impact on quality of life. This study will focus on the relationship between a-synuclein accumulation, and the cognitive impairments experienced by PD patients with the goal of finding ways to treat this difficult symptom.



Quotes from Attendees:

“All I can speak of is high praise, joy, hope, and my extended and growing community that is a direct result of this conference. **This has genuinely been a life-changer for us, or at least for me.** As I’ve mentioned to several individuals, we literally have never met anyone our age with Parkinson’s. Additionally, we have heard real, true and ACTIONABLE next steps. There is no way to quantify how beneficial this is.”

“YOPD con was the first thing I have done with any other people connected to my YOPD. I was drawn to go based on the interesting topics and meet fellow peeps, but primarily as **motivation to regain some fighting spirit and motivation that had slipped away in the last year.** The conference exceeded my expectations.”

“Thank you for putting on this event that is so important for patients and their loved ones!”

“Thank you for putting on this event that is **so important for patients and their loved ones!**”

“Thank you SO much for offering this. It didn’t seem like a first time event. Everything seemed to run smoothly, **the speakers were relevant, the food and set up was great, and the variety of activities was spectacular.**”

I would like to thank everyone for putting this on!! Definitely very beneficial and full of information. Husband was diagnosed 2 months ago. **Definitely have seen the light at the end of the tunnel & “we are in this together.”**

“We loved our weekend at YOPD con!”

Thank you for your financial support of this event!



Abbott, Acorda Therapeutics, Kyowa Kirin, Medtronic, Neurocrine Biosciences, Supernus



OPTIMISM filled the air on September 30 in Seattle, Olympia, and Bainbridge Island at our annual APDA Optimism Walks where we celebrated our local Parkinson's communities.

Top Fundraising Teams

SEAYOPD celebrates after raising more than \$37,000, the highest team total for ANY Optimism Walk around the country!

YOGA FOR PD TEAM Yoga for PD led by Peter Lynch raised \$21,205.



The weather was chilly, but spirits were high, and thanks to the fundraising efforts of nearly 500 walkers this year's Optimism Walks were a tremendous success! We crushed our fundraising goal and raised just shy of \$220,000 to pay for local support, education, and research. The Olympia walk helped push us over the top, raising \$37,447 in just their second year.

We recognized 28 individual fundraisers who each raised over \$1,000 and were awarded Circle of Optimism medals. Suzanne Cameron, Paul Herber, and Dustin Werner had record-breaking efforts in Seattle, and each raised over \$7,000. Bob Dixon and Helen Miller took home the top prizes for the Olympia walk.



The Olympia Walk was led by **PD Thrivers** which raised over \$12,000, and **CHS for Coach Miller** raised \$8,600 in their first year.



From left: Professional boxer Greg Cruz sparred with walkers in Seattle; Team Forever Optimistic and others along the Ship Canal Trail in Seattle; Olympia walkers show their support

THANK YOU TO OUR SPONSORS



SAVE THE DATE

The Magic of Hope

GALA & AUCTION
BENEFITTING APDA

**Saturday,
March 2, 2024
5:00 p.m.**

Seattle Design Center

We hope you can join us on March 2 for a festive evening of cocktails, dinner, auction items, and merriment, where you will find many ways to support and celebrate our Parkinson's community! Magic of Hope is our biggest fundraiser of the year, with a lofty goal to raise \$600,000. **The funds raised will further APDA's mission to provide support, education, and research that will help everyone impacted by Parkinson's disease live life to the fullest.**

We are pleased to be honoring **Diane Bundrant and Trident Seafoods** for their years of generous support of APDA and commitment to providing creative solutions for making a positive impact on our Parkinson's community.

We will also be recognizing our **2024 APDA Optimism Award winners**, and nominations are now open! Please help us recognize and celebrate the extraordinary individuals who are demonstrating optimism through their important contributions to our Parkinson's community, and providing inspiration and hope for all that can be achieved. You can find more information at apdaparkinson.org/magicofhope. Nominations are due January 5.

Registration will open in early December. Can't make it to Seattle on March 2? You can still participate in the online auction featuring fabulous items including sports tickets, vacation packages, and restaurant gift cards. We will also be livestreaming the event.



Honoree Diane Bundrant and late husband Chuck at 2019 Captains for a Cure.



Executive Director Kirsten Richards with 2023 Optimism Award Winner, Brian Harris

Strength in optimism. Hope in progress.

130 Nickerson Street, Suite 300
Seattle, WA 98109

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**YES! I want to help provide the support, education, and research that will
help everyone impacted by Parkinson's disease live life to the fullest.**

Please clip and return with your check in the envelope provided in the center of this magazine,
or mail to us at **130 Nickerson St, Suite 300, Seattle WA 98109**

To donate by credit/debit card, please visit our website apdaparkinson.org/northwest or call **206.695.2905**

The Northwest Chapter of the American Parkinson Disease Association is a non-profit 501(c)3 organization. Our tax ID number is 13-1962771.



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Contact me with information on how wills and bequest can support the Northwest Chapter of APDA.

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***Thank you for
your generosity!***