



DAVIS PHINNEY

Foundation For Parkinson's

every victory counts®

THE VICTORY SUMMIT[®]
VIRTUAL EVENT

MOTOR SYMPTOMS

Friday, June 24, 2022

THANK YOU FOR JOINING TODAY.

Parkinson's is officially classified as a movement disorder because it involves damage to the areas of the brain, nerves, and muscles that influence the speed, quality, fluency, and ease of movement. Motor (or movement-related) symptoms are usually the most visible elements of Parkinson's, and when you have motor symptoms that are not well managed or don't always lessen with medication, your quality of life can suffer.

During The Victory Summit Event: Motor Symptoms and Parkinson's, we'll take a deep dive into the different types of motor symptoms and what causes them, medication management strategies, how to manage motor symptoms during OFF times, how to move well and reduce the risk of falling, and more.

In addition, we will feature short movement breaks that fit the event's theme and will show you how to move to manage these symptoms. By the end of the morning, you will know more about the various motor symptoms you or your loved one may experience and how you can take action to manage these symptoms, improve your quality of life, and live well with Parkinson's today.

Today is just the beginning. Our staff, sponsors, resources, and speakers will be available today, tomorrow, and beyond to support you. We're glad you've joined us!



This program book includes a special resources section starting on page 10.

THE VICTORY SUMMIT® VIRTUAL EVENT AGENDA

MOTOR SYMPTOMS

To download today’s slides and other resources, visit dpf.org/vs-motor-symptoms.
All times listed are MDT.

9:00 – 9:10	Welcome and Agenda <i>Polly Dawkins, Executive Director, Davis Phinney Foundation</i>	11:05 – 11:45	Panel Managing Motor Symptoms During OFF Times <i>Yasar Torres-Yaghi, MDS, Attending Physician, Movement Disorders; Assistant Professor, Department of Neurology at Georgetown University</i> <i>Amanda Craig, OTR/L, Occupational Therapist and Owner, Ada Therapy Services, PLLC</i> <i>Joe Koeverden, Ambassador, Davis Phinney Foundation</i>
9:10 – 9:20	How to Live Well with Motor Symptoms <i>Davis Phinney, Founder, Davis Phinney Foundation</i>		
9:20 – 10:05	The What and Why of Parkinson’s Motor Symptoms <i>Suketu Khandhar, MD, Medical Director at Kaiser Permanente Northern California Movement Disorders Program, Kaiser Permanente Sacramento Medical Center</i>	11:45 – 12:15	Taking Action to Prevent Falls and Fall “Safely” <i>Hannah Fugle, DPT, Physical Therapist, Northwest Rehabilitation Associates</i>
10:05 – 10:45	Medication Management Strategies for Motor Symptoms <i>Aaron Haug, MD, Neurologist and Movement Disorders Specialist, HealthONE Neurology Specialists</i>	12:15 – 12:30	Closing Remarks and Takeaways <i>Polly Dawkins and Davis Phinney</i>
10:45 – 10:55	Movement Break: Boxing for Parkinson’s <i>Lori DePorter, Rock Steady Boxing Coach</i>		
10:55 – 11:05	Screen Break Step away, stretch, use the restroom, take care of yourself		

MEET TODAY'S SPEAKERS



AMANDA CRAIG, OTR/L

Amanda Craig is a licensed occupational therapist, certified brain injury specialist, and owner of Ada Therapy Services, PLLC in Boise, ID. Amanda provides individualized outpatient treatment for adults and adolescents experiencing functional “real life” deficits caused by neurological and chronic conditions. Amanda completed her bachelor’s degree from Philadelphia University/Thomas Jefferson University and a graduate degree in occupational therapy from Idaho State University. Amanda stays active in Boise, Idaho, with her husband and identical twins, mountain biking, skiing, traveling, and cooking.



POLLY DAWKINS

Polly joined the Davis Phinney Foundation as the Executive Director in 2011. Polly’s track record managing and growing organizations responsibly and with transparency for over 25 years dovetails with her humanitarian worldview. She is committed to making wise use of the Foundation’s resources, enabling it to extend its reach while staying true to its mission. Polly is passionate about helping people with Parkinson’s thrive and has become a leader in this space by providing education, creating opportunities for the community to connect, and funding quality of life research that takes the guesswork out of living well.

Polly holds an MBA in International Business from Thunderbird School of Global Management and a BA in International Studies from Earlham College. When Polly isn’t behind her desk or traveling to Parkinson’s communities around the world, you’ll find her creating music lists for her indoor cycling classes, exploring Colorado on her road bike, swimming laps outside, and hosting family and friends from around the world. She’s powered by sunshine, though, so you might also find her lying on a rock soaking up the sun like a lizard.



LORI DEPORTER

Lori DePorter is a certified personal trainer, Rock Steady Boxing Coach, and writer. After being diagnosed with young-onset Parkinson’s in 2014 at the age of 45, she became an advocate for Parkinson’s awareness, especially on the benefits of exercise, music, and dance. Lori teaches classes regularly that combine these three activities with information on neuroplasticity principles to promote healthy brain activity and growth. You can find Lori’s writings on her blog “Dance Like No One is Watching”, on BioNews Services, and via her bi-weekly column “Life, Lemons, and Lemonade” on Parkinson’s News Today.



HANNAH FUGLE, PT, DPT

Dr. Hannah Fugle has extensive coursework and training in neurological rehabilitation. She received her Doctor of Physical Therapy in 2017 from Northern Arizona University and currently practices at St. Charles Healthcare in Bend, OR. She specializes in treating individuals with neurologic diagnoses and has a particular interest in managing neurodegenerative conditions, including Parkinson's and multiple sclerosis. Additionally, she has experience treating vestibular disorders, imbalance/falls, concussion, and pelvic dysfunction. Hannah focuses on empowering her patients with skills and knowledge to promote self-management, optimize quality of life, and maintain functional mobility.



AARON HAUG, MD

Dr. Aaron Haug is a neurologist and movement disorder specialist in Colorado. He completed his pre-medical courses with honors at Creighton University and earned his medical degree at the University of Kansas. He completed a neurology residency and a movement disorders fellowship at the University of Colorado, including a year as Chief Resident. Dr. Haug focuses on Parkinson's disease, tremor, and other movement disorders in his clinical practice. He also has deep expertise in medical management and deep brain stimulation (DBS) to treat these conditions. When he's not working, he likes to spend time with his family, play ultimate frisbee, and follow Colorado Rockies baseball.



SUKETU KHANDHAR, MD

Dr. Suketu Khandhar is a Movement Disorder Specialist and the Medical Director of the Comprehensive Movement Disorders Program for Northern California, Kaiser Permanente. He completed a fellowship in Parkinson's disease & Movement Disorders at the University of California, San Francisco. Dr. Khandhar works with a team of specialists focusing on Parkinson's, Essential Tremor, and Dystonia. He is a champion of multi-disciplinary care using an integrated practice model.



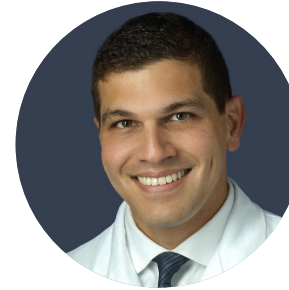
JOE VAN KOEVERDEN

Joe van Koeeverden was diagnosed in March 2012 after a year of testing to determine the cause of his dragging left leg and the tremor in his left hand. Not being able to diagnose Joe, his general practitioner sent him to the local hospital emergency department to have a complete medical exam, which resulted in a meeting with a neurologist and a Parkinson's diagnosis. Joe served as an Ambassador for the Davis Phinney Foundation and, along with his workout partner, Lanny, helps their Parkinson's chapter to reach more people with Parkinson's in Canada.



DAVIS PHINNEY

Davis Phinney was fresh off a successful professional cycling career, where he won an Olympic bronze medal in 1984 and was part of the first American team to race in the Tour de France, when he was diagnosed with Parkinson's. He founded the Davis Phinney Foundation in 2004 with the goal of helping people living with Parkinson's to improve their quality of life through education, inspiration, resources, and effective self-care. Davis' perseverance, coupled with his infectious positive attitude and dedication, inspires the work of the Davis Phinney Foundation and has earned him the reputation as a tireless advocate and mentor for others living with Parkinson's. In spring 2015, he was honored at the White House as a Champion of Change because of his work in the Parkinson's community.



YASAR TORRES-YAGHI, MDS

Dr. Yasar Torres-Yaghi is co-Director of the Lewy Body Dementia Clinic, spearheading an initiative to care for a growing population of aging patients with neurodegenerative conditions. Yaghi obtained his medical degree from George Washington University School of Medicine and completed his residency and fellowship training at MedStar Georgetown University Hospital. His sub-specialty training was in neurorestoration research in movement disorders and dementia, where he actively took part in clinical research. His research focuses on neurodegeneration and movement disorders such as Lewy body dementia and Parkinson's. Additionally, he evaluates patients with Alzheimer's disease, chronic traumatic encephalopathy, and Huntington's disease.

RESOURCES TO HELP YOU LIVE WELL **TODAY.**

You took a great step towards living well by joining today's event. Read on to learn more about other programs and resources available to help you continue on your journey.



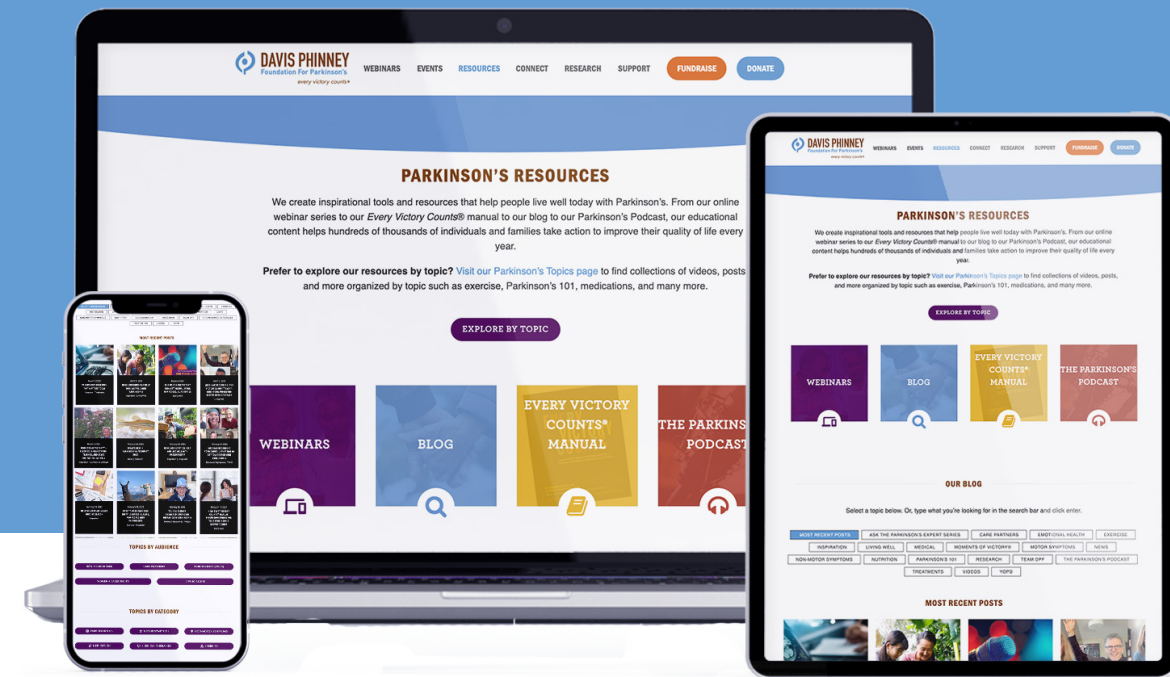
MEET OUR AMBASSADORS



When we created our Ambassador Leadership Program in 2015, we did so because we recognized that, more than anything, our community members want more connection to people who truly understand what it means to live with Parkinson's. We hear so often that the support of our Ambassadors goes far beyond resources and advice. Our Ambassadors offer people a safe place that allows for real processing and change to happen.

The experience and wisdom our Ambassadors bring to the Parkinson's community are transformative, and we hope you will reach out to them throughout your journey with Parkinson's. Connect with an Ambassador in your area or reach out to anyone you think you would connect well with, regardless of location. Ask questions, discover new resources, and get advice on how to live well with Parkinson's.

Ask questions, discover new resources, and get advice on how to live well with Parkinson's at dcpf.org/ambassadors.



CHARTING YOUR COURSE

A Parkinson's Primer for the Newly Diagnosed

Last year, we launched Charting Your Course, a self-paced four-week online program for people newly diagnosed with Parkinson's. The course consists of:

- » **Week One** – advice about reframing your mindset, taking action, building your Parkinson's care team, and reducing stress and worry.
- » **Week Two** – all about movement—why exercise is medicine for the brain, how to motivate yourself to get moving, how to find a physical therapist, and more.
- » **Week Three** – all about symptoms and how to manage them, with information and advice about many common motor and non-motor symptoms.
- » **Week Four** – a deep-dive into treatments, from medication and surgical therapies to rehabilitative and complementary therapies.

Much like today's event, Charting Your Course is positive, accessible, actionable, and filled with *just enough* information, helping you learn about Parkinson's and how to live well with it without becoming overwhelmed.

Learn more and register at dpf.org/charting-your-course.

For more information on everything from exercise, treatments, complementary therapies, and more, we've created an online resource especially for you.

Visit www.dpf.org/resources and you'll find sections on:

- » Parkinson's tools, techniques, and technology
- » Parkinson's organizations
- » Parkinson's experts and Ambassadors
- » The Victory Summit® event speakers
- » *Every Victory Counts® manuals*
- » And more!

In addition, you'll learn ways to take what you learned at The Victory Summit® event and put it into action to live well today and in the future.

EVERY VICTORY COUNTS®



*Your go-to guide for living well
with Parkinson's*



Available in print, digital, and audio.

First published in 2010, the Every Victory Counts® manual broke new ground as the only resource of its kind, devoted solely to the principle of proactive self-care and a holistic approach to managing Parkinson's. In subsequent editions, it has gained international recognition as a superb and comprehensive resource for changing the way people live with Parkinson's. Now in its sixth edition, the manual is the cornerstone of our new Every Victory Counts suite of resources, a robust collection of printed and digital manuals that embrace the Davis Phinney Foundation's philosophy of taking action to improve your quality of life with Parkinson's. In it, you'll find:

- » Essential information about Parkinson's plus dozens of topics that are frequently overlooked but critical to helping you live well
- » Insights from more than 50 Parkinson's experts, including physicians, therapists, and scientists who share cutting edge research, strategies, and ideas for living well with Parkinson's
- » Advice and inspiration from dozens of people living well with Parkinson's today
- » In-depth information about exercise, nutrition, emotional health, medication, therapies, and more

The Every Victory Counts collection includes:

- » The *Every Victory Counts* manual, print and digital
- » The *Every Victory Counts* manual for Care Partners, print and digital
- » *Every Victory Counts* Worksheets and Assessments
- » *Every Victory Counts* Discussion Guides
- » *Every Victory Counts* Companion Website
- » And more to come!

Order your complimentary copy of the Every Victory Counts manual and/or the Every Victory Counts Manual for Care Partners today at EveryVictoryCounts.org.

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www.MoreToParkinsons.com



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Biopharmaceutical company that markets two products, including INBRIJA® (levodopa inhalation powder). www.acorda.com and www.inbrija.com



Amneal

At Amneal, it's our mission to make healthy possible for people affected by Parkinson's. We believe in partnering with patients, care partners, healthcare providers, and advocacy organizations — because together, we can achieve so much more.



Patient.RytaryBooth.com

Medtronic

At Medtronic, we're changing what it means to live with chronic disease. We're creating innovative therapies that help patients get back to enjoying some of the things in life they thought they had lost forever.



www.DiscoverDBS.com

Supernus

At Supernus, we hold a fundamental belief that our science has the potential to improve the lives of people with Parkinson's. Our commitment to people with Parkinson's and their care partners is reflected in all that we do. Our pipeline of development projects, along with our four currently available Parkinson's treatments, reflect our resolve to bring innovative solutions to the Parkinson's community. www.Supernus.com/commercial-products



Kyowa Kirin

Kyowa Kirin is committed to innovative drug discovery driven by state-of-the-art technologies. We work across the world to champion new solutions for patients and caregivers in four therapeutic areas: nephrology, oncology, immunology/allergy, and neurology (CNS). You can learn more about our values, our business, and how we help patients suffering from serious illnesses, like Parkinson's, by visiting www.KyowaKirin.com.



We work on some of the hardest to treat diseases, where the need remains high and potential for life-changing impact is significant.

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profound impact.

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Actor portrayal

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Actor portrayals.

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Supernus Pharmaceuticals is proud to partner with the community to highlight the icONic ways those living with Parkinson's disease (PD) strive to live their best, most icONic lives!

We believe that every PwP (Person with Parkinson's) has an icONic moment to celebrate and share. We'd love to hear yours. No victory is too small to share—let's celebrate together!



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SEARCHING**
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TAKE ACTION TO LIVE WELL TODAY

Just a decade ago, researchers, clinicians, and people living with Parkinson's did not stress the importance of exercise, stress management, diet, and other positive life choices on Parkinson's. Today, we know that your experience can be affected in a positive way by your choices and actions. Here are some you can take right now to start living well with Parkinson's:

- » **Listen.** Pay attention to your body and report any changes to your healthcare team. Listen also to family and friends who may see changes in you.
- » **Think holistically.** Holistic health means that you look at your whole self and take an integrated approach to care. Every part of you is connected to and influenced by the other parts of you; so, it is important to address Parkinson's through lifestyle, diet, exercise, stress management, relationships, and personal and spiritual care and growth.
- » **Be informed.** Learn how personal and lifestyle habits can affect your symptoms. The more you know about Parkinson's, the more empowered you'll feel to form useful habits to combat your symptoms. For instance, physical activity is critical at all stages of Parkinson's. However, a regular exercise program will take time and energy from other aspects of your life. Knowing which activities to keep or eliminate will maximize the positive impact of the choices you can control.



Inspiration

Read "How Can Nutrition Help You Live Well with Parkinson's?" written by Ambassador and registered dietician, Marty Acevedo.

dpf.org/parkinsons-nutrition

- » **Be prepared.** Organize your healthcare documents and other important information, so you always have it on hand. Prepare for your medical appointments to get the best results from your time with the doctor.
- » **Be your own best advocate.** Ask for a referral to a rehabilitation therapist if you haven't received one. Talk with your healthcare team about your goals and concerns. Make them aware of areas you want to improve. For instance, if using a keyboard has become difficult, ask your doctor about strategies to improve hand function. If you seek treatment early and are specific about symptoms or problems that make everyday life frustrating, you'll help your doctor tailor the most effective treatment plan.
- » **Stay Connected.** Seek support from people with whom you feel comfortable sharing your thoughts and concerns. Your support system may include people you trust, such as specific family members, friends, or individuals from church or work. Support groups can be helpful, as are group exercise classes and gathering with small groups of other people living with Parkinson's who encourage and inspire you.
- » **Prioritize the symptoms you can change.** This may mean taking medicines on time to limit symptoms or beginning rehabilitative therapy to improve your posture or the volume of your voice. It will mean starting or renewing your commitment to daily exercise and may also include changing your lifestyle to promote overall health by losing weight, stopping smoking, and eating a healthy diet.

LIVE WELL TODAY

- » **Learn to live with the symptoms you can't change.** Although a combination of medications, complementary therapies, and lifestyle changes will help you manage Parkinson's symptoms, symptoms will still show up in different ways in your life. Start to learn different ways to live with the reality of symptoms as you manage them or ways to manage those symptoms that may be less responsive to therapies. For instance, if a bothersome tremor doesn't always respond to medications, try reducing the anxiety that can make them worse. Practice deep breathing relaxation techniques and intentionally reduce stress as other ways to help manage tremor.
- » **Learn about clinical research trials.** Many researchers look to understand the impact of medicines in the early stages before any other medicine has been started, and they are always looking for participants. Another significant area of research is the study of neuroprotective therapies that can slow or potentially even stop the progression of Parkinson's. While taking part in a research trial is not for everyone, many love playing a role in advancing the science of Parkinson's for the greater community. Learn more online at clinicaltrials.gov and foxtrialfinder.org.



Information

Read “6 Myths About Parkinson's Clinical Trials” to learn more.

dpf.org/clinical-trial-myths

- » **Practice gratitude daily.** Train yourself to shift your attention to things that bring you joy instead of concerns over which you have no control. Call a friend, write a gratitude letter, perform a random act of kindness, or donate your time to a cause. When you experience things that bring you joy, whether big or small, take the time to savor them and be fully present. By building little moments of gratitude into your daily routine, you will begin to see that your world is filled with things to appreciate.
- » **Stay positive.** A positive attitude keeps the focus on what you can do, not what you can't. It fosters hope. If you're having a bad day, *search for the small victories and celebrate them.* Remember, tomorrow will bring another opportunity to live well.



Information

Read “A Primer on Pain and Parkinson's” to learn more.

dpf.org/pain-and-parkinsons



Our event today and those that follow are made possible by individuals just like you who donate to “Pay It Forward.”

With your tax-deductible donation to the Davis Phinney Foundation, you can be a part of creating these events and helping us reach more people with the message that **it IS possible to live well with Parkinson's.**

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