



**DAVIS PHINNEY**

Foundation For Parkinson's

*every victory counts®*

**THE VICTORY SUMMIT<sup>®</sup>**  
**VIRTUAL EVENT**

**SLEEP AND  
PARKINSON'S**

**Friday, September 9, 2022**



# THANK YOU FOR JOINING TODAY.

Getting a good night's sleep regularly can be a challenge when living with Parkinson's. Between dealing with trouble falling or staying asleep to managing sleep disorders such as REM Sleep Behavior Disorder (RBD) or restless leg syndrome, excessive sleepiness during the day, and lack of consistency, sleep irregularities are often the most difficult non-motor symptoms to manage.

During The Victory Summit Virtual Event: Sleep and Parkinson's, we'll take a deep dive into neurodegeneration, light therapy, different types of sleep-related issues, cognition, mood, exercise, and how they all impact a person living with Parkinson's.

By the end of the morning, you will know more about the complexities of sleep and how you can take action to manage sleep-related issues so you can improve your quality of life and live well with Parkinson's today.

And today is just the beginning. Our staff, sponsors, resources, and speakers are 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 8.*

# THE VICTORY SUMMIT® VIRTUAL EVENT AGENDA

## SLEEP AND PARKINSON'S

*To download today's slides and other resources, visit [dpf.org/vs-sleep](https://dpf.org/vs-sleep).*

*All times listed are MDT.*

9:00 – 9:10	<b>Welcome and Agenda</b> <i>Polly Dawkins, Executive Director, Davis Phinney Foundation</i>
9:10 – 9:20	<b>On Sleep and Living Well with Parkinson's</b> <i>Davis Phinney, Founder, Davis Phinney Foundation</i>
9:20 – 10:20	<b>Sleep, Light, and Neurodegeneration</b> <i>Aleksandar Videnovic, MD, Associate Professor of Neurology at Harvard Medical School, Director of the Division of Sleep Medicine at MGH, and Director of the MGH Program on Sleep, Circadian Biology, and Neurodegeneration</i>
10:20 – 10:30	<b>Movement Break - LSVT BIG®</b>
10:30 – 10:40	<b>Screen Break</b> Step away, stretch, use the restroom, take care of yourself
10:40 – 11:30	<b>The Effects of Exercise on Sleep in Parkinson's</b> <i>Amy Amara, MD, PhD, Associate Professor of Neurology, University of Alabama at Birmingham</i>
11:30	<b>Closing</b> Davis Phinney, Polly Dawkins

# NOTES FROM TODAY

*Before the day begins, we encourage you to capture your thoughts about what you want to learn.*

Some people with Parkinson's indicate that **using graph paper helps with micrographia** (small handwriting). Try it out here and see if it helps you, too!



# MEET TODAY'S SPEAKERS



## **AMY AMARA, MD, PHD**

Dr. Amy Amara is a physician scientist at the University of Alabama at Birmingham, Department of Neurology. She has fellowship training in both movement disorders and sleep medicine, with a particular interest in sleep dysfunction and other non-motor symptoms in people living with Parkinson's.

She is the co-director of the UAB Sleep and Circadian Research Core. Her main research focus includes investigation of non-pharmacological interventions, such as exercise, to improve sleep, cognition, and motor symptoms in Parkinson's.



## **ALEKSANDAR VIDENOVIC, MD**

Dr. Aleksandar Videnovic is an Associate Professor of Neurology at Harvard Medical School and Director of the Division of Sleep Medicine at Massachusetts General Hospital (MGH). He directs a Program on Sleep, Circadian Biology, and Neurodegeneration at MGH. Dually trained in movement disorders and sleep medicine, Dr. Videnovic focuses his clinical work on a wide range of movement and sleep disorders.

His ongoing research programs investigate the interface of sleep, circadian biology, and neurodegeneration, with an emphasis on movement disorders and REM Sleep Behavior Disorder (RBD). His other area of interest is clinical trials in movement disorders.



## **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.



## **DAVIS PHINNEY**

Davis Phinney was diagnosed with Parkinson's fresh off a successful professional cycling career that included winning an Olympic bronze medal in 1984 and being part of the first American team to race in the Tour de France.

He founded the Davis Phinney Foundation in 2004 to help people living with Parkinson's 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.

# 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.







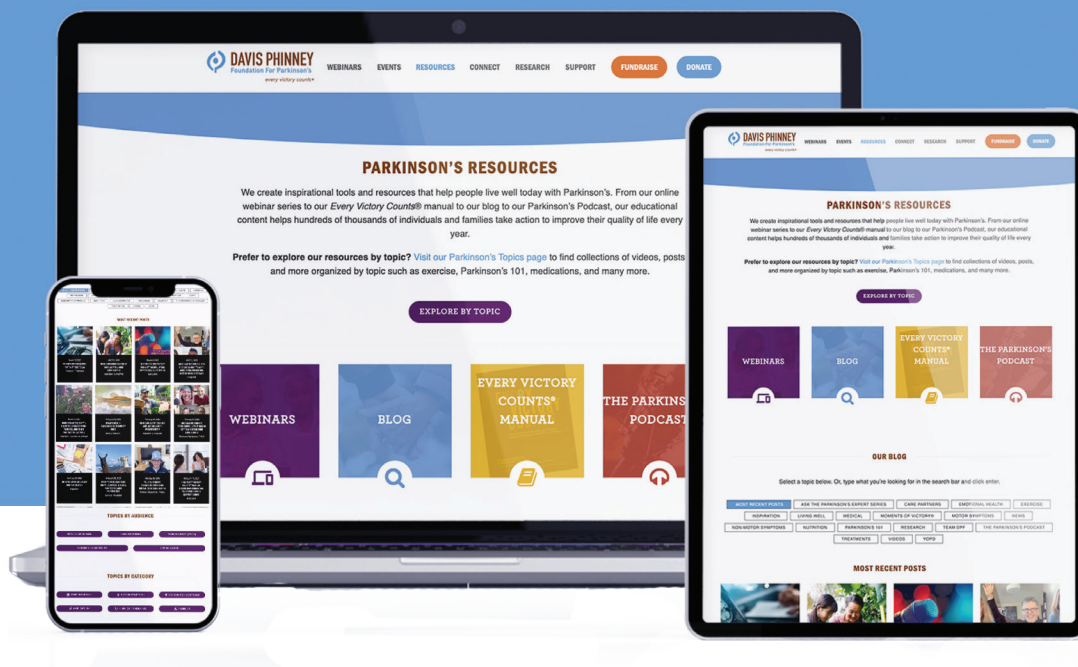
# MEET OUR AMBASSADORS



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 [dpf.org/ambassadors](https://dpf.org/ambassadors).**



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

Visit [dpf.org/resources](https://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, this guide shares a variety of ways that you can stay connected to take what you learned at The Victory Summit® Virtual Event and put it into action to live well today and in the future.



# LIVING WITH PARKINSON'S

*Everything you've ever wanted to know about Parkinson's but were afraid to ask*

Our monthly Living with Parkinson's Meetup brings together all people diagnosed with Parkinson's—young, old, early, late—for open, honest, real, and always fun conversations about everything you've ever wanted to know about Parkinson's but were afraid to ask.

Parkinson's is like a modern car. One little glitch in the hardware and all hell breaks loose. During our monthly Living with Parkinson's Meetups, we talk about all the things that break loose, go wrong, make you laugh, make you cry, go right, go weird, and everything in between.

It's the hour of truth you never knew you needed.

## JOIN US MONTHLY

*The Third Thursday of Every Month*

1 – 2 pm Mountain Daylight Time

(12 pm PDT, 2 pm CDT, 3 pm EDT, 8 pm GMT)

Learn more and register at [dpf.org/livingwithparkinsons](https://dpf.org/livingwithparkinsons).

# EVERY VICTORY COUNTS®



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



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



Available in print, digital, and audio.

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](http://EveryVictoryCounts.org).**

# THANK YOU TO OUR SPONSORS

We fight disease,  
so more you  
shines through.

**Protecting what makes you, uniquely you,  
drives us every day.**

We are Acadia, fiercely committed to elevating life through science for people impacted by CNS disorders every day. By collaborating with each other, inviting new ideas within and beyond our walls, we're dedicated to protecting everything that makes you, uniquely you — enabling brighter moments for patients and their loved ones.

Learn more about our trailblazing breakthroughs in neuroscience at [www.acadia-pharm.com](http://www.acadia-pharm.com)



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# We make healthy possible



Challenging  
Convention,  
Changing Lives



## **Acadia Pharmaceuticals**

Acadia is trailblazing breakthroughs in neuroscience to elevate life. For more than 25 years we have been working at the forefront of healthcare to bring vital solutions to people who need them most, including the first and only approved therapy for hallucinations and delusions associated with Parkinson's disease psychosis.

**[www.MoreToParkinsons.com](http://www.MoreToParkinsons.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](http://Patient.RytaryBooth.com)**



## **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](http://www.KyowaKirin.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](http://www.Supernus.com/commercial-products)**







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

Offering meaningful change and new hope for patients and their families... **that's**

***profound impact.***

To learn more about us and our innovative work, please visit [kkna.kyowakirin.com](https://kkna.kyowakirin.com)

**KYOWA KIRIN**



Actor portrayals.



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!



Visit us on Facebook! Scan here.



## ADDITIONAL SUPPORT PROVIDED BY:

abbvie

**PUTTING PATIENTS FIRST  
MEANS ALWAYS  
SEARCHING**  
FOR WAYS TO TAKE ON ADVANCING  
PARKINSON'S DISEASE

Visit [www.optionsforAPD.com](http://www.optionsforAPD.com)  
for more information

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# PAY IT FORWARD

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

By going virtual with this series, we’ve reached more people than ever before with information and inspiration to help them live well today. Each event focuses on information relevant to specific concerns. All share expert advice, experiences, information, tools, and inspiration so people with Parkinson’s and their care teams can take control and live well today.

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.**

***Thank you for helping us to create these inspirational events.***

**Contributions can be made online at [dpf.org/vs-donate](https://dpf.org/vs-donate)  
or by telephone at (866) 358-0285.**

# 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 “Help Others, Help Yourself: The Importance of Getting Involved in Your Community” to learn more.

[dcpf.org/community-involvement](https://dcpf.org/community-involvement)

- » **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](https://clinicaltrials.gov) and [foxtrialfinder.org](https://foxtrialfinder.org).



## *Information*

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

[dpf.org/clinical-trials](https://dpf.org/clinical-trials)

- » **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 “Positivity Extends Life” to learn more.

[dpf.org/positivity](https://dpf.org/positivity)

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