

every victory counts

# THE VICTORY SUMMIT® VIRTUAL EVENT NEWLY DIAGNOSED

Saturday, February 20, 2021

### "You have Parkinson's."

An estimated 60,000 people in the US hear these three words each year, setting them on a journey that, for so many, is filled with more questions than answers, especially in the beginning. But after 16 years of working to help people live well with Parkinson's, we know these three words don't have to mean giving up on the kind of life you imagined for yourself or your family. We also know that the longer it takes for someone to find the resources they need to live well, the longer their Parkinson's will present challenges that affect quality of life when it doesn't have to.

This Victory Summit® event is designed to shorten the distance between those three life-changing words — "You have Parkinson's" — and living well. We want to introduce you to a thriving Parkinson's community, to explain many of the treatments that can help with your symptoms, and to help you create daily habits that will improve your quality of life for many years to come.

Today, we welcome you to the Parkinson's community. As you set out on your unique path with Parkinson's, we hope this event will help you do so with an uplifted spirit, the motivation to take action to live well, and the support of a new network of friends who look forward to celebrating all your victories.

Today is just the beginning. Our staff, sponsors, resources, and speakers will all 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 NEWLY DIAGNOSED

To download today's slides and other resources, visit  $\underline{dpf.org/vs-newly-diagnosed}$ .

### All times listed are MST.

9:00 - 9:30	Choose Your Own Adventure: Movement Choice Amy Says Dance or Dr. Mike Says Tai Chi	12:40 - 1:10	Lunch-and-Learn: If I Can Do It, You Can Do It – Get Out and Go! Linda K. Olson, Author, Speaker, Motivator
9:45 - 10:00	The Virtual Victory Summit Event Tech Check (optional)	1:10 - 1:20	Movement Break
10:00 - 10:10	Information for the Day	1:20 - 2:00	Exercise to Live Well with Parkinson's + Q&A Michael Braitsch, DPT, Tribe Wellness (Richardson, TX)
10:10 - 10:30	Welcome and Inspiration Davis Phinney, Founder, Davis Phinney Foundation (Louisville, CO) Connie Carpenter Phinney, MS, Care Partner, Board Chair, Davis Phinney Foundation (Louisville, CO)	2:00 - 2:10	Screen Break Step away, stretch, use the restroom, take care of what you need
10:30 - 11:30	Living Long & Living Well with Parkinson's + Q&A  Dr. Cherian Karunapuzha, MD, Movement Disorder Specialist,  Meinders Center for Movement Disorders (Oklahoma City, OK)	2:15 - 2:45	Choose Your Own Adventure: Break Out Sessions How to Advocate for Yourself with Steve and Nancy Hovey Finding Your Way Around Parkinsonville with Tom Palizzi Keep Calm and Carry On with Kat Hill
11:30 - 11:40	Movement Break	2:45 - 3:00	Meet & Connect with the Davis Phinney Foundation Ambassadors
11:45 - 12:30	Medications and Parkinson's + Q&A  Dr. Aaron Haug, MD, Movement Disorder Specialist, Blue Sky Neurology (Englewood, CO)	3:00 - 3:15	Closing Remarks Davis & Connie Phinney, Davis Phinney Foundation staff, and Ambassadors

Grab your lunch or snack ahead of our Lunch-and-Learn

Step away, stretch, use the restroom, take care of what you need

Screen Break

12:30 - 12:40



### MICHAEL BRAITSCH, PT, DPT

Michael Braitsch is a licensed Doctor of Physical Therapy, a former amateur fighter, former kinesiology professor, and an internationally certified fight referee. In addition to treating individuals, Dr. Mike runs group exercise programs steeped in leading evidence from physical therapy and exercise science to help people with chronic and progressive conditions move and feel better.



### **AMY CARLSON**

Amy Carlson is a Davis Phinney Foundation
Ambassador and has been living with Parkinson's since 2012. She says that Parkinson's has changed her life, but perhaps not in the way that most people would expect. She has come to believe that in its own way, Parkinson's has saved her life, changing her in ways that she would have never anticipated. Her life has become slower, more deliberate, and more immediate. Amy finds joy in simple experiences and has come to realize that everyone has their own unique journey in life. The challenge is to find meaning in what's in front of you today.



### **AARON HAUG, MD**

Dr. Aaron Haug is a Neurologist and Movement Disorder Specialist practicing in Denver at Blue Sky Neurology. Dr. Haug is interested in medical and surgical treatments for the motor and non-motor symptoms of Parkinson's. He is involved in patient education through a variety of advocacy groups including the Parkinson Association of the Rockies. Outside the office, he likes to spend time with his family, play ultimate frisbee, and follow Kansas Jayhawks basketball and Colorado Rockies baseball.



### **KAT HILL**

Kat, a Davis Phinney Foundation Ambassador, was diagnosed with Parkinson's at the age of 48. Both Kat's father and two uncles had Parkinson's, but all were diagnosed later in life. Kat was shocked at the diagnosis yet determined to not be defined by it. Kat left her busy and demanding practice as a midwife to shift her efforts towards health and wellness. Kat believes that every day is a gift and that we can learn to live with joy and gratitude, even with challenges.



### **NANCY & STEVE HOVEY**

Steve was diagnosed with Parkinson's in 2007 at the age of 50. At that time, he and his wife Nancy didn't know anyone with Parkinson's; so, they took it upon themselves to learn as much as they could about Parkinson's symptoms and treatment. They credit Steve's frequent and consistent commitment to exercise as the biggest factor in helping him manage his Parkinson's. Together they have advocated for themselves and many others so more can learn how to live well with Parkinson's.



### **CHERIAN KARUNAPUZHA, MD**

People with Parkinson's refer to Dr. Karunapuzha as Dr. "K" at the Meinders Center for Movement Disorders in Oklahoma City where he is a Movement Disorder Specialist. Dr. K received his Fellowship and Residency from the University of Texas Southwestern Medical Center. He is American Board Certified in both Psychiatry and Neurology.



### **LINDA K. OLSON**

Linda Olson lost both of her legs above the knee and her right arm in a train vs. car accident when she was 29. She went on to have an illustrious thirty-year career as a Professor of Radiology at the University of California, San Diego, where she was the Director of Breast Imaging and the recipient of many teaching awards. She was known for her compassionate patient care and for mentoring medical students, residents, and fellow faculty members. Linda was diagnosed with Parkinson's in 2015 and is committed to empowering people living with Parkinson's and their families to live life as full as possible, in spite of their disabilities, and to get up, get out, and go.



### TOM PALIZZI

Tom was diagnosed with Parkinson's in 2008 at the age of 48. He knew very little about Parkinson's but enough to know that his life was going to change in ways he never imagined. Tom is actively engaged in the global Parkinson's community and has touched many people through his public policy and disease legislation. Tom leads Pedaling For Parkinson's™ indoor cycling classes three days a week and speaks to support groups often. He's also a Davis Phinney Foundation Ambassador and is one of our YOPD Council leaders.



### **CONNIE CARPENTER PHINNEY, MS**

Connie Carpenter Phinney is an entrepreneur, author, artist, and lifelong athlete and is extremely passionate about her work as Chairman of the Board of Directors for the Davis Phinney Foundation. She particularly enjoys sharing her experiences through the written word and as an eloquent and humorous public speaker. Connie has a MS in exercise science from the University of Colorado and completed her BS at the University of California, Berkeley. She has two adult children, Taylor and Kelsey, with her husband, Davis Phinney.



### **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.

# 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 often the work to live well happens on the most intimate levels. It happens in phone calls and on walks and over coffee, when we most need to connect with someone who really understands what we're going through. We hear so often that the support of our 60 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 is transformative, and we hope you will reach out to them as you begin 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 at <a href="https://december.com/december-12">def.org/ambassadors</a>.



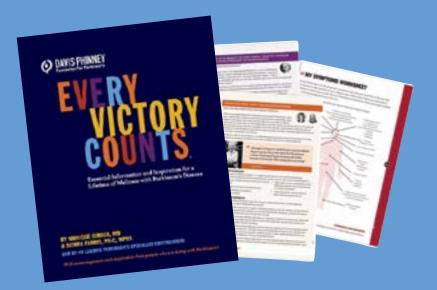
For more information on everything from exercise, treatments, complementary therapies, and more, we've created an online resource guide especially for you.

Visit **www.dpf.org/vs-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® manual
- » 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® event and put it into action to live well today and in the future.

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





# THE VICTORY SUMMIT® VIRTUAL EVENTS

People living with Parkinson's, their care partners and families, and friends of those living with Parkinson's want reliable and practical information that will help them improve their quality of life today and every day. The Every Victory Counts® manual is the gold-standard resource to help you live well with Parkinson's and achieve your wellness goals. It in, you'll discover:

- » Essential information about Parkinson's plus dozens of topics that are often overlooked but critical to helping you live well
- » Insights from over 60 people with Parkinson's, physicians, therapists, and scientists who share cutting edge research, strategies, and ideas for living well with Parkinson's
- » In-depth information about exercise, nutrition, emotional health, medication, therapies, and more

The Victory Summit is going virtual to reach more people than ever before with information and inspiration to live well today.

Join us for another event coming up this year:

- » April 2, 2021 How to Live Well with Parkinson's: By People with Parkinson's, For People with Parkinson's
- » June 26, 2021 Young Onset Parkinson's (YOPD)
- » September 17, 2021 Mental Health & Wellness
- » November 13, 2021 Care Partners

Learn more at **EveryVictoryCounts.org**.

Learn more at dpf.org/events.

# We make healthy possible







### **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.

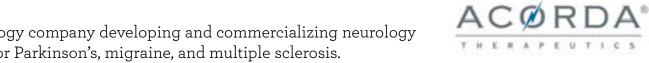


### www.MoreToParkinsons.com

### Acorda

www.Acorda.com

Biotechnology company developing and commercializing neurology therapies for Parkinson's, migraine, and multiple sclerosis.



# 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.

# **C**YOWA KIRIN

# KYOWA KIRIN IS PROUD TO SUPPORT THE DAVIS PHINNEY FOUNDATION

in its mission to help people with Parkinson's live well today.





### **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



### 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 disease, by visiting www.KyowaKirin.com.



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# Lundbeck Proudly Supports The Davis Phinney Foundation



Lundbeck is a global pharmaceutical company committed to improving the quality of life for people affected by brain diseases. We have a deep heritage of discovery in neuroscience, and we continue to push the boundaries of brain research.

Addressing the unmet medical needs of people living with brain diseases fuels our passion and drives us to make a difference... one patient at a time.

To learn more, visit www.lundbeckus.com.





### Lundbeck

Lundbeck is a pharmaceutical company focused entirely on brain disorders, including Parkinson's, which is a core area of Lundbeck's research efforts. Its employees annually participate in hundreds of Parkinson's-related events, and proudly support the Davis Phinney Foundation.

www.Lundbeck.com/us

### Medtronic

Further, Together

### 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.Medtronic.com/DBS

### Neurocrine

Neuroscience-focused, biopharmaceutical company with the first and only once-daily levodopa/carbidopa enhancer for people with Parkinson's experiencing OFF time.



www.Ongentys.com

## TREATMENT AS UNIQUE AS YOU

Our new device — the Percept™ PC neurostimulator — features BrainSense™ technology. This innovative technology captures brain signal data direct from your implanted leads. It then stores the data, so your physician can access it.\* An intuitive patient programmer enables you to track your events, such as when you took medication. Your doctor can see the events you've been logging at your next appointment via the clinician's programmer. This information may help your doctor deliver treatment that's as unique as you.\*\*

### Learn more at Medtronic.com/DBS

\*Signal may not be present or measurable in all patients.
\*Clinical benefits of brain sensing have not been established

edtronic DBS Therapy for Parkinson's is not for everyone. Not everyone will receive the same soults. Patients should always discuss the potential risks and benefits of the therapy with a nysician. A prescription is required. DBS Therapy requires brain surgery. Risks of brain surgery lay include serious complications such as coma, bleeding inside the brain, stroke, seizures, ad infection. DBS Therapy may cause worsening of some symptoms. See Important Safety formation www.medtronic.com/PDSafety.or.call. Medtronic at 800-328-0810

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# PERCEPT™ PC NEUROSTIMULATOR WITH BRAINSENSE™ TECHNOLOGY FOR DBS THERAPY



The DBS patient programmer is enhanced so you can more easily and conveniently manage your therapy.

Medtronic Further, Together

### Sunovion

Sunovion is a global biopharmaceutical company whose spirit of innovation is driven by the conviction that scientific excellence combined with meaningful advocacy and relevant education can improve lives.



### www.Sunovion.us

### 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 three currently available Parkinson's treatments, reflect our resolve to bring innovative solutions to the Parkinson's community.



www.Supernus.com/commercial-products



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# #sunovion

### **Sunovion Is Proud To Sponsor The Davis Phinney Foundation**

We are a global biopharmaceutical company focused on the innovative application of science and medicine to help people with serious medical conditions, including Parkinson's disease. Our spirit of innovation is driven by the conviction that scientific excellence paired with meaningful advocacy, research and education can improve lives.

Visit **sunovion.com** and connect with us on:





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Get to know Supernus! Scan her









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### **ADDITIONAL SUPPORT PROVIDED BY:**



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 your Parkinson's journey with your best foot forward:

- » 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 important 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 "If Parkinson's Had a Coin" written by Ambassador
Lorraine Wilson.

dpf.org/parkinsons-coin

- » Be prepared. Organize your healthcare documents and other important information so you always have it on hand. Prepare for your medical appointments in order 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 are making everyday life frustrating, you'll help your doctor tailor the most effective treatment plan for you
- » Be engaged. 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

# LIVE WELL TODAY

- » 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
- » 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 tremor worse. Practice deep breathing relaxation techniques and intentionally reduce stress as other ways to help manage tremor



Information
Read "A Primer on Parkinson's for the Newly
Diagnosed" to learn more.

dpf.org/parkinsons-primer

- » Learn about clinical research trials. Many clinical trails are available to people with early Parkinson's. 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 especially important 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, you may be empowered by taking part in the latest research and by potentially advancing the science of Parkinson's for the greater community. Learn more online at clinicaltrials.gov and foxtrialfinder.org
- » 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

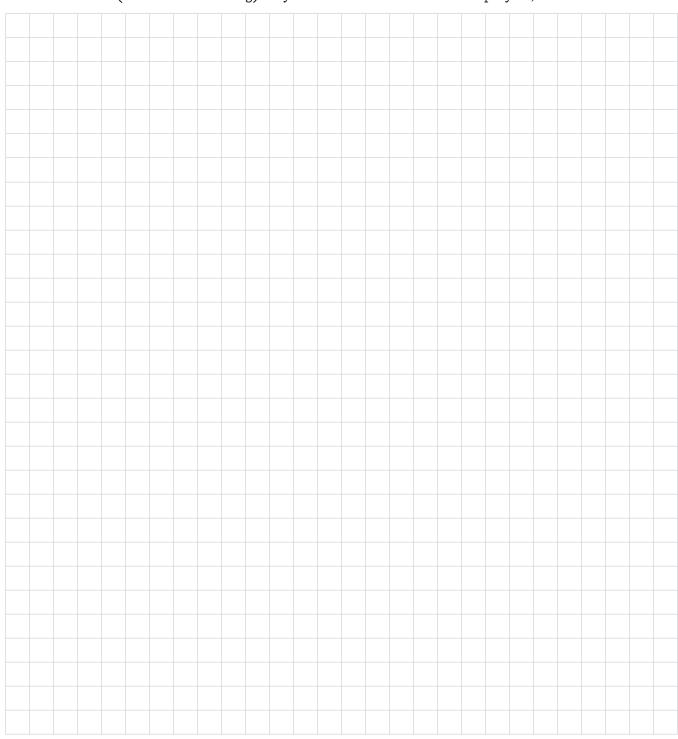


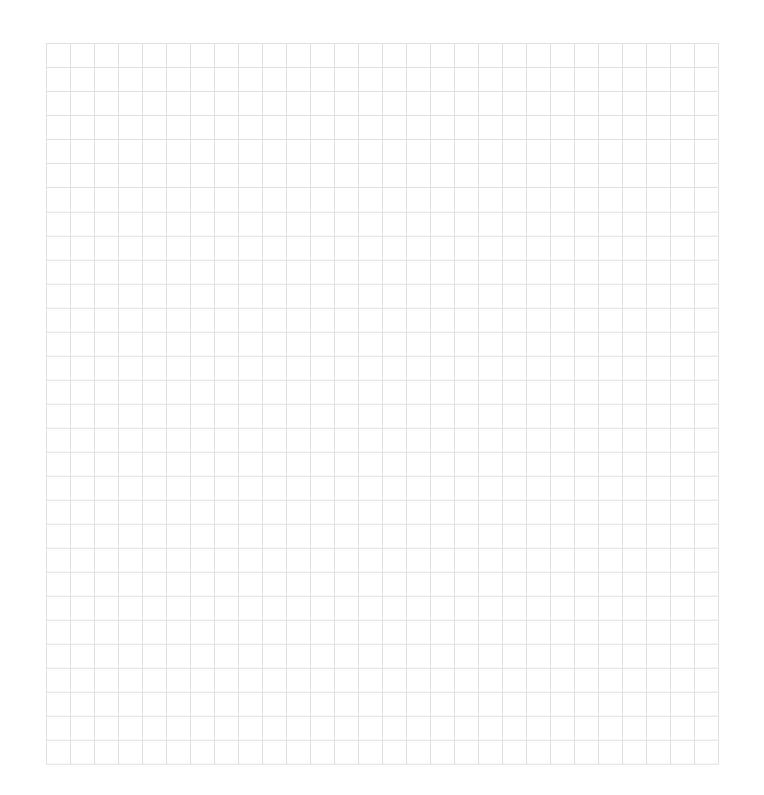
Information
Read "6 Myths About Parkinson's Clinical Trials" to learn more.

dpf.org/clinical-trial-myths

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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!





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