



DAVIS PHINNEY

Foundation For Parkinson's

every victory counts®

THE VICTORY SUMMIT®

VIRTUAL EVENT

**HOW TO LIVE WELL
WITH PARKINSON'S**

Friday, April 2, 2021

THANK YOU FOR JOINING TODAY.

“This was not part of my plan!”

Can you relate to that feeling? If so, you're not alone. We hear from people every day who say the day before they were diagnosed was their last good day. The loss they feel is too great, and the end of everything they dreamed and hoped for is too near. Maybe that's how you're feeling today. Yet maybe there's still a part of you that hopes for more and that's why you signed up for this event. Or maybe, you're feeling quite strong and resilient, but you're craving more insight and stories from people who truly get you. People who are also living with Parkinson's.

As a Foundation, we can share data and stories, we can invite Parkinson's experts to inform and educate you, and we can cite the most positive research, but we don't have Parkinson's. You do. And sometimes what you need more than anything is to be seen and heard by others who are travelling along a similar path. That's why we decided to put on an event for people with Parkinson's by people with Parkinson's. It's time to let go of the stage and the mic and hand it over to others living with Parkinson's who are ready to show you that it is possible to live well with Parkinson's today.

Today, we welcome you to our thriving Parkinson's community filled with people who are living well every day, despite their symptoms, despite their age, and despite the divide between what they had dreamed about and the life they're living today. As you navigate 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 12.

THE VICTORY SUMMIT® VIRTUAL EVENT AGENDA

HOW TO LIVE WELL WITH PARKINSON'S

To download today's slides and other resources, visit dpf.org/vs-live-well.

All times listed are MDT.

9:00 – 9:30

Choose Your Own Adventure: Movement Choice

Dance for PD® with David Leventhal or Rock Steady Boxing with Brett Miller

9:45 – 9:50

Welcome

Kat Hill, Ambassador, *Davis Phinney Foundation (Portland, OR)*

9:50 – 10:00

Living Well with Parkinson's

Davis Phinney, Founder, *Davis Phinney Foundation (Louisville, CO)*

10:00 – 10:30

Communication and Parkinson's

Cidney and Pat Donahoo, Ambassadors, *Davis Phinney Foundation (Las Vegas, NV)*

Pete Huley (*Beaufort, NC*)

Krista Ingle (*Boulder, CO*)

Moderator: Kat Hill, Ambassador, *Davis Phinney Foundation (Portland, OR)*

10:30 – 10:35

Screen Break

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

10:35 – 11:20

Exercise and Parkinson's Panel

Panelists: Allan Cole, PhD, Runner, Professor and Academic Dean, *Steve Hicks School of Social Work at The University of Texas at Austin (Austin, TX)*

Frank Swartz, Ironman (*Philadelphia, PA*)

Judith Wilson, Cyclist (*Littleton, CO*)

Moderator: Anson Rosenfeldt, DPT, PT, NCS, MBA, Physical Therapist, *Cleveland Clinic (Cleveland, OH)*

11:25 – 12:10

Nutrition and Parkinson's

Marty Acevdeo, MS, RDN, Ambassador, *Davis Phinney Foundation (Oceanside, CA)*
Moderator: Edie Anderson, Ambassador, *Davis Phinney Foundation (Venice, FL)*

Grab your lunch or snack ahead of our next session

12:25 – 12:45

Nurturing Resilience through Poetry

Wayne A. Gilbert, Retired Teacher and Professor of English and Educational Psychology (*Denver, CO*)

12:45 – 12:55

Closing Remarks

Davis and Connie Carpenter Phinney, Davis Phinney Foundation staff, and Ambassadors

1:00 – 3:00

Screen Break

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

3:00 – 4:00

Workshops (optional)

Sketching for Joy with Lorraine Wilson, Ambassador, *Davis Phinney Foundation (Abilene, TX)*

How to Tell Your (Parkinson's) Story with Carol Clupny, Ambassador, *Davis Phinney Foundation (Hermiston, OR)*

Working with Parkinson's: How to Keep Your Job, Find a New One, or Reinvent Your Career with Amy Montemarano, Ambassador, *Davis Phinney Foundation (Philadelphia, PA)*

MEET TODAY'S SPEAKERS



MARTY ACEVEDO

Marty was diagnosed with essential tremor in 2004 and with Parkinson's in 2010. She says she experienced symptoms of gait disturbance, dystonia, and REM sleep behavior disorder 10 years prior to her diagnosis. After her progression through the grieving process, Marty decided she wouldn't let her life be defined by Parkinson's. Marty felt called to help others who share this journey and quickly became involved with the Parkinson's Association of San Diego. Serving as secretary on the board of directors, she targeted her knowledge and passion towards educating others living with Parkinson's, encouraging exercise and socialization, and helping others to find their best life. Marty is most proud of her involvement in the development and implementation of an integrated, medically evidence-based program for people with Parkinson's at a local wellness center.



EDIE ANDERSON

Edie was diagnosed with Parkinson's in 2013 at the age of 60. She developed Parkinson's symptoms after undergoing several surgeries and chemotherapy in her earlier battle with breast cancer. After a year-long "pity party," Edie found the help she needed through a local support group where she met another person living with Parkinson's who told her about his passion for exercise. She says, "I have benefited physically, mentally, and emotionally from my active lifestyle." Now retired, Edie is passionate about helping others with Parkinson's discover the benefits of exercise to live well. She teaches at a variety of support groups and other Parkinson's educational events ways to develop a proactive approach to wellness. "I want to give hope to people living with Parkinson's and their caregivers by telling my story," she explains. "And showing that exercise works to improve our ability to function, which translates into a happier life for all of us!"



CAROL CLUPNY

Earthquakes tremored the inside of her legs. Anxiety pushed her to pace at her office at work. The corner of her right eye tremored followed by the right corner of her mouth and then her finger. Carol scheduled an appointment with her family physician who felt stress was causing these symptoms, but the medication he prescribed did little to help. She returned to see him after she couldn't effectively paddle her kayak. Carol was later referred to and diagnosed with Parkinson's by a movement disorder specialist in 2008. As an Ambassador for the Foundation, Carol shares her living well philosophy and resources with those living in rural areas.



ALLAN COLE

Allan was diagnosed with young onset Parkinson's disease (YOPD) in 2016, at age 48. Since then, he has devoted significant time and energy to raising awareness, providing education, fundraising, and writing about his own experiences of living with Parkinson's. Allan is a professor and the academic dean in the Steve Hicks School of Social Work at The University of Texas at Austin, and a professor of Psychiatry in the Dell Medical School. An avid writer, he's published 10 books and dozens of articles on a range of topics related to bereavement, anxiety, and spirituality. He's also an avid runner who believes exercise is one of the most essential keys to living well with Parkinson's.



CIDNEY DONAHOO

Cidney was diagnosed with Parkinson's in 2010 at the age of 47. She became involved in the Parkinson's community through cycling after participating in a tandem bike exercise study with Dr. Jay Alberts. She went on to ride RAGBRAI in Iowa with the Pedaling For Parkinson's™ team and Ride The Rockies in Colorado with the Davis Phinney Foundation team. Cidney continues to cycle, often riding tandem with her husband Pat, and has since added yoga, strength training, and boxing to her exercise regimen. Exercise helps her stay healthy and manage her Parkinson's symptoms. Cidney's mission is to "leave no Parkinson's person behind" by increasing the information and peer-to-peer support in her community.



PAT DONAHOO

Pat's wife Cidney was diagnosed with Parkinson's in 2010 at the age of 47 after a four-year journey to a diagnosis. Cidney came across the Davis Phinney Foundation as she was researching Parkinson's, and together she and Pat actively embraced the Foundation's philosophy of living well today. Pat notes the benefits living well has brought to each of them, saying: "It's kept us both off the couch and has built an active lifestyle we both follow." Pat and Cidney work together with the Parkinson's community in Las Vegas to spread the message that it is possible to live well today with Parkinson's.



WAYNE A. GILBERT

Wayne is a retired teacher and professor of English and Educational Psychology. He has published two poetry chapbooks: *Magmamystic* and *From the Ashes*. He is a full-time poet and is in demand as a performer, sometimes jamming with jazz musicians. Wayne was diagnosed with Parkinson's in 2005. He took refuge in poetry and has written hundreds of "parkie" poems, which he refers to as "metaphor medicine." Wayne is co-founder of Reconnect with Your Body, a Dance for PD® affiliated class and performance company, is a co-founder of Us-in-a-Box Theatre Workshop, and he was a founder and facilitator of Unlocked Poetry, a monthly workshop for prison poets, for several years. In 2018, Wayne received the 2018 Colorado Governor's Creative Leadership Award.



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.



DAVID LEVENTHAL

David is a founding teacher and Program Director for Dance for PD®, a program of the Mark Morris Dance Group that has now been used as a model for classes in more than 300 communities in 25 countries. He leads classes for people with Parkinson's around the world and trains other teachers in the Dance for PD approach. He received the 2016 World Parkinson Congress Award for Distinguished Contribution to the Parkinson's Community and was a co-recipient of the 2013 Alan Bonander Humanitarian Award from the Parkinson's Unity Walk. He graduated from Brown University with honors in English Literature.



BRETT MILLER

Brett opened a Rock Steady Boxing affiliated gym in 2016, in addition to providing physical therapy to people with Parkinson's in their own homes. In 2018, Brett also opened a wellness center, 110 Fitness, to provide programs for the Parkinson's community, which is now the largest in the world. As an Ambassador, Brett believes in making the most of each day and hopes to bring essential tools to those in his community and share his experience creating comprehensive wellness programs.



AMY MONTEMARANO

Amy was diagnosed with Parkinson's at the age of 48. Through the strong medical and support networks for people with Parkinson's in the Philadelphia area, Amy learned how to rely on exercise, stress management, and other wellness tools to help her live well with her diagnosis. Amy believes that living well with Parkinson's means not giving up your enjoyment of life and fully engaging with the world in a way that uses your own special purpose and energy to its highest potential. Finding purpose and meaning in her own life post-diagnosis led Amy to help people with Parkinson's and their care partners navigate employment, as well as find volunteer work or creative projects to discover their own personal adventures. For Amy, choosing to become a Davis Phinney Foundation Ambassador helps her to spread the message that it is possible to live well with Parkinson's to even more people.



DAVIS PHINNEY

Davis 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.



ANSON ROSENFELDT

Anson is a neurological specialist in the field of physical therapy. She uses her physical therapy background to lead several clinical trials examining the role of exercise and neurological disease. She has an interest in the use of technology to improve rehabilitation outcomes and improve remote monitoring capabilities. She's also a new member of the Davis Phinney Foundation's Science Advisory Board.



FRANK SCHWARTZ

Frank is a retired constitutional lawyer and law professor living in Philadelphia. He was also a long-time cyclist and distance runner; however, before 2000, he'd never dipped his toe in the world of triathlons. The death of his father changed that. He wanted to do something big to honor his dad and decided to do an Ironman. He planned on moving on once he completed it, but something happened on the way to his first race in Lake Placid. He discovered he loved it. He loved the training, the discipline, the preparation, and all of the challenges that came with it. By the time he was diagnosed with Parkinson's in 2010, he had heard "you are an Ironman" seven times. He believes that his knowledge, experience, and enthusiasm, together with the support of the Foundation, will enable him to help people with Parkinson's become endurance athletes and live well with Parkinson's for many years to come.



JUDITH WILSON

Dr. Wilson is a retired family physician whose entire career was focused on community health. Retirement came much earlier than she had expected as the demands of electronic medical records became increasingly difficult to meet and Parkinson's began to manifest itself in her professional life. When Dr. Wilson was diagnosed with Parkinson's in July 2011, her movement disorder specialist prescribed exercise as her first "medication." That moment changed her view of exercise forever. She filled the prescription by finding several favorites (spinning, boxing, yoga, weights). Spinning and contact with other spinners led to contact with the Cleveland Clinic which led to a tandem bicycle, over 6,000 miles of training, and riding RAGBRAI with the Pedaling For Parkinson's™ and the Davis Phinney Foundation's team five times. Dr. Wilson and her husband Ken use opportunities to speak at community gatherings to help spread the word about exercise and its extremely important role in slowing progression as well as living well with Parkinson's.



LORRAINE WILSON

Lorraine was diagnosed with Parkinson's early in 2017. She can still recall every detail of exiting the neurologist's office and walking to the elevator while sharing the news with her husband of 40 years. They moved into bright sunlight as they left the building, yet she recalls feeling dark inside, numb, guilty, and afraid. Her role as an educator and her insatiable desire to learn helped her move from shock and sadness to action. She assembled a multi-disciplinary team of colleagues at the university where she was teaching, and her personal and professional journeys joined forces as they began an exercise study that looked at resistance training with instability and cadence walking. Lorraine says the support from family, friends, and others with Parkinson's is critical to living well each day. Maintaining a positive outlook may not be easy, she says, but it is a worthwhile effort that lends support to others, making life that much better.

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.





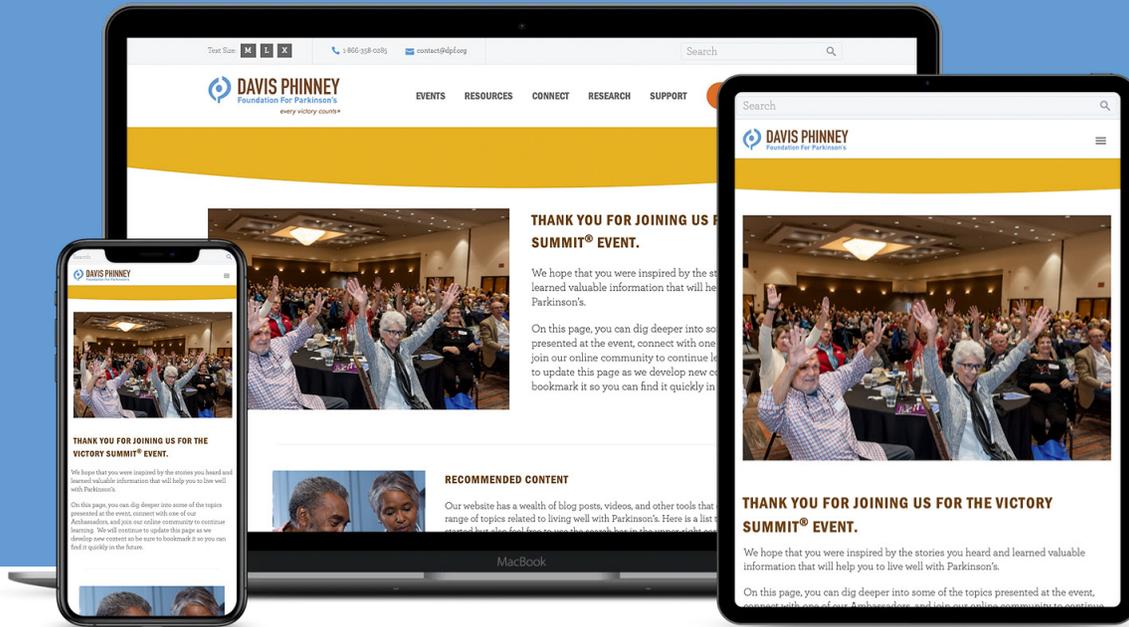
MEET OUR AMBASSADORS



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 travel your path 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 dpf.org/ambassadors.

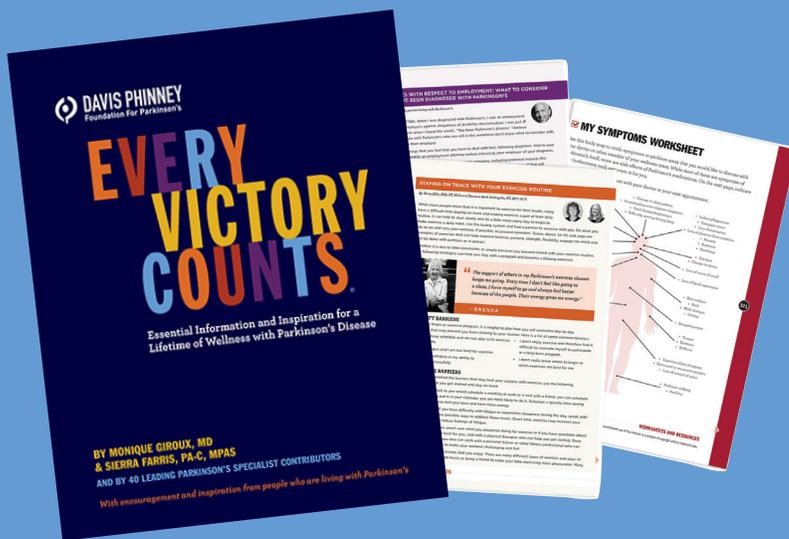


For more information on everything from exercise, treatments, complementary therapies, and more, we've created an online resource guide especially for you.

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.



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



Available in print, digital, and audio.

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

Learn more at EveryVictoryCounts.org.



THE VICTORY SUMMIT[®] VIRTUAL EVENTS

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 or watch the sessions from past events:

- » **February 20, 2021** - Newly Diagnosed
- » **June 26, 2021** - Young Onset Parkinson's (YOPD)
- » **September 17, 2021** - Mental Health & Wellness
- » **November 13, 2021** - Care Partners

Learn more at dpf.org/events.

RESOURCES TO HELP
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www.Acorda.com



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so more you
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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





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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



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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



Actor portrayal

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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.

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*Signal may not be present or measurable in all patients.

**Clinical benefits of brain sensing have not been established.

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

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At Neurocrine Biosciences, we are passionate about using breakthrough science to develop life-changing treatments for people with serious neurological conditions, like Parkinson's disease.

We are committed to the estimated one million people in the United States and six million people worldwide living with Parkinson's disease, and remain steadfast in discovering, developing and delivering treatment options that help advance the standard of care for patients around the world.



Not an actual patient



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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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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.

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*Parkinson's disease.

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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 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.** An 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

NOTES FROM TODAY

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!





PAY IT FORWARD

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

By going virtual with this year’s series, we hope to reach more people than ever before with information and inspiration to help them live well today. Each event will focus on information relevant to specific concerns. All will 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.

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