



**DAVIS PHINNEY**

Foundation For Parkinson's

*every victory counts®*

# **THE VICTORY SUMMIT® VIRTUAL EVENT**

## **YOPD**

**Saturday, June 26, 2021**

# THANK YOU FOR JOINING TODAY.

Very often, the emotional, social, physical, and psychological needs of those diagnosed with YOPD are different from those diagnosed with Parkinson's at an older age. You might be soaring in your career, expecting a baby, raising multiple school-age children at home, or getting ready to buy your first house. These are different concerns than those who are diagnosed much later in life have. That's why we want to shine a spotlight on YOPD. We want you to have the education, resources, and support you need to live well with Parkinson's no matter your age.

During this event designed specifically for people with YOPD, you will learn from and interact with Parkinson's experts and people living with YOPD on a wide range of topics that are unique to your situation. From the biology and etiology of YOPD to treatments, reinvention, exercise, and more, you'll leave with a concrete plan on how to live well with Parkinson's for many years to come.

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 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

## YOPD

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

*All times listed are MDT.*

|               |  |
|---------------|--|
| 9:00 – 9:10   | <b>Welcome and Agenda</b><br><i>Amy Montemarano, JD, Davis Phinney Foundation Ambassador, YOPD Council Member (Philadelphia, PA)</i>   |
| 9:10 – 9:30   | <b>Every Victory Counts®</b><br><i>Davis Phinney, Founder, Davis Phinney Foundation (Louisville, CO)</i><br><i>Polly Dawkins, Executive Director, Davis Phinney Foundation (Boulder, CO)</i> |
| 9:30 – 10:10  | <b>Hindsight Is 20/20: Thoughts from an Old, Young Onset</b><br><i>Pamela Quinn, Founder, PD Movement Lab (Brooklyn, NY)</i>   |
| 10:10 – 10:15 | <b>Screen Break</b><br>Step away, stretch, use the restroom, take care of what you need  |
| 10:15 – 11:15 | <b>YOPD: Biology, Treatments, and Living Well Today</b><br><i>Rodolfo Savica, MD, PhD, Faculty Mayo Clinic (Rochester, MN)</i>   |
| 11:15 – 11:25 | <b>Music and Movement</b><br><i>Jackie Hanson, Davis Phinney Foundation (Minneapolis, MN)</i>  |
| 11:25 – 11:30 | <b>Screen Break</b><br>Step away, stretch, use the restroom, take care of what you need  |

|               |   |
|---------------|---|
| 11:30 – 12:10 | <b>Meaning, Mindset, and Purpose</b><br>Allan Cole, PhD, <i>Professor and Academic Dean, Steve Hicks School of Social Work at The University of Texas at Austin (Austin, TX)</i>        |
| 12:10 – 12:40 | <b>Reinvention of Self</b><br>Amy Montemarano, JD, <i>Davis Phinney Foundation Ambassador (Philadelphia, PA)</i><br>Luke Waaler, <i>Senior User Experience Designer (Charlotte, NC)</i> |
| 12:40 – 12:45 | <b>Screen Break</b><br>Step away, stretch, use the restroom, take care of what you need   |
| 12:45 – 1:05  | <b>How to Live Well with YOPD</b><br>Amy Carlson, <i>Davis Phinney Foundation Ambassador (Monrovia, CA)</i>   |
| 1:05 – 1:10   | <b>Closing Remarks</b><br>Davis and Connie Carpenter Phinney, Davis Phinney Foundation staff, and Ambassadors   |



# MEET TODAY'S SPEAKERS



## **AMY CARLSON**

Amy 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 believes that 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 this life.



## **CONNIE CARPENTER PHINNEY**

Connie 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.



## **ALLAN COLE**

Allan was diagnosed with young onset Parkinson's (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 ten books and dozens of articles on a range of topics related to bereavement, anxiety, and spirituality. He's also a dedicated runner who believes exercise is one of the most essential keys to living well with Parkinson's.



## **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 by providing education and connection to community and funding quality of life research that take the guess work 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 and soaking up the sun like a lizard.



## **JACKIE HANSON**

Jackie joined the Davis Phinney Foundation in January 2021. Prior to joining the Foundation, she spent many years as a music educator while earning her master's degree in music therapy. During this clinical work, Jackie had the opportunity to work with many persons with Parkinson's. It was this extraordinary community of people, along with her passion for advocacy, love of projects, and drive for excellence that led her to working at the Foundation. In her spare time, Jackie can be found eating pizza, hiking with her dog Bingley, tickling the ivories, or finding a new favorite coffee shop.



## **AMY MONTEMARANO**

Amy was diagnosed with Parkinson's at age 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.



## PAMELA QUINN

Pamela danced professionally for 20 years and been living with Parkinson's for over 25. Her personal experience of Parkinson's, along with her keen knowledge of the body that stems from her professional dance training, allow her to analyze movement problems and create solutions to help manage them. She developed PD Movement Lab, a functional dance class for people with Parkinson's, which she teaches regularly at Dance for PD® in Brooklyn, for Northwell's PD program at the JCC Manhattan, and at conferences around the world.

Most notable engagements include CBS Evening News, four World Parkinson Congresses, Japan's 2nd Parkinson Congress, being featured in Jon Palfreman's book *Brainstorms*, and coaching Christopher Walken for his role in the movie *A Late Quartet*. Her choreography was featured in the opening night ceremony of the 2019 World Parkinson Congress in Kyoto, won the 2010 video competition of the WPC, and received a dance magazine award the same year. In 2019, she received a prestigious fellowship from Dance/USA for the social impact of her artistic work. She has been published twice in *Neurology Now* and in *Dance Magazine*, and she has presented at many universities, with regular engagements at Tufts University, Brown, NYU, and Rutgers. You can learn more about her approach to PD, her classes, her blog, and PD outlier interviews on her website, [pdmovementlab.com](http://pdmovementlab.com). Pam lives in New York City with her husband and two boys.



## **RODOLFO SAVICA, MD**

Dr. Savica is an Associate Professor of Neurology, practicing neurologist, and Movement Disorder and Behavior Specialist at the Mayo Clinic, in Rochester, MN. Dr. Savica has a particular interest in early onset Parkinson's and the initiatives of the Mayo Clinic Rochester regarding the clinical practice and research on early onset Parkinson's. He is involved in patient education and scientific advancements. He is the chair of the International Movement Disorders Society Task Force on early onset Parkinson's, and he leads a lab with the goals of finding a cure and improving quality of life for people with Parkinson's. He likes to spend his time with his amazing wife and lovely daughter, and he is a well-established martial artist.



## **LUKE WAALER**

Luke was diagnosed with YOPD in 2016 at age 48. After researching resources for support, he found the Davis Phinney Foundation. Working in Boulder, CO, at the time, he walked down to the Foundation's office and was greeted by John Dean, a speech-language pathologist who specializes in Parkinson's. John dropped what he was doing to talk with Luke about his new diagnosis and provide him with resources. Recalling the encounter with John that day, Luke knows that John gave him exactly what he needed at the time: hope. In 2019, Luke, his wife Jennifer, and their three cats moved from Colorado to Charlotte, NC, for a new job with Collins Aerospace. As a senior user experience designer, Luke works to make software easier to use, designing apps that help airlines avoid delays and cancellations. When he's not designing products or volunteering, you'll find him playing softball, spinning, boxing, and exploring the Carolinas with Jennifer.

# 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

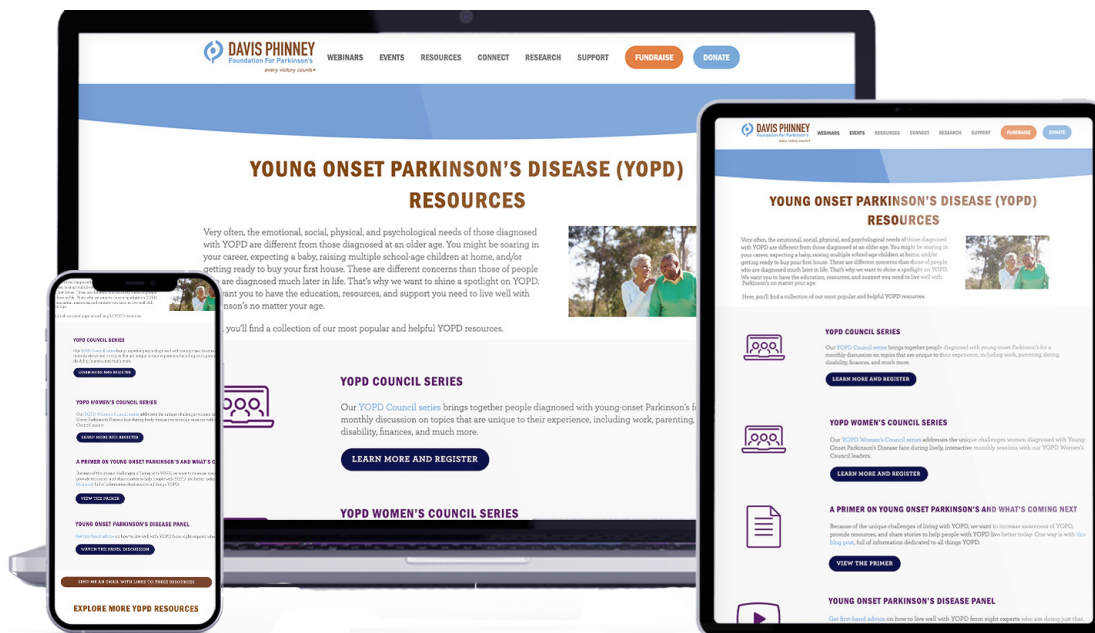


When we created our Ambassador Leadership Program in 2015, we did so because we recognized that, more than anything, our community members want more connection to people who truly understand what it means to live with Parkinson's. We hear so often that the support of our 60 Ambassadors goes far beyond 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 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).**





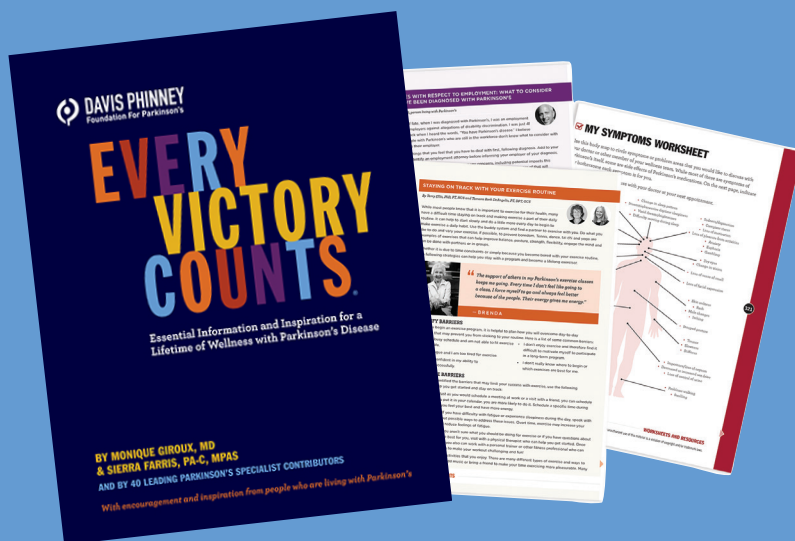
For more information on everything YOPD from exercise, treatments, relationships, medications, and more, we've created an online resource guide especially for you.

Visit [dpf.org/yopd](https://dpf.org/yopd) and you'll find sections on:

- » YOPD tools, techniques, and resources
- » Ambassadors with YOPD
- » The YOPD Council Webinar Series
- » Videos, blog posts, and podcasts
- » And more!

In addition, visit [dpf.org/vs-yopd](https://dpf.org/vs-yopd) to find variety of ways 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

Order yours today at [EveryVictoryCounts.org](https://EveryVictoryCounts.org).



# THE VICTORY SUMMIT<sup>®</sup> VIRTUAL EVENTS

The Victory Summit is 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
- » **April 2, 2021** - How to Live Well with Parkinson's
- » **September 17, 2021** - Mental Health & Wellness
- » **November 13, 2021** - Care Partners

Learn more at [dpf.org/events](https://dpf.org/events).

# THANK YOU TO OUR SPONSORS

## **Abbvie Commercial**

AbbVie, a global, researched-based biopharmaceutical company, is committed to educating patients and caregivers about Parkinson's to raise awareness about the condition, and further research to improve the lives of those living with and impacted by Parkinson's.

**[www.Abbvie.com](http://www.Abbvie.com)**

The Abbvie logo consists of the word "abbvie" in a lowercase, sans-serif font.

## **Adamas Pharmaceuticals**

Pharmaceutical company developing innovative treatments for chronic neurologic disorders.

**[www.AdamasPharma.com](http://www.AdamasPharma.com)**



## **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)**



## **Acorda**

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

**[www.Acorda.com](http://www.Acorda.com)**



# We make healthy possible



Challenging  
Convention,  
Changing Lives



# 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](https://www.acadia-pharm.com)

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# 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](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)**



Actor portrayal

# Did you know? INBRIJA<sup>®</sup> is inhaled levodopa

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You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch) or call 1-800-FDA-1088.

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(levodopa inhalation powder)  
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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](http://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](http://www.Lundbeck.com/us)**







## 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](http://www.Ongentys.com)**

# DELIVERING ON HOPE™

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

Visit us at **neurocrine.com**

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



*formerly US WorldMeds*



# 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\*\*](http://sunovion.com) and connect with us on:



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## Fred

Minnesotan  
Husband  
Father  
Springsteen fan  
DIYer  
Brother  
Hockey fan  
Golfer  
Woodworker  
Person with Parkinson's (PwP)



Working together to

# PUT PD\* IN ITS PLACE



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**Centered on CNS. Partners in Parkinson's.**



\*Parkinson's disease.

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**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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# 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 “If Parkinson’s Had a Coin” written by Ambassador Lorraine Wilson.

[dpf.org/parkinsons-coin](https://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 Young Onset Parkinson’s Disease (YOPD)” to learn more.

[dpf.org/yopd-primer](https://dpf.org/yopd-primer)

- » **Learn about clinical research trials that may be available to people with YOPD.** 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).
- » **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.

[dcpf.org/clinical-trial-myths](https://dcpf.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.*

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

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