



DAVIS PHINNEY

Foundation For Parkinson's

every victory counts®

THE VICTORY SUMMIT®
VIRTUAL EVENT
CARE PARTNERS

Saturday, November 13, 2021

THANK YOU FOR JOINING TODAY.

In 2020, a survey of 695 Parkinson's care partners highlighted how the care partner role comes with both significant emotional gains and emotional tolls. Seventy-eight percent of the care partners surveyed said the role is the most rewarding one they've ever had. Still, nearly as many said it also negatively impacts their emotional and mental health. Most said that despite feeling lonely and being overloaded with daily responsibilities, they are hesitant to ask for help, even though they need additional support. And four in five care partners agreed that they'd had a challenging time adjusting to life as a care partner.

This data makes clear that being a care partner can be both rewarding and a significant stressor. Therefore, it's essential that care partners have the opportunity to learn about everyday stressors, signs of burnout, changing family dynamics, and other care partner challenges — along with strategies to navigate these hurdles — so they can take action and feel empowered to face whatever comes their way. That's what this event is all about.

Today, you'll learn from Parkinson's experts and fellow care partners from all walks of life about self-care and mental health; how to keep your person with Parkinson's safe at home and physically and cognitively engaged; best practices in long-term care planning; and who to reach out to when you need support.

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 12.

THE VICTORY SUMMIT® VIRTUAL EVENT AGENDA

CARE PARTNERS

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

All times listed are MST.

9:00 – 9:10	Welcome and Agenda <i>Polly Dawkins, Executive Director, Davis Phinney Foundation (Louisville, CO)</i>
9:10 – 10:00	Mood and Mental Health Strategies for Care Partners <i>Jessica Shurer, MSW, LCSW, Director of Patient and Care Partner Advocacy, CurePSP (Chapel Hill, NC)</i>
10:00 – 10:50	Care Partner Panel <i>MaryGail Anderson, Barb Ankenman, John Paul Lederach, Angela Robb, Bud Rockhill, and Juwairiya Syed</i>
10:50 – 11:05	Movement Break: Occupational Therapy Exercises You Can Do with your Person with Parkinson's <i>Amber Crawford, COTA/L, Ada Therapy Services, PLLC (Boise, ID)</i>
11:05 – 11:35	How Occupational Therapy Can Help You and Your Loved One Live Well <i>Amber Crawford, COTA/L, Ada Therapy Services, PLLC (Boise, ID)</i>
11:35– 12:20	Lessons I've Learned <i>Connie Carpenter Phinney, Board Chair, Davis Phinney Foundation (Louisville, CO)</i>

12:20 – 12:30

Screen Break

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

12:30 – 1:15

Breakout Sessions

Getting Your Ducks in a Row with Judy Kinney, *End of Life Washington*

Care Partner Q&A with Connie Carpenter Phinney, Pat Donahoo, and Gail Gitin

How to Step Away from Parkinson's with Barb Ankenman

1:15 – 1:20

Closing Remarks

Connie Carpenter Phinney and Davis Phinney Foundation staff

LIVE WELL.
INSPIRE ACTION.
CONNECT THE COMMUNITY.

MEET TODAY'S SPEAKERS



MARYGAIL ANDERSON

MaryGail Anderson was care partner to her father for nine years. After 14 years as a Registered Respiratory Therapist/ ECMO Specialist with Vanderbilt Medical Center, she began a Respiratory Rehab Program for NHC (rehab and LTC facility) after she noticed that her father only received the care that he truly needed when she was there, for no one else seemed to understand the complexities of his Parkinson's and nOH. Care for her father started at home, and as his Parkinson's progressed, MaryGail and her family worked with him on transitions through independent living, assisted living, memory care, and long-term care. Then, to ensure he received the constant and consistent care he needed, MaryGail moved him back home and took care of him there with the aid of hired caregivers whom she trained. In addition to her other work, MaryGail is part of an advocacy board for the Parkinson's/nOH community via Lundbeck Pharmaceuticals.



BARB ANKENMAN

A retired business executive, Barbara is the loving care partner of her husband, Dale. Dale was diagnosed with Parkinson's in 2003 at the age of 46. Since that time, they have continued to enjoy life together, facing the highs and lows of Parkinson's as a team.



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.

Connie has been care partner to her husband, Davis, since he was diagnosed with young onset Parkinson's in 2000. Much of her resilience was learned from growing up observing how her father helped her mother navigate Multiple Sclerosis. She leads a monthly caregiver meetup via the Davis Phinney Foundation, which further informs and inspires her to share the lessons she has learned.



AMBER CRAWFORD

Amber Crawford, COTA/L, is a graduate of Kent State University and is state licensed in Idaho and nationally Board Certified as an Occupational Therapy Assistant. Amber gained a passion for OT while working as a nursing assistant, and she continues to push herself to improve her skillset to give her clients the best possible outcomes. Amber has always connected with the geriatric population, and while in college discovered a passion for working with people living with neurocognitive deficits. At Ada Therapy Services, Amber's primary goal is always to help her client live their best, most independent lives, whatever that may look like. She says the best part of her career is the diversity of the people she gets to work with. Amber lives in Idaho with her husband, daughter, grandparents, and three pets. She enjoys camping, hiking, cooking, painting, and traveling.



PAT DONAHOO

Pat Donahoo'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.



GAIL GITIN

Gail Gitin was a care partner to her husband, Gene, for more than 15 years. After many attempts to get answers, Gene was officially diagnosed with Parkinson's by a movement disorder specialist, and he and Gail began their journey to live well with Parkinson's. Living in Boulder helped Gail and her husband learn about and feel quickly supported by the Davis Phinney Foundation. With multiple opportunities through support groups, exercise classes, and lectures to increase understanding surrounding Parkinson's, Gail and Gene were able to improve their quality of life and develop a positive outlook. With five grandchildren, Gail enjoys spending time with them and setting up art projects. Her perfect Sunday involves an outdoor adventure, followed by dinner at a fine restaurant and a cocktail in hand. If she's not baking or making friends, Gail can be found at her art studio among paints and canvases!



JUDY KINNEY

Judy is the Executive Director of End of Life Washington (EOLWA) with a passion for end-of-life choices and to rouse, rally, and engage people to uphold essential rights. Judy has a master's and bachelor's in social work, with a focus on Community, Administration, and Programs. She became an end-of-life choice advocate in 2012 through her work as the Executive Director of North East Seattle Together (NEST), Seattle's first virtual retirement village, and has continued to prioritize end-of-life choices in her work ever since.



JOHN PAUL LEDERACH

John Paul Lederach is Senior Fellow at Humanity United and Professor Emeritus of International Peacebuilding at the Joan B. Kroc Institute for International Peace Studies at the University of Notre Dame. He works extensively as a practitioner in conciliation processes, active in Latin America, Africa, Southeast and Central Asia. He is widely known for the development of culturally appropriate approaches to conflict transformation and the design and implementation of integrative and strategic approaches to peacebuilding. He served as the director of the Peace Accord Matrix research initiative at the Kroc Institute and is active as a member of the Advisory Council for the recently formed Truth Commission in Colombia. He is author and editor of 24 books and manuals, including *Building Peace: Sustainable Reconciliation in Divided Societies* (US Institute of Peace Press) and *The Moral Imagination: The Art and Soul of Building Peace* (Oxford University Press).



BUD ROCKHILL

Bud Rockhill, MBA, a long-time Parkinson's care partner to his mother, is an adjunct faculty member for entrepreneurship at the Colorado School of Mines and previously taught at the University of Denver. He earned his undergraduate from Lehigh University and MBA from Harvard Business School. His experience in managing growing companies has been profiled in three case studies used at Stanford Business School and Harvard. Currently, he is the Managing Partner of Traxion and has worked in the fitness industry, destination entertainment, and online education.



ANGELA ROBB

Angela Robb is a 25-year wife and care partner for her husband, Karl, who was diagnosed with young onset Parkinson's more than 30 years ago. She and Karl co-authored the book *Dealing and Healing with Parkinson's Disease and Other Health Conditions: A Workbook for Body, Mind, and Spirit*. She is a co-editor at ASoftVoice.com, a contributor and community team member at ParkinsonsDisease.net, and a Reiki Master. Angela has advocated for caregiver issues by sharing her experiences on Capitol Hill, at various regional and national Parkinson's conferences, and as a presenter at the World Parkinson Congress. In 2015, Angela was honored at The White House as a Champion of Change in Parkinson's Disease.



JESSICA SHURER

Jessica Shurer, MSW, LCSW, is the Director of Patient and Care Partner Advocacy of CurePSP, whose mission and services are dedicated to the awareness, education, care, and cure of atypical Parkinsonism diseases — progressive supranuclear palsy, corticobasal degeneration, and multiple system atrophy. Prior to joining the team at CurePSP in October 2021, Jessica served as the Center Coordinator and Clinical Social Worker of the Movement Disorders Center at the University of North Carolina at Chapel Hill, a Parkinson's Foundation Center of Excellence and CurePSP Center of Care. She had been in this previous position since graduating from UNC Chapel Hill with her Master of Social Work in 2012. Her clinical and research interests include the psychosocial needs of navigating neurodegenerative disease, integrated healthcare models, and palliative and end-of-life care.



JUWAIIRIYA SYED

Juwairiya Syed's father was diagnosed with Parkinson's in 2018 at the age of 64 and passed away this past May. In the beginning stages of her father's journey, Juwairiya spent many hours researching symptoms of Parkinson's and the best therapies for it, and she wrote of her experiences on the community publication ParkinsonsDisease.net. Juwairiya moved to Dallas after graduating in 2017 from the University of California, Davis, and is now studying screenwriting at NYU. By writing about her and her family's journey, she hopes to help others caring for family members with Parkinson's.

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

*who are with you on your journey
as a Parkinson's Care Partner*



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 on 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 Ambassadors goes far beyond resources and advice. Our Ambassadors offer a safe place for care partners and people with Parkinson's alike that allows for real processing, support, and change to happen.

The experience and wisdom our Ambassadors bring is transformative, and we hope you will reach out to them throughout your journey as a care partner. 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 and care for your person with Parkinson's.

Ask questions, discover new resources, and get advice on how to live well at dpf.org/ambassadors.

EVERY VICTORY COUNTS®

... for Care Partners



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 part of our new Every Victory Counts suite of resources, which includes a brand-new manual designed just for Parkinson's care partners.

Your role as a care partner will evolve throughout the years, but in each stage, it is essential to equip yourself with tools, advice, strategies, and support to ensure that you and your loved one live well. We designed our **new Every Victory Counts® Manual for Care Partners** to give you just that. Throughout the new manual, we share some of the most frequently asked questions we receive from Parkinson's care partners, with responses from us, from Parkinson's experts, and from Parkinson's care partners.



Your go-to guide for living well as a Parkinson's Care Partner



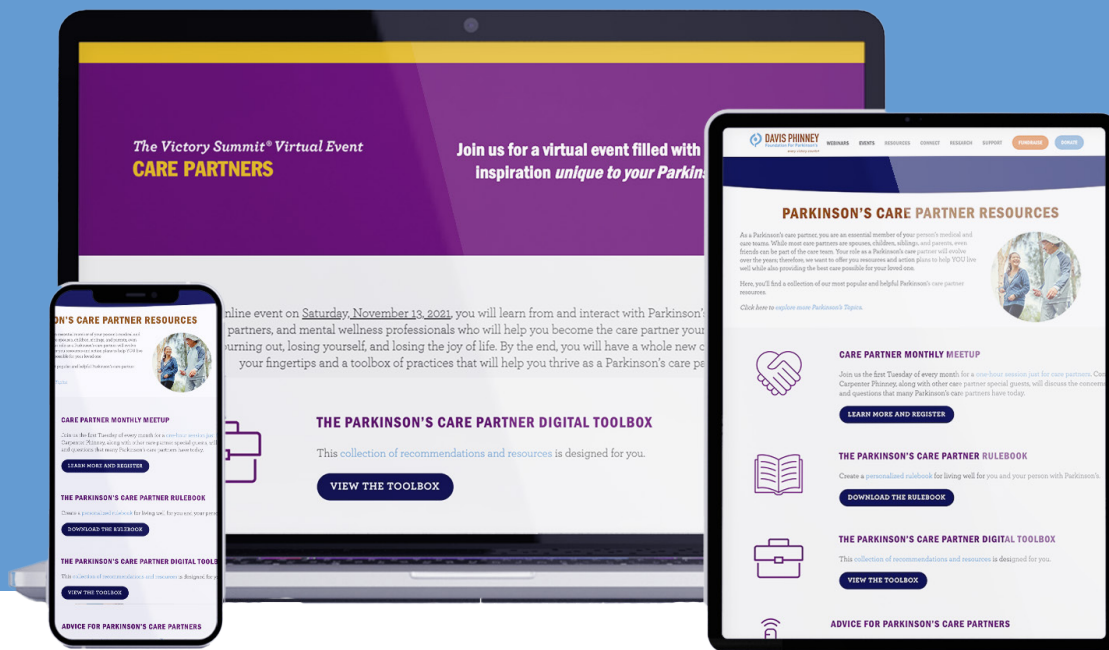
Available in print and digital.

We've designed the new manual to be accessible to all care partners, whether you care for someone young, newly diagnosed, or in the advanced stages of Parkinson's.

The Every Victory Counts collection also includes:

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

Order yours today at EveryVictoryCounts.org.



For more information on everything from avoiding care partner burnout, tips for encouraging exercise, options for complementary therapies, and more, we've created an online resource guide especially for you.

Visit dpf.org/care-partners and you'll find sections on:

- » Parkinson's care partner toolkits
- » Tips for communication, mental health, and self care
- » Opportunities to connect with other Parkinson's care partners
- » Information on care partner experts and ambassadors
- » A collection of recommendations and resources designed for care partners
- » Every Victory Counts® manual for care partners
- » Webinars, blog posts, podcasts, 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.



THE VICTORY SUMMIT[®] VIRTUAL EVENTS

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

Watch the session recordings from a past event this year:

- » **February 20, 2021** - Newly Diagnosed
- » **April 2, 2021** - How to Live Well with Parkinson's
- » **June 26, 2021** - YOPD
- » **September 17, 2021** - Mental Health & Wellness

Learn more at dpf.org/events.

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Adamas

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We make healthy possible



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Changing Lives



We fight disease, so more you shines through.

**Protecting what makes you, uniquely you,
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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
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in its mission to help people
with Parkinson's live well today.



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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.

www.Lundbeck.com/us



We strive to make
the everyday life of
people with Parkinson's
significantly better.

Adamas is a dedicated partner to the Davis Phinney Foundation in supporting the Parkinson's community.

You can learn more about our products at adamaspharma.com/products-pipeline.

Learn more about OFF and dyskinesia at PictureMoreTimePD.com.



People with
Parkinson's
and their
care partners.




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](https://www.sunovion.com) and connect with us on:



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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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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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MEANS ALWAYS
SEARCHING**
FOR WAYS TO TAKE ON ADVANCING
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for more information

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TAKE ACTION TO LIVE WELL TODAY

Living well as a Parkinson's care partner can be challenging, but there are many steps you can take every day to make the journey a positive one. 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:

- » **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 can classes and gathering with small groups of fellow care partners who can encourage and inspire you.
- » **Ask for help.** You do not have to be everything for your loved one with Parkinson's. Accept and ask for help when you need it. Be specific when you reach out for help and let people know what they can do that would be most helpful.
- » **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, and you will see life as a care partner in a much more positive light.



Information

Download and read “The Parkinson’s Care Partner Rulebook” written by Connie Carpenter Phinney and create your own a personalized rulebook for living well for you and your person with Parkinson’s.

dpf.org/care-partner-rulebook

- » **Communicate.** Adapting to life with Parkinson’s requires a true partnership between you and your loved one. Ongoing, open communication fosters closeness and connection. Practice honest communication about your needs and theirs, big decisions, and your future together.
- » **Look for signs of burnout.** Pay attention to your emotions and check in with yourself, noticing whether you’ve lately been feeling more irritable or angry, socially withdrawn, anxious and/or depressed, or if you are experiencing other red flags such as missing your own medications or medical appointments, having trouble sleeping at night, catching frequent colds, and more. If you notice that your health is compromised, now is the time to make positive changes or reach out for help.
- » **Be an advocate.** When you advocate for your person with Parkinson’s, be it during a medical appointment or in a conversation with friends, it increases awareness of Parkinson’s, builds community, and creates the opportunity for people to solve problems together. Advocating for your person with Parkinson’s often involves educating others about what your person experiences. It would be exhausting to teach everyone you interact with about Parkinson’s, but finding people with whom you can share your story is a step toward creating a more inclusive environment.

LIVE WELL TODAY

- » **Take self-care seriously.** This is often a challenge when your person with Parkinson's is constantly on the top of your mind and needs a great deal of care; however, you cannot give something you don't have. To love and care for them, you must love and care for yourself. To ease their discomfort and pain, you must be able to ease yours as well. Self-care is not indulgent or selfish. Instead, it is your ticket to living well. And when you live well, you're much better equipped to help them do the same.



Community Support

Join us the first Tuesday of every month for a one-hour session just for care partners. Connie Carpenter Phinney, along with other care partner special guests, will discuss the concerns, challenges, and questions that many Parkinson's care partners have today.

dpf.org/care-partner-meetup



Information

Read “The Parkinson's Care Partner Digital Toolbox” for a collection of recommendations and resources is designed for you.

dpf.org/digital-toolbox

NOTES FROM TODAY

Use this space to keep notes from the sessions that are particularly helpful to you.



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 have 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 and as a care partner.**

Thank you for helping us to create these inspirational events.



Contributions can be made online at
dpf.org/pif-care-partners or by telephone
at (866) 358-0285.

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