



DAVIS PHINNEY

Foundation For Parkinson's

every victory counts®

THE VICTORY SUMMIT[®] **ALBANY**



Saturday, October 3, 2020

THANK YOU FOR JOINING TODAY.

We're glad you're joining us today.

Whether this is your first time experiencing an event focused on Parkinson's, or you have attended many in the past, we're **grateful** you'll be spending the morning with us.

Today, it's okay to be unsure, to ask questions, to step outside of your comfort zone. Everyone participating today is on a unique journey, but we share so much in common. Know that even while far apart, you are part of this special community. Participate in the chat, join our group on Facebook, and enjoy these new ways of **connecting**.

Our hope is that by the time we wrap up, you will feel **inspired, motivated**, in charge, and ready to live well with Parkinson's today and every day.

Today is just the beginning. Our staff, event partners, sponsors, local resources, speakers – we will all be available today, tomorrow, and beyond to **support** you.

Thank you for joining us today. We're glad you're with us.

WHAT DO YOU HOPE TO LEARN TODAY?

Before the day begins, consider which topics you hope to learn more about. Hopefully, many of your questions will be answered. For questions that remain, this will help guide future conversations with the Davis Phinney Foundation, our speakers, or local resources.

- Motor symptoms
- Sleep disturbances
- Depression & mood
- Non-motor symptoms
- Urinary & bowel symptoms
- Nutrition
- Cognition
- Fall prevention
- Speech & swallowing
- Exercise
- Medication management
- Care partners
- Surgical therapies
- Young Onset Parkinson's
- Complementary therapies
- Supportive care

Think of something later?

Send us an email at contact@dpf.org or give us a call at (866) 358-0285.

MEET DAVIS



Davis Phinney was fresh off of 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 pioneering vision of helping those living with Parkinson's to take action 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.

PROGRAM BOOK GUIDE

page 6 **Agenda**
See what's coming up for the morning.

page 8 **Speaker Bios**
Get to know the incredible experts we have with us today.

page 12 **Thank You's**
Take a moment to acknowledge the community members and sponsors who made today possible.

page 17 **Virtual Exhibitor List**
See these national and local resources and find their contact information to follow up with them later.

page 26 **Action Steps**
Set a new goal and plan the steps that will help you achieve it!



GET MOVING WITH US **TODAY!**

You'll see this symbol on your agenda a couple of times. This represents two movement breaks we will take today. During this time, get ready to move your body, activate your mind, and try something new.

Movement Break 1: Dance Beyond Parkinson's

Dance has been known to enhance strength, coordination, flexibility, and balance. In Dance Beyond Parkinson's, we will stretch, groove, dance, be funky, kick up our heels, shout, relax, and feel good all over. Care partners and family members are always welcome! No dance experience required.

Movement Break 2: Goodemote Physical Therapy

The movement break will consist of a "Dynamic Mobility" sequence. It will include movements we use to "wake up" the joints, muscles, and nervous system and can be used as a movement prep warm-up or to help improve balance and gait.

For more information about local wellness classes, view the resource guide at dpf.org/albany-details.

THE VICTORY SUMMIT® ALBANY AGENDA

To download today's slides and other resources, visit dpf.org/albany-details.

8:30 – 9:00



Movement Break - Dance Beyond Parkinson's (optional)

Rachelle Smith-Stallman, MS, BCDMT, LCAT, *Dance Beyond Parkinson's (Albany, NY)*

9:15 – 9:30

The Virtual Victory Summit Event Tech Check (optional)

9:30 – 9:40

Information for the Day

9:40 – 10:00

Welcome and Inspiration

Davis Phinney, *Founder, Davis Phinney Foundation (Louisville, CO)*
Connie Carpenter Phinney, MS, *Care Partner, Board Chair, Davis Phinney Foundation (Louisville, CO)*

10:00 – 10:40

Cognition and Mood and How to Manage Them

Greg Pontone, MD, MHS, *Johns Hopkins University School of Medicine (Baltimore, MD)*

10:45 – 11:15

Not Just the Shakes: Non-motor Symptoms of Parkinson's

Christopher Tarolli, MD, *University of Rochester Medical Center (Rochester, NY)*

11:15 – 11:25

Break

11:30 – 12:00

Mind of a Dancer

David Leventhal, *Program Director, Dance for PD® (New York City, NY)*

12:05 – 12:25

How to Live Well with Parkinson's

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

12:30 – 12:40



Movement Break – Dynamic Mobility

Matthew Goodemote, MPT, *Goodemote Physical Therapy (Saratoga Springs, NY)*

12:45 – 1:30

Q&A Panel - Ask Them Your Most Pressing Questions + Closing

Christopher Tarolli, MD, Greg Pontone, MD, David Leventhal, Melani Dizon

1:35 – 1:50

Event and Davis Phinney Foundation Q&A

Melani Dizon, *Director of Education, Davis Phinney Foundation (Louisville, CO)*

MEET TODAY'S SPEAKERS



CONNIE CARPENTER PHINNEY, MS

Connie Carpenter Phinney is an entrepreneur, author, artist, and life-long 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.



MATTHEW GOODEMOTE, MPT

Matthew is one of just 350 specialists with his diploma from the McKenzie Spine Institute International. Matthew Goodemote offers a unique blend of exercise-based therapy and manual therapy to achieve the best outcomes possible.



KAT HILL

Kat Hill is from Portland, Oregon, where she lives with her husband and Yorkshire terrier “Baxter.” She believes that we can choose joy in our lives no matter what we’re faced with. Movement, mindfulness, and gratitude help her navigate the challenges of living with Parkinson’s. She is a retired nurse-midwife and delivered over 800 babies in her career. Now in her second act, she’s an author and advocate for finding wellness after a Parkinson’s diagnosis.



DAVID LEVENTHAL

David Leventhal 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 has co-produced three volumes of a successful At Home DVD series for the program and has been instrumental in initiating and designing innovative projects involving live streaming and Moving Through Glass, a dance-based Google Glass App for people with Parkinson's. 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 is a sought-after speaker at international conferences and symposiums, and has spoken about the intersection of dance, Parkinson's, and health at many prestigious universities, conferences, and cultural centers. Leventhal designed and currently teaches a pioneering dance-based elective course that is part of the Narrative Medicine curriculum at Columbia University's College of Physicians and Surgeons. He graduated from Brown University with honors in English Literature.



GREG PONTONE, MD, MHS

Gregory Pontone, MD, MHS, is an Associate Professor in the Departments of Psychiatry and Neurology at Johns Hopkins University School of Medicine in Baltimore, Maryland. He is an Attending Psychiatrist in the Geriatric and Neuropsychiatry division and is the Director of the Johns Hopkins Parkinson's Disease Neuropsychiatry Clinic, which focuses on diagnosing and treating the neuropsychiatric aspects of Parkinson's and related disorders. Dr. Pontone's research focuses on the interaction between neuropsychiatric symptoms such as cognitive impairment, anxiety and depression, and motor impairment in Parkinson's. After completing a medicine internship and residency training in psychiatry at Johns Hopkins, Dr. Pontone completed a two-year fellowship in geriatric psychiatry and movement disorders focusing on Parkinson's through the Clinical Research Program of the Morris K. Udall Parkinson's Disease Research Center at Johns Hopkins. He also completed a fellowship in Clinical Trial Methods in Neurology sponsored by the National Institute of Neurological Disorders and Stroke. Dr. Pontone also serves on the Scientific Review Committee and as the chair of the Cognitive/ Psychiatric Working Group for an international consortium of Parkinson's disease researchers, the Parkinson Study Group.



RACHELLE SMITH STALLMAN, MS BCDMT, LCAT

Rachelle received her bachelor's degree in Dance from the University of New Mexico and her master's in Dance Therapy from Hunter College. She has advanced training with the Mark Morris Dance Group Dance for PD® program, and for the last three years has been teaching Dance Beyond Parkinson's classes in Albany and Saratoga.



CHRISTOPHER TAROLLI, MD

Dr. Tarolli graduated from Syracuse University in 2007 and received his MD from SUNY Downstate College of Medicine in 2012. He completed his internship in internal medicine and residency in neurology at the University of Rochester Medical Center and graduated in 2016. Dr. Tarolli completed a fellowship in movement disorders and experimental therapeutics of neurological disease in 2018. He joined the faculty in 2018 and specializes in the care of individuals with Parkinson's, atypical parkinsonian syndromes, and Huntington disease.

Beyond clinical work, Dr. Tarolli is a neurological educator and is the Co-director of the Mind, Brain, and Behavior neuroscience course at the University of Rochester School of Medicine and Dentistry. He is also involved in clinical research focusing on novel technologies, practice-based research, and palliative care in individuals with Parkinson and other movement disorders.



MEET OUR AMBASSADORS

Davis Phinney Foundation Ambassadors are Parkinson's advocates who connect with people locally and digitally to help them live well. Ambassadors are available to discuss tools and strategies for improving quality of life with support groups, individuals, families, and healthcare professionals. Ambassadors speak on the subject of wellness at local Parkinson's events and support groups, and they also meet one-on-one with individuals and families.

Connect with one of our Ambassadors to ask questions, discover new resources, and get advice on how to live well with Parkinson's.

dpf.org/ambassadors

THANK YOU TO OUR COMMUNITY ACTION COMMITTEE

Thank you to the following local Parkinson's leaders involved with the Community Action Committee for not only making The Victory Summit event possible, but for committing to develop meaningful resources in your community.

Mark Burek – *Hope Soars*

Jud Eson – *Capital District Parkinson's Support Group*

Nancy Eson – *Parkinson's Community Leader*

Nancy Hovey – *Parkinson's Community Leader*

Steve Hovey – *Davis Phinney Foundation Ambassador*

Parkinson's Disease and Movement Disorders Center of Albany Medical Center

Marie Thorne – *Parkinson's Community Leader*

To find more information on the Community Action Committee and local Albany resources, download the "Online Resource Guide" at dpf.org/albany-details.

THANK YOU TO OUR SPONSORS

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.

www.rytary.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



Acorda

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

www.acorda.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



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



We make healthy possible



Challenging
Convention,
Changing Lives





KYOWA KIRIN IS PROUD TO SUPPORT THE DAVIS PHINNEY FOUNDATION

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





Actor portrayal

Did you know? INBRIJA[®] is inhaled levodopa

Ask your doctor today about INBRIJA or
visit InhaledINBRIJA.com to learn more

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

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Inbrija[®]
(levodopa inhalation powder)
42 mg capsules

EXHIBITORS

Connect with these national and local resources.

ACADIA Pharmaceuticals

Leader in developing and commercializing innovative therapies for central nervous system disorders.

www.acadia-pharm.com

Acorda Therapeutics

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

www.acorda.org

Adamas

Pharmaceutical company developing innovative treatments for chronic neurologic disorders.

www.adamaspharma.com

Amneal

We believe in partnering with patients, care partners, healthcare providers, and advocacy organizations because together, we can achieve.

www.rytary.org

Boston Scientific

Global biotechnology company developing innovative therapies for chronic neurological disorders.

www.bostonscientific.com &
www.dbsandme.com

Capital District Parkinson's Support Group

The CDPSG's mission is to provide moral support and fellowship to people with Parkinson's, their families, and care partners; to raise awareness and disseminate information regarding Parkinson's; and to act as a resource center for members and others who would like to know more about Parkinson's.

www.cdparkinsons.org

Dance Beyond Parkinson's

Now offering classes on Zoom! Stretch, groove dance, funk out, kick up your heels, shout, relax, and feel good all over! To find out more about Dance Beyond Parkinson's, visit:

www.youtube.com/user/872Rachelle/playlists

Hope Soars

The goal of Hope Soars has been to inspire the Parkinson's community to live fully while battling this disease. By increasing awareness, education, and research, Hope Soars provides resources to the Albany Parkinson's community.

www.hopesoars.org

Kyowa Kirin

A Japanese pharma group that develops innovative specialty drugs to raise the health and well-being of people around the world.

www.kyowakirin.com

Lundbeck

A global pharmaceutical company based in Denmark and founded in 1915, Lundbeck strives for global leadership in psychiatry and neurology.

www.lundbeck.com/us

Medtronic

Global biotechnology company developing innovative therapies for chronic neurological disorders.

www.medtronic.com/dbs

Parkinson's Disease and Movement Disorders Center of Albany Medical Center

Our mission is to provide comprehensive and compassionate patient-centered care to people living with Parkinson's. Our community education program empowers patients to help themselves, and our research program brings hope for a better future.

www.amc.edu/patient/services/neurosciences/parkinsons

PD Self National Program of the Movement Disorder Foundation

The PD Self program uses self-efficacy to assist people newly diagnosed with Parkinson's to develop a better understanding of the condition, while harnessing the fortitude to manage their lives.

www.pfself.org

Saratoga Support Group

Uplifting and informative support group based in Saratoga. Meetings happening virtually, email Kevin at

saratoga.parkinsons@gmail.com or Marie at softballmom300@yahoo.com for more information.

Schott's Boxing and Fitness

Schott's Boxing offers boxing for fitness classes to men and women ages 10 - 70+. Our classes are high energy boxing training with emphasis on proper form and technique.

Beginners welcome!

www.schottsboxing.com

Sunovion Pharmaceuticals

Pharmaceutical company leading the way to a healthier tomorrow by creating medicines for respiratory diseases and central nervous system disorders.

www.sunovion.us

Supernus (formerly US WorldMeds)

Our vision is to be a leading CNS pharmaceutical company developing and commercializing new medicines in neurology.

www.supernus.com/commercial-products

Thrive Physical Therapy

Thrive is a physical therapy practice based in Rochester, NY, that specializes in Parkinson's and other neurological disorders.

www.thriveptandwellness.com

Do you get dizzy when standing?

About

1 OUT OF **5**



people with Parkinson's may also have symptoms of nOH.

Learn more at nOHMatters.com

nOH
MATTERS
neurogenic Orthostatic
Hypotension



Join the community on [Facebook.com/nOHMatters](https://www.facebook.com/nOHMatters)

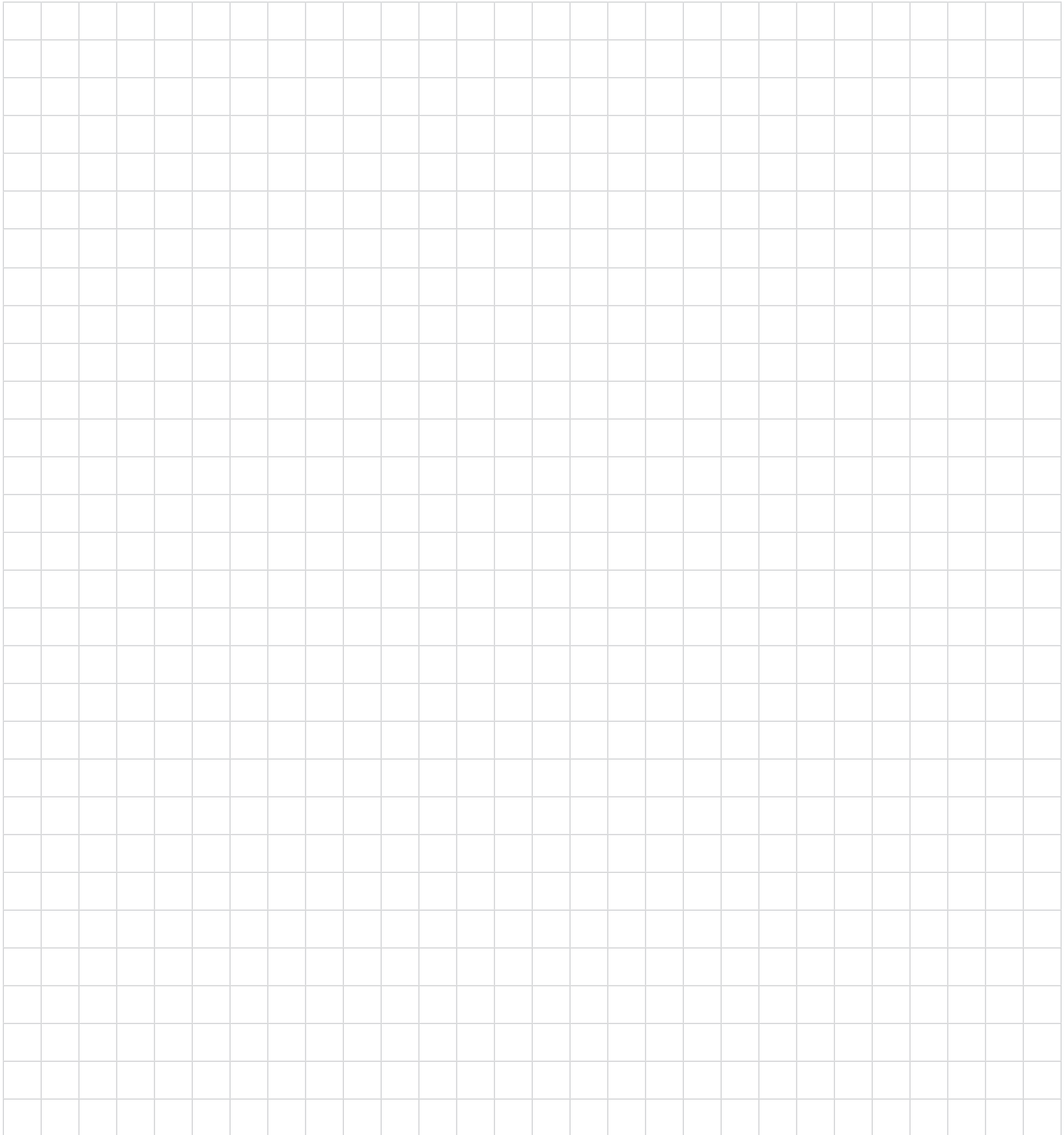
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LIVE WELL.
INSPIRE ACTION.
CONNECT THE COMMUNITY.

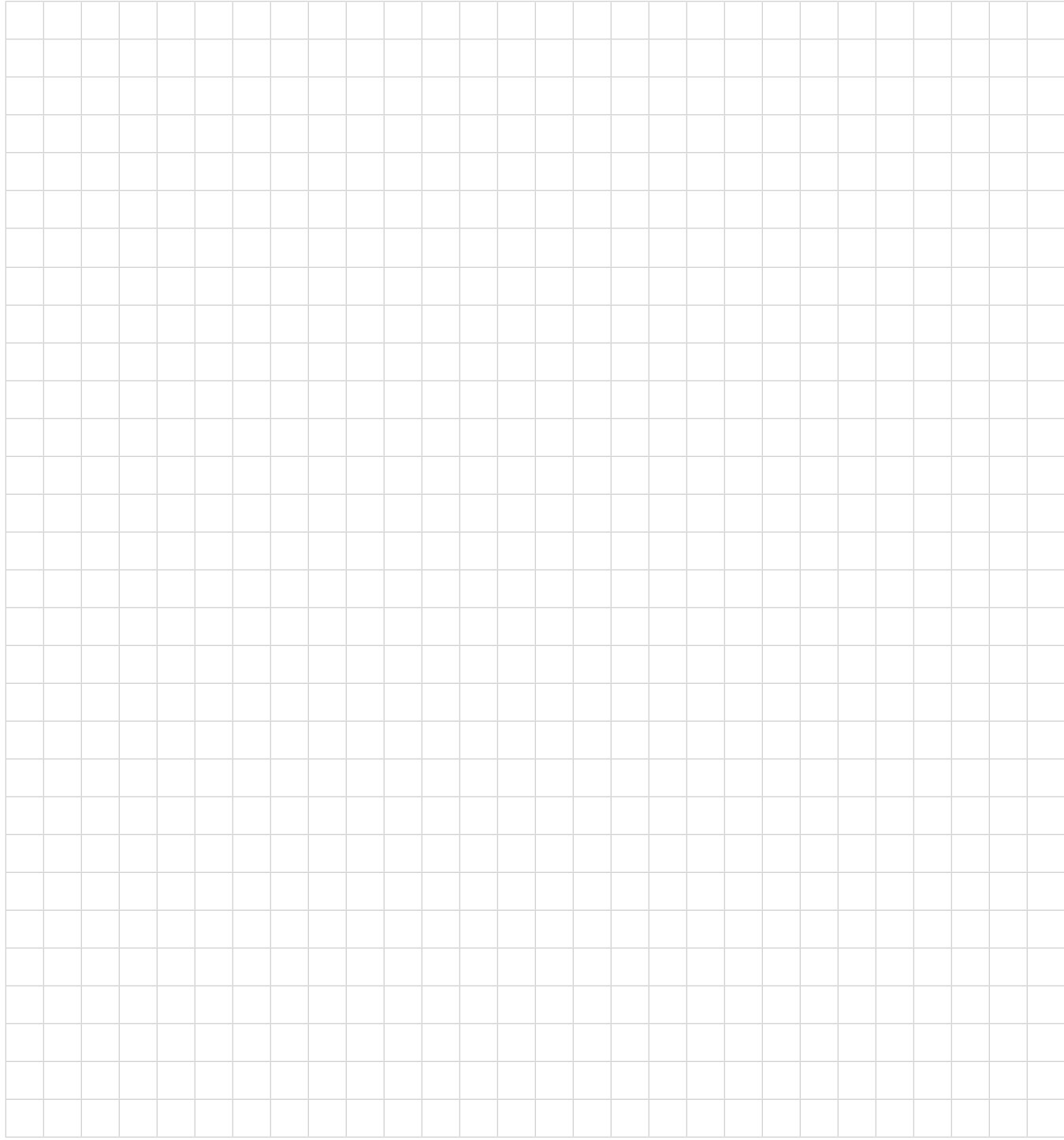


NOTES FROM TODAY

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!



NOTES FROM TODAY



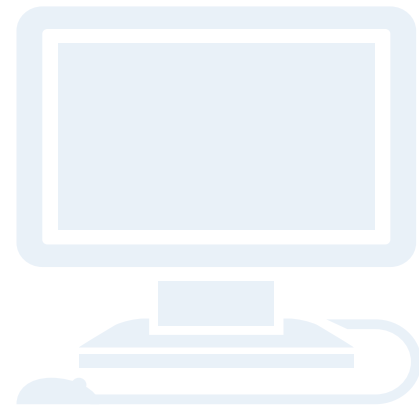


ADDITIONAL RESOURCES

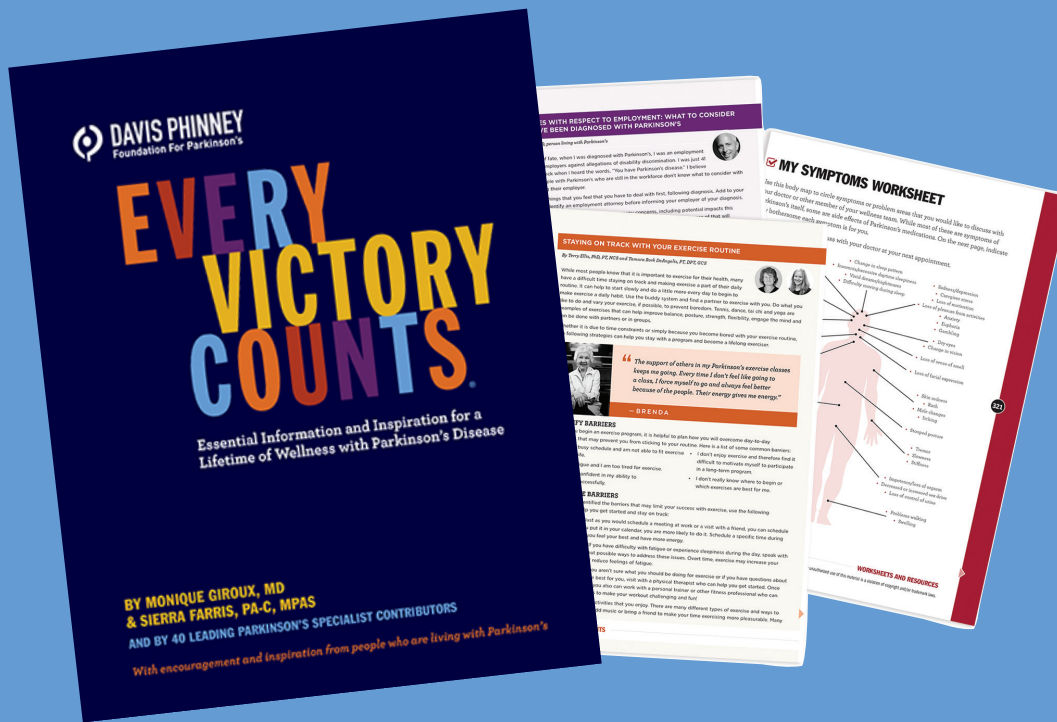
For more information on everything from exercise, treatments, complementary therapies, and more, we've created an online resource guide especially for you.

Visit www.dpf.org/vs-resources and you'll find sections on:

- » Parkinson's tools, techniques, and technology
- » Care partners
- » Local and national Parkinson's organizations
- » Parkinson's experts and ambassadors
- » Home safety
- » 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

- » In-depth information about exercise, nutrition, emotional health, medication, therapies, and more
- » Over 30 worksheets you can start using immediately
- » Insights from over 60 Parkinson's advocates, physicians, therapists, and scientists



Request a free copy or download your eBook today at EveryVictoryCounts.org or call toll-free (855) 744-6639.

Our event today for Albany was made possible by individuals just like you who made a donation to **“Pay It Forward.”**

We hope you learned a lot today and maybe even had an “aha” moment or two. With your **tax-deductible donation** to the Davis Phinney Foundation, you can be a part of creating these kind of “aha” moments in our next city!

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

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



Polly Dawkins, Executive Director



THE VICTORY SUMMIT EVENT – UPCOMING CITIES

Know someone who you think should attend The Victory Summit event? Check out our list of upcoming cities to refer a friend to this day of information and inspiration!

Learn more about upcoming events at dpf.org/vs.

Boise, ID

November 14, 2020

**LIVE WELL TODAY:
BE ACTIVE**

ACTION STEPS

Cognition and Mood and How to Manage Them

- Reduce distractions
- Focus on one task at a time
- Talk to your doctor about depression
- Exercise
- Get quality sleep
- Eat a healthy diet
- Do cognitive training/rehabilitation
- Increase social interaction

How to Live Well with Parkinson's

- Commit to exercise – go for a walk, find a class, join a gym, get a treadmill
- Update a medication list and keep it in your wallet/ purse
- Connect with your Parkinson's community
- Recognize at least one non-motor symptom to discuss with your physician

Not Just the Shakes: Non-motor Symptoms of Parkinson's

- Non-motor symptoms are common, accumulate with progression, and have a major impact on quality of life
- Pain is common in Parkinson's. Activity can help manage it
- Some simple lifestyle interventions can help to manage bothersome drops in blood pressure
- Be aware of common non-motor symptoms and highlight YOUR priorities at your next doctor's appointment

The Mind of a Dancer

- Make training fun: infuse it with imagination, creativity, and novelty
- Use music as your guide, partner, and coach
- Plan everyday movement as a choreographer does
- Harness the power of imagery—and focus on how we move
- Utilize social connections to move and to stay motivated

COMMUNITY ACTION COMMITTEE

Mark Burek – *Hope Soars*

Jud Eson – *Capital District Parkinson's Support Group*

Nancy Eson – *Parkinson's Community Leader*

Nancy Hovey – *Parkinson's Community Leader*

Steve Hovey – *Davis Phinney Foundation Ambassador*

Parkinson's Disease and Movement Disorders Center of Albany Medical Center

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