



DAVIS PHINNEY

Foundation For Parkinson's

every victory counts®

Welcomes you to

THE VICTORY SUMMIT[®] **EVENT**

NEW ORLEANS



Premier sponsor:



Saturday, June 1

New Orleans, LA

THANK YOU FOR COMING TODAY.

We're glad you're here.

Whether this is your first time at an event focused on Parkinson's or you have attended many in the past, we are **grateful** you put in the time and effort to spend your day with us.

Today, it's okay to be unsure, to ask questions, to step outside of your comfort zone. Everyone in this room is on a unique journey, but we share so much in common. Have a conversation with someone new to you. You might make a valuable connection—**or even a friend.**

Our hope is that, by the time we are saying our goodbyes, 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, organizations in the exhibition hall, and our presenters will all be available today, tomorrow and beyond to **support** you.

Thank you for coming today. We're glad you're here.

WHAT DO YOU HOPE TO LEARN TODAY?

Before the day begins, we encourage you to 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 disease (YOPD)
- Complementary therapies
- Supportive care

Think of something later at home?

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

MEET DAVIS



Davis Phinney was fresh off a successful professional cycling career—where he won an Olympic bronze medal in 1984 and was part of the first American team to race in the Tour de France—when he was diagnosed with Parkinson’s. He founded the Davis Phinney Foundation in 2004 with the pioneering vision of helping those living with Parkinson’s take action to improve their quality of life through education, inspiration, resources, and effective self-care.

Davis’s perseverance, coupled with his infectious positive attitude and dedication, inspire the work of the Davis Phinney Foundation and have earned him the reputation as a tireless advocate and mentor for others living with Parkinson’s. Because of his work in the Parkinson’s community, in spring of 2015, he was honored at the White House as a Champion of Change.

PROGRAM BOOK GUIDE

page 6 **General Session Agenda**
See what’s coming up for full audience sessions of our day.

page 8 **Breakout Session Information**
Read through the options for our breakout sessions to determine which ones you want to attend and find out where they are taking place.

page 11 **Speaker Bios**
Get to know the incredible experts we have with us today.

page 18 **Thank You**
Take a moment to acknowledge the partners and sponsors that made today possible.



GET MOVING WITH US **TODAY!**

You'll see this symbol on your agenda. This represents the movement break we will take throughout the day. During this time, get ready to move your body, activate your mind and maybe try something new.

Movement Break: Dance, Dance

Let's get moving! Join instructors Susan Bensinger and April Dayok from the New Orleans Ballet Association's Oscar J. Tolmas Charitable Trust Dance for Parkinson's Program for a music-filled movement break. Besides being a lot of fun, dance helps with balance, coordination, rhythm, and muscle strength. You don't have to be a professional—or even have any experience at all!--to feel empowered through a quick bit of dance.

THE VICTORY SUMMIT® NEW ORLEANS AGENDA

To download today's slides and learn more about our speakers, visit dpf.org/vs-nola

8:00 – 8:45

Visit Exhibit Hall

Exhibit Hall open from 8:00am – 2:30pm

8:45 – 9:00

Transition to Main Session

9:00 – 9:10

Welcome & Opening Remarks

Susan Sapir-Fields, *Louisiana Walks for Parkinson's (Metairie, LA)*

Polly Dawkins, *Executive Director, Davis Phinney Foundation (Boulder, CO)*

9:15 – 9:20

Moments of Victory®

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

9:25 – 10:10

Ready, Set, Go: Preparing for Your Appointments

Aaron Haug, MD, Neurologist and Movement Disorder Specialist (Englewood, CO)

Break #1

10:15 – 10:40

Coffee & Connection Break - Browse exhibitors and meet other attendees

10:45 – 11:10



Movement Break: Dance, Dance

Susan Bensinger and April Dayok, NOBA's Oscar J. Tolmas Charitable Trust Dance for Parkinson's Program (New Orleans, LA)

11:15 – 12:00

Get Moving: The Significance of Exercise

Madeleine Hackney, PhD, Research Scientist, Emory School of Medicine (Atlanta, GA)

Break #2

12:00 – 12:50

Lunch - Delivered directly to tables - Exhibit Hall open

12:50 – 1:00

Transition to the Track 1 Breakout Session of your choice

1:00 – 1:30

Track 1 Breakout Sessions

Read through the options on page 8

Break #3

1:30 – 1:40

Break - Transition to the Track 2 Breakout Session of your choice

1:40 – 2:10

Track 2 Breakout Sessions

Read through the options on page 9

Break #4

2:10 – 2:20

Break - Transition back to Main Session

2:25 – 2:50

Here When You Need It: Supportive Care

Benzi Kluger, MD, MS, Founding Director of the Neuropalliative Care Service and Palliative Care Research Center at the University of Rochester (Rochester, NY)

2:50 – 3:00

Closing Head Home!

Make your commitment to live well with Parkinson's!



BREAKOUT SESSIONS: TRACK 1

The following sessions will be offered from **1:00 - 1:30 pm.**

BALLROOM

Living Well with Surgical Therapies

Dr. Sarah Perez, *Tulane University (Metairie, LA)*

There comes a point in many people's journey with Parkinson's that surgery becomes an option. What are surgical options to help Parkinson's? When do you need to decide whether or not a particular surgery is right for you? In this session, Dr. Perez will delve into surgical therapies for Parkinson's.

CALCASIEU

So You Want to Be a Support Group Leader

Ben (B.J.) Bement, *PMD Alliance (Baton Rouge, LA)*

Support groups offer community, camaraderie, and relief in being able to connect with others who know what you're going through. Join B.J. Bement from PMD Alliance to learn more about starting a support group in your area. He will also share a heat map of current support groups in the area for you to consider.

BARATARIA

Care Partner Connections

Connie Carpenter Phinney, *Davis Phinney Foundation (Boulder, CO)*

With over two decades of experience, Connie Carpenter Phinney approaches her role as a primary care partner to a person living with Parkinson's with candor and humor. Join Connie for practical advice and a Q&A session (if time permits).



BREAKOUT SESSIONS: TRACK 2

The following sessions will be offered from **1:40-2:10 pm**.

BALLROOM

Advanced Technology: Wear It, Watch It, Work It

Dr. Brian Copeland, *University Medical Center-New Orleans (New Orleans, LA)*

New advancements in technology regularly emerge in the Parkinson's community and it can be hard to keep up with every new gadget, app, or device. Dr. Copeland will discuss some of the latest advancements in Parkinson's technology, including wearable tracking devices and apps, and explain their benefit for a person living with Parkinson's.

CALCASIEU

YOPD Meet and Greet

Anna Grill, *YOPN (Vienna, VA)*

Robert Cochrane, *Yes, and...Exercise! (YAX!) (Walnut Creek, CA)*

People diagnosed with young onset Parkinson's disease (YOPD) face different feelings, challenges, and roadblocks. Join Anna Grill, inspiration for the young onset Parkinson's network (YOPN), in a time to meet-and-greet other people diagnosed with YOPD. We'll break the ice—and have some fun—with the help of Robert Cochrane's improv group Yes, and....Exercise!

BARATARIA

What You Need to Know When Newly Diagnosed

Dr. Sarah Breaux, *Ochsner Health (New Orleans, LA)*

Receiving a Parkinson's diagnosis is life-changing in more than one way. Your future suddenly feels uncertain, and you probably have a lot of questions. In this session, Dr. Breaux will cover the basics of what someone newly diagnosed with Parkinson's needs to know to feel empowered, educated, and informed about where to turn when help is needed.

MEET TODAY'S SPEAKERS



BENJAMIN (BJ) BEMENT, diagnosed in 2013 at age 44, is a co-director of CAPAC. He is also the Chairman of the Moving Day Team and Art Gala Team. He is a willing participant of any activity that brings persons with Parkinson's and care partners together. He serves on the Parkinson's Foundation's Advisory Council and is an Advisory Council member of the Young Onset Parkinson's Network (YOPN). He also serves as part of the community outreach for the Quiver.org.



SUSAN BENSINGER earned a Bachelor of Arts in dance education from Pennsylvania State University and a Master of Arts in dance from George Washington University in Washington, D.C. While there, she performed with the Maida Withers Dance Construction Company. She taught dance at George Washington University, Foxcroft School, and Willow Charter School. In 2007, she was voted Teacher of the Year at Willow. Bensinger began working with NOBA in 2012 and is a trained substitute for NOBA's Oscar J. Tolmas Charitable Trust Dance for Parkinson's Program.



SARAH BREAU, MD is a movement disorders neurologist at Ochsner Health in New Orleans and Raceland, Louisiana. She earned her medical degree from Louisiana State University Health Science Center in New Orleans. Dr. Breaux completed her internship and residency in neurology at the University of Alabama at Birmingham (UAB) where she was chief resident. She completed a fellowship in movement disorders at UAB before returning home to Louisiana to practice in her hometown in the bayou region and New Orleans. She has special interest in deep brain stimulation for essential tremor and Parkinson's disease. Her passion is education and empowering patients with Parkinson's to take ownership of their life while navigating each step with resilience, determination, and steadfast spirit.



ROBERT COCHRANE, PHD is a graduate of UNLV's interdisciplinary health sciences program. His father, Dan, was diagnosed with Parkinson's in 2001, which shifted Robert's artistic lens to health. He continues to test and research the effects of improvisation and storytelling on Parkinson's. Robert has received grants from the Parkinson's Foundation and support from the Davis Phinney Foundation. Via his nonprofit, Yes, And...eXercise! (www.yesandexercise.org), Robert offers joy, optimism, and practical tools for all people in the Parkinson's community to thrive today. He lives with his beautiful wife, two teenagers, and a rambunctious puppy named Stella (though it's usually pronounced, "STELLAAAAA!") in Walnut Creek, CA. Robert is a proud care partner for his amazing parents.



POLLY DAWKINS brings 25 years of for-profit and nonprofit experience to her position as the Executive Director of the Davis Phinney Foundation. 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, connection to community, and funding quality-of-life research that takes the guesswork out of living well.



APRIL DAYOK earned a Bachelor of Arts in dance from Point Park University. After relocating to New York, she danced with Becky Radway Dance Project, Counter Tides Dance, Mark Dendy Dance and Theater Projects, and worked with the Mark Morris Dance Group's Dance for PD® program and for Pamela Quinn (dancer, Parkinson's patient, and movement specialist for Parkinson's patients). Dayok has nationally and internationally toured with Lightwire Theater and locally performed with Mélange Dance Company and ELLEvate Dance. She began working with NOBA in 2017 and is an instructor for NOBA's Oscar J. Tolmas Charitable Trust Dance for Parkinson's Program.



ANNA GRILL was a healthy, active working mom of two daughters living her best life when seemingly out of the blue, a slight tremor in her left pinky resulted in a young onset Parkinson's diagnosis at age 38. She started the Young Onset Parkinson's Network (YOPN), a 501(c)3 nonprofit organization, in 2020. It has grown to a community of over 1,100 members located in all 50 states and in 38 countries. YOPN provides free membership to all diagnosed with YOPD and their friends and family. Member benefits include virtual programming and networking sessions along with access to a robust member portal that provides valuable resources and access to services.



MADELEINE E. HACKNEY, PHD holds a Bachelor of Fine Arts in Dance Performance from New York University, Tisch School of the Arts, and a Ph.D. in Movement Science from Washington University in St. Louis. She is a tenured Associate Professor of Medicine in the Emory University School of Medicine, Department of Medicine, Division of Geriatrics and Gerontology; a Research Health Scientist at the Atlanta VA Center for Visual and Neurocognitive Rehabilitation; and an Investigator with the Birmingham/Atlanta VA Geriatric Research Education and Clinical Center. She has received funding from the Department of Veterans Affairs, the NIH, the NSF, the Patient Centered Outcomes Research Institute, the Parkinson Foundation and the CDC. She frequently reviews grant applications for the VA and the NIH, and recently for the National Endowment for the Arts. Her research has received media coverage in the *New York Times*, *Scientific American*, the *Atlanta Journal Constitution*, *National Public Radio*, and in *Musicophilia*. She has authored more than 90 peer-reviewed articles.



AARON HAUG, MD is a neurologist and movement disorders specialist at HealthONE Neurology Specialists in Denver, Colorado. He completed neurology residency and a movement disorders fellowship at the University of Colorado, including a year as chief resident. In his clinical practice, Dr. Haug focuses on Parkinson's disease, tremor, and other movement disorders, with expertise in both medical management and deep brain stimulation for the treatment of these conditions. Outside the office, he likes to spend time with his family, play ultimate frisbee, and follow Colorado Rockies baseball.



BENZI KLUGER, MD, MS is a Professor of Neurology and Medicine and the Director of the Palliative Care Research Center at the University of Rochester Medical Center (New York). He is an internationally recognized leader in the emerging field of neuropalliative care and the founding President of the International Neuropalliative Care Society (www.inpcs.org), an organization dedicated to improving models of care for persons living with neurologic illness and their families. Dr. Kluger's research focuses on developing, testing and implementing palliative care interventions for persons living with Parkinson's and other neurologic illnesses, and in improving understanding and treatment of nonmotor symptoms in Parkinson's, including fatigue and cognitive dysfunction. He is working on several writing projects (www.benzikluger.com) related to empowering people living with serious illness to better advocate for themselves and to avoid potentially dangerous and expensive medical BS.



BRIAN COPELAND, MD works in New Orleans, LA, as a neurology specialist and has 19 years' experience. Dr. Copeland is board certified in neurology and graduated from University of South Carolina School of Medicine Columbia in 2005. He completed a residency at Tulane University School of Medicine. When he's not helping patients, he likes to try local cuisine.



SARAH PEREZ, MD is a movement disorder neurologist at the Southeast Louisiana Veterans Health Care System Medical Center in New Orleans. Dr. Perez is originally from Port Vincent, Louisiana. She received her Bachelor of Arts degree in music performance majoring in clarinet at Louisiana State University, where she was a member of the LSU Wind Ensemble and The Golden Band from Tigerland. She graduated LSU summa cum laude and pursued a career as a professional musician while working as an optician at Sam's Club Optical. Her passion for helping people inspired her to pursue medicine. She attended medical school at LSU Health Sciences Center in New Orleans and completed her residency in neurology and fellowship in movement disorders at the University of Alabama at Birmingham. She met her husband, Peter Perez, at LSU when they were members of the LSU Golden Band from Tigerland. They have five children. Her professional practice includes treatment of all movement disorders, deep brain stimulation therapy, and botulinum toxin injections for various conditions. She regularly works with and teaches medical students and residents at LSU and Tulane.



CONNIE CARPENTER PHINNEY is an entrepreneur, author, artist, 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 an 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.



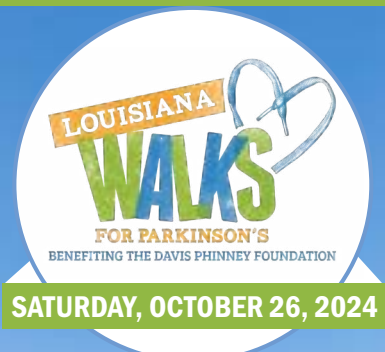
SUSAN SAPIR-FIELDS was born and raised in New Orleans, LA and has been involved with Parkinson's since 2010 when her mother Rosina (Roro) was diagnosed. In 2012, Susan joined the Louisiana Walks for Parkinson's event as the silent auction chairperson and in 2014, she started an evening support group to help those that could not attend the day group to be able to find a place for support. Susan is on many committees for symposiums and events, and now serves as assistant director of Louisiana Walks. At the first Victory Summit in New Orleans in 2016, after learning of the mission of the Davis Phinney Foundation, Susan and Michelle Lane, the walk event director, fell in love with the staff and since 2017 the walk has benefitted Team DPF.



Join us Saturday, October 26, 2024, to support the Davis Phinney Foundation's mission of helping people with Parkinson's **live well today.**

Your efforts make it possible for us to create tools, inspiration, and resources through webinars, articles, and educational events - *free of charge.*

We're excited to bring the Parkinson's community together to celebrate living well!



Visit parkinsonswalk.org to see the full schedule.

Celebrate living well with your community while benefiting the Davis Phinney Foundation for Parkinson's.

Registration Opens: 9 am
Walk Begins: 11 am

Lafreniere Park
3000 Downs Blvd.
Metairie, LA

Silent auction • Parade of prizes • Live music
Food and beverages • Kids corner
Resources for people with Parkinson's and their care partners

**LIVE WELL TODAY:
BE CONNECTED**



MEET OUR AMBASSADORS

Davis Phinney Foundation Ambassadors are Parkinson's advocates who locally and digitally connect with people to help them live well. Ambassadors are available to discuss tools and strategies for improving quality of life with support groups, individuals, families, friends, and healthcare professionals. Ambassadors speak about wellness at local Parkinson's events and support groups; 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 from other people living with Parkinson's.

dpf.org/ambassadors

THANK YOU TO OUR PARTNERS

Mission for Movement

We, people with Parkinson's Disease and our community, offer support, resources, and connections for everyone.

themissionformovement.com



Mission for Movement

Louisiana Walks for Parkinson's

Louisiana Walks (LA Walks) for Parkinson's is an annual celebration of living well, benefiting the Davis Phinney Foundation.

parkinsonswalk.org



New Orleans Ballet Association

New Orleans Ballet Association (NOBA) cultivates understanding, appreciation, and enjoyment of dance through performance, education, and community service.

nobadance.com



New Orleans Ballet Association

SPARX3 Trial

The SPARX3 study is the first randomized control trial designed to investigate the effects of moderate- and high-intensity aerobic exercise on disease progression in untreated patients with Parkinson's.

sparx3pd.com



LSU Department of Physical Therapy

The Department of physical therapy develops graduates with outstanding clinical skills in physical therapy, including diagnosis, clinical reasoning, program planning, and therapeutic intervention.

alliedhealth.lsuhs.edu/pt



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THANK YOU TO OUR SPONSORS

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



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



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



This event is also supported in part by AbbVie Grants





**BE INFORMED
BE CONNECTED
BE EMPOWERED
BE ICONIC with PD**

Actor portrayals

BE ICONIC with PD is an online community for those whose lives are touched by Parkinson's disease (PD).

Whether you are a person with PD or a care partner, we offer:

- Tips and resources for your journey with PD
- Definitions of common PD terms
- Information about PD treatment options
- Email updates so you can stay in the know



Visit
BEICONICwithPD.com
to learn more.



"The community helps you get tips and tricks. It is helpful to hear how people manage things differently."

-John, living with PD

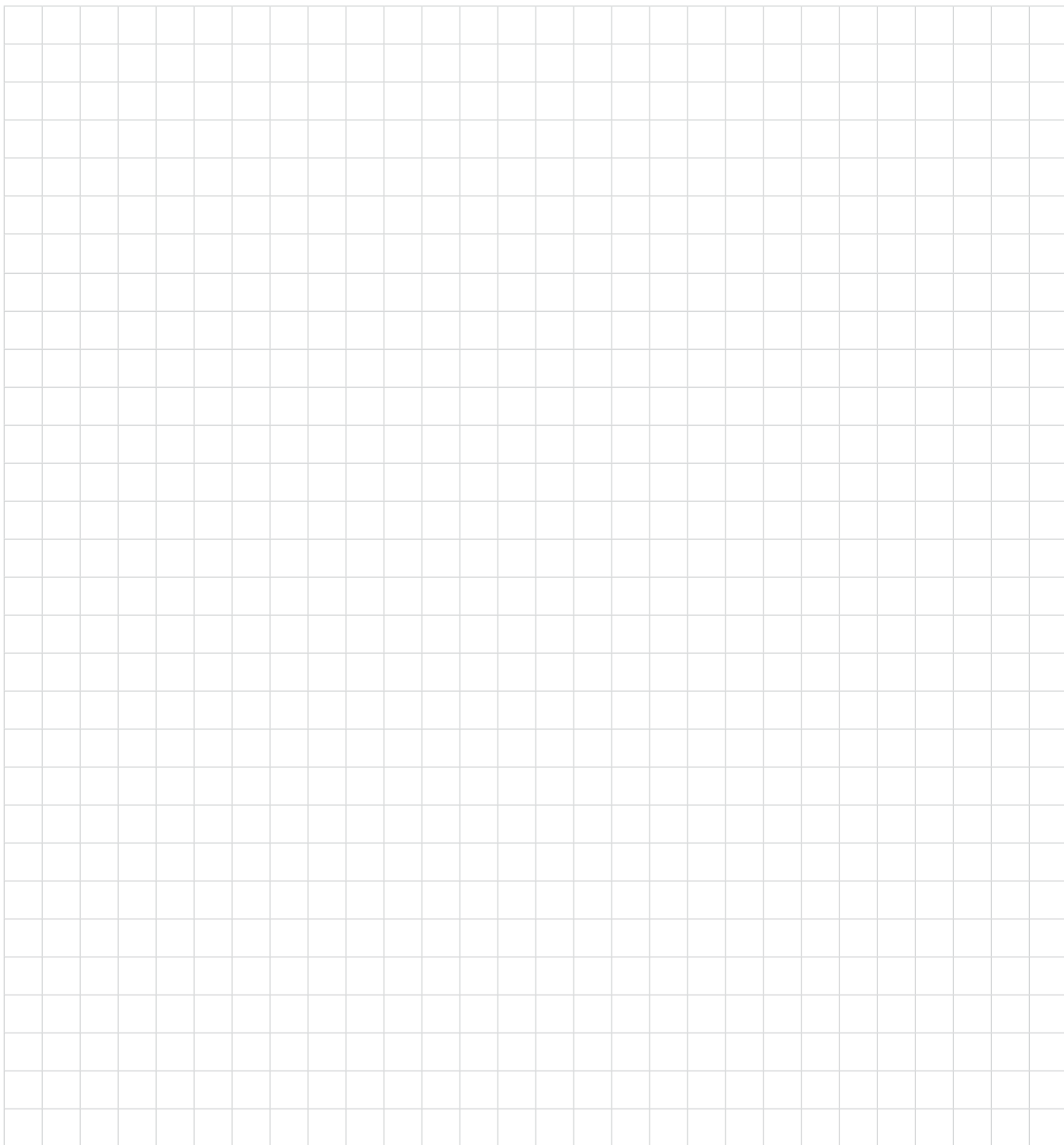


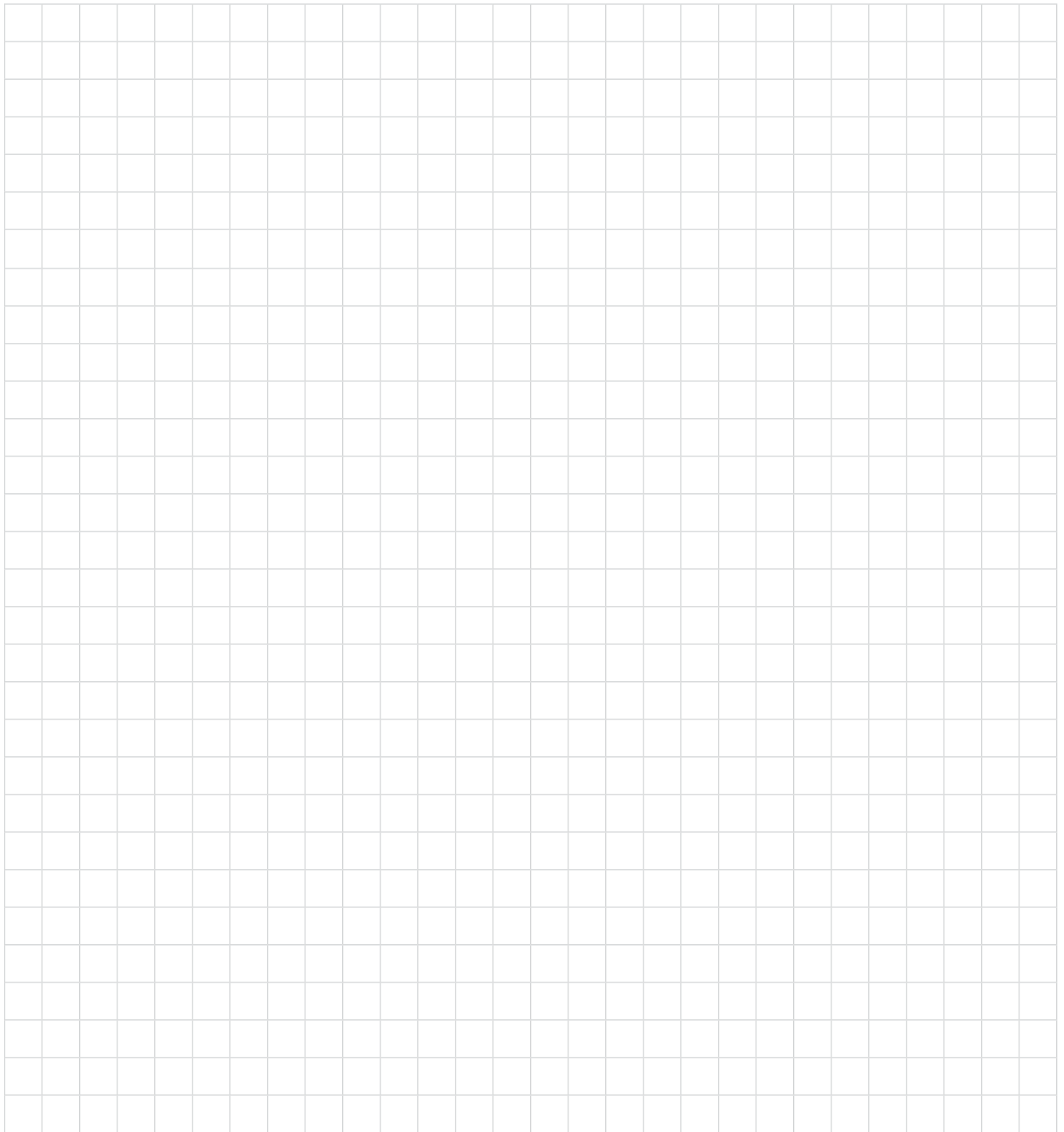
Join the discussion on our Facebook page
at [Facebook.com/BEICONICwithPD](https://www.facebook.com/BEICONICwithPD)

BE
ICONIC
WITH PD.

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!







**WHAT WILL YOU DO
STARTING TOMORROW?**



ADDITIONAL RESOURCES

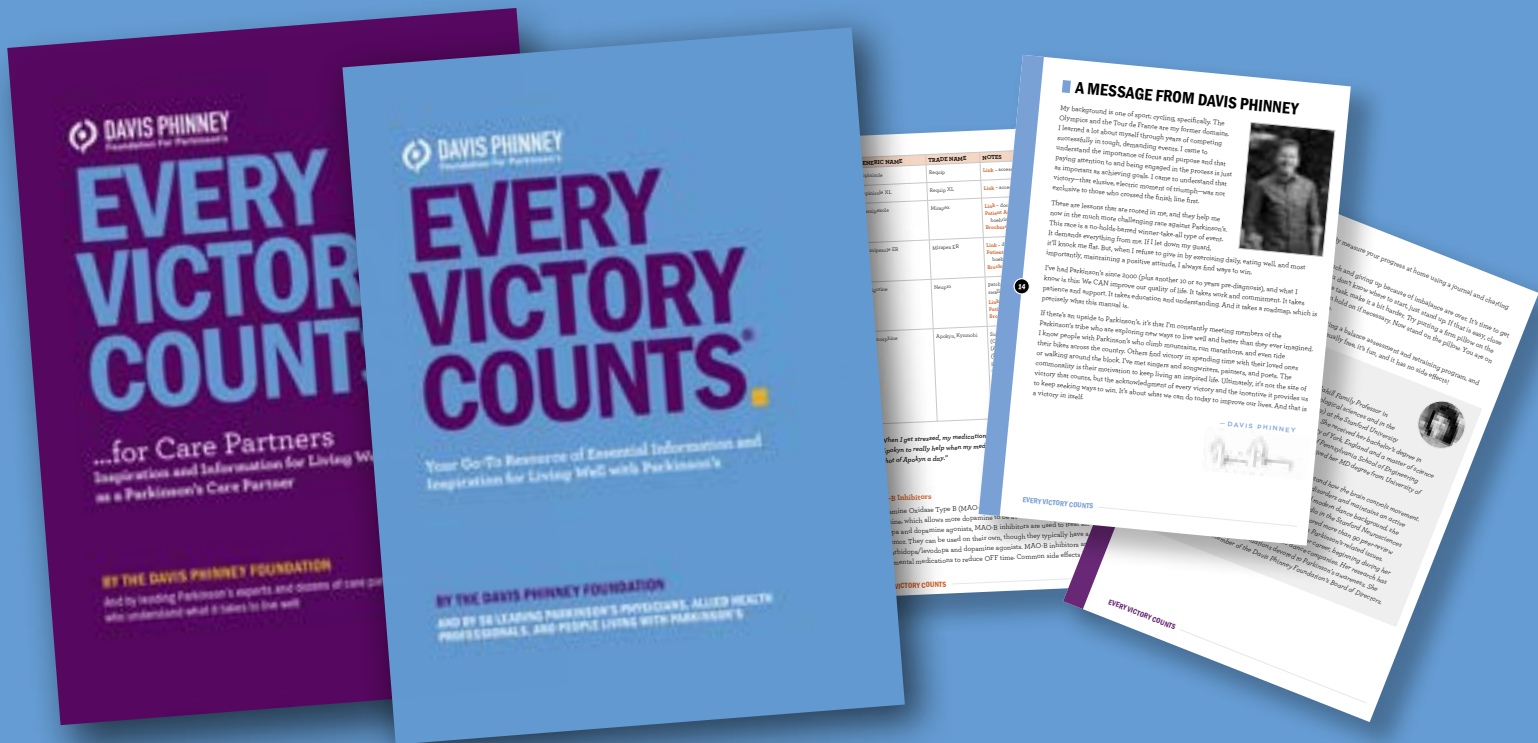
For more information on everything from exercise, treatments, complementary therapies, and beyond, we've created an online resource guide especially for you.

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!*



This guide shares ways to help you put your Victory Summit takeaways into action in your everyday life.



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 today
- » Insights from over 60 Parkinson's advocates, physicians, therapists and scientists



Download your eBook today at EveryVictoryCounts.org
or call toll-free (855) 744-6639.

Our presence today in New Orleans 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 via the envelopes on your table, online at www.dpf.org/VSNOLA-donate, or by telephone at (866) 358-0285.

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



Polly Dawkins, Executive Director



*Find out
where we're
headed next!*

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/community

Flint, MI

June 26, 2024

Hartford, CT

September 15, 2024

Green Bay, WI

October 11, 2024

PARTNERS



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New Orleans Ballet Association



Study in Parkinson's Disease of Exercise
Phase 3 Clinical Trial



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