



September 14 - 15, 2023
Minneapolis, MN

presented by



DAVIS PHINNEY
Foundation For Parkinson's

every victory counts®



Welcome to the 2023 Healthy Parkinson's Communities™ Leadership Conference!

You are here because you are a leader in the Parkinson's community. Whether embracing this role feels new or natural, empowering or a little scary, one thing is true: you are exactly what this community needs.

We started the Healthy Parkinson's Communities initiative to harness the immense energy, purpose, and drive within this community. We have a vision for a world where all people have the opportunity to live well with Parkinson's and where communities prioritize and embrace the needs of their citizens affected by Parkinson's. The actualization of this vision (and the road to achieve it) is unique to every community that joins us in this quest.

During these two days together, you will have the opportunity to both learn and share. We'll focus on building skills that support our work as mentors, advocates, and thought leaders. We'll hear from our peers about what they've learned on their journeys. We hope you'll walk away from this event renewed, with fresh ideas and inspiration to take back home.

Everyone participating in this event has a story. We all have personal and professional journeys that inform how we look at the world and the tools we bring to the table. But one thing unites us: We are committed to helping people with Parkinson's live well today.

We are immensely grateful for the planning and effort you put into being part of this event. Whether you are here with us in Minneapolis or joining from afar, we thank you for your commitment of time, energy, and enthusiasm. We hope you walk away from this time refreshed, transformed, and inspired with new information, resources, and relationships to support your journey.



Many thanks on behalf of the Davis Phinney Foundation team,

Jenna Deidel
Director of Community Engagement

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September 14

Agenda: “We ARE Innovators”

We will begin our first day by reminding ourselves that simply showing up as leaders in this space is innovative. Today’s agenda will kick off with an inspiring workshop led by our friend and peer Wayne Gilbert, followed by a panel discussion and SkillShares led by your peers. Learn more about what’s ahead on the following pages!

9-9:15 am

Welcome

Kayla Ferguson - Community Grants Manager

Sara Linn - Community Leadership Programs Manager

9:15-10 am

Keynote: Metaphor, Medicine & Parkijazz!

Wayne A. Gilbert - Practitioner of Metaphor Medicine and Parkiejazz

10-10:25 am

Movement Break

Doug Pickard - Ambassador, Parksville, BC, Canada

10:25-11:10 am

A Deep Dive into Support Groups

Facilitator: Everett Graves-Swinney

Panelists: Karen Frank, Carolyn Utesch, Doug Pickard, Stan Livingston

11:10-11:30 am

Mindfulness Moment

11:30 am-12:30 pm

Lunch Break

12:30-12:45 pm

Movement Break

Mayra Torres - Hispanic Ambassador, Phoenix, AZ

12:45-1:30 pm

SkillShare Breakouts (more information on pg. 8)

Session 1: “How to Create and Foster a Unique Needs-Based Support Group”

- *Facilitators: Karen Frank & Carolyn Utesch*
- *Room: Johnson Great Room*

Session 2: “How Come Grandpa Doesn’t Smile Anymore?”

- *Facilitators: Patti & Dan Burnett*
- *Room: Ski U Mah*

Session 3: “Using Mindset for Consistent Outcomes”

- *Facilitator: Brett Miller*
- *Room: Memorial Hall*

1:30-1:45 pm

Coffee/Snack Break

1:45-2:30 pm

SkillShare Breakouts (more information on pg. 8)

Session 1: “Overcoming Challenges to Create Victories; Lessons Learned in Facilitating a Parkinson’s Support Group”

- *Facilitators: Doug Pickard & Stan Livingston*
- *Room: Memorial Hall*

Session 2: “Speaking to the World About Parkinson’s - Sharing Your Life With Others”

- *Facilitator: Jim Allen*
- *Room: Johnson Great Room*

Session 3: “How to Set Up Your Davis Phinney Foundation Table”

- *Facilitator: Michelle Lane, Kimerly Coshow, Susan Sapir-Fields*
- *Room: Ski U Mah*

2:30-3 pm

Reflection/Networking and Closing



September 15

Agenda: “Creativity Lives Within All of Us”

During our second day together, we’ll continue to learn, share, and offer the opportunity to dive deeper into skills and creativity that live within each of us and align with our interests and pursuits.

9-9:15 am

Welcome

Everett Graves-Swinney - Ambassador Leadership Program Associate

9:15-10 am

A Deep Dive into Fundraising with Team DPF

Facilitator: Kayla Ferguson - Community Grants Manager

Panelists: Michelle Lane, Kimerly Coshow, Susan Sapir-Fields, Rebecca Reifel, Lauren Kehn

10-10:15 am

Movement Break

Barb Matheny, CAC Leader & Ambassador, Findley, OH

10:15-11 am

A Deep Dive into How to Engage Your Community with New Davis Phinney Foundation Programs

Facilitator: Sara Linn, Community Leadership Programs Manager

Panelists: Kayla Ferguson - Community Grants Manager & Devon Fulford - Director of Education & Content

11-11:15 am

Mindfulness Moment

11:15 am-12:25 pm

Lunch Break

12:30-1:15 pm

SkillShare Breakouts (more information on pg. 9)

Session 1: “Employment Law and Parkinson’s -- Wisdom, Law, and Practicality in the World of Parkinson’s”

- *Facilitator: Jim Allen*
- *Room: Johnson Great Room*

Session 2: “Death Café”

- *Facilitator: Amy Carlson*
- *Room: Memorial Hall*

Session 3: “Free Time”

- *Room: Ski U Mah*

1:15-1:30 pm

Coffee/Snack Break

1:30-2:15 pm

SkillShare Breakouts (more information on pg. 9)

Session 1: “How to Share Your Parkinson’s Management Techniques”

- *Facilitator: Tom Cosentino*
- *Room: Johnson Great Room*

Session 2: “Growing a Local Parkinson’s Organization”

- *Facilitator: Rick Buck*
- *Room: Memorial Hall*

Session 3: “Care Partner Workshop”

- *Facilitators: Devon Fulford & Polly Dawkins*
- *Room: Ski U Mah*

2:15-3 pm

Reflection/Networking and Closing

Polly Dawkins, Executive Director

ABOUT YOUR DAY 1 SKILLSHARES

How to Create and Foster a Unique Needs-Based Support Group

Carolyn Utesch & Karen Frank

In this skillshare, Carolyn and Karen will share their framework for cultivating individualized and intimate climates of support within their groups. Join this session to hear more about Carolyn and Karen's learnings and walk away with a few ideas of how to build a culture of caring and meaningful support for your support group!

How Come Grandpa Doesn't Smile Anymore?

Patti & Dan Burnett

We tend to avoid talking to our/your children and grandchildren about Parkinson's. What are ways we can initiate this conversation? Patti and Dan will facilitate this discussion and share their ideas for their upcoming book titled, "Why Doesn't Grandpa Smile Anymore?"

Using Mindset for Consistent Outcomes

Brett Miller

Take a deep dive into navigating a disciplined mindset and what it takes to target focused mindfulness and physical steadfastness in order to continue to have achievable and functional outcomes.

Overcoming Challenges to Create Victories; Lessons Learned in Facilitating a Parkinson's Support Group

Doug Pickard & Stan Livingston

Join Doug Pickard and Stan Livingston as they discuss the 10 pitfalls to avoid when facilitating a support group and shine light on the 10 benefits of joining a support group and becoming an effective leader. Come ready to ask questions you have about support groups and role-play some scenarios that can be challenging, but often lead to victories!

Speaking to the World About Parkinson's - Sharing Your Life With Others

James Allen

We will be looking at how to make presentations with energy and with purpose, and how to effectively use PowerPoint and other tools to improve presentations.

How to Set Up Your Davis Phinney Foundation Table

Kimerly Coshow, Michelle Lane, & Susan Sapir-Fields

Come learn how to set up a Davis Phinney Foundation table at local events and learn the key points to share about our resources while telling your unique story and experience!

ABOUT YOUR DAY 2 SKILLSHARES

Growing a Local Parkinson's Organization

Rick Buck

Rick will share a timeline of his experience building and growing local organizations. He will expand upon his past with other events, how that led to his role as President of his local group, and what the future holds.

Employment Law and Parkinson's -- Wisdom, Law, and Practicality in the World of Parkinson's

James Allen

Jim will explain the protections the law offers Parkinson's workers and how they can request, identify, and obtain reasonable accommodation.

Death Café

Amy Carlson

This cafe is a free-form discussion about death. It does not encourage any sort of conclusion or belief, rather it is a facilitated opportunity to discuss death, tell stories, and share experiences. Everyone attending a death cafe should be prepared to participate in the discussion.

How to Share Your Parkinson's Management Techniques

Tom Cosentino

Analyzing what you can and cannot manage when you have Parkinson's is a critical tool for reducing stress and living well. And, according to Tom, sometimes you just have to ask: "What would George Costanza do?" Join this session and laugh and learn alongside Tom as he shares some of his fine-tuned Parkinson's management techniques!

Care Partner Workshop

Devon Fulford

Coming this September, we will be offering a carefully tailored online Care Partner Training program created from feedback we've received about the needs of our care partner community. This workshop will provide an overview of the introductory webinar and full educational program including context and history, training topics, and a Q&A session.

Meet Your Speakers



Wayne Gilbert

Wayne is a retired teacher and teacher of teachers and was diagnosed with Parkinson's in 2005. He has degrees in English, history, and religion and completed graduate work in educational psychology. Since retiring in 2012, he has published three chapbooks: *Magmamystic*, *From the Ashes*, and *Sacred Chill*. Wayne leads poetry workshops and is a requested speaker for a wide variety of audiences. He refers to this work as metaphor medicine and himself as a practitioner of Metaphor Medicine and Parkiejazz. Wayne is co-founder of Reconnect with Your Body, a Dance for PD® affiliated dance class and performance company and Us-in-a-Box Theatre Workshop, and is a facilitator of Unlocked Poetry, a monthly poetry workshop for incarcerated poets in a Colorado maximum security prison. In 2018, he received the Colorado Governor's Creative Leadership Award.



Doug Pickard

Doug knew very little about Parkinson's until he met someone living with it. A chance encounter that led to a long-term relationship with Parkinson's occurred around 14 years ago when Doug was approached by a woman who had been living with Parkinson's for several years. She was looking to Doug, an exercise specialist, for help with her exercise program. From this positive experience, Doug decided to do all he could to build his skills to help as many people as possible in his hometown and beyond. Doug has created a Parkinson's-specific exercise class named "Taming the Dragon," is a local Parkinson's support group facilitator and is certified as a PWR!Moves and Rock Steady Boxing coach.



Karen Frank

Karen Frank retired from her career as a Certified Registered Nurse Anesthetist at Washington University in St. Louis, MO, when she was diagnosed with Young Onset Parkinson's disease at age 47. Karen has served as an Ambassador for the Davis Phinney Foundation for several years, primarily focusing on issues related to YOPD, mental health, and living in recovery from substance abuse. Karen formed and moderates an online support group through the American Parkinson's Disease Association St. Louis Chapter for those living with YOPD. From its inception, this group has grown to national recognition and welcomes members nationwide.



Carolyn Utesch

Carolyn is a licensed and certified occupational therapy assistant at Indiana's Bloomington Regional Rehab Hospital. She has a strong history of creating customized therapy programs for those living with Parkinson's. Carolyn is also a vibrant support group leader, a Foundation Ambassador, and a passionate Community Action Committee (CAC) leader in Bloomington, Indiana. Carolyn knows how to help others rediscover joy in movement and brings enthusiasm and resourcefulness to her community. For Carolyn, living well means doing the best she can every day, in every way.



Stan Livingston

Stan was diagnosed with Parkinson's in 2015. It has been a challenging journey, and as the disease slowly worsens, Stan finds new ways to cope. Currently, Stan facilitates two Parkinson's support groups and enjoys helping others, receiving much in return. The members of Stan's group teach and support him, and he finds strength in learning as much as possible about how Parkinson's works.



Mayra Torres

Mayra's dad was diagnosed with Parkinson's in 2019, and when he was diagnosed, he was not given any information about Parkinson's or where to go for support. Mayra's brothers and she searched for information and finally found some programs for their father at the Muhammed Ali Parkinson Center. As a care partner for her dad, Mayra has tried to learn everything she can and even became a PWR! Moves exercise instructor. Now, her dad attends Mayra's class! Since her dad has been part of these programs, he has created significant social connections and seems more joyful and confident about finding ways to live well.



Patti & Dan Burnett

Dan and Patti have been a part of the Foundation's community since Patti was diagnosed in 2013. They have lived in Summit County, Colorado for the nearly 40 years that they've been married, both involved with search and rescue with the County and Copper Mountain Ski Patrol - Patti handling search and rescue dogs and supervising the Patrol and Dan as a Mission Coordinator with the County SAR group. Dan also sells real estate to support his hobbies. They have two daughters and four grandchildren between the ages of 4 months and 5 years old) who all live within ten miles of them. They are blessed to have great support with DPF and their friends and family.



Brett Miller

Brett Miller is the founder and owner of 110 Fitness in Rockland, Massachusetts, the largest wellness center in the world for individuals with Parkinson's. A licensed physical therapist with 27 years of experience, he is a former US Army veteran and author of the book, *It's A Beautiful Day to Save Lives: A Medic's Journey to His Destiny*, available on Amazon. Brett is the co-chair of the Massachusetts Parkinson's Registry and a Commissioner on the Massachusetts State Athletic Commission. He is also an Ambassador for the Michael J. Fox Foundation for Parkinson's Research and the Davis Phinney Foundation.



James Allen

Jim Allen was born in 1957 in South Carolina. He lived all over the southeast as his father worked in structural ironwork on bridges, dams, and power stations. Jim attended the University of Georgia for undergraduate and law school. He spent three years as an attorney in the Navy Judge Advocate General's Corps, then 34 years practicing law in Washington State, Georgia, and around the country, primarily as an employment law attorney representing companies and employees. In 2014, Jim became a Trial Attorney for the Savannah, Georgia, office of the EEOC. In 2019, he began work as a prosecutor, retiring from law in 2021 after his diagnosis with Parkinson's. Jim remains active as the pastor of his church, husband to his wife of 42 years, father, grandfather, and active pickleball player.



Michelle Lane

Michelle was diagnosed with Parkinson's in June 2000 at age 32. She is a lifelong resident of New Orleans and has been married for thirty-six years to her husband, Ronnie. They have three children and two grandsons. Michelle worked for a manufacturer's representative for plumbing supplies for 17 years before retiring in 2004. Since her retirement, Michelle has been spotlighted in numerous local and national newspaper articles, been interviewed by many Parkinson's organizations, and participated in the clinical trial phase III of Rotigotine (Neupro). Michelle organized the first annual Louisiana Parkinson's Walk in April 2003, which resulted in 450 participants and raised over \$39,000 for Parkinson's research. She then founded the Parkinson's Association of Louisiana (PAL), which has been very successful in raising money for Parkinson's education, support services, and research taking place in the state of Louisiana.



Kimerly Coshow

Kimerly was diagnosed with Parkinson's in January 2001 at age 33. Since her diagnosis, she has grown to know the importance of being an active member in her treatment and learned how to be her own best advocate. Living well with Parkinson's is a daily goal involving the body, soul, and mind. In addition to having a healthy and active lifestyle, living well includes finding the right movement disorder specialist: one who listens and works with Kimerly's goals, expectations, and medical needs. As a person with Young Onset Parkinson's and an advocate, Kimerly is dedicated to changing the face of Parkinson's by engaging her peers and raising awareness across generations.



Susan Sapir-Fields

Susan grew up in New Orleans in a family of 5. She has two older sisters; Debbie, who lives in Birmingham, Alabama, and Judy, who lives in New Orleans. Susan and her sister, Judy, had a very successful boutique for 31 years. Sadly, Hurricane Ida destroyed the business, and they were forced to close. Susan is a single mom to Courtney, who lives in Dallas and works for a non-profit. Almost ten years ago, her mom was diagnosed with Parkinson's. She immediately started checking into the available resources. They found a support group and got involved. This was a new way of life. On this journey, she met Michelle Lane. They decided to start their own support group. Today, there are over 40 members. They meet once a month and do a huge walk to raise money for the Davis Phinney Foundation. Sadly, Susan lost her mom, Rosina (Roro), six years ago. Today, her entire family continues to work for the greater good of this horrible disease that affects so many people. Susan is truly a great person.



Rick Buck

Rick was diagnosed with Parkinson's in 2018; however, his doctors believe many of the symptoms they thought were from a stroke he had in 2006 were actually because of Parkinson's. Rick was glad to finally receive the correct diagnosis and immediately started taking Parkinson's medication that has, for the most part, managed his symptoms well. Rick decided to become an Ambassador for the Foundation because he believes in its mission and wants to help as many people with Parkinson's as possible to live well. Rick believes that being diagnosed with Parkinson's doesn't mean life ends. It may mean we have to make more adjustments and overcome more challenges than we probably imagined, but we can still live full, active, and happy lives. Rick hopes to provide counsel, support, and encouragement to others traveling a similar road.



Amy Carlson

On an ordinary Thursday in November 2011, the ring finger on Amy's left hand began to vibrate. By February 2012, the vibration was clearly visible, incorporated much of her left arm, and led to constant pain in her left shoulder. Later that year, Amy was diagnosed with Parkinson's. Parkinson's has changed Amy's life, but perhaps not in the way that most people think. She has come to believe that, in its own way, Parkinson's saved her life, changing her in ways that she would have never expected. Amy's life has become slower, more deliberate, and more immediate. She finds joy in simple experiences and believes everyone has a unique journey in life. The challenge is to find meaning in it.



Tom Cosentino

Tom's Parkinson's journey started in San Francisco in the summer of 2015 when his wife and daughter noticed that he was no longer swinging his left arm. Not giving it much thought at the time, Tom continued with his day. However, later that year, Tom's younger brother passed away from cancer. He was fortunate to be at his side until the end. Later that day, Tom started having tremors in his left arm, and like most people with Parkinson's, his diagnosis came months later. Since being officially diagnosed, Tom has been fortunate to meet several people within the Parkinson's community who have helped him immensely. He can safely say that if it weren't for three or four individuals, he would be a much different person today. Tom is inspired by watching people with Parkinson's participate in activities such as Pedaling for Parkinson's and Rock Steady Boxing. He sees individuals living with Parkinson's as warriors who refuse to allow Parkinson's to define their lives.

Meet Your Staff Speakers



Sara Linn

Community Leadership Program Manager

Sara joined the Davis Phinney Foundation as its Ambassador Leadership Program Manager in 2019. Born and raised in Colorado, Sara's deep connection to her community fuels her passion for creating positive change and fostering inclusivity. Her unwavering commitment to those she serves revolves around increasing access to valuable information, tools, and resources for individuals residing in the communities that shaped her own journey. Sara believes in empowering individuals and improving the systems that support their communities, ensuring a sustainable and impactful approach to change. She brings a wealth of knowledge and a compassionate spirit to her role, and her greatest inspiration lies in connecting individuals in need with the support of other like-minded souls, facilitating the human connections that forge a sense of belonging and community.

Beyond her professional endeavors, Sara loves spending time with loved ones, exploring the Colorado mountains, eating and judging every pizza known to man, and watching Marvel movies.



Kayla Ferguson

Grants Program Manager

Kayla joined the Foundation in October 2018 as a program manager, following a journey around the world that included traversing 29 countries between Japan and Peru. She leads our research and community grants program as part of the Foundation's Community Engagement team, where the most inspiring aspect for her is connecting one-on-one with people at events, listening to their stories about Parkinson's and life, and forming lifelong friendships. Her role in this community that supports and uplifts one another brings her profound joy and meaning, and her exuberance motivates those around her to take on life with positivity. Kayla's enthusiasm and ready-to-jump-in spirit is evident in all she does. When not working, you'll find Kayla scuba diving, travelling to faraway lands, hosting dinner parties, and playing with her cats.



Devon Fulford

Director of Education & Content

Devon joined the Foundation in 2023 and brings 15 years of experience in education and content management to the team. In 2008, she began her career in education at a non-profit in Fort Collins, Colorado, and has experience designing curricula and teaching writing and literature courses at two Colorado-based universities. Devon exudes passion and thrives when implementing change and providing communities in need with curated educational resources. She has a Doctor of Education in transformative leadership, a master's in creative writing, and a master's in education. A Coloradoan since the 90s, Devon lives on the front range of the Rocky Mountains with her partner, Levi, and their chocolate Labrador, The Walrus. When she's not working, you'll find her riding her Triumph Street Twin motorbike, attending live music shows, traveling, penning poetry, and advocating for conversations about topics that make us squirm.



Rebecca Reifel

Events and Development Manager

Rebecca joined the Foundation in January 2020. With over 15 years of professional experience in fundraising events and volunteer management within the nonprofit sector, Rebecca brings a wealth of expertise to her role. She holds a Bachelor's in public relations from Syracuse University and an MBA with a concentration in organizational leadership from Johnson & Wales University. Rebecca's journey with the Davis Phinney Foundation stems from two passions close to her heart — a deep love for cycling and her personal connection to Parkinson's through her father, who was diagnosed in 2011. Her dedication to making a meaningful impact in the lives of those affected by Parkinson's led her to join the Foundation, where she channels her experience and enthusiasm to drive positive change. By organizing cycling events, running initiatives, and fostering a culture of movement, Rebecca provides a platform for people to accomplish amazing feats, nurturing hope and resilience within the Parkinson's community. When Rebecca isn't pedaling away on her bike or helping others celebrate their victories, you'll probably find her playing ice hockey. Her competitive spirit and love for the game fuel her determination on and off the rink. Rebecca and her husband, Dave, also share a passion for their animals and exploring the world, allowing them to embrace new cultures and create lasting memories.



Lauren Kehn

Team DPF Manager

Lauren is a dynamic fusion of artistry, Seattle rain, and Southern charm. With a degree from the University of Washington and the title of half-iron(wo)man, she embodies unwavering determination and a contagious zest for life. Drawing from a diverse background in event management, academic advising, and life coaching, Lauren brings a rich skillset to her role. Driven by her deep understanding of goal setting and navigating obstacles, Lauren seeks to provide clarity and support to our Team DPF fundraisers, empowering them to achieve their aspirations. Her coaching expertise and ability to forge meaningful connections allow her to foster vibrant communities and cultivate a profound sense of togetherness within the Parkinson's community. These connections serve as her constant inspiration, fueling her dedication to the Foundation and its impact on the lives of those affected by Parkinson's.

When she's not making a meaningful impact through her work, you'll find Lauren making art, volunteering for her church, and spending time in the great outdoors with her husband, two boys, and other furry and non-furry loved ones.



Polly Dawkins

Executive Director

Polly brings 25 years of professional expertise to the Davis Phinney Foundation. Her experience includes 13 years working in engineering and international operations for a satellite communications provider and starting a local charity chapter of an international literacy organization. Polly holds an MBA from Thunderbird School of Global Management and a BA in International Studies from Earlham College. Her management skills align with her drive to help people with Parkinson's by providing resources, education, connections, and actionable research to improve their quality of life.

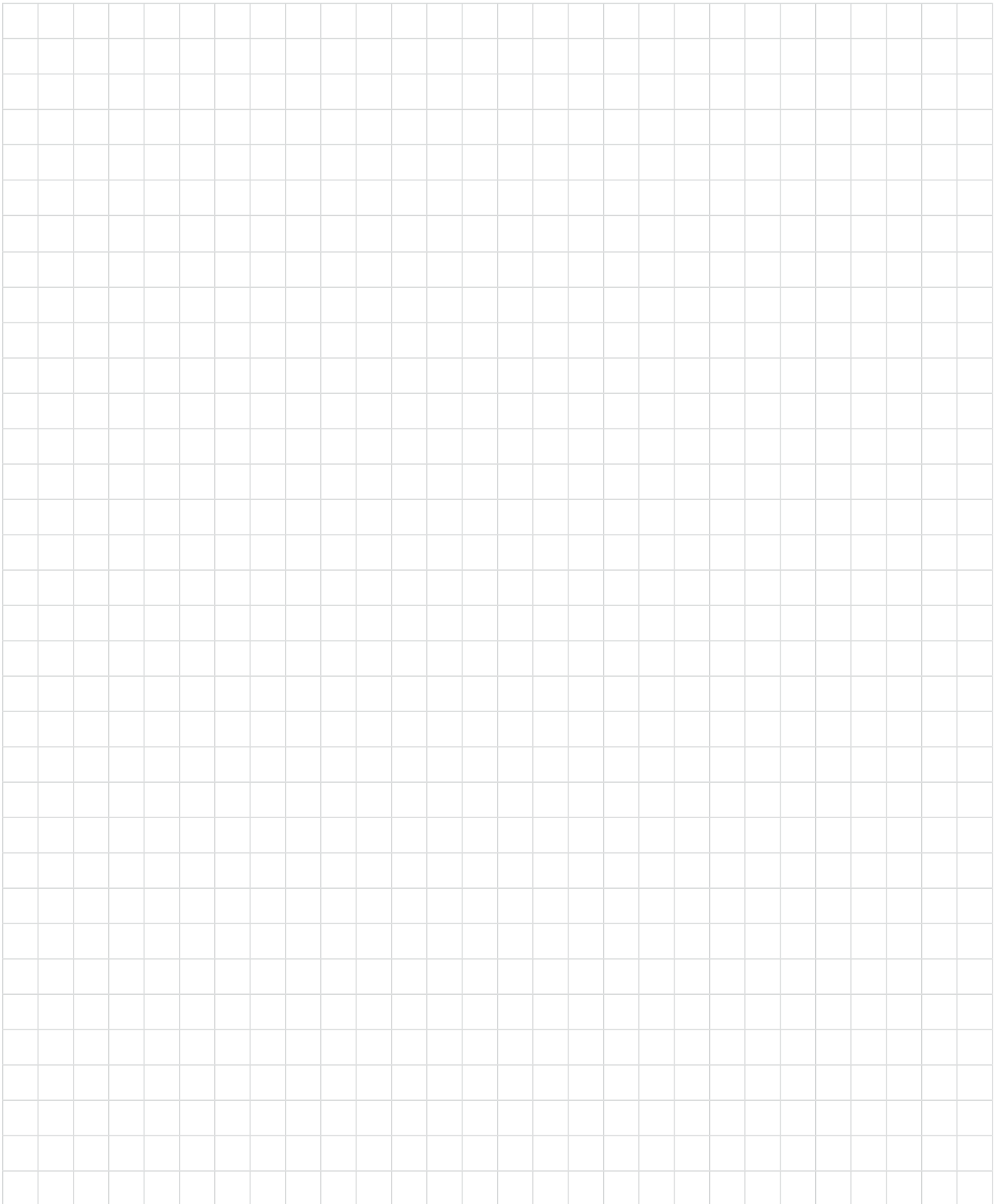
When she's not at her desk, visiting Parkinson's communities, or fundraising with donors, you'll find her creating music lists for her indoor cycling classes, cycling around Colorado, swimming outdoors, or hosting family and friends from faraway countries. Her energy sources? Sunshine and cold brew.



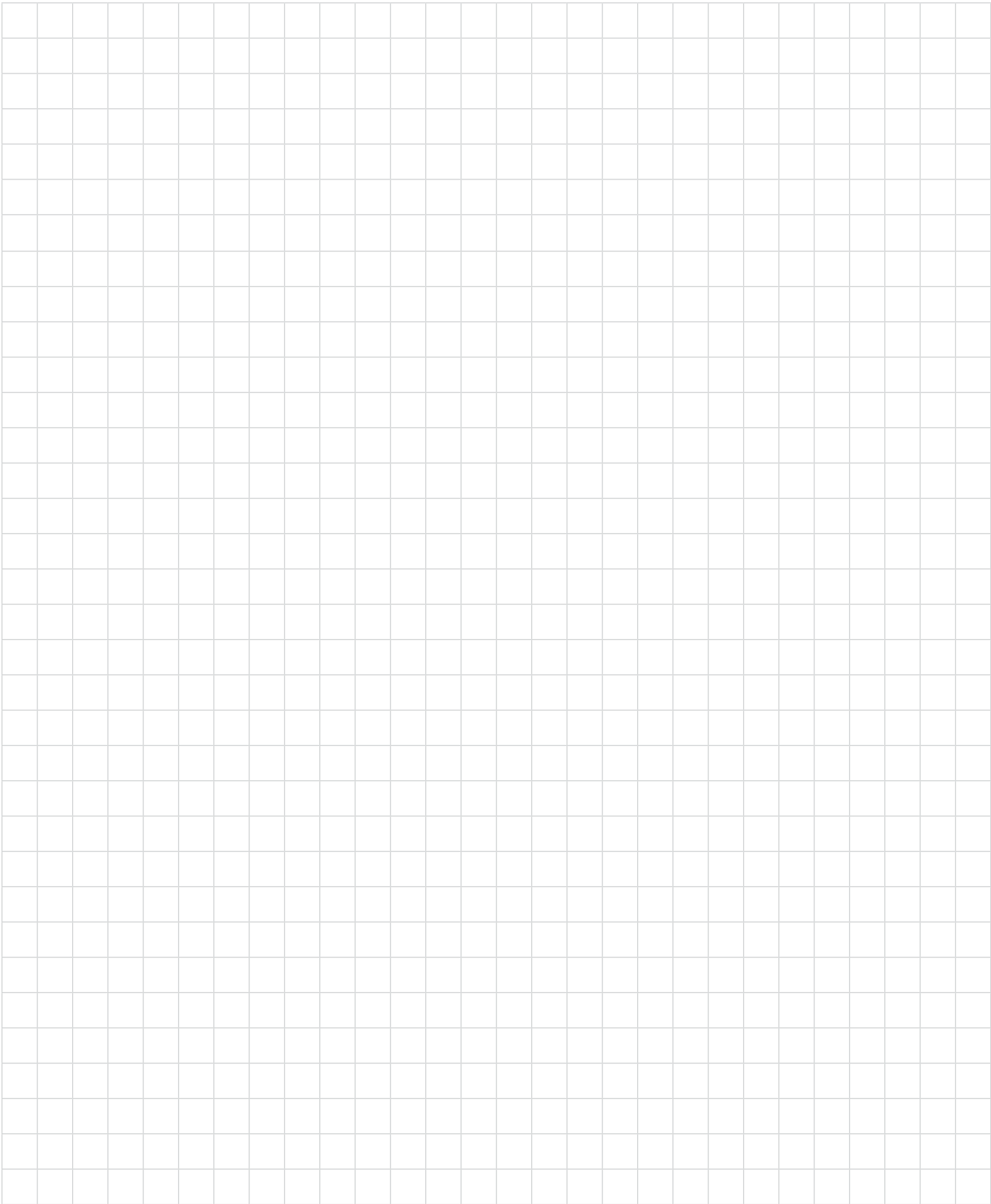
Want to learn more about a member of Davis Phinney Foundation's team? Visit dpf.org/team for bios and contact information for our staff, board of directors, and advisors.

Notes

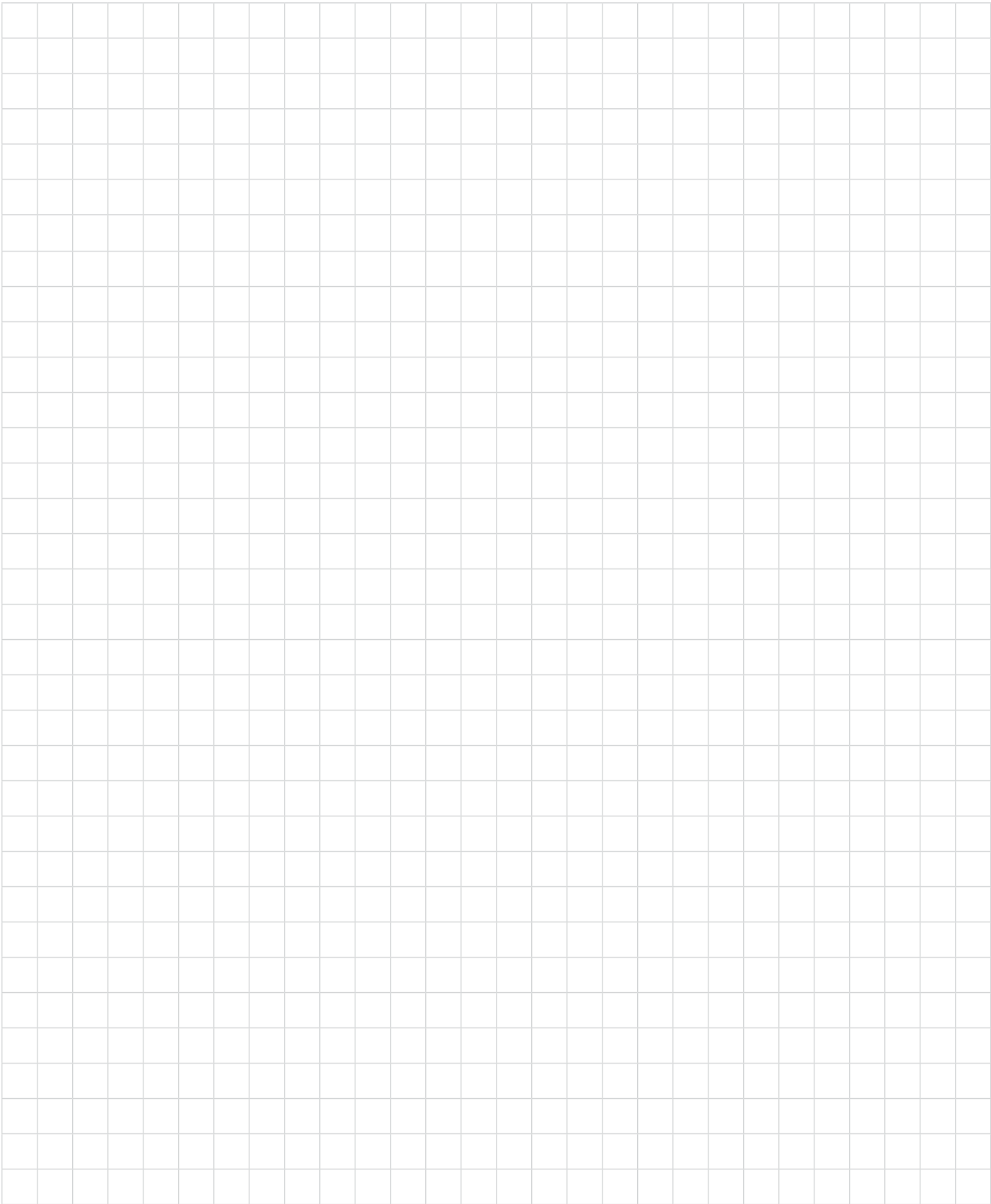
Use the space below for notes, doodles, or whatever else comes out of our time together.



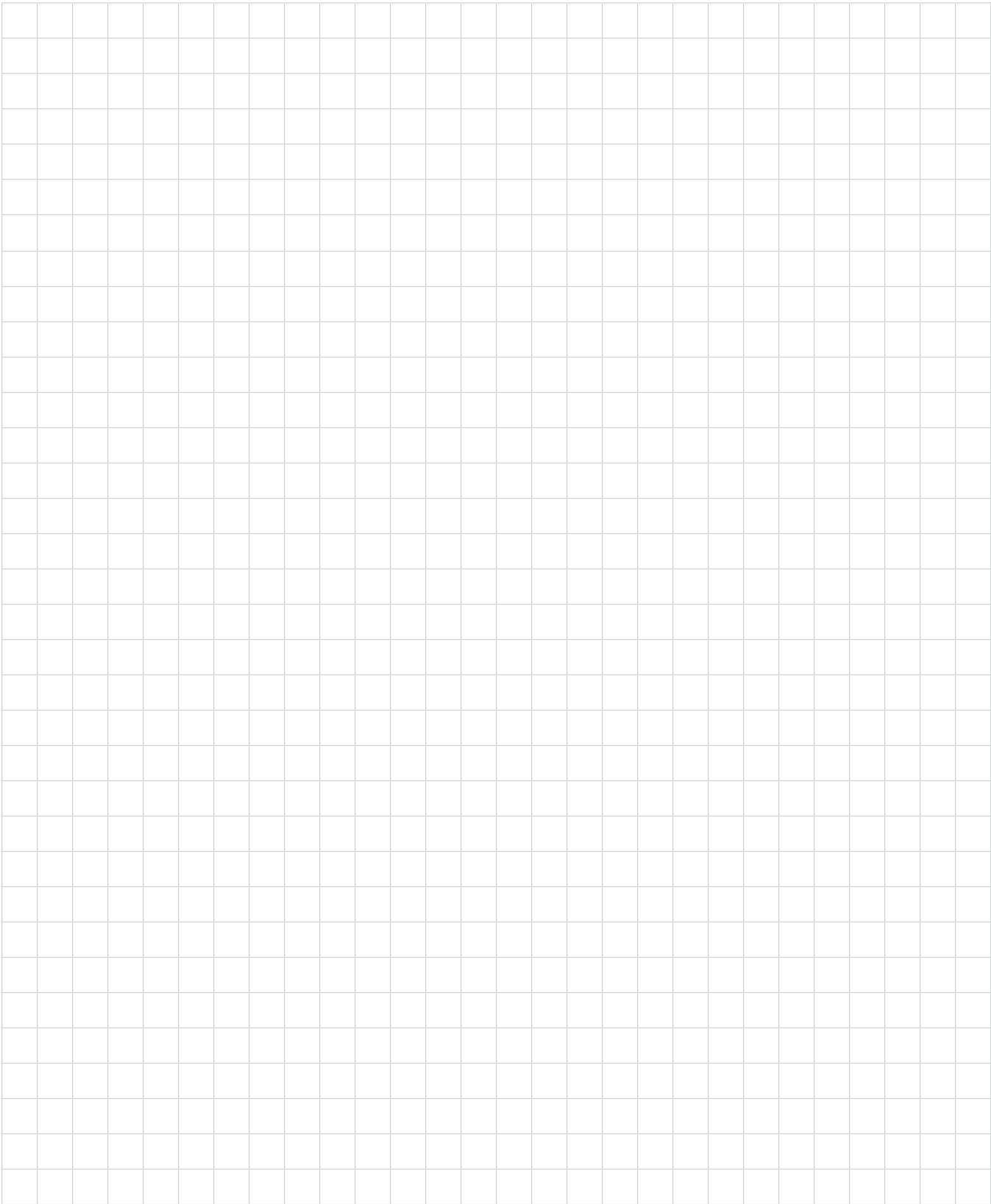
















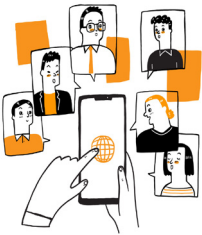
What's next?

As you prepare to head back home to your community, we encourage you to do the following:



Make a plan to stay connected with the people you met.

Whether you exchange contact information, make a plan to visit one another's virtual support group, or schedule a road trip, one of the most valuable takeaways from this weekend are the people you met. We hope you'll find a way to stay in touch and lean on one another throughout the year.



Join or visit the Healthy Parkinson's Communities HUB.

If you haven't already, we encourage you to join the HPC HUB, our private online community just for HPC leaders. There, you can stay in the know about upcoming events and opportunities and connect with others at a frequency that works well for you. Reach out to your program manager for more information on how to get started.



Make a plan to join us next year!

In addition to the 2024 Healthy Parkinson's Leadership Conference, we'll be hosting several events across the country. Make sure to connect with your program manager if you are interested in attending one of our in-person events next year and stay tuned for more details.

Need support? Have an idea? Contact is at communities@dpf.org.



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