



September 30 through October 1, 2022
Kansas City, MO

presented by



DAVIS PHINNEY
Foundation For Parkinson's

every victory counts®



Welcome to our first annual 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 as a way to harness the immense energy, purpose, and drive that exists 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 citizen's affected by Parkinson's. The actualization of this vision (and the road to achieve it) is unique to every community who 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, organizers, and world-changers. We'll hear from our peers about what they've learned on their journeys. And we'll focus on and embrace our personal strengths - the unique gifts we bring to this work.

Everyone participating in this event has a story. We all have personal and professional journeys that inform the way 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 Kansas City, 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/or 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 30, 2022

Agenda: “The Big Picture”

On our first day together, we'll focus on our vision and build skills that apply broadly to our shared work. Today's agenda features peer speakers from across our programs. Learn more about them on the following pages!

9-9:15 am

Welcome

Polly Dawkins, Executive Director and Jenna Deidel, Director of Community Engagement

9:15-9:35 am

Our Vision for Healthy Parkinson's Communities™

Steve Hovey, Ambassador Alumni and CAC leader, Saratoga Springs, NY

9:35-9:50 am

Movement Break

Brett Miller, Ambassador, Rockland, MA

9:50-11:00 am

Building Relationships: Hands-on Workshop

Gabby Dimotsantos, Community Engagement Manager

11:00-11:30 am

Building relationships: Panel Discussion

Facilitator: Jenna Deidel

*Panelists: Wendy Lewis, CEO, The Parkinson Council, HPC Grant Recipient, Philadelphia, PA
Carolyn Rhodes, President and Owner, Parkinson's Dynamics, Davis Phinney
Foundation Ambassador, Huntsville, AL
Marie Thorne, CAC Member, Balston Spa, NY*

11:30 am-12:30 pm

Lunch Break

12:30-1:00 pm

Gaining Support: Round Table Session

Sara Linn, Program Manager - Ambassador Leadership Program

1:00-1:30 pm

Gaining Support: Panel Discussion

Facilitator: Kayla Ferguson, Community Grants Manager

*Panelists: Duarte Machado, MD, Director of Program Excellence and Recognition, CFMDC, HPC Community Grant Recipient, Hartford, CT
Randy LeBlanc, CAC Leader, HPC Community Grant Recipient, Baton Rouge, LA
Michelle Lane, Event Director, Louisiana Walks for Parkinson's, Davis Phinney Foundation Ambassador, New Orleans, LA*

1:30-1:45 pm

Coffee/Snack/Stretch Break

1:45-2:45 pm

Telling Your Story: Hands-on Workshop

Carol Clupny, Ambassador, Hermiston, OR

Everett Graves-Swinney, Program Associate - Ambassador Leadership Program

2:45-3:00pm

Closing

Meet Your Peer Speakers



Carol Clupny

Ambassador, Hermiston, OR

Carol was enjoying an active lifestyle, riding horses, hiking, climbing, and snow skiing when she was diagnosed with Parkinson's at 50. Instead of slowing down, she geared up for life with this new information in tow and became involved in the Parkinson's community. She started a support group, advocated for research funding, mentored newly diagnosed women, guided those considering Deep Brain Stimulation (DBS), and became a Davis Phinney Foundation Ambassador. All her post-diagnosis adventures inspired her to write a memoir, *The Ribbon of Road Ahead: One Woman's Remarkable Journey with Parkinson's Disease*. As a former speech-language pathologist, an extra perk of putting her book out into the world involved turning her speech therapy interventions on herself so she could narrate her book for audio release. On her blog, Carol shares honest and humorous reflections of everyday life with Parkinson's. Carol and her husband, Charlie, have been married for over 40 years and are very proud of their two adult sons. When they aren't on the road in their van "Dooley," they live on a small acreage in Eastern Oregon.



Steve Hovey

Ambassador Alumni and CAC leader, Saratoga Springs, NY

Steve was diagnosed with Parkinson's in 2007 at age 50. At that time, he didn't know anyone with Parkinson's, so he and his wife, Nancy, took it upon themselves to learn as much as they could about Parkinson's symptoms and treatment. Their search soon led them to the Davis Phinney Foundation, where they learned about the importance of exercise and a healthy lifestyle, something Steve credits with significantly affecting the quality of life he continues to enjoy. Now semi-retired, Steve continues to work part-time as a business consultant and loves sharing the message that there are actions you can take to manage Parkinson's. "When I was diagnosed, the focus of the treatment was on medicine. The doctors never mentioned the benefits of dealing with Parkinson's on a more holistic level – exercise, good nutrition, and a healthy lifestyle," Steve says. "Though it's getting better, there are still too many people who aren't given this message."



Michelle Lane

Event Director, Louisiana Walks for Parkinson's, Davis Phinney Foundation Ambassador, New Orleans, LA

Michelle was diagnosed with Parkinson's in 2000 at age 32. Since then, she has become a notable advocate in her home state of Louisiana. She was the Louisiana State Director for the Parkinson's Action Network (PAN) from 2002-2017, received the Louis Fishman Award for Outstanding Advocacy in 2004, and received the Milly Kondracke award for her advocacy efforts and accomplishments in 2011. Michelle has appeared before US congresspeople, state representatives, and senators to support research for Parkinson's and was invited to speak in Washington, DC, about easing the strict guidelines on embryonic stem cell research. In 2005, Michelle and Louisiana State Senator Jim Tucker introduced a bill to create a Parkinson's registry in Louisiana that was unanimously passed by the house and senate and signed into law by then-governor Kathleen Blanco. Michelle was selected to join the Women's & Parkinson's Initiative in 2015 and to be a PAIR Advocate with the Parkinson's Foundation in 2016. When Michelle is not doing advocacy work or volunteering as a Davis Phinney Foundation Ambassador, you'll find her cooking, baking, or mixing delicious drinks for her grateful and well-fed friends and family.



Randy LeBlanc

CAC Leader, HPC Community Grant Recipient, Baton Rouge, LA

Randy was diagnosed with Parkinson's in 2005 at age 45. In his career as an engineer, Randy analyzed and corrected complex operational systems, and he viewed this opportunity as just another system that needed fixing. About six years after his diagnosis, Randy joined a newly formed support group called the Movers and Shakers of Baton Rouge that he now leads. Ten years ago, he joined the yearly Louisiana Parkinson's Conference organizing committee to support the conference that brings information about the disease to approximately 250 people with Parkinson's in his local community. In addition to his work with local groups, Randy has served as a local and regional grant approver for the Parkinson's Foundation and is the local CAC leader for the Davis Phinney Foundation. Randy became passionate about Deep Brain Stimulation (DBS) once he got the surgery in 2018 to help with his dyskinesia. True to form, Randy learned everything he could about DBS while he was contemplating it and after he began experiencing unwanted side effects post-surgery. Through that process, Randy learned the importance of self-advocacy and supporting others as they consider taking a similar path.



Wendy Lewis

CEO, The Parkinson Council, HPC Grant Recipient, Philadelphia, PA

A native of Louisville, Kentucky, Wendy graduated from the University of Louisville with a degree in Political Science. After moving to Washington, DC, after school, Wendy worked as an office administrator in the congressional office of the late US House Majority Whip, William H. Gray, III (2nd-PA). After that role, Wendy moved to Seattle and returned to the non-profit sector to work on issues that empower young adults to make responsible choices, including harm reduction and prevention programs. While in Seattle, Wendy earned an MA in Non-profit Leadership from Seattle University, one of the first in the country to offer a non-profit leadership program. In 2010, Wendy joined The Parkinson Council, and since then, The Council has reinvested over \$5.2 million back into the Greater Philadelphia region for research, comprehensive care, and quality of life initiatives.



Duarte Machado, MD

*Director of Program Excellence and Recognition, CFMDC, HPC
Community Grant Recipient, Hartford, CT*

Dr. Duarte Machado, MD is a Movement Disorders Specialist with extensive experience in movement and neurodegenerative disorders. He is a 2001 graduate of Trinity College with a B.A. in Neuroscience. He is a 2005 graduate of the University of Connecticut School of Medicine. He completed neurology residency and fellowship training at the Yale School of Medicine, where he was also chosen to be Chief Resident. Dr. Machado was subsequently recruited to join the faculty at Yale, and then since 2016 has helped with the development and expansion of the Chase Family Movement Disorders Center (CFMDC) at Hartford Healthcare where he serves as the CFMDC's Director of Program Excellence and Recognition. He has extensive experience in clinical trials for Parkinson's and has ongoing studies related to quality-of-life issues for people living with Parkinson's. Dr. Machado is also an integral part of the team responsible for the creation of a Spanish-language movement disorders clinic at CFMDC, and has been a co-PI on a project to identify and address barriers to accessing care for the Spanish-speaking population in his community.



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



Brett Miller

Ambassador, Rockland, MA

Brett is the founder and owner of 110 Fitness in Rockland, Massachusetts, an all-inclusive wellness center and the largest wellness center in the world for individuals with Parkinson's. Among many other things, Brett is also a licensed physical therapist with 27 years of experience in various settings and is certified as an Adaptive & Inclusive Trainer by the Adaptive Training Academy. He is certified in PWR!Moves®, Concept 2 Rowing, Pedaling for Parkinson's, SCW Boxing Fitness, SCW Aquatics Exercise, and Tai Ji Quan: Moving for Better Balance. Brett also holds various roles in his community, including serving as the Massachusetts Parkinson's Registry co-chair and a Massachusetts State Athletic Commission Commissioner. He is a Michael J. Fox Foundation and Davis Phinney Foundation Ambassador and is a research consultant for the Cleveland Clinic and several Boston hospitals. Brett is proud to have served as a combat medic trainer for special operations and an overseer of the construction and development of the DEPMEDS for the United States Army. He recently published his memoir, *It's A Beautiful Day to Save Lives: A Medic's Journey to His Destiny*.



Doug Pickard

Ambassador, Parksville, BC, Canada

Doug knew very little about Parkinson's until he met someone living with it. This encounter happened 14 years ago when he was working as an exercise specialist and a woman who had been living with Parkinson's for several years asked him about creating an exercise plan based on her needs. Doug immediately committed to learning about Parkinson's and building his skills to help as many people as possible in his hometown and beyond. His first order of business was to create a Parkinson's-specific exercise class called "Taming the Dragon" based on what he'd learned about the benefits of exercise for people with Parkinson's. A few years later, Doug became the facilitator of a local Parkinson's support group and was certified as a PWR!Moves and Rock Steady Boxing coach. Once certified, Doug opened his own Rock Steady Boxing affiliation, the tenth in Canada at the time. Today, Doug is expanding his practice to include aspects of music therapy through sing-along sessions and drum circles. Doug views living well with Parkinson's as staying active, being social, and keeping a positive outlook on life.



Carolyn Rhodes

President and Owner, Parkinson's Dynamics, Davis Phinney Foundation Ambassador, Huntsville, AL

Carolyn's husband was diagnosed with Parkinson's in February 2016. Soon after, they became certified Rock Steady Boxing coaches and developed a program at the local senior center where Carolyn was the fitness director. Since then, Carolyn has assessed over 400 boxers sent by their neurologists to take part in their program, which hosts 15 classes each week, including boxing, Urban Poling for Parkinson's, PWR!Moves, choir, and Dance for PD®. She also received a joint grant with the Huntsville Hospital's Parkinson's Care Clinic to start the SPEAK OUT and LOUD Crowd program, a free weekly speech class. For Carolyn, living well with Parkinson's means becoming a student of Parkinson's, studying how to be the best at tackling the challenges, and staying busy enough to help people on a similar path but not become so fixated on Parkinson's that it consumes her.



Marie Thorne

CAC Member, Balston Spa, NY

Marie was diagnosed with Parkinson's in 2013. Since then, she has been sending an upbeat monthly newsletter to over 200 people. The newsletter is on the Capital District Parkinson's website and the new Healthy Parkinson's web page. It includes information on exercise classes, support group meetings for 11 NYS counties, and Parkinson's. She also receives many phone calls from people with questions about Parkinson's that she loves responding to. Marie enjoys being the support group leader for Saratoga County and treasurer on the Board of Directors for the Healthy Parkinson's Communities of the Greater Capital Region, Inc.



October 1, 2022

Agenda: “Self Reflection”

Our second day together will celebrate our personal strengths and offer the opportunity to dive deeper into skills that align with our personal interests and pursuits.

9-9:15 am

Welcome + Opening Movement Break

Doug Pickard, Ambassador, Parksville, BC, Canada

9:15-10:15 am

Your Community Leader Superpower: Hands-on Workshop

Gabby Dimotsantos, Community Engagement Manager

Sara Linn, Program Manager - Ambassador Leadership Program

10:15-10:30 am

Break/Transition to Breakouts

10:30-11:30 am

Breakout Sessions Part 1 (more information on the next page)

The Community Tool Box

11:30 am-12:30 pm

Lunch Break

12:30-1:30 pm

Breakout Sessions Part 2

The Community Tool Box

1:30-1:45 pm

Coffee/Snack/Stretch Break

1:45-2:30pm

Closing Remarks and Celebration

Polly Dawkins, Executive Director

and a special message from Davis Phinney, Founder

About our Breakout Sessions

We are thrilled to welcome the Community Tool Box to facilitate an afternoon of learning for us. If you are participating in person, you have the opportunity to participate in any one of the three options described below. *Virtual participants will join Option 1 (described below).*

All three sessions will be conducted in two parts, one hour before lunch and one hour after lunch. As well, we will record and make these sessions available on the Hub later in the year, so you will have the opportunity to view others later if you are interested.

About our Facilitators



The Community Tool Box is a public service of the University of Kansas. It is developed and managed by the KU Center for Community Health and Development and partners nationally and internationally. The Community Tool Box is a part of the Center's role as a designated World Health Organization Collaborating Centre for Community Health and Development.

Session Description

Option 1: Creating and Maintaining Coalitions & Partnerships/Increasing Participation and Membership *(Main event space room)*

In this workshop, you will dig into what makes effective partnerships and how to keep people engaged. Whether you are leading a Community Action Committee (CAC) or want to share more information about Parkinson's in your community, it is important to have people in your corner. You will learn and take part in hands-on activities to increase participation, maintain momentum, increase your circle of influence, and plan for involving new generations of people and organizations in your work.

Recommended for: Innovators, Planners

Option 2: Advocating for Change/Influencing Policy Development (Classroom)

Advocacy and policy development can be daunting initiatives for individuals and groups to address, but you do have the power to shift efforts and influence policies. In this workshop, you will dig into what it takes to advocate for changes in your community and influence policies. This workshop will provide vast information on how to approach advocacy tactics, engage allies, respond to opposition, create an action plan, and influence the adoption of a policy.

Recommended for: Advocates, Educators, Mentors

Option 3: Enhancing Cultural Competence (Boardroom)

It is well-known that the Parkinson's community does not reflect the diversity of the greater community. Through further investigations, many have uncovered vast disparities in access to healthcare and awareness of resources necessary to live well with Parkinson's. As groups and individuals determine their place in providing resources to communities with their own unique experiences of discrimination and oppression, it is important to ensure that efforts and approaches are culturally competent and address the actual needs of the community you're looking to serve. In this workshop, you will learn about cultural audits, how to build understanding among diverse communities, and drive and champion a culturally inclusive community.

Recommended for: Advocates, Mentors, Planners



Your Community Superpower

We love using personality quizzes and strengths to help us self-reflect, develop professionally, and work together more efficiently. That's why we developed a quiz for our community leaders to help you identify YOUR community superpower.

Don't think of your result as a label, but more as an opportunity for reflection and a jumping off point. Reading about your superpower may inspire you to lean in more to your areas of interest or even push you to think outside of your usual activities to grow into another area.

Access the quiz and a complete description of your superpower at dpf.org/superpowers.



Type 1 - Advocate

As an Advocate, you can engender trust with key community change agents and draw people in, encouraging them to take action to improve their lives. You possess the necessary authority, credibility, and passion to shape and influence others. Through your leadership, you encourage and motivate individuals and communities to change the way they think and behave.

Strengths you may possess:

- » Futuristic: You are inspired by what the future can be and energize others with your visions of the future.
- » Communication: You find it easy to put thoughts into words.
- » Command: You have a strong presence where you can take control of a situation and make necessary decisions.
- » Connectedness: You find links among many things and find meaning in connections.



Type 2 – Educator

As an Educator, you are well-equipped to impart specific knowledge to key target groups to change their behaviors and practices. You can help individuals or groups learn by sharing your personal expertise and experience through speaking, writing, or facilitating group learning such as in a support group. You love finding and sharing new resources and always seem to have a growing library of tools to provide to others.

Strengths you may possess:

- » Communication: You find it easy to put thoughts into words.
- » Input: You are inquisitive, collecting information and ideas.
- » Connectedness: You find links among many things and find meaning in connections.
- » Focus: You can take a direction, follow through, and make corrections necessary to stay on track.



Type 3 – Innovator

As an innovator, you excel at creating connections that help spread innovation and ideas. You are adept at looking at the big picture and noticing opportunities for collaboration, knowledge sharing, and connection, particularly across perceived boundaries or amongst groups not previously connected with one another. You can see who needs to be in the room, notice opportunities for collective impact, and enjoy seeking and sharing knowledge.

Strengths you may possess:

- » Connectedness: You find links among many things and find meaning in connections.
- » Input: You are inquisitive, collecting information and ideas.
- » Individualization: You have a gift for figuring out how different people can work together productively.
- » Arranger: You can determine how all of the pieces and resources can be arranged for maximum productivity.



Type 4 - Mentor

Mentors recognize and cultivate the potential in others. Very often, in fact, potential is all you see! When you interact with others, your goal is to help them experience success and live well. You look for ways to challenge them and create opportunities that can stretch them and help them grow. You feel considerable pride when you see signs of growth – a new behavior learned or modified, a slight improvement in skill, a glimpse of excellence where previously there was only hesitancy.

Strengths you may possess:

- » Maximizer: You can stimulate excellence in a person or group.
- » Developer: You recognize and cultivate the potential in others, spotting signs of even the smallest improvements.
- » Connectedness: You find links among many things and find meaning in connections.
- » Relator: You enjoy close relationships with others and find deep satisfaction in working hard with friends to achieve a goal.



Type 5 - Planner

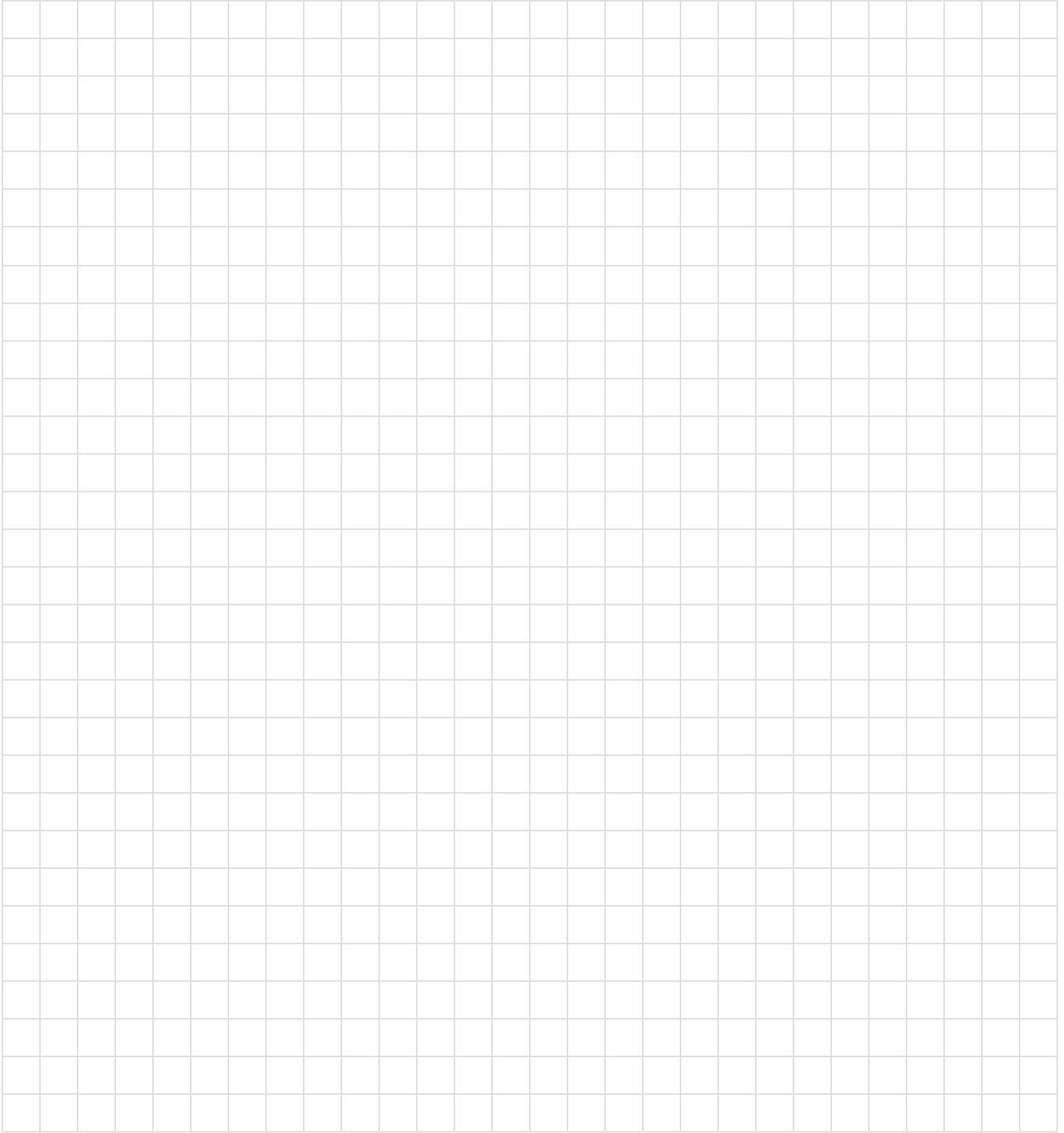
Planners have the ability to get things done by setting clear goals, building project and event plans, problem-solving, and providing organization and accountability. When faced with a complex situation involving many factors, you enjoy managing all of the variables and creating alignment toward a common goal. You are a key member of any team whether or not you are formally leading the group. Without planners, groups and individuals can get easily overwhelmed, burnt out, or stalled.

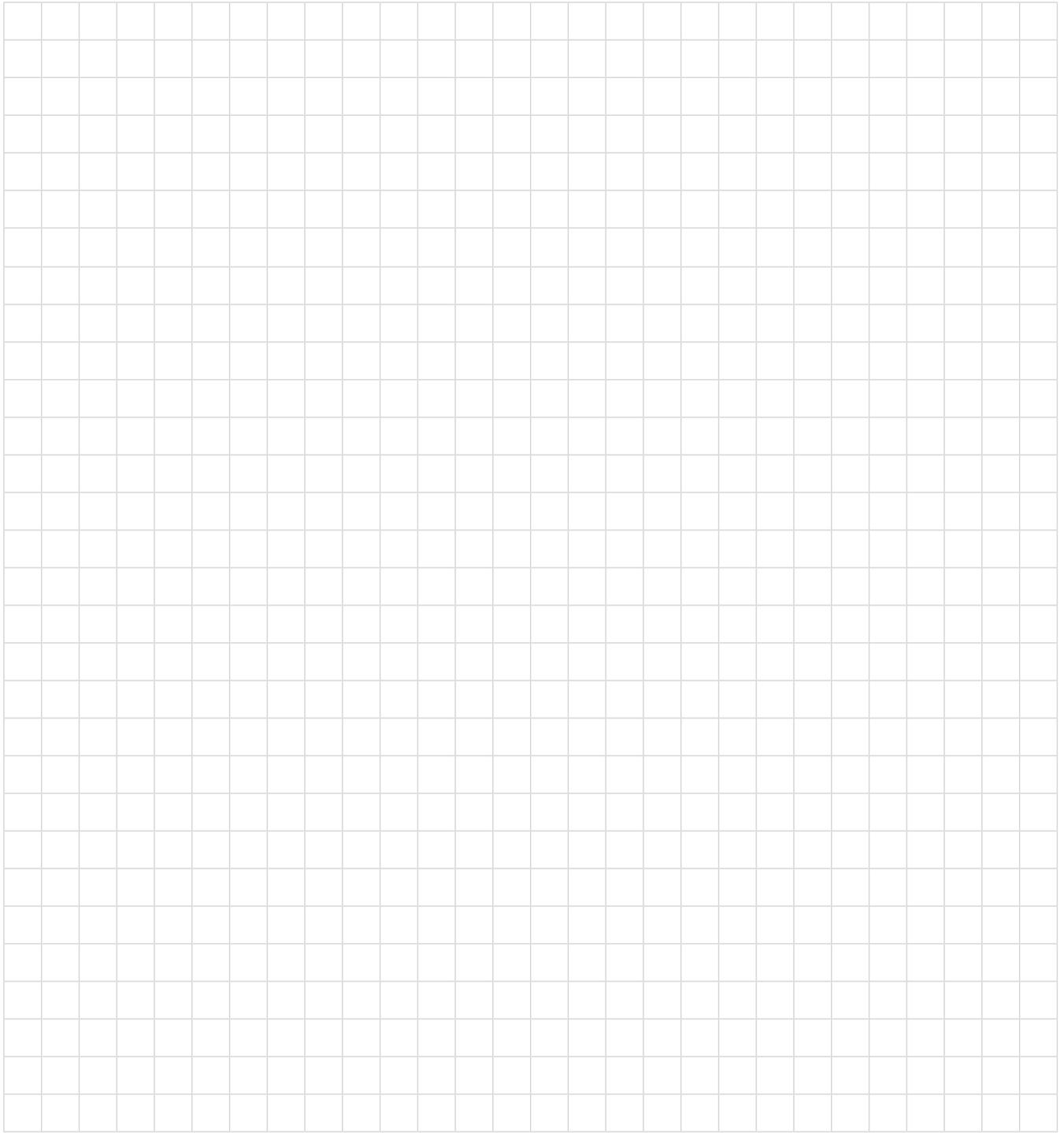
Strengths you may possess:

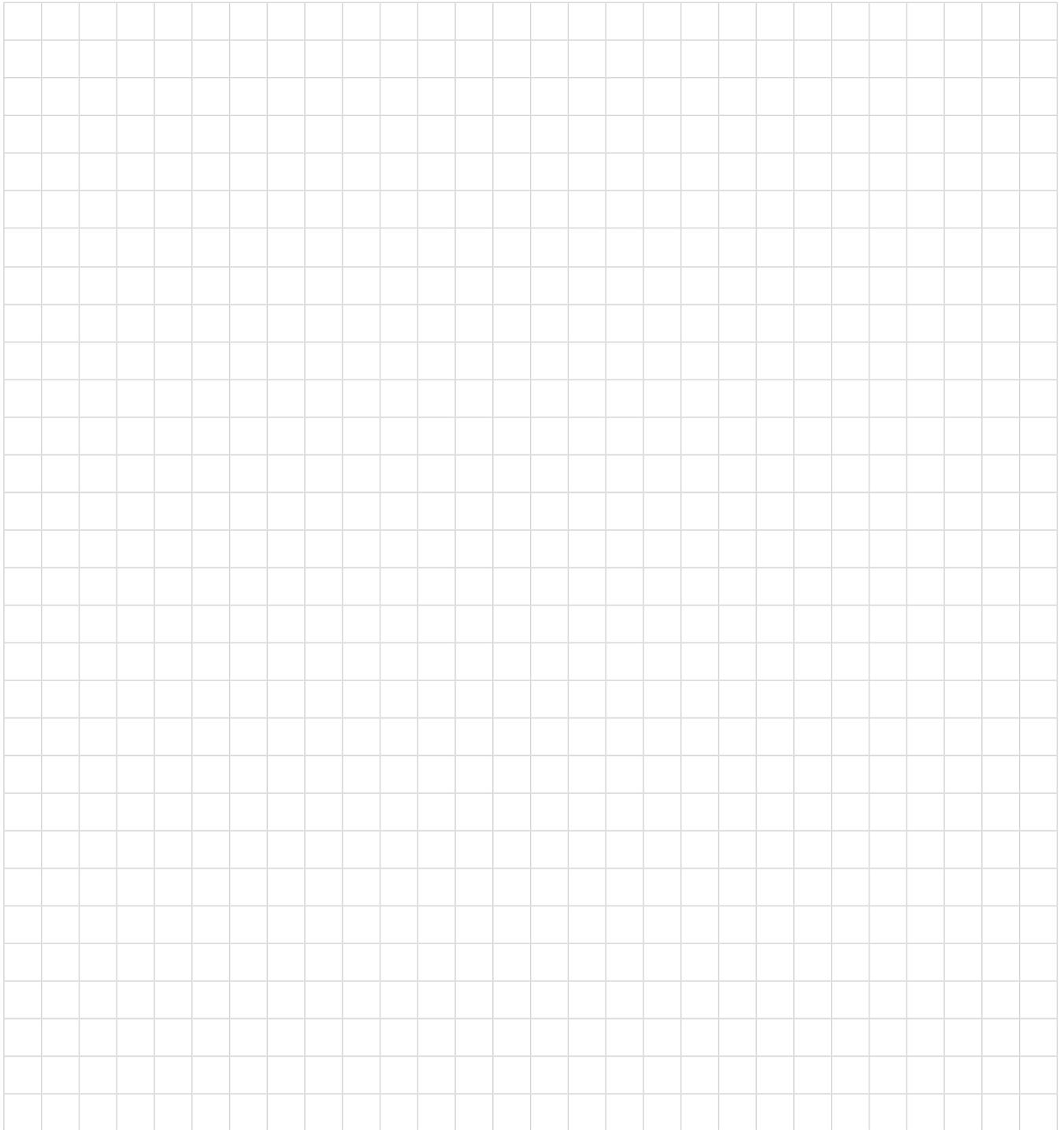
- » Activation: You turn thoughts into action.
- » Command: You have a strong presence where you can take control of a situation and make necessary decisions.
- » Maximizer: You can stimulate excellence in a person or group.
- » Strategic: You can quickly spot relevant patterns and issues to create thoughtful paths forward.

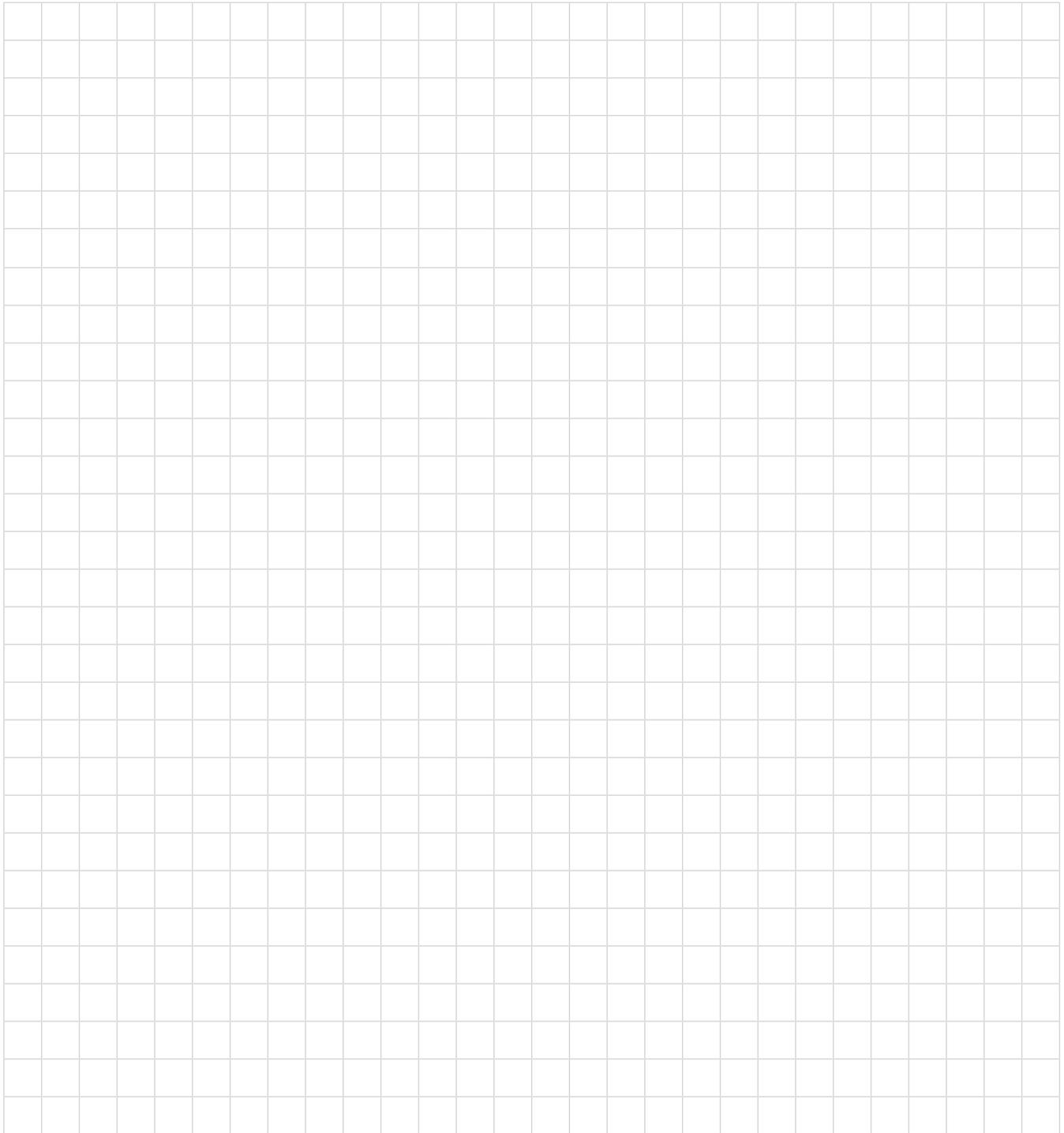
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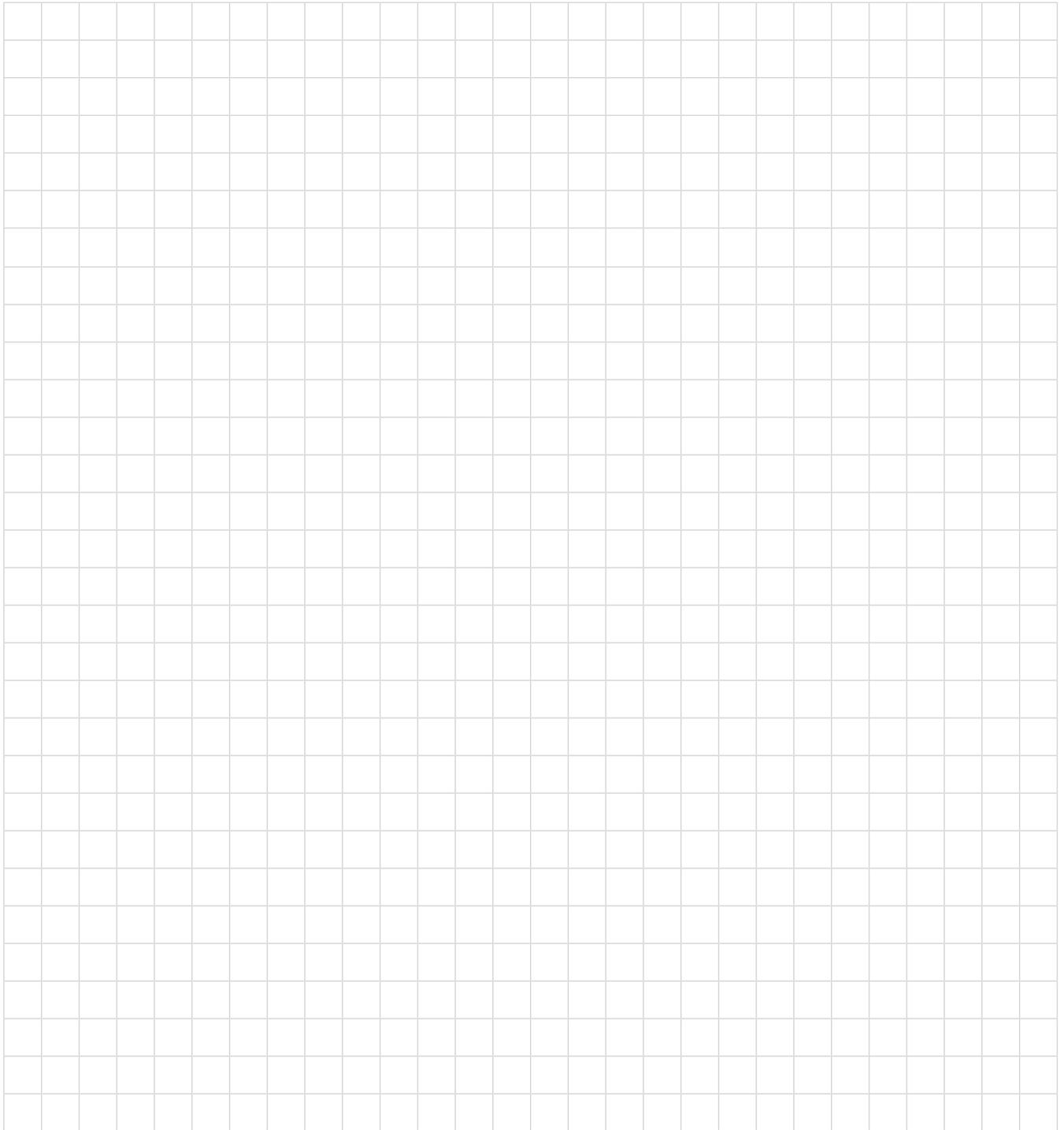
Use the space below for notes, doodles, or whatever else comes out of our time together.











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 2023 Healthy Parkinson's Leadership Conference, we'll be getting back on the road for local events across the country with our new HPC summit series and will host a Hispanic Leadership Training event at the end of the year. 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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We are grateful to the Rosina K. Sapir Ambassador Fund and Louisiana Walks for Parkinson's for supporting the Leadership Conference travel grants.

Ambassador Leadership Program Sponsors

