



HEALTHY PARKINSON'S COMMUNITIES™

Getting Started Guide

The Davis Phinney Foundation Healthy Parkinson's Communities Initiative is supported by:

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Healthy Parkinson's Communities™ Getting Started

We're thrilled you're interested in making your community healthier for people living with Parkinson's. This Getting Started Guide is designed to give you the big picture of the Healthy Parkinson's Communities (HPC) initiative and take three simple steps before registering as a member of the HPC network:

1. Get familiar with the HPC initiative and Community Action Committees
2. Complete the Community Action Committee Leadership Agreement
3. Form your preliminary Community Action Committee

We created the HPC initiative to help inspire and support communities of any size—from neighborhoods to states—that are working to change how people live with Parkinson's. Through this work, we want to change how communities embrace and support people living with Parkinson's and ensure that all people have the opportunity to live well with Parkinson's, from swift and accurate diagnosis through long-term care and engagement.

As you take the first (or next) step toward building a Healthy Parkinson's Community, we look forward to getting to know you, your team, and your community. You can expect an invitation from us to connect very soon, and we are available to support you every step of the way.

Thank you for inspiring action in your community!

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Introduction

This guide is designed to get you from where you are now to registering to join our Healthy Parkinson's Communities network, whether you're starting from square one or you've been at this work for quite some time. While every community is unique, laying a strong foundation of leadership, collaboration, and community listening is important for anyone taking on this work.

Once registered for the HPC network, you will gain additional access to tools and resources that will ensure your success. This includes access to:

- » An on-line peer-network
- » On-line leadership training tools with peer- and expert-led content where you can learn new skills, gather and share knowledge, and interact with peers
- » Our Healthy Parkinson's Communities toolkit, which provides guidance and tools to help you research and assess your community, set goals, and create a plan to achieve them
- » Exclusive access to apply for grants from the Healthy Parkinson's Communities Network Grant Fund - *Launching in 2024*
- » Our Healthy Parkinson's Communities staff who are available to help you puzzle through questions, find new connections, and more

Before registering (directions on page 7), we ask that you do the following:

1. Familiarize yourself with the Healthy Parkinson's Communities initiative and Community Action Committees (CACs)
2. Complete the CAC Leader Agreement or identify and on-board a CAC leader for your group
3. Recruit the first two or three members of your CAC

This guide will help support you through all of these steps.



If you prefer video format...

Check out [this video](#) that outlines how to get started in your community!



What is the Healthy Parkinson's Communities initiative?

We created the HPC initiative to help inspire and support communities of any size—from neighborhoods to states—that are working to change how people live with Parkinson's. Through this work, we want to change how communities embrace and support people living with Parkinson's and ensure that all people have the opportunity to live well with Parkinson's, from swift and accurate diagnosis through long-term care and engagement.

Goals of the Healthy Parkinson's Communities initiative

Based on 16 years of working in the Parkinson's community, we have identified three goals that, if achieved, will help us realize our mission—to help ALL people with Parkinson's live well—on the greatest scale possible.

- #1 – Ensure Parkinson's community leaders have the knowledge and resources they need to make a positive and sustainable change in their community
- #2 – Encourage and support data-informed initiatives designed to increase access to and engagement with resources that improve the quality of life for people with Parkinson's
- #3 – Work with communities to raise awareness of Parkinson's in their areas

Optional Additional Resources:



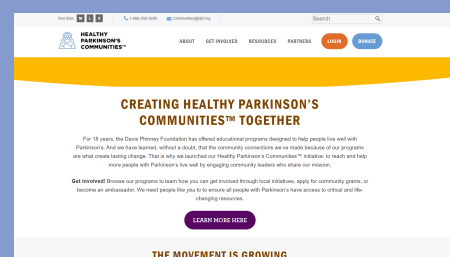
Dig Deeper

Check out this [video interview](#) with our Director of Community Engagement about the Healthy Parkinson's Communities initiative for more information about why we started this work and how we envision it looking in communities.

Dig Deeper

If you want to learn more about the HPC initiative, take a look at our website!

www.HealthyParkinsonsCommunities.org





Forming your Community Action Committee (CAC)

Raising your hand to lead change in your community can feel overwhelming; however, when you bring diverse and motivated community leaders along for the ride, the experience can be enjoyable and manageable. We hope that by sharing our process from idea to implementation, you will feel inspired and confident that you can lead change in your community through CACs.

What is a CAC and why do you encourage them?

A CAC is a diverse coalition of community leaders from local organizations, hospitals, universities, and more who make a difference in their community. We encourage them because we know from experience that we are better together bringing diverse and broad experiences to one space. Additionally, when operating alone, burnout is inevitable. However, organizing a motivated, diverse team of community leaders eases individual workloads and reduces burnout.

How can I start my CAC?

Starting a CAC is much like building a highly effective team in the workforce, but with super volunteers focused on improving your community. There isn't ONE definitive way to create an effective CAC, but we have recommendations based on our experience.

1. Determine what your community needs.
2. Identify potential people who can help to address those needs based on interest or skill and background.
3. Outline the commitment and make the ask to join your work.

Have more questions about starting your CAC?

Reach out to Gabby and/or Susana. We are happy to help!



Dig Deeper

Check out "[The What, Why, and How of Community Action Committees](#)" post on the HPC Blog to learn more about building a highly effective CAC.



TAKE ACTION CHECKLIST

You completed this step!

- ☒ 1. Get familiar with the HPC initiative and CACs



Community Action Committee (CAC) Leadership Agreement

Throughout the Healthy Parkinson's Communities™ (HPC) initiative, your role will be to inform, guide, and help facilitate a successful investment of time and resources into this community in an effort to lift up local resources and address unique needs of this local community in a sustained engagement program. While the specific commitments of leading a CAC in your area are completely up to you, we have listed below what the Davis Phinney Foundation commits to, individual commitments for the CAC Leader, and qualities that we have seen in the most successful CACs. While the list is not exhaustive, it aims to paint a picture of the work that can be done together.

Davis Phinney Foundation commits to:

- Providing tools and resources to help mobilize your community work
 - Specifically through the:
 - o HPC Blog and Community Leader Newsletter
 - o HPC Toolkit to help determine community readiness and drive success
 - o HPC HUB with leadership enhancement and capacity building activities
 - o Facilitation of weekly forums for community leaders to engage and learn from one another
 - o Exclusive access to apply for grants from the HPC Network Grant Fund
- Connecting you with other leaders to learn from each other and sharing of ideas and successes
- Being available as an engaging and inspiring consultant if you want to brainstorm, share ideas, ask questions, request resources, and/or feel stuck
- Driving our development of additional tools and resources by asking "How can we help you?"

The CAC Leader commits to:

- Representing the local community and CAC in conversations with the Davis Phinney Foundation
- Reviewing and becoming familiar with the HPC Toolkit as provided by the Davis Phinney Foundation
- Determining participation requirements for CAC members and recruiting the first 2-3 additional members for the group
- Leading/facilitating your CAC
- Reporting results to the Davis Phinney Foundation



CAC Leadership Agreement Continued... Critical Components of a Successful CAC

While no CAC is the same and is representative of the needs presented by the community, we have noticed some qualities of CACs who are typically more successful in achieving their goals. As you consider your role as a CAC Leader, reflect on what qualities resonate in you and what you could leverage from building an intentional CAC.

Qualities of Highly Effective CAC Leaders:

- Strong desire to improve the health of their Parkinson's community
- Strategic, curious, and collaborative in nature
- Organized with a high attention to detail
- Skilled facilitator and can guide groups to turn ideas into action

Qualities of Highly Effective CACs:

- Effective at creating connections and noticing opportunities
- Members have diverse skills across multiple domains in the community
- Effective at determining how different pieces fit together to achieve a common goal
- High levels of trust exist between members
- Members share ideas and the workload in executing plans

By signing this form, I understand I am acknowledging I have received, read, and fully understand the commitments made by the Davis Phinney Foundation and myself/ my organization as outlined in the CAC Leadership Agreement.

Name

Date

Signature

Davis Phinney Foundation Representative:

Name

Date

Signature



TAKE ACTION CHECKLIST

To complete this step:

- ☒ Fill and sign the CAC Leadership Agreement and send to Susana



Preparing to Register

At this stage of your journey, you have already demonstrated your investment to your Parkinson's community and hopefully received buy-in from other community leaders. Now you're ready to formally register to join the Healthy Parkinson's Communities network!

There are many ways to register and we want to make it as accessible as possible:

1. Register by completing the [on-line form](#).
2. Set up a chat with Gabby and/or Susana to complete the questions through a short conversation.
3. Send an email to Susana to receive the registration questions by email for your completion.

After you complete the on-line registration, you will be contacted by Susana with information on joining the Healthy Parkinson's Communities HUB, which includes the Healthy Parkinson's Communities Toolkit, access to on-line leadership training courses, and connection to people in other communities leading similar work.



TAKE ACTION CHECKLIST

To complete this step:

- ☒ Invite 2-3 people to join your CAC.
- ☒ Register your community as a part of the HPC Network!



TAKE ACTION CHECKLIST

Use this complete list of action items to help you take all the steps needed to successfully register your community:

- ☑ 1. Get familiar with the HPC initiative and CACs
 - Bonus: Read through our website at HealthyParkinsonsCommunities.org including skimming through our HPC Blog
 - Bonus: Join the Healthy Parkinson's Communities newsletter list by completing [this form](#)
- ☑ 2. Fill out and submit your CAC Leadership Agreement
 - ...or reach out to Gabby/Susana to discuss other options for identifying and implementing a leader for your community's CAC
- ☑ 3. Recruit two to three members to your group.
- ☑ Register by completing the [online registration form](#) or reach out to Susana for an alternate option. Celebrate - you did it!



REACH OUT IF YOU HAVE QUESTIONS



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