

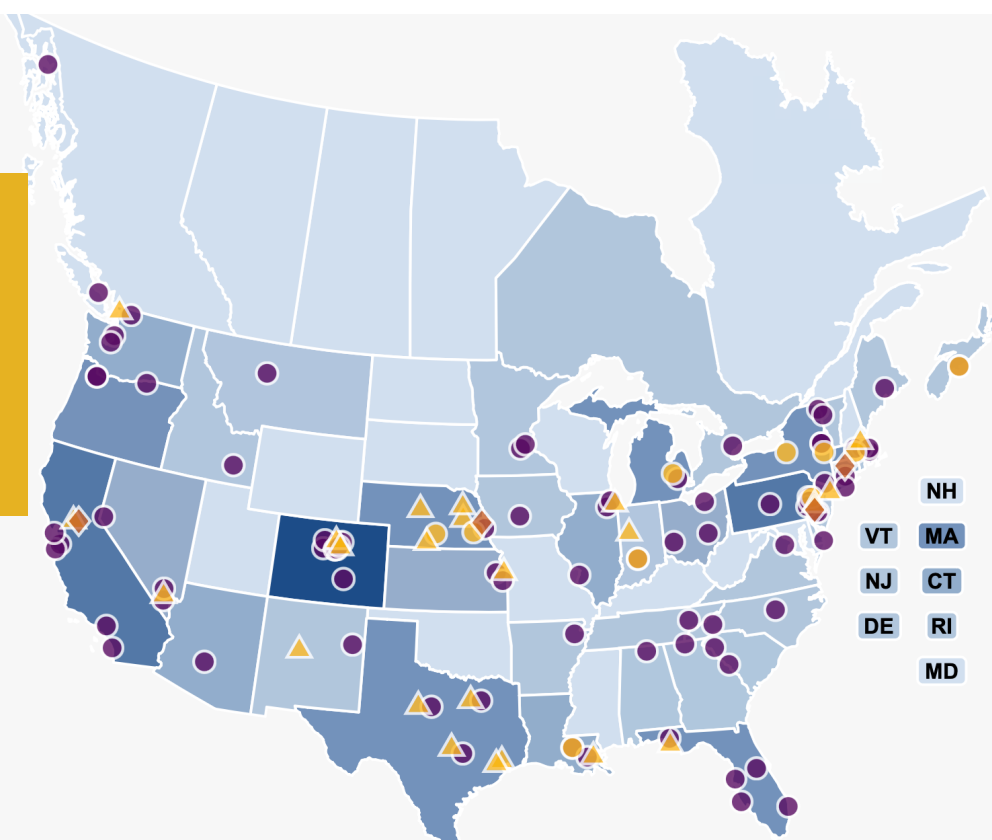


## The Movement is Growing

Since launching the Healthy Parkinson's Communities™ initiative in 2021, we've seen tremendous excitement in joining this work from communities across the US, Canada, and even as far as Australia. Community leaders join the initiative in the way that aligns best with their passions and vision. Below, you can see where we currently have Ambassadors, Community Action Committees (CACs), and funded grant projects.



Visit our website at  
[healthyparkinsonscommunities.org](https://healthyparkinsonscommunities.org)  
to explore more with our interactive map.



● Ambassadors    ◆ Community Grants    ● Registered Community Action Committees    ▲ Getting Started Community Action Committees

### 2022 AT A GLANCE

86

Ambassadors are serving 38 states and three Canadian provinces as health navigators and mentors for individuals and families.

32

Communities across the US and Canada have started the initiative in their areas.

29

Communities applied for grants that support work addressing access, awareness, and health equity.



## Ambassador Leadership Program

Our Ambassador Leadership Program was founded in 2015 and has since grown to **86 Ambassadors serving 38 states and three Canadian Provinces**. In 2022 alone, we onboarded 24 new Ambassadors and received applications from 59 people across the country.

We support Ambassadors by providing mentorship, professional development, free Parkinson's resources, and financial support so they can travel and participate in local events. **In 2022, we provided nearly sixty hours of formal professional development training** in addition to hundreds of hours of mentorship and related support.

Ambassadors touch the lives of individuals and families, share information as speakers and support group leaders, participate in public policy advocacy, and so much more. The ripples of their support are far reaching. **Our estimated 2022 impact is below.**

### AMBASSADOR PROGRAM IMPACT



**13,200**

**Individuals and families supported by an Ambassador.** We estimate that Ambassadors engage, on average, 150 people a year through their activities.



**1,690**

**Every Victory Counts® manuals distributed by Ambassadors.** Ambassadors share this critical resource with people with Parkinson's, care partners, support groups, medical students, and medical professionals.



**486**

**Individuals connected to an Ambassador through our website.** Since introducing a new search function, individuals can find and connect with our Ambassadors more quickly and easily.



**50-400**

**Individuals at each event with an Ambassador representative.** Ambassadors regularly attend and speak at local events to audiences that have exceeded 400 people. Ambassadors share resources and information at these events to help people live well with Parkinson's.



## Ambassador Leadership Program

While the reach of this program tells part of the story, this program is really about the individual service and victories of each Ambassador. Below are just a few highlights from 2022.



**Marty Acevedo (Oceanside, CA)** spent 2022 engaging with various community members in a broad geographical area. From connecting with newly diagnosed people and presenting to nursing school students to speaking at a support group, she shared resources and support that impacted many. She was also active in policy advocacy, supporting and speaking on behalf of the National Plan to End Parkinson's.



**Kat Hill (Portland, OR)** released her new book *Being Well with Chronic Illness: A guide to Joy & Resilience with Your Diagnosis* on October 18th, 2022. It's a meaningful self-help guide for those with chronic illness who are looking for a better path to wellness.



**Doug Pickard (Parksville, British Columbia CA)** launched his drum therapy website [DopaBeats](#) and opened registrations for people worldwide.



**Greg Ritscher (Panama City Beach, FL)** spoke at MANY events this year. A highlight was speaking to over 300 people as the keynote Speaker at the 10th Annual Parkinson's Symposium at LSU on July 16.



Many Ambassadors participated in Team DPF events this year, including Ride The Rockies, Tour de Victory, Copper Triangle, Louisiana Walks for Parkinson's, and Tour de Tucson.



## Ambassador Leadership Program

In addition to impacting the individuals and families our Ambassadors serve, this program has deeply impacted program participants. As we closed our 2022 Healthy Parkinson's Communities Leadership Conference, several Ambassadors took a moment to share their gratitude for the program and the purpose and community it provides. We even had one Ambassador write a poem about his experience.



Poem by Stuart Munro  
(Lake Quivira, KS)

So I took this test  
And that is what it revealed...  
That I am a mentor.

I must admit, to a little bit of  
surprise  
A slightly awkward recoil,  
I had for so many years gone my  
own way,  
Blazed my own trail,  
Unburdened by the rest of  
humanity...  
It feels so commonplace and  
ordinary  
To be described as...a mentor.

But then, I remember the many  
mentors  
Who have formed my experience  
And laid the foundations of my life  
Beginning in the nursery,  
My mother, with such unselfish  
devotion,  
Was mentoring me.

And my father, my brother and my  
sister,  
Each in their own way, were  
mentoring,  
Me, certainly,  
But by exponential extension, also  
all of my mentees.

I realize how grateful I feel  
For their mentoring of me,  
As well as the many mentors who  
have followed them  
In mentoring me.

Mentorship simply requires a  
commitment  
To improve the outcome,  
The quality of life,  
Of the mentee.  
And ensuring that every victory  
counts...

Sounds familiar, doesn't it?  
So, I say thank you to Davis and to  
everyone on the team  
For giving me the opportunity to  
discover my mentorship trait,  
And to make it count,  
As an ambassador!



## 2022 Healthy Parkinson's Communities™ Leadership Conference

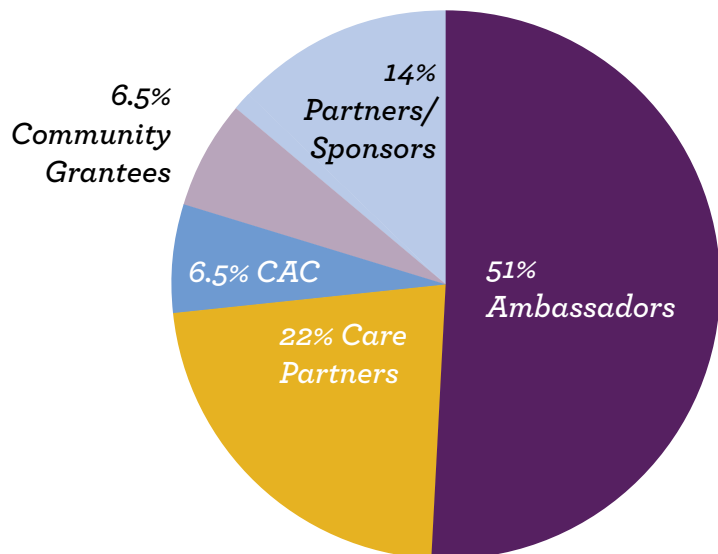


We held the 2022 Healthy Parkinson's Communities™ Leadership Conference in Kansas City, MO, September 30 through October 1. Ambassadors, Community Action Committee leaders/members, community grant recipients, partners, staff, and more joined us for two memorable days of learning, networking, and discussion.

This was also our first hybrid event; we welcomed several participants via Zoom and facilitated a collaborative experience for them simultaneous with the in-person event.

### Participant Breakdown

(Note: Does not include staff/board participants)



### 95%

Agree or strongly agree the event's content was relevant to their work in the Parkinson's community

### 90%

Agree or strongly agree that they made new connections that will support their work in the Parkinson's community

### 100%

Express feeling a sense of community and belonging with other Parkinson's community leaders



*"Thank you to the staff for creating a safe space and environment for us to share with one another and have these hard conversations with others."*

*"The event was very enriching. I had the opportunity to meet so many people that share my vision and passion - connections which will improve the work that I/we are doing."*



## Healthy Parkinson's Communities™ (HPC) Network

We began the HPC Network because we know that where you live significantly impacts how well you can live with Parkinson's. With nearly 20 years of experience educating and engaging the Parkinson's community, we have heard countless stories of people experiencing significant barriers to care, connection, wellness programs, support, and acceptance in their community.

This summer, we invited members of the Foundation community to tell us about where they live. While the first iteration of this survey could only reach a small group of respondents, we are excited to expand this data collection in 2023.

### 2022 HPC COMMUNITY SURVEY DATA



*I feel a sense of belonging in my community.*

Yes 73%

No 19%

I don't know 8%



*There is a network of professionals in the area with knowledge and tools to help people with Parkinson's live well.*

Yes 58%

No 34%

I don't know 8%



*Medical information is easily accessible for people of all backgrounds and socioeconomic levels.*

Yes 35%

No 35%

I don't know 30%



*Wellness programs for people with Parkinson's are easily accessible for people of all backgrounds and socioeconomic levels.*

Yes 42%

No 31%

I don't know 27%



*I feel comfortable advocating for what I need in my community.*

Yes 73%

No 15%

I don't know 12%



*My community is supportive of care partners.*

Yes 54%

No 19%

I don't know 27%





## Healthy Parkinson's Communities™ (HPC) Network

There are currently 16 registered communities in our HPC Network, with another 16 in the early stages of onboarding. You can learn more about our registered communities through their [community profiles on the HPC website](#).

### Registered

- » Albany, NY (2021)
- » Flint, MI (2021)
- » Baton Rouge, LA (2021)
- » Massachusetts State (2021)
- » Lincoln, NE (2021)
- » Central NY (2021)
- » Kearney, NE (2021)
- » Hornsby, NSW, Australia (2021)
- » Bloomington, IN (2021)
- » Nova Scotia, Canada (2022)
- » Shavertown, PA (2022)
- » Abilene, TX (2022)
- » Zanesville, OH (2022)
- » Cadillac, MI (2022)
- » Easton, PA (2022)
- » Indianapolis, IN (2022)

### Getting Started

- » Olathe, KS
- » Dallas, TX
- » San Diego, CA
- » Memphis, TN
- » Northwest region of US
- » Green Valley, AZ
- » Montana State
- » Lafayette, IN
- » Panama City Beach, FL
- » Chattanooga, TN
- » Maineville, OH
- » Doylestown, PA
- » Magna, UT
- » Newbury, MA
- » Las Vegas, NV
- » Vail Valley, CO



One of the first steps each community takes before joining the network is creating a Community Action Committee (CAC). CACs are local groups committed to changing the experience for people living with Parkinson's in their areas.

*Every community is unique, and so is every CAC. Depending on the needs of a given community, the groups will have different participants but are likely to include:*



*Local  
Neurologists*



*Public Health  
Experts*



*Patient  
Advocates*



*Non-profit  
Leaders*



*Allied Health  
Professionals*



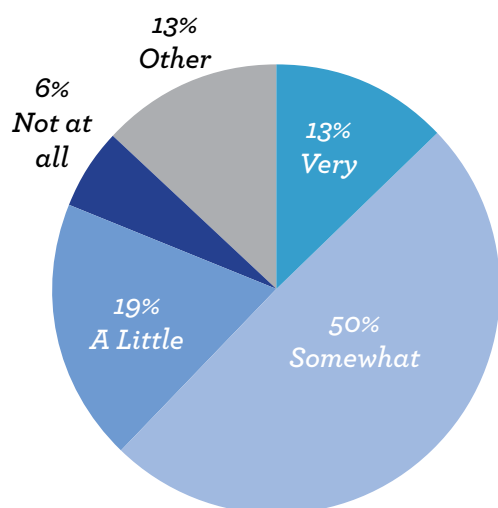
*Policy  
Experts*



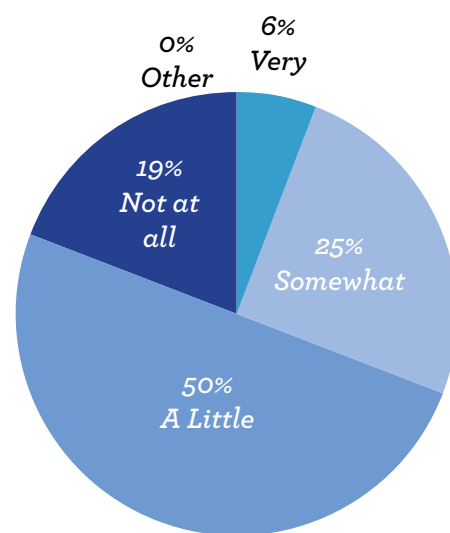
## Healthy Parkinson's Communities™ (HPC) Network

When communities formally register, they share quantitative and qualitative information about their community. This information allows us to take a snapshot of their community at the start of their engagement with the initiative and provides us with a bigger picture of the need within the Parkinson's community. Below, you can see cumulative data from the communities that have registered so far.

*On a scale from very to not at all, how accessible are professionals trained to work with the Parkinson's community?*



*On a scale from very to not at all, how aware or concerned is the greater community with the well-being of people with Parkinson's?*



*Rate your community on a scale of 1-10 on the following:*

*Avg Score*

<i>Participation/collaboration between community leaders</i>	4.4
<i>Programs and resources available for people living with Parkinson's</i>	4.1
<i>Awareness of programs and resources</i>	2.6
<i>Access to programs and resources</i>	3.2
<i>Awareness/health literacy about Parkinson's within general population</i>	2.5





## Healthy Parkinson's Communities™ (HPC) Network

The work each community does is as unique as the community itself. In 2022, we saw communities create online resource hubs, collaborate with local universities to initiate needs assessments, build partnerships with YMCAs in under-engaged areas, and much more. Below is just one example demonstrating the kind of work happening in HPC network communities.



### Shavertown, PA

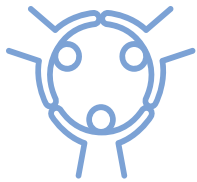
**CAC leader:** Debbie Callahan

Debbie was inspired to create her CAC after a personal experience at the emergency department of her local hospital, Geisinger Medical Center. She was given medication that is contraindicated for people with Parkinson's and experienced severe, persistent, side effects. This experience led Debbie to organize education and advocacy at the hospital around appropriate and safe medications for people with Parkinson's.

Since joining the HPC Network in March, Debbie and her CAC have made significant progress:

- » **April:** Debbie finalized a letter to share with her community and the Geisinger Medical Center administration with input from the Davis Phinney Foundation and Dr. Michael Okun.
- » **July:** The Foundation shared Debbie's story and letter on the Foundation blog.
- » **August:** Debbie shared the Parkinson's medication contraindication sheet the Foundation produced with Geisinger Medical Center.
- » **September:** Debbie's letter asking for Geisinger Medical Center to offer better care to patients visiting the emergency department received over 250 signatures from community members.
- » **October:** Debbie made another push to speak with Geisinger Medical Center administration regarding her mistreatment.
- » **November:** Debbie and Foundation Community Engagement Manager Gabby Dimotsantos met with the Geisinger Medical Center administration to discuss Debbie's experience and potential solutions for future patients.

In 2023, Debbie will remain in touch with the Geisinger Medical Center administration to ensure they make changes. She plans to pursue press interviews and an upcoming webinar with the Foundation to talk about her experiences, victories, and upcoming work.



## Hispanic Community Engagement

In August, we formally launched our Hispanic Community Engagement initiative to adapt the Healthy Parkinson's Communities initiative to serve Hispanic individuals and families affected by Parkinson's across the US, Latin America, and eventually worldwide.

Since beginning this work in early fall, we have made tremendous progress and look forward to significant growth in 2023.

---

### 2022 HISPANIC ENGAGEMENT

---



**Engaging a national and international audience.** We launched a survey to collect input from the Hispanic community on preferred methods of receiving information and produced three videos to introduce the Hispanic community to the Foundation and encourage participation in HPC and WPC.



**Fostering Hispanic community leaders and mentors.** We formed two advisory councils to help us begin adapting the Ambassador Leadership Program, training, and resources for the Hispanic Community. In early 2023, we will welcome nine Hispanic Ambassadors, all of whom participated on the advisory council.



**Facilitating collaboration to improve the experience for Hispanic individuals and families with Parkinson's.** We created the HOPE PALS coalition (Hispanic Organizational Partners Engaged in Parkinson's Awareness and Leadership Solutions) to avoid replication of efforts and foster collaboration. The group includes participants from the Parkinson's Foundation, APDA, Muhammad Ali Center for Parkinson's, PMDA, LARGE PD, Micheal J. Fox Foundation, and Promotores Embajadores de Parkinson.

As well, Hispanic Community Engagement Manager Claudia Martinez participates in several national and international councils, including the WPC Leadership Forum's Building Global Relations working group, Parkinson's Foundation Latino PD GENE Advisory Committee, and PMD Alliance Hispanic Advisory Council.



## National Engagement Advisory Team (NEAT)

Through the Healthy Parkinson's Communities™ initiative, we aim to support community leaders with the resources they need to be robust community connectors, educators, and advocates. We work with our National Engagement Advisory Team (NEAT) and many other partners to support wellness professionals in making their Parkinson's communities healthier.

In 2022, NEAT identified a need to understand what wellness professionals in their programs need to be better community connectors, leaders, and supporters for their local Parkinson's communities. We worked with Dr. Bradley McDaniels at the University of North Texas to develop the Parkinson's Wellness Professionals Needs Assessment. Early data show significant need for support in several areas:

### EARLY ASSESSMENT DATA RESULTS



*I find it easy to collaborate with other Parkinson's-focused organizations*

Strongly Agree: 38  
Agree: 98  
Disagree: 141  
Strongly Disagree: 23  
N/A: 20



*I feel well connected to my peers in other communities for peer learning and support*

Strongly Agree: 37  
Agree: 85  
Disagree: 153  
Strongly Disagree: 39  
N/A: 9



*I have what I need to build partnerships with other organizations in my community*

Strongly Agree: 21  
Agree: 108  
Disagree: 148  
Strongly Disagree: 17  
N/A: 25



*I have what I need to engage members of my community who are traditionally marginalized or underrepresented*

Strongly Agree: 16  
Agree: 84  
Disagree: 163  
Strongly Disagree: 30  
N/A: 28

*Data from this assessment will be used to determine the development of future programs and interventions from NEAT organizations, the presentation of a poster at the World Parkinson Congress 2023, and the dissemination of research findings in a peer-reviewed scientific publication.*

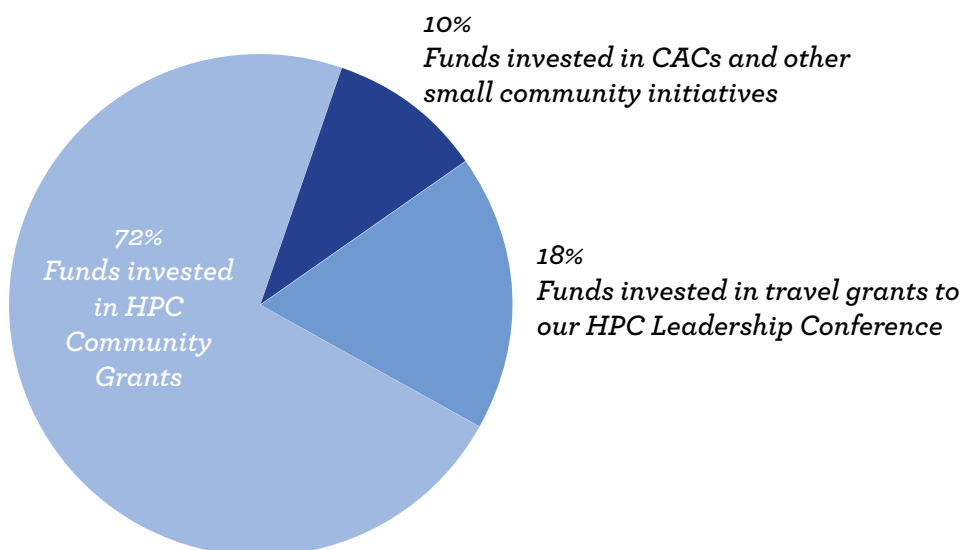


**DAVIS PHINNEY**  
Foundation For Parkinson's

*every victory counts®*

## Community Grants

Since starting our Community Grants program in 2021, we have awarded nearly \$400,000 in funds to support local initiatives and leadership development. In 2022, we renewed support for two long-term, health equity-focused initiatives, supported two new projects and three initiatives led by CACs, launched a travel grant program for our annual leadership conference, and more.



### 2021 Grantees

- » Empowering Parkinson's Communities (Parkinson's Nebraska)
- » Delaware Valley Endeavor for Racial SolidarITY in PD - DIVERSITY PD (Philadelphia, PA)
- » Improving the Health of Spanish Speaking Patients with Parkinson's: A New Model of Care (Hartford, CT)
- » Rural Outreach in Northern California (PANC)
- » Parkinson Association of the Rockies

### 2022 Grantees

- » Delaware Valley Endeavor for Racial SolidarITY in PD - DIVERSITY PD (Philadelphia, PA)
- » Improving the Health of Spanish Speaking Patients with Parkinson's: A New Model of Care (Hartford, CT)
- » CHAMPIONING MOVEMENT: NOBA Dance for Parkinson's Community Building and Outreach Activities Across Southeast Louisiana - New Orleans, LA
- » Movement Matters (YMCA of the Capital Area) - Baton Rouge, LA
- » Parkinson Association of the Rockies
- » Baton Rouge CAC/YMCA of the Capital Area
- » Capital District Healthy Parkinson's Communities (Albany CAC)
- » Kearney, Nebraska CAC
- » Neuropong

Learn more about the progress of our renewed grantees on the next page.



### **Delaware Valley Endeavor for Racial SolidarITY in PD (DIVERSITY PD)**

DIVERSITY PD, led by Wendy Lewis of The Parkinson Council, received additional funding from the Foundation in 2022 for their work creating a foundation to reach and provide high-quality care to people with Parkinson's who come from traditionally underserved communities. Their work in 2021 resulted in an impressive collaborative effort with entities, including Cooper University Health Care, Jefferson Health, Penn Medicine, the US Department of Veterans Affairs, and Salem Baptist Church of Abington. As they head into 2022 they plan to:

- » Create cohesive branding of DIVERSITY PD between all collaborating institutions
- » Execute a brain health fair to educate underserved populations about Parkinson's
- » Grow their ambassador cohort and initiate publicity to expand access to and awareness of DIVERSITY PD
- » Expand their work into the Philadelphia Spanish-speaking population

After attending our 2022 Leadership Conference, a number of our community leaders have turned to Wendy and her team for recommendations and support as they work to engage underserved groups in their communities.



### **Improving the Health of Spanish Speaking Patients with Parkinson's: A New Model of Care**

Undertaken by the Chase Family Movement Disorders Center (CFMDC), and part of the Ayer Neuroscience Institute of Hartford HealthCare (HHC), this initiative centers around quality care for Hispanic communities in Connecticut. During the first year of funding (2021), grant funds supported a significant amount of community outreach, program evaluation, and resource development.

The additional funds Hartford Healthcare received in 2022 will support the administration of surveys, analysis of outcomes data, and creation of a database that includes clinical, demographic, and narrative information that can be used by investigators with experience in qualitative research. Hartford Healthcare intends for these data to provide insight into the needs, challenges, attitudes, and preferences of the Hispanic community that may help address health inequity rather than trying to effect change based on assumptions about Hispanic patients.

This thorough and thoughtful initiative-based healthcare setting will ideally serve as a model for other healthcare institutions looking to increase equity in healthcare for their local populations.



## Healthy Parkinson's Communities™ 2023 Engagements

We're excited to get back into communities in a big way with our new **Healthy Parkinson's Communities Summits** in 2023. This series of community-driven events will focus on highlighting local resources, raising awareness, increasing health literacy, and inspiring volunteerism. Created and produced in collaboration with members of our Healthy Parkinson's Communities network, the events will focus on what makes each community unique and will include a combination of public engagements and more intimate sessions with local leaders.

We'll also host **two national leadership training events**, including our first Hispanic Leadership Conference. These events will bring together our Ambassadors, CAC leaders/members, community grant recipients, and community partners for a transformational experience filled with conversation, inspiring speakers, and sessions aimed at capacity and community building.

### HPC Summits

- » Albany, NY
- » Bloomington, IN
- » Flint, MI
- » San Diego, CA
- » Baton Rouge, LA

### Leadership Conferences

- » Minneapolis, MN
- » Phoenix, AZ

