



**2023**

# Healthy Parkinson's Communities™

*Annual Report*



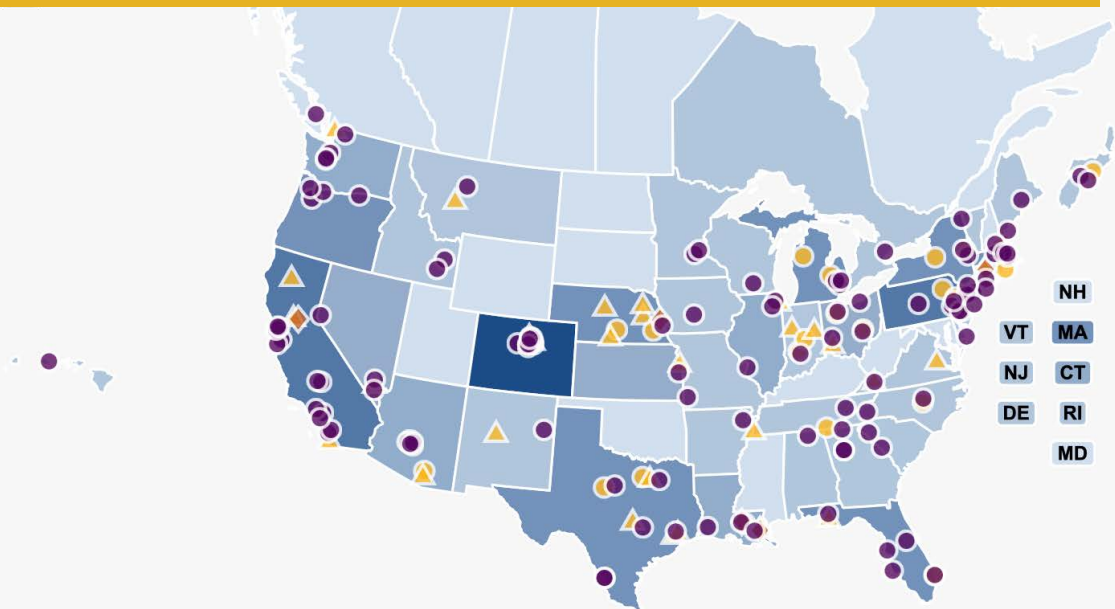


## Creating Lasting Change

The Healthy Parkinson's Communities™ initiative launched in 2021. As we close our third year, we continue to expand our work and are beginning to see the lasting impact in communities that have been engaged with the program from the beginning. In 2023, we also expanded and adapted our work to support Hispanic communities and several Spanish-speaking countries. Read on to learn more.



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

### 2023 AT A GLANCE

130

Ambassadors are serving 38 states and nine countries as health navigators and mentors for individuals and families.

53

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

175+

Leaders have been trained on advocacy and community engagement through our Leadership Conferences.



## Ambassador Leadership Program

Our Ambassador Leadership Program was founded in 2015 and has since grown to **130 Ambassadors serving 38 states and nine countries**. In 2023 alone, we onboarded 50 new Ambassadors--including 22 Hispanic Ambassadors--and received applications from 124 leaders interested in creating change for their community.

We support Ambassadors by providing mentorship, professional development, free Parkinson's resources, and financial support for travel and participation in local events. **In 2023, we provided more than 300 hours of 1:1 mentorship, meeting facilitation, and formal professional development training, and invested more than \$147,000 to provide critical support and training for our cohort.**

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 2023 impact is below.**

### AMBASSADOR PROGRAM IMPACT



**15,750**

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



**~3,500**

**Every Victory Counts® manuals distributed by Ambassadors.** Additionally, we estimate more than 6,600 other educational resources were distributed, including our Newly Diagnosed checklist and other booklets.



**600+**

**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.



**5,700+**

**Individuals at events 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.



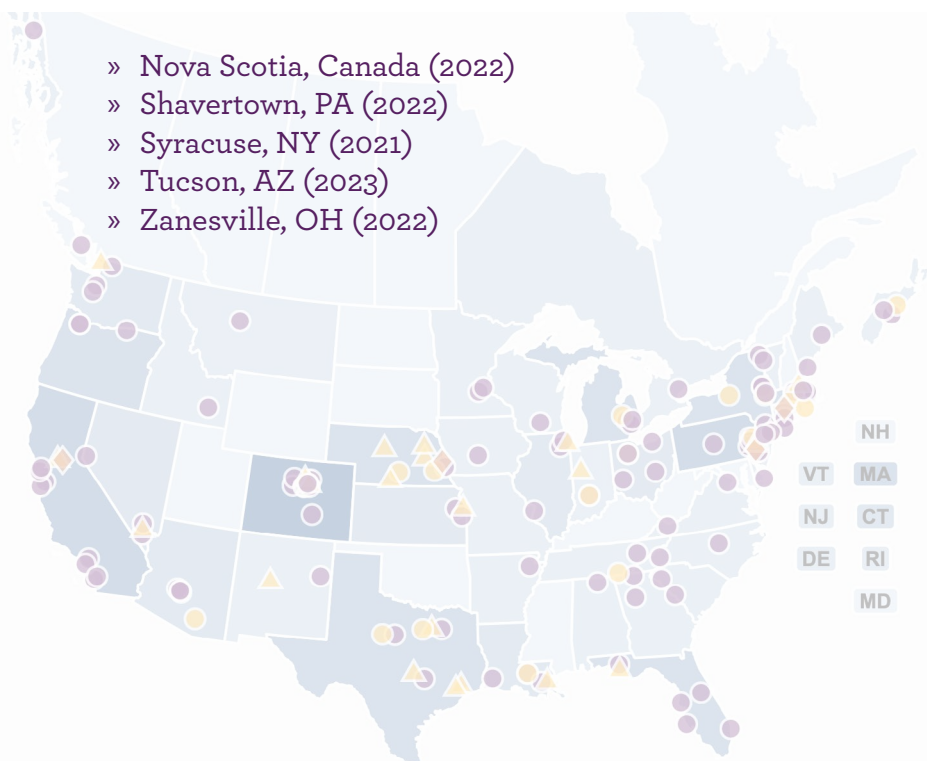
## Healthy Parkinson's Communities™ (HPC) Network

There are currently 22 registered communities in our HPC Network, with another 31 in the early stages of onboarding. Learn more about our registered communities through their [community profiles on the HPC website](#).

### Registered

- » Abilene, TX (2022)
- » Albany, NY (2021)
- » Baton Rouge, LA (2021)
- » Bloomington, IN (2021)
- » Boyton Beach, FL (2023)
- » Cadillac, MI (2022)
- » Chattanooga, TN (2023)
- » Easton, PA (2022)
- » Findlay, OH (2023)
- » Flint, MI (2021)
- » Fort Worth, TX (2023)
- » Hornsby, NSW, Australia (2021)
- » Indianapolis, IN (2022)
- » Kearney, NE (2021)
- » Lincoln, NE (2021)
- » Massachusetts State (2021)
- » Newport, RI (2023)

- » Nova Scotia, Canada (2022)
- » Shavertown, PA (2022)
- » Syracuse, NY (2021)
- » Tucson, AZ (2023)
- » Zanesville, OH (2022)



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



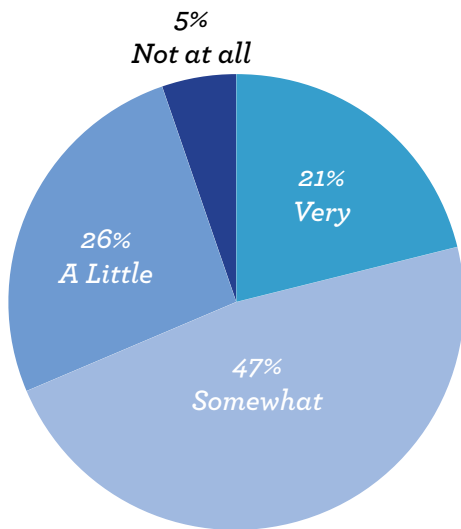
Policy  
Experts



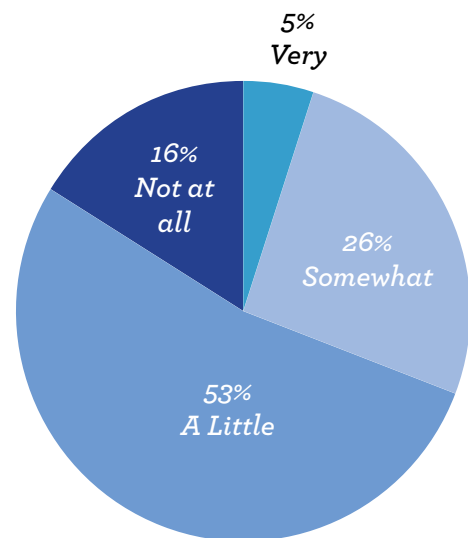
## Community-Led Change

Annually, we collect data from registered communities to assess several aspects of community awareness, engagement, and access. Below is a snapshot of the data from across our network communities, as well as some comparative data from the last two years demonstrating improvement for members of the network across several areas.

*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 wellbeing of people with Parkinson's?*



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

**Avg Score  
2022**

**Avg Score  
2023**

	Avg Score 2022	Avg Score 2023
<i>Participation/collaboration between community leaders</i>	4.4	4.6
<i>Programs and resources available for people living with Parkinson's</i>	4.1	5.8
<i>Awareness of programs and resources</i>	2.6	3.9
<i>Access to programs and resources</i>	3.2	4.9
<i>Awareness/health literacy about Parkinson's within general population</i>	2.5	2.8



## A Longterm, Multifaceted Approach to Support

**The Greater Capital Region (Albany, NY) was one of the first communities to adopt the HPC initiative.** Led in large part by Steve Hovey, a longtime Davis Phinney Foundation Ambassador, the initiative has since grown to have its own nonprofit organization with participation from a range of local leaders (including two newer Davis Phinney Foundation Ambassadors). In 2023, we partnered with this CAC to help them host their first in-person event aimed at increasing awareness of and engagement with local resources. Below is an interview with CAC leader Steve Hovey sharing their story to date.

### *What did your CAC set out to do when you originally formed?*

Our region is fortunate to have a first-class Movement Disorder Center at Albany Medical Center. We have excellent therapy practices, as well as exercise programs specifically for people with Parkinson's. What was lacking was someone who gathered all this information together and got it out to the Parkinson's community. Despite having more programs and resources available than most areas of the country, people were being diagnosed without any idea of what to do next. Our task was, and remains, to get the word out as to what is available to help people with Parkinson's live their best possible lives. We also look for areas of opportunity where we can improve or add programs.

### *What was the goal of the event we did together in 2023?*

The goal of the event was twofold. First, we wanted to educate the audience that living well with Parkinson's means more than going to the doctor and taking your medicine. It is a lifestyle choice that is multifaceted and should include exercise, community, and more. We also stressed the importance of support for care partners. The second goal was to promote the work of our non-profit, Help for Parkinson's.



### *What have you seen as a result of that event?*

The event was extremely well-received and we reached many new people. We are having the second "Living Well with Parkinson's" event on April 27, 2024 and anticipate registration to be full: 100 people.

### *What do you imagine for the future of your CAC and Healthy Parkinson's Community?*

Our goal is to continue to connect people with existing resources and ensure our local exercise classes including boxing, yoga, dance, and programs through our local YMCA, are funded and sustainable. We also plan to launch two new Pedaling for Parkinson's™ programs in locations that currently do not have them. Other priorities include financial support for local support groups and increasing access to resources by addressing transportation challenges.



## Impacting Leaders Affected by Parkinson's

In addition to the impact our Ambassadors and leaders have on their communities, these programs aim to have a positive impact on the leaders who participate in them. Below are data from our annual surveys conducted in December 2023 and January 2024.



### *My participation has...*

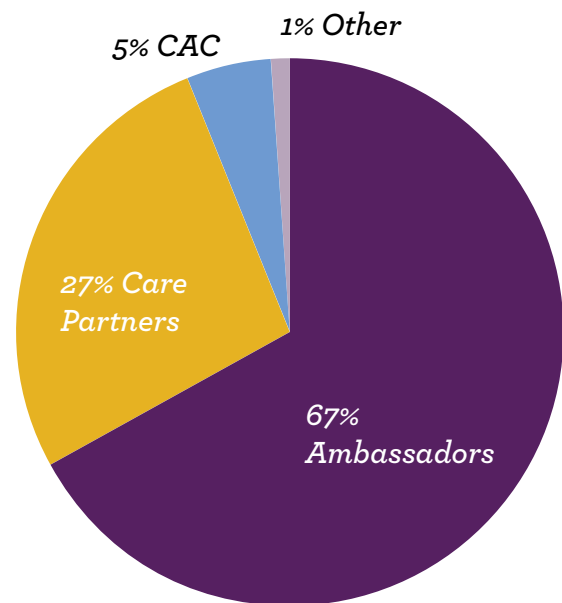
- » Increased my knowledge: 100% strongly agree or agree
- » Increased my capacity for working in the Parkinson's community: 92.4% strongly agree or agree
- » Increased my confidence in my ability to work in the Parkinson's community: 92.3% strongly agree or agree
- » Provided resources that allow me to better engage and support my Parkinson's community: 84.6% strongly agree or agree
- » Increased networking and relationship building skills: 86.7% strongly agree or agree
- » Helped me increase and/or sustain my engagement in activities that improve my own quality of life: 92.3% strongly agree or agree



## 2023 Leadership Conference Events

In 2023, we held two Leadership Conference events, training over 175 community leaders from across the US, Canada, Puerto Rico, and Mexican border cities on skills related to advocacy, community engagement, mentorship, and more.

### 2023 Healthy Parkinson's Communities™ Leadership Conference September 13-15, Minneapolis, MN



**97%**

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

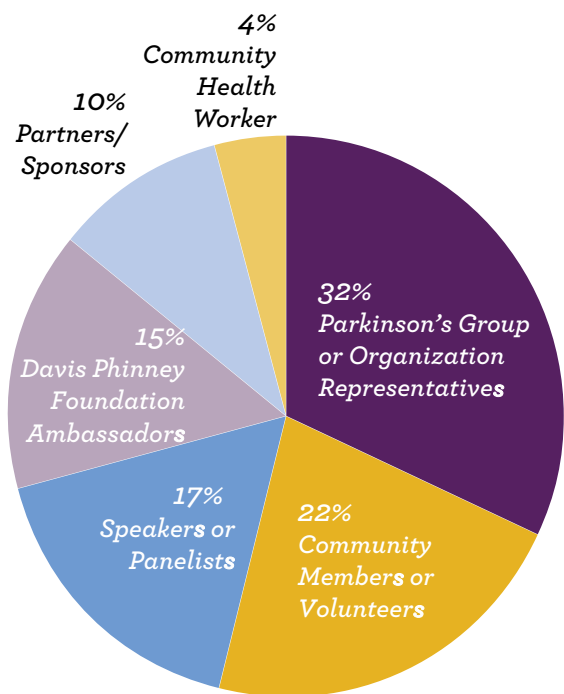
**88%**

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.

### 2023 Hispanic Leadership Conference November 30-December 2 Phoenix, AZ



**100%**

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

**94%**

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

**100%**

Agree or strongly agree the content gave them new ideas and/or skills they plan to integrate into their work in the Parkinson's community.





### Participant Testimonials:

*So grateful for this community and the support, education, and fun we all have together. Thank you for providing this space to meet new people, create new projects, and build on this momentum!*

*An unbelievable event. Being able to interact with people who have different relationships with Parkinson's was enriching. It was great to learn from the promoters and learn about their important role.*

*You really opened my eyes to the nuances of the Hispanic community!*

*Excellent conference, very complete, instructive, integrative, and inclusive.*

*Fantastic agenda. Tremendous. I have taken lots of pearls away.*

*It has been an excellent experience. I have met amazing and caring people. I feel at home. I feel grateful and blessed for being here.*

*It was great to learn about how others are helping the Foundation and how we can, too. Met amazing, dedicated people who motivate me even more to be the best leader I can be. Thank you so very much.*

*The staff did a great job of making me feel welcome as a newcomer. I appreciated being addressed by name and having my caregiver/daughter greeted as well. This may seem like a small detail but the "warmth" felt genuine. Even Davis got up and said goodbye to me which was huge! Great job to the DPF team for a successful conference.*



## **Pedaling for Parkinsons™: Now Powered by the Davis Phinney Foundation**

Founded by Dr. Jay Alberts, the Pedaling for Parkinson's program is based on research indicating that intentional exercise on a bicycle can reduce symptoms of Parkinson's. And since 2013, the program has taken hold in YMCAs, gyms, and other community spaces across the country.

In 2023, Dr. Alberts chose the Davis Phinney Foundation to become the steward of this innovative and effective program. With Davis's roots in cycling and the Foundation's history as an advocate for exercise, this was a natural next step to ensure the sustainability and broad availability of this program for people living with Parkinson's across the country (and, soon, globally).

*We spent much of 2023 preparing for a relaunch of the program which we announced in January of 2024. By the end of the year, we aim to have:*

**75**

Facilities up and running with weekly Pedaling for Parkinson's classes.

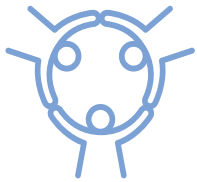
**100**

Instructors who have completed our Pedaling for Parkinson's certificate course.

**200**

Participants registered for PFP Online classes, available six days a week through the Davis Phinney Foundation.





## Hispanic Community Engagement

At the end of 2022, we launched the Foundation's first Hispanic Community Engagement program. This initiative is focused on collaboration, community leadership, and cultural sensitivity to ensure Hispanic people living with Parkinson's and their families have access to resources needed to live well with Parkinson's.

### HISPANIC ENGAGEMENT FOCUSES



#### Building Trust

The Davis Phinney Foundation is new to this community, and as such, we recognize the need to build trust through consistency, collaboration, and careful listening.



#### Storytelling

It is still the case that many individuals and families affected by Parkinson's in the Hispanic community are afraid to share their diagnosis for fear of facing stigma in their community. By sharing the stories of other members of the Hispanic Parkinson's community, we can help address this issue and get people talking, which is an important step in seeking the care and community needed to thrive with Parkinson's.



#### Creating and Sharing Culturally Empathetic Educational Resources

Engaging the Hispanic Parkinson's community is not simply about translating materials originally designed to educate other audiences. Instead, it is about creating tailored engagements and content to showcase members of the Hispanic community and delivering information using the right platforms, language, and approach to reach the intended audience.



#### Investing in Community Leaders and Mentors

It is crucial to identify and support community leaders who have the desire to act as peer mentors and health navigators for individuals and families. These members of the community are uniquely positioned to have a positive effect on the people they speak to, share resources with, and support. By fostering these trusted interactions, we can connect individuals and families with care, resources, and education to help them live well.



**2023 Acheivements at a Glance:**

- » Onboarded 22 Hispanic Ambassadors
- » Launched a [Spanish-language website](#) to showcase content and resources specific to the Hispanic community
- » Launched a monthly Hispanic Newsletter which currently has 425 subscribers
- » Created the Espacio Parkinson [video and webinar series](#), engaging hundreds of individuals and families with online content geared toward increasing Parkinson's knowledge
- » Published [15 stories of Hispanic individuals living with Parkinson's](#)
- » Hosted our first Hispanic Leadership Conference for more than 100 community leaders to learn best practices for Hispanic community engagement
- » Brought on additional, cross-departmental staff to support Hispanic Engagement and ensure marketing and content created for this community is culturally relevant and empathetic
- » Collaborated with national partners to support the Muhammed Ali Parkinson's Center's annual Hispanic educational event
- » Began collaborating with the team behind PD Movers to develop a similar resource for the Hispanic Community



**GILBERTO ADAME**  
Glendale, Arizona



**ADRIANA MARÍA AMAYA POSADA**  
Medellín, Colombia



**VERÓNICA M ARÉVALO**  
Bakersfield, California



**SABELA AVIÓN MARTÍNEZ**  
Long Island City, New York



**ROSA HERNÁNDEZ**  
San Cristóbal de las Casas, México



**PABLO LIME**  
Peñalolén, Chile



**TEOLINDA NORIEGA MORENO**  
Caracas, Venezuela



**LAURA OLMOS**  
Nuevo Laredo, Mexico



**ALEJANDRA BORUNDA**  
El Mirage, Arizona



**CLAUDIA DANKER**  
Beaverton, Oregon



**IXANDER DAVID ECHEVERRÍA RIAÑO**  
Oaxaca de Juárez, México



**ROBERTO ESCOBEDO GRAHAM**  
Ojo de Agua, México



**ELIZABETH PEÑATE**  
San Salvador, El Salvador



**JAIME ALBERTO PUERTA CANO**  
Medellín, Colombia



**FERNANDO RAMOS BARRAZA**  
Mesa, Arizona



**JAIME ROBLEDO**  
Cali, Colombia



**JORDI SANTANDREU**  
Barcelona, España



**MARTHA SUÁREZ**  
Caracas, Venezuela



**MAYRA TORRES**  
Phoenix, Arizona



**NORA VIGIL**  
Richmond, California



**ALISON NICOL WALSH**  
Tacoma, Washington



**LUCÍA WANG**  
Buenos Aires, Argentina



## Healthy Parkinson's Communities™ | Community Grants Program Update

Since starting our Community Grants program in 2021, we have awarded over \$470,000 in funding to support local initiatives and leadership development. Read on to learn more about two long-term projects that will complete their third and final year of funding in 2024.

### Renewed Grantees



#### [Delaware Valley Endeavor for Racial SolidarITY in PD \(DIVERSITY PD\)](#)

We renewed funding for the DIVERSITY PD initiative after initially funding their work in 2021. In the two+ years that we have provided funding for this group, we have seen them steadily move the needle to reach the African American community in their area and provide education, broaden awareness, and increase access to care. They have done this through consistent partnership across their local hospital systems, Parkinson's organization, and faith community. They have hosted multiple educational events, created new means of collaboration and referrals between hospital systems, and more.

In 2022, they also launched an internship program to create a pipeline for diverse professionals interested in working with people with Parkinson's in health and/or human services. Over the course of their internship, the individuals participating in this program shadow and learn about all the professions and individuals who are making the DIVERSITY PD outreach a success.

Additional highlights:

- » DIVERSITY PD's collaboration with the team at Penn has supported many new people in finding the Parkinson's care they are seeking.
- » Their efforts to reach under-served communities were recently featured in [US News and World Report](#).
- » They are utilizing the PD Movers book to spread awareness and start the conversation about Parkinson's in the African American community (more about this resource on page 4).



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

We first funded the team at Chase Family Movement Disorders Center (CFMDC)--part of the Ayer Neuroscience Institute of Hartford HealthCare (HHC)--in 2021 to support their efforts to increase patient engagement at their Spanish Parkinson's clinic. Through steady efforts to collect data, trial interventions, and create new engagement opportunities, the team behind this grant has increased the utilization of this important local health resource.

At the close of their community grant award period, they provided an update on their initiative. Key takeaways were:

- » The Chase Movement Disorders Center has been recognized by the Parkinson's Foundation as a Comprehensive Care Center.
- » They are continuing to do committed outreach to let people know the clinic exists and brainstorming creative ways to generate new patient referrals from both inside and outside the Hartford Healthcare system.
- » From October 2020 to April 2023, they saw a total of 227 patients, 47 of whom were new, and conducted 179 follow-up appointments.
- » The number of people showing up to scheduled appointments--opposed to canceling or not showing up--has noticeably increased since the start of 2023.
- » They were slightly delayed in their data collection efforts, largely due to staffing issues, but have started to get survey distribution underway and are confident they will continue to increase the number of patients in their clinic--especially once the clinic is transferred to a different part of the hospital in closer proximity to other neurology practices.



## Healthy Parkinson's Communities™ 2024 Engagements

Since 2008, The Victory Summit® event series has brought together more than 25,000 people with Parkinson's, care partners, family members, and wellness professionals for a day of information, inspiration, and community connection.

*In 2024, we are reintroducing this series in a new and expanded way to address community need like never before with two distinct event offerings.*

The Victory Summit event brings together expert speakers from around the world to speak on highly relevant and sometimes underrepresented topics addressing all aspects of living with Parkinson's, including non-motor symptoms, exercise, emotional and mental health, and much more. This full day of education and inspiration engages attendees to build on existing knowledge and resources from their community.

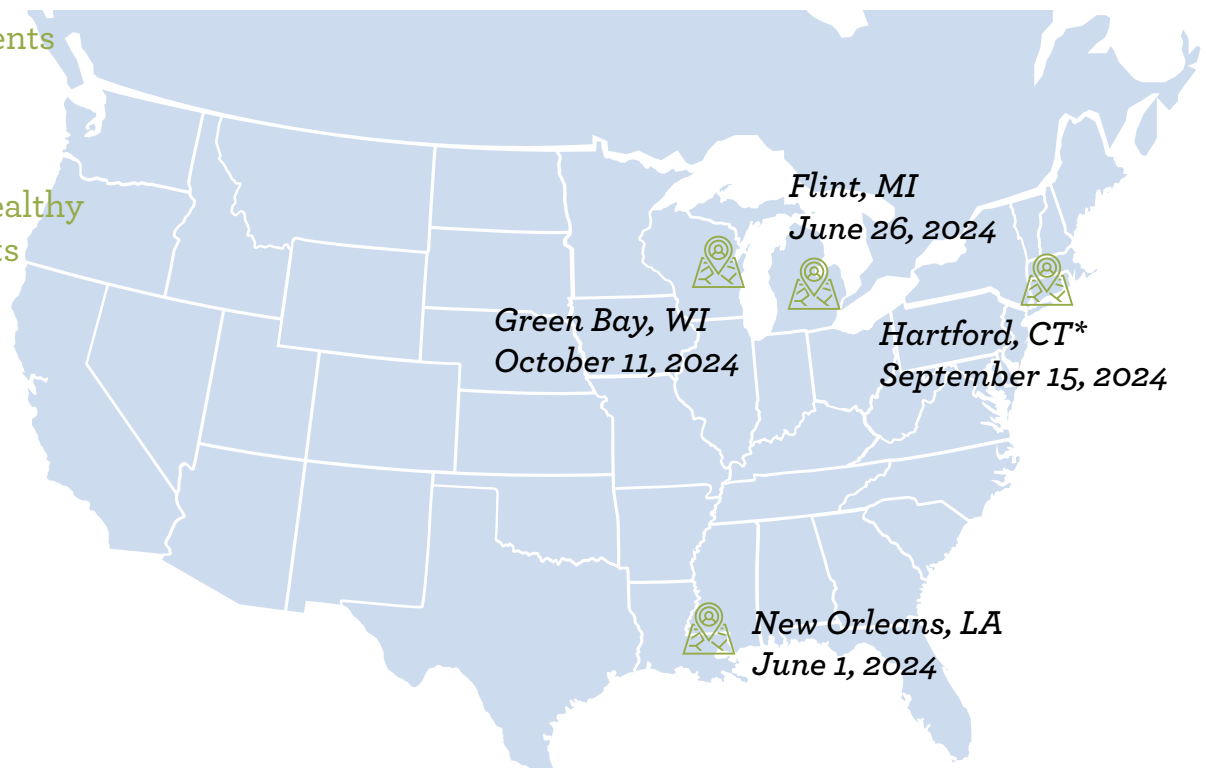
The Victory Summit Healthy Brains / Healthy Communities event focuses on improving awareness and health literacy about Parkinson's in under-engaged communities. With a focus on highlighting local speakers, wellness professionals, and resources, these events aim to expand services to the communities who need it most.

### Victory Summit Events

- » New Orleans, LA
- » Green Bay, WI

### Healthy Brains / Healthy Communities Events

- » Flint, MI
- » Hartford, CT\*



*\*Indicates Hispanic Community Engagement-focused event*