



**DAVIS PHINNEY**  
Foundation For Parkinson's  
*every victory counts®*

**ANNUAL REPORT**

**2021**

## A NOTE FROM THE EXECUTIVE DIRECTOR



*How do we grow our reach, build capacity, and become the go-to resource for all people affected by Parkinson's?*

*We double down on the mission we have held since day one: to help people live well with Parkinson's today.*

*Eighteen years ago, our founders, Davis Phinney and Connie Carpenter Phinney, imagined a better world for people with Parkinson's. A world where the cure was not the only hope. Where information and resources were not reserved for the very few. And where anyone who heard the words, "you have Parkinson's" had a place to go to get the education and resources they needed to feel better.*

*As I write this letter today, I am proud to say that the Foundation has delivered on that promise. I can also promise you and everyone affected by Parkinson's that we are just getting started.*

*In 2021, we took what we learned from many years of events, conversations, fundraising, and working with people affected by Parkinson's, and we created a new strategic plan to guide us into the next decade. This plan includes giving every community that raises its hand a set of tools and resources for living well through our Healthy Parkinson's Communities™ initiative; a robust educational program that is personalized and accessible to all; an Ambassador network that ensures that nobody feels alone in their Parkinson's journey; and development and fundraising events that fuel our work, create connections, and inspire action.*

*To achieve this type of growth, we will invest in technology, infrastructure, expertise, and innovative programmatic initiatives at every turn. These actions are how we will achieve significant and much-needed change—addressing health disparities, breaking down barriers to access, and changing the world for people with Parkinson's. To succeed in this effort will require diversifying our partners, earning the trust and investment of new funders, and laser-focusing our efforts to measure and demonstrate that what we are doing is making a difference.*

*Thank you for being part of this and for your continued support.*

A handwritten signature in black ink, appearing to read "P.D.". The signature is stylized and fluid.

Polly Dawkins  
Executive Director

# THE FUTURE OF THE DAVIS PHINNEY FOUNDATION

For more than 17 years, we have served the Parkinson's community as one of the only national organizations wholly dedicated to living well. As we look to the future, we are called not simply to continue this commitment to the well-being of people affected by Parkinson's but to expand – creating access, providing personalized experiences, and meeting people with Parkinson's, their families, and their communities where they are.

As we grow our reach and impact, we intend to do so in a way aligned with our values, maintaining our high touch and deep connection to the Parkinson's community. This requires us to invest in technology, infrastructure, expertise, and innovative programmatic ideas to succeed. Finally, and perhaps most importantly, it requires us to invest in our greatest resource: our people.

The center of our work always has been and continues to be people. People drive everything we do, from our staff and leadership to our volunteers, fundraisers, and community leaders. We have seen first-hand what we can achieve together when we invest in building the capacity of our team.

Beyond strategy, this is our means to achieve significant and much-needed change—addressing health disparities, breaking down barriers to access, and changing the world for people with Parkinson's. To succeed in this effort will require diversifying our partners, earning the trust and investment of new funders, and laser-focusing our efforts to measure and demonstrate that what we are doing is making a difference.



**making a difference  
BEYOND STRATEGY**

## OUR STRATEGIC PRIORITIES



### Deliver a Personalized Experience

We'll advance the capabilities that will enable us to deliver a personalized Parkinson's experience to serve individuals' unique needs better.



### Diversify Funding and Engage Donors

We'll enhance the Foundation's funding strategy to build capacity, meaningfully engaging with our donor community to support our research, education, and grantmaking efforts.



### Broaden Our Reach and Promote Health Equity

We'll accelerate the expansion of our programming to engage people throughout their life and across communities, focused on achieving health equity and well-being for all people affected by Parkinson's.



### Build Capacity and Improve Outcomes

We'll develop the systems, teams, and technologies to fulfill our mission and continue improving outcomes for the people and communities we serve.



### Measure Our Impact

We'll advance our work by measuring and publishing impact metrics demonstrating how our programs affect well-being and quality of life.

**BUILDING**

# HEALTHY PARKINSON'S COMMUNITIES™



Over the last two years, the concept of “community” has evolved so much. For many of us, digital tools have allowed us to learn from and connect with people beyond geographic boundaries. And yet *where* you live still has a profound impact on *how* you live. For these reasons, we created the Healthy Parkinson’s Communities initiative.

Since launching this initiative in January 2021, we have engaged with more than 30 communities across the US, Canada, and beyond. We’ve heard from community leaders that they want to create lasting change, and we raised our hand to do so. Now, the staff support, tools, and resources provided by the Davis Phinney Foundation through the initiative are actively providing the support necessary to make that happen.

In 2022, we’ll expand our support, implementing a new online hub to connect community leaders, harnessing the power of the collective to increase capacity and solve complex problems. And we’ll host the first Healthy Parkinson’s Communities Leadership Conference in Kansas City to convene advocates and leaders from across the country for two days of inspiration, relationship building, and knowledge sharing.



# IMPACT

## HEALTHY PARKINSON'S COMMUNITIES



*"I joined this group to be a voice in my community because Parkinson's has stolen the voice of so many people I care about. I hope that by being a part of this impactful team, I can give the Parkinson's community here a loud voice to speak up and speak out."*

*- Anne Johnson, Community Action  
Committee Leader,  
Kearney, NE*



*"Central New York joined the Davis Phinney Foundation Healthy Parkinson's Communities initiative because we wanted to work with other communities to share information that will help to improve the lives of people living with Parkinson's. We believe that this opportunity can help us to ensure that our community is providing the most accessible services for everyone, and everyone is aware and supportive of people living with Parkinson's."*

*- Mary Anne Corasaniti, Community Action  
Committee Leader, Syracuse, NY*



*Our community programs received generous support from the  
Dellora A. and Lester J. Norris Foundation*



### HEALTHY PARKINSON'S COMMUNITIES GRANT RECIPIENTS:

Durango, CO  
Hartford, CT  
Philadelphia, PA  
Northern California  
Nebraska



### AMBASSADORS:

In 2021, we expanded our Ambassador cohort and currently have 72 Ambassadors representing 35 states and regions in Canada.



### HEALTHY PARKINSON'S COMMUNITIES NETWORK:

*\*Indicates community is part of a statewide network initiative*

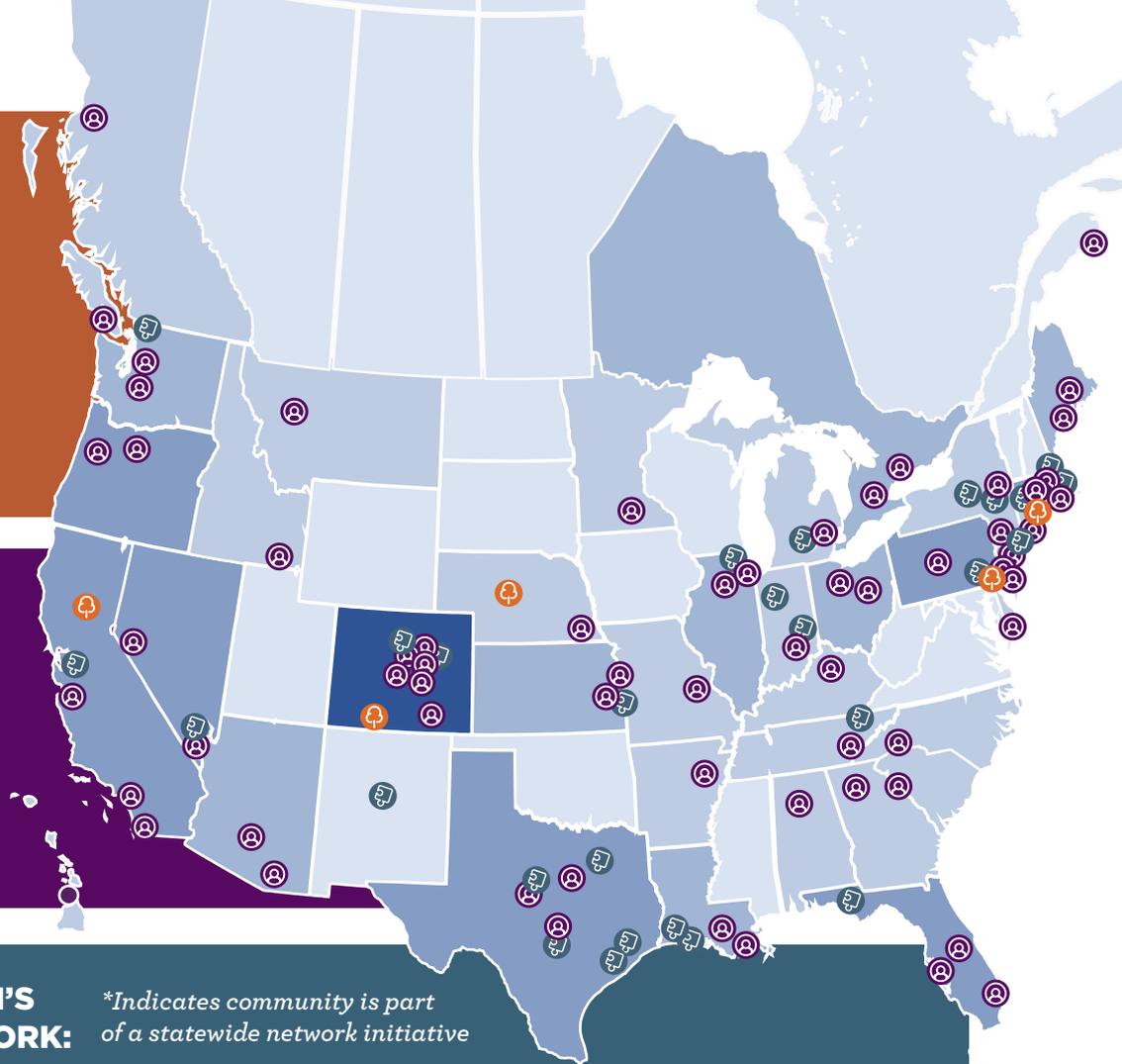
#### Registered:

Bloomington, IN  
Baton Rouge, LA  
Massachusetts State\*  
Flint, MI  
Albany, NY  
Syracuse, NY  
Lincoln, NE\*  
Kearney, NE\*  
Nova Scotia, Canada  
Hornsby, NSW, Australia

#### Getting Started:

Sacramento, CA  
Boulder, CO  
Denver, CO  
Panama City Beach, FL  
Chicago, IL  
West Lafayette, IN  
Olathe, KS  
New Orleans, LA  
Longmeadow, MA\*  
Dracut, MA\*  
Nebraska State\*

Beatrice, NE\*  
Norfolk, NE\*  
Columbus, NE\*  
Belen, NM  
New York, NY  
Las Vegas, NV  
Doylestown, PA  
Abilene, TX  
Crosby, TX  
Cedar Park, TX  
Dallas, TX  
Houston, TX  
Bellingham, WA



**SUPPORTING**

**COMMUNITY INNOVATION.**

**ADDRESSING**

**AWARENESS & ACCESS.**

In 2021, we also formally launched our Healthy Parkinson's Communities Grant Program and funded initiatives across the US to address health disparities, awareness, and health literacy while embracing a holistic and collaborative approach to living well. Each of the projects we funded is community-driven and takes creative and place-specific approaches to change how people live with Parkinson's.



**EXAMPLES OF OUR FUNDED PROJECTS:**



**DELAWARE VALLEY ENDEAVOR FOR RACIAL SOLIDARITY IN PD (DIVERSITY PD)**  
*Philadelphia, PA*

Led by The Parkinson Council, this project has brought together a cross-sector team including movement disorder specialists, religious leaders, and community health workers to build relationships and provide education and access to quality care for underrepresented communities.



**EMPOWERING PARKINSON'S COMMUNITIES**  
*Nebraska (statewide)*

Led by Parkinson's Nebraska, this project aims to use public television to provide Parkinson's education and improve health literacy and awareness, particularly within rural communities in Nebraska.

The Foundation's role in this work goes well beyond funding, however. In 2021, we collaborated with national and local leaders to research and design place-specific interventions to address awareness and access within three diverse communities. In partnership with leaders from Dance for PD®, LSVT® Global, PMD Alliance, Pedaling for Parkinson's™, Rock Steady Boxing, and others, we worked with grassroots leaders in Baton Rouge, LA, Albany, NY, and Kearney, NE, to assess each community and create a strategic approach to address Parkinson's awareness and access. We will implement these plans in 2022 with funding from the Foundation, resulting in toolkits and case studies to help other communities lead this work in their own areas.

## OUR COMMITMENT TO

# HEALTH EQUITY

In 2020, we made public our commitment to addressing inclusion, diversity, equity, and access (IDEA), launching our Health Disparities and Parkinson's webinar series, implementing an IDEA advisory board, and expediting the launch of our Healthy Parkinson's Communities initiative.

This year, we met regularly with our IDEA advisory board, which challenged our internal processes, strategy, and programs, helping to illuminate the work ahead in ways like never before. With their guidance and commitment from our leadership team and board, we implemented new practices to assess vendors and investments, engaged with experts in digital accessibility, and made changes to our hiring processes. We also continued to produce our health disparities webinars and engaged community members and contributors from underrepresented communities in our education and outreach work.

In 2022, we plan to expand staff and board engagement in IDEA work, bring on consultant support to provide training and conduct an audit of our internal systems, and implement a multi-year plan for changing how we work from the inside out.



# EDUCATION TODAY

REVITALIZATION

REVISION

CREATION

Last year was a year of creation, revision, and revitalization for the Foundation's education department. We released a wholly reorganized, restructured, and updated edition of the Every Victory Counts® manual. With it, we launched the new Every Victory Counts suite of resources, including the Every Victory Counts Manual for Care Partners, an online hub, new discussion guides, a best-in-class searchable medication guide, and much more. We also launched the immediately successful online program called "Charting Your Course: A Parkinson's Primer for the Newly Diagnosed," which reached almost 800 people and is filling a need previously unmet in the Parkinson's education space.

We produced five events in The Victory Summit® Virtual Event series that were engaging, educational, and well attended by people worldwide (including one attendee who joined us live while on a flight from Mumbai to the States!). In those events and throughout our webinar series, blog, podcast, and memorable video series (like the week-long "Camping with Parkinson's" collection and the three-event "Holiday Concert Series"), we passed the mic to dozens of people living with Parkinson's, giving them the stage to share their stories, advice, and living well strategies.

We look forward to engaging more with our community, reaching new communities, tailoring our content, designing impactful new programs, and continuing to amplify the voices of people with Parkinson's everywhere in the coming year.

## looking back

### 2021 EVENT HIGHLIGHTS

-  NEWLY DIAGNOSED
-  HEALTH DISPARITIES AND PARKINSON'S SERIES
-  MENTAL HEALTH & WELLNESS
-  CONSTIPATION AND THE GUT
-  CARE PARTNER MEETUP

## what's next

### 2022 EVENT HIGHLIGHTS

-  AUTONOMIC SYMPTOMS IN PARKINSON'S
-  MEDICAL MYTHS
-  SLEEP AND PARKINSON'S
-  MONTHLY JOY WORKSHOPS
-  YOPD COUNCIL SERIES

 - The Victory Summit® Virtual Events

 - Webinars

# EVERY VICTORY COUNTS®



## CHARTING YOUR COURSE:

### A PARKINSON'S PRIMER FOR THE NEWLY DIAGNOSED

First published in 2010, the Every Victory Counts® manual broke new ground as the only resource of its kind, devoted solely to the principle of proactive self-care and a holistic approach to managing Parkinson's. In subsequent editions, it has gained international recognition as a comprehensive resource for changing the way people live with Parkinson's. Now in its sixth edition, the manual is part of our new Every Victory Counts suite of resources, which includes a manual designed just for Parkinson's care partners, worksheets and assessments, discussion guides, and a companion website.

#### EVERY VICTORY COUNTS® MANUAL\*

- 8,167 print copies ordered of the main manual
- 5,809 digital downloads of the main manual
- 1,656 unique visitors to the companion website
- 1,370 digital downloads of the manual worksheets



#### CARE PARTNER MANUAL\*

- 3,160 print copies ordered of the care partner manual
- 670 digital downloads of the care partner manual

*\*Data based on 2021 orders only*

Launched in 2021 in response to feedback from our community, Charting Your Course: A Parkinson's Primer for the Newly Diagnosed is a program that helps shorten the distance between three life-changing words—"You have Parkinson's"—and living well. The four-week course guides participants to reframe how they look at their diagnosis, understand the importance of movement in managing symptoms, and explore the treatment options currently available to help maintain their quality of life.

"I find the material rich and worth revisiting – especially regarding mindset – and sincerely appreciate the sensitive and caring way you present it. You know what you're doing, which is not often easy to find, especially these days!"

#### COURSE IMPACT

- 2,037 course website visitors
- 777 course participants

#### TOP VIDEOS





**TEAM DPF**  
every victory counts®

**IN 2021...**



**3,942**

**TOTAL FUNDRAISERS**



**\$1,088,130**

**TOTAL RAISED**

Every year, thousands of people worldwide join Team DPF and take on the fun and fulfilling challenge of fundraising to help us achieve our mission. This community of fundraisers and advocates currently contributes over 30% of the Foundation's total revenue each year. With great and small efforts, we make a more significant difference together than we ever could alone. Because of dedicated fundraisers and supporters, Team DPF raised over **one million dollars** for the Foundation in 2021!



*"I support the Foundation to help 'pay it forward' in recognition of the extensive information, exercises, and strategies they have provided to me over the years so I can live well with Parkinson's now."*

*- Jim Cunning*



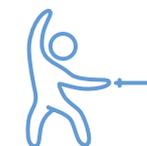
*"I am confident that my Team DPF story is the beginning of a new chapter for me where I will be able to contribute more to the Parkinson's community. Please thank everyone at the Foundation for me."*

*- Helen Power*



*"I wasn't sure what to expect when I joined the Tri to Victory event, but I found it rewarding to be making these connections with the other Tri to Victory teammates. It was a turning point for me. You're not alone!"*

*- Diane Kephart*



## THE IMPACT OF

# QUALITY OF LIFE RESEARCH

Since 2006, we have been committed to funding clinical research focused on developing, validating, and increasing access to treatments and therapies that improve the quality of life for people living with Parkinson's. This research has led to profound and impactful discoveries in exercise, deep brain stimulation (DBS), telehealth, and more.

In 2021, we selected a project that explores the critical cross-section of our interests in exercise and DBS. The project will help us gain knowledge in this area and engage a population of people living with more advanced Parkinson's who are often left out of Parkinson's research.

With your support throughout 2022 and beyond, we look forward to continuing our investment in clinical research focused on exercise therapies and interventions.

## FUNDED PROJECTS:



### EXERCISE IN ADVANCED PARKINSON'S DISEASE WITH DEEP BRAIN STIMULATION

"I hope this study will provide the confidence, support, and data to help people who are in the later stages of Parkinson's or who aren't regular exercisers take ownership of their bodies and their movement."

- Sana Aslam, DO, *Barrow Neurological Institute*



### COMMUNITY-BASED CYCLING CLASS FOR SLOWING DISEASE PROGRESSION

"The Davis Phinney Foundation is nationally and internationally known for their work in Parkinson's. Their mission to help people with Parkinson's live well today echoes the mission of our study to examine the impact of community-based cycling on symptom management."

- Anson Rosenfeld, PT, DPT, NCS, MBA, *Cleveland Clinic*



### "SMART" CYCLING COMPUTERIZED CONTROLLER

"We know there's a lot of individual variability in the primary symptoms and how people with Parkinson's adapt to the exercise. Through the funding received from the Davis Phinney Foundation, we're able to develop individual, adaptive exercise interventions that improve function over time and reduce the progression of symptoms."

- Angela Ridgel, PhD, ACSM-EP, FACSM, *Kent State University*



### REMOVING BARRIERS TO DEEP BRAIN STIMULATION SURGERY FOR WOMEN WITH PARKINSON'S

"We're consistently seeing that women are less likely to receive Deep Brain Stimulation than men. Through this study, we're developing a decision support tool to help women make informed, value-based decisions when considering surgery."

- Michelle Fullard, MD, MSCE, *University of Colorado, Department of Neurology*

Thank you to the Donald and Janet Doles Giving Fund for their generous support of our Quality-of-Life Research Fund in 2021.

# BY THE NUMBERS



We're expanding our content offerings to help people with Parkinson's take an integrated approach to care. We aim to address Parkinson's through the facets of lifestyle, diet, exercise, stress management, relationships, personal and spiritual care, and so much more so that people with Parkinson's can improve their quality of life and live well every day. Here's a look at Foundation engagement throughout 2021.



## TOP RESOURCES

- *Every Victory Counts® Manual*
- *Charting Your Course*
- *Newly Diagnosed Resources*
- *Living well with Parkinson's videos*
- *Care Partner Resources*
- *Online blog content*

# OUR REACH

## TOTAL IMPACTS

# 735,874

Our community had an insatiable appetite for the resources we provide. Thank you to our community for taking the time to read, watch, and download the information and resources we created to help people with Parkinson's live well today.



### WEBINARS

- 26,488 webinar registrants
- 43 webinars hosted
- 5 special live events hosted

## TOTAL REACH

# 1,160,950

Through fundraisers, community gatherings, research and grant opportunities, blog posts, webinars, social posts, support group meetups, and sponsorships, we reached more people than we ever have before.



### THE VICTORY SUMMIT® EVENT SERIES

- 5,266 event registrants
- 2,236 participants joined live
- 15,477 video views of event recordings



# 2021 TOP BLOGS

**257**

**BLOGS PUBLISHED**

**590,000+**

**BLOG USERS**

**TOP 10**

- 1** *What's New in Parkinson's: February 2021*
- 2** *How Sunlight Can Help You Live Well with Parkinson's*
- 3** *I Have Parkinson's. Should I Get a COVID Vaccine?*
- 4** *6 Things to Know About Parkinson's and Vision*
- 5** *Keep on Moving with a New Online Parkinson's Exercise Program*
- 6** *A Primer on Balance and Parkinson's*
- 7** *5 Simple Exercises to Train Your Balance and Live Well with Parkinson's*
- 8** *You Don't Have to Have OFF Times with Parkinson's*
- 9** *How to Exercise to Get Results from Parkinson's Exercise Programs*
- 10** *Live Well with Parkinson's in 2021 with the Help of Our Living Well Calendar*



# THE PARKINSON'S PODCAST™

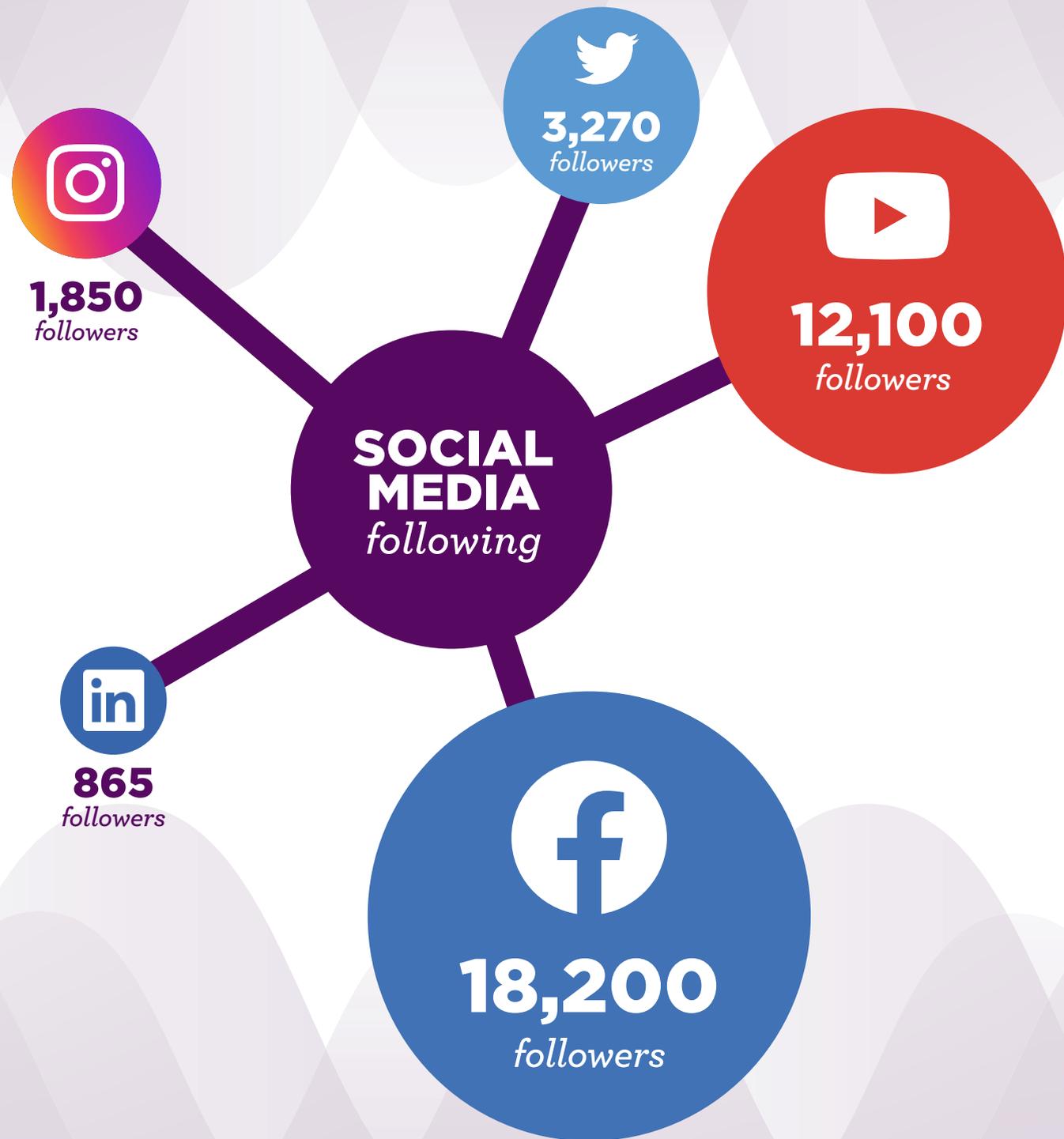
**67,932**

**TOTAL DOWNLOADS**

The Parkinson's Podcast covers topics ranging from Parkinson's basics to how to talk to kids and families about Parkinson's, palliative care, exercise, mindfulness, medications, and much more.

**TOP 10**

- |   |  |
|---|--|
| <b>1</b> <i>A Story of Hope and Inspiration</i>                   | <b>7</b> <i>Dementia and Later-Onset Parkinson's</i>                           |
| <b>2</b> <i>Managing Mood and Anxiety</i>                         | <b>8</b> <i>YOPD Council: Q&amp;A in July</i>                                  |
| <b>3</b> <i>Constipation and the Gut</i>                          | <b>9</b> <i>Cultural Context and Parkinson's</i>                               |
| <b>4</b> <i>OFF in Parkinson's</i>                                | <b>10</b> <i>YOPD Council: Regaining Confidence in Young Onset Parkinson's</i> |
| <b>5</b> <i>A Conversation with Brian Grant and Davis Phinney</i> |  |
| <b>6</b> <i>YOPD Council: Nutrition</i>                           |  |



Helping people with Parkinson's live well *today*

Davis Phinney Foundation



Davis Phinney Foundation for Parkinson's  
13.1K subscribers

SUBSCRIBE

Home Videos Playlists Community Channels About

## YOUTUBE CHANNEL

**11,947**

SUBSCRIBERS

**379,762**

VIDEO VIEWS

**8.32**

MINUTES OF AVERAGE WATCH TIME

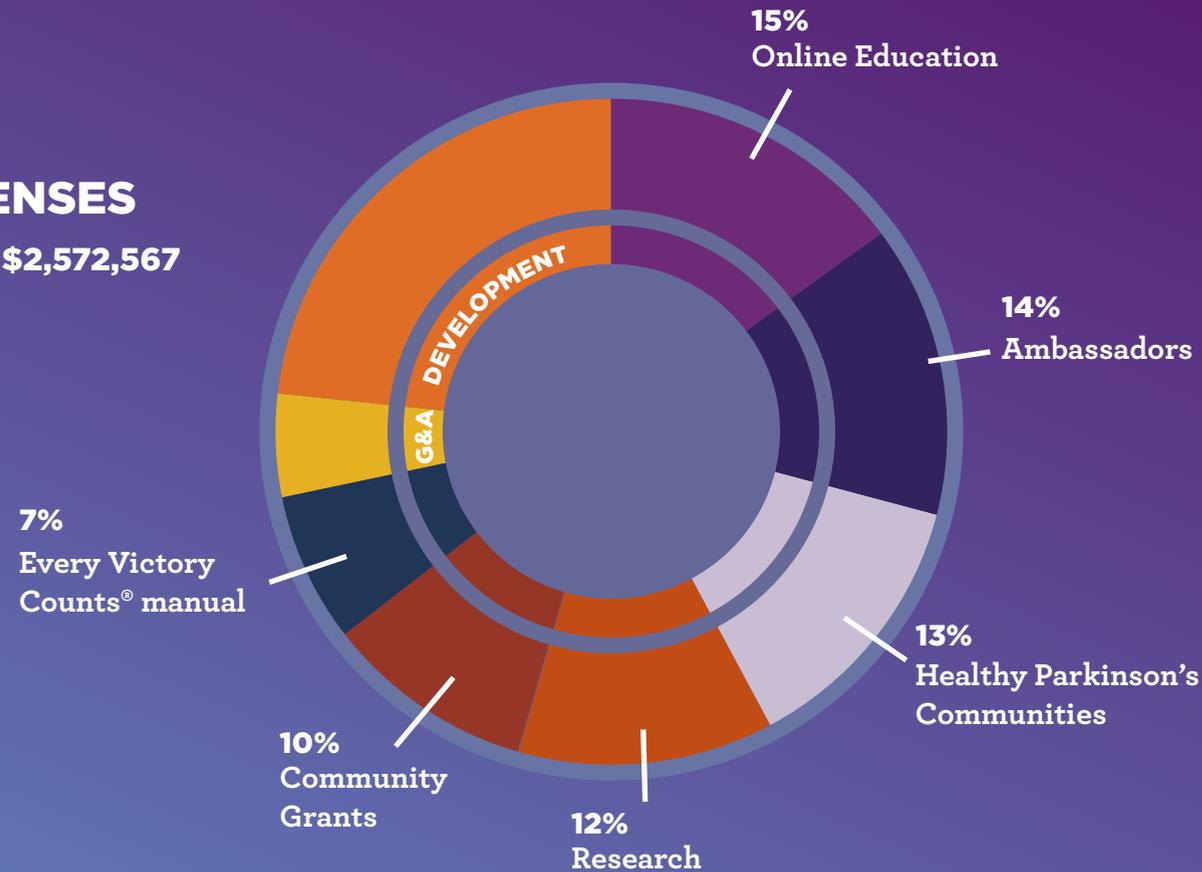
## TOP 10

- OFF Times and Parkinson's*
- How to Exercise to Get Results from Parkinson's Exercise Programs*
- Managing Mood and Anxiety in Parkinson's*
- Speech, Voice, and Parkinson's*
- Living Well with Parkinson's with Allan Cole*
- Everyday Habits to Live Well with Davis Phinney*
- Medications for Non-motor Symptoms in Parkinson's*
- A Conversation with Brian Grant and Davis Phinney*
- How Sleep Changes Over Time with Davis Phinney*
- Deep Brain Stimulation: The Latest Advancements*

# 2021 OUR FINANCIALS

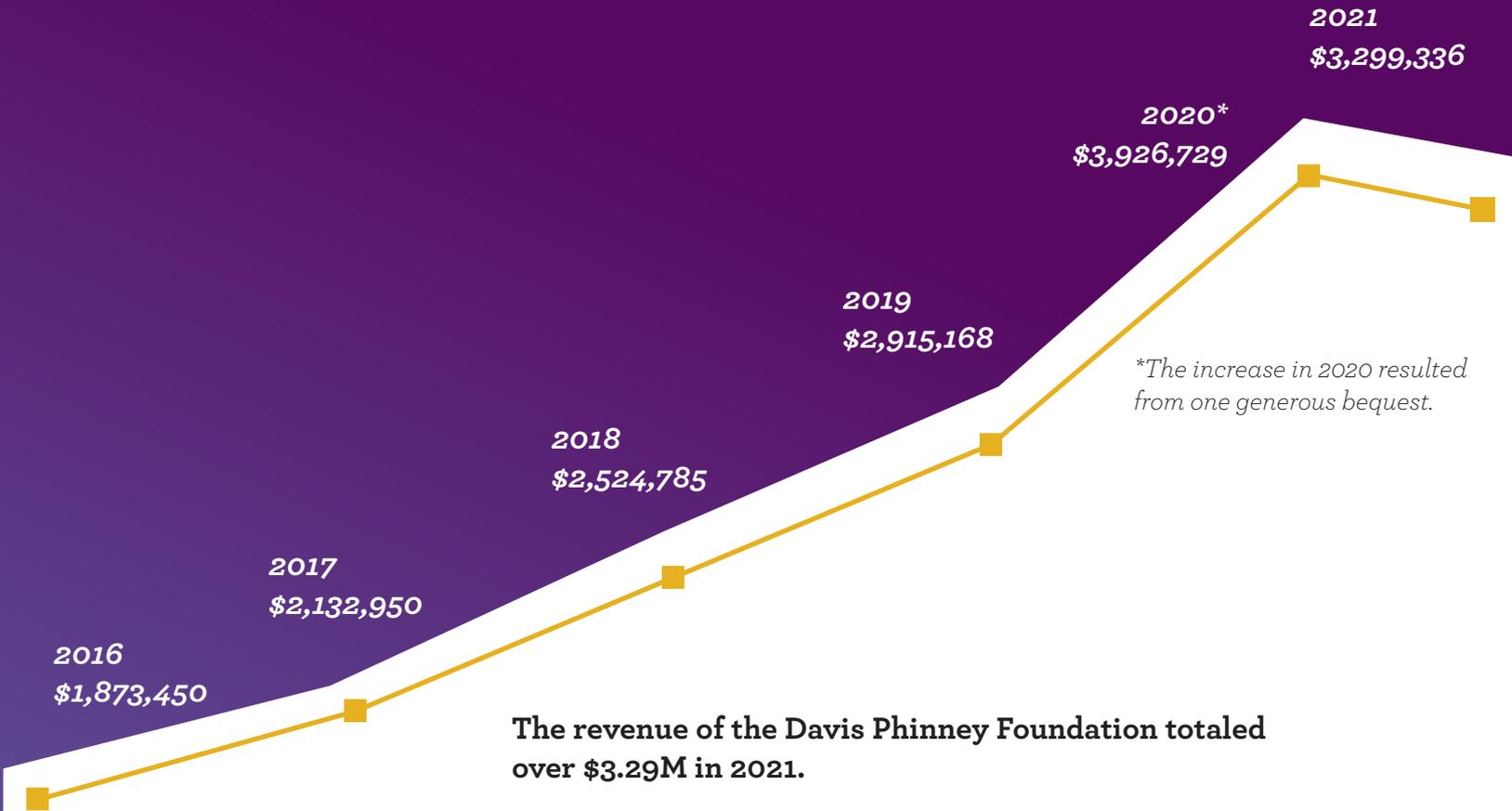
## 2021 EXPENSES

\$2,572,567



## 2021 REVENUE

\$3,299,336



\*The increase in 2020 resulted from one generous bequest.

The revenue of the Davis Phinney Foundation totaled over \$3.29M in 2021.

Our growth in 2021 came primarily from the generous support of individual donations and grassroots fundraising efforts conducted on behalf of the Foundation, which was bolstered by the return of in-person events. Our corporate partners remained committed to supporting our work to help more people with Parkinson's live well. The outpouring of support we've received through donations, fundraising, and planned-giving initiatives has allowed us to continue investing in quality-of-life research, launch our community grants program, and build Healthy Parkinson's Communities in support of those we serve.

## SPECIAL THANKS TO:

Abbott Laboratories  
AbbVie  
AbbVie Grants  
ACADIA Pharmaceuticals  
Acorda Therapeutics  
Adamas Pharmaceuticals  
Amneal Pharmaceuticals  
Anthony Family Foundation  
Bob and Janie Mullet Family  
Endowment Foundation  
BOCO Gear  
Boston Scientific  
Carpenter Family Fund  
Christ the King Lutheran  
Church, Kenner, Louisiana  
Consolo Family Fund  
Cornell Family Foundation  
Dellora A. and Lester J. Norris  
Foundation  
Deutsche Bank Matching Gift  
Eddy Rando/Creekside Bikes  
Flagstaff House Restaurant  
Flexential  
Gartner Matching Gift Program

Greenwood-Leflore County  
Chamber of Commerce  
Humanity United Matching Gift  
Illinois Tools Works Matching  
Gift Program  
Johnson & Johnson Matching  
Gifts Program  
Kurath Giving Fund  
Kyowa Kirin North America  
Lewis Snitman Family  
Charitable Fund  
Lundbeck  
Malcolm Stack Foundation  
Medtronic  
Milender White Construction  
Morgan Family Foundation  
Neugeboren O'Dowd PC  
Neurocrine Biosciences, Inc. nQ  
Medical  
Opelika Bicycle Advisory  
Outside Events  
Parkinson Canada  
Paycom  
Peak to Peak Retreats  
Pierce Family Fund

Primal Wear  
Raytheon Technologies  
Matching Gift  
Rick Baker Insurance  
Robert and Karen Browne  
Family Fund  
Rosen Family Fund  
S&P Global Matching Gift  
Sunovion Pharmaceuticals  
Supernus  
Team Evergreen Bicycle Club  
Tebo Properties  
The D.J. Kahlo Fund  
The Driscoll Foundation  
The Omidyar Group  
The Paul Hines Marathon  
The Sunshine Foundation  
Theravance Biopharma  
Two Octobers  
UCB  
Wahoo Fitness  
Wells Fargo  
Wild Bill's Warriors Foundation  
William T. and Susana D.  
Huston Family Foundation



We're grateful for the generosity of corporations, small businesses, foundations, and grant funders. Their donations, matching gifts, grant awards, in-kind services, and employee programs provided 32% of our annual revenues in 2021.

# OUR TEAM

*Without the dedication, expertise, and support of those on these pages, we would never have achieved all we did in 2021. We are grateful to work in collaboration with everyone listed here and so many more who volunteer their time, speak at our events, contribute to our educational content, and champion our work.*

## BOARD OF DIRECTORS

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Eden Mussie, MBA



**DAVIS PHINNEY**  
Foundation For Parkinson's  
*every victory counts®*

***Thank you for your  
support!***



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