

**2020** Living well with Parkinson's TODAY.



A note from the Executive Director

## What keeps people strong, connected, and living well when a crisis hits?

Action.

From the beginning, the Davis Phinney Foundation has talked about the importance of prioritizing action every day by exercising, making social connections, taking medications, attending medical appointments, advocating for yourself, and much more.

And in 2020, when the world went into lockdown, that prescription didn't change. We did.

We took everything we used to do in person and brought it online. We traded in-person hugs for chatting on Zoom, fist bumps on the top of peaks for virtual high fives, week-long rides for a month-long global challenge, and intimate conversations over coffee for long phone calls and handwritten letters. It wasn't ideal, but it worked. Taking action worked.

The truth is that people living with Parkinson's are masters at transformation. The collective resilience, attitude, and strength of this community inspired us to make these necessary changes to continue to fulfill our mission in unique ways.

As we look ahead to 2021, we know we aren't out of the woods yet, but we know this resilience and commitment to our mission will always guide us in the right direction. Thank you for supporting our work and believing in us every step of the way. We can do what we do because of you.

With gratitude,

Polly Dawkins

Executive Director

# 844,812

Total impacts in 2020 including virtual events, webinars, engagement with video and social channels, and much more.

In 2020, we helped more people than ever before.

In spite of the challenge of not being able to gather, we still delivered the information, inspiration, and resources people need to live well to more individuals and families than ever before through digital channels and community collaborations.



The Victory Summit® online events

2,894 registered attendees

1,500+
attendees watched live

17,000+
views of recorded
event content



The Every Victory
Counts® manual

**4,498**print copies distributed

2,652 copies downloaded

4,000+
audio book downloads



The Parkinson's Podcast™

**34,966** downloads

Top Episodes:
New Research, Medication, and
CBD Oil in Parkinson's with
Dr. Trevor Hawkins

Palliative Care, Not Just for End of Life: A Holistic Approach to Treating Parkinson's with Dr. Maya Katz

How to Exercise & Live Better with Parkinson's with Dr. Jay Alberts



Live Well Today Webinar Series

**36,713** registered attendees

25,754
views of recorded
webinar content



YouTube Content

**8,998** subscribers

**561,318** video views

8.5 min

average watch time



Blog Content

319,000+

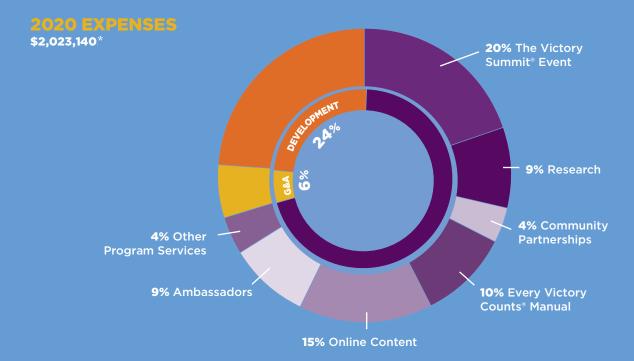
blog users

Top Posts:
Poles and Parkinson's: How Pole
Walking Can Help You Live Well
(and Stronger) with Parkinson's
- 4,426 views

How to Live Well with Parkinson's... Even When You're Locked Down – 3,707 views

Rigidity and Parkinson's: What it is and How to Treat it – 3,564 views

## **2020** Our Financials



#### **2020 REVENUE**

\$3,872,917





#### The revenue of the Davis Phinney Foundation totaled nearly \$3.9M in 2020.

Our growth during 2020 came primarily from an outpouring of support from individuals. Through donations, fundraising, and planned giving, contributions from individuals and families accounted for 59% of our total funds raised. In addition, our corporate partners remained committed to supporting our work and helping more people live well with Parkinson's even while our programs continued to shift as new information about COVID-19 came to light.

"FINALLY, an understandable explanation of all the various medications and uses. I can't wait to get the slides to share with my wife!!!!"

"THIS IS THE BEST
PRESENTATION I
HAVE EVER SEEN
regarding medications
and their intended use."

"These are my people. Thank you for giving us the chance to connect in this way."

"This has really
been an awesome
program. Everyone
involved has
been so very
informative. Thank
you for all your
efforts and time."

## From our community...

These are just a few of the hundreds of comments, chats, emails, and messages we received from participants about our educational programs this year.

"Excellent! I've listened to many Parkinson's webinars. This one was by far the best."

"Huge thanks to
everyone today and DPF
for putting together a
great and informative
summit!"

"This program was extremely helpful.

Every question I had was explained."

"I can't believe how much I've come to rely on this group. I can hardly wait for the next session!"

## **2020** Education TODAY

In 2020, we produced over 50 webinars and videos, hosted The Victory Summit® event virtually for five communities, and published 148 blog posts. We started a monthly meetup for care partners and a monthly YOPD Council, and we designed our new YOPD Women's Council. Finally, we took advantage of time and technology to give our community members more chances to share their passions and expertise. Lorraine Wilson hosted a series on how to use sketching as a tool for living well. Wayne Gilbert began a "medicine as metaphor" poetry class to help people write about and share their experiences. And we gave the mic to many of our Ambassadors so they could teach others what they do to live well.

Our goal with these experiences is to connect more deeply and in real-time with the wide variety of people affected by Parkinson's. Several people have said that these sessions have become a lifeline for them. It's a chance for them to try something new, ask questions, get support, and feel connected to people who are on similar paths. While everyone misses being in person, they're grateful to have the next best thing.

We look forward to expanding our virtual offerings in 2021 to meet the needs of Parkinson's communities everywhere. We also look forward to the day we can all come together in person again.









#### 2021: WHAT'S NEXT

The Victory Summit event is going virtual to reach more people than ever before with information and inspiration to live well today. Each event will focus on unique information tailored for each audience and will be recorded and made available for people to learn from for years to come.

- » February 20, 2021 Newly Diagnosed
- » April 2, 2021 How to Live Well with Parkinson's: For People with Parkinson's, By People with Parkinson's
- » June 26, 2021 Young Onset Parkinson's Disease (YOPD)
- » September 17, 2021 Mental Health & Wellness
- » November 13, 2021 Care Partners

## 2020 Going Virtual, Staying Local

When it became clear that we couldn't host our in-person educational events as planned, we immediately switched gears to discuss how we could deliver to the communities we had made promises to. Our biggest concern: How could we deliver an event that was uniquely local from a screen far away?

Luckily, we already had the answer: Community Action Committees (CACs).

CACs are groups of Parkinson's leaders that played a big role in planning the original events; so, when it came time to shift, they sprang into action. They helped their local community members get more comfortable using Zoom. They connected us with local speakers and leaders of exercise classes to ensure attendees had access to local people and organizations that could support them right away. Their commitment to connecting their community with information and inspiration was unwavering.

As attendees logged on to each event, the chat lit up with introductions, gratitude, and recognition. CAC members and Foundation staff welcomed each person on and celebrated each of them for showing up.

And in those moments, we weren't just in boxes on screens or in an anonymous chat room, we were together... in Louisiana, Michigan, Nebraska, Albany, and Boise. And it's because of the dedication of these community leaders that we could create such a memorable experience for their communities.



## 2021: WHAT'S NEXT

Inspired by the success of our community partnerships, we are launching our new Healthy Parkinson's Communities™ initiative to deepen our commitment to collaboration and supporting local efforts to help people live well with Parkinson's.

Learn more by visiting <u>HealthyParkinsonsCommunities.org.</u>

Thank you to these individuals and organizations that collaborated with us in 2020 through CACs and The Victory Summit® events:

#### Louisiana

BG Colley
Jan Hondzinski, PhD
Michelle Lane, Event Director,
Louisiana Walks for Parkinson's,
Davis Phinney Foundation
Ambassador
Randy LeBlanc
Sage Outpatient,
Day Neuro Program
Susan Sapir-Fields,
Event Coordinator, Louisiana
Walks for Parkinson's

Dominique Thomas, CMA, Ochsner Health System Movement Disorder Team

#### Nebraska

Barry Branson, Davis Phinney
Foundation Ambassador
Ashlyn Cramer, PT, DPT,
GI Balance & Mobility Center
Kathy Erickson, Blue Rivers Area
Agency on Aging

Stephanie King-Witt,
Witt's Warriors/Project
Parkinson's Central Nebraska
Jessie Kohn, University of
Nebraska Lincoln
Lincoln Parkinson's Disease
Support Group
Parkinson's Nebraska
Julie Pavelka, Nebraska
Medicine
Cheri Prince, PT, PDWELL
YMCA of Greater Omaha

#### Michigan

Michigan Parkinson Foundation

#### Albany, NY

Mark Burek, Hope Soars
Jud Eson, Capital District
Parkinson's Support Group
Nancy Eson
Nancy Hovey
Steve Hovey, Davis Phinney
Foundation Ambassador
Parkinson's Disease and

Movement Disorders Center of Albany Medical Center Marie Thorne

Boise, ID

Northwest Parkinson's

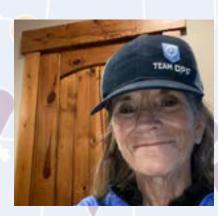
Foundation

Parkinson's Resources of Oregon

Spencer Stucki, Davis Phinney

Foundation Ambassador











## **2020** Critical Community Connectors

At the beginning of 2020, 24 individuals joined our Ambassador Leadership program and brought our cohort to nearly 60 people across the US and Canada. They set personal goals, added local events to their calendars, and more.

Then, everything changed, and our Ambassadors stepped up.

They started virtual support groups and exercise classes. They educated people about technology. And they continued to connect via phone and video calls with families facing a new Parkinson's diagnosis, new levels of isolation, worsening symptoms, and new care partner pressures.

Ambassadors also deepened their internal roles at the Foundation. Their pulse on local communities across the US and Canada became more critical than ever to understand how people with Parkinson's were coping and what they needed from us. Ambassadors hosted new workshops, spoke at our virtual events, and joined us in creating new resources like our YOPD Council series.

We are always in awe of this group of leaders, but their response and perseverance this year is something we will never forget. And as we move into 2021, we do so with an even greater understanding of the depth of creativity, commitment, and resilience within this group and how dedicated they are to helping people live well with Parkinson's.







# 2020 The Most Fun We Ever Had (Not) Together

In a typical year, we engage hundreds of participant-fundraisers at some of the best walking, cycling, and running events across the country. When these events shuttered in 2020, the possibility that we might go a whole year without connecting with this community through training, fundraising, and taking on challenges that embody our value of living well set in, and we had to act.

We did something we'd never done before. In July, we created a virtual athletic and fundraising event called the Every Victory Counts Challenge. We invited everyone to declare a personal challenge to get moving for the month and share it in our online event village. We made badges and print-at-home bibs and created mini-challenges encouraging people to show off their Team DPF swag or wear red, white, and blue on July  $4^{\rm th}$ .

And we had a blast.

"This was a new experience for me and it turned out to be a great blessing and life direction changer.

Participating gave me new confidence and strength that was greatly needed. Thank you for helping me to realize that I can still live well and be active and be strong and do hard things!" - Wendy Ericson

Hundreds of people joined us by setting goals to dance every day, run a marathon one mile at a time, get out on their bikes, take online boxing classes – you name it. The online event village became a hub of encouragement, positivity, and connection. People shared their victories and defeats, and we lifted each other up.

During a world shaken by isolation and turmoil, this event became a bright spot for so many – us included. What grew out of necessity will now be an event we look forward to every year.



In spite of event cancellations, Team DPF still had huge successes in 2020. In 2021, we look forward to a year that (hopefully) includes some of our great in-person events along with a continuation of virtual events.





\$673,745\*raised

in 2020 to support our mission to help people with Parkinson's live well today

\*Based on pre-audit data

## 2020 Quality of Life Research

Due to COVID-19, researchers had to pause some of the projects we are currently funding; however, we have great news about two projects.

Dr. Jay Alberts and Dr. Anson Rosenfeldt completed the study we funded on Community-Based Cycling Classes for Slowing Parkinson's Disease Progression. Their research sought to discover 1) if Pedaling For Parkinson's (PFP) could slow Parkinson's progression and 2) which individuals respond the most (more slowing of Parkinson's progression) to this type of exercise. Their results showed that after six months of regular cycling classes, participants' MDS UPDRS-III scores *fell* by 3.79 points. Parkinson's literature reports annual *increases* in MDS UPDRS-III from 3.2 to 8.9 points. These data indicate that individuals who regularly participate in a group cycling class may experience a slower disease progression rate than those who do not.

As we looked ahead to 2021, our Science Advisory Board invited grant applications that addressed historically underrepresented populations' unique needs. We received a record number of applications, and the project they chose to fund is *Removing Barriers to Deep Brain Stimulation Surgery for Women with Parkinson's Disease.* 

Led by Dr. Michelle Fullard from the University of Colorado, the research team seeks to 1) elucidate the barriers to Deep Brain Stimulation (DBS) surgery for women and 2) develop evidence-based decision aids and a DBS Ambassador program to address these barriers. The central hypothesis is that women's informational needs are often overlooked and that a gender-sensitive intervention will improve decision readiness and satisfaction with the decision-making process.

We are excited to be able to support this important work and look forward to sharing the study results.

# 2003-2020

Dr. Alberts and his colleagues have dedicated 17 years to studying the effects of exercise, primarily forced cycling, on motor and non-motor performance. Each project has inspired the next, and the research continually supports the belief that forced and high-intensity aerobic exercise improves motor function (and more) in people with Parkinson's.

## 2003

Dr. Alberts notices during a group bike ride that after pedaling a tandem bike with him, his friend with Parkinson's experienced dramatic improvement in her handwriting.

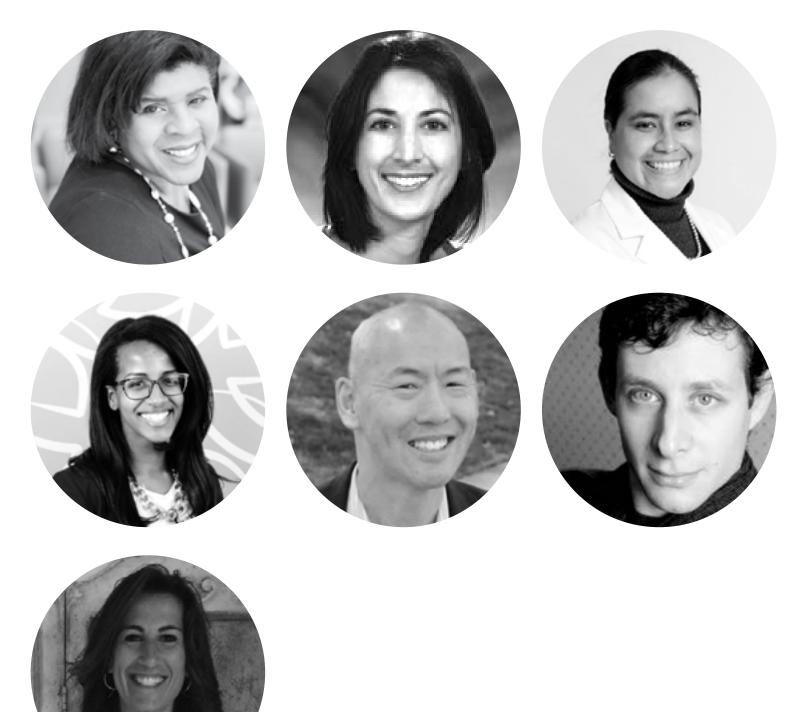
## 2009

Dr. Alberts uses grant funding from the Davis Phinney
Foundation to study the effects of exercise on cognitive and motor functioning in a group of people newly diagnosed with Parkinson's.

## 2015

Dr. Alberts and his team begin examining the effects of forced exercise cycling on motor and non-motor performance in a clinical trial called CYCLE.

Visit <u>dpf.org/alberts-timeline</u> for the full story.



Visit <u>dpf.org/IDEA-board</u> to learn more about our advisors.

# **2020** Committed to Changing Health Disparities One Step at a Time

In 2020, as hundreds of thousands of people in the US poured into the streets to protest racial injustice, and as the crisis of health disparities in our country became more apparent than ever, we were all presented with a choice: We could stay the same or use this moment to step up and commit to changing issues of systemic disparities in our own worlds.

Addressing the necessary changes needed to undo systemic inequities and counteract bias doesn't happen overnight, but instead through consistent steps taken every day. In 2020, we invested in internal and external structures that will help us take those steps today and deepen our commitment to the entire Parkinson's community. We...

- » Began a webinar series so we could learn together about the complex issues of health disparities and Parkinson's
- » Put an inclusion, diversity, equity, and access (IDEA) advisory board in place
- » Set our vision and outlined a strategy and goals to address issues of bias and access within our work
- » Expedited the launch of our new Healthy Parkinson's Communities™ initiative and grants program that will enable us to support change at the community level

Helping people live well with Parkinson's means acknowledging and addressing the many barriers and disparities that make it nearly impossible for so many people to get diagnosed and receive the care they need. We hope our commitment today will enable better care for everyone tomorrow.

## **2020** The Future Awaits

Looking back, 2020 gave us time to pause, reflect, and reimagine our vision for the future. Our goals are big, but this year reminded us that not only can we accomplish them, we must.

Parkinson's and all neurological disorders are on track to double by the year 2040. As need increases, we must adapt and grow to meet this challenge. Because of the work and support of so many people over the past 16 years, we've built a sturdy foundation that allows for the necessary boldness it will take to achieve our vision.

We're energized by this important work, and we extend out gratitude to you for joining us as we strive to help *all* people with Parkinson's live well today.



## **2020** Our Supporters

We had **10,587 donors in 2020**. Our supporters contribute through recurring gifts, planned giving, volunteering, and donations large and small to make a difference in the lives of people and families affected by Parkinson's.

There are so many incredible ways that people give to the Davis Phinney Foundation. Here are just a few of thousands of examples of striking generosity and commitment to our mission.



#### Peloton Club

When asked why he gives monthly as a part of the Peloton Club, Stephen Chase said, "When I get the note each month thanking me, it reaffirms my connection to the Foundation."





#### Leadership Circle

Daniel King, a member of our Leadership Circle, has been a supporter of the Foundation for more than 15 years becaus of the inspiring way Davis Phinney lives well every day.

Gifts at the Leadership Circle level help support our educational, programmatic, and research initiatives, and ensure these critical resources are available for years to come.



### Gifts in honor or memory

Gail Gitin made a gift in memory of her late husband, Eugene Gitin, MD, who was a physician and philanthropist. This generous gift will help us publish the latest edition of the Every Victory Counts® manual

Gifts made in honor or memory of someone are deeply personal and remind us every day why we do what we do.



#### Legacy Gifts

This year, the Charlotte Stall estate donated an extraordinarily generou gift to the Foundation. Her gift had a profound impact on our work this year, and it will help us grow the ver programs she participated in for many years to come.

Legacy gifts and charitable bequests make a big difference in our ability to serve the Parkinson's community, now and in the future. Please notify us if you have mentioned the Foundation in your will.



#### Volunteers

Volunteers help the Foundation in a variety of ways, from assistance at our offices to volunteering through fundraisers and special events with Team DPF.

Volunteers help us perform at an Olympic level and enhance our support for the Parkinson's community.

## **2020** Our Fundraisers



**Team DPF** is an impressive, athletic, outgoing, and fun-loving support network, **over 3,000 strong**, that helps spread the word and raise funds for Parkinson's education, research, and quality of life at established events and others they create.



J and Lorraine Wilson raised \$8,219 in 2020. J rode his recumbent trike 6,000 miles and Lorraine organized a silent auction featuring handmade quilts and other art.





Adin Baird, filmmaker, cyclist, and friend of Taylor Phinney, organized the Next Stage Bike Sweeps. Everyone who signed up had the chance to win an Allied Cycleworks Able bike custom painted by Taylor and inspired by Davis's journey and everyone's journey to live their best lives.



Wendy and John Paul Lederach and their team, Wendy's Crew, didn't let event cancellations stop them. They raised over \$60,000 riding their bikes this summer and hope to participate in Copper Triangle again soon.



Cheryle Brandsma virtually rode The Colorado Trail (nearly 500 miles) on her stationary bike during the month of July as part of our Every Victory Counts Challenge.



Steve Quam participated in a Team DPF music video fundraiser orchestrated by Ambassador Amy Carlson and compiled and produced by Donnie Sorah.

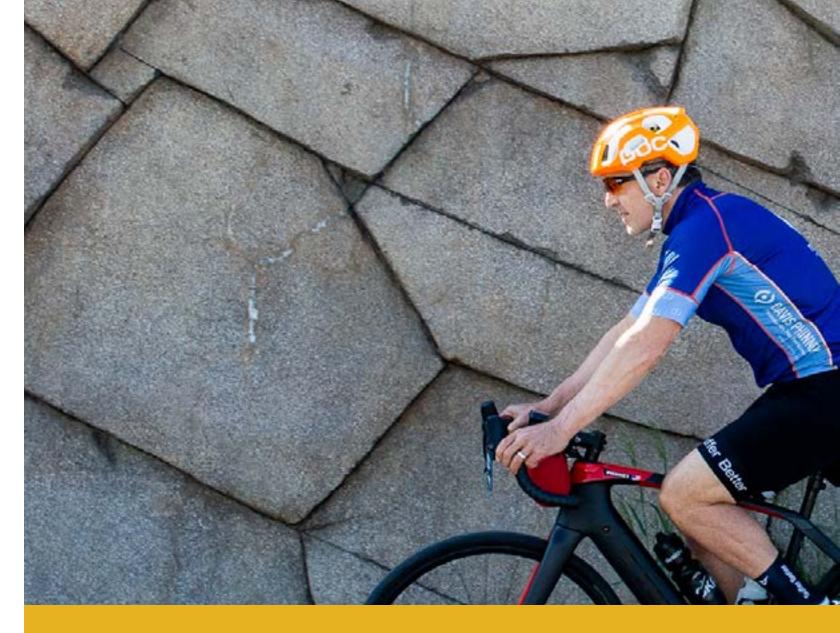
## **2020** Special Thanks

110 Fitness AbbVie Grants ACADIA Pharmaceuticals Acorda Therapeutics Adamas Pharmaceuticals Amneal **BOCO** Gear Boston Scientific Capital Group Charitable Foundation Cornell Family Foundation Deleuze Family Foundation Dellora A. and Lester J. Norris Foundation Google Gift Matching Program Greenwood-Leflore County Chamber of Commerce Humanity United Matching Gift Illinois Tools Works Matching Gift Program

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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 34% of our annual revenues in 2020.

## **2020** Our Team

Without the dedication, expertise, and support of those on these pages, we would never have achieved all we did this past year. 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 more.

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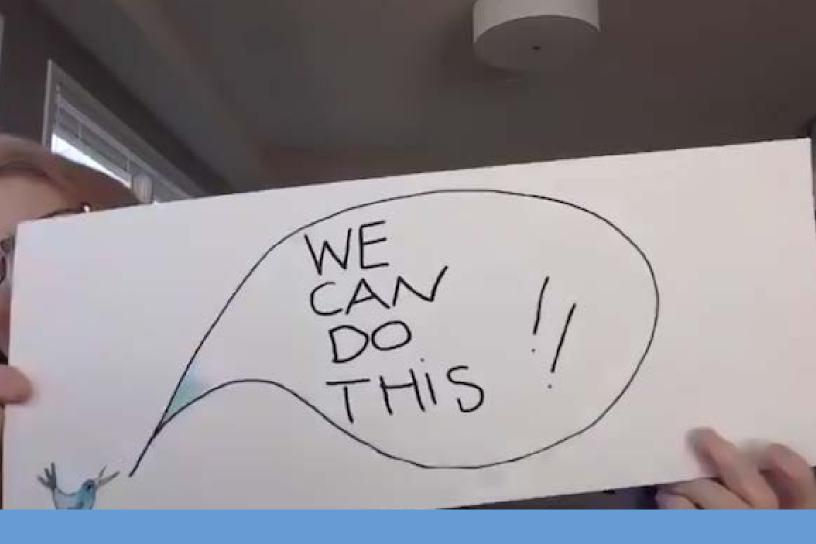
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\*Recent alumni °In memoriam





every victory counts

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