



DAVIS PHINNEY
Foundation For Parkinson's

every victory counts®

2018 Year in Review



*A note from the
Executive Director*

In recent months, I have met with a number of individuals living with Parkinson's who were feeling lost. I've spent time in coffeehouses and at exercise classes with them and each time I am struck by two things:

We have learned so much about living well with Parkinson's in the last 15 years as an organization...and we still have far to go to create a world in which people with Parkinson's are supported, understood and connected.

The truth is, many individuals and families find themselves without direction or community whether they have just been diagnosed or have been living with Parkinson's for many years. Like my new friends, they feel lost. But, it doesn't take that much to begin to bring them out of isolation. It could be something as little as a conversation, an introduction to a new practitioner or ally in the community or trying a new exercise class that inspires them to take action. A small step in the direction of living well goes so far.

As our work continues to grow and evolve (as you'll see in this report), we continue to think about the future and what our community needs. At the forefront of this for us is meeting people where they are--in their local support groups, online, wherever they are on their path to living well--and creating highly personalized, positive interactions at every step along the path of living well with Parkinson's.

Thank you for your part in this work. It truly does change lives.

With gratitude,

Polly Dawkins
Executive Director

2018

DAVIS PHINNEY FOUNDATION :

Our impact in *this year...*

In 2018, we reached more than half a million individuals and families around the world with our information, resources and experiences. With a dramatic increase in our online offerings, including the first broadcast of The Victory Summit® event, we are reaching more people than ever before with the message that you *can* live well with Parkinson's today.



4,265

attendees of The Victory Summit® event in six cities across the U.S. and Canada and through our digital broadcast in August.

139

youth and people with Parkinson's who participated in pilots of Sidekicks™: Uniting Youth and People with Parkinsons.



11,643

print and digital copies of the *Every Victory Counts*® manual distributed.

49,631

downloads of the Exercise Essentials video as well as worksheets and other free, printable resources.

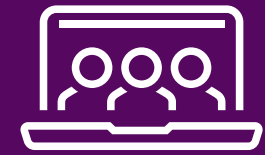


4,919

individuals and families who met with a Davis Phinney Foundation Ambassador in 2018.

\$37,000

granted to communities to support local exercise and wellness classes for people with Parkinson's.



381,320

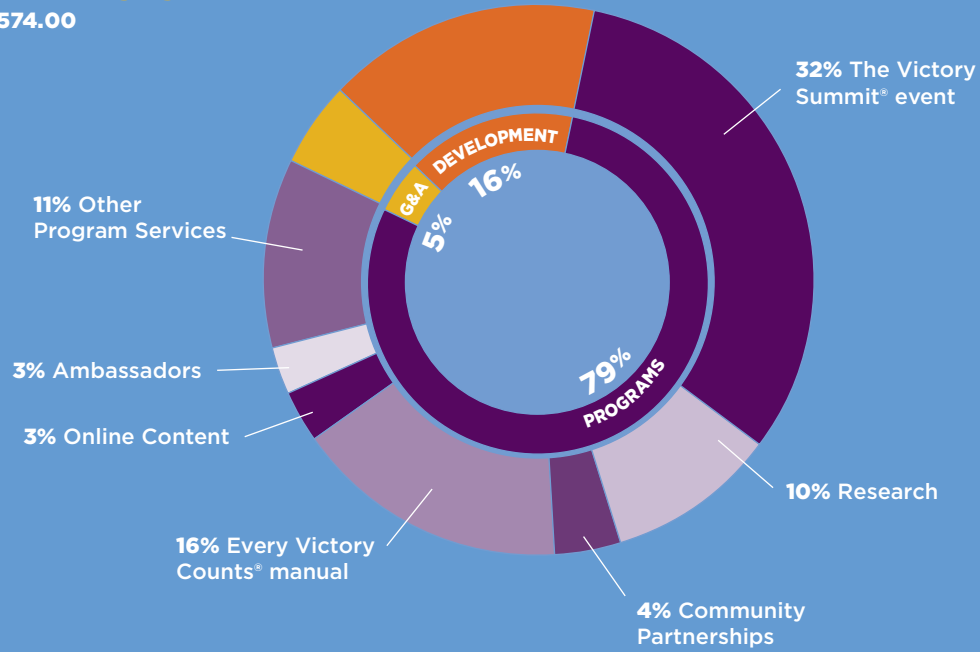
individuals and families using our digital resources including our website, newsletter and Facebook community.

15,783

individuals and families downloading and listening to the first season of The Parkinson's Podcast™.

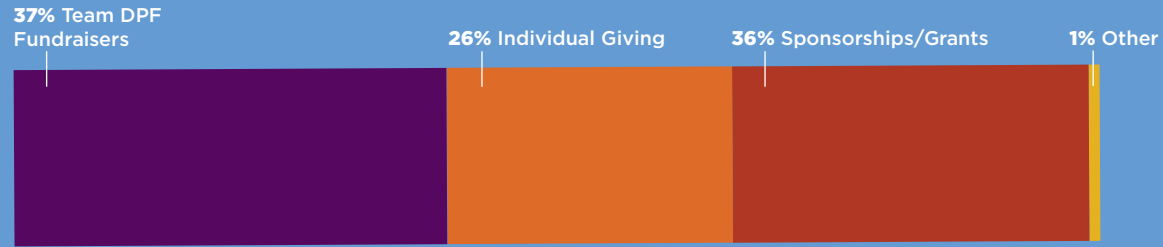
2018 EXPENSES

\$2,329,574.00

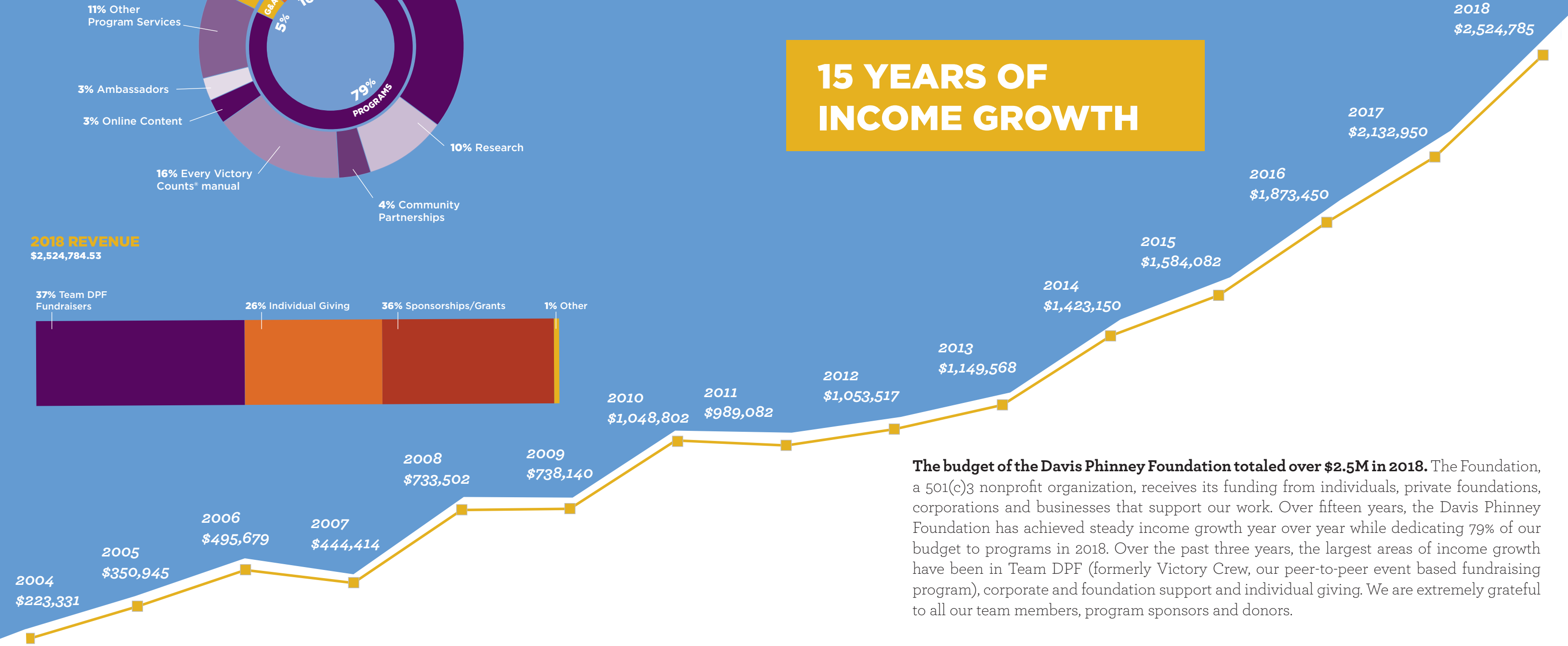


2018 REVENUE

\$2,524,784.53



15 YEARS OF INCOME GROWTH



The budget of the Davis Phinney Foundation totaled over \$2.5M in 2018. The Foundation, a 501(c)3 nonprofit organization, receives its funding from individuals, private foundations, corporations and businesses that support our work. Over fifteen years, the Davis Phinney Foundation has achieved steady income growth year over year while dedicating 79% of our budget to programs in 2018. Over the past three years, the largest areas of income growth have been in Team DPF (formerly Victory Crew, our peer-to-peer event based fundraising program), corporate and foundation support and individual giving. We are extremely grateful to all our team members, program sponsors and donors.



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DAVIS PHINNEY FOUNDATION : Reaching People Wherever They Are

From broadcasting The Victory Summit® around the world to fostering thousands of personal connections in communities across the country...from creating content to inform the newly diagnosed to exploring the needs of people across years and decades of living with Parkinson's, we are invested in meeting people wherever they are. Our programs are evolving and growing to meet and anticipate the needs of people with Parkinson's, care partners and families, and expanding to educate the next generation and engage surrounding communities. This is how we are aiming to change what it means to live with Parkinson's.

These are our victories of 2018.

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DAVIS PHINNEY FOUNDATION :

Out of the ballroom and into the *living room...*



Jessie Zweibel

*The Victory Summit®
Program Manager*

Ten years ago, Davis Phinney took the stage at the very first The Victory Summit® event to welcome attendees and thrust his arms skyward in a “V” for victory. Now, 39 events and 20,580 attendees later, we’re still committed to our initial vision: to cultivate the growth that happens when people with Parkinson’s and their loved ones are welcomed by their community, connected to the right resources and provided the information and inspiration to live well today. That focus is what makes The Victory Summit event so unique and what has allowed it to stand the test of time.

In 2018, we hosted six events throughout the US and Canada; however, one of the most exciting changes we implemented in 2018 was The Victory Summit event live broadcast. Over 1,500 people from all over the world tuned in live while our speakers presented from the stage in Los Angeles. Support groups across the globe came together for ‘watch parties,’ and we heard gratitude over and over from people who had wanted to attend for years and were now finally able to join us. So, with the amazing support of our community, we’re excited to be offering two live broadcast events in 2019 from Austin and Tucson.

Our reputation for hosting high-touch events that inspire action has allowed us to affect people with Parkinson’s and their care partners in ways we would never have predicted when we took the stage for the first time all those years ago. We look forward to continuing to innovate and evolve this program to meet the diverse needs of each community we visit for many more years to come.



4,265 annual attendees...and counting.

Looking back, we’re excited about how far we’ve come over the past decade.

Over the last ten years we’ve...

- » Grown from hosting 350 attendees at one event in 2008 to hosting more than 4,265 attendees at six events in 2018
- » Hosted The Victory Summit event in 34 US cities and in Ireland, Malaysia and Canada
- » Gone from having one partner in our event city to as many as eight
- » Evolved from having just general sessions to having multiple, fully developed breakout tracks to address the growing needs and voices in our Parkinson’s communities

2019: WHERE WE’RE GOING NEXT

» *The Victory Summit event will travel to Reno, Austin, Indianapolis, Philadelphia, Ottawa and Tucson in 2019. Combined with two live broadcasts planned in April and December, we will reach more individuals and families than ever before with the event this year.*

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DAVIS PHINNEY FOUNDATION :

Living well at every stage...



Benzi Kluger, MD

*Speaker,
The Victory Summit® Event*

Over the past year, I have worked with the Davis Phinney Foundation to incorporate elements of palliative and supportive care into their educational programming as an advisor and speaker.

Briefly, palliative care is an approach to the care of people affected by serious illness that focuses on improving quality of life by addressing medical symptoms, psychosocial concerns, spiritual well-being and planning for the future. Although often associated with hospice and cancer, palliative care can be appropriate at any point in an illness (including time of diagnosis), can be provided alongside other treatments and can help patients and families set priorities to engage more in their life goals. Steve Pantilat, MD, an international leader in palliative care, describes it as “Living as well as possible for as long as possible”.

To begin educating people with Parkinson’s and their care partners on the many potential benefits of palliative care, I worked with The Victory Summit® event team to develop a new agenda which we premiered in Seattle in December. Sessions included general information on palliative care, working with difficult emotions, pain, advance directives, mindfulness and care partner support.

“I learned how to have the strength to talk to my family about my emotions and what to expect as Parkinson’s progresses.”

- Attendee of The Victory Summit - Seattle

The response from participants was overwhelmingly positive. Between 98-100% of people who attended these breakout sessions said they would attend similar events in the future, feel the information they received will improve their quality of life and believe they are more prepared for the future.

I look forward to working with the Foundation to expand in this direction and also find for more opportunities to educate people affected by Parkinson’s on the full spectrum of care, support, treatments and solutions that are available to them as they travel this path.

We premiered several new breakout sessions as part of the new palliative care agenda. Attendees surveyed responded positively to these topics including:



A Holistic Approach to Parkinson’s Care
» 99% of respondents said they would attend another session like this in the future.



Advance Directives & Care Planning
» 100% of respondents said they knew more strategies to prepare for their future after attending this breakout session.



Mindfulness & Meditation
» 98% said the information learned in this breakout session will improve their quality of life.

2019: WHERE WE’RE GOING NEXT

» Additional initiatives to address living well at every stage of Parkinson’s are in early stages including a concept for a “Parkinson’s Roadmap” to help individuals and care partners better locate themselves on the Parkinson’s journey and prepare for the future.



20 DAVIS PHINNEY FOUNDATION : 18 Creating learning *communities*...

Since 2010, the *Every Victory Counts*® manual has been *the* go-to resource for people living with Parkinson's and their care partners. Since its release, more than 43,000 printed copies have been circulated in the United States and Canada, and with the release of the eBook version in 2014, people all over the world have downloaded and added this resource to their living well toolkit.

For years, we have heard from support group leaders and Davis Phinney Foundation Ambassadors about the ways they have used the *Every Victory Counts* manual as a tool for teaching, conversation and community learning. In 2017, we decided to create a tool that would allow anyone to easily adapt the manual into a textbook with structured learning sessions around some of the most popular topics.

This past year, the *Every Victory Counts* curriculum was developed and piloted in three locations. Comprised of nine learning modules, the curriculum includes both an instructor's guide and a learner's guide and walks participants through topics including the Parkinson's mind-body connection, assembling a wellness team and goal-setting. Every session is structured to include

conversation, interactive activities and reflection, and is designed to help even novice instructors lead a group successfully.

The *Every Victory Counts* curriculum is the first of many steps we are taking towards building more connections and increasing our impact. A natural extension of our successful Ambassador program, with this initiative we look forward to training "living well leaders" and equipping them with the tools they need to make a difference in their communities.

2019: WHERE WE'RE GOING NEXT

» In April, we will print 15,000 copies the *Every Victory Counts* manual complete with updated content. We will also formally launch the *Every Victory Counts* curriculum.

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DAVIS PHINNEY FOUNDATION :

Making personal connections in 21 states...



Alex Reinhardt

*Community Outreach
Manager*

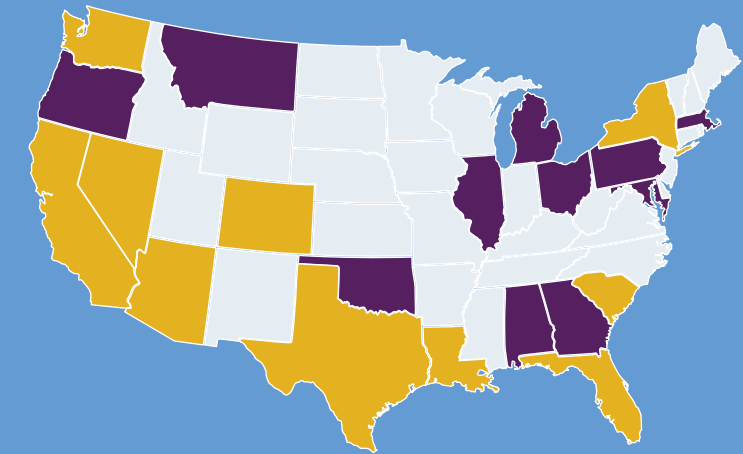
Davis Phinney Foundation Ambassadors are individuals living with Parkinson's who are passionate about our mission to help people with Parkinson's live well today and who want to connect others with the quality of life resources the Foundation has to offer. This program began because we saw a growing need for resources and education for people with Parkinson's who lived in areas that weren't served by large hospitals, universities and research centers and who might be isolated. We needed more boots on the ground, and therefore the Ambassador program was born.

In 2015, we welcomed 10 Ambassadors into this program. By the end of 2017, we had a cohort of 15 Ambassadors, and now, our community has grown to 38 Ambassadors who have the potential to impact upwards of 15,000 people this year alone. In 2019, we look forward to empowering this group of people to help us build more informed, more connected Parkinson's communities in cities across the US. With their diverse experiences and backgrounds, we never know what great ideas they're going to come up with next, and we learn so much from them everyday making us a stronger organization than we could ever be without their input.

Ambassadors affect the lives of individuals and families living with Parkinson's in their local areas by:

- » *Starting and facilitating support groups*
- » *Inviting Parkinson's experts from their communities to speak or offer workshops*
- » *Educating individuals, families, local organizations and healthcare professionals about the Davis Phinney Foundation and our philosophy of wellness with Parkinson's*
- » *Hosting fundraisers*
- » *Hosting tables at Parkinson's events*
- » *Spearheading and teaching exercise classes and programs*
- » *Organizing or attending and participating in advocacy events*
- » *Building relationships with Parkinson's experts in the community and passing along information about local initiatives, research projects and clinical trials to their groups*
- » *Assisting in the development of The Victory Summit® events in their local areas*
- » *Helping deliver the pilot programs for the Every Victory Counts® manual curriculum and Sidekicks™*

38 AMBASSADORS
21 STATES
15,000+ POTENTIAL IMPACTS



2019: WHERE WE'RE GOING NEXT

» *In February, we hosted our first annual Leadership Conference to convene our full cohort of Ambassadors along with care partners, staff and board for a weekend of learning and planning for the year ahead.*



20 DAVIS PHINNEY FOUNDATION : 18 Changing the *future* of living with Parkinson's...

The impact of intergenerational relationships, living situations and learning environments is being explored in new ways across many sectors. For example, this year's Stanford Center on Longevity Design Challenge - which we are pleased to participate in again as sponsors and judges - is focused on the concept of "intergenerational design."

When we launched Sidekicks™: Uniting Youth and People with Parkinson's, an intergenerational program created in partnership with Lundbeck, our main focus was on how the program would affect Parkinson's participants in the areas of social isolation and personal meaning. And while the program has achieved these goals, we have also begun to understand the impact engaging future generations can have on everyone.

Every Sidekicks program begins with a pre-education session for all youth participants. In this session, school-aged youth learn about Parkinson's symptoms as well as the challenges people with Parkinson's often face. Youth participants are given ideas for how to interact with and support their Parkinson's "sidekicks" when they meet and begin working together.

Upon reflection, a number of our Parkinson's participants this year remarked that working with their youth sidekicks not only increased their confidence and made them feel less alone, but it restored their faith in the next generation. It gave them hope for a better future.

With Sidekicks, we are tapping into a nuance of living well that has tremendous potential to make change: by creating more empathy, understanding and inclusion, people with Parkinson's can live well and more confidently in more spaces. By instilling these values in the next generation, we can begin to change how Parkinson's is supported and understood in the future.

"For such a simple idea, Sidekicks delivers powerful and emotional results. One of our recent Parkinson's participants shared some joyful tears just having the opportunity to get out and spend time with the children. As the sessions went on, she built a very special bond with her student partner. That one hour each Friday brought as much joy to both her and the student as it did to the rest of us just feeling the warmth of their laughter and smiles."

- Tom Palizzi, Davis Phinney Foundation Ambassador and Sidekicks participant

2019: WHERE WE'RE GOING NEXT

» *In 2019, we will host Sidekicks workshops in 10 cities across the US.*



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DAVIS PHINNEY FOUNDATION :

Riding *together*, changing lives...

Our most successful Team DPF events are not always about scale, but about passion, dedication and community. There are so many shining examples of groups rallying around a community leader to ride and raise funds that allow us to do our work. One of these is the phenomenon of the Growling Beaver Brevet.

On its face, the Growling Beaver is a small boutique gravel ride that winds its way along quiet roads in a small Canadian town. But below the surface is what makes this ride special: a community's love for a true example of living well with Parkinson's-Evan Siddall. It's this motivation that has made this event more than the sum of its parts and allowed its participants to raise more than \$1M in just four years to help people with Parkinson's live well in the US and Canada. And it's directly because of this event's success that we have been able to expand our work in Canada, now producing The Victory Summit® event and increasing our ability to distribute the Every Victory Counts® manual in Canada every year.

This is the heart of Team DPF. *Every* fundraiser is doing it for someone who inspires them or who they love. And while we know what an impact this has for our fundraisers on a personal level, the impact their contributions have on our community is even greater.



1,134,700 miles

walked, run and ridden on mountains, roads and stationary bikes.



3,321 participants

fundraising around the world.



\$1,043,818* raised

in 2018 to support our mission to help people with Parkinson's live well today.

**Based on unaudited data.*

FUNDRAISING LIFETIME RECOGNITION

We'd like to extend special recognition to those events and individuals who have gone above and beyond, raising more than \$100k over the course of their involvement with Team DPF.

\$1M+

- Copper Triangle
- Growling Beaver Brevet

\$500K+

- Ride The Rockies
- Tour of Sufferlandria

\$250K+

- Evan Siddall

\$100K+

- Reid Hunter
- Cheryle Brandsma
- Brandon Halcott
- John Paul and Wendy Lederach
- Steve Hovey
- Ray Anderson
- Kevin Cartin and Kathleen Donohue
- Rick Baker
- Joe Williams
- Tom Casey
- Iron Horse Bicycle Classic
- Sub-5 Ride
- RAGBRAI
- Road to Victory

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DAVIS PHINNEY FOUNDATION :

Your prescription - exercise.



Jay Alberts, Ph. D.

The Edward F. and Barbara A. Bell Family Endowed Chair, Lerner Research Institute, Cleveland Clinic

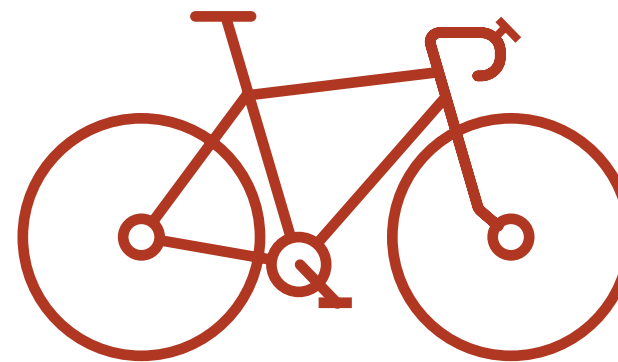
Founder, Pedaling for Parkinson's

In 2003, I rode Des Moines Register's Annual Great Bike Race Across Iowa (RAGBRAI) on a tandem bicycle with a person with Parkinson's. After we'd ridden together for a few days, I noticed a significant improvement in her physical abilities. It led me to wonder whether exercise, specifically cycling, could help improve function in a person living with Parkinson's.

This discovery served as the inspiration for subsequent research funded by the Davis Phinney Foundation into the value of cycling for people with Parkinson's. One study demonstrated that an eight-week bout of high-intensity aerobic exercise delivered on a stationary bicycle reduced motor symptoms of Parkinson's by 35%.

These findings led me to start Pedaling for Parkinson's (PFP), a nonprofit committed to promoting community-based exercise programs for individuals with Parkinson's. The PFP classes are typically conducted three times per week, year-round and focus on high-intensity cycling. Currently, there are over one hundred PFP classes in YMCAs and community centers throughout the United States and the world. Through PFP, we've created an avenue that empowers people with Parkinson's to take an active role in their treatment via exercise and community.

After more than a decade of fielding emails and calls from people with Parkinson's expressing how beneficial PFP programs are, my colleague Dr. Anson



Rosenfeldt, and I decided it was time to study the effects of these PFP programs systematically. With funding from the Davis Phinney Foundation, the project is well underway.

Dr. Rosenfeldt is now leading the project to examine the effect of *real-world* aerobic exercise by monitoring individuals with Parkinson's during their PFP cycling classes at four different PFP locations throughout the United States. Motor and non-motor symptoms, as well as cadence and heart rate will be tracked for 12 months. This study will help to answer many questions about the long-term effects of aerobic exercise in Parkinson's, and we envision it will be the first step to developing a true Parkinson's-specific exercise prescription. We are profoundly grateful for the support of the Davis Phinney Foundation in pursuing this endeavor.



Engaging our community
in changing what it means
to live with Parkinson's

This fall, we surveyed our community on the topic of OFF to find out how often and to what extent people with Parkinson's experience OFF and whether they have the language they need to share their experience with their doctors.

We received more than 1,600 responses and hundreds of questions and comments on the topic. Survey data revealed that OFF is a common experience and that there appears to be a correlation between frequency and severity and discussion with one's doctor – with a lack of discussion and understanding leading to more disruptive OFF.

This data points to a critical need for more and improved communication regarding OFF to improve quality of life.

2019: WHERE WE'RE GOING NEXT

» *We will be sharing this data at the World Parkinson's Congress in Kyoto, Japan in June, but we are not stopping there. Informed by this study, we will also host a webinar on the topic of OFF this fall for a variety of health care providers to begin to bridge the gap between the experiences of our community and their medical teams' comprehensive understanding of this issue.*



2018 DAVIS PHINNEY FOUNDATION :

Making information and resources available when, where and how our community needs it.

Living with Parkinson's is a 24/7 experience. So, to serve our community well, we need to look beyond our one-day events.

The reality is that many of the people we serve may never be able to attend our live events or connect in person with our staff, Ambassadors or other friends of the Foundation. Therefore, our digital and social hubs are critical to helping us fulfill our mission: to help people with Parkinson's live well today.

In 2018, we doubled-down on our online digital education content, hired a full-time Content Manager and made a commitment to produce new content across several different media platforms on a consistent basis. As a result, we increased our website users by over 20%, our Facebook likes by 49% and the content published on our blog by 248% over the previous year.

This past year we...

- » Published 147 new blog posts
- » Created five new comprehensive content guides
- » Launched our first season of The Parkinson's Podcast™ with 10 episodes
- » Created and launched our Ask the Parkinson's Expert video series with 23 videos
- » Partnered with pharmaceutical companies to write several blog series
- » Planned our first webinar and online course

We reached nearly 400,000 people via this content, and we significantly advanced our recognition and reputation in the Parkinson's community. Most importantly, we continued to build meaningful relationships with our community of readers through our surveys, outreach and "email us at any time" invitations.

It may take a lot more time and energy to deliver such a high-touch experience to the people we serve, but we wouldn't have it any other way. The better we know our community, the better we can help them live well with Parkinson's.

2019: WHERE WE'RE GOING NEXT

» In 2019, we will host seven webinars, create another season of The Parkinson's Podcast™ and focus new content on topics like the gut microbiome, Parkinson's progression and planning and nutrition

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DAVIS PHINNEY FOUNDATION :

Leadership Circle Donors

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Peter Huley
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Chris Huth
Thomas Isaacson
Carol and Charles Jenkins

We had more than 9,000 donors in 2018 and we can't thank everyone enough for your support. The names on these pages represent the Davis Phinney Foundation Leadership Circle, a group of supporters making a tremendous impact for our work in the Parkinson's community every year. With Leadership gifts of \$1,000 or more, these donors help the Davis Phinney Foundation lead the way in changing how people live with Parkinson's. We greatly appreciate this support for our programs and research.

Timothy and Irene
Kilgallon
Daniel King
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David and Lily Kwok
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William Wentworth
Pamela Wesley
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John Winant
Martha and Gary
Ziegelbauer
Mark Zobrist
Chris Zwolfer

Team DPF is a stellar group of individual and team fundraisers out riding, running, walking and even boxing on behalf of the Foundation. This year, we had over 3,300 fundraisers engaged in this peer-to-peer fundraising program, and we invite any and all to join us. The Honor Roll, shown here, is made up of people who raised \$3,000 or more this past year. Our deep gratitude goes out to the entire Team DPF for representing the Foundation, having fun and pursuing your passions to help people with Parkinson's live well.

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DAVIS PHINNEY FOUNDATION :

Team DPF Honor Roll



Faisal Ahamed
 Sheri and Scott Archibald
 Chris Atwell
 Doug Bahniuk
 Doug Blades
 Bruce Bond
 Oliver Borgers
 Rob Bruce
 Dan and Patti Burnett
 Kevin Cartin and
 Kathleen Donohue
 Steve Casamento
 Joel Cash
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 Stephanie Clark
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 Harrison Kopp
 Kevin Kwok
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 William Latimer
 Mike Laurie
 John Paul and
 Wendy Lederach
 Angie Lederach and
 Jeff Yoder
 Nan Little
 Coe and Bill London
 Ian Lurie
 Andrew MacEachern
 Stephen Magee
 Tony and Victoria Maschio
 Kevin McDowell

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 Bob and Janie Mullet
 Marc Murnaghan
 Linda Musante and
 Lynn Bryan
 Duane Newton
 Rich Noble
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 Ethan Perlyn
 Greg Post
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 Debbie and Kevin Schmid
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 Evan Siddall
 Lara Speirs
 Ray Stitt
 Kristin Vannorsdel
 Mara Vernon
 Jonathan Weyman
 Randy Williamson
 Judith and Kenneth Wilson
 Jeff Yoder
 Blair Zaritsky
 Marti Ziegelbauer



TEAM DPF
every victory counts.

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HealthONE
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Without the dedication, expertise and support of those on these pages, we would never have achieved all we did in the 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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