

Q&A With Davis Phinney Foundation Director Polly Dawkins

The name Phinney is synonymous with American cycling. Davis Phinney's professional career spanned 1984 to 1993, and he amassed 328 wins, including 73 professional victories and two stages of the Tour de France.

He also transformed into an all-round threat during the second half of his career, winning the final edition of the Coors Classic (1988), as well as short mountainous U.S. stage races like Killington and the Fitchburg Longsjo Classic. Davis's wife, Connie Carpenter-Phinney, was also a world-class bike racer as well as a speed skater. She was the first women's Olympic road race champion in 1984 and a twelve-time U.S. national champion. In 1972, she became (and still is) the country's youngest winter Olympian, competing in the 1500 meter speed skating events in Sapporo at age 14.

Their son Taylor enjoyed a meteoric rise to cycling fame at any early age, winning Paris-Roubaix (juniors) and then two consecutive individual pursuit gold medals at the world track championships. He later won stages at the Giro d'Italia, the U.S. Pro Challenge and the Tour of California, and will perhaps be best remembered for his courageous fight to return from a career-threatening injury in 2014 to return the top level of the pro peloton.

Davis Phinney legitimized the role of American sprinters, and along with Greg LeMond and Andy Hampsten, firmly established U.S. riders at the front of the international peloton. But Davis's life took an unexpected turn after he retired, when he was diagnosed with Parkinson's Disease in 2000. Parkinson's is a degenerative neurological disorder that affects nerve cells in the brain, slowly robbing its victims of motor control. It affects movement, the autonomic nervous system, mood and health, and cognition – to varying degrees in individual people. But rather than let the condition stop him, Davis rose to the challenge. Not only has he become an inspiring example of how to live well with Parkinson's, he has leveraged his status and visibility to rally resources and funding, in order to help others continue to live a better life with the disease.

In 2004, Davis and Connie founded the Davis Phinney Foundation (DPF) to help raise the visibility of Parkinson's disease, to conduct broader outreach and educational programs, and to contribute to research into both living better with Parkinson's and treatment programs that may ultimately lead to a cure. During the intervening 16 years, the Phinneys have been instrumental in exploring and promoting new approaches and better ways to live with the condition. After their earlier and wildly successful athletic pursuits, they shifted gears and have effectively created an important second chapter in their lives. Says Phinney, "As a second, or even third act, I feel fortunate. To be able to make a tangible mark in your life is a gift, and to be able to give others hope is vitally important to me. Ironically, many people in our Parkinson's "tribe" have little or no idea about my cycling history. They just know me as the namesake of a trusted Parkinson's foundation – which I find very cool."

To learn more about the objectives and accomplishments of the foundation to date, The Outer Line recently sat down and talked with DPF Executive Director Polly Dawkins. Dawkins has led the foundation since 2011.

The Outer Line: Thanks for meeting up with us. So, give us a brief history and overview of the foundation. How did the organization originally get started?

DPF Executive Director Polly Dawkins: Well, Davis never originally had any plans to do all of this. But within the first few years of his diagnosis, various people approached him about starting an organization to draw more attention to Parkinson's. He agreed to contribute his name and visibility, and the Foundation launched in 2004.

Meanwhile, and contrary to what his doctors were telling him, Davis was finding that by maintaining a more active lifestyle, he was actually feeling better. At the time, most doctors didn't recognize or recommend much activity for people with Parkinson's; the consensus medical recommendation was rest. With some of these new ideas in mind, and as the family adjusted to Davis's condition, the Phinneys decided to step up and become more involved with the work of the foundation. As it became more formalized, the foundation started to raise more money, hired additional staff, and started to create programs and resources to help even more people.

TOL: Can you tell us a little about what your organization looks like today?

PD: Certainly, we run a very transparent organization. Our offices are in Louisville, Colorado, where we currently employ 18 people. Four of us are involved with fund-raising activities, and the rest are involved with programmatic development, outreach, marketing, content development and education. We also have a couple of administrative support people to make sure everything runs smoothly.

In addition, we have a number of very important external ambassadors who help us run various fund-raising or educational events. This is a group of about 60 "super volunteers," some of whom have Parkinson's themselves. Our budgeted revenue goal for this year is \$3 million. We have been growing the size of that budget by around 15% a year, so, modest but pretty steady growth.

TOL: And how would you describe the overall mission or objectives of the foundation?

PD: The theme or general purpose of our organization is based around the mantra that Parkinson's sufferers need more and better information on how to live well with the disease. We want to get the message out there that people with Parkinson's need to take a proactive approach to healthy living. Of course we all want to see a cure for Parkinson's, but we aren't content just sitting around and waiting for that to happen. There are a lot of things you can do to enjoy a better life, things that unfortunately a lot of people have not been aware of. So, our main mission is to produce better informational programs, webinars, actual how-to manuals and a wide variety of other educational resources for people with Parkinson's – to basically to help people with the condition to live better. In 2008, we were probably reaching something like two or three thousand people a year, today we believe we are reaching – and positively impacting – around 800,000 people a year. Since 2010, our "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 48,000 printed (and free) 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 tool-kit.

TOL: Let's step back for a minute. Help us get a better understanding of the scale or magnitude of the disease. How widespread is Parkinson's, and what are the current methods of treatment?

PD: It is estimated that there are about a million people in the U.S. living with Parkinson's. There are about 60,000 new diagnoses each year, and it is the second most prevalent neurological disease in the country after Alzheimer's. Parkinson's affects more people than those with multiple sclerosis (MS), muscular dystrophy (MD), and amyotrophic lateral sclerosis (ALS) combined. This is a fact that people often miss, since Parkinson's is talked about so much less than the others. Plus, our experience and research strongly suggests that this incidence rate is probably under-reported, because it's rarely a straightforward diagnosis. As we have reached more and more people, it seems that almost everyone knows someone or has a family member who suffers from Parkinson's. Our objective is to make sure more people know about and understand the disease, and what you can proactively do to better live with it.

Interestingly, there aren't actually any black-and-white or completely defining tests for the occurrence or

existence of Parkinson's disease – it's a bit of a gray area. For example, only 20% or 30% of people with Parkinson's exhibit the tremors, rigidity or slowness of motion which most people associate with the disease. And in fact, many people with Parkinson's, or their support groups, are more worried about other, non-motor issues – depression, digestion, constipation, appetite, etc. – than they are about the other motor-related issues. Oftentimes, these other related issues are actually bigger day-to-day challenges or lifestyle concerns.

Most people who are living with Parkinson's take medications that work to restore dopamine in the brain. Dopamine is a chemical that your brain uses to send signals that help you move your body. People with Parkinson's don't have enough dopamine-producing cells to control their movements effectively. And unfortunately, the current drugs still don't eliminate all the symptoms.

It was not that long ago that you had doctors basically saying that Parkinson's is just a bad condition, and there's not much you can do about it. And unfortunately, most doctors were prescribing rest as the best way to deal with it. Now we know better; now we know that you have to take the initiative yourself. I think the single greatest accomplishment of our foundation is that we have helped raise awareness of the fact that movement and exercise actually help – that active exercise is now widely accepted as one of the key ways to keep the symptoms of Parkinson's under control. Almost every symptom of Parkinson's is improved through physical activity. And some of those benefits are longer-lasting too – going for a good bike ride doesn't just improve your symptoms for the rest of the day – the positive effects can be more long-lasting. One of the key things we're looking at right now is exactly what specific types of exercise seem to be the most productive or helpful in terms of controlling symptoms – and we're excited about what we're learning.

TOL: So tell us a little more about your main educational and research programs.

PD: Well, only about 10 percent of our budget goes to actual research, to hard science. Over the years, we have investigated topics like how to help with improved speech and swallowing – some of the most critical difficulties of the disease. We have tried to figure out why Tai Chi is good for cognition; we've looked at the effects of music on gait and balance. And we've looked hard at how nutrition and diet can help in dealing with Parkinson's; there hasn't been a lot of good information available on that.

One of our most significant research undertakings has been with Dr. Jay Alberts of the Cleveland Clinic, regarding programs of what we call forced intensity exercise. This has really plowed new ground in better understanding the positive effects of exercise for people with PD.

Dr. Alberts was actually riding RAGBRAI (the one-week cross-Iowa bike event) one year on a tandem with a person who had Parkinson's. As the week went on, Dr. Alberts gradually realized that his partner's symptoms were abating the more she rode. As he dug into this more, he started to find that there was a connection between exercise intensity and symptom reduction. Not only that, he found that those positive effects tended to last for a while – that even after you stop with the increased exercise program, you still enjoy some symptomatic benefits.

This exercise is now referred to as neuro-protective, and Alberts' insights gradually led to a whole new way of treating and thinking about Parkinson's. In fact, today we help to sponsor more than a hundred "Pedal for Parkinson's" community programs, where people show up three times a week to a spin class for this "treatment" protocol. These programs have resulted in great improvements for many patients, not to mention the additional benefits of greater social connections and interaction. Davis himself largely attributes his current well-being to this program.

TOL: Wow, that's pretty amazing. How, specifically, can cycling contribute to better control of Parkinson's symptoms?

PD: We can't really say that cycling is guaranteed to help everyone, but several recent research studies have shown that a lot of people experience significant benefits from pushing the pedals on a regular basis. I would just paraphrase from one of our presentations, and say that, depending upon pace and intensity, cycling has been shown to improve overall motor function and reduce tremor activity; reduce bradykinesia (or slowness of movement); reduce rigidity; improve aerobic capacity, cognitive function and mood; and simply increase joy and social connections. Of course, cycling imparts many of those benefits to people without Parkinson's too!

TOL: So, how are you generally funded? What sorts of individuals or institutions represent your typical types of donors?

PD: We have three main funding sources, each contributing roughly a third of our total revenue. The first third or so comes from what I would describe as grass-roots programs – fun neighborhood or more regional things like runs, rides, dance-a-thons and so on. Obviously, because of Davis, most of our community events center around different types of cycling events, and include several well-known organized rides.

We have been the sole fundraising beneficiary of Colorado's annual Copper Triangle ride for many years and always have a great team of rider/fundraisers, many of whom complete this challenging course in honor of friends and family living with Parkinson's. A portion of the registration fees are donated to the Foundation and then our fundraisers commit to raising money on top of that to help us do our work.

We are also one of just a handful of official fundraising teams at the Ride The Rockies event each year. When you ride and fundraise for us at this event, you receive great SAG support, laundry service, fun team gatherings, and more. Because of the high level of commitment for this event (in terms of challenge, time and fundraising minimum) our team is filled with some of the most dedicated rider/fundraisers we have, and many come back year after year to ride with us.

We also host a RAGBRAI team with Pedal for Parkinson's at this annual party of a ride. Our team of rider/fundraisers have a blast every year and we always try to think of fun, "only-at-RAGBRAI" kinds of experiences we can create with the team. This past year, we created limited-edition Evel Kneivel-inspired kits for the full team to wear on an honorary Davis Phinney Day. We also raised awareness for Parkinson's at the event through roadside signs and a shout-out from the stage at the concert in the evening.

All in all, we had over 3,300 TEAM DPF fundraising cycling participants at our events in 2019, who rode some 1.1 million miles, raising over \$1 million in support of the cause.

Another rough third of our funding comes from corporate sources – pharmaceutical companies, medical device companies and other organizations that manufacture or sell products for the Parkinson's community. Most of this money comes through event sponsorships or direct grants.

And the final third or so comes from individuals – people who we have impacted one way or another, who simply write us checks, some big and some small.

TOL: Have some of Davis's old teammates or competitors contributed to the foundation?

PD: Well, as you know, back in the old days, a lot of those guys didn't really make much money. So, I'd say not too many of them have been major financial contributors. But several of Davis's old friends have lent their name and celebrity status to events, races, fund-raising dinners and that sort of thing. Davis's son Taylor has made some generous contributions. Folks within the cycling industry, like David McQuillen of The Sufferfest has always been a big contributor.

But while we're on this topic, I want to make one major point. As opposed to many other charitable organizations, we are not an endowed foundation. We don't have any huge benefactor, or any big endowment which keeps us going financially. We have to basically raise every penny we spend, and do that every year. So we have to stay on our toes – if our funding levels should go down, we would simply have to cut back on very important programs, and obviously, we don't want to do that.

TOL: Are there other similar foundations or research organizations out there looking at the same issues, and how do you coordinate with them?

PD: Sure, there are several peer foundations out there on the national level. The Michael J. Fox Foundation is probably the best known; it is much more involved with pharmaceutical research, which we don't do. There are several other organizations which do a mix of research, education and advocacy work. While we might compete a little with each other for funding, we generally cooperate and get along well, because we are all working towards the same objective. And there are many, key research organizations out there too. Leading medical research institutions would include Anschutz Center of the University of Colorado, the University of Rochester, the Cleveland Clinic, the Mayo Clinic, the University of Florida, and many others.

TOL: How active is Davis, or other members of his family, in the actual work of the foundation? What role does he play in terms of fund-raising, visibility, and so on?

PD: I think Davis is quite proud of the organization, what it has accomplished and his role in it. He is the visionary behind the organization – he is sort of like a walking litmus test for the work we do, what's the most important, what programs will have the biggest effect on people with Parkinson's and so on. He is not involved in the day-to-day management of the foundation, but he is a board member. He comes into the office a couple times a month. He helps inspire us, to push our work further, to find more new ways to reach more people – to help the people with Parkinson's that he calls "his tribe."

TOL: Finally, I'm sure all of our readers would like to hear a little more about how Davis is actually doing today. How is his general health, what kinds of cycling activities is he involved with, and what's the longer-term prognosis?

PD: I would say that Davis is doing very well, particularly considering that he has been living with this diagnosis now for almost twenty years. He goes to Pedaling for Parkinson's classes several days a week – he also goes to boxing classes, where the students learn better muscle control through boxing with punching bags. And he believes in challenging yourself cognitively as well as physically; for example, he is currently going to a singing class. He still enjoys regular bike rides. He takes part personally in many of our fund-raising rides, and lately he's been active in promoting e-bikes for keeping people with Parkinson's active. He serves as a spokesman at almost all the foundation's educational programs. Connie is very active in the foundation as well; she is the Board's Chair, and is super-involved, particularly with the external education and fund-raising events.

TOL: Where would you hope to see the organization in five year's time?

PD: Our primary objective and passion will always be about helping people with Parkinson's live well today – with the emphasis on today. We are excited about our ongoing research projects, the innovations that are coming out every day to help people live better with Parkinson's, and continuing to be at the forefront of educating people about Parkinson's, and inspiring them to support such a worthy cause. As we grow, we hope to continue reaching more and more people, and helping them to live happier and more fulfilling lives.

Editor's Note: Following our discussion with Ms. Dawkins, Davis Phinney also weighed in, adding, "I'm

immeasurably proud of the work that our Foundation does for the Parkinson's community – our tribe, as I call us. And not to sound trite, but while I wouldn't have chosen Parkinson's disease thankfully, I have choices as to how I live with it. Through utilizing many of the methods first espoused by the DPF, 20 years post-diagnosis I can truly say – I'm living well with Parkinson's.

By Steve Maxwell, January 22nd, 2020.