Coast to Canyon: Cycling to Beat Parkinson’s
By Colin Stokes

When my mother, Joan Stokes, was 15, she biked 120 miles in one day on a commuter bicycle. I was 40 before I broke that record. I never had to ask her why she did it. Her personality drove her sense of adventure. She wanted to bike 120 miles, so she did. That sense of adventure was only taken over by her Parkinson’s disease (PD) in her last two years.

My mother passed along her love of adventure and cycling to me. It’s in my genes. I grew up in Trowbridge, England, where my mother would pedal with me everywhere. After she taught me how to bike, it wasn’t long before I was riding ten miles to visit my older sister. I would later bike to Cambridge every day, snow or rain. I was soon routinely biking 25 miles round-trip to get to my first job.

As an adult, I moved to California. After my parents retired, they enjoyed visiting me and the piers of San Clemente, which reminded them of past vacations. We would go on summer adventures to the Grand Canyon, Arizona, Utah, New Mexico and Nevada. Looking back, I am thankful that the initial years following my mother’s Parkinson’s diagnosis allowed us to still fulfill our wanderlust. These trips inspired my route for “Coast to Canyon,” my 700-mile cycling fundraiser for Team Hope™ for Parkinson’s. On May 20, I will leave the coast, more particularly one of Mum’s favorite piers, and pedal to the Grand Canyon.

Since breaking my mother’s 120-mile record ten years ago, a lot has changed. I became an ultra-distance cyclist, taking part in 500-mile and 1,000 mile races. Unfortunately, over the course of ten years, I also saw my mother change.

At Mum’s funeral, my father, Harold Stokes, asked well-wishers to donate to the Parkinson’s community instead of sending flowers. Inspired by my father,
Breaking Boundaries Every Day
By Allison Topperwein

I've had Young-Onset Parkinson's disease for at least six years. But it wasn't until New Year's Eve of 2014 that I was diagnosed. I've always been active. Growing up, I did gymnastics, cheerleading, track and cross-country. When I was a young adult, I became a certified personal trainer. Two years before my diagnosis, I began working out regularly, lifting weights and cardio-training three to five days a week. I felt good. Exercise gave me the strength and energy I needed to keep up with my toddler.

After I was diagnosed, I was put on the trifecta of PD drugs: Azilect, Mirapex and Sinemet. Then I read how exercise was the ONLY THING proven to slow the progression of PD. So I began training much harder than ever. At my local track, I ran up to a mile at a fast sprint. I walked the bleachers, working my way up to three sets of ten to strengthen my core. Bleachers were tricky at first because of my balance problems, but by repeatedly sticking to my routine, balance became less of an issue.

I eventually worked up to a 400-meter sprint, finishing only ten seconds slower than my high school time! The summer heat led me to begin working out indoors. After renewing my gym membership, I went there from three to five days a week to lift weights, alternating upper and lower body. Because my left arm has the tremor, I lift as heavy a weight as I can with my left shoulder to compensate for the stiff, rigid movement and lack of strength.

Last August, I began to train for the Savage Race – seven miles interlaced with an intense 25-obstacle course. As part of my training, I started going to my daughter’s elementary school twice a week to use the monkey bars. I realized after the race that PD affects recovery time. When I used to work out or compete, I would be out for a couple of days, and then I had the energy and stamina to pick up where I left off. Although I finished strong, the Savage Race demolished my energy for about a month. I lost five pounds of muscle and when I went back to the gym, I had to cut back considerably and work my way back up.

I was recently accepted to be an American Ninja Warrior competitor. Why did I apply? Because I wish to break boundaries. I want to inspire people to get off the couch. I want people with PD to realize this disease can be controlled to a major extent by exercise.

My PD therapy is doing weights, running the track and training. I've experienced the benefits of exercise on my sleep. I also have more energy, stamina and strength than many healthy men my age.

The National Parkinson Foundation (NPF) is instrumental in fighting this disease. NPF is a leader in discovering how incredibly important it is to exercise. Early on in my process, someone with PD told me, “Whatever you do, don’t stop. If you stop, the disease will take hold of you.” To be part of the NPF team that lives this principle every day, a team that motivates and educates about movement and exercise, was a no-brainer for me.

(continued pg 4)
Introducing Precision Care for Parkinson’s
By Peter Schmidt, PhD, NPF Senior Vice President, Chief Mission Officer

Precision medicine is a new trend in medicine that integrates the variability of each patient – their genetics, environment, behavior, disease pattern, and preferences – to inform their care. In Parkinson’s, the concept of precision medicine takes on new dimensions. In many ways, Parkinson’s care is simple: Treatment centers around replacing dopamine, both through an array of medications and through helping people increase production of their own dopamine (along with other benefits) by such means as exercise and support.

However, in practice, today’s best Parkinson’s care reflects the preferences of the neurologist as well as the patient: Researchers with NPF’s Parkinson’s Outcomes Project find that across our Centers of Excellence, different neurologists treat similar patients in very different ways. This is what we call the “art” of care; just as Rembrandt and Michelangelo created their masterworks by channeling their own insight, the very best Parkinson’s care is less systematic and more a reflection of the unique combination of training, experience, and wisdom of great neurologists.

While this model currently delivers the best treatment to those who can avail themselves of a top-quality neurologist, our mission is to help everyone with Parkinson’s. How do we extend the reach of today’s best neurologists to guide the care of patients they’re not able to help directly?

A physician named Brent James, an expert in writing clinical trial protocols, had an idea that could change healthcare. Clinical trial protocols are instructions to physicians for treating trial participants – which drugs to use and when, and which therapies to recommend. Dr. James’s insight into what makes a good protocol is that it should not be so simple that it addresses only the most common situations, nor so complicated that it is confusing. Importantly, it should guide the physician to use the protocol when appropriate, but to use their own judgment in deciding when to provide treatment not suggested by the protocol.

Dr. James told the doctors who work for him, “Consider the protocol to be a suggestion. Always give your patient the best care you believe is appropriate. But instead of starting from zero, start from the protocol.” Using this approach, Dr. James and his colleagues cut deaths from pneumonia by 40 percent and deaths from coronary-bypass surgery to half the national rate.

In 2014, Dr. James came to an NPF Centers of Excellence meeting. He told us, “Here’s a major way to help people with Parkinson’s: Write the protocol for Parkinson’s care.”

Societies such as the American Academy of Neurology prepare guidelines for Parkinson’s care. However, here’s the challenge: New ways to treat Parkinson’s continue to be discovered. A number of new drugs have been approved by the FDA since the last update to the guidelines and these new drugs are not in any guidelines. The new drugs are being used to great effect by the artists of Parkinson’s care, but without guidelines, there’s no blueprint for the rest of the medical community on how to follow their lead.

This is the power of NPF’s Parkinson’s Outcomes Project: By continuously tracking the current practices of today’s best Parkinson’s specialists, we have created what is essentially a system for developing guidelines based on results in real patients as they occur. Think of it as “paint by numbers” for the widest cross-section of physicians and neurologists, based on the work of the Rembrandts of Parkinson’s care.

Looking at the work of Parkinson’s experts, NPF researchers see how the differences between physicians affect outcomes, and we are also seeing subtleties of impact, such as how one approach delivers better motor results while another, better mood. By observing and documenting the work of many practitioners and the results for patients, NPF is day by day creating the insight that will help inform models of precision care for Parkinson’s.
The Hidden Patient
By Vaughn Edelson, NPF Director of Education

“T
he hidden patient.” If you care for someone with Parkinson’s disease, or any chronic illness, you likely understand the origins of this nickname. The hidden patient is not the stubborn relative who refuses to go in for a check-up. It’s the person for whom caregiving takes precedence over self-care.

There is an abundance of research on Parkinson’s disease, as well as a wealth of information and support for the people who have it. Their caregivers, on the other hand, get much less attention. Ruth, who cares for her husband, Henry, said, “As long as you dress up, with makeup on and your hair done, they think you’re ok. And some days I’m crushed.”

NPF is changing that, by spearheading both research and new resources for caregivers of people with PD. Through our Parkinson’s Outcomes Project, the largest-ever clinical study of Parkinson’s disease, we have already studied sex differences in Parkinson’s caregiving—women with PD have fewer informal caregiving resources and are more likely to use formal, paid caregiving; and the impact of caregiver transition—we found that switching caregivers is associated with worsening clinical outcomes and health-related quality of life for people with PD; among other topics.

We are continuing to collect information about the caregivers of the nearly 9,000 people with PD enrolled in the study, and we are using this data to inform new resources and programs for caregivers.

In 2014, NPF launched CareMAP (www.caremap.parkinson.org), which addresses the day-to-day aspects of caregiving. It’s not always a fun job, helping with meal prep and trips to the bathroom, but these tasks are essential and unavoidable for the vast number of people who regularly take care of a loved one with PD. The web site and complementary workbook, Caring and Coping, address the dual role of all caregivers: caring for someone else, and, just as importantly, caring for yourself.

Now, 21 how-to videos are available in Spanish, at www.caremap.parkinson.org/espanol, to provide practical caregiving tips to the many Spanish-speaking caregivers in the U.S. and around the world who sorely lack resources to provide better care for their loved ones and themselves. While aimed at family caregivers, the content is also appropriate for professional aides.

Unfortunately, caregiver self-care too often gets pushed aside as the next inevitable PD crisis arises. To help caregivers get the information and tools needed to cope in the moment, NPF is hosting a Caregiver Summit on Monday, September 19th, in Portland, OR (right before the World Parkinson Congress). This daylong event will bring together caregivers from all over the U.S. and the world to share their caregiving experiences and strategies, build their caregiving confidence, and find strength in the knowledge that they are not alone. Learn more and register at www.parkinson.org/summit. See you in Portland!

Breaking Boundaries Every Day cont. from pg 2

I look forward to not only helping plan, but also participating in the first Moving Day® in Dallas/

Fort Worth, TX! I went to college in Dallas and I think it’s the perfect spot to show the rest of America how Texans are pounding the pavement against Parkinson’s.

Allison Toepperwein is a single mom, blogger and fitness enthusiast who is overcoming Parkinson’s. She blogs about living with hope at www.LitWithinBlog.com.

To participate in a Moving Day® event near you, visit www.Parkinson.org/MovingDay for upcoming locations and dates. Below are the Moving Day events for June.

June 4 Moving Day® DC
June 4 Moving Day® Silicon Valley
June 11 Moving Day® Kansas City
June 18 Moving Day® Cleveland

www.parkinson.org
Why I Gave to NPF for the First Time

By Christine Riley

I gave my first gift to the National Parkinson Foundation during the match campaign that’s on now. I enjoyed writing “$500” on the check, knowing NPF would receive $1,000. I’m excited about what that larger sum means for research into Parkinson’s disease.

My father was diagnosed with Parkinson’s ten years ago, but I suspect he had it for 15 or 20 years without realizing it. With 20/20 hindsight, I see that Dad probably had rigidity and shuffling issues in early 2000. Dad passed away in October of 2015.

This past January, I was doing a little research on Parkinson’s. I sent an email to the NPF Helpline asking whether the disease is hereditary or an auto-immune disorder. I shared the knowledge I gained with my brother and with a co-worker also concerned if it was hereditary. I contacted NPF’s Helpline because I wanted information from the research source, rather than some random Internet page.

Then I received an email from NPF about the start of the matching campaign, and learned my gift would double. I knew this was the perfect time to donate – to make sure the research continues and that the education about Parkinson’s is out there.

Dad was a physician. My mother was his primary caregiver till the last year of his life. Mom had the foresight in 2005 to move from their home in Harrisburg, PA, to a retirement community with staged living. That’s when I knew Dad was starting to need more and more medical attention. Dad was pissed about the move for a good year and half – he didn’t like change – but after a while, seeing others with Parkinson’s gave him a lot of comfort. As a physician, he was embarrassed to fail the clock test [drawing the hands of a clock]. But he didn’t feel so bad when he saw other retired physicians fail the clock test due to Parkinson’s.

I feel it’s important to give right now, when my money will be maximized. Research is so critical, and it shouldn’t stop and start. There’s always a real possibility funding will dry up; and the grant process takes a long time. But my doubled donation – together with yours and everyone else’s – can keep truly essential research moving forward.

I think of my father every day. For those of us who have seen family members struggle, it’s a hard road for everybody. I often think: If you don’t give, you don’t get. And what we want to get are the results of Parkinson’s research. We need to keep the research going and we need to keep Parkinson’s in the forefront.

That’s why I gave my first gift during the match campaign, when it will do the most good.

Join Christine and give a gift before May 31 so that your donation is doubled and helps NPF achieve twice the research results. Donating is fast, easy and secure at www.Parkinson.org/match.

Landmarks Light Up to Support the Fight

Office towers, libraries, hotels, bridges, and entire city skylines across the United States shone blue during Parkinson’s Awareness month in April. We thank the NPF communities that rallied together to show support for Parkinson’s as landmarks bathed in blue light became dazzling beacons of hope and awareness.
Coast to Canyon: Cycling to Beat Parkinson’s cont. from pg 1

my gears were set in motion because I wanted to do more for the Parkinson’s community too, incorporating what my mother and I loved – cycling.

“Coast to Canyon” will be a three-day, 700-mile, roughly 65-hour journey. My goal is to raise $15,000 for Team Hope™. Several friends will ride with me. Our support team of family and friends will back us up, keeping us hydrated, iced and alive. I will be riding three bikes: TIME VXR, Specialized S-Works Roubaix and the Felt AR2. Definitely not the commuter bike my mother rode in her youth.

My father has been busy calling media to promote my ride. We share the opinion that the more people who know about “Coast to Canyon,” the more people know about Parkinson’s.

I believe the power of movement is a healing force for the mind and body. I wish there had been more of an emphasis on movement at the beginning of Mum’s 15-year fight.

However, I am thankful to have the opportunity to take this ride in her honor. This sojourn allows me the opportunity to revisit those family trips I’ve relived hundreds of times, one pedal at a time.

NPF Endurance Events

JUNE
1 Global Running Day
15 300 Imperfect Jumps for Parkinson’s

OCTOBER
9 Bank of America Chicago Marathon
16 IRONMAN® 70.3® Arizona
30 Marine Corps Marathon

NOVEMBER
6 TCS New York City Marathon

FEBRUARY 2017
5 Humana Rock ‘n’ Roll New Orleans Marathon

For more information, visit www.parkinson.org/endurance for the list of events and details on each.

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Up to 10% of Every Purchase Helps Beat Parkinson’s Disease
1,000 Participating Stores
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No Additional Costs to You
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NPF Legacy Society

Legacy Society members are a select group of donors who have recognized NPF in their wills, trusts, estates and other planned gifts.

Their generosity and forethought will help thousands of people with Parkinson’s live better lives in the years to come.

As an NPF Legacy Society member, you will have the satisfaction of knowing that you are continuing our tradition—helping to ensure the future strength of NPF through your generous support.

We recognize and thank members by listing your name in NPF’s Annual Report. If you have already named NPF as the beneficiary of a planned gift, we welcome you as an NPF Legacy Society member.

If you would like more information about how you can become a member, please visit www.parkinson.org/plannedgiving

You can also contact Amy Gray, Senior Vice President of Constituent and Community Relations, at agray@parkinson.org or 305-537-9906.