



THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

THE FOX FOCUS

ON PARKINSON'S

FALL 2013 NEWSLETTER

SPECIAL *think/able* ISSUE

AS MICHAEL J. FOX RETURNS TO TV, FOUNDATION CONTINUES PUSHING TOWARD A CURE

think/able celebrates the power of optimism

BY HOLLY TEICHHOLTZ

This fall, television viewers across the United States and Canada are welcoming Michael J. Fox back into their living rooms every Thursday night. The debut of “The Michael J. Fox Show” is remarkable not only for bringing Michael back to a starring role on network television (something no one would have anticipated when he retired from “Spin City” due to his progressing Parkinson’s disease). It has also placed Parkinson’s squarely back in the national conversation — a conversation already transformed by The Michael J. Fox Foundation for Parkinson’s Research (MJFF), which Michael launched in 2000 with the exclusive goal of funding research to speed a cure for the second most common brain disease worldwide.

“What I had in mind was an organization built for speed, eschewing bureaucracy and taking an entrepreneurial approach toward helping researchers find a cure for Parkinson’s,” Michael says. “There was no existing blueprint for accomplishing what we wanted to do. We were faced with the challenge of inventing a new system.”

The Foundation grew quickly from startup to the world’s largest nonprofit funder of Parkinson’s research, and has made grants totaling more than \$375 million to research

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FROM THE EDITOR

Dear Friend,

Welcome to the “think/able” edition of The Michael J. Fox Foundation’s newsletter! With Michael J. Fox’s return to a weekly sitcom, Parkinson’s disease is in the spotlight, sparking new conversations around our shared mission — finding a cure in our lifetime.

Like the think/able project (michaeljfox.org/thinkable), this special issue highlights the power of optimism and determination to achieve our goals. You’ll read how members of the think/able community are taking action to speed a cure.

In our spring issue, I asked you to share your thoughts on our newly redesigned newsletter. We’ve included several responses below. I hope you’ll continue this conversation by emailing me at Ishoor@michaeljfox.org. I also encourage you to explore the issue online at michaeljfox.org/foxfocus.

With gratitude,



Lauren Shoor
Associate Director, Development Marketing & Communications

FROM OUR READERS

“This is easy to read and understand for lay people. Please keep it up for all of us out here.”
A loyal reader

“The layout has simple, great design. The photos give the stories a real ‘personal and human’ meaning.”
Carolyn Bookstaber

“I read the entire issue. Maybe it’s because I’m a newly diagnosed patient, but I believe it was more than that. The articles were succinct, but I still felt well-informed; the layout and structure was one of the easiest to read and maneuverable online.”
Susannah Griffin

“Simple, truthful, informative, hopeful and fresh. Thank you.”
Janice Holland-Hill

ABOUT US

The Michael J. Fox Foundation is dedicated to finding a cure for Parkinson’s disease through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson’s today.

MJFF publishes *The Fox Focus on Parkinson’s* twice a year. To subscribe or unsubscribe, email info@michaeljfox.org. Submit questions and letters to the editor below.

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IN YOUR WORDS — ON PREMIERE NIGHT

On September 26, MJFF’s social channels were abuzz with the premiere of “The Michael J. Fox Show.” Read highlights and join the conversation:

 **Twitter & Instagram:**

 @MichaelJFoxOrg

 **Facebook:** facebook.com/michaeljfoxfoundation

 **Blog:** blog.michaeljfox.org

Chris Coffey @proffcoff

Is this Heaven? No, it’s an Iowa premiere party for @MichaelJFoxShow #ThinkAble

TinyDancer @_walkerlaura

Optimistic and inspiring! Finally a real show depicting real life challenges. @realmikefox #ThinkAble

Missy Spangler @MissySpangler22

We will beat #Parkinsons and we will smile, laugh & #ThinkAble



Patty Hammond

My husband has Parkinson’s disease. We loved the show. He says he’s going to a Halloween party as Michael J. Fox. LOL!

Sara J. Stuckey

I liked that it was about a family that has all sorts of issues — Parkinson’s just happens to be one of them. Can’t wait to see more episodes!



Nicole Jarvis (pictured left)
@JarvisCureMD

Premiere Party! So fun! Find the cure! #ThinkAble

Creations4Parkinsons@Creations4PD
#ThinkAble we just finished a party and raised \$1,600 in three hours for MJFF. Can’t wait to see the show.



Janet Landrum Trieschmann

Doesn’t necessarily represent my experience with PD, but it’s not intended to be a documentary. Admire MJF for his courage and dedication to research.



Ed Bowman

I’m 18 months into my diagnosis, and I thought it was funny and relatable. I was up for a promotion recently, and I found myself doing the same thing as Mike Henry before he went on the air — hoping that my meds were in full effect so that the board would concentrate on my qualifications and not my disease. The show is good for Parkinson’s awareness, especially because people need to be aware that we are just like they are.



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MICHAEL J. FOX RETURNS TO TV

teams all over the world (about 30 percent of funds go to international investigators). *The New York Times* has called MJFF “the most credible voice on Parkinson’s research in the world.”

As Michael sees it, his decisions to start the Foundation and to return to full-time acting now are united by a common theme. “It’s funny... people ask me about returning to NBC this fall the same way they asked me about launching a research foundation 13 years ago,” he says. “Whether it’s meant being the founder of MJFF or an actor with Parkinson’s, I guess I just realized: Why can’t I?”

“Just a dad with three kids”

Now Parkinson’s families, along with the greater TV audience, are tuning in to Michael’s show with compassion, interest and (of course) good humor. And in addition to laughing at the trials and tribulations of newsman Mike Henry, many are also seeing themselves in Michael’s alter ego.

The show deals with Parkinson’s mostly through a kind of benign negligence. Michael has been careful to say that the show isn’t really *about* Parkinson’s, and the script treats its main character, a guy with Parkinson’s disease, like — well — a guy.



“I’ve been told it’s really audacious to do a show about someone living with Parkinson’s, and not make a big deal of it,” Michael says. “Not playing soft piano music underneath it and slow motion... just a dad with three kids, living in New York and trying to get back to his old craft.”

The status quo is still not good enough

But as our CEO, Todd Sherer, wrote in a *Scientific American* op-ed published the week of “The Michael J. Fox Show” premiere, for Michael and the millions living with Parkinson’s, the disease is far from benign and the status quo is not good enough. “Medication and therapies alleviate some symptoms, but create their own problems and fail to address all the effects of Parkinson’s. And for every patient, a community is affected, as the impact of the disease ripples to loved ones and caregivers.”

The Foundation continues to push hard toward its mission of finding the cure in our lifetime. Since inception, the Foundation has transformed Parkinson’s research by applying significant resources, tenacious problem-solving, and unwavering urgency to the pursuit of a cure. And it is working. Today, more Parkinson’s drugs are in development than ever before. Multiple methods to improve the delivery of levodopa (the current gold-standard treatment for Parkinson’s) are in late-stage testing, and new treatments in development show promise to alleviate the side effects it brings. More attention is being paid to the nonmotor symptoms of the disease, such as mood and sleep disorders and cognitive impairment. And findings mainly from Parkinson’s genetics studies have opened entirely new avenues to treatments that could slow, stop or even prevent disease progression, something no currently available treatment can do.



Photo courtesy of NBC

think/able and the power of optimism

The question we’ve heard most often this year at The Michael J. Fox Foundation is: After more than 20 years with Parkinson’s, how is Michael doing well enough to go back to work? There’s no simple answer. He acknowledges the good fortune he has in a loving, supportive family and financial independence, which have provided advantages in dealing with his disease.

One thing is clear: Michael is world-famous for looking at even his greatest challenges through a lens of optimism and humor. In a recent interview with *Rolling Stone* magazine, he said, “People said, ‘Are you sure you can take it on? Are you sure you can deal with it?’ And I said, ‘No, I’m not sure I can, but I want to and I have an opportunity to.’”

The power of that brand of optimism shouldn’t be underestimated. An ever-growing body of research links a great attitude to better long-term health outcomes. (A 2010 study published in the American Heart Association’s journal *Circulation* showed that optimists and those with a sunnier outlook on life were 14 percent less likely to die from *any* cause than their more pessimistic counterparts.) Taking an optimistic view also often goes hand-in-hand with feeling

empowered to shape your own destiny.

In fact, the Foundation has launched its new think/able project in celebration of the optimism that led Michael both to launch our Foundation in 2000 and return to full-time acting 13 years later — optimism shared by the Foundation as it continues its hunt for a cure. The think/able community, aligned around the common goal of curing Parkinson’s disease in our lifetime, believes that “our challenges don’t define us — our actions do” and celebrates the everyday optimism and proactivity that help us all be more “like Mike.” We want you to be part of it — visit michaeljfox.org/thinkable to learn more and get involved.

After all, as MJFF Co-Founder Debi Brooks noted in a recent post for *The Daily Beast*: “Each day brings new hope, and we will keep at this until Parkinson’s is a thing of the past. Until then, we’re on a mission to make sure patients and those who care about them know that every one of us has what it takes to be part of the solution. So join us — the more involved we get, the better we are likely to feel. And the better we feel, the healthier we’re likely to be.”

“The Michael J. Fox Show” airs Thursday nights at 9:30 p.m. on NBC.



THE SHERER REPORT

A NOTE FROM OUR CEO

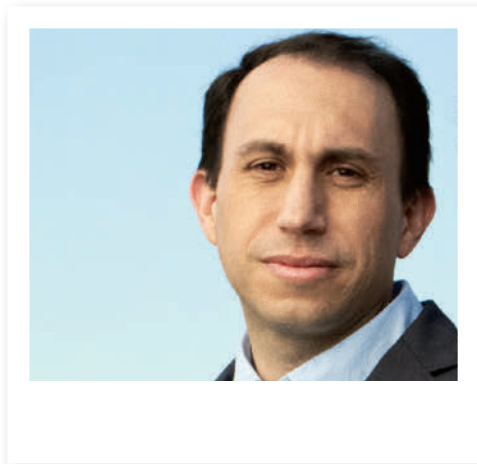
Todd Sherer, PhD, says now is the time to mobilize around PD research

I'm one of the millions who's been tuning in to NBC for "The Michael J. Fox Show" on Thursday nights this fall. While I'm laughing along with the rest of the country, Michael's return to his own sitcom means more than a new favorite show for us in the Parkinson's community. It has created a fresh opportunity to reflect on our shared goal of finding a cure for Parkinson's disease (PD) in our lifetime.

As I recently wrote in *Scientific American*, for the five million Parkinson's patients worldwide, the current status quo is not nearly good enough. Medication and therapies alleviate some symptoms, but create their own problems and fail to address all the effects of PD or stop disease progression. And for every patient, a community is affected, as the impact of PD ripples to loved ones and caregivers. This is a global problem — one that we can and must solve.

Looking back over the last year, we have made some strides. There's still much work to be done, but we know more than we did and those discoveries will shape our future research.

We're taking steps toward establishing biomarkers. The first published results out of the MJFF-led Parkinson's



Progression Markers Initiative (PPMI) — in *JAMA Neurology* in August — show lower levels of some proteins in spinal fluid of PD patients compared to levels in healthy controls. These findings were from a subsample of the 600 PPMI participants, so our next step is to validate these outcomes in the larger group. We're also going to test these levels in the same patients as the study goes on to monitor for changes. We're optimistic that this may be a biologic marker that we can use to diagnose and track PD.

We're hastening translation of genetic discoveries into Parkinson's treatments.

We know some gene mutations underlie Parkinson's risk, onset and progression. We're funding research and organizing scientists to understand the pathology and mechanisms of these mutations so we can learn how to approach them with interventions to offset their effects. What we learn about genes like alpha-synuclein, LRRK2, Parkin and Pink1 will inform development of disease-modifying therapies for the broader Parkinson's community, including those with idiopathic disease.

One of the first of these therapies is in clinical study; we've funded a trial testing a vaccine from AFFiRiS AG that targets

and helps remove the alpha-synuclein protein, whose clumping is the pathological hallmark of PD. Additionally, MJFF-funded research investigating the GCase enzyme in the brain is the basis of a promising new partnership between biotech Amicus Therapeutics and pharmaceutical company Biogen Idec. Loss of GCase enzyme activity, from mutations in the GBA1 gene, has been linked to alpha-synuclein accumulation. A drug targeting this mechanism could be disease-modifying.

We're diving deeper into non-motor symptom treatments and better delivery of levodopa.

Our sponsored Phase 1b clinical trial of Sanofi's drug AVE8112 to treat mild cognitive impairment in PD patients is under way, and we're working with the U.S. Food and Drug Administration to construct the most efficient paradigm for getting new cognition drug candidates approved. We're also funding a study to test a drug therapy for chronic constipation and studies into orthostatic hypotension and heart rate variability among PD patients. Just this fall, MJFF research partner Civitas Therapeutics announced a \$38-million deal to complete the Phase 2b study of their inhaled formulation of levodopa and initiate a Phase 3 study. (Read more on p. 8.)

And so, with purpose re-examined and determination redoubled, we head into 2014. Here are our promises to you:

- *Until there is a cure, we will never ease the pedal off high-impact Parkinson's research.* We're on the cusp of critical findings and game-changing discoveries, such as biomarkers. With your help, we have made significant strides toward breakthrough treatments, and more new Parkinson's drugs are in development than ever before. We need your support to keep these moving forward.

- *We will create robust platforms for patients and their loved ones to participate in and directly inform Parkinson's drug development.*

Technology today exists to expand the role of patients in research far beyond chat board information sharing and support. MJFF is pushing forward technological solutions to gather data directly from patients, then make it available to researchers, enabling investigators to develop new therapeutic avenues directly tied to patients' greatest needs.

- *We will continue taking calculated risks to forge a path that can help define the next generation of scientific collaboration.*

I fervently believe that partnerships are the path to better treatments and cures for Parkinson's, and you'd be hard-pressed to find many scientists who disagree. The problem is, investigators still work in a system that feeds on secrecy and competition. Our Foundation is working hard to conceptualize and implement new models for collaboration.

Michael J. Fox is fiercely optimistic, and I'm so glad to see him back on the screen. His attitude is infectious, and it's inspired us all here at the Foundation to dream of the day when every Parkinson's patient can return to a career they love — or better yet, never leave it in the first place. I hope it inspires you, too. The cure is out there. Together we'll find it.

Todd Sherer

Tell me what you think about these reports — and what you'd like me to cover in future editions. Email theshererreport@michaeljfox.org.



'BETTER' LEVODOPA WOULD 'MEAN EVERYTHING TO ME'

BY NATE HERPICH

The days vary greatly for Ellen Maguire, 54, an artist living with Parkinson's disease. Often, she spends hours working in her studio to create stained glass mosaics (read more on p. 24). But on other days, she feels like she's unable to get much done, stuck in a state of feeling like she's "moving through pudding."

Maguire experiences the roller coaster of "on/off periods" common to many people taking Parkinson's medication. Every three hours or so, she takes levodopa/carbidopa. On the good days, she can feel the medicine kick in quickly like magic; on the bad days, she feels little therapeutic effect.

"The off periods remind me almost every day that I have this disease," she says. "So I focus on the day I'm in because I never know what tomorrow will bring."

Improving an imperfect gold standard

It's a common refrain for many Parkinson's patients: What will tomorrow bring? Unpredictable on/off periods can greatly interfere with daily life, and are perhaps the major concern for people living with PD today. For this reason, in addition to looking for new drugs, The Michael J. Fox Foundation and the Parkinson's field at large are hard at work to improve existing treatments so that they more consistently deliver therapeutic benefits.

The key to success: finding better ways to deliver, and then maintain, therapeutic levels of levodopa in the bloodstream. "An improved delivery method is what I've always hoped for," says Maguire. "Something that would even out my days would mean everything to me."

Since it was first prescribed for Parkinson's in the late 1960s, levodopa has been the so-called gold standard therapy for PD. Today, people with Parkinson's take the drug in conjunction with carbidopa, a therapy meant to prolong the life of levodopa in the bloodstream, and, in turn, its therapeutic effect. But this combination, as Maguire can attest, is still largely imperfect.

Inhaled relief from on/off periods

The good news is, the past few years in PD research have returned significant and positive clinical study results for new therapies that have been shown to lessen on/off periods in people with PD.

This spring biotech Civitas Therapeutics announced positive clinical trial results for their inhaled formulation of levodopa, called CVT-301. The Phase 2a study, funded in part by MJFF, showed that, when administered to patients in an off state, CVT-301 provided a rapid improvement in motor function.

CVT-301 is designed to work as a sort of "rescue drug" to be taken in conjunction with the traditional pill form of levodopa/carbidopa. The idea is that patients would be able to self-medicate by taking a puff from an inhaler when they feel an off period coming on. This puff would bring the amount of levodopa in the bloodstream back to a level that provides a therapeutic effect.

The device, similar to an asthma inhaler, is small enough to fit in a jacket pocket or a purse. And it works fast — in some cases, in just five minutes. Here's why: Any drug delivered via the lungs will get into the bloodstream faster.

"Recently, MJFF committed to partially fund our Phase 2b study of CVT-301. This grant was an important milestone that helped us secure an additional \$38 million of venture capital funding to support the balance of our Phase 2b trial and the

initiation of our Phase 3 studies in the second half of 2014. Upon completion, we should be in a position to file for FDA approval — with the goal of having CVT-301 available to patients soon thereafter," according to Civitas CEO Glenn Batchelder.

Other methods deliver positive clinical results

Inhaled delivery isn't the only treatment in development. Other promising approaches in various stages of clinical testing include:

- A levodopa/carbidopa intestinal gel (LCIG) delivered into the small intestine via a pump attached to the body during waking hours. In 2012, AbbVie (formerly Abbott) announced positive Phase 3 clinical results that showed the pump could reduce off periods by as much as four hours per day, while on time without dyskinesia increased by more than four hours. LCIG is already available in Europe under the brand name Duodopa.

“.....
Something that's even a little more consistent would change my life... It would be the biggest thing I could hope for.
”

- A levodopa/carbidopa "pump patch" from Israeli drugmaker Neuroderm is a device no larger than a credit card, made up of a reservoir where the drug is stored, and a series of painless micro-needles, which pump the therapy under the skin and into the bloodstream continuously. The company shared positive Phase 1 results last spring. Not long after, MJFF announced support for a planned Phase 2 study to better understand its efficacy.

- Improved pill forms of levodopa/carbidopa could also ease on/off periods. In 2012, Intec Pharmaceuticals announced positive results from a small proof of concept study into an "accordion pill" formulation of levodopa. The pill is compressed into capsule form, then opens slowly in the stomach, providing a more continuous release of levodopa into the body. MJFF is currently funding Intec for follow-on research.

Hope for a more consistent day

"It's encouraging that so many therapies designed to improve the delivery of levodopa into the bloodstream are currently in clinical testing," says MJFF CEO Todd Sherer, PhD. "We look forward to working closely with these companies to drive such promising research to the next level.

"Still, there's much work to be done to help those living with the disease today. We hear from many Parkinson's patients about their struggles with on/off periods and dyskinesia. To be able to make a real difference for these patients, and to do so in the not-so-distant future, would be very meaningful for them."

Patients such as Bud Coughlan, of Pride's Crossing, Massachusetts, takes his medication every two hours. But on most days, he feels little, if any, therapeutic effect after lunchtime. He maintains a positive attitude and exercises regularly, saying, "I'll do whatever I can do to get through my experience with PD."

But still, there are those moments when he can't participate in activities with his granddaughters or wife, Angie. "Something that's even a little more consistent would change my life," he says. "I could see my friends and family more frequently. Honestly, it would be the biggest thing I could hope for."



ANSWERING QUESTIONS FASTER: POSITIONING RESEARCH FURTHER TOWARD A CURE

BY MAGGIE MCGUIRE

Virtue or not, patience is not something you find a lot of at The Michael J. Fox Foundation. There is still much to be done to find the cure for Parkinson's disease, and we're working urgently to get there.

MJFF speeds the delivery of new therapies by identifying research roadblocks and building the infrastructure to overcome these challenges. While one might think of the lab scientist scratching his head in front of a row of test tubes, the race toward discovery includes non-scientific hurdles, too. Difficulties in recruiting clinical research volunteers, sharing resources and obtaining regulatory approval can all slow

the already long journey from hypothesis to clinically available treatment. Foundation initiatives are working to move past these impediments to breakthroughs.

Connecting patients and healthy volunteers with studies

Before a new drug or treatment can be made available to the public, scientists must prove that the intervention is safe and effective and figure out what dose works best. Clinical research needs volunteers to help answer these questions, but studies have strict requirements for participation.

It can be difficult to find people who meet these eligibility requirements.

It is even more difficult to find people who are eligible, live near the study site and want to participate. The frustration works both ways, too. As an enthusiastic potential research volunteer, you may run into trouble finding the studies in your area that you are eligible for. Some scary statistics: Thirty percent of all clinical trials fail to recruit a single subject, and 85 percent of trials finish late due to recruitment troubles. Despite a willingness to participate, fewer than 10 percent of PD patients take part in trials.

The MJFF Fox Trial Finder Web site lets interested Parkinson's patients and their loved ones (who can participate as healthy controls) create a secure profile with basic demographic information and medical history. The tool reviews clinical studies in our database and refers matches based on geography and eligibility requirements. Fox Trial Finder also lets researchers search the database for volunteers who may be eligible for

their studies. With more than 23,000 volunteer profiles and over 300 studies at sites around the world, the system advances research by bridging the gap between interested participants and the studies that need them. (Read more on p. 21.)

Sharing resources to identify biomarkers

Most studies exist in silos where researchers recruit their own volunteers, collect and catalogue data as they see fit, analyze their results and then publish their findings years later. There is a better way. The MJFF-led Parkinson's Progression Markers Initiative, which aims to identify biological markers of PD onset and progression, makes de-identified data from its more than 660 participants available to qualified researchers after an easy online request process. To date, PPMI data has been downloaded close to 90,000 times by researchers around the world, and the initiative has received 27 requests for biosamples.

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THREE QUESTIONS FOR A RESEARCHER: RUSH UNIVERSITY'S DR. JEFF KORDOWER

Among Dr. Jeffrey H. Kordower's titles are Jean Schweppe-Armour Professor of Neurological Sciences, professor of neurosurgery, director of the Research Center for Brain Repair and head of the Neuroscience Section at Rush University Medical Center. He's an international authority in the area of movement disorders, with special expertise in experimental therapeutic strategies for Parkinson's disease, and has authored landmark papers on cell replacement strategies and gene therapies. We're proud to call him a member of our Scientific Advisory Board.

We spoke to Jeff for our Three Questions

for a Researcher feature and learned what his days are like in and out of the lab.

MJFF: What is the biggest challenge you face in your research today?

JK: I have 15 people in my laboratory. It is a great challenge to maintain funding, especially NIH funding, to move research forward as well as support the individuals who work in my lab long-term. I'm a risk-taker, and the funding environment is generally risk-averse. We need more innovative projects and the resources to test new ideas. It'd make a huge difference if government funders, private industry and even patients themselves advocated

for the funding and resources to move progress forward.

MJFF: What is one thing people would be surprised to know about your daily work with PD?

JK: I think that people would be surprised that as a PhD neuroscientist I do a lot of work evolving into clinical trials with human patients. Many people think PhDs only work in the lab with experimental models and microscopes, but I have been involved in the design, execution and assessment of clinical trials, too.

MJFF: How do you unwind after work?

JK: I like to spend time with my girlfriend, Anne, and my sons, ride my motorcycle and scuba dive. I'm close to

my master of scuba diving certification, and I recently did a wreck dive off the coast of North Carolina. When I was diving around the wreck, I counted about 45 tiger sharks. It was awesome. I'm going shark diving again in the Bahamas next year. —MM



From left to right: SAB members Franz Hefti, PhD, Peter Reinbart, PhD, Joseph Jankovic, MD, Jeffrey Kordower, PhD, and Andrew Singleton, PhD

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POSITIONING RESEARCH FURTHER TOWARD A CURE

As PPMI grows this year to now examine pre-motor symptom biomarkers of PD, investigators will continue to share data. (Hear from PPMI volunteers on p. 20 and 34.) This real-time, open-access model strategically hastens the pace of research toward drug development and a cure.

PPMI also sets the stage for a quicker next generation of research. When drug compounds are ready for clinical testing, investigators have a pool of volunteers from PPMI who have already shown interest in participating in research and for whom researchers have a rich profile of information. Additionally, if PPMI characterizes a reliable biomarker for PD, drugs can be tested faster. Rather than waiting for a change in clinical symptoms,

TAKING RISKS TO REAP THE REWARDS

The drug development industry is a numbers game. To invest in a potential therapeutic, pharmaceutical companies, and even the government, ask researchers to show them why they think the intervention will work, and they want data. Researchers often face a funding dilemma — they design studies to get to more data...but, how do they get their studies off the ground before the compelling data exists? Parkinson's researchers come to The Michael J. Fox Foundation. We're strategic and ask for basis and background of a concept, too, but we take chances. We're eager to act on ideas faster, and we're not satisfied with the shuffle of drug development. We want to leap ahead.

MJFF invests in high-risk, high-reward projects to accelerate progress. Initial findings make these studies more attractive to industry and government, and we're happy to hand them off. That means we can focus on the next wave of innovation, and we'll keep it up until we get to a cure. —MM

researchers can measure any change on a molecular level. That information on the drug's results affects advancement through clinical testing and regulatory approval.

Addressing regulatory issues

MJFF is taking other steps to move drugs through the “valley of death” from laboratory discoveries to medications in patients' hands. Foundation researchers co-chaired a meeting with 40 key leaders, including 16 representatives from the U.S. Food and Drug Administration, in April to identify the regulatory requirements for pursuing therapy for mild cognitive impairment with Parkinson's disease (PD-MCI).

“Better understanding of who PD-MCI patients are, how to recognize PD-MCI through diagnosis, and how to measure improvement in these patients are critical steps to filling an unmet need so that treatments can be tested in the clinic and ultimately approved by regulatory agencies,” wrote MJFF's Lona Vincent, MPH, and Jamie Eberling, PhD, in an outcomes summary.

Attendees of the regulatory roundtable deemed that existing cognitive scales can be utilized for trials in the short-term, but to better serve patients' needs, the PD field can develop its own optimal scale for later studies. By driving these discussions, the Foundation progresses research down the road to clinically available therapies.

At MJFF we're in the business of answers. We strive to stay informed about the process of making things happen, and we're taking action. We're identifying the problems along the way and building infrastructure to overcome them to move us toward the big answer patients need: the cure for Parkinson's.



1 IN 2 PEOPLE OVER AGE 60 ARE LIVING WITH SMELL LOSS

100% OF MAJOR BRAIN DISORDERS ARE ASSOCIATED WITH SMELL LOSS

96% OF NEWLY-DIAGNOSED PARKINSON'S DISEASE PATIENTS HAVE LOST SOME ABILITY TO SMELL

7 IN 10 PEOPLE LIVING WITH SMELL LOSS DON'T KNOW IT UNTIL THEY ARE TESTED

ESTIMATES SUGGEST SMELL LOSS MAY PRECEDE A PARKINSON'S DISEASE DIAGNOSIS BY UP TO 10 YEARS

10 YEARS SMELL LOSS vs. DIAGNOSED WITH PD

Alzheimer's disease
ALS Huntington's disease
Multiple Sclerosis

SMELL & YOUR BRAIN

People over 60 who **DO NOT** have Parkinson's disease are needed

TAKE THE SMELL SURVEY

michaeljfox.org/takethesmellsurvey

THE MICHAEL J. FOX FOUNDATION FOR PARKINSON'S RESEARCH

A 2,400-KM PILGRIMAGE — WITH PARKINSON'S AND A POSITIVE OUTLOOK

BY LAUREN SHOOR

Many people living with Parkinson's find physical activities, such as walking, cycling and yoga, help them manage their symptoms. Yet few are likely to embark upon a 2,400-km pilgrimage. But Patrick Demoucelle has done just that.

Four years ago, Patrick and his wife, Anne-Marie, were considering where to travel with their young children during a holiday. On a whim, they decided to take a five-day hike from their home in Kraainem, Belgium, near Brussels, to the home of Patrick's parents. All four of the Demoucelles loved it and wanted to continue — but with their next journey they would set a truly lofty goal.

Their chosen destination: Santiago de Compostela, Spain. Known as the Way of St. James, this undertaking has been one of the most important Christian pilgrimages since the ninth century, when the remains of the apostle James were discovered in the city. For the Demoucelles, however, the focus has been more on their experience as a family, and living with Patrick's Parkinson's.



The Demoucelles en route to Santiago de Compostela



From left to right: Arnould, Patrick and Magdelaine Demoucelle

On his 40th birthday, Patrick was diagnosed with young-onset Parkinson's. This diagnosis would eventually lead them to “change everything,” when he and Anne-Marie quit their high-powered jobs to form their own firm. Today they think of themselves as “one man, one woman, one business, one charity.”

The Demoucelles' profession revolves around providing motivational training to executive clients, primarily in Europe. Their philosophy — both in their professional and personal lives — embodies the power of think/able. Patrick says, “We've made the choice to be positive at least 99 percent of the time. While it's not always easy, it's a gift you give yourself.” Anne-Marie echoes, “You can see the impact Patrick has on our clients. If he can be so positive while living with this disease, they believe they can, too.”

The couple also offers their training services pro-bono to The Michael J. Fox Foundation. “Not only is MJFF dedicated to curing this disease, they're working hard to make life more bearable for all of us living with PD now. So we want to help them be as effective as possible,” say the Demoucelles.

In 2012, they decided to further accelerate MJFF's efforts through a substantial financial contribution from

their Demoucelle Parkinson Charity. Say Anne-Marie and Patrick, “We invest in the organizations we believe can make a real difference.”

In their own lives, their family's multi-year trek to Santiago de Compostela has given them a new sense of purpose. During every summer holiday, they take a series of one-week hikes, each time picking up where they left off. With less than 700 km to go, they most recently crossed the Pyrenees, entering into Spain. Says Anne-Marie, “Every time we say the last week was our favorite yet.”

For Patrick, the pilgrimage has allowed him to monitor the progression of his disease, and to focus on “the here and now.” He says, “Don't give up, even

when you're 'off.' Walk backward if you can't walk forward. Train your body to keep moving, and train your brain to think positive. Positive energy has a positive impact.”

In two years, the Demoucelles will reach their destination — Santiago de Compostela's famous cathedral, where tradition calls for pilgrims to burn something. For Patrick, this will be a pack of dopamine, and the booklets of his medications. Their advice for other families living with PD? “Give yourselves little, realistic challenges,” says Anne-Marie. Patrick continues, “Even if it's difficult at first, you'll feel such victory.”



TAKING CARE TO SPEED A CURE — ONE MONTH AT A TIME

When her mother, Barbara, was first diagnosed with Parkinson's 15 years ago, Alexandra Cherubini was a college undergraduate en route to a semester abroad in Samoa. At the time, she knew little about the disease or what it might mean for the future.

While Parkinson's has been a challenge for her family, Alexandra shares that her mom is doing well. “As a family, we do our research and try to figure out what's most helpful to her,” she says. This is made easier by their close proximity, as she and her husband, Camillo Alvarez, and her parents all live in Boston.

Not long after Barbara's diagnosis, she and her husband, Julian, got involved with The Michael J. Fox Foundation. Over the years, they've supported MJFF financially



Barbara and Alexandra Cherubini

and hosted pre-race dinners for Team Fox marathoners as well as Research Salons in their home so Foundation leadership can provide updates to supporters in their community.

Both Alexandra and Camillo have joined her parents at several MJFF events, including the annual gala, *A Funny Thing Happened on the Way to Cure Parkinson's*. In 2011, shortly after the Foundation announced the \$50-million Brin Wojcicki Challenge, they decided to do more by setting up a recurring gift.

“The idea was sparked by the Challenge,” Alexandra says. “We wanted to take advantage of the opportunity to

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TAKING CARE TO SPEED A CURE

double our impact. And I was thrilled to learn there was a monthly giving program.” Since then, they have contributed \$75 each month.

“Too often I’ll set something aside I want to support but simply forget to do it. With my monthly gift to MJFF, I know it’s already taken care of.”

With a Boston group recently becoming

part of the network of Team Fox Young Professionals, Alexandra plans to expand her role in speeding a cure for Parkinson’s. (Read more on p. 32.) She feels the time couldn’t be better, with the excitement surrounding Michael J. Fox’s new show. “I love watching it,” she says. “There are so many things you can relate to when Parkinson’s is in your family. This will really help other people understand. The more awareness we can raise, the better.” -LS



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SPEED A CURE ALL YEAR LONG**

SET UP YOUR MONTHLY GIFT TODAY AT michaeljfox.org/monthlygiving

Every gift is 100%
tax-deductible.

It’s a safe and
easy way to give.

Change your
contribution at
any time.

Questions? Contact us at (800) 708-7644 or donations@michaeljfox.org.

TEXAS-SIZED TEAM FOX EVENTS

When it comes to their fundraisers, Team Fox members often say: “Go big or go home.” James Little and Pam Wood, Texans living with Parkinson’s in San Antonio and Dallas (respectively), have taken this mantra to heart.



James Little and his wife, Janan

“Personal touch” yields record results

James Little has spent his career in the oil and gas business and has always been involved in charitable causes. But after he was diagnosed with Parkinson’s five years ago at age 56, he decided to dedicate his efforts to The Michael J. Fox Foundation.

On May 2, 2013, James hosted his inaugural Team Fox event, a gala dinner at San Antonio’s Grand Hyatt, featuring a silent auction and musical entertainment. Among the more than 300 guests in attendance was San Antonio Major Julian Castro, who issued a



Pam Wood and members of her tennis team, who are helping with her Team Fox event

proclamation declaring it “Benefit for Parkinson’s Day.” That night James set a new record for a first-time Team Fox event, raising an astonishing \$201,000.

The response from his friends and family who generously stepped up to help was amazing, James says. “It was absolutely perfect. Not because of me, but because of everyone who contributed. And people are still talking about it months later.”

While pulling off such a huge event is a challenge, James sees it as a tremendous opportunity to generate awareness about Parkinson’s. He is already making plans for future Team Fox events.

A simple secret to his fundraising success is the personal touch. He explains, “I think it makes a real difference when you ask your friends in person for their help — and then follow up to thank them.”

“.....
When people understand more, they want to do whatever they can to support you.
.....”

Instead of allowing his PD to get him down, James says it has inspired him to find ways to convey to others what it’s like to live with the disease. “When people understand more, they want to do whatever they can to support you.”

“All you have to do is ask”

Team Fox member Pam Wood is also aiming high for her inaugural event. On November 23 she is hosting what may be Team Fox’s first-ever Western swing dance. With a “Wild West” costume competition and silent auction, “there will be something for everyone,” she says.

The idea came about after Pam attended a similar dance over a year ago, benefiting another charitable organization. Though not much of a dancer, she had the time of her life.

Not long after, she was diagnosed with young-onset Parkinson’s disease (YOPD). As she turned to The Michael J. Fox Foundation for more information, she entered the Foundation’s Facebook photo contest to help raise awareness. Pam quickly discovered her competitive streak (earning fifth place) and an online YOPD

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TEXAS-SIZED TEAM FOX EVENTS

support group. That's how she connected with Team Fox mentor Nancy Mulhearn, who helped get her event off the ground.

"People are interested and want to help," she says. "I've learned all you have to do is ask." As she has met more people in the Parkinson's community, she feels it is her mission to help fellow patients live better with PD. She says, "I feel the love of everyone behind me. And that motivates me to want to do even more."

Along with a rigorous exercise regimen,

which includes tennis, weight training, water aerobics and yoga, Pam volunteers her time for Parkinson's clinical studies. Currently enrolled in a biomarkers study and a voice training project, she continues to look for new trial match opportunities through Fox Trial Finder.

Pam has already surpassed her initial \$20,000 fundraising goal, so she upped it to \$40,000. She says, "For the first time in my life, I feel I have a real purpose — to raise funds and awareness for this disease. I want to do everything while I'm able to." —LS



UPCOMING TEAM FOX EVENTS

CONNECT WITH THE PARKINSON'S COMMUNITY NEAR YOU AT A TEAM FOX EVENT!



1.30.14

SWING FOR A CURE
FORT MYERS, FLORIDA
michaeljfox.org/swingforthecure



3.19.14

WESTERN MASTERS ART SHOW
GREAT FALLS, MONTANA
westernmastersartshow.com



2.2.14

MIAMI MARATHON & HALF MARATHON
MIAMI, FLORIDA
teamfox.org/miami



5.4.14

TD FIVE BORO BIKE TOUR
NEW YORK, NEW YORK
teamfox.org/5boro



3.15.14

ROCK 'N' ROLL MARATHON AND HALF MARATHON
WASHINGTON, DC
teamfox.org/dcrocknroll



5.4.14

BMO VANCOUVER MARATHON AND HALF MARATHON
VANCOUVER, BRITISH COLUMBIA
teamfox.org/vancouver

FIND THESE AND OTHER TEAM FOX EVENTS AT TEAMFOX.ORG

**TURNING THE TABLES:
CLINICAL TRIAL COORDINATOR BECOMES A VOLUNTEER**

BY LIZ JOYCE

Laurie (who prefers not to share her last name) has worked for 20 years at a major university medical center as a nurse and coordinator conducting clinical trials. So when she was diagnosed with Parkinson's disease in 2009 at age 58, Laurie knew her course of action: participating in clinical research to be on the cutting edge of new therapies and contribute to a cure for her disease.

Soon after her diagnosis, Laurie learned of an ongoing NIH clinical trial that would cover all expenses for volunteers to travel to the Washington, DC, area to participate. "When I was the one running the trials, I saw how much my patients got out of it," she says. "I was all for it."

Over three days of blood and sleep tests, Laurie was impressed by the sheer amount and quality of the care she received. "A doctor spent three hours talking with me explaining every detail of the clinical trial, assessing my symptoms, and reviewing my overall medical history," she recalls. "After that, I was hooked."

In 2011, Laurie signed up for Fox Trial Finder, The Michael J. Fox Foundation's online clinical trials matching tool (foxtrialfinder.org), to find more PD trials. To date, Laurie has participated in more than 10 studies targeting cognition, symptoms, side effects and even the genetics of PD.

"It isn't scary," she says. And she appreciates the extra personal attention



Laurie (right) with her husband, daughter and Airedale terrier

she gets from the trial investigators, physicians and coordinators. "They are truly invested in you."

Three months after participating in her first trial, Laurie discovered the blood test had revealed a mutation in her LRRK2 gene, the most common genetic contributor to PD. Believing her sisters might also carry the mutation, making them prime candidates for PD genetics studies, Laurie urged them to participate, too.

Laurie's sisters aren't the only family members taking action to help speed a cure. Her daughter is running a marathon this fall to raise funds for Parkinson's research through Team Fox. Mother and daughter share a love of exercise, as Laurie enjoys doing Jazzercise, jogs five times a week and goes on hour-long walks with her two dogs each day to help manage her PD symptoms.

Every six weeks, Laurie signs in to Fox Trial Finder to explore new trial matches, send messages to coordinators and work toward participating in her next trial. "I want to help find a cure for this disease," she says. "The only way to get there is by seeing results in clinical trials. And the only way to see results is by getting people to participate. It's humbling to know you are contributing to improved medications, treatments and ultimately a world without Parkinson's."



CARE PARTNER SPREADS THE WORD ABOUT RESEARCH PARTICIPATION

Poughkeepsie, New York, is almost a two-hour drive from New Haven, Connecticut. Bob Hankin, a 77-year-old semi-retired homebuilder and land developer, makes the trip twice a year to participate in the MJFF-led Parkinson's Progression Markers Initiative (PPMI) at the Institute for Neurodegenerative Disorders in New Haven, one of 32 study sites conducting the study.

While Bob doesn't have Parkinson's himself, Marilyn, his beloved wife of 53 years, was diagnosed with the disease 18 years ago. Bob has taken part in multiple research studies as a healthy volunteer, or control.

"There's no question that participating in clinical research, especially in those studies where we're both involved, makes our bond stronger, and it certainly makes me feel better doing whatever I can to make my wife's life better," he says. Bob says he likes the access to top physicians and scientists at the cutting edge of research because "the quality of care is superb," and they are informed teachers about the disease and the state of the science.

“
The ultimate goal here is to find a cure, and, short of a cure, find the best way ... to live and manage the disease until the cure is available. You're only going to find that through clinical research.”



Marilyn and Bob Hankin

He feels so strongly about the role clinical research plays in the pursuit of a Parkinson's disease cure that Bob encourages others to participate. PPMI recently launched a new study arm looking for 100 people with known PD risk factors, such as smell loss, to identify biological markers of early disease. Since most people with smell loss don't know they have it, PPMI is asking anyone 60 years or older without Parkinson's to take a smell survey. Bob has handed out hundreds of promotional postcards at senior events encouraging his peers to take the survey and participate in the study if eligible.

"The ultimate goal here is to find a cure, and, short of a cure, find the best way for my wife — and the millions of others with Parkinson's — to live and manage the disease until the cure is available. You're only going to find that through clinical research," says Bob.

Learn more about the PPMI smell loss study and take the survey at michaeljfox.org/takethesmellsurvey. (Read more on p. 13.) —MM




FOX TRIAL FINDER BY THE NUMBERS

Fox Trial Finder is MJFF's online tool, helping connect Parkinson's patients and their loved ones with the clinical trials that need them. By participating in clinical research, these volunteers are speeding our progress toward a cure.

Below is a snapshot of Fox Trial Finder — by the numbers.*

 **23,375 REGISTERED VOLUNTEERS** are helping us reach our goal of **30,000 IN 2013** — and a cure in our lifetime.

 **77%** of volunteers have PD, **23%** do not.

 A global resource, Fox Trial Finder is available in **10 COUNTRIES AND 5 LANGUAGES**

Countries: United States, United Kingdom, Canada, Ireland, Australia, France, Germany, Italy, Austria and Spain

Languages: English, French, German, Italian and Spanish

458 PD CLINICAL TRIALS are currently recruiting volunteers.



500+ TRIAL TEAM MEMBERS use Fox Trial Finder to recruit study volunteers.



12% OF FOX TRIAL FINDER VOLUNTEERS report they have already enrolled in a study.



OVER 500 ATTENDEES

took part in MJFF's first clinical trials fairs in Chicago and New York City — connecting recruiting sites with the local PD community. Seven fairs so far are planned for 2014.

* As of October 25, 2013

DEEP BRAIN STIMULATION: A “LIFE-CHANGING DECISION”

Eight years ago, at 53, Dan Stark decided he needed to make a dramatic change.

He was taking 2100 mg of Sinemet (levodopa/carbidopa) a day to try and eke whatever lasting benefits he could out of his medication, with the hopes of getting some relief for his Parkinson’s disease. But severe dyskinesia resulted, essentially “ruling his life.”

Stark had read about a surgical procedure called Deep Brain Stimulation, or DBS, which works by stimulating malfunctioning motor circuits in the brain with electric pulses from a pacemaker-like device, offering real help for those struggling with the motor symptoms of PD and dyskinesia. So he asked his physician about the procedure and made what he now calls the “life-changing decision” to get DBS.

Since 1993, when the first positive study results were published establishing the use of DBS to treat PD and essential tremor, more than 100,000 people like Stark have undergone the procedure worldwide.

Still, DBS is not for everyone. Certain people respond more favorably to the treatment than others. Some are unable to undergo the invasive surgery to implant the DBS device, which usually involves two separate procedures for each side of the brain. Doctors also need to implant the lead and adjust it periodically. And it’s important to remember: DBS treats the symptoms of PD. It is not a cure.

Whom — and how — DBS can help

The mechanism underlying DBS’ therapeutic effect is not clearly understood.

(This is not uncommon; the mechanism of action behind many common medical interventions, including aspirin, remains unknown, as DBS pioneer Andres Lozano, MD, PhD, of the University of Toronto, has pointed out.) Scientists continue to evolve in their position on when, and how, the procedure might be most effective.

Physicians have begun, however, to better understand who might be good candidates for DBS, and who might not be. (Of course, you should always consult your physician to make decisions about your own personal treatment regimen.)

Irene Hegeman Richard, MD, a professor of neurology and psychiatry at the University of Rochester School of Medicine and a member of MJFF’s Scientific Advisory Board, provides a high-level profile of those who are typically good candidates for the procedure. They usually:

- Have idiopathic PD;
- Experience an excellent response to levodopa but have developed motor complications, such as wearing-off or dyskinesia;
- Do not have an unstable psychiatric condition;
- Do have good cognition;
- Do not have significant gait/balance problems when “on;” and
- Are healthy enough to undergo surgery.

Individuals who might be candidates for DBS must undergo a series of tests from their physician and various specialists in order to determine if they do, in fact, qualify for the procedure.

A long road to optimization

Even for those who are good candidates, and who make the nontrivial decision to have electrodes implanted into the brain, there’s still a long road ahead. The procedure often requires patients to return frequently to their doctor to fine-tune the

device. And after all of that, the therapeutic benefit can vary widely.

Stark, for one, noticed only limited therapeutic benefit in the first six months following the surgery. Then he changed doctors and found one who better understood the optimal settings for him — leading to a seven-year period of living almost symptom-free. Now eight years later, he will soon see his doctor to tweak the device, as he has recently noticed some symptoms return.

Evolution, expansion and new questions

Scientists continue working on DBS technology to maximize benefit and minimize complications. The treatment is currently being studied for its possible application earlier in the disease course, as well as its ability to treat non-motor symptoms of PD.

Lozano explains: “While DBS is very effective for the motor signs and symptoms of PD, it is less so for the non-motor and non-dopamine responsive features of the illness. But scientists are hard at work to better understand how DBS might treat these symptoms as well.”

Research has shown that DBS can be effective for a period of 10 years or longer; anything beyond this will push the existing frontier. New issues associated with surgical intervention at an earlier age are likely to surface, explains Lozano, including how the device, and the brain, respond to ongoing adjustments over time.

Lasting relief for some

As for Stark, he’s down to 400mg of Sinemet a day and plays tennis and golf regularly. Today, he says, “most people can’t even tell I have Parkinson’s disease.”

Harriett Dekker, who had DBS 12 years ago, and Avi Shefet, who just recently underwent the procedure, echo Stark’s enthusiasm.

Before DBS, Dekker struggled with bradykinesia. But since then, she has made

trips to New Zealand and Australia. More than a decade later, she says she believes DBS was a positive experience.

Shefet, for his part, says that he was unable to even turn over in bed prior to DBS. But post-surgery, he has already traveled to Europe and Israel. He’s even resumed his passion for sailing on the weekends.

“DBS gave me my life back,” he says. “I would do it again in a heartbeat.” —NH



NOTE: The medical information contained in this article is for general information purposes only. The Michael J. Fox Foundation has a policy of refraining from advocating, endorsing or promoting any drug therapy, course of treatment, or specific company or institution. It is crucial that care and treatment decisions related to Parkinson’s disease and any other medical condition be made in consultation with a physician or other qualified medical professional. Every patient is different, and responses to treatments like DBS may vary.

MJFF RECOGNIZES DBS PIONEER

Last May, MJFF awarded its Robert A. Pritzker Prize for Leadership in Parkinson’s Research to Alim-Louis Benabid, MD, PhD, widely recognized as one of the pioneers of DBS.



Benabid pictured center with Todd Sberer, PhD, and Michael J. Fox

GET MOVING!

In this ongoing series, people living with Parkinson's share their passion and how this activity is improving their outlook

**ELLEN MAGUIRE
MADISON, CONNECTICUT**

What's your passion? A year ago I started working with stained glass, using glass from old windows I've salvaged. It brings me such joy to see the light shining through a piece I've created and to share it with others. My husband, Mike, built a studio for me — called the Grout Grotto — and I spend 15 to 20 hours in it each week.

How does it help you? I feel lucky to have found my passion. It absolutely improves my quality of life and provides me with such a feeling of accomplishment. As with anything, I've learned to organize it to suit my on/off periods — doing the tricky work when I'm on and saving the easier tasks for when I'm not.



Is this a new pursuit for you? I've always enjoyed doing crafts, but had never pursued one art form like this before.

What else helps? I'm part of a small support group, and I'm grateful to have people in my world with PD. But I'm not about to let Parkinson's stop me from doing the things I love — like gardening, cooking and traveling. Although I've never enjoyed exercise, I stay active, eat a healthy diet, and stay up to date on the latest research.

How do you think/able? I don't give into PD and I'm not concerned with what others think or say. Everyone has something that's a struggle. Keep pushing yourself and incorporate something into your every day that brings you joy.



**ROB MCLAREN
HALIFAX, NOVA SCOTIA**

What's your passion? Recently diagnosed with PD, now it's exercise. I do Pilates several times a week at a studio and at home. When the weather is good, I bike, kayak and walk as much as I can. I have a training bike set up inside, which I used frequently while preparing for New York's Five Boro Bike Tour last May.

How does it help you? It's easier for me to maintain constant motion, so biking suits me well. And I feel like it's challenging my brain to make new connections. Stretching and building my core strength through Pilates keep me limber.

Is this a new pursuit for you? Now that I'm retired, I focus more on maintaining a regular exercise routine — which became a higher priority after my diagnosis. But I've always enjoyed cycling and had done several tours through Europe after university. When training for the Five Boro, I have to be more careful about fatigue and pacing myself.

What else helps? Once a month, I go for a massage, which relieves muscle strain. I've also found acupuncture

beneficial, although it doesn't stop the shaking. I try to avoid stress — being retired makes that easier.

How do you think/able? I try not to think too much about what may happen in the future — it's better to focus on the here and now. Create a balanced life — for me, that's exercising regularly, maintaining a

good diet and staying rested. And, of course, taking my pills on time. Along the way, you'll find various tricks that help you manage, whether it's cruise control while driving or the anti-shake feature on a camera. —LS



FROM POLITICS TO PARKINSON'S AWARENESS

BY LIZ DIEMER

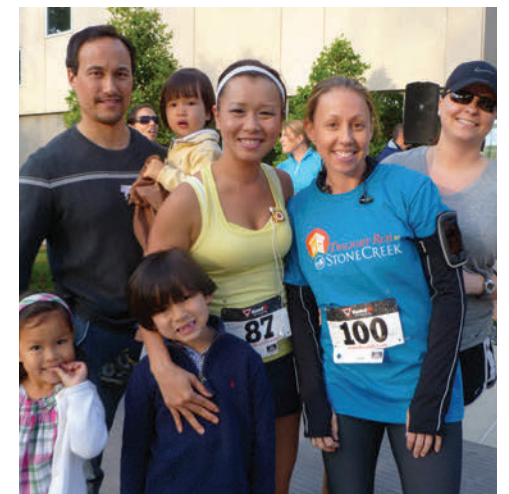
The Annual Stone Creek Twilight Run in Covington, Louisiana, is a unique family event. It kicks off at dusk and comprises a one-mile fun run, 5K race and celebratory post-race pool party with dinner, music and entertainment. Founded in 2010 by Team Fox member Quentin Dastugue and his wife, Penny, following Quentin's diagnosis with Parkinson's disease, the event is only the latest chapter in his longstanding commitment to community engagement. A New Orleans native, Quentin was first elected to the Louisiana House of Representatives at age 23 and went on to serve four terms. In his subsequent career in real estate, Quentin was known in the community for his active involvement in local charitable causes.

"One of the unanticipated surprises of having PD and hosting this event," says Quentin, "has been the unique friendships that Penny and I have been able to create with others directly touched by Parkinson's." Such was the case with Steve and Cynthia Kragthorpe, who joined the Twilight Run Committee in 2011 after Steve's PD diagnosis was made

public. An assistant coach for the Louisiana State University (LSU) football team, Steve recalls how "after meeting a Parkinson's friend in Quentin, I was inspired to join the effort to find a cure. Over the past two years, we have become great friends who have also enjoyed becoming MJFF supporters."

With a larger event committee on board, the Twilight Run expanded in 2011 with the addition of a formal Poolside Patron Party, held a few days before the race and featuring dinner, live music and a silent auction. Sponsored by corporations and local businesses, the Patron Party was a creative and successful way for the committee to broaden the donor pool while increasing the awareness around Parkinson's.

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Participants from the 2013 Annual Stone Creek Twilight Run

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FROM POLITICS TO PARKINSON'S AWARENESS

In April, Stone Creek 2013 brought together 250 runners and walkers who took part in the family-friendly events and festivities. More than 1,000 tickets to the Patron Party also were sold, with silent auction items ranging from golf outings and vacation home rentals to autographed sports memorabilia from LSU. "We have a great turnout year after year," Quentin says. "We're so grateful for the community's ongoing support of our efforts."

While event proceeds were initially split across a few organizations, this

year the event committee selected The Michael J. Fox Foundation as sole beneficiary. Proceeds totaled \$54,100, an all-time high for the event, earning a spot on the list of Team Fox's top 2013 fundraisers.

So what's next for the Stone Creek crew? "We'll continue expanding and improving our Annual Twilight Run events," says Quentin. "But we've also started exploring the possibility of adding a new fall event. We don't know what 2014 will bring, but we're ready to make it the best year yet."



CREATING COMMUNITY IN BREW CITY

Diagnosed with young-onset Parkinson's disease (YOPD) in 2006, Gene Jacobus didn't want to be defined by the disease, says his wife Colleen. But she knew a time would come when they'd be ready to get more involved.

They soon came across The Michael J. Fox Foundation, and as they learned more, they liked what they saw. Colleen says, "MJFF has a smart formula and a solid business plan. With no endowment, it's clear their only stake in the game is to cure the disease." In 2007, the couple decided to step up financially with a contribution, which they have continued since.

Last year the Jacobuses attended the annual gala, *A Funny Thing Happened on the Way to Cure Parkinson's*, and participated in the New York Research Roundtable. There they were introduced to fellow Wisconsin native George Prescott, a long-time member of the MJFF Board of Directors who has lived with Parkinson's for nearly 15 years. Gene says, "We were so impressed by George and everything he's done for the Foundation. Yet he's so



Pre-race dinner hosted by the Jacobuses

humble and friendly. His positive attitude keeps everyone going." That's when Colleen started to wonder how she could bring MJFF to Milwaukee, their hometown.

"I wanted to open up our network to the Foundation, and help connect everyone here who was touched by Parkinson's," she says. To share the latest in PD research with their community, the Jacobuses and Prescotts joined forces to co-host a Research Salon at their country club, held on June 14. And to tap into a

younger generation, Colleen decided to turn Milwaukee's Summerfest Rock n' Sole Run on June 15 into her very own Team Fox event.

Thanks to Colleen's background in fundraising and special events, everything went off without a hitch. During the Research Salon, Parkinson's patients and families appreciated the opportunity to hear about promising research from Brian Fiske, PhD, vice president of research programs at MJFF. "Living with Parkinson's is like a puzzle you're trying to fit together," says Gene. "So the more you know, the better." Along with the information he gained at the Salon, Gene learned about the need for clinical trial volunteers. "People have helped me in the past," he says. "If there's anything I can do to improve the future for other patients like participating in a trial, I'll do it."

Following the Salon, the Jacobuses hosted a spaghetti dinner at their home for the members of "Team Fox Brew City," who were taking part in the 5K, quarter marathon or half marathon the next day. With more than 70 runners on the team, they raised over \$35,000 — a very impressive sum for a first-time event. Colleen says, "The run was a fun way to bring everyone together. And it helped create more buzz around the Salon to get the right people in the room. Initially, you may think you don't know many people with PD. Surprisingly — and unfortunately — it affects more than you realize."

She continues, "At the Salon and the race, everyone had so much enthusiasm. For patients, it's helpful to see others like you. We'll definitely do this again next year. We want to keep up the momentum." —LS



RESEARCH AT YOUR FINGERTIPS:

Hear from experts in PD research at panel discussions, moderated by MJFF's Contributing Editor Dave Iverson.

UPCOMING HOT TOPICS WEBINARS

11.21.13
Surgical Interventions

12.11.13
What We Learned in 2013

LEARN MORE AND REGISTER AT
michaeljfox.org/bottopics

UPCOMING RESEARCH ROUNDTABLES

MJFF is coming to the following cities in in the next few months:

Boston, Massachusetts
(11.18.13)

Philadelphia, Pennsylvania
(11.19.13)

Keystone, Colorado (3.3.14)
Toronto, Ontario (4.9.14)

LEARN MORE AT
michaeljfox.org/researchroundtable

THE RECIPE FOR HOSTING YOUR OWN “MICHAEL J. FOX SHOW” VIEWING PARTY

On September 26 over 2,000 Foundation friends hosted premiere parties in celebration of Michael’s return to prime time with “The Michael J. Fox Show.” Keep the laughs coming throughout the season by gathering your friends and neighbors for a viewing party in your community!

BEFORE



CHECK

your local listings for when the show will air



INVITE

your guests using our custom invitations



CREATE

a plan for the evening’s activities



WHIP UP

party snacks with recipes from Michael’s wife, Tracy

DURING



SET

the vibe with Sam Fox’s favorite music, by friends of MJFF



READ

Michael’s special message to your guests



POST

your party photos online using the hashtag #ThinkAble



TEST

your Michael knowledge with our trivia game



WATCH

the exclusive on-set interview with Michael

AFTER



THANK

your guests for coming



ENCOURAGE

your guests to get involved at michaeljfox.org/ThinkAble



ASK

guests to share how they #ThinkAble to achieve their goals

NO AGE LIMIT FOR TEAM FOX

The Team Fox community brings together people of all ages. In this ongoing series, we talk with younger Team Fox members who are getting an early start on raising funds and awareness for Parkinson’s research.

**LUKE O’NEIL, 15
DARIEN, CONNECTICUT**

**Coast to Coast Bike Ride for Parkinson’s
Funds Raised: \$11,600**

Why Team Fox: My grandfather has Parkinson’s and I wanted to do what I could to help find a cure.

Why a cross-country bike trip: I decided to cross the country on a bike this summer because I knew it would be a challenging but unforgettable experience. I also hoped it would help me build courage and leadership skills.

Greatest challenge: The hardest day was biking 120 miles through the Mojave Desert and up the San Gabriel Mountains.

Greatest reward: Knowing that I would get to see my family at the end.

What’s next: Keep fundraising for Team Fox!

How I think/able: Choose something big and don’t forget to be creative.



Why Team Fox: My grandfather has been living with Parkinson’s for over 15 years.

Why races: I enjoy running — I’m on the cross country team at my high school.

Greatest challenge: Having to watch my grandfather deal with the disease and knowing that there is no cure.

Greatest reward: Knowing that I am doing what I can to help people with Parkinson’s.

What’s next: I am running a half marathon in October for Team Fox and focusing on my junior year while looking at colleges.

How I think/able: Don’t get hung up on raising huge sums of money — every little bit helps.



**IAN NORDEN, 16
NORTH HAVEN, CONNECTICUT**

**Hamden Road Race 5K, Connecticut
Irish Festival 5K, Independence Day
5000, Woodmont 5K
Funds Raised: \$750**



READY TO GET STARTED? Go to teamfox.org today to register and get your special online Party Planner.



Why a lemonade stand: We have had success with lemonade stands in the past and chose to also make crafts to help bring in more money.

Greatest challenge: Getting customers to come to our stand. But we did have one guy who donated \$100 and then came back to donate another \$100!

Greatest reward: Showing others that we are good citizens and that we will never give up on finding a cure.

What's next: We want to continue raising money for Parkinson's by selling our arts and crafts.

How we think/able: By believing we can find a cure!

JJ MALLORY (13), LAURIE FRATTINA (10), NICHOLAS FRATTINA (8), SHANNON MALLORY (6) AND ERIN MALLORY (10)

**BEACH HAVEN, NJ
Team Fox Summer Stand
Funds Raised: \$540**

Why Team Fox: To show support for our uncle, John Ryan, who has Parkinson's and runs marathons to raise funds with Team Fox.

**HANNAH STEPHENSON, 9
DANVILLE, CALIFORNIA**

**Projects for Parkinson's
Funds Raised: \$1,000**

Why Team Fox: My dad has Parkinson's.

Why Projects for Parkinson's: I picked projects like recycling and selling lemonade that I can do.

Greatest challenge: Recycling is a lot of work, and I need a lot of help to do it.

Greatest reward: All of the people that help me. My teachers at school, neighbors, friends and family bring me recycling and then help me sort and redeem for money. Two of my friends from Brownies donated their cookie money to me when they found out that it was going to Team Fox.

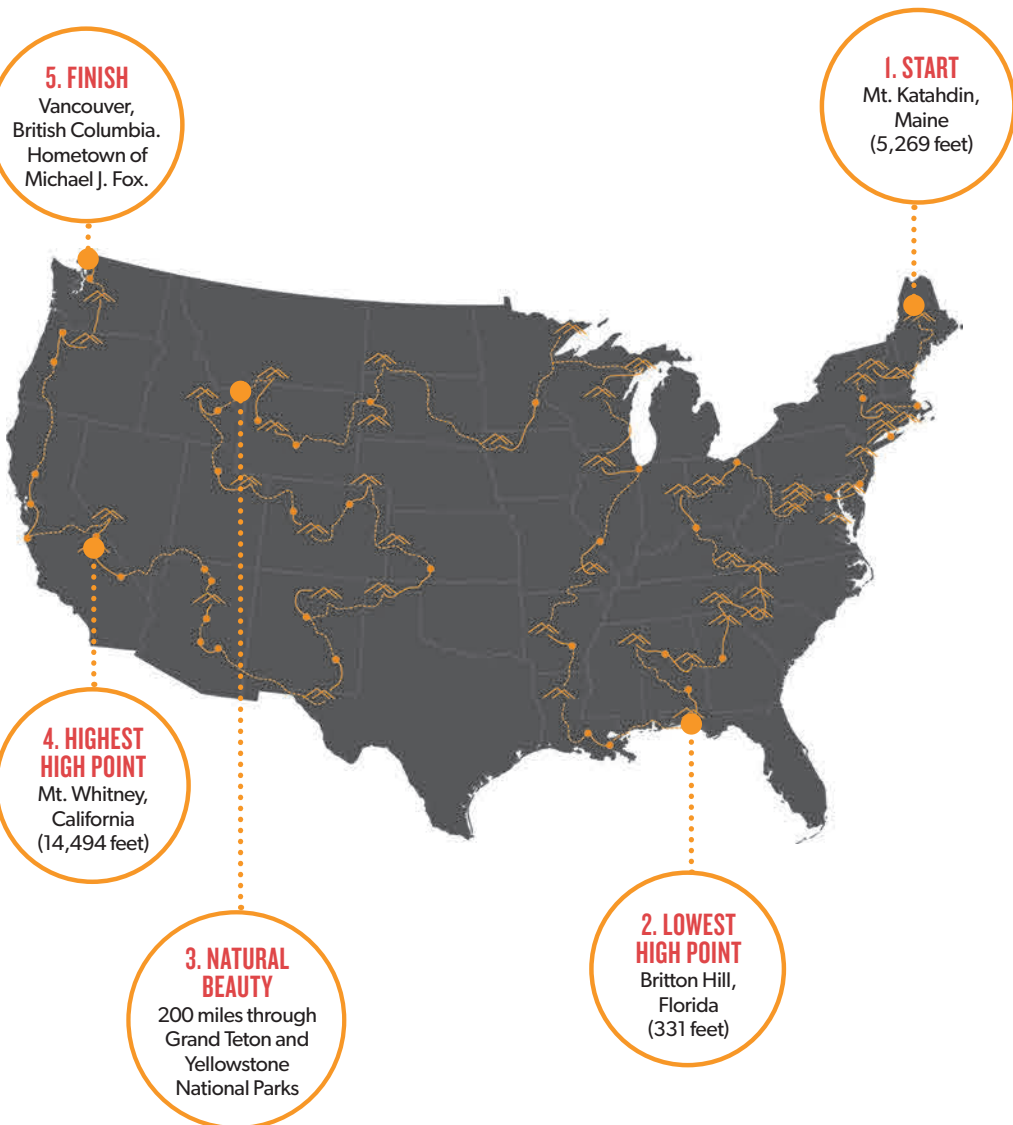


What's next: I hope to go to New York one day and meet Michael J. Fox!

How I think/able: Set small goals and work super hard. —LD

TOUR DE FOX

The Michael J. Fox Foundation is hitting the road...and the trail. You challenged him, and now MJFF staff member Sam Fox is ready to take it on. In the summer of 2014, Sam will bike more than 5,000 miles through all 48 of the lower United States, stopping to climb to each state's highest point along the way. The physical task is daunting, but the real test will be getting as many volunteers from the Parkinson's community as possible to join the Tour. See several of the route's highlights on the map below and start thinking about how you can be involved. Join in on a bike stage, climb a state high point, or attend one of the many Tour de Fox social gatherings across the country.



**FOR DETAILS AND HOW YOU CAN JOIN THE TOUR DE FOX
VISIT MICHAELJFOX.ORG/TOURDEFOX**

TEAM FOX YOUNG PROFESSIONALS

The Team Fox Young Professionals are networks of young people inspired to speed a cure for Parkinson's in their communities. Interested to learn more or join one of our groups? Email us at teamfox@michaeljfox.org.



BOSTON

Established in: 2013

Signature Event: Party for Parkinson's Gala



CHICAGO

Established in: 2012

Signature Event: Party Like a Fox Gala



NEW YORK

Established in: 2010

Signature Event: Sunday Funday



SAN FRANCISCO

Established in: 2011

Signature Event: Foxes and the Chocolate Factory



WASHINGTON, DC

Established in: 2013

Signature Event: Premiere Party for "The Michael J. Fox Show"

FROM THE PATIENT COUNCIL: STILL FLYING HIGH WITH PARKINSON'S



"A day at the office" for Astronaut Rich Clifford

Everyone on The Michael J. Fox Foundation's Patient Council has "a good story," and a unique experience living with Parkinson's disease. Michael "Rich" Clifford's story just happens to involve flying in outer space.

Rich was diagnosed with Parkinson's in 1994 at 42, four years after the former military test pilot was asked to join NASA's elite astronaut corps. Two years later, he was climbing aboard the shuttle *Atlantis*. While NASA's medical staff and senior management knew he had PD — and were confident in his ability to fly — few others were aware.

Of his decision to keep his PD private, Rich says, "I didn't want to be identified as the man with PD flying in space. Plus I felt the focus should be on the mission, not someone on the mission." Years later, he retired from Boeing in 2011, where he'd worked since his third and final shuttle mission. Not long after that, he opted to share his diagnosis with the public.

Since then, Rich has become an increasingly well-known figure in the Parkinson's community, speaking to support groups and PD organizations. He encourages patients to stay active by figuring out what works best for them. He says, "Learn everything you can about the disease and don't be afraid to talk to people — including your doctors. The more you know, the better you'll feel."

As a former astronaut, Rich is no stranger to medical testing and advocates participating in clinical research. He completed a profile on Fox Trial Finder (foxtrialfinder.org) and is recruiting others to follow suit. He's already taken part in a two-week vocal training study, which he credits for "giving me my voice back — when I hadn't even realized I was losing it." Rich also submitted his DNA for genetic testing to 23andMe. He says, "In the long run, early diagnosis of PD through genome analysis could help patients minimize the effects of the disease."

He first met Michael J. Fox, whom he calls "an inspiration to everyone," last year in California. Not long after, Rich joined MJFF's Patient Council, an advisory body providing strategic input across numerous fronts, such as how to best convey patient priorities to the research community and content for patient education and outreach.

"I'm honored to be a part of this Foundation, which is at the forefront of the field," Rich says. He appreciates MJFF's record of efficiency, with 89 cents of every dollar spent going straight to research. "They understand we won't have a cure for PD until we understand the cause." Along with his fellow members of the Patient Council, Rich hopes to help MJFF ramp up its fundraising efforts and spread the word about the need to invest in brain science.

Looking back, he admits he misses flying tremendously and, like anyone, has his moments of frustration with Parkinson's. But, he says, "I try to stay positive. And I can't say enough about people I've met with the disease. We're all looking for a solution." —LS



FROM THE BOARD: CHAIRMAN WOODY SHACKLETON

One Family's Pursuit of a Cure

In fall 1999, Woody Shackleton was at Foundry Networks when it earned a place in Wall Street history as the second-best initial public offering debut ever. Thanks to this success, Woody was able to retire early. But another door would soon open to him.

In 2001, Woody's father-in-law, Harry, was diagnosed with Parkinson's disease. Through the family's search to learn more, they stumbled upon the recently established Michael J. Fox Foundation. He credits MJFF with helping him and his wife, Denise, better understand PD and how their family could stay connected to the field's latest developments; they soon became significant donors.

Woody recalls: "The more people we met, the clearer it became that this group had the strategic vision and the right caliber people to chart a new course that would take us to the cure we all wanted."

The Shackletons' involvement with MJFF soon became a family affair. In 2006, Woody's younger daughter, Megan, joined the MJFF staff full-time, working there for the next four years.

In 2007, Woody became a member of MJFF's Board of Directors. At the time, one question before the Board involved Team Fox, launched the previous year. He says, "I really pushed to expand it as a means to increase awareness and raise funds for research. It's a tremendous feel-good community surrounding a shared cause." The remarkable subsequent growth of Team Fox, which has raised nearly \$25 million to date, is one of his proudest contributions as a Board member.



Woody Shackleton (pictured right of center) and his family

All four Shackleton children have carried the Team Fox banner. In her role as Team Fox Officer, Megan was instrumental in helping to advance the program; she also ran four marathons as a member, raising over \$66,000. In 2011, Courtney, the eldest, helped organize the San Francisco Young Professionals for Team Fox (read more on p. 32). And twins Kyle and Drew ran the 2009 Chicago marathon and qualified for the 2012 Olympic trials wearing their Team Fox bibs, donating their prize money to MJFF as the fourth and fifth American finishers.

At a Board meeting in 2011, Woody learned that the Parkinson's Progression Markers Initiative (PPMI) faced difficulty recruiting men over the age of 60 with no biological PD connection. Fitting those criteria, Woody agreed to participate. "It's good to be a part of the day-to-day combat to find a cure up close," he says of his participation.

Woody became Board Chairman in 2012, which he deems an honor and a privilege. As Chairman, he pushes for aggressive, novel approaches. "We must do whatever it takes to attract the capital required to keep driving all avenues toward a cure," he says.

"When the final chapter is written, not only will MJFF have played a key role in finding a cure for PD, but it also will have changed the paradigm for how medical research is pursued. That's a real game-changer." —LS

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FALL 2013