



THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

THE FOX FOCUS

ON PARKINSON'S

— SPRING 2013 NEWSLETTER —

PARKINSON'S DISEASE: MORE THAN A MOVEMENT DISORDER?

PPMI Expands to Define PD's Pre-motor Symptoms

BY NATE HERPICH

Last July at the Movement Disorders Society (MDS) annual meeting in Dublin, Ireland, scientists debated whether Parkinson's disease (PD) was rightly defined as purely a movement disorder.

More and more, scientists explained, research indicates that Parkinson's may involve multiple systems in the body beyond the central nervous system, and it may affect these systems before the motor symptoms of the disease set in.

Now the Parkinson's Progression Markers Initiative (PPMI), The Michael J. Fox Foundation's landmark study to identify biomarkers of Parkinson's disease, is expanding to address this evolving understanding of PD head-on. In 2013 the study is launching a pre-motor cohort to shed light on what happens in the body prior to the onset of PD's motor symptoms.

This new arm of PPMI focuses on three particular volunteer groups that could help scientists detect the presence of Parkinson's earlier, and develop treatments that more holistically address the disease. The study will evaluate and follow people who don't have Parkinson's but may be at increased risk to develop PD, including:

- people with a loss or reduced sense of smell;
- those with rapid eye movement sleep behavior disorder (RBD);
- those with a mutation in the LRRK2 gene (the single greatest genetic contributor to PD known to date).

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FROM THE EDITOR

Dear Friend,

Welcome to The Michael J. Fox Foundation's redesigned and renamed newsletter! With a new size and format, we hope it is easier for you to read, take with you, and share with others. You contributed our new name, *The Fox Focus on Parkinson's*, through our Facebook competition. Throughout the issue, you'll read about the people who are bringing their particular focus to our shared goal of making Parkinson's history — including scientists, patients, Fox Trial Finder volunteers and Team Fox supporters.

We value your contributions to our ongoing conversation about speeding a cure. "In Your Words" highlights your comments from Facebook and Twitter (p.3). And to help you get to know MJFF better, you'll hear from our CEO (p.6), members of our Scientific Advisory Board (p.5) and Board of Directors (p.30), and Contributing Editor Dave Iverson (p.16). We've also pointed out how to take action or find more information on our Web site (michaeljfox.org).

We know you value our efficiency, with 88 cents of every dollar we spend going directly to our research programs. From now on, we'll publish two newsletters a year instead of three. Every edition will be available online, with multimedia extras, at michaeljfox.org/foxfocus.

I look forward to continuing our conversation. Let me know what you think of the redesign, and what you'd like to see in future issues, at landerson@michaeljfox.org.

With gratitude,



Lauren Anderson
Associate Director, Development Marketing & Communications

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 therapies for those living with Parkinson's today.

The Fox Focus on Parkinson's is published twice a year by The Michael J. Fox Foundation. To subscribe or unsubscribe, email info@michaeljfox.org.

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IN YOUR WORDS

With more than 200,000 likes on Facebook and 18,000 followers on Twitter, The Michael J. Fox Foundation's social media space is getting conversations started across the Parkinson's community. Join in:

 **Twitter:** @MichaelJFoxOrg

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 **Blog:** blog.michaeljfox.org

michaeljfox.org @MichaelJFoxOrg
How has your family rallied in response to #Parkinsons? Share your responses w/ #PDlove

Drew Garber @mypointofdrew
My dad and grandma both have PD. They stay strong and positive, and do it with a smile. True inspiration. #PDlove

Jason @DubVfan
My grandpa had #Parkinsons and my aunt has it as well. I stay educated on the disease to help anyway I can. #PDlove

Lawren Romero @LawrenRomero
My dad was recently diagnosed. His positivity inspires me to learn more so that I can better support him. #PDlove

Sam Wollner @samwollner
Foundations are the new VC. @MichaelJFoxOrg will almost certainly be involved when a cure is found for PD.
—John Crowley @cbsbcconference

Adam Scott Bristol @AdamSBristol
Incredible. Making a real difference. MT @MichaelJFoxOrg has ~500 active grants and has funded \$313M since inception.

Dan O'Brien: I am honored to be a participant (starting today!) in a clinical trial in the Boca Raton, FL area through your Foundation and Dr. Stuart Isaacson. Thank you for the chance to make a difference!

Carol Ladner Loper: I never knew much about Parkinson's until my husband was diagnosed with it a couple of years ago...Glad I found the Foundation's site to read more about it. Thanks.

Gwen Schroeder @gweyen
My work for @TEAMFOX & @MichaelJFoxOrg continues to enrich my life, year after year. Help me do the same for others: bit.ly/gwen4teamfox

William Martin @BillMartinSF
Impressed @MichaelJFoxOrg is prioritizing #Parkinson's targets 4 both disease-modifying & motor & non-motor symptoms. #PDTc2012

Florence Hext Thompson:

I never knew about Michael Fox's foundation for Parkinson's research. How wonderful, I have an older brother who has it and it is sad to see him in this condition but I know that he is still who he has always been — a strong man and my sweet brother. He is doing better with the help of research. I thank you Michael J. Fox for all your effort. You ARE making a change.

Paul Chichester:

It is fantastic that a mainstream TV sitcom will depict a character with Parkinson's, showing us the human side, with humour, to the disease. MJF continues to pioneer in bettering the understanding of the condition on the world stage. I hope it is a huge success and gets aired in the UK.

continued from page 1 > **MORE THAN A MOVEMENT DISORDER?** “If scientists can learn more about the biological processes taking place in people with any of these three conditions, they may be able to define biomarkers at an even earlier stage,” says Ken Marek, MD, principal investigator of PPMI and president and senior scientist at the Institute for Neurodegenerative Disorders in New Haven, Connecticut. “This type of information could be vital for Parkinson’s drug development, leading to new targets for drugs to attack the disease before it starts.”

Since PD is a complex neurodegenerative disorder with many underlying causes that differ according to the individual, identifying a biomarker requires sophisticated methods of measurement targeted at various aspects of the disease. For this reason, a large-scale undertaking is required to bring scientists together toward reaching this critical goal. PPMI is that effort. Launched just two years ago, PPMI has already become an invaluable resource for the PD research community at large.

PPMI’s open-source research model means that well-characterized biosamples and robust clinical data are available to scientists around the world in real time — providing an immense, unprecedented resource to speed and unify disparate biomarker validation studies and bring therapeutic breakthroughs closer. To date, PPMI data has been downloaded more than 40,000 times by scientists.

In early 2013, PPMI hit an important milestone, as researchers from the University of Pennsylvania published the first ever paper using PPMI data (on impulse control disorders and PD). PPMI investigators made five presentations on different studies associated with PD at the Movement

Disorders Society meeting last summer.

“We are already seeing that people with Parkinson’s have different levels of certain proteins in their cerebrospinal fluid (CSF),” says John Trojanowski, MD, PhD, co-director of the Neurodegenerative Disease Research at the University of Pennsylvania. Trojanowski and Les Shaw, PhD, co-lead the PPMI Biomarker Core and were part of a team of PPMI researchers who presented at MDS.

To date, Trojanoskwi, Shaw and team have analyzed the CSF of more than 100 PPMI volunteers, finding that those with PD have lower levels of the proteins tau, alpha-synuclein and beta-amyloid in their CSF. Over the course of the next year, they will aim to further validate these results in a much larger study group.

“The hope is that through PPMI, we’ll eventually be able to establish a test for PD. It could be something that measures hormones in our blood or proteins in CSF and would be an invaluable tool to help us determine whether or not a person has the disease,” Trojanoskwi explains. No such diagnostic test currently exists for Parkinson’s disease.

While the initial cohort’s recruitment period is nearly complete, the new pre-motor cohort, and others being considered for the future, will continue to require the vision and investment of those who sign up to participate.

Theresa Salzer, 47, of Waynesville, Ohio, is one of those who have already devoted their time, and bodily fluids, to the search for a cure for PD. Diagnosed in March 2012, she has completed several PPMI visits at the University of Cincinnati study site.

Theresa learned that she had Parkinson’s following a visit to a hand specialist to address lingering discomfort in her hand. Prior to a potential surgery,

her physician recommended she visit a neurologist, who told her that she likely had PD. She then visited two more neurologists in order to confirm her diagnosis. In some ways, she says, she was lucky that the hand doctor had experience with Parkinson’s, and was able to help get the diagnosis right, and determine what was going on with her body before surgery. Often a Parkinson’s diagnosis can take years, and misdiagnosis is a common reality for many who later learn they have PD. Finding a biomarker could help to definitively diagnose people with the disease, and to do so earlier.

Theresa is hopeful that science will find a cure for PD in her lifetime. But, more than concerning herself with her

own health, she worries for her four sons, and the possibility that they could one day develop the disease, too.

“You have to get involved to make a difference,” she says. “I want to be able to say that I was a part of finding a cure for this disease.”



LEARN MORE

The pre-motor cohort of PPMI is recruiting three specific groups: those with RBD sleep disorder, those with a smell deficit, and those with mutations in the LRRK2 gene. To find out if you might be a candidate, visit michaeljfox.org/PPMI

GET TO KNOW: KEN MAREK, MD

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

KM: How to identify the people who might be at risk for Parkinson’s. This year, PPMI is expanding so that we can learn more about the biological changes that take place before symptoms arise. If we can figure that out, we may be able to develop drugs that might prevent Parkinson’s altogether.

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

KM: Parkinson’s is a complex disease, so the search for a biomarker requires a large-scale, collaborative effort like PPMI. The good news is, PD researchers from across the globe are collaborating every day. Already, scientists from 30 different countries



have applied to use data and specimens culled from PPMI. Our model is working, and I’m looking forward to seeing researchers use the data to find new ways to help patients.

MJFF: How do you unwind after work?

KM: I’m a big baseball fan, and spend a lot of my time rooting for the Yankees. I also like to write short stories. —NH



Ken Marek is a member of MJFF’s Scientific Advisory Board and the principal investigator of PPMI.

THE SHERER REPORT

A NOTE FROM OUR CEO

Todd Sherer, PhD, shares how far we've come in PD research, and what lies ahead.

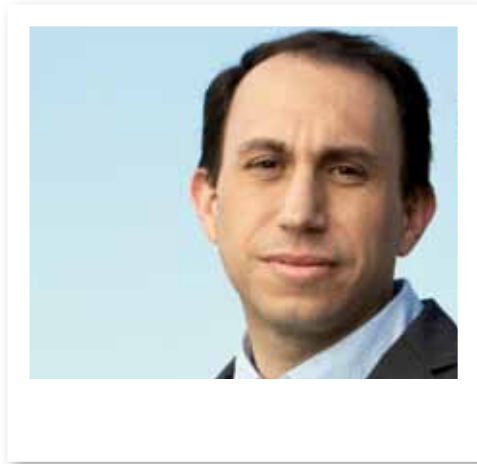
This Parkinson's Awareness Month, The Michael J. Fox Foundation (MJFF) recognizes the vast progress we've made in Parkinson's research in the 12 years since our inception — and thanks you for being an instrumental part of our work.

Today we have moved tangibly closer to real results for patients. And I am optimistic that the momentum we've built over the past year in particular will continue to propel us forward to the goal we all want to reach — new treatments, and a cure for Parkinson's.

In 2000, this was not the case. The field was at a crossroads: Scientists had a limited understanding of the biology behind Parkinson's disease (PD); symptomatic treatments almost exclusively focused on dopamine-based drugs; and no centralized force existed to coordinate PD drug development in a field that was quickly losing interest.

But while we've made a lot of progress, in many ways we're just now getting to the hardest part. The good news is, with your help, we're ready to tackle new challenges head-on.

Here are a few examples of how far we've come, and what lies ahead: Researchers continued to make significant strides in 2012 toward better



understanding the biological processes at work in PD — essential knowledge to developing treatments that could slow, or even stop, the disease from progressing in patients' brains and bodies. Last fall, we had the opportunity to convene a workshop to address a budding hypothesis in the field — that the protein alpha-synuclein, which behaves abnormally in the brains of all people with PD, spreads from cell to cell. This evidence is providing us with new insight into the onset of Parkinson's disease, and its progression. In fact, the first-ever alpha-synuclein-based drug candidate, which entered clinical testing last year, works by addressing this cell-to-cell transmission of alpha-synuclein. The research is sponsored by Austrian biotech AFFiRiS with MJFF funding, and results are expected by year-end 2013.

More and more scientists believe that better Parkinson's treatments will bypass the traditional focus on the dopamine system. Recent clinical trial results show that the pipeline for novel, non-dopamine-based therapies to treat the symptoms of PD, and dyskinesia, is strong. Novel drug candidates targeting brain chemicals such as glutamate, serotonin and adenosine all yielded encouraging returns in the clinic. But the

road ahead is marked by substantial hurdles, as pharmaceutical companies such as Addex Therapeutics work to push their drug candidates through stringent testing that will cost millions of dollars. Follow-on funding, even when results are good, is never a sure thing.

The good news is, I can say with confidence that in my 15 years in PD research, I've never before seen the kind of enthusiasm from industry to delve into the Parkinson's space that I see today. Our Foundation is working urgently to bring together all the key players to make sure novel ideas get traction, and then lay out the next steps to get these ideas into the clinic.

In 2012, we entered into a first-of-its-kind collaboration with Sanofi to develop an existing Alzheimer's drug candidate for Parkinson's-related cognitive decline. I'm happy to report that a clinical study launched in early 2013. Also last fall, Vanderbilt University partnered with Bristol-Myers Squibb to develop a glutamate-based drug that represents an entirely new class of treatment for the symptoms of Parkinson's disease. These kinds of relationships, merging scientific innovation with industry resources, will ultimately be critical to bring new treatments to market.

But as you know, drug development is expensive and risky. Decades are invested, and billions of dollars spent, on treatments that all too often languish in "the Valley of Death" — that resource and expertise gap where an idea born in a university or biotech loses steam, and fails to secure the necessary support to move forward toward the clinic. None of the successes I've discussed in this report are immune to this challenge. Ongoing progress depends on strategic investment and collaboration, certainly among scientists, but especially from the Parkinson's community.

Here, too, I see good news: The PD community's desire to do their part and get involved is greater than ever. For instance, through the growing Team Fox network thousands are coming together to forge new bonds and take action locally. Thousands more are speeding research by completing profiles on Fox Trial Finder (foxtrialfinder.org), where they are matched with the clinical trials that need them, and which will be expanding into Western Europe this year. As you read in our cover story, thanks to hundreds of volunteers around the globe, we are close to meeting the original recruitment goal for PPMI. Additional opportunities exist to be a part of this landmark biomarkers study through the newly launched pre-motor cohort of PPMI, which is searching for individuals who do not have Parkinson's but do have smell deficits, a sleep disorder called RBD, or a mutation in a gene called LRRK2. People who have lived with the disease for several years are also taking part in critical research to identify new biomarkers through BioFIND, a discovery effort that launched last fall.

Whether you contribute by participating in research, attending a Team Fox event in your community, or making a gift to the Foundation, you are invaluable to our progress. We count on you for so much, and I'm truly grateful for your dedication. The answer is in all of us, working together. This Parkinson's Awareness Month and all year long, thank you for all you do.

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.

CLINICAL RESEARCH VOLUNTEER “JUST KEEPS ON TRUCKIN’”

While participating in a clinical study can be as simple as giving a blood sample or spitting in a tube, it can also require time, money and energy. Recognizing the effort required on the part of patient collaborators in research, Parkinson’s trial personnel typically express tremendous gratitude for every single volunteer who signs up.

Nadine Wiand, 56, a nurse and Parkinson’s patient from Youngstown, Ohio, is taking clinical research participation to another level: She has now participated in four studies. And she’s constantly looking for more.

Nadine first found her opportunity to get involved with clinical research when she picked up the December 2011/January 2012 issue of *Neurology Now* with Michael J. Fox on the cover. In it, she read about Fox Trial Finder (foxtrialfinder.org), the Foundation’s clinical trial matching tool. When she got home, she immediately logged on and completed a profile.

Her first thought: Wow, this is really easy to use. “I’m not computer savvy at all,” says Nadine, “but in very little time at all, I was already finding potential matches. If I can navigate my way through it, anyone can.”



Nadine Wiand with her granddaughter, Lauren

Nadine has participated in a genetics study, one on dyskinesia and another on the non-motor symptoms of PD. She’s also sent in her at-home DNA kit to MJFF research partner 23andMe, to be a part of their growing community of people with Parkinson’s — a valuable resource for researchers looking to learn more about genetic contributions to the onset and progression of PD.

Nadine continues to look for more ways to get involved in clinical research. She doesn’t plan to stop, even after she’s gone — she intends to donate her brain to science when she dies.

“Maybe my purpose in life is to be a part of science,” she says. “It’s rewarding that people are able to learn from me, and from my condition. Sure, there are good days and bad days. But I take one day at a time. I just keep on truckin’.” —NH



READ MORE

Scan this code with your smartphone to read the *Neurology Now* interview with Michael J. Fox on Fox Trial Finder. Get a free mobile app for your smartphone at <http://gettag.mobi>.

FOX TRIAL FINDER SEEKS 30,000 REGISTERED VOLUNTEERS THIS YEAR

Officially launched in April 2012 to help increase the flow of willing volunteers into clinical trials that urgently need more people, Fox Trial Finder (foxtrialfinder.org) already has made inroads into the problem: 15,000 people with and without Parkinson’s disease have completed profiles to find the best trial matches and be alerted when new trials begin. In 2013, Fox Trial Finder is taking on the ambitious goal of attaining 30,000 registered volunteers. The site is expanding into Europe while continuing to pursue new U.S.-based volunteers.

“While 30,000 volunteers sounds impressive, even that number is merely a milestone on our path. Estimates hold that it would take at least 70,000 volunteers to fully populate every clinical trial under way in Parkinson’s today,” says Debi Brooks, co-founder and executive vice chairman of MJFF. “We continue working to educate our community about the urgent need for patient collaboration in research, and to provide tools that make it easier for patients and their loved ones to get involved.”

In early summer, foreign-language versions of the Fox Trial Finder site will begin to launch in France, Italy, Spain, Germany and Austria. The expansion will add more than 200 new Parkinson’s disease trials to the Fox Trial Finder database. MJFF is also focusing on increasing registered English-speaking volunteers in the United States, United Kingdom, Ireland, Australia and Canada.

New technology will support Fox Trial Finder’s growing numbers. A recent update makes it easier to keep track



Fox Trial Finder Ambassador Hal Halvorsen and his wife, Mary

of your matches — volunteers will now receive weekly email alerts when a new trial is recruiting in their area and needs participants who match their profile. Future updates will continue to improve the user experience for both volunteers and trial teams. —NH



PARTICIPATE IN RESEARCH

Visit foxtrialfinder.org to complete your profile today.

“By signing up for Fox Trial Finder, you are reducing enrollment delays and speeding vitally needed results from clinical trials. Even if you haven’t yet found a trial that is the perfect match, one will come along that needs someone just like you. Through your participation, you help eliminate a critical roadblock in our path toward better treatments for patients.”

—Danna Jennings, MD, Institute for Neurodegenerative Disorders

HOPE FOR A “NORMAL” LIFE — FOR PATIENTS AND FAMILIES

BY LAUREN ANDERSON

“It’s easy to allow a chronic illness to take over a family’s life,” she says. “So you try to keep life as normal as possible, as long as possible.” Adds her husband, who has had Parkinson’s for over 30 years, “I may live with it because I have to — but I haven’t let my disease define who I am.”

The couple of 46 years, who prefer to remain anonymous, first became involved with MJFF not long after its doors opened. An attorney, he was diagnosed while still in his 30s, at a time when there was little or no awareness of young-onset Parkinson’s disease (YOPD). She was an educator, and their son was still in elementary school. It could be difficult, at times, to keep family life normal. She says, “It’s not easy to have a parent with this disease. Our son couldn’t play catch with his father, and that was hard on both of them. But today we’re so proud of how sensitive he is to helping others.”

Since their retirement, they’ve been able to spend more time with their son, who now has two young children of his own (currently at “delicious ages,” according to their grandmother).

Today, they stress the importance of finding a movement disorders specialist, especially for the newly diagnosed. “We’ve seen what a difference this makes, both through our experience and that of our friends — now that we’re at the age when people are typically diagnosed,” he says.

When The Michael J. Fox Foundation

was launched, Parkinson’s had already been a part of this family’s life for almost two decades. They tuned in immediately to his announcement, along with the rest of the nation and the world. “It’s been incredible to see the attention Michael and his Foundation have brought to this disease,” she says.

“A friend invited me to join her at a Research Roundtable the Foundation was hosting,” she continues. “I was so impressed with what I heard — the research, the approach and the people. We became contributors early on.” Since their first gift of \$20 in 2002, they have increasingly supported the Foundation each year.

Last year, the timing was right for them to make a significant contribution. He says, “The Foundation has always been a highly responsible steward of our contributions. They demand accountability from researchers and themselves.” His wife adds, “Behind any charitable gift is someone who’s worked very hard. Giving to MJFF, we’re confident our money is working just as hard to develop improved treatments. The Foundation understands Parkinson’s as a complex disease, and for that reason, they leave no promising stone unturned. They’re pursuing multiple targets and working with teams all over the world to speed progress.”

As they’ve watched the Foundation evolve, the couple has especially appreciated the development of Team Fox. “When an illness comes into a family, people want to make something good out of the bad,” she says. “Team Fox has enabled thousands of people at all ages to contribute in big and small ways. We’re grateful to the Foundation for giving the community a platform to advance research and feel empowered to help their loved ones with PD.”

While they are modest about their

philanthropy, family and friends have noticed their belief in The Michael J. Fox Foundation. And whether by directing gifts to the Foundation to mark important life events or by joining Team Fox, their loved ones have been inspired to get involved, too. “It’s meant so much to our family,” she says. “It’s a way for them to pay tribute to my husband.”

As anyone touched by Parkinson’s

knows, the disease affects the entire family. “While there may be one million people with PD in the United States,” she says, “millions more are impacted. The sooner we can find better therapies, the sooner all of our lives will return to normal.”

“Every day, you choose your own path,” her husband adds. “You take control.”



GET MOVING!

Work Out Your Parkinson’s Symptoms

Many people with Parkinson’s report that exercise helps them manage their disease. Five individuals talk about their routines — and how staying active is improving their physical and emotional outlook.

ANNETTE O’BRIEN WINTER PARK, FLORIDA

What’s Your Exercise Regimen? I take a Spinning class (three times a week) and Dance for Parkinson’s (twice a month). To stretch and weight train, I work out with a personal trainer two or three times a week. I also ride my three-wheeler bike, Trixie. My husband, Neill, and I bike together, and often visit my grandkids. Even if I’m having trouble walking, I can always pedal my bike.

How Does Exercise Help You? Dance has improved my balance, and is such fun. Even in a wheelchair, you can still do the hand motions. Spinning and bike riding help with my motor skills and prevent stiffness. The social aspect is my favorite part, especially since you can isolate yourself with PD if you aren’t careful. Everyone has different outlooks and symptoms, so we all help each other.



Annette O'Brien and Trixie

Are You New to Exercise? When I was young, girls’ sports weren’t emphasized. This is the most active I’ve been in years. I had DBS (deep brain stimulation) surgery last summer, which made such a difference — especially for my dyskinesia. I was able to ride Trixie before DBS, but couldn’t have done the Spinning or the dance classes to this extent. While I’m not the best in class, I keep on trying.

What Else Helps? I’ve participated in several clinical studies and feel I’m a part of educating the next generation. There are all these people helping you, the least you can do is try and help, too.

Any Words of Wisdom? Connect with others who have PD. You may think you’re alone, but you come to realize how many are touched by it — and are working toward a cure.



John Coppola

**JOHN COPPOLA
BROOKLINE, MASSACHUSETTS**

What's Your Exercise Regimen? I work out at the gym six days a week, alternating between 40 minutes on a stationary bike and 40 minutes lifting weights. In season, I play golf and walk the course. My golf game hasn't necessarily improved over the years, but it hasn't gotten any worse.

How Does Exercise Help You? I'm no world-class athlete, but exercise definitely helps me mentally. Although I may hate it while I'm working out, I feel pretty good once it's over. You're doing something to take action against the disease.

Are You New to Exercise? I've always been this active. After my Parkinson's diagnosis, I figured it couldn't hurt to keep it up.

What Else Helps? I've been a part of a clinical study for the past five years. I've learned a lot from my participation, including how to better tolerate living with PD. I'm glad to contribute to research as a patient.

Any Words of Wisdom? Find and do the things that make you feel like you're in control of your disease.

**BRIAN BAEHR
TEMPE, ARIZONA**

What's Your Exercise Regimen? I try to exercise daily, sometimes just for 20 minutes, but ideally for 45 minutes. I lift weights, swim, do yoga, bike, play baseball and golf. I focus on strengthening my core muscles through yoga or other exercises. It's all thanks to my son, Matt, who developed a training program for me four years ago.

How Does Exercise Help You? My "off" periods are less extreme, and I'm able to achieve my "on" periods with less medication. It's improved my overall physical health, and my emotional state, too. I just feel better.

Are You New to Exercise? I was a physically fit dad, going to the gym two to three times a week. But I wasn't nearly as disciplined. I'm in better shape now than in years.

What Else Helps? Acupuncture has made a real difference. Like exercise, it



From left to right: Riley, Preston, Brian, Kaye and Matt Baehr with Sam Fox (second from the left)

enables me to function better with my PD. Our family has also gotten involved with Team Fox, hosting the Baehr Challenge annually since 2010. This feels great — to raise money for PD research and get people engaged in our community. Along the way, I've become something of an ambassador for those with young-onset PD in our area. I feel better helping others, especially for the newly diagnosed.

Any Words of Wisdom? Find a support group. It's like getting a lifestyle cookbook for PD. You figure out what works for you and what doesn't. It's less scary when you're managing PD, instead of it managing you.

**SUSAN KAUFFMAN
LAKE FOREST, ILLINOIS**

What's Your Exercise Regimen? I aim for four to five rigorous workouts each week at the gym, and work with a personal trainer to build my balance and strength. I also coach an adult swim team and am in the water with them twice a week.

How Does Exercise Help You? Exercise improves my attitude — important since Parkinson's can go hand-in-hand with depression. I have more energy, and it takes longer for my symptoms to kick in. When I'm in the water, I don't have any symptoms at all.

Are You New to Exercise? I grew up as a swimmer and swam in college. But I'm more dedicated now and am taking better care of myself.

What Else Helps? I love helping others, so I joined Team Fox. I've hosted

several swim-a-thons and cycled twice in the New England Parkinson's Ride. Team Fox made me realize that I wasn't alone in my disease, and once people understood what I was going through, they wanted to help, too.

Any Words of Wisdom? Parkinson's is different for everyone. Keep up the search for your right combination — in terms of medicine, doctors, exercise, support groups. Once you find it, go for it.



Susan Kauffman and her daughter, Grace



Gary Schmitz

**GARY SCHMITZ
GRAPEVINE, TEXAS**

What's Your Exercise Regimen? Three times a week, I go to Punching out Parkinson's, a non-contact boxing training program run by world champ Paulie Ayala. To help keep this free to all people with PD, we've started fundraising. I also run occasionally, and kayak.

How Does Exercise Help You? When I first started boxing, I was at 13 pills a day. I was able to maintain most of last year at four pills daily. But Parkinson's doesn't stop, so I recently increased back up to eight pills — but still less

than 13. I'm regaining my coordination, flexibility and strength. You learn to never give up, even when you're knocked down. I have my confidence back — and recently ran my first 5K.

Are You New to Exercise? No, although I am new to boxing, which I'd imagine is easier to start before 50! I'm in the best shape since high school.

What Else Helps? I've volunteered for several clinical studies. It doesn't require much of me, and I don't see why you wouldn't want to help advance research. With Team Fox I can help unite the local PD community.

Any Words of Wisdom? Find something active you like to do. In an exercise group, you'll push yourself harder than training alone, and your mood will be better. Every day you sit there, Parkinson's wins. —LA



MICHAEL J. FOX RETURNS TO THE TV LINEUP

BY CHRISTINA BRDEY

After a 12-year hiatus, Michael J. Fox will return to primetime television this fall in this first starring network role since he retired from “Spin City” in 2001. The single-camera comedy, premiering on NBC this September, will mirror real life as Michael plays a working family man living with Parkinson’s disease. As Mike Burnaby, he is a husband and father of three returning to work as a newscaster after taking time off to deal with his Parkinson’s diagnosis. His co-stars will include Betsy Brandt (“Breaking Bad”) and Wendell Pierce (“The Wire,” “Treme”).

Michael took a break from acting full-time in 2001 to pursue a new career — advocating for increased funding and awareness for PD, resulting in the launch of The Michael J. Fox Foundation for Parkinson’s Research. He has nonetheless remained in demand as an actor, with regular guest appearances (and award nods) on “Boston Legal,” “Rescue Me,”

“Curb Your Enthusiasm” and “The Good Wife,” among others.

So what allows Michael to return to television full-time after a hiatus of more than a decade? While some media reports have speculated that he must have access to some kind of newly approved drug, this is not the case. Michael has spoken publicly about his success in using amantadine (a flu medication frequently prescribed off-label in Parkinson’s) to address his dyskinesia. Today he credits the right combination of medication, support and an active lifestyle with his ability to head back to a regular work routine. And, as he mentioned recently to David Letterman, playing the role of someone with Parkinson’s also helps.

Here at the Foundation, we’re looking forward to welcoming Mike Burnaby into our living rooms every week! We can’t wait to see Michael put Parkinson’s on the national stage in an entirely new way — leavened by his signature humor and impeccable comic timing. Stay tuned to the Foundation’s blog (blog.michaeljfox.org) for the latest developments on what will surely be our favorite new television series.



Tracy Pollan and Michael J. Fox with their children (from left to right) Aquinnah, Sam and Schuyler Fox

HOLLYWOOD RAISES THE BAR TO END PARKINSON’S

Earning Over \$100,000 and New Friends Along the Way

BY MIRANDA LANZILLOTTI



From left to right: Melanie Frankel, Andrea Kavooosi, Jacob Fenton, Dianna Mannheim and Justin Sternberg

Team Fox ended 2012 on a high note: with a record-setting annual fundraising total of \$6.3 million and an inaugural West Coast event that was a huge success. Raising the Bar to End Parkinson’s, hosted on December 5, brought to Parkinson’s research more than \$100,000 worth of attention from the Hollywood scene.

The event committee included Jacob Fenton of United Talent Agency, Melanie Frankel of USA, Andrea Kavooosi of The Rothman Brecher Kim Agency, Dianna Mannheim of Sony Pictures Entertainment and her fiancé, TV writer Justin Sternberg. Each with a personal connection to Parkinson’s, the five friends knew they could make an impact through a star-studded night in Los Angeles.

The event served as the unofficial launch party for Culver City’s new gastropub, Public School 310, whose executive chef is Fenton’s husband, Phil Kastel. Among the nearly 200 guests in attendance were stars including “The Big Bang Theory’s” Kaley Cuoco, “Modern Family’s” Ty Burrell and “New Girl’s”

Max Greenfield. For the entertainment, “American Idol” finalist Casey Abrams performed.

But this wasn’t the committee’s first go at fundraising for MJFF. Their ties date back to the Foundation’s earliest days when Sternberg interned on “Spin City.”

Before the idea of Team Fox was born, Sternberg had his hand in a host of fundraisers benefitting PD research. And, as members of the Junior Hollywood Radio and Television Society (JHRTS), the committee organized smaller events to benefit MJFF. Now having made their mark in the entertainment world, the committee reengaged with Team Fox in an even bigger way. So, they raised the bar.

To help pull this off, they secured sponsorship donations from top networks, established an honorary celebrity committee and amassed a gift bag rivaling that from the Emmy’s. Along the way, they learned they share personal connections to Parkinson’s with colleagues and friends — which came as a surprise. This all-hands-on-deck effort exceeded their expectations, setting the stage for greater success in years to come.

Sternberg says, “The thought that five of us could band together and make a difference here is the greatest feeling in the world. There is nothing too hard, too out of reach or too difficult when it comes to helping people in need. We’re excited to raise even more funds in 2013.”



CONTRIBUTING EDITOR AND PD PATIENT SHARES “THE PARKINSON’S EXPERIENCE”

Journalist and Parkinson’s patient Dave Iverson has been a public broadcasting producer and anchor for 30 years, and is a founding member of MJFF’s Patient Council. This year he expands his activities with the Foundation, joining our team as contributing editor.

“Sharing various aspects of the Parkinson’s experience is one of the most important ways we work to keep patients informed and optimistic about what the future holds,” says Holly Teichholtz, vice president of marketing & communications at MJFF. “We’re committed to telling the Parkinson’s story as authentically as possible by working with superlative documentarians who themselves have first-hand experience of PD. We’re grateful that we can offer Dave’s unique perspective and analysis to the MJFF community.”


As contributing editor, Dave combines a patient’s perspective with expert journalistic insights on Parkinson’s research news. He first worked with the Foundation when he interviewed Michael J. Fox for his 2009 FRONTLINE special on Parkinson’s disease, “My Father, My Brother and Me” (available in its entirety at pbs.org). Since then, he has worked with MJFF to produce and record dozens of audio podcasts with the world’s top PD researchers, as well as short video reports on timely Parkinson’s research in his series “The Parkinson’s Minute” (all podcasts and videos are available at www.michaeljfox.org/multimedia).



Dave is also taking on a greater role in the Foundation’s educational offerings to the Parkinson’s community. At Research Roundtables around the country, Dave leads in-depth panel discussions with researchers working on the front lines, covering such topics as drug development, research participation, depression, nutrition and exercise. Through our Hot Topics Webinars, which you can participate in live or access on-demand, Dave is bringing your questions and concerns into the conversation. Look for Facebook posts in advance of each Webinar, and comment with the questions you’d like to see discussed. Dave will work to include as many of the most popular

questions as possible in each conversation. (If you participate in the Hot Topics Webinar, you can also submit your question directly in response to the conversation.)

“I’m a lucky guy in many ways — my challenges with PD are less than what many face,” Dave says. “But I’m also fortunate because I’ve had this opportunity to work with the Foundation. I hope what I can do, working with the talented and dedicated staff at MJFF, is to help tell the story of the research the Foundation is supporting and how it’s getting us that much closer to stopping Parkinson’s in its tracks.”

He continues, “When you have a condition like Parkinson’s, you try to figure out what you can do to contend with it. And we need people to participate in this story: to volunteer for clinical research, to participate in Team Fox events, to support critical research projects. It’s all part of this overarching effort to defeat PD.” —NH 

“I hope what I can do . . . is to help tell the story of the research the Foundation is supporting and how it’s getting us that much closer to stopping Parkinson’s in its tracks.”



RESEARCH AT YOUR FINGERTIPS:

UPCOMING HOT TOPICS WEBINARS
LEARN MORE ABOUT HOT TOPICS
WEBINARS AND REGISTER AT
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4.23.13
Patient Engagement

5.21.13
Update on Trophic Factors

6.27.13
Biomarkers

UPCOMING RESEARCH ROUNDTABLES
Hear from experts in PD research at panel discussions, moderated by Contributing Editor Dave Iverson. MJFF is coming to the following cities in 2013:

Chicago, Illinois
Houston, Texas
Minneapolis, Minnesota
New York, New York
Philadelphia, Pennsylvania
Toronto, Ontario

LEARN MORE AT
michaeljfox.org/researchroundtable

THE RECIPE FOR HOSTING YOUR OWN PANCAKES FOR PARKINSON'S

Pancakes for Parkinson's made its debut at the University of Virginia in 2004. Since then, this event has been hosted **more than 100 times** around the world. Now a signature Team Fox event, Pancakes for Parkinson's is a terrific — and tasty — way to bring together your community to raise awareness and critical dollars for PD research.

1 GET STARTED!



SET
a date



CREATE
your Team Fox page



ORDER
your Team Fox gear

PRO TIP:
Find more Team Fox apparel at Fox Shop shop.michaeljfox.org.

2 DETERMINE THE DETAILS



PICK
a location



FIND
local sponsors



ORDER
your supplies

3 SPREAD THE WORD



INVITE
community members



ASK
for volunteers



START
fundraising

4 EDUCATE & HAVE FUN!



ORGANIZE GAMES
for kids & adults



GATHER
raffle or auction items



CREATE
a Parkinson's awareness table

5 SAY thanks!



RECOGNIZE
event sponsors



HAND OUT
goody bags



SEND
thank-you notes to your donors



READY TO START FLIPPING FLAPJACKS? Go to teamfox.org to get started today! Be inspired by other Pancakes for Parkinson's stories at michaeljfox.org/pancakes.

NO AGE LIMIT FOR TEAM FOX

The Team Fox community brings together people of all ages. We talked with some of our younger Team Fox members who are getting an early start on raising funds and awareness for Parkinson's research.



Sarika (third from the right, back row), Neha (left, front row) and Meeraya Mathur (third from the left, front row)

SARIKA (14), NEHA (12) AND MEERAYA (8) MATHUR AJAX, ONTARIO

Toronto Waterfront 5K
Funds Raised: \$16,665

Why Team Fox: We like to put a lot of effort into fundraising for Team Fox because our mother, Soania, has Parkinson's. Through Team Fox, we hope to educate others about this disease by raising awareness.

Why a 5K: We did the 5K because it was an event in which everyone (all 20 members of our group) could participate in, regardless of age or ability. Even with the torrential rain, we still managed to make the best of the situation and definitely enjoyed the experience.

Greatest challenge: People want to help, but sometimes you have to be

persistent in reminding them. We don't feel awkward asking for money. It's not for us, it's for a great cause.

Greatest reward: The greatest reward for us really is knowing that we're contributing to a great cause, and that with just a little bit of work on our part, we can benefit the lives of many people — including our mom.

What's next: We plan on continuing our campaign "Pennies for Parkinson's." During this event we make an educational presentation to our classmates about PD, and we raise money through games and selling bracelets.

Best advice: Everything counts. Even if you donate a little, it makes a difference. We take so much for granted — and we have so much to be grateful for. Be proactive.



Carley Finnegan (center)

**CARLEY FINNEGAN, 15
JACKSON, NEW JERSEY
Pancakes for Parkinson's
Funds Raised: \$1,340**

Why Team Fox: My stepdad was diagnosed with Parkinson's four years ago. I wanted to do something, so at first I did all the school reports I could about Parkinson's. Then my mom and I found Team Fox last year.

Why pancakes: I saw it on the Team Fox Web site, and I thought it looked cool.

It seemed like something I could do on my own.

Greatest challenge: Our original venue fell through, so we had to find another place fast. My parents helped me connect with our local Applebee's. Then there was Hurricane Sandy. We didn't have power for 13 days, making it hard to sell tickets. And many of our friends and family were affected much worse. I wasn't sure anyone would be able to come.

Greatest reward: I couldn't believe all the people who came out to support me. My friends know more about Parkinson's, and I've met more people who have a connection to the disease.

What's next: My sister has multiple sclerosis (MS), so I want to host an event that could benefit her. I'd like to do both a Parkinson's and an MS fundraiser each year.

Best advice: Don't give up. Somehow, it will all work out.

**ADAM SIROTA, 13
ROSLYN, NEW YORK
New York Half Marathon
Funds Raised: \$1,322**

Why Team Fox: My best friend's mom, Sharon Greif, has Parkinson's. I've known the family for a long time. And a grandparent of another friend has PD. Once I decided to run the half, it made sense to run for Team Fox since I know people with PD.

Why a half marathon: I like running — I do track and cross country. I knew it would be a good challenge for me.

Greatest challenge: It's a lot of work to train for the race. I'd do shorter

distances during the week and longer runs on the weekend. It was a pretty busy schedule. But it helped that my mom ran with me during my training.



Greatest reward: The best part is the end. Your family is there cheering you on, the adrenaline kicks in, and you sprint to the finish. I enjoyed fundraising, too — talking to people about Team Fox and why the cause means something to you. It was cool to be able to raise some awareness.

What's next: I'm running the half again for Team Fox this spring. In

2012, I finished in 1 hour, 42 minutes. I'm not sure I'll be able to beat that, but I'll try. Either way, I love the experience.

Best advice: Work hard. Do something you think you couldn't do — something unexpected. It will make you feel great.

**JAKE PEARLSTEIN, 12
BRYN MAWR, PENNSYLVANIA
Philadelphia Half Marathon
Funds Raised: \$7,591**

Why Team Fox: I'm close to a family member who has Parkinson's, so I wanted to incorporate that into my bar mitzvah project.

Why a half marathon: I'd already done the Broad Street Run, which is 10 miles.

But I wanted more of a challenge. I like to do things out of the ordinary. The half marathon seemed like the right fit.

Greatest challenge: The training can be tough to fit in your schedule. It seemed like I was always running. Almost every day someone would tell me that they saw me out there. But it was worth it.

Greatest reward: During the race, I saw family members at eight different points along the way. It helped keep me going. Crossing the finish line was amazing. I didn't want to stop.

What's next: I hope to get into the full marathon next year. I don't mind fundraising — it's for a good cause. And I'm looking forward to the Team Fox MVP Awards Dinner.

Best advice: Train as much as you can. Never be lazy, no matter what you're doing. If you're able to run, you don't realize how lucky you are — and how hard that would be for someone with Parkinson's. Stay focused on your goal. —LA



THE POWER OF SHARING YOUR STORY

Last fall, The Michael J. Fox Foundation's "Tell Us Your Story" Facebook campaign rallied voices across the Parkinson's community, encouraging them to share their unique stories with others.

The campaign challenged individuals to post their stories and share them with friends and family before year-end. Every "like" or "share" a story received by December 31 would garner a \$5 donation to MJFF, up to \$60,000, courtesy of pharmaceutical company UCB, Inc. The social media marketing firm Syncapse donated their services to develop the Facebook application at no cost, so every dollar raised went directly to the Foundation's research programs.

"When someone has the opportunity to share their story, it can be an invaluable service to someone going through the same experience and realizing they are not alone," Laxmi Wordham, chief digital officer, told *Neurology Now* in December.

Within three weeks of the campaign's launch, the PD community resoundingly answered the call — over 200 stories were shared more than 18,000 times.

Says Bryan Roberts, "Once you receive the diagnosis, there are really two roads you can choose. You can allow the disease to win and lead a diminished life or you can continue to achieve your goals while serving as an advocate for greater funding and research. I decided to take option number two and have not looked back."

While the fundraising challenge has ended, the "Tell Us Your Story" app remains live on the Foundation's Facebook page. As *Neurology Now* reported, "...the money raised by the campaign is a powerful resource in the

fight against the disease. But just as powerful are the stories themselves — and the way in which they can unite and inspire members of the PD community."

Facebook groups are proving valuable for connecting people with Parkinson's across the country and the world. Bret Parker, a member of Team Fox and MJFF's Patient Council, launched his own Facebook group for the young-onset Parkinson's (YOPD) community. Discussions range from disclosure and dealing with workplace issues to clinical trials and treatment options. "Having met so many exceptional YOPD patients who grapple with the same things I do, I wanted to leverage technology to bring us all closer together so we could compare notes and support each other," Bret says.

No matter what your story is, you are not alone. Join the conversation and connect with thousands of others in the Parkinson's community at:

t Twitter: @MichaelJFoxOrg

f Facebook: facebook.com/michaeljfoxfoundation

🗨️ Tell Us Your Story: Look for the "Tell Us Your Story" logo on The Michael J. Fox Foundation Facebook page.

—CB

“...I wanted to leverage technology to bring us all closer together so we could compare notes to support each other.”

SAM FOX SPARKS A MOVEMENT AT SXSW

MJFF Outreach and Engagement Officer Sam Fox, 25 (no relation to Michael J. Fox), continues racking up the miles — and the dollars — in his pursuit of a cure for Parkinson's disease. Sam, a gifted athlete who ran track and field at Yale and excelled at the high jump, routinely challenges himself with feats of endurance to raise funds for Team Fox. His goal: inspire others to do whatever comes naturally to be part of the movement to speed a cure.

Most recently, Sam brought his message to the 2013 South by Southwest (SXSW) Interactive Festival in Austin, Texas, where he challenged himself and the SXSW crowd to dream up his next extreme adventure.

"SXSW-Interactive attracts an innovative and driven audience that's willing to take risks to succeed," Sam says. "It was an honor to contribute to that energy, and to introduce the crowd to the work of Team Fox and MJFF."

As part of the Community and Activism panel, Sam told the crowd how inspired he is by working with Team Fox and other members of his generation who are coming together to collectively move mountains — leaving the world better than they found it.

Sam's previous feats include hiking over 2,650 miles along the Pacific Coast Trail in 65 days (about one and a half marathons a day) and running over 100 miles in a single day, from Manhattan's Times Square to Southampton, New York. He completes his acts of ultra-athleticism to honor his mother, Lucy, who has Parkinson's, and to raise funds for The Michael J. Fox Foundation — over \$200,000 to date.

When not lacing up his shoes for his next endeavor, Sam guides Team Fox members to optimize their strategies for maximum fundraising potential. Stay tuned to see where his feet and his contagious spirit of optimism lead him next. —CB



From left to right: Matthew Bieszard, David Smith, David Soiles and James Pilkerton ran with Sam Fox (center) in his Hamptons Hundred-Miler

ESTATE PLANNING FOR A FUTURE CURE

THE LEGACY OF A GREAT ADVENTURER

Terry Weinberger, of San Diego, California, met her late husband, Brent, over 40 years ago. At the time, she was an assistant in the office of his medical practice, where he was a podiatric surgeon. “He treated patients regardless if they could pay,” says Terry. “What he saw first was a person who was in pain and scared. That was always his first diagnosis.”

The couple soon married and devoted the next 25 years to working together in Brent’s practice. They traveled extensively — dogsledding in Montana, bridge jumping in New Zealand, safari in East Africa and backpacking in Nepal. “What a ride we had,” says Terry. “He constantly pushed me to try new things. He had such an adventurous spirit.”

While Brent was a lifelong “health nut,” says Terry, who exercised daily, troublesome symptoms began to appear not long after retirement in 1995. It took years to accurately diagnose his Parkinson’s. Nonetheless, he maintained an active lifestyle, and the Weinbergers continued their travels.

At 76, in the final year of his life, Brent went skydiving for the first time. It was one of the last items on his bucket list, says Terry, and he mustered up every ounce of energy he had left to do it. “He said it was the most fun thing he’d done in five years. I think he appreciated the sense of being in control again.”

Although Brent always joked he planned to live forever, at a certain point, he realized the situation had shifted. That’s when the Weinbergers began thinking about the road ahead — and their estate plans.



Brent Weinberger, MD, skydiving

Terry says, “He told me if we could do something to help other people in the future, that’s the legacy we want to leave.” As a physician, he was fascinated by finding a cure for his disease. He did much of his own research and closely followed the progress of The Michael J. Fox Foundation. In 2009, the couple made their first gift to the Foundation. Supporters of many causes each year, “We felt it was better to give away what you had than to spend it on ourselves,” Terry says.

With no children, the Weinbergers were able to invest a substantial portion of their estate in their hope for a cure for PD. They established a \$1-million charitable gift fund to benefit MJFF, which went into effect in 2012. Each year throughout the life of the fund, the Foundation receives \$100,000, and Terry receives an annuity payment. “Brent never complained about his Parkinson’s, but he didn’t want anyone else to suffer,” Terry says.

Just before Brent passed away in October 2011, “He told me he’d had a wonderful life,” says Terry. “He would miss only two things: watching the sunset from our deck, and me.”

“Ours was an adventure until the very end,” she says. And she is keeping up this spirit on her own. She joined a local travel club and spends more time

with friends. To keep her company, she recently got a new puppy, named Zack. She also is learning to take better care of herself, after being a caregiver for many years. “Before he died, Brent gave me a list of things to do,” she says. “Being happy was one of them. I’m trying to keep my promise to him.”

A HEALTHY FISCAL AND PHYSICAL OUTLOOK

Not long after Shirley and Dennis Gillespie, of Rye, New Hampshire, retired, they started making some changes. After spending more than 20 years together in New Hampshire, they thought they’d give a winter a try in Arizona, where they had bought a vacation home several years prior. They acquired a new puppy, Colt, who has been a fun but challenging addition to the family. And, they began thinking seriously about estate planning.

With no children, the Gillespies wanted to ensure their hard-earned assets went to a good cause. Because Dennis had been diagnosed with Parkinson’s over six years ago, Shirley suggested and her husband agreed they look to The Michael J. Fox Foundation, as a potential “win-win for everyone,” they say.



Shirley and Dennis Gillespie with Colt

As do many with Parkinson’s, Dennis actively researches his disease and finds the Foundation’s Web site a valuable resource. He says, “Michael J. Fox has good reason to make sure the dollars his Foundation raises are used wisely and efficiently. The Fox Foundation is right on the ball when it comes to funding Parkinson’s research.”

Like many retirees, the Gillespies had another concern: ensuring a guaranteed income throughout their retirement. They were interested in a charitable gift annuity, in which they would transfer assets to a charitable organization that, in turn, would annually pay them a fixed sum, depending on their age, throughout their lifetime. Upon connecting with the Foundation, Shirley says, “The staff was so helpful. We were amazed at how easy and fast it was to set it up.” They established a charitable gift annuity of \$100,000.

Planning their estate isn’t the only proactive step Dennis and Shirley have taken. Exercising more regularly, they both enjoy walking and yoga, along with working out at the gym and partaking of the club’s many activities — all of which helps Dennis better manage his Parkinson’s. To accelerate research, Dennis is also interested in participating in a clinical study, which he discussed with his neurologist. He is using Fox Trial Finder, the Foundation’s clinical trial matching tool, to research trials that might be a good fit.

Say Dennis and Shirley, “However we can make sure the research is done on this disease — for us and for the future — we’ll do it.” —LA

To learn more about estate planning to benefit The Michael J. Fox Foundation, please call (800) 708-7644.



O CANADA! A CYCLING SUCCESS

Building Connections and Community in Calgary

They met by chance. But considering how much Laurine Fillo and Ken MacKenzie have in common, perhaps it was only a matter of time.

They live near each other in Calgary, Alberta. Ken teaches at the school where Laurine's niece and nephew are students. Both have young-onset Parkinson's disease (YOPD). Laurine was diagnosed 10 years ago, at 38. Ken was diagnosed a year ago, at 43. Each is passionate about staying fit. Since his diagnosis, Ken has become an avid Spinner, also competing in bike races and triathlons. Laurine manages her PD through walking, running, dance and yoga. They feel better, physically and mentally, when they're working out. Just as important is doing something they believe can help combat their disease.

They met at a YOPD support group, though Laurine attends meetings infrequently, and soon became friends. Laurine and her family had been talking about starting their own event to raise

funds for Parkinson's research; Ken had the idea for a Spinning fundraiser. Forming Team Macquarie, their mutual friend Dave Lougheed and his colleagues Tara Baker, Aaron Johnson and Trish Leadbeater took the lead by joining Team Fox and helping organize this event. "I couldn't hide my tremors anymore," Ken says. "I decided I might as well go for it."

On November 4, Pedal for Parkinson's Research made its debut as a stationary bike relay race. Calgary's Trico Centre for Family Wellness was packed on race day, with 150 bikers and dozens of volunteers and supporters cheering them on. "It was a little crowded," says Laurine. "But the energy was electric. Several teams came in costume and are already planning what to wear at our next event."

In 25 teams of six people, each participant rode for 10 minutes to cover the greatest collective distance in an hour. For many, it was a family event,

“ I couldn't hide my tremors anymore. I decided I might as well go for it. ”

with students from Ken's school forming teams to support their teacher and coach. He was especially proud when one of his volleyball teams took home the grand prize.

While they originally hoped to raise \$10,000 or \$15,000, Ken and Laurine instead found themselves with a total of over \$58,000. In accordance with the staff support policy at Macquarie Private Wealth, where Dave Lougheed is an employee, all funds raised by the event were matched by The Macquarie Group Foundation — bringing the sum to more than \$116,000. They also made inroads with the wider Calgary community, and across generations. "We couldn't believe we had created this," says Ken. They're already planning their next Team Fox event.

"Parkinson's can be a frightening disease," says Laurine. "But the more people are educated, the more they can help. And it lifts a weight." Adds Ken, "The kids at my school now understand why my hand shakes. We joke about it, and it's lighter for all of us. They also know Parkinson's isn't just a disease for older people."

Their advice for fellow Team Fox members? "Plan a daytime event the whole family can take part in. Keep it short and sweet — no more than two hours," says Laurine. Ken says, "Have fun. Make it about getting people together. For us, that's what Team Fox is all about." —LA



UPCOMING TEAM FOX EVENTS

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



4.23.13

PANCAKES FOR PARKINSON'S
ORANGE, CT
teamfox.org/goto/jodyculmone



9.7.13

NEW ENGLAND PARKINSON'S RIDE
OLD ORCHARD BEACH, ME
teamfox.org/neparkinsonsride



5.5.13

BMO VANCOUVER MARATHON
VANCOUVER, BC
www.teamfox.org/vancouver



9.21.13

DANVILLE D'ELEGANCE
DANVILLE, CA
danville-delegance.org



6.6.13

TIPS FOR PARKINSON'S
NEW YORK, NY
teamfox.org/tipsforparkinsons



10.13.13

BANK OF AMERICA
CHICAGO MARATHON
CHICAGO, IL
www.teamfox.org/chicago

FIND THESE AND OTHER TEAM FOX EVENTS AT TEAMFOX.ORG

SURPASSING A \$50-MILLION CHALLENGE

Expensive Work Continues to Keep Potential New Treatments Flowing Forward

In 2011, The Michael J. Fox Foundation announced a \$50-million opportunity for supporters to double their impact in the pursuit of a cure for Parkinson's. Two years later, in early 2013, MJFF shared it had completed the Brin Wojcicki Challenge, earning all \$50 million on the table. In fact, because of the enthusiasm and generosity of the Foundation's community of donors, Challenge-eligible giving exceeded the original goal by about \$3 million — all of which was also matched.

Meeting the Challenge was no small feat. Its success would require — and inspire — thousands to take action. And they did. People joined this movement as new friends to the Foundation, as returning supporters who had given prior to 2010, and as steadfast multi-year donors who stretched their giving.

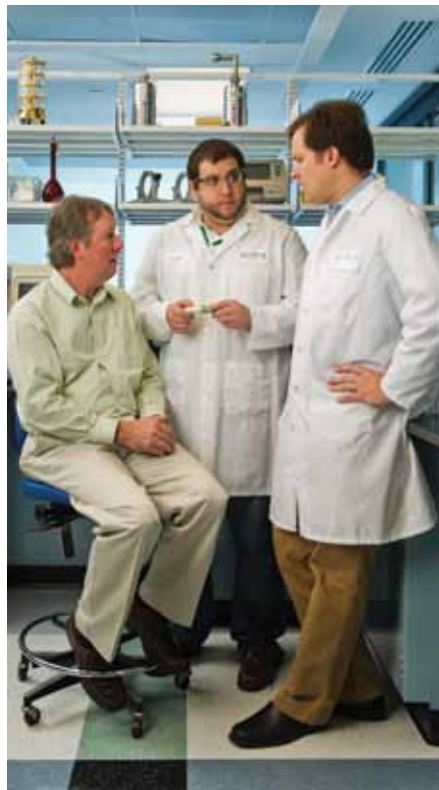
Behind the Challenge was the generosity of longtime supporters Sergey Brin, co-founder of Google, and Anne Wojcicki, co-founder of 23andMe, a personal genetics company. At the conclusion of the Challenge, their personal giving to MJFF totals more than \$157.5 million since 2004.

"Anne and Sergey's friendship to our Foundation and to Parkinson's patients worldwide is awe-inspiring," says Michael J. Fox. "As if a \$50-million match weren't tremendous in its own right, they've gone above and beyond their initial commitment to match the \$3 million extra ponied up by our incredible supporters. There's no doubt the Challenge has made our community stronger and more vibrant in its passionate pursuit of a cure."

AN OPPORTUNE MOMENT AND AN URGENT NEED

Mr. Brin and Ms. Wojcicki chose an opportune moment in Parkinson's drug development to launch the Challenge. The Michael J. Fox Foundation and its research partners believe that the pipeline of new Parkinson's treatments is as robust as it has been in decades, if not ever. Understanding of the factors underlying disease onset and progression is increasing, and insights from genetics are opening new avenues for therapeutic development.

In 2013 we are continuing our critical work to mobilize the researcher and patient communities in the hunt for medical breakthroughs patients can feel in their everyday lives. We remain particularly focused on:



- **The search for a disease-modifying treatment.** This spring, results are expected from Ceregene, Inc.'s most recent MJFF-supported Phase 2 clinical trial of neurturin, a trophic factor that could help restore dopamine neurons in the Parkinson's brain. As Parkinson's genetics continues to revolutionize the field, MJFF is growing its initiatives focused on alpha-synuclein and LRRK2, the two most important genetic targets in PD. The Foundation's landmark biomarker study, PPMI, has nearly completed recruitment and is analyzing baseline data (all of which has been made available to the research community at large in real time). PPMI is launching a new arm to study people at increased risk for the disease.

- **Looking beyond the dopamine system.** Today there is a better understanding than ever that



Parkinson's involves a constellation of symptoms that go well beyond dopamine signaling. MJFF-enabled partnerships with Bristol Myers Squibb, Sanofi, Addex and other major pharmaceutical firms are pushing new classes of symptomatic therapies, as well as treatments for cognition and dyskinesia, closer than ever to the clinic.

- **Increasing the flow of willing volunteers for clinical research through Fox Trial Finder.** Fox Trial Finder (foxtrialfinder.org) has already registered 15,000 patient and control volunteers who want to be matched to the best trials for them. In 2013 the site comes online in five more European countries and aims to double its registered volunteers to 30,000.

Yet in the midst of this promising activity, government and commercial sources of research funding continue to dry up. Especially as more research approaches the clinic, where costs rise steeply, there has never been a more important time or a greater need for the Parkinson's community to work together to ensure sufficient funding to keep the most promising projects moving forward.

"Our Foundation's promise to Parkinson's patients is to work urgently to identify and fund the projects closest or most critical to practical therapeutic relevance," says Todd Sherer, PhD, MJFF's CEO. "We're grateful to our Challenge participants and our entire community of supporters for helping us continue to fulfill that promise. And we hope to count on them to build upon this momentum in the year ahead." —LA

FROM THE BOARD: FREDERICK "SHAD" ROWE

The Best Ideas —
on Investing and Parkinson's

MJFF Board member Frederick "Shad" Rowe of Dallas, Texas, likes to make the most of an opportunity. So perhaps it's unsurprising he would co-found an event to leverage his business expertise and contacts — and raise funds to speed a cure for Parkinson's.

Shad built a career in the investment business, and currently serves as managing partner of Greenbrier Partners, Ltd. Over the years, he has attended many events for investors, where well-known money masters share their insights. Following his diagnosis with Parkinson's in 1998, he got an idea: He could host his own symposium.

Shad and his good friend and business associate John Neill both had a cause close to their hearts. For Shad it was The Michael J. Fox Foundation, and for John it was The Vickery Meadow Youth Development Foundation (VMYDF), which provides programs for low-income youth in Dallas. In the fall of 2007, they hosted the inaugural Great Investors' Best Ideas (GIBI) Investment Symposium as a premier investment forum in Dallas. They underwrote the event's costs so that every dollar they raised through ticket sales would support the two organizations.

Last October, Shad and John hosted the sixth annual GIBI event, with more than 1,100 attendees; this year's event is on October 29. To date, they have raised more than \$6 million, split between



MJFF and VMYDF. Shad says, "GIBI has taken on a life of its own. Along with raising a lot of money, it's raised awareness for both causes. I happily admit that one of those is self-serving — a cure for PD."

Shad feels fortunate that he's able to maintain a full schedule with Parkinson's, though he has made some adjustments. "You assess your priorities and figure out how to achieve them," he says. Among these is talking with the newly diagnosed. "Life isn't over. Parkinson's can be coped with. Find a good movement disorders specialist and take the time to get the meds right."

Through his service on MJFF's Board of Directors, he stays up to speed on the latest in research. He admits his frustration that a cure hasn't come faster. But he knows the Foundation's sheer focus and global perspective will yield results. "Your first inclination is often to support the doctors and hospitals you know, which is only natural. The problem is there's a lot of duplication among scientists. I choose to support The Michael J. Fox Foundation because you get more bang for your buck. They're a clearinghouse for all PD research, which is more efficient and more effective," he says.

"My advice? Stay active and find others with the disease. Parkinson's has actually made me a better person. It's funny how it can all fit together." —LA



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