

ACCELERATING THE CURE SPECIAL YOU-POWER EDITION

The newsletter for friends and supporters of The Michael J. Fox Foundation for Parkinson's Research

SPRING 2011

This Parkinson's Awareness Month (and Beyond!), "You-Power" Can Help Speed the Cure.

Let Us Show You How!

The mission of The Michael J. Fox Foundation is to accelerate better treatments for Parkinson's disease, and ultimately a cure. But the power to make it happen comes from you... your time, your creativity, your commitment, your can-do spirit.

"When we have a cure for Parkinson's disease, it won't be because of me or the Foundation," said Michael J. Fox. "It will be because of the countless people who decided to get involved. From scientists in labs to clinical trial participants to the people who share our vision and help drive it financially — we all have a role to play."

From research breakthroughs to reaching out to friends, from writing a check to running a race, from signing up for a trial to speaking up on social media, from creating an event to collaborating across the science and business communities, our progress is You-Powered. That's why MJFF is now laying the groundwork for proactive engagement with a global community of people from all walks of life... with one common purpose.

No matter how you contribute to the fight against Parkinson's, you're on a team where everyone's additions are invaluable — and the whole is far greater than the sum of the parts. This Parkinson's Awareness Month, we want to help you get involved. Here are a few of the many ways you can help power a cure:

Take Part in a Clinical Trial: Clinical trials need participants to bring new therapies to market. This summer, The Michael J. Fox Foundation is launching Fox Trial Finder, a smart and simple Web-based tool to connect willing volunteers with the clinical trials that urgently need them, streamlining the flow of participants into studies and speeding progress toward therapeutic breakthroughs. You can use Fox Trial Finder whether you are living with Parkinson's or not.

If you're newly diagnosed, one study you might match with is the Parkinson's Progression Markers Initiative (PPMI), our landmark effort to develop biomarkers of PD. www.michaeljfox.org/foxtrialfinder

Fund High-impact Research: Raising money for research is at the heart of our mission. The power of your contribution, and your imaginative approaches to motivating others to give, has enabled us to fund over \$230 million in scientific activities to date. Thank you for your energy and enthusiasm in designing and leading fundraising events in your community, or simply for trusting us to invest your gift — of whatever size — in the most promising research.

Help Spread the Word: Accelerating a cure means making sure you have the best information, and then sharing that information with others. By becoming an advocate, you can work to ensure that sufficient resources — whether financial or intellectual — are devoted to the task. Educate yourself to speak out, or get formal training through the Parkinson's Action Network, the unified voice of advocacy for the U.S. Parkinson's community. It's the You-Power of advocates that can make a powerful difference

Get Connected: Take care of yourself and others by staying in touch with your community. This April, The Michael J. Fox Foundation wants to hear your story — and Facebook is the place to share it with a network of friends and supporters. Share your story in words, photos or video. Also be sure to "like" the Foundation to get regular Foundation updates, and to help spread the word that our progress is You-Powered — and you're in. www.facebook.com/michaeljfoxfoundation

To learn more about all the ways you can get involved and stand with The Michael J. Fox Foundation this April and beyond, visit www.michaeljfox.org.



ELENA OLIVO

NEWS FROM THE CEO

I recently read an article in the newspaper that reported on scientists' changing views of human communities and how they evolved. While my work at The Michael J. Fox Foundation seems far removed from evolutionary anthropology, I found myself relating much of what I read to the work our Foundation does every day. One line in particular has stayed with me: "Because humans are unusually adept at social learning, including copying useful activities from others, a large social network is particularly effective at spreading and accumulating knowledge."

That line hit home because it reflects one of our Foundation's core beliefs: Models that encourage greater networking and collaboration are critical keys to unlock life-transforming treatments for Parkinson's disease. We've seen what happens when the researchers we work with partner and share resources: therapeutic hits are more likely to move to the next stage, new research avenues are opened up, and the field as a whole moves forward faster.

Now we're taking this idea broader, hoping to mobilize the wider public in the fight against PD. It's an ambitious goal, no doubt, but we think this community is up to the challenge.

This spring we're launching a brand new set of initiatives to make it easy, fun and gratifying to roll up your sleeves and get personally involved in making Parkinson's disease a thing of the past. There are countless ways to take part, whether you choose to participate in clinical research, fund our scientific programs, advocate for increased research funding, or simply share your personal story on Facebook.

As Michael has said often, the cure for Parkinson's disease won't come because of him, the Foundation or any single individual. It will come from countless people coming together and making the decision to get involved. Another way to put it: Our progress is you-powered. However you take action, this hour, this month, or this year, your contribution is invaluable. We are so grateful to have you on our team.



Katie Hood, CEO

OUR PROGRESS IS YOU-POWERED...

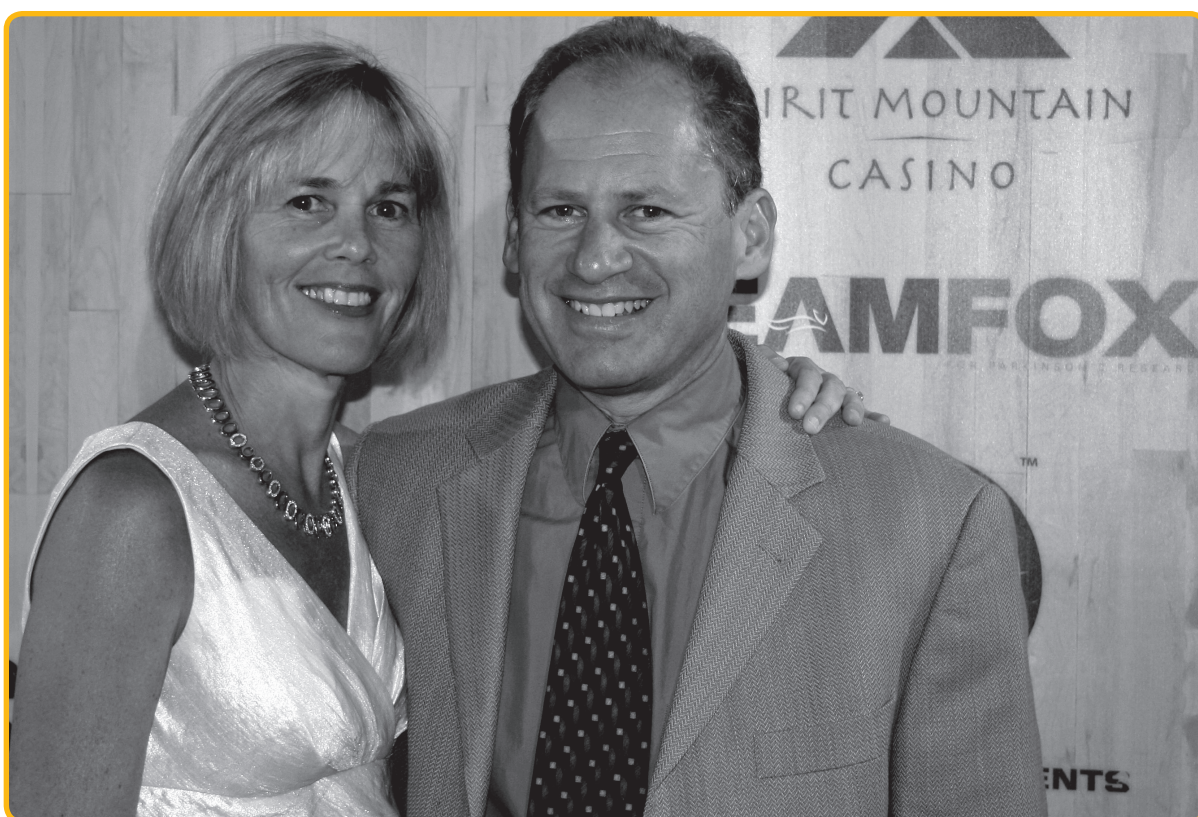
You-Power in Action

Foundation friends and supporters tell the stories of their personal involvement in helping to speed a cure

Every spring, *Accelerating the Cure* features the stories of people whose support of the Foundation powers our progress toward life-transforming treatments for Parkinson's disease. This year, we're all about highlighting the many creative ways that individuals from all walks of life can get involved. Here, in their own words, a few of our many inspirational friends and supporters tell the stories of what brought them to the Foundation and the impact that their participation has had on their lives.

SHARE YOUR STORY WITH US! The Michael J. Fox Foundation wants to hear your story — and this April, Facebook is the perfect place to share it. If the Foundation can reach 100,000 fans by April 30, actor and MJFF Board member Ryan Reynolds will donate \$10,000! Visit www.facebook.com/michaeljfoxfoundation to “like” us and share your personal story in writing, pictures or video.

Karen and Marc Jaffe: “I have a voice”
PPMI, Team Fox, Advocacy



Karen and Marc Jaffe

Karen: When I first found out I had Parkinson's I cried. I was only 49, healthy, and working long hours as a surgeon and OB/GYN. Stunned, I went to the MJFF Web site, and immediately I decided that I had a friend in Michael. I thought, if he can do it, so can I. So began my relationship with MJFF.

For a long time, my husband, Marc, and I kept my Parkinson's a secret. But ultimately I had to do the bravest thing I could do as a physician with PD, and that was to put this secret behind me. We have teenage kids, and we feel that it's important to set an example for them.

Marc: So we're telling our story. I'm a comedy writer, and I wrote a play about our family's journey with PD, called “Side Effects May Include...”. It was performed earlier in the spring and we're putting it on again at the end of the month as a Team Fox fundraiser here in Cleveland.

I wrote the play because I wanted to share with other people who might be going through something similar. The funny stuff was easy to write — that's what I do — but this was my first foray into something with such gravitas. The writing was pretty honest and I think people felt it. Everyone has dealt with something. Still, when the play premiered I was surprised how much people actually got about Parkinson's.

Karen: Marc has also become personally involved in PD research. On our anniversary last September, he surprised me with a card saying he had enrolled in PPMI as a control. He's doing it in spite of some issues he had with a lumbar puncture in the past. He's already undergone lumbar puncture for the study, and everything went off without a hitch.

In February, with the encouragement of Marc and my kids, I was interviewed about my journey by the local news here in Cleveland. A couple of days later I went to the MJFF Web site, and there was the interview online. Three years ago I had looked to that same page for reassurance, and now it was my story that was going to give people hope.

I have to agree with Michael when he says that for everything he's lost from this disease, he has gained so much more. Sure, my life has changed dramatically. But I've met some wonderful people. And I have a voice.

Karen Jaffe is a physician, PWP and advocate for Parkinson's clinical research participation. Marc is a best-selling author and former writer for “Seinfeld.” They live in Cleveland, Ohio. “Side Effects May Include...” will be performed to benefit MJFF on April 30 at The Ratner School in Pepper Pike.

David Standaert, MD:

“What's really impressive is that it's the patients who are driving this”

MJFF Scientific Advisory Board Member, PPMI Site Investigator (University of Alabama, Birmingham)

When I first joined MJFF's scientific advisory board, I was so refreshed with their philosophy toward curing Parkinson's. They invest all their money and resources into working toward that goal today. A lot of foundations operate on a 20-year plan. MJFF wants to be out of business 20 years from now.



David Standaert

One of the most exciting aspects of how MJFF is investing these resources is their devotion to new treatment and therapy. This was a new idea when Fox started doing this, and now other organizations are following suit. Very early on, Fox decided that instead of trying to understand everything there is to know about the brain, we needed to focus on what we can use to make a difference to people.

As a site investigator with PPMI, I'm optimistic about the study. It is entirely new to put a cohort of patients under the diagnostic microscope to learn as much as we can about the early part of the disease, where so much is happening. This study is going to shed light on how Parkinson's works and help us find potential biomarkers. And what's really impressive is that it's the patients who are driving this. They're the ones volunteering for a five-year study because they know they are making a difference. I believe they are.

Dr. Standaert is a member of the Foundation's scientific advisory board and the site investigator for PPMI at the University of Alabama, Birmingham.

... ARE YOU IN?

Dean Sutherland, MD:

“Participating in trials is an opportunity to sense your own importance in the greater scheme of things”

Neurologist, Advocate for Clinical Trial Participation

Parkinson’s clinical research has a huge opportunity and need for participants — both patients and people who don’t have the disease. Very few patients actually participate in clinical trials, although most say that they would if they were given the chance by their doctors. In terms of the progressive nature of PD, everyone who has it is concerned with where they’re headed in the future. Participating in trials is one way to tackle these concerns head on. It’s an opportunity not only to help others, but to sense your own importance in the greater scheme of things.



Dean Sutherland

Recently, MJFF came to me with an idea for a Web-based tool called Fox Trial Finder that would connect patients to trials in their area that need people with their particular characteristics. We know it’s been hard to get information like this, and so the idea is to match people with specific trials, and inform them about how to get involved. I’ve been one of MJFF’s advisors on the development of Fox Trial Finder. My role is to share with the Foundation the kinds of questions and concerns I hear from patients about participating in trials, and trends I’m aware of in how doctors tend to treat and communicate with newly diagnosed patients.

By making it much easier for PD patients to find research in their area, we believe we can significantly increase the numbers of trial participants. And that’s critical to speeding progress toward breakthroughs.

Dr. Sutherland is a neurologist and movement disorders specialist in Sarasota, Florida.

Liz Camp:

“I feel honored to be a part of what the Foundation is doing”

Team Fox

I remember back in 2008 I was watching the NYC Marathon and I saw Michael with his family cheering on the runners. I’d always admired his acting, but also had so much respect for how he turned his Parkinson’s into something positive. I introduced myself and found out about Team

Fox. From that moment I knew that if I ever ran a marathon, I would do it with them.

In April of 2010 I decided to join the team. My goal was to raise \$5,000, but thanks to the generosity of so many wonderful people, I ended up at over \$10,000. One of the big events that



Liz Camp and Michael J. Fox

I organized was a fashion fundraiser at a local boutique, where 20 percent of sales went to Team Fox. Support in the local community grew; my mom even started teaching yoga classes on the beach, donating the funds raised.

Throughout my training, Team Fox really helped to alleviate my anxiety as a first time marathoner. They were always upbeat, and gave us great recommendations about how to prepare. I plan to continue running for PD, and I’ve encouraged others within my training group to join Team Fox. I feel honored to be a part of what the Foundation is doing.

Liz Camp lives in Ft. Lauderdale, Florida

Matt Mitchell:

“I felt like my dad was right there with me”

Team Fox



Matt Mitchell

Last fall I ran the ING NYC marathon. I dedicated the race to my father, who had recently passed away from Parkinson’s. When I saw Team Fox was running, I instantly knew that joining was the right thing to do.

My father was such a gracious man. He took an interest in everyone he met, and I see those qualities in the people I have met who are

associated with MJFF. I was humbled by their interest in what I was doing, and the opportunity to meet folks with similar stories who had such energy and spirit was truly amazing.

I was pretty nervous to run New York. It was my first marathon, and the course is as tough as they come. But I remember right around the 20-mile mark, when it was particularly difficult, I felt like my dad was right there with me. I got through it, and even met my goal in terms of time.

I will continue to run for Parkinson’s. This April, 20 of us in Vancouver will run for PD. I find that every step I take opens three or four new doors. People tend to think of Parkinson’s as this niche disease, and it’s absolutely not the case. I’ve met so many people who want to run because PD is part of their lives in one way or another.

Matt Mitchell lives in Vancouver, Canada. The running team he founded, “The Goods,” will take part in the Vancouver Sun Run on April 17 to benefit MJFF.

Steven Braithwaite, PhD:

“I believe we are truly on the cusp”

MJFF-funded Researcher



Steven Braithwaite

MJFF provides great flexibility for researchers like me. They are willing to take on somewhat riskier projects, because they recognize that risk is a requirement for progress. MJFF is always one step ahead in the field in determining what needs to be funded — for example, with PPMI, they are now validating biomarkers to enable effective clinical trials of the future. I initially came into contact with MJFF while a researcher at Wyeth, and I have seen firsthand how they have worked to make Big Pharma understand that Parkinson’s is a disease it should be focusing on.

MJFF is also really good at bringing researchers together to energize each other’s work. In my past work with the LRRK2 gene, for example, Fox brought us into collaboration with researchers at Mt. Sinai School of Medicine to productively apply novel models to our studies. That kind of teamwork is incredibly refreshing.

We are now moving away from merely treating symptoms of Parkinson’s and toward finding a treatment that can halt the progression of the disease. MJFF is devoting unprecedented resources to this worthy search, and I believe we are truly on the cusp of finding such a therapy.

Dr. Braithwaite is a researcher with Signum BioSciences in Monmouth Junction, New Jersey.



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SPRING 2011 / TIME TO GET INVOLVED

FOX TRIAL FINDER

THE MICHAEL J. FOX FOUNDATION FOR PARKINSON'S RESEARCH

Fox Trial Finder is a smart and simple solution to connect willing volunteers with the Parkinson's disease clinical trials and studies that urgently need them, streamlining the flow of participants into studies and speeding progress toward therapeutic breakthroughs.

Visit www.michaeljfox.org/foxtrialfinder to learn more and pre-register to be notified when the tool is launched in summer 2011.

In New York? Look to the night sky on April 8!



EMPIRE STATE BUILDING LIGHTING PARTNER

April 8, 2011, has been proclaimed The Michael J. Fox Foundation for Parkinson's Research Day in New York City — and to help us mark the occasion, the Empire State Building will be lit orange on April 8 to honor the Foundation and Parkinson's patients, supporters, and researchers worldwide. If you're in New York City that night, be sure to look up!

The Empire State Building image © is a registered trademark of ESBC and is used with permission.

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