MARK SELIGER

THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

ACCELERATING THE CURE

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

SPECIAL CHALLLENGE EDITION

FALL 2012

Double Your Impact:
Don't Leave Challenge Dollars on the Table

BRIN WOJCICKI CHALLENGE
for THE MICHAEL J. FOX FOUNDATION FOR PARKINSON'S RESEARCH

Genia Brin is thoughtful, soft-spoken and not given to hyperbole. When asked about her son and daughter-in-law's $50-million fundraising challenge to The Michael J. Fox Foundation, with characteristic understatement she deems it "ambitious."

"Sergey and Anne make good decisions, and I've been very proud of them and all they've done for the Foundation," she adds.

That's Sergey (Brin, co-founder of Google), and Anne (Wojcicki, co-founder of personal genetics company 23andMe), a Silicon Valley power couple doing everything they can to help speed a cure for Parkinson's disease. In addition to the genetics research under way through 23andMe's Parkinson's Research Community (visit 23andme.com/pd or see the back cover to learn more), the husband and wife are longtime supporters of MJFF. Early in 2011, they announced their intention to match up to $50 million in new and increased gifts to MJFF through December 31, 2012. They will also match gifts from donors who have not given to the Foundation since 2010 or earlier. The Challenge increases MJFF's capacity to fund research that would otherwise go unfunded and tackle key roadblocks that prohibit progress toward better outcomes for patients.

ANN BILLINGSLEY

MJFF Co-Founder and Executive Vice Chairman Debi Brooks (left) and Patient Council member Genia Brin

More than 25,000 individuals, corporations and foundations joined the Challenge in 2011. To date, the Foundation has earned an astonishing $35 million toward the $50-million goal. Now, in the final months, MJFF must raise $15 million.

When asked about her hopes for the Challenge, Genia says simply: "That the Foundation can do more of the same — fund research both to find a cure and produce medications that can improve patients' lives today."

A former NASA scientist, Genia was diagnosed with Parkinson's in 1998 at age 50. Both she and Sergey carry a mutation in their LRRK2 gene, the single greatest genetic contributor to Parkinson's discovered to date.

A member of the MJFF Patient Council since its inception in 2009, Genia appreciates the deepened understanding she's gained of the Foundation's work. She has enjoyed interacting with MJFF staff members and weighing in on Foundation initiatives, especially the launch of Fox Trial Finder and strategies for patient education and outreach. "They're definitely on the right track," she says. She has completed her profile on Fox Trial Finder (you can, too, at foxtrialfinder.org or by scanning the code on the back cover) and looks forward to connecting with a suitable trial when she finds the right one. And she hopes people will be inspired to join the Challenge.

"It's important to get the full match," she says. "It would be silly to leave dollars on the table. For those of us who are patients, we simply can't afford to."

There's still time to join the Challenge and this incredible movement. A gift of any size in 2012 is a chance to help speed research and better treatments for millions of Parkinson's patients worldwide. Double your impact now! ***Visit michaeljfox.org/challenge.***

THE SHERER REPORT

MARK SELIGER

In 2012, The Michael J. Fox Foundation is seeing the impact of many years of investment in breakthroughs for both symptomatic and disease-modifying treatments for Parkinson's disease. Through your help — and your participation in the Brin Wojcicki Challenge — you can keep these treatments moving forward.

Todd Sherer

Todd Sherer, PhD, CEO

Read The Sherer Report at michaeljfox.org/TheShererReport

Progress Is Tangible and Next Steps Are Worth Driving Forward:

Double Your Impact While the Brin Wojcicki Challenge Is in Effect

Every advance brings new challenges. The costs of driving any therapy along the pipeline increase exponentially as drug candidates get closer to pharmacy shelves. Drug developers must identify new partners (both pharmaceutical companies and the government) to bring these treatments to a place where they can gain regulatory approval and have a real impact on patients' lives. Today's MJFF lacks sufficient resources to singlehandedly carry a potential treatment through all phases of clinical testing, but we can and must help ensure promising targets aren't left languishing in the pipeline. With your support of the Challenge, we can continue playing a key role in building partnerships to push therapies forward.

I'm encouraged by recent progress (I've highlighted a few key breakthroughs below), and MJFF will continue doing whatever it takes to drive every promising therapy toward practical patient relevance.

Potential breakthroughs for symptomatic treatments

In previous Sherer Reports, I discussed some exciting potential treatments for dyskinesia — involuntary movements that are a side effect of long-term use of dopamine replacement therapy. In the past few months, we've received more good news on this front. These results demonstrate that the pipeline for novel, non-dopamine-based therapies for dyskinesia is strong — perhaps the strongest ever. A significant breakthrough for dyskinesia treatments may be on the horizon:

- Addex Therapeutics, in a Phase 2a study partially funded by MJFF, reported that their novel glutamate anatagonist (dipraglurant) was safe and tolerable, and that it effectively reduced dyskinesia in PD patients. The company is now seeking a pharmaceutical partner to move this drug into later stages of clinical development. If all goes well, the company predicts that a glutamate-based treatment could be up for regulatory approval by 2016 or 2017.

- Positive data from an early clinical trial funded by MJFF demonstrating that a drug targeting a neurotransmitter called serotonin (often associated with depression) holds potential as a dyskinesia therapy. The next step for a team of researchers including Anders Björklund, MD, PhD, from Lund University, and contract research organization PsychoGenics, will be to design a larger-scale study to better understand how well this drug, called eltoprazine, might work in treating dyskinesia.

- An MJFF-funded study led by Christopher Goetz, MD, and Glenn Stebbins, PhD, of Rush University in Chicago identified the best clinical scale for measuring patient response to dyskinesia therapies. In the past, clinicians used several different scales to measure dyskinesia, without any real evidence that they accurately measured the efficacy of a given drug. Now, researchers should be able to design accurate clinical trials to verify if a dyskinesia drug is working.

Turning back the clock: disease-modifying approaches and biomarkers

More promising clinical results have been reported on a potential disease-modifying therapy called isradipine, which is already FDA-approved to treat high blood pressure. In 2007, laboratory work at Northwestern University established that isradipine is neuroprotective in pre-clinical models of PD. In 2008, MJFF funded a clinical study testing isradipine in early PD patients. That study has now established the dose at which most patients are able to take isradipine without significant negative side effects. This information is critical to move forward. A team led by Tanya Simuni, MD, of Northwestern, is applying to the National Institutes of Health in order to conduct further research into isradipine.

The Parkinson's Progression Markers Initiative (PPMI), MJFF's landmark biomarker study, continues to make significant progress. More than 470 individuals (of a needed 600) have enrolled, and the real-time data made available online has been downloaded more than 26,000 times by scientists around the world. At the Movement Disorders Society Meeting in Dublin, Ireland, in June, five PPMI investigators presented early results. Industry interest in PPMI remains strong as we added three new drug companies as funding partners, bringing the total to 12. (To learn more about PPMI, scan the code on the back cover or visit michaeljfox.org/ppmi.)

This fall, the Foundation is building on the PPMI infrastructure with novel studies designed to complement the initiative. This month we are announcing the launch of BioFIND, a collaboration with the National Institute of Neurological Disorders and Stroke (NINDS). While PPMI is aimed at validating existing biomarkers already identified by researchers, BioFIND will be devoted to finding entirely new ones. The most promising of these new leads will move seamlessly into PPMI for verification. Individuals who have had PD for at least five years, but not more than 15 years, may be eligible to participate, along with those who do not have the disease.

The Foundation is also planning to establish a new cohort of PPMI participants. The goal is to characterize changes taking place in the body before the motor symptoms of Parkinson's become evident. This would allow for earlier diagnosis and faster development of treatments that could slow the progression of the disease (something no currently available PD treatment can do). More information on this initiative will be forthcoming later this year.

Progress on other fronts

Progress was not limited only to projects within the MJFF portfolio. The Neupro® dopamine agonist patch was re-launched in the U.S. market in July. Two additional dopamine-based therapies, a levodopa-carbidopa intestinal gel and an extended-release version of Sinemet®, continue to show promising results and should approach FDA regulatory review within the next year. All would provide more options for PD patients and neurologists to manage the disease, while limiting side effects.

Finally, this summer was a disappointing one for Alzheimer's drug development. We learned of unfortunate results from the Phase 3 trial of bapineuzumab, a treatment being tested by Pfizer, Johnson & Johnson and Elan to target beta amyloid clumps — the pathological hallmark of Alzheimer's. This followed closely on the heels of another unsuccessful Phase 2 trial of the drug. In addition, Eli Lilly announced what some considered to be a kind of "mixed bag of results" around their drug candidate solanezumab. Basically, their study showed that the drug did not slow cognitive decline in two separate studies involving around 1,000 Alzheimer's patients each. But when researchers combined the data from the studies, they were able to find some evidence showing it might do so. The word is still out on solanezumab, and whether or not drug companies will want to invest in a critical new trial for the drug remains uncertain.

It is worthwhile for the Parkinson's community to stay abreast of developments in Alzheimer's drug development, because successes and failures in one brain disease can impact investments in another. Parkinson's patients and researchers are all too familiar with risky clinical trials and the immense frustration and disappointment that follow when they fail. Yet even failures have value — they get us closer to understanding what does work, and how to better focus future efforts. Our Foundation will continue working to ensure that no promising treatment goes undeveloped for lack of investment — but we rely on your generous support to keep moving forward toward breakthroughs.

A movement toward a cure

No progress would be possible without you, the committed friends, donors and patients. We are truly grateful that you support our plan of action, and your gift has never been more important than it is today — to the Foundation and Parkinson's patients everywhere.

The $50-million Brin Wojcicki Challenge is in its final days. In the next three months, we must raise $15 million to meet our goal. I hope we can count on you to help us leverage our momentum and make groundbreaking opportunities in PD research a reality. Learn more at michaeljfox.org/challenge.

Thanks again for being a part of our movement. Together, we will cure this disease.

DOUBLE YOUR IMPACT! GIVE NOW AT MICHAELJFOX.ORG/CHALLENGE

A Challenge to the Challenge

To honor her mother, Merrie, who has Parkinson's, Meredith Boone Tutterow ran the 2011 Bank of America Chicago marathon for Team Fox. But her family's involvement with Team Fox and The Michael J. Fox Foundation didn't stop there. In fact, it has only increased. Along the way, they've inspired others to join Team Fox — and to leverage the Brin Wojcicki Challenge while it's in effect.

Meredith confesses she's not a natural born runner. "Some people run a marathon through sheer force of will," she says. "I'm one of those people."

At 40, Meredith knew if she ever ran a marathon, it was now or never. She challenged her mom's sister, Susan McClellan, 60, who had run marathons before, to race with her. Susan recruited her friend, Patty Elkus, 50, to run with them, and the Merrie Miles was born.

"For 18 weeks, all I did was work, run and sleep," says Meredith, who finished in just over five hours, Susan and Patty not far behind. "Completing the marathon — and seeing my whole family cheering me on along the way — was a peak life experience. My mom and dad saw me run. And so did my kids. People from all points of our lives supported our team, to honor my parents."

The Merrie Miles raised over $40,000 — a figure that was ultimately *quadrupled*. Meredith's dad, Dan Boone, matched every dollar the team raised, doubling their efforts to more than $80,000. Thanks to the Brin Wojcicki Challenge, that was doubled again, to over $160,000.

"We are huge fans of the Foundation and their approach," Dan says. "They understand that patients want research funders to take risks and be willing to fail to reach the reward."

Merrie Miles' legacy keeps on going. "The marathon was an opportunity for us to talk to our kids about Parkinson's in a way that we hadn't before," says Meredith. In January 2012, Meredith's daughter Abby turned 10 and hosted a Pancakes for Parkinson's birthday party. She raised over $2,000 for Team Fox, matched by her grandfather, which the Challenge doubled to $8,000. Her grandparents flew in from Atlanta to surprise her. Abby says, "My friends and I felt like we were making a difference. I also learned I wasn't the only one whose grandparent has PD."

In April, the Merrie Miles team, together with Merrie and Dan, attended Team Fox's annual MVP Awards dinner for top fundraisers. "It was so inspiring for all of us," says Dan. "Merrie got to spend time with Michael J. Fox, and we loved hearing about the progress the Foundation was making."

Abby Tutterow with her grandparents, Dan and Merrie Boone

Meredith Boone Tutterow, Susan McClellan and Patty Elkus

At the dinner, the Boone family also learned about an upcoming Team Fox expedition to climb Mt. Kilimanjaro, Africa's highest mountain, in August. Eager to plan their next event, they started talking about a family Team Fox trek to Kilimanjaro. Two family friends, Alice and McKnight Brown, were inspired to join this year's trip as the Merrie Mountaineers. They summited on August 29 and raised over $30,000 for Parkinson's research, which was doubled by the Challenge.

Prior to her family's involvement with Team Fox, Merrie had stayed relatively quiet about the disease she'd had since 2001. "She didn't want to be seen through the lens of a disabled person in any way," says Dan. But both Dan and Meredith agree Merrie has gained something even more important than an outpouring of support. It's enabled her to be more public about her Parkinson's, and has changed her perspective. "It helped us deal with the disease a little bit better," says Dan. "She's learned to embrace it — and that you can turn it into something truly positive."

A Role for Everyone

Bill Price and his father, Bill, Sr., shared a connection more unusual than most: their Parkinson's disease. In fact, they were diagnosed within a year of each other.

Bill, Sr., was diagnosed eight years ago, at age 67. Like many family members, Bill did research to learn more about the disease, including exploring the MJFF Web site and reading Michael J. Fox's memoir, *Lucky Man*. It was then he started picking up on potential PD symptoms of his own, such as his index finger twitching. A real estate developer based in Naples, Florida, Bill initially wrote this off. But by the time he saw a neurologist several months later, his symptoms had progressed. He was diagnosed with young-onset PD at age 49.

Bill Price with his son Matt, father Bill, Sr., and grandson Nate

Father and son's PD progressed at different rates, Bill Sr.'s faster. But Bill's symptoms grew increasingly debilitating. The tremor on his left side worsened, and his gait and flexibility were affected. He began to explore his treatment options. Last winter, he underwent Deep Brain Stimulation (DBS) surgery. It's given him "a second chance," he says.

"It makes so clear the effect symptoms were having on my life, and the challenges all patients face. I'm truly grateful, and I want to do what I can to help while I can."

When he lost his father to Parkinson's-related complications last May, Bill could think of no better way to honor his father's memory, and his own future, than by making a gift to The Michael J. Fox Foundation. Knowing he could double his impact through the Brin Wojcicki Challenge, he was especially motivated to give as much as he could. This year, inspired by his father and the Challenge, he gave $25,000, a tenfold increase over his previous gifts to the Foundation.

"When you're diagnosed at a younger age," he says, "you have your whole life in front of you. You want to know that smart people are figuring out how to best allocate research dollars to get results. I like the Foundation's entrepreneurial approach, as that's my style."

Bill has also asked others to take advantage of the Brin Wojcicki Challenge. While he was preparing for DBS, he was very public about it, sharing frequent updates on his Facebook page. If the surgery was successful, and it was, he asked his friends to show their support by making a contribution to MJFF.

"That's what's so great about the Challenge," he says. "Everyone can play a role."

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Register for Fox Trial Finder to find the clinical trials that need you. Help us get to 15,000 volunteers in 2012!

Learn more about PPMI's search for a biomarker and the study's early results.

If you have PD, you can become one of the 10,000 volunteers speeding genetic research through 23andMe. Scan to participate or visit 23andme.com/PD.

ACCELERATING THE CURE is published three times a year by The Michael J. Fox Foundation. Two issues are mailed to donors who have given $25 or more within 12 months. The year-end issue is mailed those who have given $25 or more within three years. All three issues are mailed for free to those with a PD connection. Make a gift of $25 or more to subscribe at michaeljfox.org/donate. Or subscribe or unsubscribe by emailing info@michaeljfox.org, or register online at michaeljfox.org/register. Past issues are available at michaeljfox.org. Submit questions, comments and feedback to the editor at the address to the right.

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