



MARK SELIGER



THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

THE FOX FOCUS ON PARKINSON'S

FALL 2014 NEWSLETTER

TRACKING PARKINSON'S DISEASE

Wearable devices and big data analytics amplify the patient voice in Parkinson's drug development.

BY MAGGIE MCGUIRE

Parkinson's is a constant — from the moment you wake up to the hour you fall asleep, if you can sleep. Patients and doctors know this, but what doctors know about an individual's disease isn't framed in those terms.

You may see your doctor once every six months or so for an hour (or less). Those few minutes of observation and whatever you can remember to share—who has the time to keep a diary? — determine your treatment regimen until your next appointment.

If you've participated in Parkinson's clinical trials (thank you!), you know that researchers rely on the same subjective measures — periodic clinical exams and patient diaries — to evaluate a drug candidate's effect. With millions of patients living with varied Parkinson's experiences and with limitations on clinical data gathering, investigators are looking through a peephole at a whole population.

The good news: Emerging technologies mean there could soon be a better way. The Michael J. Fox Foundation is leading efforts to test new tools that can track Parkinson's all day, every day, objectively and accurately, in tens of thousands of people and with a greatly reduced burden on patients.

The Michael J. Fox Foundation has partnered with global computing pioneer Intel on a new initiative using wearable devices to capture measurable data on some features of living with Parkinson's (like slowness of movement, tremor and gait disturbances), and then analyze that data to gain new and deeper insights into the nature of PD. *continued on page 4* >

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to learn about
high-impact MJFF
research toward new
PD treatments.

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Partners in Parkinson's

Our nationwide strategic health initiative has engaged thousands since its May launch. Learn more on page 9.

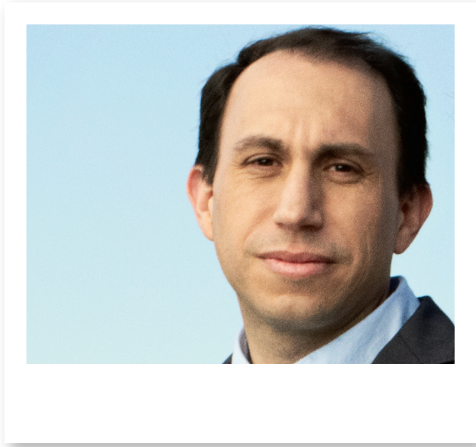
THE SHERER REPORT

A NOTE FROM OUR CEO

“So, how close are we to curing Parkinson’s disease?”

That’s the question I am most frequently asked as CEO of The Michael J. Fox Foundation. It never gets easier to answer, given the starts and stops of science and the shape-shifting complexity of the challenge. In our short history, we have made significant strides toward the cure, but we also have uncovered new, deep and unexpected challenges. Today, great momentum is building in PD research, including several important success stories from just the past few months, which you can read about in this newsletter. Nonetheless, we remain focused and sober about the task ahead. As treatments progress further in testing, costs rise significantly, meaning that our steady leadership — funding, convening, and problem-solving — has never been more needed or important.

As we have since day one, we continue to pursue several high-priority avenues to develop a disease-modifying therapy for Parkinson’s disease — the “Holy Grail” of Parkinson’s drug development, a treatment that could slow, reverse, or even prevent disease progression. Increased understanding of the causes of PD, especially genetic causes, has helped scientists identify therapeutic approaches undreamed of only a decade ago, with real capacity to modulate the disease process at the cellular level. Specifically, the alpha-



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synuclein and LRRK2 genes (and related proteins) have emerged as the most promising and highest-priority targets for disease-modifying therapies. Therapeutic efforts in these areas highlight the indispensable role played by our Foundation in pushing this work closer to patient relevance.

LRRK2 mutations were first linked to PD in 2004, and drug development advanced quickly. As an enzyme, LRRK2 was seen as highly druggable by biotech and pharmaceutical firms with extensive experience (mostly from cancer research) developing drugs against this type of molecule. Several large pharma companies moved into the field quickly, many establishing collaborations with MJFF to complement drug development efforts. We spearheaded consortia dedicated to patient cohorts (assembling and following large groups of carriers of LRRK2 mutations), LRRK2 biology (uniting disparate research groups working to shed light on the structure and function of LRRK2), and LRRK2 research tools including biomarkers. Significant progress was achieved in a relatively short period of time, and individual projects advanced relatively quickly (by scientific standards) toward the clinic. Nonetheless, the reality is that a great deal of work and investment remain before LRRK2 drugs

may be ready to enter clinical trials. MJFF continues to serve as a central hub for the field, applying vital expertise and allocating significant resources to keep this target moving forward through the challenging pre-clinical phases of development.

Alpha-synuclein mutations were first linked to PD in the late 1990s. Alpha-synuclein was soon found to play a role in all cases of Parkinson’s disease, not just in patients who carried mutations. Intensive effort was devoted to understanding alpha-synuclein biology and lighting the best therapeutic path forward. Progress has been steady, albeit slow, as researchers work to unpack weighty challenges — for example, the function of alpha-synuclein (in normal and disease states) remains unknown. What is coming clear, though, is that too much alpha-synuclein is toxic to brain and body cells; lowering synuclein levels is a key potential therapeutic strategy. MJFF has continued to push the field forward, taking risks on early therapeutic programs that are now bearing young fruit: In August we reported the results of the first-ever alpha-synuclein clinical trial. This milestone study (conducted by Austrian biotech AFFiRS — read more in our Newsbriefs on page 8) demonstrated that targeting alpha-synuclein was safe in PD patients, and provided the required rationale for further clinical testing. Several other synuclein strategies led by biotech and pharmaceutical companies are similarly proceeding through development. MJFF continues to provide crucial direction to the field by sussing out and articulating the best clinical development path for advancing alpha-synuclein based treatments.

In sum: The “genetics revolution” in Parkinson’s continues to shape our field. But LRRK2 and alpha-synuclein are not the only approaches we are tracking in

disease modification. For example, efforts focused on isradipine have reached Phase III testing through a partnership between MJFF and the National Institutes of Health. This calcium channel blocker, already approved by FDA to treat high blood pressure, has now been shown with MJFF support to hold potential to slow or stop Parkinson’s progression.

To definitively establish disease-modification, every one of these efforts requires better clinical trial models and tools — all of which are currently being developed by MJFF through the Parkinson’s Progression Markers Initiative (PPMI), our global clinical trial seeking biomarkers of PD.

It is clearly a long and winding road to the cure. As our supporters well know, even failed trials inform our approach, and by supporting multiple parallel efforts, we increase our chances of success. Our bets, by definition, become bigger and more risky as we enter clinical testing, where positive small, early studies require larger more expensive investments. We can’t know which of these approaches or trials will allow us to achieve our ultimate goal. We do know, and hear from our partners again and again, that financial and scientific support from MJFF is indispensable in giving each approach its best chance of success.

So how close are we to the cure? Closer than we were yesterday... but not as close as we’ll be tomorrow. Thank you for helping us get there.

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.



BIG DATA FOR PARKINSON'S

continued from page 1 >

While a wristband or smartphone could never replace your face-to-face interactions with a physician, these gadgets could complement those office visits and give you, your physicians and researchers more data from which to gain insights about your disease.

For the first time, data science offers the opportunity to correlate the field's genetic and molecular understanding of Parkinson's with patients' actual, lived experience of the disease.

"The variability in Parkinson's symptoms creates unique challenges in monitoring progression of the disease," said Diane Bryant, senior vice president and general manager of Intel's Data Center Group. "Emerging technologies can not only create a new paradigm for measurement of Parkinson's, but as more data is made available to the medical community, it may also point to currently unidentified features of the disease that could lead to new areas of research."

Making Sense of Wearable Device Data

Early this year MJFF and Intel launched a study to evaluate three wearable devices for tracking measurable features of PD: Were they user-friendly? What kind of data could researchers collect? How might that data help track Parkinson's?

Participants with and without PD wore the devices during two clinic visits and at home over four days. Intel engineers are now comparing the data captured by the devices to clinical observations and patient diaries to characterize the wearable data as it relates to Parkinson's.

Another small study later this year will similarly aim to capture response to PD medications.

Building the Tools to Analyze the Data

Intel's technical expertise allows us to collect and analyze all the data from these

wearable devices. The ones we used in our study captured 300 observations per second, per patient.

The Intel engineers developed a cloud-based platform to collect and store massive volumes of de-identified data from study participants. They also are developing algorithms to uncover patterns, nuances and anomalies revealed by the data. Qualified researchers will be able to access the de-identified data, too, to advance their own studies.

Gathering Lots of Data for Deeper Insights

In the future, researchers using wearable devices in their studies could upload their data to the platform for analysis using the Intel algorithms. These researchers uploading their de-identified data to the platform may also choose to allow its inclusion in larger, population-scale studies. We envision a collection of data from tens of thousands of patients that Intel big data approaches can comb to unearth insights into Parkinson's disease.

More data and tools for analysis could answer critical questions such as how to best time medications, how does the disease progress, and what new drugs are having an effect, which is ultimately what patients need.

Speeding Research with Objective Data

Supplementing subjective measures like clinical exams and patient diaries with wearable devices could help researchers test new therapies faster.

"It is difficult, oftentimes, to detect a meaningful change in symptoms or disease progression to alert us that an investigational intervention is working — whether improving symptoms or slowing the disease," said William Marks, MD, MS-HCM, Professor of Neurology at the University of California, San Francisco and a consultant to The Michael J. Fox Foundation on our Intel partnership.

"With sensors acquiring objective data 24 hours a day, we can gather a huge dataset on each person's function and should be able to detect smaller changes that occur over shorter periods of time. Therefore we'll be able to say that we need to pursue a treatment in question and not abandon it or 'We're not seeing a signal, let's move on to a different approach,'" said Dr. Marks.

Empowering Patients to Contribute to Research

Wearable computing can capture and transmit data 24 hours a day, seven days a week, and all you have to do is put on a watch or drop a smartphone in your pocket. This could shift the paradigm for how patients can contribute data on living with Parkinson's and help ensure that research goals are aligned with patients' most pressing priorities and needs.

As Michael J. Fox told *USA Today* when asked about the Foundation's partnership with Intel: "The answers are within us. We just need to find a way to let people into our brains both literally and figuratively to help us figure this out."



HOW TO GET INVOLVED

The use of wearable devices for tracking Parkinson's disease is currently being tested in a clinical trial. The next phase of this study is recruiting in New York, Boston and Tel Aviv this fall. You can learn more about this study and other studies that may need someone like you by creating a profile on Fox Trial Finder (foxtrialfinder.org).

See page 14 to learn more.



Bret Parker

"Parkinson's isn't everything I am all the time."

One patient recounts his experience in the MJFF/Intel wearables trial

Recording his Parkinson's disease symptoms in a diary is not how Bret Parker, 46, chooses to spend his day. It's time-consuming, and he prefers activities that don't require him to focus on his PD, like running and hanging out with his family and friends. So when Fox Trial Finder alerted him to volunteer for a new study testing wearable computing devices to effortlessly monitor the daily experience of people with PD, he jumped at the chance.

Over four days as one of 30 clinical trial volunteers, he wore two watches and carried a smartphone in his pocket — all measuring various aspects of his symptoms. He also kept a standard patient log documenting when he took his medication and "on/off" times.

"I pay attention to my Parkinson's, but it's not everything I am all the time," Bret says. "The wearables did that monitoring for me in a way I didn't even notice, and the study allowed me to take an active role in the process for developing a cure."

“A BIGGER IMPACT...ON A BIGGER AND BRIGHTER STAGE”

Two pioneering organizations come together to speed better treatments for movement disorders that affect millions of lives.

BY KIMBERLY CASTLEBERRY

The Michael J. Fox Foundation (MJFF) and The Bachmann-Strauss Dystonia & Parkinson Foundation (BSDPF) are forming a collaborative research alliance to generate greater awareness and deeper investment in advancing dystonia and Parkinson’s disease research. Through the partnership, BSDPF is establishing a major prize for dystonia research to be conferred annually by MJFF.

“We greatly value the many years we’ve worked with Bachmann-Strauss. We both share a commitment to advancing research that will lead to transformative medical treatments patients so urgently need,” said Todd Sherer, PhD, CEO of The Michael J. Fox Foundation. “Our goal is to continue speeding high-impact scientific findings that will benefit dystonia and Parkinson’s patients worldwide, sooner rather than later.”

The Bachmann-Strauss Prize for Excellence in Dystonia Research will broaden public knowledge, recognize major scientific discoveries and incentivize the work of dedicated researchers in dystonia, an under-funded movement disorder and an under-recognized symptom of PD. Additionally, the partnership with BSDPF will enhance support of critically needed research that explores overlaps in the underlying causes, development and treatment of dystonia and PD through MJFF.

BSDPF and MJFF have shared a productive working relationship for nearly a decade collaborating on major studies, sharing scientific advisors and funding

many of the same researchers. Several experts involved in BSDPF’s movement disorder centers of excellence also serve on the MJFF Scientific Advisory Board.

Beginning January 1, 2015, BSDPF will transition its daily operations to MJFF and refocus its funding in support of the prize. In its search to find a partner, Bachmann-Strauss was looking to align with an organization that could help bring greater prominence to dystonia, as well as a shared goal of accelerating better treatments for patients. MJFF has leveraged significant resources in areas that overlap between Parkinson’s and dystonia research, funding millions of dollars in research in this area since our inception in 2000. The work MJFF is driving in basal ganglia circuitry and deep brain stimulation has benefitted dystonia patients significantly.

“Our goal is to continue speeding high-impact scientific findings that will benefit dystonia and Parkinson’s patients worldwide, sooner rather than later.”

“We have always had a dual mission of funding research to find better treatments for both dystonia and Parkinson’s,” said



L to R: Bonnie Strauss, founder and president, The Bachmann-Strauss Dystonia & Parkinson Foundation; Michael J. Fox, founder, The Michael J. Fox Foundation for Parkinson’s Research; and Thomas W. Strauss, vice president and treasurer, The Bachmann-Strauss Dystonia & Parkinson Foundation.

Bonnie Strauss, founder and president of BSDPF. “By partnering with MJFF now and taking on this new role, we can make a bigger impact and bring greater attention to these two debilitating movement disorders on a much larger and brighter stage.”

People living with Parkinson’s can have dystonia as a symptom of their disease, or dystonia can exist as its own disorder. While some experts estimate that as many as 40 percent of PD patients are living with dystonia, the relatively

limited population of people affected makes it challenging to generate awareness and attract funding for research. Through MJFF’s global network, prestigious platform and wealth of resources, the alliance will elevate knowledge of dystonia, and its connection to Parkinson’s, to new and broader audiences.

The first Bachmann-Strauss Prize for Excellence in Dystonia Research will be presented at a ceremony in New York City in May 2015.



READ MORE ABOUT THE PRIZE
at michaeljfox.org/research/bachmann-strauss



THE
BACHMANN-STRAUSS PRIZE
FOR EXCELLENCE IN DYSTONIA RESEARCH



FALL 2014

RESEARCH NEWS BRIEFS



Funding Deals Mark De-risking Successes

Investors took notice of the great promise in Parkinson's research this fall with a flurry of activity. In late August, biotech Civitas filed for an initial public offering. Weeks later, it was sold for \$525 million on the strength of its "asthma inhaler" delivery system for levodopa (read more below). Neuroderm, developing a levodopa skin patch, has filed to go public. Sapiens, which is developing optimized deep brain stimulation technology, was acquired by larger company Medtronic, and biopharmaceutical company MedGenesis struck a deal with Pfizer to continue progress on its GDNF delivery system. MJFF has funded each of these projects, and these partnerships support our de-risking model that aims to make promising projects attractive to funders who can usher them through the development pipeline.



Parkinson's Vaccine Reported Safe in Phase I Trial

The first Parkinson's vaccine in clinical trials passed an early hurdle to further development this summer. In August researchers from Austrian biotech AFFiRS announced positive Phase I results showing their vaccine was safe and tolerable in people with PD. The drug aims to slow or stop Parkinson's progression by targeting the protein alpha-synuclein, which clumps together in the cells of people with PD. MJFF funded part of the Phase I study and is supporting the study's next step testing a booster vaccine. Read more at michaeljfox.org/affirsvaccine.



New Technologies Could Reduce "Off" Episodes

Many people with PD experience "off" periods – when the effects of levodopa wear off before it's time for the next dose. Patients are left vulnerable to rigidity or slowness of movement. A more reliable and consistent method for delivering levodopa could help. Two potential drugs supported by MJFF achieved important results over the summer and are moving forward in development. Both test emerging technologies for better levodopa delivery. One is an inhaled form of levodopa (mentioned above), similar to rescue inhalers used in asthma, providing quick and reliable relief. The other is a rapidly dissolving apomorphine film strip, similar to Listerine strips, placed under the tongue to quickly restore motor function. (Current apomorphine therapy requires injection.) Watch our Webinar about off episodes at michaeljfox.org/offwebinar.



Biomarkers Study Publishes Early Findings

The Parkinson's Progression Markers Initiative (PPMI), the landmark Parkinson's biomarkers study sponsored by MJFF, continues to recruit people with PD risk factors: smell loss, REM sleep behavior disorder or specific genetic mutations. At the same time, researchers are beginning to share findings from the first group of volunteers, 400 people with Parkinson's and 200 controls. A study published in August reported depression, anxiety and fatigue are more common in people with early PD. The researchers also shared that depression may be undertreated; two-thirds of patients who screened positive for depression were not taking an antidepressant. Read more about depression and PD on page 12 or listen to a podcast at michaeljfox.org/depression.

EMPOWERED PATIENTS: Partners in Parkinson's Connects the PD Community with Valuable Resources

BY KIMBERLY SAWICKI

This past May, The Michael J. Fox Foundation and AbbVie, a Chicago-based pharmaceutical company, launched Partners in Parkinson's, opening the door for patients and families across the United States to connect with specialists, learn more about Parkinson's and get involved in the PD community. So far, over 4,000 members of the Parkinson's community have signed on to learn how to "discover the benefits of team."

"No two cases of Parkinson's disease are alike. Patients and caregivers need high-quality, trustworthy information and resources that can help navigate a Parkinson's diagnosis and progression," said Debi Brooks, co-founder and executive vice chairman of The Michael J. Fox Foundation. "Partners in Parkinson's provides tools to empower the Parkinson's community to take an active role in their own care, now and in the future."

Finding the Right Doctor

Partners in Parkinson's is focused in part on the value of specialist care to manage the progressive symptoms and stages of Parkinson's disease — something too few patients make part of their care regimen. According to a survey conducted online by Harris Poll on behalf of The Michael J. Fox Foundation and AbbVie in early 2014, as few as 28 percent of Parkinson's patients are currently seeing a movement disorder specialist. This lack of awareness of specialty care means Parkinson's patients are not getting to the right doctor, which



may hold implications for their ability to appropriately evolve their treatment plans and manage their disease at all stages.

"There are so many questions that need answering and there's so much hunger for information," said Dave Iverson, Parkinson's patient and MJFF contributing editor. "Getting smarter about your own story so you can tell that story and get the support you need is crucial."

Education and Support as a Next Step

To address the knowledge gap, Partners in Parkinson's offers virtual and face-to-face opportunities for patients and families to connect with vital tools and resources. Its educational website (www.partnersinparkinsons.org) features the first-ever online tool enabling patients to locate a movement disorder specialist (developed in collaboration with the International Parkinson and Movement Disorder Society). The website also includes comprehensive information about PD with a downloadable Parkinson's disease guide and the ability to connect with an AbbVie Parkinson's Disease Advocate for one-on-one support.

"Partners in Parkinson's aims to empower patients with the knowledge they need to proactively address care needs from diagnosis through advanced disease," says Maureen Conley, general manager, neuroscience, AbbVie.

“The goal of this initiative is to help Parkinson’s patients and families develop a plan of care that adapts as their symptomatic and lifestyle needs change over time.”

Partners in Parkinson’s in the Community

Parkinson’s affects communities across the country, and Partners in Parkinson’s will visit cities across the United States in 2014 and 2015, providing free, full-day educational events. These events take place on weekends and feature educational panel discussions moderated by Dave Iverson on topics including the variability of Parkinson’s disease, what to

know, ask and expect at an appointment with a movement disorder specialist and updates on PD research. Attendees may then choose from breakout sessions on taking a holistic approach to living well with PD, the benefits of strengthening ties with family, friends and the PD community and a special session where attendees may ask additional questions about PD. Each event also includes a resource fair, open all day for attendees to meet with local organizations, healthcare providers and other groups all based in their community.

Since the inaugural event in May, Partners in Parkinson’s events have benefitted patients and caregivers at

every stage of Parkinson’s. “I wish this was around when my mom was first diagnosed,” said Partners in Parkinson’s event attendee Susan Bilotta and daughter of a Parkinson’s patient. “If we had this then, it would have been very different — from her coming out about Parkinson’s, to her initial treatments, to the information available to help our family deal with it.”

National and local Parkinson’s organizations are also collaborating in Partners in Parkinson’s, uniting to bring education on different aspects of living with PD directly to patients. National Presenting Partner The Davis Phinney Foundation (DPF) signed on in early

2014, lending its expertise in helping patients live well holistically with Parkinson’s disease. DPF has led a breakout session, “Living Well with Parkinson’s: A Holistic Approach,” at each of the 2014 events. National Participating Partners the Parkinson’s Action Network and the Parkinson’s Disease Foundation are present in the resource fair at each event in 2014. Local presenting and participating partners attend events in their city, connecting with patients and families who may be just around the corner.

FOR MORE INFORMATION and a schedule of upcoming events, **visit partnersinparkinsons.org**.

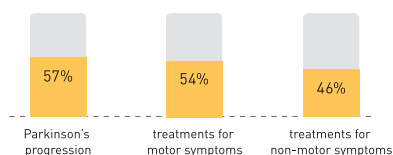
PATIENT ENGAGEMENT IN PARKINSON’S CARE CAN IMPROVE OUTCOMES FOR ALL

People with Parkinson’s who play an active role in their care may not only help themselves live better with their disease but also can contribute to better outcomes for the Parkinson’s community. A survey of Parkinson’s patients conducted on behalf of The Michael J. Fox Foundation and AbbVie showed that seeing a specialist can help patients better understand the disease and learn about research participation opportunities.

Get Informed

Knowledge is power. More than half of people with Parkinson’s don’t know where to turn for Parkinson’s information and support.

Too few patients feel informed or very informed about...



Movement Disorder Specialists: Your Untapped Resource

Not enough Parkinson’s patients know about or take advantage of adding a movement disorder specialist to their Parkinson’s care team. Only...



...28% of patients are currently treated by a movement disorder specialist



...45% have ever seen a movement disorder specialist



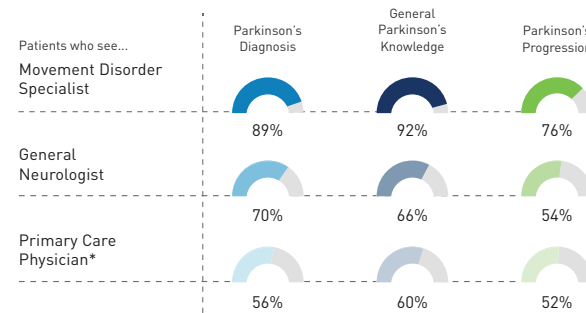
...48% could pick the definition from a list

Movement Disorder Specialist
a neurologist with additional training in Parkinson’s disease

Movement Disorder Specialists Spark Important Discussions

Patients who see a movement disorder specialist as their main Parkinson’s doctor are more informed about the basics of managing their disease.

Percentage of patients who say they are informed or very informed on:

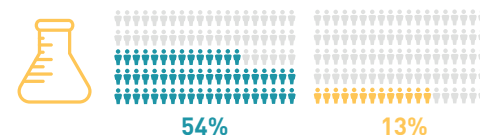


Patients who see a movement disorder specialist are more likely to discuss comprehensive Parkinson’s issues. At most or every visit:



Help the Entire Parkinson’s Community: Enroll in Research Studies

Four times as many patients who see a movement disorder specialist feel informed or very informed about clinical research opportunities compared to those who have never heard of this specialist.



Enrolling in research studies allows patients to contribute to new treatments that will benefit the whole Parkinson’s community.

FIND A MOVEMENT DISORDER SPECIALIST

Visit partnersinparkinsons.org to find a movement disorder specialist in your area and connect with other resources to optimize your care.

ANXIETY, DEPRESSION AND PARKINSON'S DISEASE:

A Q&A with movement disorder specialist Irene Hegeman Richard, MD.

Dr. Irene Richard, a member of MJFF's Scientific Advisory Board, answers questions about depression and anxiety and their link to Parkinson's disease.

Q: How do I know if I am depressed or just having a normal emotional reaction to dealing with Parkinson's?

A: While changes in mood and level of anxiety can be normal reactions to diagnosis with a serious disease, clinical depression is something different. There is an increased frequency of depression and anxiety in Parkinson's. Depression and anxiety can occur at any time during the course of Parkinson's (even before the onset of motor symptoms).

Q: Is depression in Parkinson's treatable?

A: It is a potentially serious but generally very treatable condition as long as it is recognized. In fact, a study I was involved in found that two common antidepressants can ease depression in people with PD. (Work with your doctor to find the treatment plan that's right for you.) The treatment for depression and anxiety is different from the treatment for other Parkinson's symptoms (such as tremor or slowness). The most important thing is to be aware and to be sure that you, your friends, family and doctors are on the lookout for signs and symptoms of depression.



Irene Hegeman Richard, MD

Q: What does the research tell us about the link between depression and Parkinson's?

A: Researchers believe that depression and anxiety in Parkinson's may be due to underlying changes in brain chemistry and circuitry that are caused by the disease. The circuits in the brain that control movements are closely associated with those that control mood. In addition, we know that Parkinson's can be associated with several different brain chemicals, not just dopamine (the neurotransmitter that is lost in Parkinson's). For example, there can be disturbances in serotonin, which is known to regulate mood. *(Editor's note: Research from MJFF's PPMI study recently confirmed the link between depression and PD. Read more about PPMI on the opposite page).*



Irene H. Richard is a Professor in the Department of Neurology, Movement Disorders and in the Department of Psychiatry at the University of Rochester.

In His Genes

After discovering he carried a Parkinson's-implicated genetic mutation, Jon Gilman got busy.

BY KIMBERLY CASTLEBERRY

Jon Gilman, a software engineer in Boston, is into health and fitness. He runs. He bikes. He practices yoga. And he uses apps to track all of his physical activity. He even worked for the developer of an app called RunKeeper, which turns a smartphone into a digital personal trainer.

Motivated to learn more about how his body works using data science, Gilman decided to be genetically tested earlier this year through 23andMe, the personal genetics company founded by longtime MJFF supporter Anne Wojcicki. Reading through the analysis of roughly one million letters of his DNA, Gilman wasn't surprised to discover that he has a gene commonly found in sprinters. More surprising was the revelation that he carries a mutation in his LRRK2 gene — linked to more cases of Parkinson's disease than any other gene discovered to date.

“.....”

“I didn't know what to think...I quickly learned there were a lot of ways to be proactive.”

.....”

“There's no history of Parkinson's in my family. I didn't know what to think about it at first,” he recalls. Uncertain what the news meant for his health, he did what any rational person would do — he took to Google.

LRRK2 is of interest to pharmaceutical

companies as a promising drug target in Parkinson's. The gene is a kinase, which means it functions as a kind of on/off switch inside body cells. Drug-makers have a lot of experience with kinases, primarily from years of cancer research, which could benefit the process of developing drugs to target kinases implicated in other diseases.

While only a small percentage of individual Parkinson's cases are caused by genes, studying them can benefit everyone living with the disease. Even rare mutations provide a window on critical cellular events that may also take place in non-genetic cases of disease. Looking through that window can point researchers in the direction of new treatments. This kind of information is what Gilman found when his Google search led him to the MJFF website.

“I quickly learned there were a lot of ways to be proactive,” he said.

Continued on page 16 >



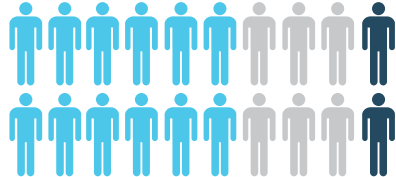
L to R: John Gilman, longtime Team Fox member Jimmy Choi and Jon Gilman's wife Cara at a Team Fox Pedal for Parkinson's event in Boston.

WHY FOX TRIAL FINDER?

Clinical trials are a final and crucial step to discovering new treatments for Parkinson's disease. Volunteers with and without Parkinson's are constantly needed to participate in order to drive new treatments toward pharmacy shelves. It can be difficult to know how to get involved. Fox Trial Finder is a great place to start.

THOUGH 60%

of people with Parkinson's say they would be willing to participate in a trial,



FEWER THAN 10%
ever do

**AND EMPTY TRIALS =
EMPTY PHARMACY SHELVES**



Here's your chance to
**BE PART OF
THE SOLUTION**



**FOX TRIAL
FINDER**

makes it easy to find
the trials that need you



CREATE A PROFILE
on Fox Trial Finder
and you'll:

- Receive a custom list of trials in your area
- Message anonymously and safely with trial coordinators
- Join a community of volunteers committed to driving PD research forward

Today,
85% OF CLINICAL TRIALS
face delays and
**30% NEVER EVEN GET
OFF THE GROUND**
due to a lack of volunteers

But when more volunteers enroll, PD research becomes

**FASTER, CHEAPER
AND MORE EFFICIENT**



**AND MEDICAL
BREAKTHROUGHS**
are made possible



No amount of funding or other resources can ever make up for a lack of volunteers. Join the 35,000+ people who have already signed up to make a difference. foxtrialfinder.org



L to R: Laurine, Mark, Kyle, Logan and Darve Fillo

CALLING ALL TECH-GEEKS: Clinical Trials 2.0 Need You

BY ELIZABETH JOYCE

Laurine Fillo, a Calgary-based photographer, wife and mother of three, was diagnosed with young-onset Parkinson's at 38 in 2003. A classic early adopter, Laurine was one of the first in line to turn to technology as a means of monitoring her health. Each morning she puts on her FitBit wearable sensor that tracks her steps, calories burned and sleep. So it's no wonder that she gravitated to Fox Trial Finder, MJFF's online clinical trials matching tool, and dove headfirst into trials that are using technology to accelerate new discoveries.

"I thought, 'I should look into this and see what it's about.' Turns out it was really easy to find trials that needed volunteers like me."

Laurine has participated in several studies leveraging technology to help researchers better diagnose and treat PD, including a study using wearable computing to gather information about certain Parkinson's symptoms. (See page 5 to learn more about another recent trial involving wearables.)

Earlier this year, Fox Trial Finder notified Laurine of a Web-based study she could participate in from home. "It just landed in my inbox. All I had to do was click on a link." Participants are asked to complete surveys to help researchers assess complementary and alternative

approaches to PD, such as taking supplements or practicing yoga.

The study appealed to the self-described "tech-geek" for two reasons. "First, I'm very much of the mindset to try new things, including complementary approaches, to help manage my symptoms. Yoga, cardio exercise and dance help me feel better, and so do acupuncture and regular massages. Second, I appreciate how computing now gives me the power to contribute to research. Participating in a Web-based trial allows patients like me to be heard in PD research, even if we don't live near a research center."

Emerging technologies are changing the face of Parkinson's disease research, and the participation of PD patients and family members alike remains crucial. For Laurine, the decision to stay involved is a simple one. "The only way to advance PD research is for people with the disease to provide information about what we experience," she says. "And if scientists out there are eager to do the research, we should step forward and get involved. Participating in research studies helps us all get one step closer to a cure."

TO FIND OUT ABOUT

PD clinical trials that need you,
visit foxtrialfinder.org.

GROWING ENGAGEMENT

Founder of Team Fox Young Professionals Joins MJFF Leadership Council

Last summer, The Michael J. Fox Foundation's Leadership Council welcomed four fresh faces to the group. One of the Council's new members is Loren Berger, an old friend of the Foundation.

Berger ran the New York City Marathon for Team Fox in 2008, shortly after his grandfather's diagnosis with Parkinson's disease. He found the passion and energy of the Team Fox community so inspiring, he was hooked — on running and on MJFF.

In 2009 Berger founded the Team Fox Young Professionals of New York, a group he chaired until 2013, creating a model for proactive groups of 20- and 30-somethings in Boston, Chicago and other cities across the United States. Team



Loren Berger runs the 2013 ING New York City Marathon for Team Fox.

Fox Young Professionals groups support each other, engage with the community and fundraise to help speed high-impact research.

"In the beginning, we were throwing stuff against the wall to figure out what kind of events worked best," he said. During Berger's four years as chair, he oversaw the group's annual "Sunday Funday," which caught on and grew into

the MJFF-funded Parkinson's Progression Markers Initiative (PPMI), the Foundation's landmark biomarker study that launched a new arm to investigate genetic traits associated with the onset and progression of PD. Gilman had an initial screening in July and has officially enrolled.

"Throughout the process, I just felt good contributing to something bigger than myself, hoping that I can play a small part in finding a cure for Parkinson's," Gilman explains. "And that's true of my whole experience with the Foundation. The more we can do to raise money and awareness now, the better chance we'll have of finding a cure."

the Young Professionals' signature event. (Sunday Funday has raised more than \$35,000 for MJFF to date.)

From there, joining the Leadership Council was a "natural evolution in my involvement both personally and professionally," he said.

Established in 2009, the Leadership Council has 15 members who provide leadership and financial support for the Foundation's research programs while acting as advisors and ambassadors.

"Many of the most active supporters of The Michael J. Fox Foundation are the adult children and grandchildren of people living with Parkinson's disease," Berger said. "The Leadership Council aims to engage this group and provide an outlet to support Parkinson's research in a way that makes sense to us — we have shown it's possible to have fun, raise critical dollars and share scientific information through personal stories."

Leadership Council Chairman Scott Scheffrin agrees.

"The Council is made up of individuals at a certain point in their lives and careers

who want to financially contribute to — and connect with — MJFF," Scheffrin says.

"We work to provide opportunities for more Parkinson's families to engage with the Foundation's work and take part in the mission to speed a cure."

Berger's own family story is what inspired him to run that first marathon. When his grandfather first began experiencing symptoms, doctors couldn't diagnose him properly. Vertigo, high blood pressure and several other conditions were considered. With his grandfather passing away shortly after he was finally correctly diagnosed with PD, Berger says the ordeal was frustrating.

"I got involved with MJFF at a time when I definitely needed it," he shares. "It's amazing how welcoming everyone has been of me and my family."

Share how you stay engaged in the Parkinson's community. Follow us on Facebook at facebook.com/michaeljfoxfoundation

IN HIS GENES *Continued from page 13*

With the facts in hand, he made a decision. He would keep running and biking and tracking all of his physical activity. But along with his heart rate, blood pressure and number of miles covered, he would include another set of numbers — dollars for Parkinson's research.

This fall Gilman and his wife, Cara, ran the Bank of America Chicago Marathon for Team Fox. He also participated in the Team Fox event Pedal for Parkinson's in April. But he didn't just stick to his athletic comfort zone. He joined the Team Fox Young Professionals of Boston and signed up to participate in

EDUCATION @ MJFF



MJFF provides a variety of opportunities to learn more about life with Parkinson's, and the promising research under way to speed improved therapies into patients' hands.

THIRD THURSDAYS WEBINARS On the third Thursday of every month, join our live webinars at 12 p.m. ET to learn about the various aspects of living with Parkinson's disease and the Foundation's work to speed medical breakthroughs. Visit michaeljfox.org/webinars to learn more, view previous webinars and to register for an upcoming one.

PARKINSON'S PODCASTS Subscribe to our podcast series to hear more about the latest scientific understanding and therapies in development. Search "The Michael J. Fox Foundation" on iTunes to find our podcasts and subscribe.

Get Active, Support Research

MILES FOR A CURE

RACE TO \$50K



Last year, MJFF's inaugural **MILES FOR A CURE** challenged you to run, walk or bike to raise critical dollars and awareness for Parkinson's research. This year, our sponsor Medtronic DBS Therapy wants to match your miles again — this time in a race to \$50,000, one dollar and one mile at a time.

Our challenge to you is to help us reach our goal as fast as possible. Miles for a Cure began on October 3, so there's no time to waste — the sooner we can raise \$50K for Parkinson's research, the closer we'll be to new treatments and a cure. For every mile you run, walk or bike, Medtronic will donate \$1 to MJFF to help speed high-impact Parkinson's research, up to \$50,000.

Get started before the race is over!



1 DOWNLOAD THE CHARITY MILES APP:

It's easy to use and available for iPhone or Android. (If you don't have Charity Miles, use our Manual Miles form online to input your miles daily)



2 GET MOVING

Run, walk or bike to rack up \$1/mile.



3 TELL YOUR FRIENDS

Spread the word to your social networks.

VISIT MICHAELJFOX.ORG/MILESFORACURE FOR MORE INFORMATION AND TO GET STARTED TODAY.

FIND YOUR SUMMIT WITH



Starting this spring, Sam Fox (no relation to Michael) will travel 5,000 miles through 48 states in 3 months to raise \$500,000 for Parkinson's research. And he is inviting you to take part in it.

Learn how to hike, bike or celebrate with Sam at michaeljfox.org/tourdefox.

100 DAYS, 100 WAYS TO SPEED A CURE

With fall in full swing and the holidays just around the corner, now is the time of year when many of us turn our thoughts to giving back to the causes that matter most. It's an ideal time to engage your community in raising funds and awareness for The Michael J. Fox Foundation and Team Fox looks forward to showcasing how our members are doing so. We've been working with the Team Fox community long enough to know that the most powerful fundraising ideas come straight from our members. Whether they run marathons or organize a dress-down-day at work, this group is always finding creative ways to help speed a cure. Our new 100 Days, 100 Ways campaign celebrates that can-do spirit.

From September 23 through New Year's Eve, Team Fox is sharing all the ways our members are making the most of the last 100 days of the year. And we want you to get involved! Whether you **Get Moving** by participating in a local Turkey Trot, **Join In** by hosting a festive party, or **Inspire Others** to give by including an appeal in your holiday card, there are countless ways, big and small, to get involved before 2014 is out.

"Everyone who joins Team Fox gives 100 percent to our shared mission of speeding a Parkinson's cure. And thanks to



an anonymous donor, this year 100 percent of donations made by Team Fox members go straight to high-impact research," says Jason Rice, director of development for the Foundation. "100 Days, 100 Ways serves as a jumping-off point for Team Fox to continue fundraising strong through the last 100 days of the year while inspiring others to get involved, as well."

The countdown is on — are you ready to join us? Through December 31, we will be compiling Team Fox photos to share how our members continue to move the needle toward a cure. Help us tell the story of the last 100 days of 2014 by joining the conversation online and sharing your photos on Facebook, Twitter and Instagram using **#TF100Days**. Visit teamfox.org/100days to be inspired by what others are doing, and see if your submissions have been featured! However you choose to join us through the end of the year, thank you, as always, for bringing your passion and creativity to our shared mission to cure Parkinson's disease.



Team Fox Members Give 100%. Literally.

The Michael J. Fox Foundation knows how hard our inspiring Team Fox members work to raise donations. That's why anonymous donors cover the costs incurred by the Foundation to run the Team Fox program — so every penny of proceeds donated to MJFF by Team Fox members can go straight to our high-impact research programs to help speed a cure for Parkinson's disease.

MILLION-DOLLAR MOMENTUM:

Team Fox Achieves “Mind-Blowing” Milestones in Fundraising

BY KIMBERLY SAWICKI

Since its inception in 2006, Team Fox, MJFF’s grassroots fundraising program, has seen thousands of members transform their unique passions into events and feats toward a cure for Parkinson’s.

The program began with just 200 members and has since expanded into a global movement of over 6,000 individuals and families who have passed through Team Fox’s doors, finding creative ways to help put an end to Parkinson’s disease. The perseverance of these members has resulted in incredible fundraising achievements that MJFF could never have dreamed of, including individual events that have now crossed \$1 million in cumulative fundraising.

“It’s mind-blowing that we’re celebrating individual Team Fox events that have raised \$1 million for Parkinson’s research,” says Michael J. Fox. “We know it takes a lot of hard work, passion and dedication to raise those big dollars.”

First to cross the \$1-million mark was the bartending competition Tips for Parkinson’s. Established in 2006 by Team Fox member Susan Bilotta, whose mother lives with Parkinson’s disease, “Tips” has grown from 100 friends in a pub on New York City’s East Side to a highly anticipated event attracting over 700 guests. Having crossed the million-dollar mark, Susan shows no signs of slowing down. She continues inviting friends, family and the community to test their bartending skills in support of research.

Jim and Chris Edlund, of the Danville D’Elegance (DDE) Foundation, marked their event’s 10th anniversary in September,

which also reached \$1 million in cumulative giving with its annual weekend of automotive events in historic Danville, California. The event, organized by DDE’s dedicated committee members, started with a small group of 20 volunteers in its first year and has since exploded in popularity, engaging more than 200 individuals who diligently raise funds for MJFF. The Edlunds have a long family history of Parkinson’s disease, prompting them to establish their foundation to raise funds for research. Danville D’Elegance, a classic and exotic automobile festival, attracts hundreds of car enthusiasts from around the country and has steadily increased its fundraising goals each year, in part through the contributions of national and international sponsors.

Edna Woods of Merrimack, New Hampshire, and her family hosted their 7th annual New England Parkinson’s Ride in September, sending their cumulative giving to MJFF across the \$1-million mark. Edna launched the ride in honor of her son, Chris, who was diagnosed with Parkinson’s disease in 2006 at age 41. This year, 600-plus riders took to the streets, winding through beautiful country roads — for as many as 100 miles — surrounding Old Orchard Beach, Maine.

“Team Fox members inspire us every day by coupling creativity with immense generosity,” says Sheila Kelly, vice president of development at MJFF. “We can’t wait to see what our fundraisers have in store next.”

To learn about how you can become a Team Fox member or attend and support a Team Fox event in your area, visit teamfox.org.



RaceTrac team members participate in the company’s annual Run for Research 5K Fun Run to benefit MJFF.

RaceTrac Surpasses \$1 Million in Cumulative Giving

RaceTrac, the chain of gas stations and convenience stores found throughout the southern United States, has long supported MJFF’s mission to cure PD. Now, RaceTrac has surpassed \$1 million in cumulative giving to MJFF. This impressive milestone is due in large part to RaceTrac’s dedicated team members who participate each year and encourage the community to give back. The company’s support of the Foundation began in 2010 with its “Coffee for a Cause” in-store promotion, which raises funds and awareness throughout April, Parkinson’s Awareness Month. Since 2011, RaceTrac also has hosted an annual Run for Research 5K Fun Run in Atlanta, which recently expanded to Dallas/Fort Worth.



WORKING TOWARD A CURE

Workplace giving is a resourceful and effective way to help make a difference in Parkinson’s disease research.

Together with your employer, you can make tax-deductible donations through payroll contributions. Whether you work for the federal government or a corporation, you likely have access to one of these options:

Through the **Combined Federal Campaign (CFC)**, as well as state and local campaigns, federal government and military employees can support The Michael J. Fox Foundation. The annual campaign season is under way. If you would like to give to MJFF through the CFC, please enter CFC code #12227 on your pledge card.

Double the impact of your donation to Parkinson’s research by taking advantage of your employer’s **matching gift program**. Not sure they offer one? Just reach out to your human resources department and you could start doubling, or even tripling, the impact of your donation to MJFF.

Supporting MJFF through a **workplace giving campaign** allows you to further PD research through payroll pledges. These donations are automatically coordinated through your employer, making it easy for you to help MJFF find a cure for Parkinson’s.

IN YOUR WORDS

Join the more than 350,000 friends on Facebook and 27,000 followers on Twitter who share their stories and feedback every day!

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DISCOVERING #CLINICAL TRIALS:

Cassandra Hradek
@CassandraHradek

Just signed up for @MichaelJFoxOrg
#Parkinsons trial finder! #volunteer
#foryougrandma

Terry Gibson @Bookmark_Terry

Do you, like me, want to help
@MichaelJFoxOrg fight #Parkinsons
but have no funds? Look into
Clinical Trials. I did.



FRIENDS AND FAMILY FOR A CURE

Lauren Kovel My grandfather passed away in 2010 from P.D. I miss him so much, he was so brave and remained cheerful despite his deterioration. I received my B.S. in Biology in May, and I hope one day to be able to conduct P.D. research and give help to those fighting it, including an inhaler med, and a genetics testing trial. Looking forward to the day we hear there is a cure!

MegAnne Duke @MegAnne Because we felt helping cure Parkinson's was the best way 2 celebrate our wedding. @MichaelJFoxOrg #SayiDuke @TEAMFOX pic.twitter.com/zoSRKfSNN2

"A GOOD WALK SPOILED"



L to R: Peter Benedek, George Stephanopoulos, Michael J. Fox and Harlan Coben.

The Michael J. Fox Foundation's July golf event, Breaking PARKINSON'S, was the most successful to date, raising more than \$800,000 for Parkinson's research. This year's event was the highest attended, with 130 golfers teeing off under sunny skies at Winged Foot Golf Club in Mamaroneck, New York. "I started golf in my 40s with Parkinson's, which is the ultimate optimism," Michael J. Fox has said. The 2015 event will take place Monday, July 27, at Winged Foot.

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

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