PROPELLING RESEARCH INTO THE 21ST CENTURY

MJFF launches Fox Insight, collaborates with key tech industry players including Apple and Intel on technology-enabled research tools.

BY KIMBERLY SAWICKI AND HOLLY TEICHHOLTZ

The Michael J. Fox Foundation’s new online clinical study Fox Insight (foxinsight.org) is seeking volunteers with and without Parkinson’s disease. Fox Insight aims to gather the world’s largest dataset on the day-to-day experience of living with Parkinson’s disease (PD).

Anyone with a computer and an Internet connection can participate in Fox Insight. It is open to Parkinson’s patients worldwide, as well as people who do not have PD. During their first visit, interested volunteers consent to participate and provide information about their personal experience related to Parkinson’s disease through a guided virtual study visit made up of simple questionnaires. Fox Insight then prompts participants to come back every 90 days for subsequent “virtual visits.”

A variety of built-in tools also helps manage and optimize care. An Appointment Keeper, Physician Report, printable summaries of questionnaires and access to other recruiting PD clinical trials all are offered within Fox Insight’s dashboard.

Fox Insight debuted in March as Apple Computer announced its first foray into medical research through ResearchKit, a platform for the development of iPhone apps that can streamline patients’ contribution of data to research toward cures. In conjunction with the launch of ResearchKit, biotech

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MJFF fosters collaboration among competing pharma companies.

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New fellowship program will increase resources to train movement disorder specialists.

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Tour de Fox
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RARE COLLABORATION AMONG COMPETITORS TO SPEED LRRK2 DRUGS

With leadership from The Michael J. Fox Foundation, drug companies put patients first in unusual collaboration.

BY MAGGIE MCGUIRE

The Michael J. Fox Foundation has united three competing pharmaceutical companies in a consortium to advance the development of drugs targeting LRRK2. Mutations in the LRRK2 gene are the most common genetic cause of Parkinson’s disease (PD). While genetic cases of PD are rare, understanding the genetics of PD can lead to treatments for everyone with the disease. For this reason, LRRK2 is of great interest to drugmakers, who see the possibility for a disease-modifying medication (a drug that could slow or stop the progression of PD) in so-called LRRK2 inhibitors. Researchers hypothesize that lowering activity with these drugs could protect brain cells from the damage caused by PD.

With the goal of accelerating progress on LRRK2, MJFF has established a roadmap for studying the target and has funded $90 million in LRRK2 research to date.

A bump in the road

Every drug must overcome hurdles on its path to market. Last January, one such potential hurdle was identified for LRRK2 inhibitors. In a paper published in the journal Science Translational Medicine, authors from biotechnology company Genentech and MJFF reported that they had observed changes in the lung tissue of pre-clinical models after introducing a so-called LRRK2 inhibitor. Researchers proposed a consortium approach to illuminate the nature and scale of safety issues surrounding LRRK2. Research groups from Genentech, Merck and Pfizer signed on to join the LRRK2 Safety Initiative.

As members of the consortium, each group submits a different LRRK2 inhibitor compound for independent testing to determine if some inhibitors are safer than others — that is, whether changes in lung tissue varied depending on the inhibitor used. Data on each compound is shared across the consortium. This is a highly unusual arrangement in the competitive world of drug development.

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MJFF organizes drug development leaders to move forward

Concerns around LRRK2 inhibitors first came to light early in 2014. MJFF rapidly organized a meeting with field leaders. Because kinase inhibitors are a common class of drugs, a handful of companies already had compounds designed to target LRRK2.

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But the members recognize that by working together, they’re more efficiently growing the field-wide understanding of the safety and impact of LRRK2 inhibitors.

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THE SHERER REPORT

A NOTE FROM OUR CEO

“What should we be aware of this Parkinson’s Awareness Month?”

We declare it to our loved ones. We tweet it, blog it and post it on Facebook: April is Parkinson’s Awareness Month. But of what, exactly, are we trying to raise awareness?

At The Michael J. Fox Foundation, we want Parkinson’s families to be aware that we’re making real progress on the road to a new generation of PD treatments and a cure. Milestones met in the last six months inspire unprecedented optimism, while new initiatives require our ongoing attention and participation.

The first months of 2015 brought approvals from U.S. Food and Drug Administration for two new formulations of levodopa/carbidopa (read more on page 11). The traditional formulation of this so-called “gold standard” treatment for Parkinson’s still leaves much to be desired, bringing disabling side effects with long-term use and failing to address many of patients’ most important needs. These new formulations can reduce motor fluctuations and increase “on” time without dyskinesia.

Still, too many aspects of PD remain untouched by the current crop of available treatments. That’s why our in-house team of PhDs and MDs continues to prioritize funding for a rich pipeline of treatments for the motor and non-motor symptoms reported by patients to be the most troubling. These include new approaches to deep brain stimulation (page 10), cognitive impairment and constipation.

Meanwhile, we’re still tirelessly working toward patients’ greatest unmet need: a therapy to slow or stop disease progression. Here, too, good news. Several MJFF-funded companies researching compounds that target alpha-synuclein — the sticky protein that clumps in the brain and body cells of people with Parkinson’s — have recently announced lucrative investment deals to advance their projects (page 10). Development of drugs against another high-priority target, LRRK2, hit a bump in the road last year, but we have assembled a rare consortium of field leaders to strategize and keep moving forward. We outline our game plan on the opposite page.

All of us at The Michael J. Fox Foundation realize how much we need you to reach our shared goals. We hope that this month — and each one after — you will gain a renewed awareness of how much power you have to change the prognosis of Parkinson’s.

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
PROPELLING RESEARCH INTO THE 21ST CENTURY continued from page 1

Sage Bionetworks released Parkinson mPower, a patient-centered, iPhone app-based study of symptom variation in Parkinson’s disease, available for download via the iTunes App Store. Sage and MJFF are now collaborating on the further development of mPower, and later this year will jointly conduct a study of participants contributing data through both mPower and Fox Insight.

“Today the technology exists to study and measure every aspect of Parkinson’s disease — and not just in a few dozen or hundred people, as has traditionally been the case in Parkinson’s clinical trials, but in hundreds or thousands. And not just once or twice a year in a clinician’s office, but 24/7,” says Todd Sherer, PhD, chief executive officer of MJFF. “For the first time, we’ll have data to help answer fundamental questions — like when in the course of their disease people should start taking levodopa in order to get the best symptomatic benefit, or how to accurately predict who will respond to certain treatments, or why patients progress at different rates.”

Changing the paradigm of clinical data capture

Traditional clinical studies, the final, vital stage of research before a new treatment comes to market, are the most expensive part of drug development, costing millions or even billions of dollars. Clinical testing also is slowed by a chronic lack of volunteers in sufficient number. This can cause the drug development process to stall and some trials must be repeated or scaled back. Even worse, potential new therapies can be abandoned. These factors individually and collectively lengthen the time it takes for new treatments to come to market.

“Patients and families know that their participation in research is a requirement to speed progress toward cures,” says Debi Brooks, MJFF co-founder. “MJFF is working to build the on-ramps. Technology-enabled solutions, such as mobile apps and virtual studies, cannot replace traditional clinical trials. But they hold immense potential to complement field-wide efforts, in part by opening the door to many more research volunteers.”

While cost and recruitment challenges necessarily limit cohort sizes of traditional trials, home computers and smart phones can reduce the burden of participation for thousands of individuals — collecting data at relatively low cost. Computing solutions for the analysis of large datasets also are rapidly growing in sophistication.

This creates an entirely novel opportunity to amplify the patient voice in research by tying unmet medical needs directly to outcome measures for drug development. Individuals’ health can now be tracked in detail using self-reported data and mobile devices equipped with sensors that continue to improve in their accuracy. According to a recent report in The Economist, currently about 2 billion people around the world have access to smartphone technology, and 80 percent of adults will use an Internet-connected mobile device by 2020.

Core to the MJFF philosophy, all data collected through Fox Insight will be de-identified and made available to researchers worldwide for independent studies. Making this data available to the research community at large can rapidly accelerate progress by reducing research costs and promoting replicable results. As always, stringent measures are in place to protect participants’ privacy. Any data that directly identifies a study participant is removed before data is transferred to researchers for analysis. Participants’ contact information will never be sold, rented or leased.

mPower/Fox Insight 2015 Combined Study

Later in 2015, MJFF and Sage Bionetworks will jointly conduct a study of participants contributing data through both mPower and the Fox Insight platform. The combined study aims to amplify the voice of Parkinson’s patients and elevate their role as partners in research.

mPower participants with a diagnosis of Parkinson’s disease will be given the opportunity to consent to provide their data to the combined study. Additionally, MJFF will make Fox Insight users aware of the opportunity to download the mPower app and participate in the combined study. Pending results of the combined study, MJFF will further develop and customize mPower to leverage the potential synergies of the mPower mobile app study platform and the Fox Insight platform.

A commitment to developing emerging technologies for patient benefit

The Michael J. Fox Foundation is committed to developing emerging technologies for the benefit of Parkinson’s patients. In August 2014, the Foundation announced an ongoing collaboration with Intel Corporation to develop big data analytics and wearable technologies to speed Parkinson’s drug development. Intel has developed an open-source platform for data collected through wearable computing. The platform supports an analytics application developed by Intel to process and detect changes in the data in real time. By detecting anomalies and changes in sensor and other data, the platform can provide researchers with a way to measure the progression of Parkinson’s disease objectively.

In the near future, the platform could store other types of data such as patient, genome and clinical trial data. In addition, the platform could enable other advanced techniques such as machine learning and graph analytics to deliver more accurate predictive models that researchers could use to detect change in disease symptoms. These advances could provide unprecedented insights into the nature of Parkinson’s disease, helping scientists measure the efficacy of new drugs and assisting physicians with prognostic decisions.

Later in 2015, Intel and MJFF plan to launch a mobile application that enables patients to report their medication intake as well as how they are feeling in an effort to enable medical researchers to study the effects of medication on motor symptoms via changes detected in sensor data from wearable devices.

Learn more about Fox Insight or enroll today by visiting foxinsight.org.
In January, the U.S. FDA approved two new formulations of the “gold standard” traditional Parkinson’s treatment carbidopa/levodopa. Duopa and Rytary are designed to lessen “off” time — when symptoms return prior to the next scheduled dose of medication. Rytary is an oral extended release capsule and Duopa is a gel formulation of carbidopa/levodopa infused directly into the small intestine. (Learn more on page 11.)

Dr. Rachel Dolhun, MJFF’s resident movement disorder specialist, sat down with Claire Henchcliffe, MD, a movement disorder specialist in clinical practice at New York- Presbyterian Hospital/Weill Cornell Medical Center to discuss “off” times and strategies for optimizing treatment.

**Targeting “off” time: New treatments to lessen motor fluctuations**

**Dr. Rachel Dolhun: In my practice, patients often had difficulty recognizing and describing wearing off symptoms because they are so individualized and can be so varied. Do you see this in your clinic?**

**Dr. Claire Henchcliffe:** My patients do exhibit a wide range of symptoms — both motor and non-motor — when wearing off. They also differ with regard to the rate of onset — symptoms can come on gradually or appear suddenly and unpredictably. Some people have a vague sensation of generalized fatigue in the afternoons, or subtle mood changes or profuse sweating prior to taking their pills. In these cases, it takes a bit of probing to figure out that this is actually “off” time. Others experience a more distinct return of resting tremor or localized dystonia and pain before their next medication is due. It can be hard for patients to determine what is and isn’t part of Parkinson’s.

**RD:** As you mentioned, correctly diagnosing wearing off required a good amount of discussion with some of my patients. Once we determined symptoms were from wearing off, there were multiple options for treatment, including lifestyle and medication adjustments. What is your typical approach to management?

**CH:** Treatment is, of course, tailored to each person. First, I address behaviors that might be making medication less effective — such as missing or accidentally delaying scheduled drug doses, eating a lot of protein before a dose, or taking carbidopa/levodopa with meals. If that’s not enough, it’s then possible to adjust the dosage of medication and/or the timing of administration, and also to consider adding another drug to the medication regimen.

**RD:** I, too, tried to optimize a patient’s current therapies before prescribing another medication when treating wearing off. At times, however, this led to frequent dosing of carbidopa/levodopa that became too cumbersome. Do you think there will be an opportunity to replace what patients are taking now with the new formulations of carbidopa/levodopa?

**CH:** I certainly see a place for these drugs in my clinic. Both are designed to deliver a more steady concentration of medication and therefore lessen off time. I see Duopa as an alternative to deep brain stimulation (DBS) in those with uncontrolled motor fluctuations who either don’t want DBS or aren’t ideal candidates for it. I anticipate using Rytary in my patients with advancing disease or those who have inadequate control on their current medications. I hope the new formulations will lighten the number of medication doses required per day, decrease the number and severity of off periods, and eliminate the need for rescue therapies for unexpected off episodes.

**RD:** New therapies like Duopa and Rytary are available only because people with Parkinson’s volunteered for the clinical trials that tested them. As a busy practicing physician, I experienced how difficult being aware of and communicating these opportunities for research participation to patients could be. How do you handle this?

**CH:** It can be challenging, but I just do my best. As for talking to patients about research and opportunities for participation, this is a conversation that evolves over time, across several visits — everything doesn’t have to be covered in one appointment. Aside from that, it’s an exciting time to be treating people with Parkinson’s. Telling them about what’s in the pipeline, including innovative approaches like vaccines and gene- or cell transplant-based strategies, gives us both hope for improved quality of life now and a disease-modifying therapy in the future.

NOTE: The medical information contained in this newsletter is for general information purposes only. The Michael J. Fox Foundation has a policy of refraining from advocating, endorsing or promoting any drug therapy, course of treatment, or specific company or institution. It is crucial that care and treatment decisions related to Parkinson’s disease and any other medical condition be made in consultation with a physician or other qualified medical professional.
Making the Most of Your Next Doctor Appointment

Rachel Dolhun, MD, offers tips for working effectively with your physician

The physician-patient relationship is just that — a relationship. No matter what kind of doctor you see for your Parkinson’s, effective communication and understanding is key to optimizing care.

1. PRIOR TO YOUR VISIT.
Think about the interim since your last appointment. Were there any changes in health, medications prescribed by other physicians, or life in general? How are your symptoms: the same, better or worse? Thinking about this information ahead of time will allow you to convey your concerns succinctly so they can be incorporated into the care plan.

2. DURING YOUR VISIT.
   - Bring all of your pills (not just prescription drugs but any over-the-counter medications, herbs and supplements), in their bottles, to each appointment. If there is any question about how you are taking your medications, it can be answered during the appointment.
   - Let a family member or care partner accompany you. This person can relay pertinent symptoms you may not be aware of, ask questions you might not have thought of, provide an opinion on next steps and help you remember and incorporate changes to the care plan.
   - Be honest and open. Your doctor needs all the information you can provide about your medical history; if you are (or aren’t) taking medications as prescribed, and any need for clarification about your condition or recommendations for treatment.

3. BETWEEN VISITS.
Stay in touch with your physician’s office. If you experience side effects from prescribed medications, if pressing questions arise or you encounter a significant change (such as a fall or hospitalization), don’t wait to contact your doctor; call for additional guidance prior to your next scheduled visit.

Learn more about specialty care for Parkinson’s at partnersinparkinsons.org

Training the Next Generation of Parkinson’s Specialists

New program will expand the base of fellowship-trained movement disorder specialists.

BY KIMBERLY SAWICKI AND RACHEL DOLHUN, MD

When Parkinson’s patients get to the right doctor, it often leads to better optimization of care, greater engagement in the Parkinson’s community, and more participation in clinical research,” says Debi Brooks, co-founder of The Michael J. Fox Foundation for Parkinson’s Research.

Movement disorder specialists are neurologists with extra training in movement disorders, including Parkinson’s disease (PD). They see a greater number of PD patients than other physicians and often participate directly in research.

Resources for training are limited
Lack of sufficient financial support for centers to train movement disorder specialists is just one hurdle to ensuring there are enough doctors to meet PD patients’ needs.

“Unfortunately, more people want to enter the field than there is funding to allow. Many fellows are unable to specialize in an area that is only going to grow in demand,” said Matthew B. Stern, MD, director of the Parkinson’s Disease and Movement Disorders Center at the University of Pennsylvania Health System and president of the International Parkinson and Movement Disorder Society (IPMDS).

The Edmond J. Safra Fellowship in Movement Disorders

To address this issue, with leadership support from The Edmond J. Safra Foundation, MJFF created The Edmond J. Safra Fellowship in Movement Disorders. The overarching goal is to grow the global base of movement disorder specialists. Equipping these fellows with a strong clinical background and complementary research education enables them to improve the overall care of PD patients. Clinician-researchers observe the nuances of the patient experience leading to a greater understanding of disease. This increased understanding will open up new avenues to better therapies.

“The talented young clinician-researchers who will be chosen as Edmond J. Safra Fellows represent great hope for all of us, and I am so proud to be supporting them at the beginning of what will certainly be stellar careers full of groundbreaking achievements,” said Mrs. Lily Safra, Chairwoman of The Edmond J. Safra Foundation and a member of MJFF’s Board of Directors. “With The Michael J. Fox Foundation’s leadership, this initiative will surely make a profound impact on both research and patient care in the years to come.”

Competitive centers from across the world expressed interest in training this next generation of specialists and selecting the candidates proved difficult. The review committee, which met in early March, took into account factors including the institution’s clinical structure and research environment and the associated opportunities, support and innovative programs offered to each fellow. Awarded fellows will begin training in summer 2016.

The Edmond J. Safra Fellows will answer the growing clinical need and bridge the gap between the clinic and the lab. In doing so, they will help people live better with Parkinson’s now and speed progress toward a cure.
Research Optimizes Deep Brain Stimulation Treatment

Deep brain stimulation is a transformative therapy for some people with Parkinson’s. Electrodes implanted in the brain send impulses or signals that control brain activity and alleviate symptoms. However, currently DBS treats only the same set of symptoms eased by available medications: tremor, rigidity and slowness of movement. An MJFF-funded project is researching the effect of DBS on a different brain region to treat posture instability and gait difficulty. Other work supported by the Foundation aims to refine DBS devices to fire impulses only when needed, instead of continuously. That would help avoid side effects, as well as lengthen the time before surgery is necessary to change the battery.

Good News for Projects to Slow Parkinson’s Progression

Three companies developing drugs to slow or stop the progression of Parkinson’s celebrated milestones early this year. Neupore Therapies and Neurophage (MJFF grantees) and Prothena are all testing compounds against clumps of the protein alpha-synuclein, thought to cause cell death. Neurophage recently secured $10 million in venture capital to advance its lead compound. Two days later, Neupore announced it will team up with Belgian drugmaker UCB in a deal worth up to $480 million to grow the study of Neupore’s compounds. Both projects could move to testing in humans as soon as the end of the year. Prothena’s vaccine approach is already in clinical trials. The company shared positive results from its safety study in control volunteers; they’re now testing in people with Parkinson’s.

23andMe Announces Pharma Deal and Therapeutics Group

Genetics testing company 23andMe is taking strides toward drug development. In January it announced a major deal with pharmaceutical company Genentech to analyze genetic information from more than 3,000 people with Parkinson’s to identify new drug targets and therapies for PD. Later this year, the partners will start enrolling participants for whole-genome sequencing to uncover nuances and trends in Parkinson’s genetics. In March 23andMe released news of its own therapeutics group that will pore over its genetics database themselves as the starting point for identifying new therapies.

FDA Approvals Bring New Parkinson’s Therapies to U.S. Market

In January the U.S. Food and Drug Administration (FDA) approved two new formulations of traditional Parkinson’s therapy levodopa/carbidopa. Both therapies are designed to avoid “off” time — when symptoms return before it’s time for the next dose of medication. MJFF awardee Impax Pharmaceuticals announced the approval of RYTARY, an extended-release, oral capsule formulation of the drug. Less than a week later, the FDA approved AbbVie’s Duopa gel formulation of carbidopa/levodopa enteral suspension. The treatment, approved in Europe under the name Duodopa since 2004, is delivered directly into the small intestine via a small infusion pump and tube. The drug bypasses the stomach and thereby some of the absorption issues impacting oral medicine. Duopa requires patients wear a large external “box” in the belt region that may require maintenance.

Third Thursdays Webinars and Friday Twitter Chats

Join MJFF and expert panelists for live webinars at 12 p.m. ET on the third Thursday of every month. 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, watch previous webinars or to register for an upcoming one.

STILL WANT TO LEARN MORE? The Friday following each Third Thursdays Webinar, MJFF hosts a Twitter chat. MJFF’s resident movement disorder specialist, Dr. Rachel Dolhun, continues discussing that month’s topic and answers more of your questions. Follow us on twitter.com/michaeljfoxorg and join our next conversation. #FoxPDchat
FOX TRIAL FINDER ANALYSIS SHEDS LIGHT ON PARKINSON’S STUDIES AND VOLUNTEERS

BY CHRISTINA BRDEY

Since its launch in 2011, Fox Trial Finder, The Michael J. Fox Foundation’s online clinical trial matching tool, has registered more than 40,000 potential research volunteers and lists nearly 450 ongoing Parkinson’s studies in nine countries. In February 2014, the Journal of Parkinson’s Disease published the first peer-reviewed paper on Fox Trial Finder. Baseline analysis found:

> Family connections to Parkinson’s may motivate research participation among control volunteers. Of 19,243 registrants with PD, only 12 percent listed an immediate family history of disease, while 49 percent of participants without PD reported a family connection.

> Volunteers’ proximity to trials limits study enrollment. The findings confirmed a geographical imbalance with only 10 of the top 20 areas of study sites also being in the top 20 areas of volunteers, making the case for use of technology to involve participants in areas without traditional “brick-and-mortar” studies.

> Time since diagnosis does not appear to be an eligibility factor in the listed studies. Most studies were recruiting for patients with a Hoehn & Yahr score (a measure of disease progression) of 1 or 2, but 66 percent of listed studies were recruiting for patients with a score of 5. The average age at diagnosis was 58 years.

Learn more about how you can become part of the pursuit of a cure at foxtrialfinder.org.

RARE COLLABORATION AMONG COMPETITORS continued from page 2

“The Michael J. Fox Foundation is fostering conversations that may not otherwise happen but are essential to moving this research forward,” said Warren Hirst, PhD, group leader in the Pfizer Neuroscience Research Unit. “By working together we can overcome obstacles and make progress towards new therapies.”

Next Steps
The companies will announce initial results from the LRRK2 Safety Initiative testing later this year. Their studies continue as they strive to answer questions surrounding the use of these drugs to treat Parkinson’s.

“The best outcome would be for these companies to stop working together because we’ve solved for some of these unknowns,” said Todd Sherer, PhD, MJFF CEO. “We want them to go back to their labs and race to the finish of getting drugs closer to patients.”

GALVANIZED TO CURE PARKINSON’S

Last November, hours before MJFF’s annual gala fundraiser, A Funny Thing Happened on the Way to Cure Parkinson’s, Michael J. Fox and Ryan Reynolds sat down with fellow MJFF Board member and TODAY Show co-host Willie Geist — whose father, Bill Geist, also has Parkinson’s — for a segment on family and PD. The trio shared stories about how they’ve each integrated PD into their own family dynamic. “It kind of galvanized everybody else, to sort of seek resources,” Reynolds noted of his family’s response to his father’s diagnosis. “And for us, it’s in a strange way, it’s really kind of brought us together.”

THE COUNTPDOWN TO TOUR DE FOX IS ON.
ALL THAT’S MISSING IS YOU.

Join endurance athlete and MJFF staff member Sam Fox (no relation to Michael) as he makes his way to your state this summer.

HIKE, BIKE OR CELEBRATE WITH SAM AND HELP RAISE $1 MILLION FOR CUTTING-EDGE RESEARCH

FIND YOUR SUMMIT AT: WWW.TOURDEFOX.ORG

CAN’T JOIN SAM ON THE ROAD? Support by making a donation. For a limited time, every dollar donated to Tour de Fox will be matched dollar-for-dollar thanks to the generosity of an MJFF Board member.
Overcoming “the Subtraction of Parkinson’s”

Patient council members Soania Mathur, MD, and Dave Iverson both live with Parkinson’s disease, but they share more than that diagnosis. Soania interviewed Dave about his role as the Foundation’s contributing editor and Partners in Parkinson’s moderator, and their shared commitment to staying engaged in the Parkinson’s community.

Soania: Dave, you not only create award-winning films on Parkinson’s disease, but you are in many ways the journalistic voice of The Michael J. Fox Foundation through webinars, podcasts and events. Was being proactive in the PD community a conscious choice for you?

Dave: I guess, when I think back, its starts on the day of my diagnosis. Two things stand out — the shock of the news of course, but also something that happened hours later. My doctor and I happened to wind up on the same streetcar in San Francisco, which abruptly came to a stop. I remember looking up and catching his eye. He looked at me, smiled and said, ‘Well, just remember from now on, it’s all about balance.’ I think about that incident often because in so many ways, living with this condition is about balance, both literally and figuratively. And for me, part of that process has been to be engaged from the start.

Soания: You have a family history with Parkinson’s. Did having that history give you a framework for coping with this disease?

Dave: Yes, for example, my dad was a lovely, graceful man and he dealt with having Parkinson’s with great peace. He always had the point of view that it could be worse; there are tougher things than this. So I think I did learn that from him. On the other hand, there’s sometimes a danger in being too accepting. I think you have to figure out how to be graceful and accepting, but also push back at the same time — again, it’s a balance.

Soania: Acceptance doesn’t equal complacency — that’s something we take to heart in my own family, and it’s what I try to communicate in my children’s books. (Editor’s note: Soania has recently published her second children’s book, “Shaky Hand’s — A Kid’s Guide to Parkinson’s Disease,” which is available on Amazon.)

Dave: Exactly.

Soania: So what are some of the ways you’ve found to push back?

Dave: I do think that participating in research is the single most important thing that we as a community can do.

Soania: Yes — we’re an integral part of the process.

Dave: As you know, the percentage of people who participate in research is quite small. But we all have to join in the effort if we’re looking to make faster progress. It’s also an opportunity to learn more and get extra information about what’s going on with your PD. I don’t know if this is true for you — in fact, I’m sure it’s not because you’re a scientist by training, a doctor — but for me, as sort of the classic non-scientist, who stumbled his way through high school science, it’s all been a revelation. I have this fascination now with neuroscience. Nothing like a little self-interest to change your orientation as to what you find fascinating!

Soania: Do you now see a difference in the landscape of education and resources available to people diagnosed today?

Dave: I think there are so many more resources than there were when we were diagnosed. I think Michael and his Foundation have impacted people’s understanding that they themselves are part of the solution.

Soania: I feel the same. What was it that made you want to devote time to helping the Foundation in its mission?

Dave: I had the opportunity to interview Michael for a film about six years ago. And I came away from that inspired by the Foundation’s laserlike focus on advancing research. It’s important to have something to believe in when you’re living with this disease. And the Foundation is something I’ve come to believe in without reservation.

Soania: Absolutely. The sense of community it has created is really vital when you’re facing the challenges this disease brings.

Dave: Yes! I’m not sure you remember this, but you and I were once talking about support groups. I made this kind of offhand comment that I’m not really a support group kind of guy; and you looked at me and said, ‘Yes, you are,’ referencing our conversations as part of the Foundation’s Patient Council. And of course, it’s true. Not everyone sees themselves as a “support group type,” but it’s important to find support where it makes sense, because it’s so empowering.

Soania: Absolutely. It helps to know you’re not facing it alone.

Dave: Exactly. I’ve come to think of Parkinson’s as a disease of subtraction. It takes things away, one by one. Whether that’s the swing of your arm, your sense of smell or whatever it happens to be. So addition becomes really important; you have to figure out what you can add back into your life. I feel incredibly lucky and blessed for the opportunities the Foundation has given me to add things back in.

Soania: How do you feel about the future? Do you have hope for the future?

Dave: Enormous progress is being made. Does that mean I think there’s a cure around the corner? No, actually. I don’t think there’s a cure around the corner, but I absolutely believe that we will find a way to slow down disease progression, if not bring it to a standstill. That will happen. And our job is to do everything we can to hasten that day. I think, by being active in whatever way makes sense for us, and by staying as healthy as we can so we get to benefit when that day arrives.
Tip of the Iceberg

Team Fox family and friends ramp up support “for every mom with PD.”

BY STEPHANIE PADDOCK

Meet Megan Pliszczyk, 36, of South Glens Falls, New York. After her mom, Donna, was diagnosed with Parkinson’s disease (PD) in 2010, Megan sought the opportunity to get involved in the PD community, turning first to The Michael J. Fox Foundation’s website for answers.

“I’m so proud of my daughter — she already understands the importance of our cause.”

An avid runner, Megan soon completed her first NYC Half Marathon with Team Fox, raising over $14,000. Since then, she has run the NYC Marathon (2014) and the Walt Disney World Half (2015). And last year she enlisted the help of her best friend, Alexis, to create a Fox Trot 5K for Parkinson’s Research. The event — a 5K race and a virtual run — inspired more than just her local community, it attracted runners from almost all 50 states.

Megan’s athletic feats have stirred her network of family and friends to establish Team Fox Adirondacks — an enthusiastic group who are always there to cheer her on along the way. This passionate bunch also comes out to support the creative events she’s put together, such as a “Dine to Donate” campaign at a local Subway sandwich shop and a “Paint N’ Sip” painting class (where participants learned to paint an adorable fox on canvas), each of which raised hundreds of dollars for PD research.

Megan’s daughter, Lucy, 6, is her biggest fan. After seeing her mom train for races all to support PD research, she wanted to help. “Lucy’s Lemonade” raised over $160 in its first day. A few weeks later, and with the addition of a hot dog stand and other treats, Lucy bumped that number up to $600 in one day.

“Her new goal is to raise enough money to cure Parkinson’s before she turns 10,” Megan reports. (Go Lucy!)

What’s next for 2015? Megan’s got lots of foxy ideas. The second annual Fox Trot 5K takes place on April 18. She’s also planning a jewelry party and possibly a Pancakes or Pints for Parkinson’s event. And of course, there are plenty of miles to log — because she’s definitely crushing another 26.2 in this year’s NYC Marathon.

“Once I discovered Team Fox, I knew exactly what I wanted to do, but running turned out to be just the tip of the iceberg,” says Megan. “I’m so proud of my daughter — she’s so young, but she already understands the importance of supporting our cause. For my mom, and every mom with PD, I just can’t wait to figure out what my next fundraiser will be.”

A CHAMPION FOR POSITIVITY

BY KIMBERLY SAWICKI

Anna Mee, 38, started 2013 feeling good. Following her diagnosis with breast cancer two years earlier, the Scotts Valley, California wife and mother of two young daughters had undergone several cancer treatments, including a double mastectomy, and her prognosis was good. Anna and her husband, Art, were looking to the future with hope.

But soon Anna noticed a small tremor in her left hand. After seeing several doctors and eventually finding her way to a neurologist, she heard something utterly unexpected: You have Parkinson’s disease.

“When you first learn of something like Parkinson’s — especially after all Anna went through with cancer — you can feel isolated,” says Anna’s mother, Chris. “She wasn’t sure what it meant for her future, so she decided it was time to learn more.”

Anna decided to start by reading Lucky Man and Always Looking Up, Michael J. Fox’s memoirs of his life before and since his Parkinson’s diagnosis. Inspired by his famously optimistic attitude, Anna decided she wouldn’t let Parkinson’s define her.

“In his books, Michael describes how he came to see Parkinson’s as an opportunity to display his true nature — a tendency toward positivity and action,” Anna says. “It was inspiring — I’m like that too, and I knew this was a chance to feel empowered.”

Anna wanted to connect with others who had Parkinson’s. With her husband and her parents, she began connecting with supporters of The Michael J. Fox Foundation, including at Foundation events.

“After meeting many others like us, our hope grew,” says Chris. “Everything the
IN YOUR WORDS
Every day our social community inspires us and one another with their best tips for living well with Parkinson’s. Join the more than 435,000 friends on Facebook and 45,000 followers on Twitter who continue the #Parkinson’s conversation!

Twitter & Instagram: @MichaelJFoxOrg
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HELPING A FRIEND NAVIGATE PARKINSON’S
Vanessa Kahn
Help keep them socially and physically active. Help them retain the fun in their lives.

Peggy Harris Walker
Keeping the Parkinson’s patient and caretaker engaged in activities, friendships and life outside of the home as long as possible then bringing life to the home when the patient can no longer go on outings.

POSITIVE WORDS FOR THE NEWLY DIAGNOSED
Mary Neilans
Educate yourself about this complex disease. You’ll need to be your own best advocate to manage decisions with your health team in the years to come.

Tony Saitta
Find a specialist. Don’t fret about every possible symptom—it’s different for all of us. Stay active. Live every day enjoying it even more, not wasting it by worrying.

Sharon Skindell
Take it one day at a time. No sense “living” in the future or the past. Just enjoy today and deal with what today brings.

THE MICHAEL J. FOX FOUNDATION LAUNCHED IN 2000 WITH ONE GOAL IN MIND:
CURE PARKINSON’S AND GO OUT OF BUSINESS.
We’re proud of our track record of efficiency, with 89 cents of every dollar spent going straight to the science. We can keep that momentum going by saving on costs. That’s why we’re encouraging our community to visit us online and experience our new, enhanced digital newsletter. Help us save on printing and postage costs by opting to receive the newsletter digitally. Visit michaeljfox.org/newsletter to opt in today.

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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