



MARK SELIGER



THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

THE FOX FOCUS ON PARKINSON'S

— SPRING/SUMMER 2016 NEWSLETTER —

A NEW FUTURE FOR PARKINSON'S PUBLIC POLICY

BY ALLYSE FALCE

This spring, The Michael J. Fox Foundation (MJFF) and the Parkinson's Action Network (PAN) announced plans to operate as a single organization, with the goal of advancing the development of improved Parkinson's disease (PD) therapies and ensuring access to new treatments once they come to market.

"The state of Parkinson's drug development has changed considerably over the last decade, and as a result, so have advocacy priorities," said Todd Sherer, PhD, MJFF CEO. "As more potential treatments enter clinical testing, we need an integrated public policy strategy to work with decision makers who dictate access to these therapies."

Key staff members from PAN will join MJFF to form the Foundation's new Public Policy team, which will operate primarily out of Washington, DC. Ted Thompson, who served as president and CEO of PAN from 2014 to 2016, joins MJFF as senior vice president of public policy.

"As we work to speed a cure, we must be equally focused on other therapies and services that benefit patients living with Parkinson's disease today," said Thompson. "Together we can move the needle on improved disability policies, better veteran benefits and broad access to a wide range of health care services."

An Evolving Landscape

Since MJFF launched in 2000, the landscape of Parkinson's disease drug development has evolved significantly. At MJFF's founding, the state of Parkinson's research as a whole lay primarily in basic research —

continued on page 4 >

ADVICE
FOR MANAGING
DYSKINESIA

on page 8

IN THIS ISSUE

7 Research Briefs

FDA recommends approval of PD psychosis drug, a new clinical study of alpha-synuclein and the next generation of movement disorder specialists.

10 Ask the MD

Learn how to advocate for your best care, navigate the Parkinson's journey and optimize treatment.

12 The Power of the Patient Voice

A Q&A with Parkinson's advocates (and friends) Steve DeWitte and Israel Robledo.

16 How To: Speed a Cure

Karen Jaffe (Shaking with Laughter) and Marcia Guberman (Pocono Fox Trot) shed light on hosting successful fundraisers.

COULD SMART DEVICES HELP US TEST NEW DRUGS?

BY MAGGIE KUHL

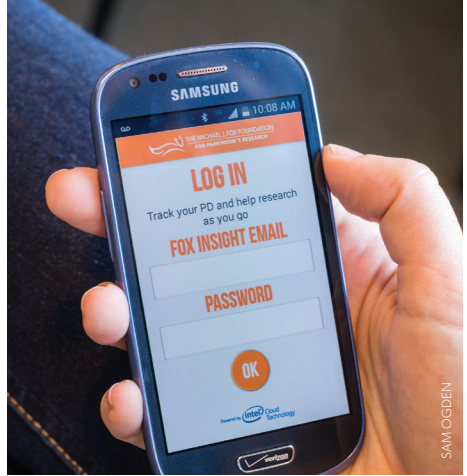
Today in most clinical trials testing a therapy to treat Parkinson's motor symptoms, researchers assess the drug or intervention's impact by using a rating scale and patient diaries. Researchers observe patients at periodic clinic visits, or participants take the drug and each day record any effects on their symptoms. These methods are not unreliable, but they are subjective, burdensome to patients and time-consuming.

But a new Phase III trial is testing an approach that could bring significant change. The Michael J. Fox Foundation (MJFF) has united two of its research partners, Cynapsus Therapeutics and Intel Corporation, for a pilot study testing the potential of wearable computing devices (smartwatches and smartphones) and "big data" analytics in clinical trials of Parkinson's medications.

"Clinical studies are the most expensive and time-consuming stages of drug development. Data science approaches may help accelerate the pace of progress," said MJFF CEO Todd Sherer, PhD. "We are optimistic that these technologies will allow drug developers to objectively gather and analyze much greater volumes of data and more quickly reveal critical insights into potential new treatments."

Uniting Two MJFF Partners

Cynapsus, a Toronto-based biotech, is testing a new formulation of a drug that helps patients return to an "on" state (when symptoms are well managed) from an "off" state (when medications stop working before it is time for the next dose). The drug, apomorphine, is already approved for this use, but is available only in an injectable form. Cynapsus has developed a thin-strip, under-the-tongue formulation (called APL-130277



in testing) that's much easier to use. MJFF funded Phases I and II of this work, which successfully teed up the Phase III trial — the final stage before applying for FDA approval.

In parallel with supporting the development of new therapies, MJFF is committed to developing new technologies that could increase both the effectiveness and the efficiency of Parkinson's research. In August 2014 the Foundation launched an ongoing data science partnership with computing giant Intel. The goal of the partnership is to develop platforms to store large volumes of patient-generated data from online and wearables studies ("big data"), and to develop sophisticated algorithms allowing researchers to glean insights from that data.

The Cynapsus pilot study unites these partners to investigate how clinical trials can use "big data" to learn more about PD and measure the impact of therapies.

Albert Agro, PhD, chief medical officer of Cynapsus, hopes that "the data analytics capabilities enabled by Intel and The Michael J. Fox Foundation will allow us to better evaluate how APL-130277 is helping patients."

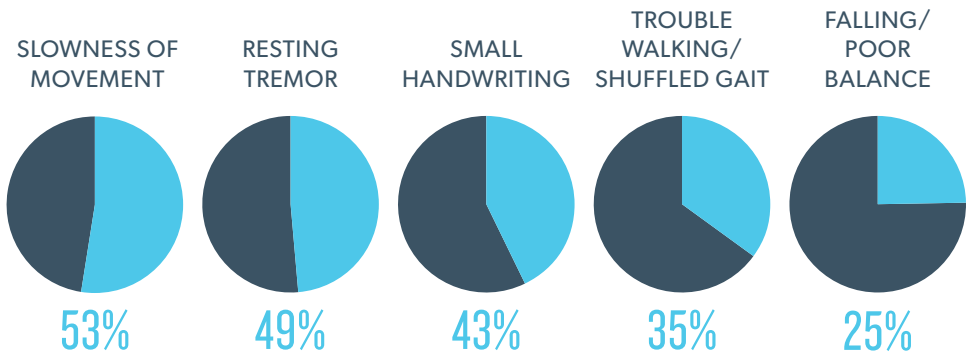
continued on page 13 >

What Motor Symptoms Affect PD Patients Most?

Fox Insight is an online observational study where you can share information about your symptoms, overall medical history, family neurological history and quality of life by completing online surveys and questionnaires every 90 days. Enroll today at foxinsight.org.

By the Numbers

Fox Insight collects data for researchers such as the prevalence of symptoms frequently associated with Parkinson's disease (PD). The below percentages reflect the portion of users who report these common motor symptoms.



About Fox Insight



By studying the responses of thousands of volunteers over time, researchers will get a better sense of how Parkinson's disease progresses differently across individuals, allowing scientists to develop new therapies and treatments for people with PD.

A NEW FUTURE FOR PARKINSON'S PUBLIC POLICY

continued from page 1 >

the field held only a rudimentary understanding of the biology of PD, little biomarker development was taking place, researchers were working with the (now-eclipsed) premise that dopamine replacement alone could meet Parkinson's patients' medical needs and few promising drug candidates were advancing toward clinical testing.

Today, more drug development programs are reaching late-stage clinical testing and more companies are individually developing regulatory and reimbursement strategies where a collaborative approach, orchestrated by a centralized and unbiased convener, could be more effective. Joint leadership from MJFF and PAN also will help reduce redundancy among drug developers who until now have navigated such processes and conversations on their own.

"The integration of PAN and Fox brings together the best of both organizations," said Carol Walton, CEO of The Parkinson Alliance and executive director of the Parkinson's Unity Walk. "PAN's public policy expertise and MJFF's research background, coupled with a knowledgeable and engaged patient community, will create the best possible outcomes for those living with Parkinson's disease today."

Community Dialogue

Earlier this spring, MJFF and PAN launched a dialogue with members of both organizations' communities to ensure that Fox's program addresses patients' top public policy concerns. In February, PAN's grassroots advocacy leaders participated in a webinar with Sherer, Thompson and PAN Texas State Director and Board member Israel Robledo to learn about the integration and provide feedback on programmatic priorities. At the annual PAN Forum, the

conversation continued in a session featuring Sherer and Thompson that was led by Mort Kondracke, a founding Board member of both organizations. Attendees asked questions, shared concerns and offered thoughtful insights about Parkinson's policy. (Community feedback gathered at the webinar and Forum have informed both a white paper available at michaeljfox.org/policy and planning for the Foundation's programmatic activities.)

A committee comprising members of PAN's Grassroots Leaders program, which has been essential to strengthening local support for policies that benefit patients, will give patients a seat at the table and will help shape MJFF's advocacy efforts. Representatives of state, regional and national PD organizations who formerly sat on the PAN Board now will participate as part of the Foundation's Unified Parkinson's Advocacy Council, providing ongoing counsel to ensure MJFF remains the unified voice of the PD community on all policy matters. The Foundation also is forming a Public Policy Council made up of experts who can provide guidance and advice on policy strategies.

"The high-quality work of PAN and MJFF grassroots advocates will make this a very effective partnership," said Robledo. "It's not just new drugs that are important — it's anything that improves a patient's quality of life, such as therapy services or telemedicine. Our leaders bring breadth and depth of experience advocating for all these issues."

To learn more about MJFF's new public policy department, or to read our white paper, please visit michaeljfox.org/policy. To read a Q&A with Israel Robledo on Parkinson's policy, turn to page 12.



THE SHERER REPORT

A NOTE FROM OUR CEO



MARK SEIGER

Expansion on the Shoulders of Community

As you read on the front page, The Michael J. Fox Foundation (MJFF) has formally established a Parkinson's public policy program. While our efforts engaging government leaders and regulators are expanding, our dedication to curing Parkinson's disease (PD) and improving quality of life is unwavering. At the same time, we know that we can pursue these ambitious goals only with the strong support of the Parkinson's community.

As you'll read on page 7, studies are moving forward around the most important drug target in Parkinson's. As more alpha-synuclein projects advance into clinical trials, MJFF has launched a study to measure this protein in different parts of the body to test potential therapies and track disease progression. We're also learning more about LRRK2, identifying its cellular "partners" for more ways to measure treatments and intervene in the disease process.

And we're amid a rush of symptomatic treatments toward pharmacy shelves: a new therapy for PD psychosis, novel formulations of existing drugs for quick rescue from "off" episodes, and drugs to offset involuntary movements called dyskinesia.

These advancements are possible because of the collaborative spirit of companies, academic researchers and study participants. Investigators are joining MJFF to move these therapies to and through clinical testing. And Fox Trial Finder (foxtrialfinder.org), our online tool to connect the community

with clinical studies, now includes more than 50,000 registered volunteers (see page 6).

Patients also are helping us learn more about this disease from their own homes. Fox Insight (foxinsight.org) is our virtual clinical study, where patients and loved ones can contribute data on living with PD. And in a pilot study, we've brought pharmaceutical company Cynapsus together with tech giant Intel to assess whether wearable computing (such as smartwatches) can help scientists evaluate the effect of a drug while lessening the burden on patients to maintain diaries (see page 2).

Government officials and insurance companies are critical partners, too — in helping make treatments accessible and in building programs to allow people with Parkinson's to live well with disease. As we enter a new era of public policy with these stakeholders, we again turn to the PD community for assistance. Read a Q&A on page 12 with two advocates who are helping shape our new efforts in public policy.

In this fast-paced world of possibility — of novel insights, new treatments and extended programs — we are so grateful to have the community behind us as we pursue our ambitious agenda. Your optimism and participation fuel progress.

Thank you for your continued support.



Todd Sherer

FOX TRIAL FINDER: THE “MATCH.COM” OF PARKINSON’S CLINICAL STUDIES

Fox Trial Finder is MJFF’s online clinical trial matching tool that makes it easier for patients and their loved ones to get involved in Parkinson’s research. Check it out for a list of studies in your area looking for volunteers like you. Register to receive email updates about new trials.

www.foxtrialfinder.org

More than

570

trials are listed in the database

Some studies test

NEW DRUGS OR TREATMENTS

while others observe volunteers to learn more about PD

Nearly

54,000

users have registered so far

People with

ANY STAGE

of Parkinson’s and those *without the disease* can participate

CLINICAL TRIALS MAY AIM TO

- » stop the underlying disease progression
- » treat motor symptoms such as tremor or gait problems
- » prevent or ease non-motor aspects of PD including dementia, anxiety and constipation

RESEARCH NEWS BRIEFS

SPRING/SUMMER 2016



FDA Panel Recommends Approval of Parkinson's Psychosis Drug

On March 29, 2016, an advisory committee to the Food and Drug Administration (FDA) voted 12-2 in favor of approval of Nuplazid, a drug for Parkinson's disease psychosis (hallucinations and delusions). Currently, doctors may adjust dopamine medications or prescribe anti-schizophrenic drugs, but those block dopamine receptors and tend to worsen motor symptoms. Nuplazid (the compound pimavanserin) from Acadia Pharmaceuticals works on the serotonin system, easing psychosis without worsening motor aspects of Parkinson's disease. Read more, including an update on the FDA's May 1 decision, at michaeljfox.org/nuplazid.



MJFF Launches Study of Where to Measure Alpha-synuclein

The protein alpha-synuclein is known to clump in the brain and body cells of people with Parkinson's. Patients also may have altered levels of the protein in various biofluids (e.g., blood, spinal fluid) and tissues (e.g., skin, colon tissue). Researchers want to measure alpha-synuclein to track disease and study the impact of new therapies. A new MJFF-sponsored study (the Systemic Synuclein Sampling Study, or S4) aims to identify which biofluid or tissue is best for this purpose by systematically analyzing samples from 60 people with PD and 20 control volunteers. The study will be carried out at seven clinical sites in the United States and Canada. Learn more and get involved at foxtrialfinder.org.



Investing in the Next Generation of Movement Disorder Specialists

Two MJFF-funded efforts are expanding the global base of neurologists concentrating on Parkinson's care and research. The Edmond J. Safra Fellowship in Movement Disorders — launched in 2015 — grants funding to academic medical centers to train Parkinson's clinician-researchers. This year, five centers in the United States and one in Germany were selected; each will guide one specialist through a two-year program. This spring, MJFF is also co-sponsoring, with the Movement Disorders Society, a two-day course for neurology residents. It focuses on common movement disorders, including PD, and allows those considering the field to learn from international experts. Read more at michaeljfox.org/safra2016.

DR. DOLHUN TALKS PD

MANAGING DYSKINESIA



Dyskinesia is a type of “too much” movement that can occur in Parkinson’s, a disease well-known to decrease mobility. These extra motions are commonly flowing or dance-like, so they appear as wriggling or twisting, but they may be jerky. Dyskinesia isn’t the rhythmic resting tremor that is often part of Parkinson’s, although it can be difficult to distinguish the two. Dyskinesia can involve any body part and could look like swaying, head bobbing, or a general fidgeting or restlessness. Frustratingly, dyskinesia typically occurs during “on” time, when Parkinson’s symptoms are otherwise adequately controlled.

Parkinson’s Disease and Medications Contribute to Dyskinesia

Sometimes dyskinesia is referred to as a side effect, or complication, of the medications used to treat Parkinson’s disease (PD). While it’s true that extended use of drugs (primarily levodopa) contributes to dyskinesia, other factors — such as disease duration — play a role as well. As PD progresses, more dopamine-producing brain cells are lost and the brain becomes more dependent on medications. Levodopa works well to supply dopamine, but because of the way traditional formulations must be given, dopamine levels in the body and brain fluctuate. Over time, the brain experiences greater difficulty adjusting, and this leads to dyskinesia.

Medication Adjustments and Surgical Therapies Can Manage Dyskinesia

Multiple options are available for managing dyskinesia. Which is chosen depends on a person’s symptoms, situation and current medication regimen. Medication changes should be undertaken carefully and only after thoughtful discussion with your physician. Knowing what doctors consider when dyskinesia arises can help you start the conversation. A few of the possible treatments are:

PROVIDING LOWER DOSES OF LEVODOPA MORE FREQUENTLY

The goal is to give enough medication in an individual dose to reach the “on” state (when symptoms are controlled) but not so much that dyskinesia occurs. The risk of reducing the dose is that it might not be adequate to overcome the “off” state (when symptoms are not well-managed) and/or it might not last until the next dose of medication is due.

CHANGING TO A LONGER-ACTING FORMULATION OF LEVODOPA

The aim of these preparations is to keep steadier levels of dopamine in the system. Two drugs in this category — Rytary and Duopa — were approved in 2015. Rytary is an oral capsule that contains both immediate- and extended-release levodopa and carbidopa; Duopa is a levodopa/carbidopa gel that is continuously infused into the intestine by an external pump.

ADDING AMANTADINE

Amantadine, which works on the glutamate (another brain chemical) pathway, is commonly used to lessen the severity of dyskinesia. (This drug began as a flu medication and gained approval for PD after it unexpectedly eased Parkinson's symptoms and dyskinesia.)

REFERRING FOR DEEP BRAIN STIMULATION (DBS)

DBS typically works best for people who still get a good response to levodopa but experience complications, such as dyskinesia and significant motor fluctuations ("off" periods). Surgery usually allows for medication reduction, which limits dyskinesia. Not everyone is a candidate. Check out my recent "Ask the MD" video on DBS at michaeljfox.org/ask-the-md.

New Therapies Are in Development for Dyskinesia

Researchers, including several funded by MJFF, are working in multiple areas to develop better therapies to treat, and possibly even prevent, dyskinesia. Treatments include drugs that modify brain chemicals other than dopamine and innovative surgical techniques. Potential prevention strategies center on improvements to the current levodopa formulations. All of the treatments discussed in this section are in Phase II or Phase III clinical trials.

Three anti-dyskinesia medications, which work on non-dopamine chemical pathways, are in mid- to late-stages of clinical testing. Eltoprazine modifies serotonin levels, while dipragulrant works on glutamate. An extended-release preparation of amantadine (see above) also is in trials. This new formulation is designed to achieve the highest medication levels in the morning and afternoon — when it's needed most — and drop to lower concentrations in the evening, when the potential side effect of insomnia could interfere with medication benefit.

A surgical modality for dyskinesia in research trials is focused ultrasound (FUS). This procedure concentrates beams of sound waves to destroy a small area of tissue in the brain (one of the same regions targeted with DBS) while leaving other areas of the brain relatively unharmed. It doesn't require a surgical incision, anesthesia, or the electrodes and battery that DBS does. FUS is typically a one-time procedure that takes effect immediately, but it's permanent and irreversible.

Novel formulations of levodopa, which might lessen — and even prevent — dyskinesia are in the pipeline as well. The aim of these preparations is to keep levodopa concentrations more steady in the body and brain. An "accordion" pill releases medication slowly for better absorption and more consistent levels. Liquid levodopa is infused continuously under the skin through either a skin patch or a device similar to an insulin pump.

Finding a balance between too little and too much movement in advancing Parkinson's can be challenging. Medication adjustments (and DBS, in some cases) can help, though, and therapies in development will potentially increase patients' options. A wider variety of therapies (and a potential solution) for dyskinesia is just one of the ways MJFF is working to improve the lives of people living with Parkinson's today.



Rachel Dolbun, MD, is a movement disorder specialist and vice president of medical communications at MJFF.

The medical information contained in this article 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.

Ask the MD: **Advocating** for Your Best Care

The journey with Parkinson's is unique and can be difficult to navigate, especially given the complexities of the medical and insurance systems. No one knows Parkinson's disease (PD) better than those who are living with it; you know more about your PD than anyone else. Coupling this knowledge with your doctor's expertise can help you optimize your treatment. Here are four tips on how to advocate for your best care:

1

LEARN

1. **Learn about Parkinson's disease.**

Knowledge really is power. Being educated about PD will allow you to evaluate your symptoms, find the right physician(s) and ask good questions. Read about the different symptoms associated with PD as well as the available treatment options and ongoing research. Ask your doctor and other people with Parkinson's for credible sources of information.

2

OBSERVE

2. **Be in tune with your Parkinson's disease.**

Only you can know what symptoms you're experiencing and if and how they're changing. Pay attention to whether symptoms are worsening or new ones are arising. Observe how your medications make you feel — do they improve your symptoms, cause side effects or both?

3

SPEAK UP

3. **Speak up for yourself.**

Discussions with your doctor should be honest and direct — if (s)he doesn't know what's truly bothering you, it can't be addressed. MJFF's Fox Insight Physician's Report (available at foxinsight.org) is a tool that can help guide conversations in the doctor's office. Keep open lines of communication with loved ones and caregivers, too. Share how you are feeling physically and emotionally. Tell them what you need, and ask them to do the same.

4

BUILD

4. **Build your care team.**

It'll look different for every person with Parkinson's, but each team should ideally include a movement disorder specialist (a neurologist with specialized training in PD). This physician can help round out the team with other experts who treat specific symptoms. Having a Parkinson's specialist manage the nuances of your care and medication — basically having a medical professional who will advocate for you — is one of the best ways you can advocate for yourself.

Ask the MD: Insights for Patients and Caregivers



Rachel Dolhun, MD, addresses popular Parkinson's topics and translates the latest research in blog posts and videos.

www.michaeljfox.org/ask-the-md



Medical Marijuana and Parkinson's

The role cannabinoids may play in the treatment of Parkinson's, and the need for further research



Parkinson's Diagnosis and Biomarkers

What to expect from the diagnosis process, and the need for an objective measure of Parkinson's disease



Exercise and Parkinson's

The benefits of physical activity, and considerations for starting and maintaining a workout regimen



Diet and Parkinson's

How nutrition and dietary adjustments may be helpful when taking certain medications and for managing non-motor symptoms



Caregiving and Parkinson's

Practical advice for managing Parkinson's with your partner on a daily basis, and guidelines to help you stay well while doing so



Partners in Parkinson's offers free in-person and virtual events to help the PD community optimize care and connect with resources. These full-day sessions and webinars feature caregivers, clinicians, researchers, allied health care professionals and people living with PD.

To learn more, visit partnersinparkinsons.org/attend-an-event.

2016 Events

ALL SATURDAYS

May 14

Oakland, California

June 4

Cincinnati, Ohio

October 1

New York City, New York

EVERYONE CAN PARTICIPATE
ON MAY 14 IN THE OAKLAND,
CALIFORNIA SESSION BY
STREAMING ONLINE.

“When We Share Our Commitment to a Cure, Our Passion Comes Through”

As the Michael J. Fox Foundation and the Parkinson’s Action Network announce plans to integrate and operate as a single entity, Parkinson’s patients and advocates (and good friends) Steve DeWitte and Israel Robledo talk to MJFF about the power of the patient voice and their hopes for the future of Parkinson’s public policy.

MJFF: What was your path from being diagnosed with Parkinson’s to becoming leaders in the PD community?

Israel: For me it was first about coming to terms with my diagnosis because I was only 42. I had work and family responsibilities to fulfill. I went through depression, where the focus was on me and my concerns about the advanced stages of the disease. But after about nine months, I turned a corner and decided the focus would be on supporting others and finding a cure.

Steve: I was about 46 when I showed symptoms. I didn’t know what PD was. I did a lot of research online. That’s when I first connected with Israel, because he was writing a great blog. I went from learning to a more proactive stance. I was diagnosed in 2005 and soon after, I started a support group with eight people. Now we have three chapters and more than 150 people. Some of them have gone on to raise funds for research, take part in clinical trials or speak with legislators.

MJFF: What is it like to see results emerge from your advocacy?

Israel: I always had an interest in the political process, and I enjoy talking to my congressman and my senator to share why research is needed. One day my representative

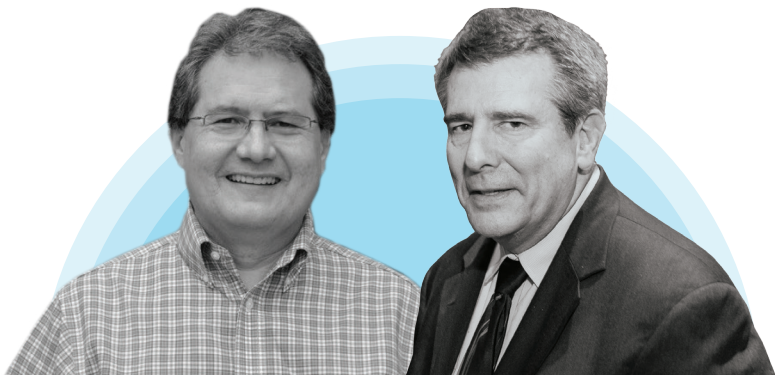
said to me, “I think of you when Parkinson’s comes up on the floor. You have showed me what it’s like to have Parkinson’s.”

Steve: I formed three principles, or areas, that patients must take on themselves — education, clinical trials and advocacy. There’s no better way to say, “This is why we need a treatment,” than to have a patient tell that story.

MJFF: You’ve also both taken part in clinical trials. Why is research participation important to you?

Israel: We sometimes hear researchers say that patients are not participating in trials. Patients say they don’t know where to go. It’s a huge hurdle we need to work on. We’ve covered major ground, but education is key. And it’s a shared responsibility.

Steve: There are excellent tools to close that gap. Fox Trial Finder (foxtrialfinder.org) is one. When you register, you see the projects that may be best suited to you in particular. You can reach out for more information, but researchers can also reach out to you. Your identifying information remains private until you are ready to reveal it. Fox Insight (foxinsight.org) — MJFF’s online research study — is also a great tool. Patient-contributed data is going to be incredibly valuable to researchers working toward better treatment options.



ANDREW KIST

Israel Robledo (left) and Steve DeWitte

MJFF: What role will the patient voice play in the future of Parkinson’s research?

Israel: The voice of the patient will be much stronger because that’s what happens when we come together to focus on a cure and the quality-of-life issues that impact people every day. We need treatments to let people live their lives.

Steve: The more the patient’s voice is included in the research process, from conception of an idea to development of a treatment, the quicker the science will move forward.

MJFF: What advice would you share with others interested in getting involved in PD public policy and advocacy efforts?

Israel: Think through your passions, and develop a message to share with others. For example, my style is tenacious but respect-

ful. It takes time and patience, but when we develop our own personal message and stay true to it, our passion comes through. We’re committed to finding a cure.

Steve: I invited a state legislator to a support group. He looked around the room and saw his friends and neighbors who he didn’t know had Parkinson’s. He said, “When we’re looking at a bill related to Parkinson’s, I’ll think about my family, my friends and my neighbors and it’ll impact how I vote.” An advocate is someone who shares their story in order to make a difference to help themselves and others. Anybody can do it.



Israel Robledo has served as Texas state director for the Parkinson’s Action Network. Steve DeWitte sits on the MJFF Patient Council.

COULD SMART DEVICES...

continued from page 2 >

Measuring Drug Impact with Smart Tools

A small group of volunteers in the Cynapsus Phase III trial will use a wearable computing device and the Fox Insight smartphone application (developed by MJFF and Intel) to contribute data on movement and medication effect. The data will be securely collected, de-identified and evaluated by Intel, then stored in a cloud platform that

will allow researchers to investigate Parkinson’s disease, “off” episodes and the efficacy of APL-130277.

“At this point, this is a proof-of-concept study testing feasibility and utility,” said Sherer. “Is it possible to capture this data easily? What can we learn from its analysis?”

Depending on the results of pilots like this one, he adds, future studies may routinely make use of wearable devices and smartphone applications.



ROCKING AND LAUGHING FOR A CURE

This past November, 1,000 MJFF supporters filled the Waldorf Astoria New York ballroom for a night of special performances at A Funny Thing Happened on the Way to Cure Parkinson's, the Foundation's annual gala. Music legend John Fogerty joined Denis Leary, David Letterman and others in lending their talents to help raise more than \$5 million to support research. To date, Funny Thing has raised more than \$65 million to help speed a cure for Parkinson's.

To learn more about the 2016 event, visit michaeljfox.org/funnything.



Clockwise from top left: John Fogerty and Michael J. Fox perform at the gala; Julianna Margulies and her husband Keith Lieberthal enjoying the show; Nancy Jarecki (left) and Katie Couric; David Letterman addresses gala attendees; Michael J. Fox and Tracy Pollan with their son Sam and daughter Esmé.

“HOPE KEEPS US GOING”

BY ALLISON BOILES

While standing in the middle of New York City’s bustling Grand Central Terminal, Carol Case came to a realization. “We’re going to take lemons and make lemonade and we’re going to make a difference.”

The year was 2007. Months earlier, Carol’s husband, Ira Lieberman, had been diagnosed with Parkinson’s disease (PD) — an unexpected turn of events for the couple, whose fruitful careers and grandchildren had previously kept them busy.

The Michael J. Fox Foundation soon became a vital source of information for Carol and the Case/Lieberman family. As she and Ira contemplated life changes for their retirement, such as moving to a warmer climate, they were encouraged by their friend and MJFF Board member Ed Levy to get involved in the Parkinson’s community.

So when the couple moved cross-country to start a new life in San Diego, Carol immediately took action to increase awareness of PD. “After Ira’s diagnosis, I didn’t feel like it was the end of the world — I didn’t want him to feel that either. There was someone out there fighting. That made a huge difference to me.”

Carol’s goal was to spread the support she felt from MJFF to others in the PD community. She also knew she wanted to fundraise to help drive research toward a cure. Within three months of her move to San Diego, she hosted her first “friendraiser” to introduce patients and families to the Foundation’s latest research priorities and educational resources. She built on this experience by participating in a Partners in



Carol Case with her husband, Ira Lieberman.

Parkinson’s panel, sharing her perspective as a caregiver with the event’s 721 attendees. (Learn more about Partners in Parkinson’s on page 11 or at partnersinparkinsons.org.)

Soon, the PD community in her new hometown began to see Carol’s home as a hub of information and support — and Carol as a connector and catalyst, embracing newcomers and helping them navigate their post-diagnosis journey. Today, her relationship with Ira has expanded to include wife, nurse, trainer and cheerleader — going beyond managing medications and attending doctor’s appointments to equip him with tools and encouragement to manage the new challenges that come his way.

To other caregivers and those living with Parkinson’s she shares this message: “There’s hope. That’s what keeps us going. You have the disease, there’s no getting away from that. So now how do you have it? That is up to you.”



SHIFTING GEARS TO SPEED A CURE

BY KAT MCCARRICK

Team Fox is the community fundraising arm of The Michael J. Fox Foundation. Meet some of the dynamic grassroots fundraisers committed to curing Parkinson's and learn how you can get involved.

What does it take to host a popular Team Fox event, build a community resource for patients and families and jump-start a cycling fundraiser? Just ask seasoned fundraising veteran and MJFF Patient Council member Karen Jaffe. Since launching *Shaking with Laughter*, a Cleveland-based fundraiser, in 2011, Karen and her husband Marc have raised nearly \$750,000 for PD research. Their fifth comedy show and gala will take place Saturday, August 27, in Cleveland. Karen credits much of her and Marc's success to a sincere, consistent "message of hope that has really resonated with people."

She also connects her community with vital resources, reminding them that hosting an event isn't the only way to be involved. This includes helping found InMotion, a fitness and wellness center for those affected by PD and other movement disorders. And after this summer's gala, Karen will transition her Team Fox efforts to the Tour de Fox Series — cycling events that follow up to last year's 14,000-mile, \$2.5-million campaign by MJFF ultra-athlete and staffer Sam Fox. The bike ride Karen organized as part of the original Tour has been secured as a returning stop.

On top of it all, she continues to motivate others to join Team Fox, saying, "I've seen its ability to bring people under the umbrella, into the conversation and to make them feel empowered."



Top: Karen Jaffe (second from left), her husband Marc, and their daughters Alena, Jana and Sarah (left to right).
Bottom: Marc and Karen at *Shaking with Laughter*.

CYCLE TO SUPPORT PARKINSON'S RESEARCH.

Starting this summer, join us for rides in the Great Lakes, California Wine Country and Pacific Northwest.

To learn more, visit tourdefox.org.



Fox Trotting for a Cure with Team Fox

BY ALLISON BOILES

Marcia Guberman of Milford, Pennsylvania, admits she knew little about Parkinson's disease (PD) when she was diagnosed in July 2013. She quickly threw herself into research — both online and in-person — to connect with anyone who was also living with the disease.

As she learned more, Marcia was eager to support the Parkinson's community — to help speed a cure, but also to provide others with the valuable information that helped her navigate her diagnosis. That's when the idea for the Pocono Fox Trot first came to her.

In 2015 Marcia organized the Pocono Fox Trot for Parkinson's Research, a 5K and community walk to benefit Team Fox, with

the help of a dedicated circle of family and friends, including co-founder Rolland Grote, Marcia's husband, Erwin, and their children Dana, Jeff and Steve.

The Pocono Fox Trot gathered 215 participants to raise more than \$20,000 for Parkinson's research — an impressive amount for first-time Team Fox fundraisers. And in 2016, the team hopes to make the event bigger and better.

The key to their success? "Many more people are touched by Parkinson's than we all realize," says Marcia. "Those were the people who came out and donated. It was amazing to see how many people in this small area where I live are affected by Parkinson's."



The Pocono Fox Trot team presents a check to Stephanie Paddock (center), director of Team Fox.

HELP US MAKE EVERY STEP COUNT.

Find a Fox Trot near you or organize your very own walk/run event with Team Fox.

Visit teamfox.org/foxtrot to put your talents (and sneakers) to use.





TAKE NOTE OF THE POWER OF A MONTHLY GIFT!

Help the Foundation do even more to move the dial toward a cure for Parkinson's. Recurring donors who contribute \$30 or more each month will receive an exclusive notebook and pen set as a token of our appreciation. Become a monthly donor by visiting michaeljfox.org/monthlygiving.

IN YOUR WORDS

Every day our social community inspires us and one another. Join more than 625,000 friends on Facebook and 70,000 followers on Twitter who continue the **#Parkinsons** conversation.

Dave G. January 1, 2016

Diagnosed with YOPD in 2012. Have finally got meds and diet semi-controlled. Will work on exercise and try to participate in a study through MJFF this year. Looking forward to being a part of research to help find a cure or at least to help alleviate symptoms.



Victoria D. November 15, 2015

Fantastic to see patients, MJFF and the research community working together closely. Such collaborations WILL be game changers.



David S. January 19, 2016

An amazing effort from you all. Since I was diagnosed with Parkinson's disease I have been astonished at the courage, determination and integrity of others out there. This foundation has been like a lifeline for me to merge into a wider family all over the world.



Kathy C.

September 11, 2015

The most precious thing you can give is your time for both caregiver and for the person with Parkinson's. A visit would break up the daily "old" routine. Show your appreciation for the caregiver.



Twitter & Instagram: @MichaelJFoxOrg

Facebook: facebook.com/michaeljfoxfoundation

LinkedIn: linkedin.com/company/the-michael-j--fox-foundation-for-parkinsons-research

Blog: blog.michaeljfox.org

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, including an interactive version. To change your subscription preferences, email info@michaelfox.org. Submit letters and questions to the editor at the email address below.

Chief Executive Officer
Todd Sherer, PhD

Founder
Michael J. Fox

Co-Founder and Executive Vice Chairman
Deborah W. Brooks

Sr. Vice President, Communications & Content Strategies
Holly Teicholtz

Editor
Cheryl Blowers
newslettereditor@michaelfox.org

BOARDS AND COUNCILS

BOARD OF DIRECTORS

Jeff Keefer,
Chairman
Woody Shackleton,
Vice Chairman
Holly S. Andersen, MD
Glenn Batchelder
Mark Booth
Jon Brooks
Barry J. Cohen
Andrew Creighton
Donny Deutsch
David Einhorn
Karen Finerman
Lee Fixel
Nelle Fortenberry
Michael J. Fox
Willie Geist
David Glickman
David Golub
Mark L. Hart III
Skip Irving
Edward Kalikow
Amar Kuchinad
Edwin A. Levy
Marc S. Lipschultz
Ofer Nemirowsky
Andy O'Brien
Douglas I. Ostrover
Tracy Pollan
George E. Prescott
Ryan Reynolds
Frederick E. Rowe
Lily Safra
Carolyn Schenker
Curtis Schenker
Richard J. Schnall
Anne-Cecilie Engell Speyer
George Stephanopoulos
Bonnie Strauss
Rick Tigner
Fred G. Weiss
Sonny Whelen
Peter Zaffino

FOUNDERS' COUNCIL

Lonnie and
Muhammad Ali
Steven A. Cohen
Albert B. Glickman
John Griffin
Andrew S. Grove
Katie Hood
Jeffrey Katzenberg
Morton M. Kondracke
Nora McAniff
Donna Shalala, PhD

LEADERSHIP COUNCIL

Richard Fitzgerald,
Chairman
Daisy Prince,
Vice Chairman
Omar Abdel-Hafez
Shakeeb Alam
Loren Berger
Felix Bhandari
Susan Bilotta
Dev Chodry
John S. Daly
Julia Kelly
Justin Lepone
Rafi Rosman
Scott Scheffrin
Bill Shepherd
Ryan Squillante

PATIENT COUNCIL

Carl Bolch, Jr.
Eugenia Brin
Ken Cater
Christopher Chadbourne
Carey Christensen
Rich Clifford
Quentin Dastugue
Steve DeWitte
Anne Cohn Donnelly,
D.P.H.
David Eger, PhD
Bill Geist
Cindy Gray
Lynn Hagerbrant
David Iverson
Karen Jaffe, MD
Nicole Jarvis, MD
Soania Mathur, MD
Tony Mendez
Hilton Mirels, MD
Bret Parker
Eric Pitcher
William (Bill) Richter
Bryan Roberts
Richie Rothenberg
Margaret Sheehan
Dan Suwyn
W.N. (Bill) Wilkins

SCIENTIFIC ADVISORY BOARD

Alberto Ascherio, MD, Dr PH
Erwan Bezard, PhD
Anders Björklund, MD, PhD
Susan Bressman, MD
Robert E. Burke, MD
Angela Cenci-Nilsson, MD, PhD
Marie-Françoise Chesselet,
MD, PhD
P. Jeffrey Conn, PhD
Mark R. Cookson, PhD
David Eidelberg, MD
Matthew Farrer, PhD
Thomas Gasser, MD, PhD*
Charles (Chip) Gerfen, PhD
J. Timothy Greenamyre, MD, PhD
Franz F. Hefti, PhD
Etienne C. Hirsch, PhD*
Oleh Hornykiewicz, MD
Ole Isacson, MD (Dr Med Sci)
Joseph Jankovic, MD
Jennifer Johnston, PhD
Jeffrey H. Kordower, PhD
J. William Langston, MD
Andres Lozano, MD, PhD
Kenneth Marek, MD
Eldad Melamed, MD
Kalpana M. Merchant, PhD*
C. Warren Olanow, MD
Bernard M. Ravina, MD, MSCE
Peter H. Reinhart, PhD
Ian J. Reynolds, PhD
Irene Hegeman Richard, MD
Ira Shoulson, MD*
Tanya Simuni, MD*
Andrew Singleton, PhD
David G. Standaert, MD, PhD
Dennis A. Steindler, PhD
Matthew Stern, MD*
Caroline Tanner, MD, PhD, FAAN
Malú G. Tansey, PhD*
David M. Weiner, MD
Michael Zimmond, PhD

**Executive Committee*