

The Fox Focus on *Parkinson's*

Fall/Winter 2022

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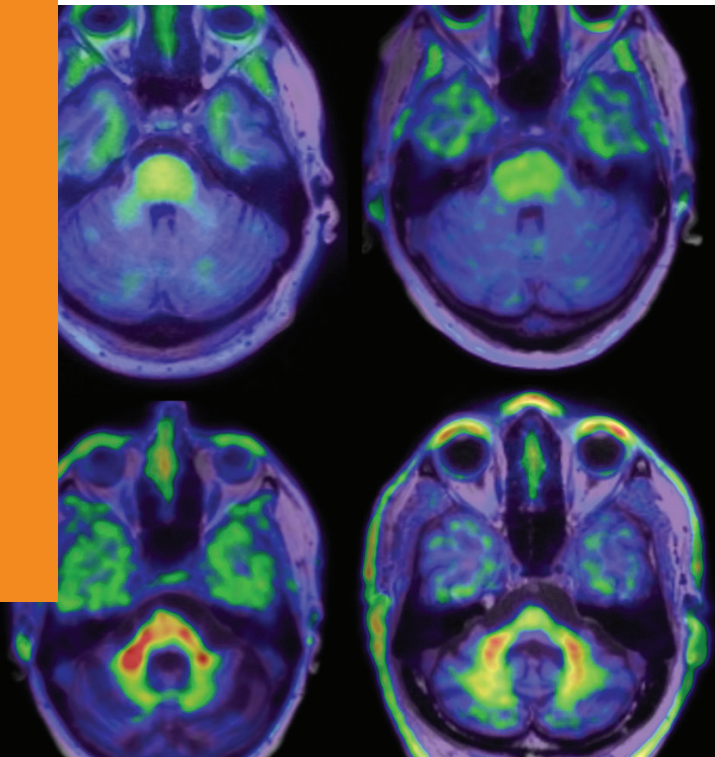



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THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

A portrait of Michael J. Fox, smiling, wearing a dark blue sweater. The background is dark and out of focus. An orange arrow points from the left edge of the image towards the text.

“When we first started the Foundation, we asked a simple question: why can’t we cure Parkinson’s? Then, we knew what would get us there: our belief in taking risks and willingness to do whatever it takes.”

— **Michael J. Fox**

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Message from the CEO:

If Not Us, Who?



Scientists from across the globe witnessed an extraordinary sight at the International Conference of Alzheimer's & Parkinson's Diseases in Barcelona, Spain, last March.

Images of alpha-synuclein activity in the brains of living people appeared on screen for the first time, marking a game-changing step forward in the development of a sophisticated research tool that scientists have pursued avidly for more than a decade, which would allow us to see more clearly the role of alpha-synuclein in Parkinson's disease (PD).

If validated, this imaging tool — the one reported in Barcelona was developed by Swiss biotechnology company AC Immune — could revolutionize how Parkinson's research is conducted and how long it takes for new therapies to be validated. (Read more about the new imaging tracer and its significance to the field on p. 8).

The pursuit of this elusive imaging tracer was 13 years in the making. Over the last decade, The Michael J. Fox Foundation (MJFF) has

spent tens of millions of dollars to pursue alpha-synuclein imaging — \$5 million alone to AC Immune since 2015. This monumental effort was led by our dedicated and tenacious Senior Vice President of Research Resources, Jamie Eberling, PhD, who has worked on the project since she first joined MJFF in 2009.

The hard work of Jamie and so many others — our numerous research partners, clinical trial volunteers, donors and more — has paid off in this extraordinary discovery. It's the result of many years of persistent work, all in the pursuit of something that we weren't certain we could find.

But it also reflects the organizing principle for so much of what we do: to tackle the challenges with the highest risk, yet the greatest rewards. Throughout our short

Above: A moment to celebrate: MJFF's Jamie Eberling, PhD, receives the Foundation's first If Not Us, Who Award from CEO Debi Brooks, for her dedication and leadership leading to the alpha-synuclein visualization discovery. For more on Jamie's 13-year journey to this point, see p. 8.

“The organizing principle for so much of what we do: to tackle the challenges with the highest risk, yet the greatest rewards.”

history, when we have contemplated such risks — from the alpha-synuclein tracer to the launch of our landmark clinical study Parkinson’s Progression Markers Initiative — we have asked ourselves: why should we be the ones to take this risk? Why should we be the ones to drive it?

Michael’s response has always come in the form of a question: “If not us, who?” That question governs every choice we make as we endeavor to address the unmet medical needs of people and families with PD. It will continue to motivate us until we reach our goal of eliminating Parkinson’s.

Since our inception, there have been many generous partners who have enabled us to pursue the boldest ideas to move PD research forward. Few have been as influential and extraordinary as the late Lily Safra — visionary philanthropist, MJFF Board member and chairwoman of the Edmond J. Safra Foundation — who passed away earlier this year. The following page provides just a snapshot of her transformative contributions

that forever changed the course of Parkinson’s research and care.

We wouldn’t be able to drive discoveries toward a cure without you — our community, our critical partners in this mission. We are enormously grateful for your support in so many ways – contributing to research, engaging with our Parkinson’s resources, fostering collaboration and funding research. The power of community plus research is indisputable — and you’re proving that every day.

As we celebrate this milestone on the path to a new tool for the detection of Parkinson’s, we are clear-eyed about the work still to be done to find a cure. But we know through your help, anything is possible.

With gratitude,



Debi Brooks
CEO and Co-Founder

Remembering Lily Safra

The Michael J. Fox Foundation honors the extraordinary legacy of a world-class philanthropist whose support changed the course of Parkinson's disease research and care.



The Michael J. Fox Foundation lost a generous partner and the world lost a visionary philanthropist with the passing of Lily Safra in July. Mrs. Safra leaves a legacy of serving others through her unmatched generosity and immense compassion for humanity. As chairwoman of the Edmond J. Safra Foundation for more than 20 years, Mrs. Safra provided transformative support to hundreds of organizations around the world in the name of her late husband, Edmond J. Safra. Her philanthropy extended to education, science and medicine, religion, culture and humanitarian relief.

Edmond J. Safra lived with Parkinson's disease, and Mrs. Safra was passionately invested in finding a cure. Guided by a deep understanding of the Parkinson's family experience, she became one of The Michael J. Fox Foundation's earliest and most important champions. Within months of MJFF's launch, she joined the Foundation's Board of Directors, setting in motion a cascade of grant-making over the next two decades that undoubtedly changed the course of Parkinson's disease research and care.

"Lily's friendship was instrumental in establishing our path and expanding our work further than we could have dreamed," said Michael J. Fox and Tracy Pollan. "She sharpened our vision and lent us her strength so that we might make a greater difference in the lives of all people and families touched by Parkinson's disease. We will be grateful forever."

A seasoned and strategic philanthropist, Mrs. Safra was keenly aware of the opportunity to transform the Parkinson's experience through long-term commitments by the Edmond J. Safra Foundation. Brought into key conversations at critical junctures throughout MJFF's short history, she was a stalwart advocate for MJFF's biggest and boldest scientific initiatives. Her breathtaking personal generosity was paired with her work through the Edmond J. Safra Foundation, which has been a seminal partner to MJFF throughout our existence.

In 2003, Mrs. Safra's visionary support allowed MJFF to establish the Edmond J. Safra Global Genetics Consortia resulting in the first



“Lily’s friendship was instrumental in establishing our path and expanding our work further than we could have dreamed.”

— Michael J. Fox and Tracy Pollan

genome-wide association study of Parkinson’s, a vital step in identifying genetic changes linked to the disease. Over subsequent years this program would come to revolutionize scientific understanding of the genetics of PD, opening avenues of research still avidly pursued to this day.

A true paragon of the power of philanthropy to catalyze scientific breakthroughs, Mrs. Safra provided the first individual leadership gift to MJFF’s landmark clinical study, the Parkinson’s Progression Markers Initiative, in 2010. Since then, the study has changed how research is done and what scientists know about the brain. It is a cornerstone of our understanding of disease and has heavily influenced clinical trial design and spurred a significant increase in industry investment in PD. The study’s extraordinary growth is possible because of the uninterrupted flow of support from the Edmond J. Safra Foundation and Mrs. Safra.

In an effort to address the worldwide shortage of movement disorder specialists (neurologists with specific training in Parkinson’s disease),

the Edmond J. Safra Foundation partnered with MJFF in 2014 to establish The Edmond J. Safra Fellowship in Movement Disorders. The program provides funding for clinical centers to train more clinician-researcher neurologists worldwide, effectively growing the global base of movement disorder specialists treating people with Parkinson’s and contributing to research toward new and improved treatments.

In 2020, MJFF honored Mrs. Safra’s remarkable 20 years of leadership giving and strategic collaboration with the inaugural Edmond J. Safra Humanitarian Award. The award recognized her decades-long commitment to speeding a Parkinson’s cure and bettering quality of life for people and families living with the disease.

“Mrs. Safra was a true giant of philanthropy and someone we have been privileged to know and work with from the beginning,” said MJFF CEO Debi Brooks. “Her compassionate spirit will remain a constant source of inspiration for us all.”

Research Briefs



New Levodopa Treatment Close to Approval

An under-the-skin, continuous infusion of levodopa is close to possible approval by the U.S. Food and Drug Administration. Levodopa is the “gold standard” PD medication to treat motor symptoms. Currently, levodopa comes in the form of a pill, a dissolvable tablet, a gel infused into the small intestine and an inhaler. Infused levodopa may expand options for people with Parkinson’s whose symptoms are not well-managed with other formulations. Drugmaker AbbVie submitted the therapy for regulatory review. If approved, it could be available in early to mid-2023.

Large-scale Investments Advance Inflammation Therapies

Two therapies that aim to reduce brain inflammation and protect brain cells are taking sizable steps with MJFF funding. Neuropore Therapies received a \$4.8-million grant for laboratory development of drug NPT1220-478 and a future human trial. A \$6.2-million grant to Longevity Biotech will support the first human study of the drug LBT-3627. Both therapies work against inflammation in Parkinson’s. These large investments are allowing the companies to generate critical data that may position them for other partnerships and acceleration toward patient hands.

LRRK2 Drug Enters Next-stage Clinical Trial

Denali Therapeutics and Biogen are enrolling participants in their Phase IIb LUMA study testing an inhibitor to lower activity of the LRRK2 protein and slow disease progression. Parkinson’s is linked to higher LRRK2 activity, with and without a mutation in the LRRK2 gene. The LUMA study will enroll at three U.S. sites about 640 people diagnosed with Parkinson’s in the past two years who do not have a LRRK2 mutation. A study for mutation carriers will launch later this year. MJFF has invested heavily in studies to profile and measure the LRRK2 pathway, which have allowed these milestones toward a therapy to slow or stop Parkinson’s disease.



Study Aims to Engage Asian Americans in Research Studies

In an effort to make research more inclusive and ensure the development of therapies that will benefit everyone living with PD, Tufts University researchers with MJFF support will explore barriers and motivators that Asian Americans face in accessing care and participating in research studies. The team also aims to develop culturally appropriate programs and resources. More inclusive research and care practices can improve outcomes for underrepresented populations and lead to findings that may benefit a broader Parkinson's population. This study is one in a growing portfolio from the Foundation exploring and mitigating factors that hinder inclusive research.

People with Parkinson's Share Views on Advanced Disease Treatments

In order to clarify the most important needs and treatment preferences of the Parkinson's community, health consulting firm RTI Health Solutions is examining the Parkinson's community's opinions on invasive treatments addressing the motor problems of advanced disease. These options include levodopa/carbidopa gel infused in the small intestine, deep brain stimulation and focused ultrasound. The study — funded by MJFF — aims to inform industry and health care providers of preferences around these types of treatments. That information may guide study investment and design decisions, as well as treatment recommendations.

The Image Worth a Decade of Scientific Resolve

By Kat Mehlhorn

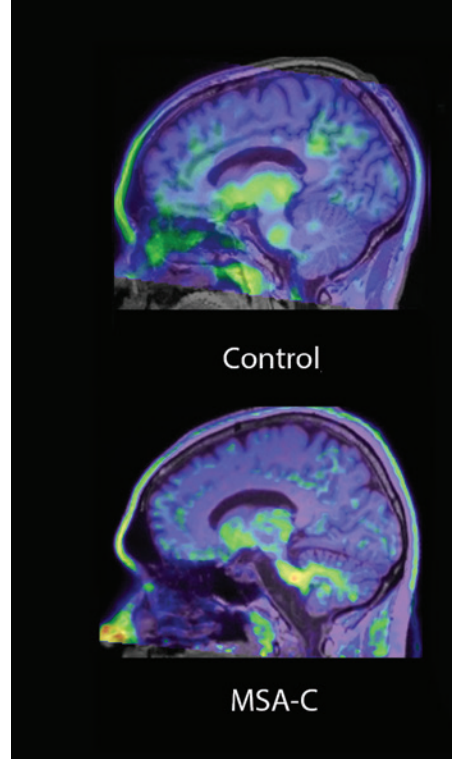
Jamie Eberling, PhD, The Michael J. Fox Foundation's senior vice president of research resources, watched intently as researchers out of Lund University and Skåne University Hospital in Sweden shared the first images of alpha-synuclein in the living brain — a sight that brought tears to her eyes. Using a PET (positron emission tomography) tracer developed by Swiss biotechnology company AC Immune, the images represented a glimmer of hope after more than a decade of trial and error.

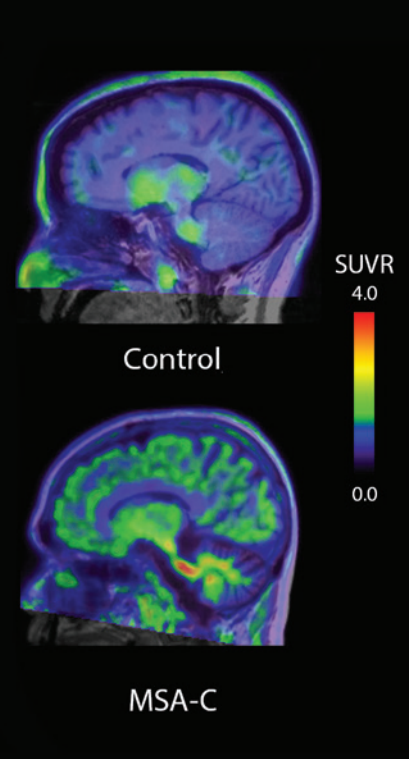
Since it was discovered in the 1990s that the protein alpha-synuclein aggregates in the brains of people with Parkinson's disease, MJFF and its partners have been on a quest to visualize this activity in the living brain. At the same time, drugmakers have aggressively pursued alpha-synuclein as a key target for therapies designed to treat PD. (Currently, there are 15 trials of potential Parkinson's therapies targeting alpha-synuclein.)

“Early on, we heard from companies that this would be a game-changer for drug development,” says Eberling, who has pioneered the Foundation's imaging program since she joined in 2009.

But if we can't visualize alpha-synuclein in the brain, how can we know if these new therapies are effective?

While these clumps are visible through post-mortem tissue analysis, seeing alpha-synuclein in the living brain would enable researchers





The first images of alpha-synuclein in the living brain. The orange and yellow coloration on the bottom two scans reveal alpha-synuclein accumulation in the cerebellum region of the brain; the top two scans are of the brains of control subjects without disease.

PHOTO COURTESY OF RUBEN SMITH, SKÅNE UNIVERSITY HOSPITAL

Since it was discovered that the protein alpha-synuclein aggregates in the brains of people with Parkinson’s disease, MJFF and its partners have been on a quest to visualize this activity in the living brain.

to confirm diagnosis, identify volunteers for clinical trials and assess drug efficacy faster. Medical imaging, such as a PET scan, is a non-invasive tool to measure biochemical changes happening in real time. Imagine comparing a PET scan taken pre-treatment with another taken post-treatment to determine the impact of a new therapy. “Early on, we heard from companies that this would be a game-changer for drug development,” says Eberling, who has pioneered the Foundation’s imaging program since she joined in 2009. Similar strategies in Alzheimer’s have had a pivotal effect on accelerating drug development for that disease. “This is the breakthrough in Parkinson’s that will make things go quicker.”

Yet few study teams were working on synuclein PET tracers at the time, in part because this was seen as one of the most daunting challenges in Parkinson’s research. Eberling’s team at MJFF hosted a workshop in 2010 to figure out how best to support the field to take steps into this arena. Uniting key stakeholders, the Consortium

to Develop an Alpha-Synuclein Imaging Agent was born and with it, a research roadmap and essential tools that are used today by many groups. “The Foundation set out to help lay the groundwork for how things should be done, as well as providing significant resources to jump-start the search. Without that, it would have almost certainly taken much longer to get here,” says Eberling.

MJFF also found creative ways to leverage philanthropic capital to attract more interest in this vital field. In 2016, MJFF announced a \$2-million Alpha-synuclein Imaging Prize to be awarded to the first team to achieve successful selective imaging of alpha-synuclein in the living brain. And in 2020, The Ken Griffin Alpha-synuclein Imaging Competition — a \$10-million commitment launched in 2019 to spur development of an imaging tracer — awarded three teams significant funding to accelerate work in this area. One of those teams was AC Immune, which MJFF has granted more than \$5 million since 2015. The

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The Image Worth a Decade of Scientific Resolve (continued)

competition is made possible by the support of Ken Griffin, founder and CEO of global alternative investment firm Citadel, whose father lives with PD.

Those initiatives are paying off. “This is certainly not the finish line, but it proves that an alpha-synuclein PET tracer is feasible,” says Eberling. It’s important to note, AC Immune’s tracer did not show differences in alpha-synuclein in people with idiopathic PD versus control volunteers, which thus far has stumped researchers. Rather than give up, they tested the tracer in individuals with multiple system atrophy (MSA) — a related parkinsonism. In MSA, there may be more alpha-synuclein present, accumulating faster and in different regions of the brain, which makes it easier to detect with PET imaging. These findings could have immediate impact on diagnosing and treating people with MSA, commonly misdiagnosed as PD. As the project continues, AC Immune and Lund University are evaluating additional diseases, including genetic PD.

“There’s every reason to think that we will have a tracer that also works in PD very soon,” says Eberling.

“This is a transformative step toward achieving our vision for developing precision medicines to treat neurodegenerative diseases. It was made possible by the close collaboration between AC Immune, Skåne University Hospital, Lund University and MJFF,” said Professor Andrea Pfeifer, CEO of AC Immune. “We look forward to continuing the collaboration to expand on these results.”



Parkinson’s researchers viewed the first images of alpha-synuclein in the living brain in Barcelona, Spain, last March.

Other groups are also making headway in the development of alpha-synuclein tracers. The Ken Griffin Alpha-synuclein Imaging Competition concludes this fall, when scientists will have the opportunity to evaluate data from the other awardees, Merck and Mass General Brigham, as well. Another MJFF grantee, German biotechnology company MODAG, hopes to have data from studies of their alpha-synuclein tracer this year. Alpha-synuclein accumulates in the brain in multiple forms, and these different forms may have an impact on symptoms in Parkinson’s and other diseases that involve alpha-synuclein, such as dementia with Lewy bodies. Varying forms of alpha-synuclein may require multiple tracers. More tracers mean better diagnosis and therapies for all.

For Eberling, the real fulfillment came when she presented the news to the Foundation’s Patient Council, advisors who bring the patient perspective to MJFF’s work. “These individuals have trusted me to get the job done and finally, I could provide some hope and encouragement around this elusive target we’ve been chasing for years,” she says.

PPMI: With Help from Everyone, Achieving Goals Faster

By Christina Destro



Ken Marek, MD, leads MJFF's Parkinson's Progression Markers Initiative as principal investigator.

Emerging findings from The Michael J. Fox Foundation's landmark Parkinson's Progression Markers Initiative (PPMI) are helping researchers build a dynamic study to explore and better treat the spectrum of Parkinson's disease. Enrolling people diagnosed decades ago alongside the newly diagnosed and even those who have not been diagnosed but may be at risk for Parkinson's, PPMI is building a network of volunteers and scientists to speed new therapies.

This real-time strategy for discovery came into play over recent months. Analysis of data contributed by more than 20,000 individuals who had enrolled in PPMI's online study showed smell loss is one of the most important signals of risk for Parkinson's disease. The study quickly pivoted to a new strategy to rigorously test the olfactory (smell) sense of tens of thousands of older adults who do not have Parkinson's. (If you are 60 or older and do not have Parkinson's, please visit mysmelltest.org/FoxFocus to get started.)

Critical findings like this are coming from an influx of data since PPMI's expansion in 2021. Since it first launched in 2010, PPMI has been an extraordinary open source of data for researchers. Today PPMI offers varied ways for the Parkinson's community to join the study that could change everything. More than 28,000 volunteers are sharing information online. And more than 1,200 are participating in person at medical centers across the world.

Calling on the Newly Diagnosed

PPMI has a particular need for people recently diagnosed with Parkinson's who are not yet taking PD medication. (If this is you, please visit michaeljfox.org/newly-diagnosed to learn more and volunteer today.) Enrolling people early in their disease allows the study to plot biology and experience, from the earliest signs of Parkinson's through its later stages. The initiative is still following hundreds of its first participants, now more than 10 years from their diagnosis. These early volunteers have contributed to new tests and knowledge that may help diagnose disease and predict symptoms such as memory and thinking problems.

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PPMI: With Help from Everyone, Achieving Goals Faster (continued)

Since the study's expansion, more than 50 sites (including a new site in Lagos, Nigeria) are recruiting an additional 1,000 newly diagnosed volunteers to join in contributing valuable data and biological samples.

“Learning you have Parkinson’s can be frightening, and few people are thinking about clinical studies,” says PPMI Principal Investigator Ken Marek, MD. “When people are diagnosed, they often first ask, ‘What can I do?’ Probably the most important thing people can do is join a research study like PPMI. People can make valuable contributions to research toward better treatments and cures.”

In fact, the earliest months and years with PD are a fleeting window when your participation in studies may provide greater value to research than in any subsequent time in the Parkinson’s journey. MJFF often hears from patients and families who did not get involved during this critical time and later came to wish they had done so.

Reaching Those “At Risk” for Parkinson’s

In addition to seeking individuals age 60 and up with smell deficits, PPMI also is enrolling people with other risk factors: acting out dreams while asleep (REM sleep behavior disorder or RBD) or having a genetic mutation linked to the disease. Enrolling people with these risk factors — a goal of 2,000 new volunteers in this group — will allow scientists to start the first prevention therapy trials.

For Otis Peoples, 71, a retired police sergeant and current behavioral health therapist in



Otis Peoples, pictured with his wife, Linda, has learned about his risk for PD from PPMI.

Chicago, Illinois, participating in a Parkinson’s research study offered a unique opportunity to help him learn more about his own risk for the disease. His wife, Linda, noticed he was acting out his dreams. He would punch, wrestle and talk while asleep. When Peoples was diagnosed with RBD and learned about its connection to Parkinson’s, he took action and joined PPMI.

“Maybe that will be my purpose: to help find a cure for this disease,” says Otis.

Gathering Data on Health and Disease

While PPMI is aiming to connect with people recently diagnosed and with certain risk factors, the study has opened to anyone over age 18 in the United States. Volunteers — with and without PD — can add to the study through its online platform, sharing information on health and disease over time. The more PPMI captures about brain health and aging, the faster science can move to cures.

PPMI is making progress in its ambitious goals, but many more volunteers are needed. However you have been touched by Parkinson’s, you can make a difference in ending it.

If you’ve been diagnosed with Parkinson’s in the past two years, visit michaeljfox.org/newly-diagnosed to connect with PPMI.

The Different Paths to PPMI

Whether you are recently diagnosed with PD, have experienced symptoms or have no known connection to the disease, PPMI needs your help in accelerating research for new treatments and a cure. See the different paths PPMI volunteers can take on the journey to speed a cure.



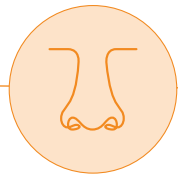
Online Platform

Complete sets of questions on health and disease every 90 days.

Open to anyone over age 18 in the U.S., with or without Parkinson's disease.

Smell Test

Enter answers from the free scratch-and-sniff test. Results may send you to the online platform or a study site. Open to anyone over age 60 without Parkinson's disease.



Study Sites

Contribute data and biological samples at visits over time.

Open to anyone over age 30 diagnosed with PD in the last two years.

Take the Smell Test Challenge

Your sense of smell plays an important role in monitoring brain health as you age. Ongoing smell loss can be a sign of cell damage associated with brain disease. In fact, emerging results from MJFF's landmark study show that smell loss may be one of the most important signals of Parkinson's risk.

Everyone aged 60 and older without Parkinson's disease can help scientists explore this link.

Request a simple scratch-and-sniff test today at mysmelltest.org/FoxFocus.

PPMI will mail you a test, which takes about 15 minutes to complete. Then you'll enter your answers online. Your results may mean you are eligible to join PPMI at a medical center.

You can also help by spreading the word: everyone over age 60 — family, friends, neighbors, community members — can take the smell test.

Edmond J. Safra Fellowship Expands Access to Expert Parkinson's Care and Fuels Research Progress

Whether you're new to Parkinson's or you've been living with the disease for some time, you've likely asked, "Who's the best doctor?" For people with PD, the best doctor is a movement disorder specialist — a Parkinson's expert, who has completed additional training in diagnosing and treating the disease, and who also listens and cares for you as a whole person, not only a person with Parkinson's.

"Because movement disorder specialists see more people with PD, they're better able to spot the disease's nuanced direct and indirect effects. They can quarterback a care team and tailor a treatment plan to each person's unique symptoms and circumstances," says Rachel Dolhun, MD, movement disorder specialist and MJFF's senior vice president of medical communications.

The challenge: There simply aren't enough movement disorder specialists. Many people

know this all too well, in the form of long wait times or distant travel for appointments.

To meet this need, the Edmond J. Safra Fellowship — a collaboration between The Michael J. Fox Foundation and longtime partner the Edmond J. Safra Foundation — trains doctors how to expertly care for people with Parkinson's and other movement disorders and how to lead research in the field.

The program, which has, to date, graduated 27 movement disorder physician-scientists around the world, is on track to train 72 new specialists by 2028. This global network exponentially increases patients' access to expert care and fuels research advances.

To further the fellowship's impact, the program recently launched a complementary initiative, the Edmond J. Safra Movement Disorders Research Career Development Award. This competitive research funding

→ For people with PD, the best doctor is a movement disorder specialist, a Parkinson's expert who will listen and care for you as a whole person.

opportunity for fellowship alumni aims to support an individual's trajectory to independent scientific investigator who can propel Parkinson's research forward.

The 2022 awardees are Conor Fearon, BE, MB, PhD, fellowship class of 2022, and Anne Weissbach, MD, fellowship class of 2020. Each will receive a \$50,000 grant to support a two-year research project on Parkinson's and related disorders. (See box.)

As both physicians and scientists, Edmond J. Safra Fellowship graduates rely on their relationships with people and families living with Parkinson's to inform research toward meeting the most pressing needs. Fearon describes, "We follow patients to understand their journey, interacting with them closely and getting to know them. That collaboration is what helps bring out our understanding of the disease. In that way, I think movement disorders is unlike any other field of medicine."

The Inaugural Edmond J. Safra Movement Disorders Research Career Development Awards



Conor Fearon, BE, MB, PhD

Consulting neurologist;
Dublin Neurological Institute;
Dublin, Ireland

Combining his expertise in electrical engineering and movement disorders, Fearon aims to develop quantitative, non-invasive biomarkers to diagnose and track Parkinson's and related diseases by analyzing eye movements and pupillary changes. He anticipates his findings will improve diagnosis and enhance research of Parkinson's.



Anne Weissbach, MD

Junior Group Leader; Movement Disorders Unit; Institute of Neurogenetics Lübeck; Lübeck, Germany

Using non-invasive brain stimulation, Weissbach will evaluate unique brain signals in people with inherited Parkinson-dystonia syndromes, diseases with symptoms of both PD and dystonia, a muscle cramping that can be part of PD or a condition on its own. She hopes this work will lead to better understanding of and treatments for Parkinson's and dystonia.



Historic Legislation to End Parkinson's Introduced in Congress

This summer, the U.S. House of Representatives introduced the first-ever legislation devoted solely to ending Parkinson's disease. *The National Plan to End Parkinson's Act* (H.R.8585) will unite the federal government and the private sector to make an actionable plan to help prevent and cure Parkinson's, alleviate financial and health burdens on American families, and ensure those living with the disease have access to the care they need.

MJFF's public policy team in Washington, D.C., worked closely with colleagues in Congress to prioritize work on *The National Plan to End Parkinson's Act* since the beginning of the year and, as this newsletter went to print, is working with both sides of the aisle in the House and Senate to advance the legislation through this session of Congress.

This is historic legislation for PD, which will create a win-win for individuals impacted by this disease, and for the government. The public-private advisory council created as part of this bill will report every year to Congress on their progress and impact in ending Parkinson's.

A 2019 study co-funded by The Michael J. Fox Foundation found that Parkinson's costs the U.S. \$52 billion every year, half of which is shouldered by the federal government. That annual cost is expected to grow to \$80 billion by the year 2037, as the number of people with Parkinson's is expected to double by the year 2040.

As has been demonstrated by a similar approach to Alzheimer's, a national plan to end Parkinson's has the potential to: dramatically increase federal research funding; improve early diagnosis; spark new care models; create Parkinson's prevention standards; address health disparities in diagnosis, treatment and clinical trial participation; and enhance public awareness of the disease.

More than 10,000 members of the Parkinson's community have asked their Representative to support this important bill. Call or email your Representative in Congress at 202-225-3121 and ask them to co-sponsor *The National Plan to End Parkinson's Act*. Visit michaeljfox.org/advocacy to take action today. And stay tuned to our channels for regular updates on this legislation.

PD Resources for You and Your Family, 24/7



Whether you're new to Parkinson's disease, have been living with PD for years or you care for someone with the disease, The Michael J. Fox Foundation offers free educational resources to answer your most critical questions. Share them with your friends and family so they can learn too.

Third Thursdays Webinars

Join thousands of viewers live at 12 p.m. ET on the third Thursday of every month for in-depth discussions with expert panelists on living with Parkinson's disease and MJFF's work. Recent topics have explored the lesser-known symptoms of PD; sleep issues; and how to make the most of your telehealth visit. All webinars are also available on demand, any time, at michaeljfox.org/webinars.

The Parkinson's Podcast

Hear from a wide range of experts on topics of interest to the PD community with our hosted podcasts. Recent episodes feature practical tips for managing the early years of Parkinson's disease and the experience of acting out dreams while asleep. All podcasts are available via our website at michaeljfox.org/podcasts, or by subscribing in iTunes or through your smartphone podcast app.

Guides for Living Well with Parkinson's

Learn practical tips and real-world advice for navigating life with PD with MJFF's free, easy-to-read guides written by movement disorder specialist Rachael Dolhun, MD, senior vice president, medical communications, and other experts. Our popular Parkinson's 360 guide addresses the unique journey that every person diagnosed with PD takes. (Available also in Spanish; see below.) Download the guides at michaeljfox.org/guides.

Parkinson's 360 en español

Parkinson 360 es un conjunto de recursos desarrollados por la Fundación Michael J. Fox para las personas y familias que conviven con esta enfermedad y una guía sincera con la que cualquier persona afectada por la enfermedad de Parkinson se puede identificar. Accesa la guía a michaeljfox.org/conociendo-la-enfermedad-de-parkinson.



Dr. Dolhun Talks PD

Parkinson's and Skin Cancer: What to Know



Rachel Dolhun, MD, is a movement disorder specialist, board-certified neurologist and senior vice president of medical communications at MJFF. Follow her on Twitter @RachelDolhunMD.

Many people are surprised to learn that Parkinson's disease increases risk for the skin cancer melanoma. Scientists aren't exactly sure why. It may be that the same factors, such as older age, increase chances of both diseases. Or, these conditions may share similar disease-causing pathways or proteins. Research into this link — long supported by The Michael J. Fox Foundation — could lead to better understanding, diagnosis and treatment of both PD and melanoma.

The risk of melanoma is still low when living with Parkinson's. But it's important to be aware and to take steps to protect yourself. Consider these tips:

See a skin doctor

Visit a dermatologist, a skin specialist, at least once a year. They will thoroughly examine your skin, noting any concerning areas, and can offer treatment recommendations for dry, flaky or oily skin, something many people with PD experience.

Check your skin

Once a month or so, take a good look at your skin. Check for new or changing moles and differences in color, size, shape or thickness. Don't forget to look at nails, between fingers and toes, and on your scalp and back. (Use a mirror or ask a loved one to help.) If you notice changes, see your dermatologist.

The medical information contained in this newsletter is for general information purposes only. The Michael J. Fox Foundation for Parkinson's Research 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.

Wear sunscreen

Wear sunscreen year-round, even on cloudy days and during short periods outside. The American Academy of Dermatology recommends sunscreen be broad-spectrum (block UVA and UVB rays), SPF 30 or higher and water-resistant.

Dress for the sun

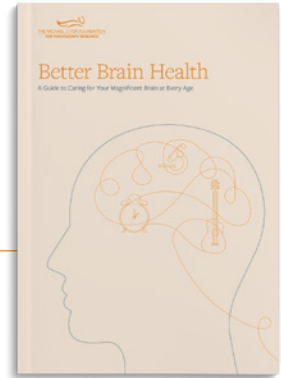
Use sunglasses to protect your eyes and a wide-brimmed hat to cover your head and ears. And wear lightweight and light-colored clothing. In general, try to avoid the sun in the middle of the day, when it's most intense, and enjoy the shade instead of direct sun.

Avoid tanning beds

These emit UV light, which can cause skin cancer. If you want a tan, try self-tanning lotion.

Get enough Vitamin D

Vitamin D helps keep bones healthy. This is especially important for people with Parkinson's who may be at risk for falls. The sun is a good source of Vitamin D, but foods and supplements also can provide this essential nutrient. Have your doctor check your vitamin level and ask about the best foods to eat and whether to take a supplement.



Better Care for Your Brain

Whether you live with Parkinson's or love someone who does, there are simple steps you can take in everyday life to boost your brain health. From a healthy diet to regular exercise to building positive connections with others, research is piecing together the puzzle of how best to care for your brain, how to prevent disease and, if disease does arise, how to best treat it.

A brand-new resource from The Michael J. Fox Foundation, *Better Brain Health: A Guide to Caring for Your Magnificent Brain at Every Age*, explores the concept of being at risk for brain disease and offers easy-to-follow steps to support your brain health.

This guide is for everyone — younger or older, living with disease or not, and will empower you to take steps today to care for your brain. Download the free guide at michaeljfox.org/brainhealth.

Visit michaeljfox.org/ask-the-md to learn more about living well with Parkinson's and recent Parkinson's research topics.

Team Fox Member Jessica Krauser Is Just Getting Started



By Kat Mehlhorn

In 2019, when Jessica Krauser of Powell, Ohio, was diagnosed with young-onset Parkinson's disease at 37, she felt relief. After years of experiencing symptoms and knowing something was off, she finally knew why.

Of course, hearing the diagnosis wasn't easy. At the time, she was going strong in her career in pharmaceutical marketing consulting and had young twins. "My husband took it hard at first because his mind started to go to the worst place," says Krauser. But she had done her research. "I was scared, but not that scared. I knew that there were steps I could take to manage and slow my symptoms," she says.

She started medication and joined a local gym for people with Parkinson's. Then COVID-19 hit, and she found herself burnt out, not prioritizing her health. In 2021, she made the

difficult decision to step back from her work for a while.

Not long after, she received a surprise that changed everything. "Since my diagnosis, my friends were unsure how to help me because from the outside, I'm fine," says Krauser, "but they know me best." One night, she showed up to dinner and her friends were wearing shirts that read 5K for JK. They had created a 5K running event to benefit Team Fox, MJFF's grassroots fundraising program, and scheduled it for that October.

The inaugural 5K for JK attracted more than 400 runners and raised \$86,000 for Team Fox, plus another \$10,000 for the local PD community. "I want a cure in my lifetime, but I also support research for my kids and their generation," says Jessica.

More Ways to Walk toward a Cure: As this newsletter went to press, The Michael J. Fox Foundation and the Parkinson's Alliance announced a transition of the Unity Walk, held annually in NYC's Central Park. Learn more and follow along at michaeljfox.org.





5K for JK co-founders Michelle Adams, Jessica Krauser, Carrie Schaefer and Melissa Carlson, with MJFF's Mary Havlock (third from right). Not pictured: Steve Brandenburg.

While planning for the second annual 5K for JK this October, Jessica is using her marketing background to expand 5K for JK's footprint. She started a podcast, formed a 501(c)3 nonprofit organization and is considering

adding other events in different locations. "It's important to me to educate others that you can live well with the disease," says Jessica.

A Family's Legacy of Lacing Up for a Cure

This November, Ryan Ashdown, 23, of Cleveland, Ohio, will take on the New York City Marathon, a feat he will share with his late mother, Maureen Ashdown. A dedicated fundraiser since the earliest days of Team Fox, Maureen completed 12 marathons to raise funds on behalf of her father who lived with Parkinson's. After his mom's passing this May, Ryan decided to continue her incredible legacy of fundraising for Parkinson's research.



Ryan Ashdown with his mother Maureen.

He is one of 150 runners representing Team Fox in the 2022 TCS New York City Marathon on November 6. One hundred percent of the funds they raise go directly to the Foundation's research programs.

On the Road Again: Parkinson's IQ + You

By Christina Destro

A hotel ballroom was buzzing in Boston, Massachusetts as nearly 300 community members gathered in May for the first in-person Parkinson's IQ + You since 2020. The educational event offered patients, families and care partners the chance to reconnect and learn about the latest research and resources.

The series of free in-person events, which began in 2019, is returning to cities around the country, with visits to the New York Tri-state area and San Francisco Bay Area planned this fall. Past Parkinson's IQ + You events in Atlanta, Georgia; Phoenix, Arizona; and Southern California have brought together more than 2,300 attendees.

Hosted by MJFF, the events kick off with an educational session on what it means to build a Parkinson's care team. A person with PD and their care partner, movement disorder specialist, physical therapist and speech therapist share practical tips for navigating the disease and making the most of visits with specialists. Attendees can also hear from experts on a research panel about the latest



scientific advancements and the value of research participation.

At every Parkinson's IQ + You event, participants can connect with more than 30 groups at the Partner Expo, including national PD organizations and local support groups, care options and exercise programs. Foundation staff help enroll volunteers in research, including MJFF's landmark Parkinson's Progression Markers Initiative study.

Attendees in Boston credited the program and panelists with providing valuable information to help with the diverse challenges of living with Parkinson's.

"Having so many resources in one place was very valuable," said Kristine Faubert, 58, Weymouth, Massachusetts. "The panelists were very knowledgeable, and the question-and-answer period was facilitated so well. It was a wonderful event."

For more information and to register for upcoming Parkinson's IQ + You events, please visit michaeljfox.org/pdiq.

And the Oscar Goes to...

Michael J. Fox to Receive Academy's Humanitarian Award



Among the many distinguished titles Michael J. Fox holds — iconic actor, best-selling author, Parkinson's advocate — is a new one coming this fall: Oscar Award winner. On November 19, during the 13th Governors Awards, the Academy of Motion Picture Arts and Sciences will honor Michael with the Jean Hersholt Humanitarian Award. Each year, this honorary Oscar statuette is given to “an individual in the motion picture arts and sciences whose humanitarian efforts have brought credit to the industry.”

In 1998, Michael set off a cascade of events that would leave an enduring mark on the field of Parkinson's. It was that year he disclosed his diagnosis to the world and committed to doing all he could to speed research. Only two years later he would open the doors of The Michael J. Fox

Foundation and work to galvanize patients, families and researchers to partner together to end PD. And today, more than two decades since its inception, the Foundation crosses more than \$1.5 billion in global research funded — a milestone bigger than Michael himself admits he ever thought possible.

With his characteristic humility, Michael has always deflected any praise and credits the Parkinson's community with the enormous advancements made in understanding the disease and progress toward a cure. Yet, he is the catalyst who helps us to see the power we each hold to help end this disease. His ability to stir the humanitarian instinct in each of us might be his greatest contribution and is worthy of this prodigious Oscars honor.

Please join us in congratulating Michael. And stay tuned to michaeljfox.org for more on where to watch the ceremony.

MJFF in the News



Waking Up to MJFF in the Morning

Raising awareness of the connection between acting out dreams and risk for developing Parkinson's, ABC's *Good Morning America* correspondent Will Reeve interviewed MJFF's Rachel Dolhun, MD, movement disorder specialist; and MJFF Patient Council member Gary Rafaloff during Parkinson's Awareness Month in April.

Breaking Language Barriers

MJFF Patient Council member and 20-time Grammy Award-winning producer Sebastian Krys discussed his Parkinson's journey and ongoing commitment to generating awareness of Parkinson's in his community, in the March issue of *People en Español*.



Double Your Impact on Parkinson's Research

This November 29, on Giving Tuesday, your gift will count twice. For every \$1 you donate, \$2 will support critical research.

We have an ambitious \$4 million goal — generously matched by families who share our mission to find a cure. Join them — and thousands more supporters — to help us end Parkinson's.

Learn more at michaeljfox.org/foxfocus-match2022 and follow our channels for updates.



About Us

The Michael J. Fox Foundation (MJFF) is dedicated to finding a cure for Parkinson's disease through an aggressively funded research agenda and to ensuring the development of improved 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@michaeljfox.org. Submit letters and questions to the editor at newslettereditor@michaeljfox.org.

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