

Michael J. Fox:

This is Michael J. Fox. Thanks for listening to this podcast. Learn more about the Michael J. Fox Foundation's work and how you can help speed a cure at [MichaelJFox.org](http://MichaelJFox.org).

Speaker 2:

Navigating Parkinson's disease can be challenging, but we're here to help. Welcome to the Michael J. Fox Foundation podcast. Tune in as we discuss what you should know today about Parkinson's research, living well with the disease, and the foundation's mission to speed a cure. Free resources like this podcast are always available at [michaeljfox.org](http://michaeljfox.org).

Larry Gifford:

Hello and welcome to the Michael J. Fox Foundation Parkinson's podcast. I'm Larry Gifford, a proud member of the Michael J. Fox Foundation patient council, founder of [pdavengers.com](http://pdavengers.com), and the host of another podcast called *When Life Gives You Parkinson's*, which is beginning its third season this fall. Joining me for this edition of the Michael J. Fox Foundation Parkinson's podcast, reprising her cohost role from the limited edition COVID-19 series from this summer, Rachel Dolhun MD, the MJFF vice president of medical communications and a certified movement disorder specialist. Hello, Rachel.

Rachel Dolhun:

Hey, Larry. It's great to be back co-hosting the podcast.

Larry Gifford:

Yeah, I miss our chats and the cars honking their horns outside your window.

Rachel Dolhun:

If you miss it that much, I'm sure we can arrange some sort of home swap.

Larry Gifford:

That would be amazing.

Rachel Dolhun:

Doing a podcast, it's really so much fun for me, and it's a good break from all of the meetings I usually sit in and all of the tight deadlines that my boss, Holly Teichholtz, gives on all my projects.

Larry Gifford:

I should stop you right there because also joining us is Holly Teichholtz, chief marketing officer for the Michael J. Fox Foundation. Holly, welcome.

Holly Teichholtz:

Oh, sure. Haze the new gal. By the way, in spite of her snarky comments, I not only know Rachel, but I have crowned myself the president of the Rachel Dolhun fan club. So I will happily take the teasing.

Rachel Dolhun:

The feeling is mutual. Lots of love here.

Larry Gifford:

Well, welcome to you both. The best part of this time of year, I think, are the fall previews, whether it's what the watch on TV, what movies are premiering. I'm really into what fashion's in style, as you can tell. Today, all we need to know though is, we need to wear orange, and listen close, because we have the Michael J. Fox Foundation fall preview for virtual events and activities. All things that you can plan for this fall. Plus, some behind the scenes backstories you don't want to miss. So let's roll out our virtual orange carpet and get rolling.

Rachel Dolhun:

Everybody knows a little thing called COVID sort of crashed and burned a lot of our plans this year, including most of what we had planned for Parkinson's awareness month back in April. And that also includes many of the things that we planned for this fall, including something called the New York City marathon-

Larry Gifford:

I've heard of that.

Rachel Dolhun:

... This fall, in November. We usually have a really good showing by team Fox, but we've had a little bit of time to prepare and we've got a lot of good things for this fall, some really cool events. And there's, I'm using my air quotes, "virtually" something for everyone.

Larry Gifford:

Nice, nice. Michael J. Fox Foundation will be kicking off 12 months of initiatives recognizing the 20th year as an organization, which will continue through the end of 2021. This fall, many of the events we discussed today fall under the Here Campaign. What does that mean exactly, Holly?

Holly Teichholtz:

I'm so glad you asked, Larry. So, some of our faithful podcast listeners may know that the foundation's tagline is that we are here until Parkinson's isn't. Honestly, it says it all about our commitment to our mission, and also what's baked into our DNA, which is that when Michael started our foundation, the idea was never to stick around forever, but really to create such a targeted infusion of resources into the problem of Parkinson's disease, that we're going to eradicate it for once and for all, and when we do that, Michael likes to say, we're going to go out of business.

Holly Teichholtz:

We came up with that tagline around the end of last year. Little did we know that COVID was going to come along and that we would have a bit of a delay in really celebrating our tagline and bringing it to life, like Rachel said, through this whole series of virtual events taking place at the end of this year now. We're so excited to share this with our community through a kickoff weekend that's happening at the very beginning of October. And really, while we don't celebrate anniversaries, what we do want to celebrate and highlight is all the progress and impact that we've made together in really a pretty, relatively short time, 20 years. Not really being that long in the scheme of things, but lots of things to point to with tremendous amount of hope.

Larry Gifford:

Yeah, we'll get into some of that as the podcast goes on. You mentioned community. Community is so important, especially right now in the middle of this pandemic. And we are bringing people together all over the world for the virtual 5k, 10k. Holly, virtual exercise is my favorite kind.

Holly Teichholtz:

You and me both, Larry. You and me both. And especially in a global pandemic. If exercising my right to eat more ice cream and watch more television is wrong, then I really don't want to be right.

Larry Gifford:

I have a feeling that's not what you mean by virtual 5k, 10k.

Holly Teichholtz:

Well, this is so cool. So one of the things that we know in Parkinson's is that exercise is so important; really helps people feel better, manage their symptoms. It's a way of inspiring our communities around us too. And so like Rachel mentioned, we have a whole group of team Fox athletes who usually run in the marathon and run in 5k, 10ks that we put on as an organization, and ride bikes for hundreds of miles. We're going to gather everyone virtually. And when I say everyone, I mean everyone. We have got more than 3,000 people worldwide who are going to be putting on their team Fox singlets and walking or running 5k or 10k, depending on their interest and their level.

Holly Teichholtz:

What they're doing is telling their communities about that. Even though they're doing it in their own communities, maybe they're walking in their neighborhoods or trails near them, or honestly, even on a treadmill, but it's really inspiring to see people really, as Michael himself has said, kind of put their ... There's not much more you can do than put your own sweat into this mission. And we see that because our amazing community has already raised more than half a million dollars for research, just through this quote, unquote, I'm using my air quotes too, Rachel, I want to be like you, just through this "virtual" exercise.

Holly Teichholtz:

And the best thing, Larry, you know this, is that because of the generosity of a group of underwriters, we are able to take 100% percent of those proceeds that come in through team box and put them directly into our research mission. So we don't pay for overhead, we don't pay for the fundraising with those dollars. That goes straight into funding critical Parkinson's research.

Larry Gifford:

That's amazing.

Holly Teichholtz:

I can't think of a better way to launch us into the end of the year.

Larry Gifford:

Now, if I want to get involved, what do I need to do to sign up?

Holly Teichholtz:

It's actually so easy. Your first pit stop on this race is MichaelJFox.org, which is our website. And I hope that you'll come and do that before September 20th, because if you do, we're going to be able to get you your packet full of your t-shirt and your race number, your water bottle, and all the fun tchotchkes that you need to really know that you're part of it. You'll get those in time for-

Larry Gifford:

You need that stuff.

Holly Teichholtz:

Yeah. It's not a hobby if you can't have fun tchotchkes and sort of logos on your shirt, as far as we're concerned.

Larry Gifford:

If I don't have Michael J. Fox t-shirts, I don't know what I'd wear on the weekend.

Holly Teichholtz:

And we want to keep it that way. So if you sign up before September 20th, you're going to have all the materials you need to start telling everybody what you're doing if you want to raise money by doing this. And we're going to kick you off at three o'clock on October 2nd; we're actually even going to have a virtual ribbon cutting. And then all weekend, we hope you'll send us your pictures and your stories. We're going to have ways for you to do that through our social channels and on our website, so that we can share your story with our whole community. And then between now and when you do the run, you can visit our website again. We're going to have tips from running coaches, we're going to have warmup exercises. We're going to have stories of other people who are doing the run/walk with you. By the way, in case you think you're too far away to do this, I just want you to know, we've had people sign from as far away as Switzerland.

Larry Gifford:

Wow.

Holly Teichholtz:

And I think that Switzerland is pretty far away, if you know what I'm saying.

Larry Gifford:

I do.

Holly Teichholtz:

So, I really hope that everyone will just come check it out. And even if you're not running yourself, be sure to stay with us that weekend. There's going to be so much great inspiration. I can't wait to be a part of it.

Larry Gifford:

Sounds great. Rachel, when I was first diagnosed, my gait was so bad I could barely walk. And so I thought, why on earth would an organization taunt me by suggesting I run a 5k to raise research dollars? But we should take a minute to explain why exercise is so important for people with Parkinson's.

Rachel Dolhun:

Yeah. You raise a really good point. And it seems very unfair when you have these people out there running marathons and doing these other incredible feats, when even for people without Parkinson's, it can make you wonder, what can I do? And it makes me remember this motivational quote that sometimes motivates me, that I have hanging in my closet by my workout gear, funnily enough, that says, the only bad workout is the one you don't do. And I say this because what I always say in Parkinson's is that the best exercise is the one you will actually do. So whatever exercise that you will do and do regularly, is the one that's good for you. So that's why we have it as a run/walk, or crawl, maybe. So, whatever you'll do, is good for you. And exercise is so important in Parkinson's. And I feel like I'm saying this all the time, but it's good for your general health, but in Parkinson's, it's also good for decreasing your motor and your non motor symptoms. It helps your medication work better. And if you do it with other people, it helps prevent or lessen the isolation that can come along with Parkinson's. So it's good for everything, and it's just as important as the medication that you take.

Larry Gifford:

That's great. And just do what you can do.

Rachel Dolhun:

Exactly. Exactly.

Larry Gifford:

I know Jimmy Choi's out there breaking world records and that's awesome.

Rachel Dolhun:

Making us all look bad.

Larry Gifford:

Wow. But not everybody needs to do 100 burpees in 30 seconds.

Rachel Dolhun:

Exactly. Exactly.

Larry Gifford:

I love Jimmy Choi, by the way. Can I just say that? Isn't he amazing?

Rachel Dolhun:

Who doesn't?

Larry Gifford:

So, that same weekend, Holly, the weekend of the 5k, 10k, there's a special founder's fireside chat. It sounds cozy. Sounds like a hot ticket too. What is this?

Holly Teichholtz:

Yes. We have taken a page out of FDR's playbook. In all seriousness, if there's anyone more just inspirational and wise than our organization's founder, Michael J. Fox, I haven't found that person yet. And one of the great privileges of what we do at the foundation, and especially what our team does, is whenever we get the chance to really bring Michael's voice to everyone who's in our community and who's in this mission with us. Michael, together with his co-founder, my boss, Debbie Brooks, they really started the organization with this vision 20 years ago. And a couple of things are remarkable that sound different, but they are really the same. All the progress that we've actually made in a short time, and also just how consistent the vision has been the whole time. Again, this idea of bringing the real urgency and the acceleration to the research that is going to bring us better treatments and a cure faster.

Holly Teichholtz:

We cannot wait. We have enlisted a good friend of the foundation, Cliff Leaf. Our listeners may know him as the editor in chief of Fortune Magazine. They may also know him as the guy behind the Brainstorm Health blog and conference. So he is very [inaudible 00:12:54] in the world of biomedical research and neuroscience. And he has sat down with Debbie and Michael in the past and he will be doing it again. And it'll really be kind of an intimate discussion, we hope, where Michael and Debbie will share again, what caused them to want to bring an entity like the Michael J. Fox Foundation into the world, what their vision was, and what they think when they think about all the progress that we've made thus far, and where we're going next.

Holly Teichholtz:

And you are so right, Larry, it's a total hot ticket. They're so fun to listen to. Cliff is also just the best. He's so smart about the way that he kind of gets Michael and Debbie to share what they really think, kind of the story behind the story, of the scientific progress, but also the tremendous community that the foundation has built. So if you want to take part, all you got to do is, again, visit our website, click on the link. Get your ticket. It's free of charge. And please be there with us for this really exciting conversation that we can't wait to hear it ourselves. We're inspired by Michael too. And we can't wait to share it with our community.

Larry Gifford:

Oh, that sounds like a great night. So I'm looking forward to that. That's going to be great. Speaking of great conversations, Rachel, you've done such a great job talking with the PD community through your blog, Ask the MD. I now hear there's something called Ask the MD In Conversation. What is that?

Rachel Dolhun:

Yeah. As you said, Ask the MD is our video and blog series, where I talk about commonly asked questions and popular topics in Parkinson's care and research. And over the years, we've done a lot of different topics, everything from exercise to deep brain stimulation, to tips for care partners. And we're evolving it now to do a new series called Ask the MD In Conversation, where I get to ask you the questions. So I'm sitting down with different members of the community and asking them about their experiences and their perspectives on these different topics in Parkinson's.

Rachel Dolhun:

So in the first edition, out later this month, I talk with Jeff Keefer, who's a board member of the Michael J. Fox Foundation and a person with Parkinson's, on his thoughts on newly approved treatments for Parkinson's that he's using to treat off time, which is when symptoms return between medication doses, and his optimism on the research pipeline and where research in Parkinson's is headed next.

Holly Teichholtz:

Larry, I have to jump in here because Rachel is not giving herself enough credit. When she says that she gets to ask the question, first of all, you should know that the rest of our team has a little nickname for Rachel, and that nickname may or may not be Sanjay Gupta, and that we are routinely in conversations with Rachel ourselves to make sure that if CNN is calling, she is not taking that call. But I have to say, I had a chance to watch this amazing conversation that she had with Jeff, and it is so wide ranging. They covered everything from Jeff's feelings, having been the chairman of our board during a period when actually two drugs that the Fox Foundation funded were getting very close to FDA approval and coming to market, how he feels about those drugs himself as a Parkinson's patient, when he uses them and sort of his opinions about them. But also, even just his amazing way of expressing things. Like when Rachel asked him about off time, he said, "I call those my zombie times." I mean, it was such an interesting sneak peek at this high powered guy, really just letting us in on how he thinks about his role with the foundation and his life with Parkinson's is unusual. Not everybody could have led a conversation like that. And that's why, Rachel, please, don't take that call from CNN.

Larry Gifford:

I like the zombie time. When I'm off, I'm in my bubble. I have my own personal atmosphere and nothing else matters.

Holly Teichholtz:

I have to say though, Larry, I mean, in no way would I ever make light of this because I understand how very serious these things are for everyone who's living with Parkinson's. But I will just say, there is something that I value so tremendously about being able to have these kinds of frank conversations with the people living with the disease, helping others who may be newer to Parkinson's or just experiencing a different version of it. Sometimes just saying different ways that we're living with these things in our own day to day lives can help actually crystallize a really important insight for somebody else. So I get that Rachel is our certified movement [inaudible 00:17:55] specialist, and she has all of the really important ways of understanding how to talk about these things to doctors and other people who are in the care team. But I also just really appreciate the opportunity to hear the straight poop for how we think about these things for ourselves and what it really feels like to live with this disease. I just think that's a really important piece of what we're trying to do at the Fox Foundation.

Larry Gifford:

That's great to hear. I mean, it is important because as somebody with Parkinson's, oftentimes you just need to know that what you're experiencing isn't an isolated event. It's something that other people have gone through and they've survived and they're living every day and putting one foot in front of the other and getting on with it. Rachel, you're also involved in relaunching the cognition guide, which is being made possible by Acadia. What is that and how will folks be able to get a copy?

Rachel Dolhun:

So a little bit of background before we get into that. Cognitive changes, or thinking and memory changes, are something that people with Parkinson's and their family say they worry a lot about and they regularly ask about. Will they happen? What do they look like? When might they come on? And information on this topic that was understandable and kind of practical or useful was really lacking. So next year, we'll be updating the guide and creating some complimentary materials on the topic to reopen and continue the discussion, especially as there may be a new treatment option for people with Parkinson's who have significant cognitive changes. So you can stay tuned to our website and your email for those resources.

Larry Gifford:

And those guides are just amazing resources. As someone with Parkinson's, I can tell you, my wife and I, we're dealing with new symptoms all the time. So it's a resource you don't know you need until you need it. And so we're happy it's there. So Acadia, thank you for all the efforts that they've put into the guides, and Rachel, all the effort that you've put into the guides. It makes it so useful. So we really appreciate that. Now, this may not be on your radar, but this fall there is a US presidential election. I don't if you've realized it.

Holly Teichholtz:

What?

Larry Gifford:

I know. It's crazy now. No, we're all very much aware. What you may not be aware of is which House and Senate races or what issues are important as it relates to Parkinson's. But our good friend, Dave Iverson, will be back behind the mic to host a pre-election policy roundup webinar on October 15th. Holly, what can we expect?

Holly Teichholtz:

It's really interesting because at the foundation, we have a whole group devoted to thinking about public policy and the ways that it intersects with the Parkinson's experience and with Parkinson's research and access to care. And this is actually something that is relatively new to the Fox Foundation. We could talk a little bit more about when and why we sort of brought into the fold of our mission. But what I think is so exciting about the October 15th event, and many people may have already voted, because I know that voting is a little different this year, a lot of people are doing it early or they're doing it by mail, but what we're hoping to do on October 15th, a couple of weeks before the election, is really bring together just a succinct conversation for everyone in our community to know what issues to watch in this election so that no matter how those individual races may turn out, we know what ball to keep our eye on and where our advocacy efforts need to lie.

Holly Teichholtz:

And by the way, I should just mention, Larry, of course, as a 501(c)(3) organization, the Fox Foundation can never get involved in advocating for specific candidates or campaigns. So certainly, there's none of that going on with us. But regardless of which candidates win which races, there are certain issues that are really important to us. And those include things like making sure that the National Institutes of Health is adequately funded for Parkinson's research. So this is the organization in our government that spends our tax payer dollars on the priorities that we advocate for. And so Parkinson's needs to be a really important part of the NIH agenda, and we need to raise our voices to make sure that our



members of Congress and our government is putting that front and center. Or we're all living in a global pandemic right now, and there are certain things that have come along to affect the way people live with Parkinson's, whether that's telemedicine or coverage for mental health care, different forms of care that people with Parkinson's particularly needs. So we need to make sure that we're speaking up about the importance of accessing those kinds of care.

Larry Gifford:

Holly, I want to take a peek behind the orange curtain a bit. When the foundation was established in 2000, there wasn't anybody on staff focused on shaping public policy. What shifted?

Holly Teichholtz:

Oh, that's such a good question, Larry. So, what's actually really interesting about the Fox Foundation, and I've worked at the foundation, I should say, for 15 years, which is crazy, and I never thought that I would stay anywhere for 15 years, but what I always say is that it's never been the same job two years in a row. So when the foundation was really young, it was about five years old when I first joined, there was a strong need to focus on putting our resources into really getting the research machine going. So there was a fairly dry therapeutic pipeline in Parkinson's research, and that's sort of the fancy term that gets used to describe the research projects that have been started, with a chance to lead to a better treatment.

Holly Teichholtz:

So that pipeline was a little bit on the dry side. And the Fox Foundation really spent the first, honestly, 10 years just making significant investments in the millions of dollars in grants to the best research teams around the world to really create that energy and movement in the pipeline. And what happened was, the pipeline did in fact start to pick up a lot more activity. In fact, today we say it's about the most robust therapeutic pipeline that Parkinson's has ever seen. But what happens as these treatments begin to come closer to market approval is that really, the nature of the problem solving that an organization like ours has to do just expands because it doesn't matter if these treatments exist if we don't have policies in place that makes it possible for the widest range of people living with the disease to access them.

Holly Teichholtz:

As we were getting to be into our 15th, 16th year, and we were really starting to see these treatments approaching approval, it became increasingly important and mission centric for us to take on policy as part of our mission, and to really feel like it was a critical piece of our precious donor raised capital was going to be used to create organization around advocating for public policy in support of the Parkinson's community. And so that is what we did. And that's why that mission joined our organization a little bit later, but really at an important and timely moment for Parkinson's drug development.

Larry Gifford:

That's always interesting to hear how an organization evolves over time and meets the needs of their mandate. It's really interesting.

Larry Gifford:

Coming up in the next episode of the Michael J. Fox Foundation Parkinson's podcast. Soon after the big election this fall, we'll all be able to pick up a brand new book by Michael J. Fox. Come on, Holly. Spill the beans. Give us exclusive details.

Rachel Dolhun:

Spoiler alert.

Larry Gifford:

Come on now.

Holly Teichholtz:

Oh my gosh.

Larry Gifford:

And we're just getting started. We have a lot more to cover, but we'll do that next time, on part two of the Michael J. Fox Foundation Parkinson's podcast, fall preview.

Larry Gifford:

For more information, visit [MichaelJFox.org](http://MichaelJFox.org) or click on the links in our show notes. Thank you for listening to the Michael J. Fox Foundation Parkinson's podcast. If you like it, please leave a rating and a review on Apple podcasts. It really helps us raise awareness of the podcast. Please share this episode with your friends and followers on social media. For everyone at the Michael J. Fox Foundation who is here until Parkinson's isn't, thank you for listening. I'm Larry Gifford. You can follow me on Facebook, Twitter, and Instagram; it's the same handle, @ParkinsonsPod. Be well. We'll talk to you next time.

Speaker 2:

Did you enjoy this podcast? Share it with a friend or leave a review on iTunes. It helps listeners like you find and support our mission. Learn more about the Michael J. Fox Foundation at [MichaelJFox.org](http://MichaelJFox.org). Thanks for listening.

Michael J. Fox:

This is Michael J. Fox. Thanks for listening to this podcast. Learn more about the Michael J. Fox Foundation's work and how you can help speed a cure at [MichaelJFox.org](http://MichaelJFox.org).