

Larry Gifford: Today on the Michael J. Fox Foundation Parkinson's podcast.

Todd Sherer: My wife wanted to buy me a t-shirt that says you were social distancing before it was cool, but I think we all realized that no matter how introverted we are, those connections with people are so important.

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).

MJFF: 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: Hi, I'm Larry Gifford. I'm the host of the podcast, "When Life Gives You Parkinson's." I was diagnosed at 45 years old. Like you, trying to figure out everything I need to do to be healthy, well, and safe during the COVID-19 pandemic. That's why the Michael J. Fox Foundation for Parkinson's Research and I are teaming up to launch this limited series podcast.

Larry Gifford: Each episode is designed to help people with Parkinson's Disease and their care partners navigate their way through the COVID-19 pandemic and joining me each episode is the foundation's own board certified movement disorder specialist, and vice president of medical communications, Doctor Rachel Dolhun. Hello, Rachel.

Dr. Rachel Dolhun: Hi, Larry. As I usually say, I'm here in my one-bedroom apartment on a busy street in New York City, so apologies in advance if you hear the background noise.

Larry Gifford: The horns honking. The rumbling of the trucks.

Dr. Rachel Dolhun: Quieter than usual. So today we're going to talk about how COVID-19 is affecting Parkinson's research, a topic very near and dear to our Foundation and to the Parkinson's community, because they're counting on us to keep research moving forward so that we can get to more new treatments and ultimately a cure for the disease.

Larry Gifford: We're going to start with a very cleverly titled segment, here's what I'm hearing. What are you hearing? All right. So I'm hearing Ongentys, a drug to increase the amount of levodopa that reaches the brain, has been approved by the FDA, but won't be released right away because of COVID-19.

Doctor Rachel D...: That's right. This is a new drug known as opicapone, made by accompany Neurocrine Biosciences.

Larry Gifford: That's fun to say, opicapone.

Dr. Rachel Dolhun: So it's a type of drug that works to lessen off time, which is when levodopa wears off before it's time for the next dose and symptoms such as stiffness, slowness, tremor, or even anxiety or mental fogginess come back. This is actually the 15th new Parkinson's therapy that's been approved by the FDA since 2014. So that means more options. And that's really important because not every drug works for every person. Our Foundation has done a lot of work over the past couple of years to connect patients to drug makers and regulators for a dialog about off time, including meetings, summits, and surveys on our online study, Fox Insight. We're really pleased that we've been able to play a role in increasing research and investment in this area, which has led to new treatments to better address patients unmet needs.

Dr. Rachel Dolhun: And as far as what you mentioned about the COVID aspects of the story, it's important to remember that there's always a gap between the approval of a new drug, and when it becomes available to patients in a mainstream way. This gap can be several months or more under the best of circumstances. And that's because companies have to ramp up manufacturing and distribution, educate physicians, work with payers, and do all kinds of tasks related more to the business of science, than the science itself. So yes, given the way that COVID is changing and disrupting some of these activities, it's not surprising to see that the company's ability to get the drug from approval to pharmacy shelves may be impacted to some degree.

Larry Gifford: No, that makes sense. That makes sense. I'm hearing about so many great people in the Parkinson's community who are offering free online classes for exercise, meditation, yoga. I mean, it's so great to see everybody coming together.

Dr. Rachel Dolhun: It is and managing stress and staying active are absolutely critical right now. Parkinson's or not. All of those strategies you mentioned are helping people. Our Foundation had a webinar on mindfulness a couple of weeks ago, featuring Nataly Kogan, who's a mindfulness expert that you might know from her TED Talk or her book "Happier Now." And you can access that webinar on demand or download it as a podcast in our Foundation's COVID resource hub on the homepage at [michaeljfox.org](http://michaeljfox.org). There's also many Parkinson's exercise programs. As you said, from boxing to dance to you name it that now have online programs. And it's really great to see the community coming together in this way.

Larry Gifford: I'm also hearing that scientists want to recruit a lab's army of at least 12,000 volunteers to help them find the vital clues that will lead the life saving strategies to prevent and treat the deadly coronavirus. Anyone over the age of 16 can take part of this groundbreaking Covidence UK investigation. You know, Covidence, all you need is access to the internet around an hour a month, and the determination to get behind this British initiative. It doesn't matter where

you live. It's [www.qmul.ac.uk/covidence](http://www.qmul.ac.uk/covidence). We'll put that on the show notes. So a lab's army of 12,000 volunteers, Rachel, that sounds awesome.

Dr. Rachel Dolhun: I love this focus on online research you can do from anywhere and online surveys like this. Researchers can gather a lot of data quickly in real time, and individuals can make an impact from their own home. We're seeing a number of these studies, including one sponsored by Mount Sinai researchers that I just participated in for people in New York City, which as you know, is the epicenter of the pandemic in the United States. And coincidentally, also our Foundation's headquarters. I should also say that for people with Parkinson's our online study, Fox Insight, is conducting a survey about Parkinson's and COVID to understand if and how the virus affects symptoms, care, and other aspects of the disease. And people both with and without Parkinson's can take that survey at [foxinsight.org](http://foxinsight.org).

Larry Gifford: And they should, I've taken it. It was really quick, but you feel like you're helping come up with something new and different and you're adding your perspective. And so you can be a part of whatever's next. So [foxinsight.org](http://foxinsight.org), come on.

Michael J. Fox: COVID-19 is testing us all in ways we never imagined. Around the globe, individuals, families, and nations are arising to this challenge with courage and grace. I'm especially grateful for the research community's quick response to this crisis. For our part, the Foundation is making this commitment. We will flex to researchers' needs in any way we can to keep critical neuroscience moving forward with the least possible disruption. Together, we will pull through this and be stronger than ever.

Larry Gifford: Speaking of research, let's bring in the guru of research. Todd Sherer is the PhD CEO of Michael J. Fox Foundation. Todd started his career as a bench researcher studying environmental causes of Parkinson's at Duke University, UVA, and Emory University. He joins us now. Todd, thank you for being here.

Todd Sherer: Thanks Larry. Glad to be here.

Larry Gifford: Our listeners want to know how this pandemic is affecting the development of better treatments for Parkinson's. Back in March, nature.com reported that because of Coronavirus, there'd be a near shutdown of all clinical research. I saw reSTORbio delayed the phase 1b2a trial of RTB101 in patients with Parkinson's disease due to COVID-19 level four alerts in New Zealand. I saw another article today that we may be set back for decades. What is the current state of Parkinson's research?

Todd Sherer: Yeah. So we definitely have been impacted in Parkinson's research, much like the rest of the world, by the COVID-19 situation. We are fortunate in some ways that the end of 2019, we had incredible momentum in Parkinson's research, lots of new discoveries, lots of new understanding of the mechanism of the disease.

This led to a number of clinical trials, either being planned or active, for testing new therapies for Parkinson's.

Todd Sherer: Clinical research has been impacted by the current situation, really because a lot of clinical research requires in-person visits of the participants and for many very important reasons, there have been limitations on the otherwise healthy people coming to clinical centers to undergo tests and different procedures as part of clinical trials. Also we really have been focused on maintaining the capacity of the medical systems for the emergencies that are uncovering.

Todd Sherer: So a lot of the ongoing trials had to postpone or delay these clinical visits. Many have been able to convert some of the assessments to remote monitoring, so things like teleresearch, which is doing clinical visits remotely, have been able to replace some of the assessments. But anything that requires sort of a biological sample, a blood test, brain imaging, those have, for the most part, been impacted because it was very hard to run those procedures. Many universities closed down and this led to some of the labs being shut down or delayed in their work and we're hoping those will get started up as soon as possible. But right now we're being cautious and starting them up carefully.

Todd Sherer: New trials that are being planned, those are continuing to be planned. A lot of the protocol writing and regulatory work can still be done and the Foundation has really been trying to do a lot to continue to promote alternative ways to do research. We do have Fox Insight study, which you could participate from your own home by doing online surveys and questionnaires. We'll definitely be hoping that these clinical research studies could come up and running as quickly as possible, as long as it's safe to conduct them.

Dr. Rachel Dolhun: So, Todd, tell us a little bit more about what we are doing to learn from this situation and how the Foundation is working to respond to this and keep things moving so that we're up and ready when this is all, hopefully, over and behind us.

Todd Sherer: Yeah. So there's a couple of things that we've been focused on and doing in this regard. In terms of clinical research, the Foundation has invested over the years in trying to improve how we conduct clinical research and to use much more remote monitoring of participants, whether that's wearing devices like motion detector watches, app-based assessments, and also online surveys like Fox Insight. So that work is continuing and we believe that this will be even more important going forward in clinical research.

Todd Sherer: It also just helps in general to get better insight into patient's everyday activities to get information between clinical visits. I think this is an important opportunity that will gain a lot of steam because of this unfortunate situation in terms of integrating more technology into clinical research.

Todd Sherer: On the laboratory side, what we have done for our grantees and we've been in contact with our grantees. For those that don't know, the Fox Foundation funds research worldwide so 30% of our grants are outside the United States. So we have grantees all over the world and we've been in contact with all of them and assessing the situation in their local areas. We have allowed and provided an extension for all of our grants so people have more time to complete their research with the grants that were made, given this interruption that they've had.

Todd Sherer: We are also working to commit new grants as quickly as we can with the resources that we have, because we do want to make sure that our Parkinson's researchers are ready to go as soon as the labs reopened and that they're able to keep their research teams in place and keep that momentum that we had going into Parkinson's research before this all started.

Todd Sherer: So that's a lot of work that we're doing now with the grantees. We'd really want to try to minimize the disruption, minimize the loss of momentum that we have as much as possible.

Larry Gifford: From my vantage point, Todd, COVID-19 seems to be proving that if there is a will, there is a way in terms of research and developing treatments and finding cures. I mean, the amount of collaboration and red tape being slashed seems like a great precedent being set for what could be the next stage for the Parkinson's community to come up with a cure. What are you learning from how the world's scientific communities are collaborating these days?

Todd Sherer: Yeah. I mean, I think this has been really important to see and the Fox Foundation always put the collaboration, sharing of data at the forefront of all the research that we fund. Some of the major studies that we work on, particularly our Parkinson's Progression Markers Initiative, makes all of its data available in real time to the research community and we're seeing how critical that is in the current situation of COVID-19 where we need this information right away as it's happening. So we have been pushing that kind of approach from at least the last decade at the Fox Foundation and I think what we're seeing is that this is the way research needs to be conducted.

Todd Sherer: I think what we're also learning is that time, of course, is of the essence and that we need to act very urgently. I think this is also very important to the Parkinson's community for us to continue push forward as urgently as we can.

Todd Sherer: I think not only is it the sharing of the data that's critical, it's what we call research multidisciplinary or interdisciplinary research is necessary. In the case of COVID, there's people with expertise in epidemiology, in public health, in virology, in immunology, in pulmonology. All need to bring their expertise to the table so we can really get a handle on what's happening and how can we treat and mitigate what's going on with the virus.

- Todd Sherer: In Parkinson's, we need these multidisciplinary approaches as well, cell biology, neuroscience, clinicians, neurosurgery, genetics. That's another area that the Fox Foundation has worked on over the years, to get all these experts at the table, bringing their unique expertise together so that we can really get the most insights and move things forward as quickly as possible.
- Todd Sherer: I think the other thing that we've seen is that we need to come up with new ways of pushing the research forward and looking at how can we take advantage of regulations and not see them as barriers for pushing new therapies forward. I think there's been a lot of lessons that we've seen from this pandemic on how we could be more creative about conducting trials and getting results more quickly.
- Dr. Rachel Dolhun: Todd, in addition to the researchers and the people participating in research, we also, of course, need doctors and we are funding a program to train more movement disorder specialists who are also researchers, the Edmond J. Safra Fellowship in Movement Disorders, which of course is near and dear to my heart. But talk a little bit about that program and how that's continuing during this time, which is also really important to stress.
- Todd Sherer: Yeah, I think what we've found in this pandemic, but we knew this in Parkinson's disease for some time, is the need to have a wide depth of expert clinicians and researchers who understand the details of the particular disease that's being treated and studied. And in Parkinson's, we've known for some time that there's a shortage of people with this expert training in movement disorders. So this is additional training that you get beyond a neurology residency to have great expertise in treating movement disorders. And Parkinson's disease, as many of you know, is a very difficult disease to treat as a clinician. There's such variability in the disease, variability and the presentation of the symptoms and response to treatments, and it takes a real experienced hand to navigate the disease from the physician side.
- Todd Sherer: So in partnering with the Edmond J. Safra Foundation, over the last few years, we have been supporting this particular training, this scholarship training in movement disorders, to build up an army of clinicians who have skills, learning at the feet of the experts on how to treat Parkinson's disease, and also be at the cutting edge of research so that we can bring the discoveries from the laboratory into the clinic and conduct more innovative trials and make sure that we're targeting the biggest needs of the patient community. And it's a really important program because we want to make sure people have access to this type of care.
- Larry Gifford: For sure. It's an amazing program. And going to an MDS over a neurologist for me was light and day, and I feel so supported by my MDS. It's a great thing that you guys are doing and supporting. One of the cool events that I got to participate in, the Michael J. Fox Foundation put on with the Parkinson's IQ + You events, which we've had in Atlanta and Phoenix and Anaheim. And we had this whole schedule and then COVID came along, and now I'm like, "Oh, but I

don't get to see everybody anymore." You have a lot of events that have been canceled because of this, but you're finding alternative ways to connect with the community.

Todd Sherer: Yeah. This has been also one of the real negatives of this situation with COVID, is we made the decision in March to postpone all of our large in-person events for safety of the participants and we didn't want our staff traveling around the country and everything. A lot of good reasons to postpone, but it's a real negative to not be able to do these events because there's such a need for, in terms of the PDIQ events, such a need for education in the community so people can understand and have the skills and tools to have the best ways to deal with this disease today.

Todd Sherer: And the events we've had usually have 500 to 1000, even 1500, participants, that come in person for a full day educational event, really to understand how to interact with their doctors, what other resources are available to them in terms of physical therapy and mental health that they should be thinking about, what local clinician sites, what local support networks are available in those communities.

Todd Sherer: And what we've done is tried to pivot because we don't know when we'll be able to do these events again, so we've pivoted to use technology and use the digital space to really get that information out to people through podcasts and webinars and just the connection. I'm very concerned in my own life, and I think for everyone out there about sort of the negative mental health consequences of social distancing, and really making sure people know that the Parkinson's community is still there for them. And this is something that Fox Foundation is committed to and remain committed to in terms of supporting the community. And people are living with Parkinson's today and COVID or no COVID, still 50,000 plus people, they get diagnosed with Parkinson's in the United States alone this year.

Larry Gifford: Wow. I grew up with my mom saying, "Everything happens for a reason," and I didn't always believe her, but I do now. I hear a lot of prognostications around lessons that society may learn from COVID. What do you hope the Michael J. Fox Foundation learns? And in general, what the Parkinson's community may learn from this really weird time in our lives?

Todd Sherer: Yeah. I keep trying to look for the silver lining, and I'm sure there is one, and hopefully we'll all be able to look back and say, "Oh, that was great. We learned all this important stuff." But there are some things that I do think we're learning on this. So one thing just on the community side, we've been talking for years at the Fox Foundation, and with some of our researchers that we work with, on expanded telemedicine for Parkinson's patients. It's been validated. You can do an exam for the most part by telemedicine for a Parkinson's patient. And this is now happening basically overnight because of COVID. And we're really pushing on the policy side to make sure something like that continues because we do

think that patients would have much more frequent interactions with their clinicians if we had more widespread telemedicine. So that's just one example.

Todd Sherer: I think what we found, or what I've learned more specifically, biggest lesson that I've learned from this situation, everything starts with your health. Health drives everything for yourself and for society. Everything kind of derives from good health and it's our economic prosperity, our happiness, any adventures we take, travel, things that we do. And we're seeing that now on a societal level and what it's reminded me of sort of why I've gone into my career that I chose in the first place, we have to invest in health. Science is the basis of that investment, so funding research, getting new treatments out for people, improving how care is delivered. I mentioned the example of telemedicine.

Todd Sherer: And what can we do that's not just in a drug? What can we do for ourselves for our health? Exercise, diet, taking care of ourselves, making the most of every moment that we have when we have our health because everything is deriving from there. So we have to commit to our own health. How do we reduce our stress? Importantly, how do we maintain that social connection? My wife wanted to buy me a t-shirt that says you were social distancing before it was cool. But I think we all realize that no matter how introverted we are, those connections with people are so important and these are things that are remind you of.

Larry Gifford: Yeah.

Todd Sherer: And the other thing that I've been reminded of kind of specifically from the Foundation perspective is that science and developing new drugs is a team sport. So it takes people with the disease, their families to participate. It takes those interdisciplinary, multidisciplinary teams. It takes people to fund science, whether that's the federal government or philanthropists. And it takes the whole community to have a commitment, to see that science through to the end and know that there'll be failures along the way, but that we all benefit when we get to the success. Every incremental success that we can have improves our health that much more, and then we can enjoy more of all the other good stuff that we want in life. And finally, this has been something the foundation, from the day Michael founded it, has had in its DNA, which is urgency.

Todd Sherer: What we saw with this particular unprecedented pandemic is that the entire world got turned upside down, basically on a day's notice. I remember the day where Fox Foundation was doing our practice work from home day, just in case we were going to have to go remote. And it was the night before that day and that was the night where the NBA canceled the season, Tom Hanks announced he had had COVID and we were doing our practice day the next day and midday, the school district in my town announced that school was closed indefinitely. And all of a sudden the whole world had changed. So that urgency, that Fox Foundation has always had a don't put off put tomorrow what you could do



today, and time is not neutral for people who have a chronic disease like Parkinson's.

Todd Sherer: And I think that the Foundation and its staff just gets triply committed to that kind of motive when we see something like this happening, because all those trials and all that research that's being impacted now, we want to get it restarted and get to those answers so that we don't have research that gets slowed the next time something disastrous like this happens.

Larry Gifford: Rachel, do you remember that the practice day?

Dr. Rachel Dolhun: Oh, very well. Todd was ready to kill me because I was trying to go on an international trip during that time. It was actually right before everything shut down. I tried to go on an international trip and I was very quickly on my way back from the international trip to working remotely from home. So it was a little bit of a whirlwind for me, but I'm thinking it all starts with you. I mean, and there's so much impact that one person can make for the collective, for the whole community, for the whole world. Whether that's staying at home to protect others, participating in an online research study to help researchers while we're all being socially distanced or physically distanced to help other people. I do think it's this moment where we have kind of all paused and been forced to slow down - which is not a concept we're familiar with in New York City - has really been a time to reflect and think about what's valuable and important and I do think is a good lesson in moving forward.

Larry Gifford: Yeah, it's really cool. I've been connecting with people on Zoom. Every week I pick five people that I've met online, that I communicate through Twitter and I invite them to a Zoom call and it's the first time we've seen each other, really in person and talk to each other. And it's really cool. Now, Todd, I hear you're a great teacher.

Todd Sherer: Well, it wasn't a voluntary decision. I have a five year old and an eight year old, so I'm currently co-teaching with my wife kindergarten and third grade. And one thing that's fun is I've gotten to relearn what a rhombus is, which I know I knew at one point in my life, but after not succeeding as well in one assignment that I'd hoped, I had to go back to re-read up what all the different polygons were. I think there are lessons that the children are learning too about some of the things that Rachel just said, how we all have to take care of each other and that sometimes you have to make a sacrifice for others. And hopefully those will be lessons that people can take with themselves as we kind of roll back, hopefully sooner than later, into the new normal.

Todd Sherer: The other thing that I've learned and been very so excited about seeing is these heroic individuals who are signing up for these vaccine trials. We all want the vaccine and we hear that it could take 12 to 18 months or longer. What we know for sure is that if no one signs up for the trials, it will take forever.

Larry Gifford: Right.

Todd Sherer: Even in our space in Parkinson's, this is a lesson for all of us to know that the faster we want those results, we all should have to step in any way that we can to provide the information that's needed to develop the new treatments. So I think in general, one of the other things I'm hopeful for is this whole new appreciation for the importance of science, which I think unfortunately, we've drifted away from at least in the United States over the past period of time and that innovation and science is really the path to the future. It's what made America such a strong country and we should be reinvesting in that and supporting that.

Larry Gifford: That's a great point. And it's a great place for us to conclude this conversation that could continue for days because we just love talking to you, Todd. So thank you for joining us.

Todd Sherer: No, thank you, Larry. Thank you, Rachel. Everyone stay well.

Larry Gifford: Todd Sherer is the CEO of the Michael J. Fox Foundation for Parkinson's Research. Rachel Dolhun, thank you again. This was a great show.

Dr. Rachel Dolhun: Yep, another information packed episode.

Larry Gifford: Rachel is the Vice President of Medical Communications for the Michael J. Fox Foundation and a board-certified movement disorder specialist, neurologist. I'm Larry Gifford. You can connect with me on social media @parkinsonspod on Facebook, Twitter, and Instagram. You can email us at [info@michaeljfox.org](mailto:info@michaeljfox.org).

Dr. Rachel Dolhun: Thank you for joining us. Be sure to check out the [michaeljfox.org](http://michaeljfox.org) website for more information on research, Fox Insight and Fox Trial Finder. Click on Take Action and look down the third column labeled Participate in Research.

Larry Gifford: Stay safe, connect with your Parkinson's community, keep exercising. We'll get through this together.

MJFF: 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).