

Todd Sherer: What Debi and Michael brought to the table was more of the optimism, the yes instead of no because. We're not going to fund this because, and here's your 75 nuanced reasons in detail why not to pursue this line of research. But a yes if. Yes, if this person's right, we might be onto something, let's give it a chance.

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: Hello, 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 and host of another podcast called When Life Gives You Parkinson's.

October 31, 2020 marked 20 years of the Michael J. Fox Foundation. It's not necessarily a milestone to celebrate because the ultimate goal is to find a cure and go out of business. However, it is entirely appropriate for us to marvel, honor, and even celebrate the impact this organization has had in the way that Parkinson's is seen and treated. I hope to revisit different aspects of MJFF's history over the next few months. The first episode here delves into milestones and momentum into Parkinson's research, 20 years of impactful research into Parkinson's, improving quality of life for people with Parkinson's and getting us closer each day for a way to stop PD in its tracks.

My guests today have been the driving force of Michael J. Fox's vision. Debi Brooks co-founded the foundation with Michael J. Fox and is the Executive Vice Chairman, and Todd Sherer PhD. Todd joined MJFF in 2004 as the Associate Director of Research Programs. He is now the Chief Executive Officer of the Michael J. Fox Foundation for Parkinson's Research. Oh, I can't wait to get started. Thank you both for being here.

Debi Brooks: Glad to be here.

Todd Sherer: Thanks, Larry. Always great to be here with you and hear what Debi has to say, too.

Larry Gifford: You guys behave yourselves. I don't want to have to break up any fights.

Today we're going to walk down memory lane. We'll be listening to audio from some of the people who've played a central role and had a front row seat to 20

years of research momentum. And I think we should probably start with Michael J. Fox, who founded the organization with a singular focus.

Michael J. Fox: We decided to focus on research and it really helped us to pinpoint where we wanted to go and see where it took us. We had a theory that I still hold to that the science is ahead of the money. It's just a matter of getting the right science together with the right money.

Larry Gifford: But, Debi, I suppose you might remember the first time that Michael said the science is ahead of the money?

Debi Brooks: Yeah. One of the things that's so amazing about Michael is not just his insights but he just can simplify and focus everybody on the core task at hand. That clarity of the science ahead of the money just says it all. It is a simple phrase that resonates with the patients and families and also with the scientific community. It's truth.

Larry Gifford: Yeah, it is truth, and it makes total sense. Before MJFF you were a Goldman Sachs executive, Michael was a TV star and a movie star. How did you end up joining forces?

Debi Brooks: Well, we seem like an unlikely pair but our passions were not exactly the same, but they were really complementary. So, of course, Michael as a patient once he was public and realized that he might have an important role to play in galvanizing the community, he wanted to figure out how to get involved. I had left my career at Goldman Sachs principally to get involved with the nonprofit sector but not with a specific mission in mind. I was one of those people that any time I was at a fundraiser and saw a video, you could count on me to be moved and think, oh my goodness, this is such important work. And I still feel like that, of course. I didn't have a personal connection to Parkinson's nor did I know Michael, but I really had developed a passion and a belief that it's not enough to be philanthropic, but there was a real opportunity to have philanthropy capital be more impactful.

And so in going into the nonprofit sector, I really wanted to bring some of that passion and that specificity and in meeting him, it was just so clear. He and I shared the right values. And I think that's the perfect place to start when you're building anything.

Larry Gifford: What were those values?

Debi Brooks: Well, for me, it was that productivity of capital. Sounds a little like business jargon, but I'm really passionate about that. And even in the phrase, the science is ahead of the money, that's the first step. And then you have to really think about, okay, so how do you think about matching up the right money to the right science? That is something I was always interested in making sure that if you're going to do it, figure out how to move the dial.

I'm kind of a "act on it" kind of person. That's my version of urgency. Michael's is the same version and I think so many patients and families hold, which is now is better than the future. What can we do today? Given what we know, what actions can we take? So, that notion of productivity, the value around urgency, we both feel very strongly about accountability. He had his name and reputation on the line and I felt strongly... I kind of am earnest. I think also we both recognized that collaboration would be needed. So how do you think about partnering? So I think these things were coming together and pretty clear right from the get-go. In our first meeting we felt that connection.

Larry Gifford: Now, when you announced that you were launching the Michael J. Fox Foundation for Parkinson's Research, how was that news received by the research community?

Debi Brooks: I think there was a lot of enthusiasm. Michael, even though he'd been diagnosed and hid his illness for seven or eight years, he was at this point public and had mentioned those intentions. There was no organization really in place quite yet. So by the time I was hired and had the chance to put together a very quick game plan, I think there was a lot of pent up interest. I knew that Michael would, of course, inspire people with Parkinson's and their families, but I had a sense scientists would get excited and inspired by that, too. And that really did play out. Folks were excited about the attention, but I think they were tuned into the promise that Michael would be successful in raising awareness and bringing together community. Researchers are wise. They know where to sniff out some good capital opportunities. And so I think that enthusiasm also was at hand.

Larry Gifford: You opened the doors on October 31, 2000. Has the vision and mission of the organization evolved much since then?

Debi Brooks: Well, of course we've evolved. We've learned about how to put our money to work. But the philosophy, I think, is the same. There's no end to the amount of money that you could spend on research, so we had to really think about whatever amount of money we were going to be able to raise, whether it was a couple million dollars in the first handful of years versus now well over a hundred million dollars a year, you have to know how to spend it smartly. And I think that asks-

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Debi Brooks: You have to know how to spend it smartly. And I think though, that aspect is still how we treat our daily and our annual plans. We want to be as smart as we can with whatever money we can assemble from our funding partners and just make the most of that deployment at any point in time.

Larry Gifford: Now, you had mentioned the importance of urgency earlier. As you grow, as the organization grows into a \$100 million years of investment every year, does it become harder to have that urgency?

Debi Brooks: I think that urgency is a state of mind and a practice. So I don't think you lose it intentionally. What I've seen and witnessed, and Todd could speak more to this as well, is that the further we've gotten into this, the more complex some of the scientific opportunities have become, or the orchestration around some of the biggest needs in terms of scientific leadership and breakthrough. And so it's not that we're less urgent, but there are times when what we're trying to accomplish is extremely complex. And we are wise to devote the right amount of time to getting that right. There's no point in rushing to the wrong actions. And so today I think it's a bigger ship, but I remain impressed with our program team's ability to really adapt and evolve and respond and lead. And all those things have to be done thoughtfully.

And so urgency, I think one of the things I'm most proud of is when I get the chance to connect with people out in the community and people who know us well or people who are just meeting us and maybe I'm the second person they've met from the Fox Foundation. One of the most consistent things I hear is the how people in our community experience the Fox Foundation team. And you hear the values that Michael and I felt strongly about kind of reflected back in the way in which the team interacts with everybody that we engage with, their heart and head put to work on doing whatever it takes to move the dial. And I think that that reminds me, I get that constant reminder that urgency is one of those things, and it's certainly valued by the people with Parkinson's and their loved ones.

Larry Gifford: Todd, she invoked your name. So I'm going to bring you into the conversation. You entered The Michael J. Fox Foundation when it was four years old. How hard is it to have that urgency as you grow and grow and grow?

Todd Sherer: Yeah, thanks Larry. Maybe I'll make a few comments just to add into what Debi said and then use my liberty to then answer your question. First, one of the things I think... I was in the scientific community in 2000. So I got to see the foundation first from that side. And then as I joined, as you said, in 2004, seeing it grow and develop from the inside. One of the things about urgency that I think was clear from the beginning, which is still very active at the foundation, relates to even the discussion that you were having with Debi around the science being ahead of the money. One of the other things that Debi and Michael really emphasized from the beginning was also to focus the time of scientists and clinicians and other researchers on conducting the research and not on seeking the funding.

So scientists spend a lot of time writing applications and submitting and resubmitting, and that's time spent away from actually investigating the research, the disease, and developing the therapies. So that kind of process shortcut that was brought in shortening applications, getting decisions out very

quickly, getting the money out to the scientists very quickly was very core from the beginning. And I think that is the urgency in action. And that made a huge difference to the scientific community, not just getting the money, but getting it quickly so you could actually move your research forward. And ultimately, the goal is that moves the ball down the field faster for people waiting for the outcome of the new treatments. And that's something that we have maintained throughout at the foundation about really a goal of getting the money out to the researchers as quickly as we can from when it comes in.

And in fact, Debi and Michael are so urgent and aggressive that we commit grants even before we have the money many times, and then we raise the money as it's going. And that really is the core of trying to deliver the best from that research as quickly as possible. And that's something that we still do even as, as Debi was saying, as the projects become more and more complicated, you can risk the chance of just paralysis by analysis. And that's something we really avoid. We start going and you learn as you go. And I think that is really a critical component of the urgency.

Larry Gifford: That's great. I'm going to play another sound bite here. Dr. Andrew Singleton is a distinguished investigator at the National Institutes of Health and serves on the Scientific Advisory Board for the foundation. He remembers the early days of excitement and anticipation.

Michael J. Fox: There was a certain frenetic energy to that organization, just this view of we have a blank slate, let's move forward, let's see what we can do, and that's incredibly exciting.

Larry Gifford: How do you keep that excitement over the years? Because I know when I was diagnosed with Parkinson's three years ago now, the Fox Foundation is exciting. Like it's one of the first places I went to. And even just talking to you guys, I'm excited. So somehow you've kept that excitement alive. And I don't know how you do it.

Todd Sherer: I think from my perspective on this, the excitement first comes with the people that work at the foundation. They're very committed to the mission. And we get excitement in two directions. The science and the research that's happening in Parkinson's is very exciting. There's been significant breakthroughs in our understanding of the disease, the development of new clinical trials, new drugs that make it to the market. So success begets excitement. But then I think we also get a lot of energy from the community that we interact with, the families and the people really pushing for more advances from the community. So those inputs, the fact that we are really out there with both the research and the scientific community, I think really helped to maintain and build on that excitement, and the desire to really deliver outcomes for both of those groups keeps us motivated.

Larry Gifford: Debi, do you want to add to that?

Debi Brooks:

Well, we saw successes early. And the nature of the successes have changed, but that was so motivating and so empowering. And I always am mindful to say the Fox Foundation didn't create the science that we fund. In fact, the day we started putting grants out there, we didn't conjure up the scientific ideas. They were there, there just wasn't the right funder for those ideas. And that had a... It was a combination of the size of money that we were able to put out even early. It wasn't huge, but our first grant program, we issued 10 \$100,000 grants, and that's serious money in research philanthropy. And it got people excited, but it was always also that we were willing to take more risk.

And so taking that risk and moving quickly, Todd described some of our process enhancements that we introduced right out of the gates. And that was very stimulating and reinforced all that excitement. And that started to work. I think about our first RFA that we put out in the marketplace-

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Debi Brooks:

First RFA, that we put out in the marketplace and we knew nothing, we didn't know any people, we had no database of scientists to reach out to and there was really no backdrop of understanding. For me and Michael, our backgrounds were not in this area, so we didn't know what to expect, and as we put out our first kind of request for proposals from the scientific community, we were absolutely blown away by the response.

Now of course I said, we didn't know what to expect but within a couple of weeks, I happened to be at a meeting at The National Institutes of Health, and they asked, "How's it going?" And I said, "Well, we got 220 applications from about... From scientists in 20 different countries, and geez, we have \$1 million to give away but the total request was for over \$20 million." And their jaws dropped, and I thought, Oh my goodness, this must be good news.

And so I just could see, I could just see in those early months. But even in the early years there was magic going on here. And again, it's not that we created the magic in the science, but we enabled an environment of new possibilities. And again I think that we are... We remain kind of right in between at the nexus of so many ways in which action can be facilitated. And I think that, we continue to feel the jazz that comes from that. And I think that does Todd's right. The staff is right in the mix of that, and we get a lot of encouragement reinforcement, but we are also... We are dedicated to staffing the hard stuff.

I mean, we're animal about being problem solvers. And so these things come together and they continue to come together. It's one of the elements of being at this for 20 years and not being bored, or burnt out or discouraged. It's hard work, it is definitely hard work.

But this considerable flow of energy that comes from pulling more and more people in, getting more and more things happening, as we've expanded what

we can put to work each year, we're no longer in the business of doing things in sequence. There is a sequence to getting aha moments to the drug store shelf, but we don't have to do one thing at a time, we can now do so many things concurrently and it just... There's a momentum and a vibrancy to that, that I think does have a feedback loop that goes right back to keeping everybody energized and focused.

Larry Gifford: I love how the Fox Foundation has an animalistic attitude. You used a animal as an adjective and I love that.

Debi Brooks: We are a fox.

Larry Gifford: Oh, of course, yeah. You mentioned that first RFA, it was January 1st, 2001, the announcement of the first round of research grants, Michael, truly putting his money where his mouth was, as the foundation use profits from his first book, Lucky Man, to fund the foundation's first research grants. And I'm going to read from the release. "Grants should involve research that could reasonably be expected to shed light on the cause of Parkinson's disease and or lead to the development of a cure or better treatments for the disorder. Grant applications should be no more than five pages in length, and five pages was italicized. The deadline was February 1st, 2001, just one month." Why was five pages italicized?

Debi Brooks: Well, so as we were getting started again, we knew nothing, went to school quickly though. And I still have this very visceral response to some of the early interactions that helped guide our early choices, and one of them was an unsolicited phone call from Mike Milken. He has famously been involved in cancer research for many decades actually, and with Michael's public declarations and the launch of the foundation, Mike Milken called my office and said, "Hey, I'm in town. I'd like to meet you and Michael. I feel like I could be helpful."

And I actually knew of Mike Milken from my Goldman Sachs days, and I thought that well, this is so interesting, he's definitely a brilliant thinker. And Michael and I met and one other board member. The three of us met Mike Milken for what I thought was going to be lunch at the St Regis Hotel in New York city.

And in 40 minutes, he had hot water with lemon in it, and the three of us just sat there and took it all in. He just gave us a lot of quick observations, and the insights and he was interested in helping us kind of get some of the shortcuts. To be exposed to some of the shortcuts. And so he had said, and it's true, scientist spend all this time raising money for their work, and even when you're raising money from the US government, which is... Had traditionally been the largest funder of Parkinson's research in the world, I think we're now close to surpass... I think we've maybe with surpassing them. But at the time they were giving more and they were the largest, and it would be common to submit up for proposal and put a 25 page application plus dependencies.

And to Todd's earlier point, you'd submit that and then maybe in the next nine months, there would be a grant review, and then within the nine months after that, you might get a check, and plus or minus a little bit, depending on the cycles. And so these were high labor intensive and time intensive cycles.

And so for us to be out in the marketplace and say five pages, which meant make it easy, which by the way in turn I found out later a lot of scientists didn't think that was so easy. It was a lot harder to cram it all in, the five pages, but it really did help crystallize. And our review committee was equally dubious and I said, "Oh, come on, let's just try it." Naive Debi, "Let's just get to give a shot." But they were actually all quite taken with it after the first try and we've never turned back. But that five pages and also that really fast turnaround, those were Seminole shifts and I think it was showing the field we were going to try things [crosstalk 00:25:18]

Todd Sherer:

I was just going to add to this what Debi said about trying things. It's also the philosophy that was brought into the evaluation of the proposals. So scientists are very conservative by nature and want a lot of evidence, and there's a tendency to really be able to demonstrate you've already completed the projects before you can win the funding for the project, which in some ways makes the question of, why you need the funding for the projects a question, right? As a scientist, you will submit a paper or a document or a proposal, and you're frequently will receive a response that says, "This was a well-written and well conducted project."

I have 75 minor comments, and it's all the critiques of every aspect, and it just how scientific minds work. And what Debi and Michael brought to the table was more of the optimism. The yes instead of no because... We're not going to fund this because... And here's your 75 nuanced reasons and detail why not to pursue this line of research.

But a yes if... Yes if this person's right, we might be onto something, let's give it a chance. And I think that was also a really significant change in the philosophy of really trying to push people to do things they had not done before in Parkinson's research. By having bringing that to the table in how we select the projects. And that's how you lead to change. If we just keep funding projects that we know are going to work, and we've never succeeded with the treatments we want, you're kind of in a loop. And I think that was very significant and that's still to...

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Todd Sherer:

... in a loop. I think that was very significant, and that's still to this day we'll fund part of projects or we'll go back to people and say, "You were onto something. We're willing to fund this, but make these changes. But we want to see this get a chance and see if it works out."

Larry Gifford: Debi, did you hire Todd?

Debi Brooks: Yes. Actually, Todd was a grant recipient at the Fox Foundation. He had been a Fellow in the lab of one of our scientific advisors. I remember Tim Greenamyre calling and saying, "Hey, listen. Todd's probably not going to launch his own lab. He's going to look to do something different. He's exceptionally capable. You need to talk to him." And so myself and I think at that time maybe Katie Hood, we met with Todd, and we were just at this time where I had a deep appreciation for the fact that I had a lot of things I could bring to the table in terms of process ideas, the chutzpah to try things differently, the naivete to sit in a room with a bunch of scientists and say, "Oh, let's try it." And they wouldn't argue with me. I was just a different beast for them.

And I certainly had been able to connect with a small number of generous donors in the early stages of our work. But it became clear to me quickly that we really needed PhDs on staff. It was mostly about the difference between asking volunteers to show up a couple of days a year, set their egos and their priorities aside, and come in and set a course for you. That's a more traditional model to kind of outsource the scientific point of view and the scientific selections. And I just felt like, listen, science is not our twice a year work. Science is our everyday work, and I need people who are here every day thinking about this. And so it was a perfect storm to be able to connect with someone like Todd and kind of have him join our team, and importantly he's obviously had a scientific career, but he was still relatively, in some ways, junior in his career.

And that was important too, to have a scientist who was interested in a new way of thinking about this, because Todd talked about before how having the scientific community appreciate that we were going to try things differently, I had to train the reviewers, my scientific advisors. They were all reticent about this, too. "I don't think this'll work. Five pages? That's not enough." So to bring in a scientific team and to build a scientific internal point of view, it also meant having someone who was open to thinking about science in a new way, and so it was a terrific opportunity for the Fox Foundation. And obviously I think I selected well.

Larry Gifford: [inaudible 00:03:32].

Todd Sherer: I did get a letter that said your interview went well, but I have these 75 critiques.

Larry Gifford: Oh, do you remember that first meeting, Todd?

Todd Sherer: So interestingly, one of the things that I was excited about with the foundation was, as Debi mentioned, I had a grant from the foundation. And one of the things that Debi mentioned earlier was the accountability component of the foundation funding. So in most cases when you receive funding, you're sort of

given the grant and left on your own. Do what you want with it. You do have to submit progress reports, but they're more perfunctory, and you're only really evaluated when you're ready to come back for new funding, and at that point you could propose a completely new project. So there's not really a close eye on what you did with the money, and did you actually follow through on what you had proposed? So that was not going to fly with Debi and Michael, because of the accountability to the donors who had given the money, but also to the outcome, to the mission we're trying to do to move this process and project forward for new treatments.

So as part of the fellowship, they actually organized what was called an assessment meeting, which was unheard of in the scientific community, where in the middle of our fellowships, all the Fellows, there were 12 of us, all came to New York and we were actually required to present the work that we had done in the first year of our fellowship. So again, this would be pre-published preliminary data. Michael always jokes that the scientists, when it's the kid in the room who covered his paper so no one could copy off of him or her. But you were being asked, and actually you were asked, and the context of the second year of your fellowship was dependent on doing it. So it was kind of the way Debi asks people to do things. You really had no choice.

So there was obviously a stick part of this. But the carrot part of this was what really got me excited about the foundation, because now here I was a junior fellow presenting my work, and the audience were 11 other fellows, but all the mentors. So 12 leading scientists from across the world in the Parkinson's field, and I was getting feedback in a very constructive way. "Have you tried this? Oh, I could send you this reagent from my lab. Have you ever thought of doing this?" And my research was getting better in the minute in real time while I was having this interaction.

And I just got very excited about this was a new way to really advance research, not send people off on their own with the money, and really make people be part of a community of funded researchers. I do think that people that are funded by the Fox Foundation do experience that because they get the funding, they get the connections, and they get the support of our scientific staff. We're rooting for their success because it helps the mission. It helps develop new treatments. And that kind of hooked me into really being part of this. That was probably in 2002 maybe, many, many years ago.

Larry Gifford: Oh, so many milestones and so much momentum. And we're only through the first four years. On the next episode, as we explore 20 years of impact research into Parkinson's-

Debi Brooks: We might be able to detect early someone who has yet to show motor features.

Larry Gifford: To find out more on how you could participate in Parkinson's research, head over to the website, [michaeljfox.org](http://michaeljfox.org). Debi and Todd will join me again for part two of this special podcast series of Milestones and Momentum in Parkinson's

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