Michael J. Fox: ... More than I met Michael Fox. They meet Beyonce, they meet everybody, they're not concerned about Marty McFly. But all of you, that means something. Especially if you're in the constituency of one of the people that you meet today. That has a big impact on decisions that are made because they're more afraid of you, their constituent, than they are of me.

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

Speaker 1: 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.

Larry Gifford: Hello. Welcome to the official relaunch of the Michael J. Fox Foundation Parkinson's Podcast. I am so happy that you are here. I'm Larry Gifford. I was diagnosed with Parkinson's at the age of 45 in August 2017. I'm a proud member of the Michael J. Fox Foundation patient council, the host of Parkinson's IQ + You events, and founder of pdavengers.com. You might recognize my voice from another podcast I host called, When Life Gives You Parkinson's. I'm lucky, I still work full time, I'm the national director of talk radio for Corus Entertainment across Canada. My wife, Rebecca and I both grew up in Ohio. We've spent most of our 20 years of marriage on the West Coast from Los Angeles, to Seattle to now Vancouver, Canada. Our son Henry is 11. Like most YOPD families we're adjusting every day to the wrenches that Parkinson's throws our way as it pertains to family, and career and what I'm able to do one day and not the next.

Having worked in radio for more than 30 years, I feel fortunate to be able to serve the Parkinson's community by hosting podcasts and events, sharing stories, and helping to bring important information to you regarding wellness, advocacy, and research. I'm thrilled that the foundation has invited me to host these monthly conversations. We're going to get to know each other bit by bit over time.

But before we dive into today's episode, I do want to acknowledge Dave Iverson. For years, we listened to Dave host these conversation, host webinars, panel discussions and more for the Michael J. Fox Foundation. While Dave's still around... Hi Dave. He's irreplaceable. He set a standard that I'm going to strive to meet, and I hope I do him and you proud. As we are all learning through the COVID-19 pandemic, healthcare, immunizations, health guidelines, mandates and laws can get very political, and dicey, and red tapey, and a bit prickly. Passions run high. The same is also true in advocating for Parkinson's treatments, research, dollars and policy.

Michael J. Fox: We should be able to give them a shopping list of areas that they could help and show how we've paved the way and greased the skids. I always say from one of my favorite movies, Full Metal Jacket, "Come in for the big win." Come on in for the big win. We're setting it up to make breakthroughs in areas and we need FDA, we need NIH, we need everybody to come in and help us carry the ball across the finish line.

Larry Gifford: You know that voice. That's Michael J. Fox in 2017 at a lobbying event in Washington, D.C. He's right, we need everybody including you. In March 2020, the federal government passed the CARES Act, providing fast and direct economic assistance for American workers and families, small businesses, and preserves jobs for American industries during COVID-19. That means our advocacy from you and me is even more important now to make sure policy and decisions address urgent needs of the people with Parkinson's. Our stories, our experiences, our passions need to be heard and shown to our lawmakers if we have any hope of bringing about change. Your journey, whether a person with Parkinson's or a partner in Parkinson's, is extremely important and valuable in lobbying lawmakers. Here's how Michael J. Fox puts it.

Michael J. Fox: You're not out there to batter doors down or to scream at people. It's just here we are, we're constituents, we're Americans, we're Parkinson's patients. We've done our work, we've showed up, we've represented our feelings and our case, we've raised money almost equivalent to what the government... We're the second largest funders of Parkinson's research after the federal government, and it's getting closer. The gap is getting narrower.

Larry Gifford: It is important to note that members of Congress want to hear from you. Here's Shayne Woods, senior policy advisor to Republican congressman from Florida, Gus Bilirakis.

Shayne Woods: It's all about building relationships with us. You get to know us, we get to know you. We want to hear your stories. In this town of how things get done, you're the reason why they do. While we continue to focus on addressing the challenges of COVID-19, we are still working on everything else Congress is charged with doing. So, we want to know what's important to you. Your voice does matter.

Larry Gifford: Most people have heard of Parkinson's, but most people don't understand what we endure. Each of us are on our own paths, and some of us need more access to movement disorder specialists, and there are communities in every country, including the United States, that need better trained doctors for early diagnosis. Everyone needs equitable access to old and new medications, treatments, therapies, and counseling. Most of all, we need a cure. A cure.

We need to stop this. We need policy changes to make our lives better and to secure more dollars towards finding the way to halt Parkinson's in its tracks. So, what can we do? What do we say? How do we even talk to our representatives? And does it really make that big of a difference? There are a lot of questions swirling around this topic and to help us make sense of it, I want to introduce you to my special guests today. Ted Thompson, JD, is the senior vice president of public policy for the Michael J. Fox Foundation. For the record, JD is not his nickname. It stands for Juris Doctor. Hey Ted, thanks for being here.

Ted Thompson: Hey there, Larry. Thanks for having me, appreciate it.

Larry Gifford: And welcome to Israel Robledo, a great policy advocate. He serves on the executive council for Parkinson's Movement, which is the integration panel for the congressional directed medical research program, and the editorial board of the Journal of Parkinson's Disease. He's a pal of mine from the Michael J. Fox Foundation patient council. Israel, thank you for taking time to be part of the pod.

Israel Robledo: Thank you for inviting me. It's great to be here.

Larry Gifford: There are different types of advocacy, and what we're talking about today revolves around lobbying, which at its essence is trying to influence lawmakers to care more about Parkinson's disease. Ted, in this area of advocacy, how do you measure success?

Ted Thompson: It's sometimes difficult to measure success because, especially at the federal level, you can work your heart out and do everything right, and engage dozens or hundreds or thousands of advocates on an issue, and still come up empty just because of the somewhat dysfunctional nature of how the federal government works. So metrics for success can range from things like how many meetings advocates had with their elected officials, how many action alerts were sent to their offices, how many social media posts, and retweets and things like that have occurred. All of it aimed toward affecting public policy, in this case, namely the votes of members of the House and Senate. So, the collective weight of all that is really what will help tell us whether we're being successful in our efforts.

Larry Gifford: All right. I want you to get out your scoring pencil, Ted. This is the best test you'll ever get because you get to self-evaluate. What grade would you give the Foundation as it relates to the success measurements you've just outlined?

Ted Thompson: I'm not going to be arrogant, we can always do better. So I'm going to give it an A minus, and I'm that because since the policy department was formed at the Michael J. Fox Foundation, it's an organization wide effort. Our policy team is only what people see because we've got tremendous backup support from marketing communications, digital strategies, pretty much every department. So, we have a really broad based effort within the Foundation to assure that we're making as many touch points as possible. So it's really not just that single action alert that gets emailed out and somebody takes action on, we've got a much more holistic approach here at the foundation. So that's why I'm willing to score it so high, because we have had much more direct impact since the policy department was formed at the Michael J. Fox Foundation than we had been able to have previously.

Larry Gifford: When did that happen?

Ted Thompson: That was a little over four years ago; 2016.

Larry Gifford: Wow.

Ted Thompson: I can't believe it's been that long. Yeah.

Larry Gifford: Yeah. And think about how much you've done, that's amazing.

Israel Robledo: I wanted to touch a little bit on what Ted was talking about as far as the measurement of success. For me, success for me as an advocate, building relationships with staff members, Senate and House side, and being able to call them up to where they know your name, they know what you're calling about, or mostly what you're calling about, unless there's something different that comes up. And idea is that, those relationships, very far.

I have an example where one of my congressman's chief of staff went to work for a committee, and when I went back the next time, the gentleman that replaced him, he says, "Paul told me you were going to be coming, and he told me that this is what you work on," and he says, "Thanks for letting us know, and thanks to you, we are still continuing the process of helping with Parkinson's." So that was a neat experience for me.

Larry Gifford: Israel, Ted went to law school. What drew you into public policy?

Israel Robledo: Being diagnosed with Parkinson's and knowing that my voice could be used to help improve the quality of life of people with Parkinson's, and a big part of that has been through public policy at work.

Larry Gifford: What is it like to sit down with a congressman or a senator, and really, you tell your story and advocate?

Israel Robledo: For me, it's a very natural process, because I don't mince words when it comes to taking their time, because I've been known to have been told, "You don't waste time, do you?" And say, "No," because we only have a certain amount of time, and when it's a congressman, he could be called to vote within your 15 minutes that you have scheduled or whatever that amounts to.

But to be able to say, "This is who I am. This is what I go through, and this is why we're here," it's a basic outline for everyone that I talk to, because what it does is, it allows me to be able to answer their questions, rather than running out of time and saying, "Oh, by the way, this is what we want from you. These are our asks."

For me, it's very natural. It can be nerve wracking, because if you have a senate majority leader and you're meeting in his office, and you're saying, "This is why we're here," and he says, "Oh, don't tell me. Don't give me numbers because I know them backwards and forwards." And you're taken aback in some ways, because you're like, "Okay, but where do I go in to tell you exactly what I need for you to do?"

Larry Gifford: So it challenges the brain when the brain's the problem.

Israel Robledo: Yes, absolutely. Absolutely.

Larry Gifford: How receptive are they?

Israel Robledo: Very receptive. I often share that my congressman said to me, he says, "When things come up that have to do with Parkinson's, you're the person I think of in the back of my mind, who has come to me and said, this is what we need." And it's impressive when they do that. Because just another example is, I've gotten a call from a senator's office, and the young lady says, "I don't know if you remember me, but I'm with Senator So and So's office, and you came and you talked to us about this. And the senator wanted me to call you and ask you if you could give us some more information?" So very receptive.

Larry Gifford: Oh, that's great. COVID-19 has caused a lot of death and fear, but at the same time, Coronavirus seems to have been a catalyst for more discussion around telemedicine and mental health, both really big topics for the Parkinson's community.

A Fox Insight Survey on COVID-19 has come back. From April 23rd to May 23rd, the COVID-19 survey obtained 7,209 responses from people with or without PD, and of the respondents, 62% reported canceled healthcare appointments, involuntary reductions in needed in-home care, or difficulty obtaining medication. Non-white race and lower income were independently associated with difficulty obtaining PD medications. Telemedicine appointments, reported by 39% of the people with PD, but those with lower household income were less likely to attend appointments through telemedicine.

We've been advocating for more access to telemedicine and access to mental health treatment for years. Ted, how can we leverage this for the PD community, while still respecting the ongoing spread of COVID-19?

Ted Thompson: Well, this is actually one way to really help stem COVID-19 infections, is through telemedicine. We've been pushing for it for years for a variety of reasons, unrelated to a pandemic, but given the pandemic, it's absolutely for the health and safety of the patient that we need telemedicine now more than ever. And the usage of telemedicine has skyrocketed beyond anything that had ever existed before, which shows that the patients and the providers want this.

There have been surveys done too, talking about what patients prefer, and a lot of patients prefer the doctor appointment from home, because they don't have the stress of driving and parking. Oftentimes, with diseases like Parkinson's, your movement disorder specialist is not just five minutes away. Sometimes they're five hours away, and you have to plan an overnight.

And so telemedicine not only makes it more convenient, we've heard from some folks who, prior to the pandemic, had never been able to actually see a movement disorder specialist. But because of the pandemic and the availability of telemedicine, they have now been able to see a specialist via telemedicine, and they've gotten a better care plan, they're on the right medications. So for them, their lives have actually gotten better.

And so, given that we do know that there's a neurologist shortage in this country, and a movement disorder specialist shortage even greater than that, this is like the only tool available to expand access to the specialty care that Parkinson's patients need. So we are continuing to push hard to make this permanent.

Larry Gifford: Yeah, it's pretty amazing. Israel, what is the biggest argument against telemedicine?

Israel Robledo: The biggest one that I've heard was that it's not secure. The other one was, if I've never seen a patient, and so I don't know their background and our argument has always been like I mentioned. It links to non-contact for us when it's in the Parkinson's community. And also, it moves on to the mental health side as well, because to have telehealth by video, again, for mental health issues lends itself quite nicely to what we're doing with the Fox Foundation.

Larry Gifford: Well, and what's interesting is, you think about just having it available doesn't mean you have to use it. I mean, it probably is if the doctor wants to do it and thinks they could be successful at it, why not let them?

Ted Thompson: One of the other issues that has come up through the years is the licensure issue, because one of the greatest impediments to telemedicine is, for example, if you know of a movement disorder specialist in New York and you live in Delaware, where there aren't any, you cannot do a telemedicine visit with that New York doctor, unless he or she is licensed in Delaware as well. And so that has become a big impediment.

Those issues have been waived during this period. Our view is that, maybe back in the 1940s or '50s, there would have been significant differences in the practice of medicine in different parts of the country, but we're in 2020. I don't think you're going to see dramatically different care, and if you do, it would be that telemedicine will give you access to the better care because you are able to see the doctors that really specialize in this.

One side note on this whole conversation, I read that telemedicine visits skyrocketed. We mentioned that earlier, but I've been reading that medical practices are not embracing it fully, and the reason they're not is because, given that the rules are not permanent allowing access to telemedicine, it's sending a mixed signal to the providers, because they actually have to invest some serious cash into building out a secure telemedicine practice. And if they don't believe or don't know that this is going to be a permanent way of life in the practice of medicine, they're hesitant to make that investment.

So that's one point, and then of course, if you've got smaller providers, a one or two-person shop, they just can't afford to do it necessarily. So those are a couple of other interesting factors. And then, finally, the United States, unfortunately, does not have countrywide access to the internet, because we don't have enough broadbands throughout the country. So there are pockets, even in states like New York and California that everybody thinks are so modern, there are pockets where they don't actually have access to the internet, and those pockets are typically where the patients that need telemedicine the most happen to live.

So hopefully, as part of the COVID response, part of an infrastructure build that has been talked about now for several years, hopefully will include a real investment to get broadband throughout the United States so that all patients and providers can participate in telemedicine.

Larry Gifford: Yeah, that would be tremendous. That's amazing. Israel, you mentioned that you live in Texas. It's quite a hotspot right now for COVID, and thankfully, you have not had COVID. But April 7th was the first day that there were more than a 1,000 cases reported in a single day in that state. Fast forward three months, and for the past few weeks, most days, it's greater than 10,000. How has the rising numbers in Texas affected the precautions that you're taking?

Israel Robledo: I'm in Midland, which is about a population of 180,000. My movement disorder specialist is 500 miles away in Houston. That's the hotspot.

As far as our community, it's basically stay in, keep your hands washed, stay away from each other, basically. Going out, we've noticed that the local stores are doing more of the preventative measures, requesting people to wear masks. Odessa, which is about 15 miles away, has twice the number of people diagnosed with COVID. We can't figure it out. We don't know what's going on, but it's popping up everywhere. Sadly, we often said, "It was hard enough to shut everything down when this started. It's going to be much harder, exponentially, to back to reality and normalcy because we don't know this virus well enough."

As a person with Parkinson's and honestly, [inaudible 00:21:19] I asked my wife one day, I said, "Do you want me to go to the store and get these items?" and she says, "No!" I said, "Well, I can do that." She says, "Do you realize that your Parkinson's could put you in danger?" I was like, "Oh, but I feel well." It's interesting that others watch out for us sometimes, where we think, "Oh, I'm invincible. I'm good. I'll go."

Larry Gifford: Well, going to the grocery store is a pleasure when you're socially isolated and socially distanced. How has that impacted your Parkinson's?

Israel Robledo: It's really interesting because I noticed the symptoms much closer than I would if I was out on campuses as a schoolteacher, and I cover several campuses. But I noticed a lot more of what I deal with in waiting for the medications to kick in, and when I can't move at all.

It's fascinating. Again, it's like, "Wait a minute. I'm okay. I'm feeling okay," but then the meds don't work, or they take longer to work. As far as impacting me, I just notice it a lot more. And it may be that I ignore it most of the time, as I'm busy.

Larry Gifford: Yeah.

Israel Robledo: That's a good question.

Larry Gifford: It's interesting. You can feel the waves of the Levodopa kicking in and wearing off, for sure.

Israel Robledo: Absolutely.

Larry Gifford: Ted, the congressional August recess is quickly upon us and members of Congress are going home. What is the opportunity for regular folks living with PD?

Ted Thompson: Well, Israel described perfectly what we are attempting to grow, in terms of an army of Parkinson's advocates where they know your face, they know your story, you are who they think of when they have issues come up. But unfortunately, because of the coronavirus, COVID-19, that is not possible in the same way.

As we've been building out our grassroots program, I've been saying, "I'm trying to turn the clock back 30 years, before email, before social media, because what worked best then works best now, and that is the individual relationships that you develop with the member of Congress and/or their staff.

Larry Gifford: Oh, I thought you were going to talk about smokey backrooms and dealmaking.

Ted Thompson: Well, one could have a whole podcast on whether that was a better method.

But it's a challenge for us because we really encourage that in-person activity, and we talk about how, when you meet with a member back in their district or state, they're not going to be called out for a vote or a committee meeting. They're more relaxed. You typically have a little bit more time.

Which, all of that is true in normal times, but in these times we've had to be a little bit more creative. We are engaging around the August break with Congress, we're planning basically a month-long rollout of different activities, different actions that advocates can take. The two priority issues are expansion of telemedicine and expansion of access to mental health. We haven't really touched on that, but that's not just a huge issue for the Parkinson's community, where 40 to 60% of patients have some mental health needs through the course of their disease.

It's nationwide, especially during a pandemic like this, and the lockdowns, and the recessions. We are active. We actually have put together the most comprehensive August recess plan that we have ever had.

The other thing that I'll mention is, for those people who have already met with their elected officials or have gotten to know them like Israel has, if you have their email address, you can email them directly and ask, "Hey, can I get a phone call and talk to you about these two issues?" Because all the congressional staff are working from home just like we are, and they could be working from home until there's a vaccine, which could be nine months, a year, maybe shorter if we're lucky. It's just a different approach.

But one thing we don't encourage, which we used to encourage heavily, is phone calls. Because if you call the congressional office, there's nobody there to answer the phone, and their message box are typically filled. That's where the action alert is the mechanism to reconnect with them via email. We have tweeting capabilities to connect with the members of Congress. Their offices really follow the social media closely, so that's another good opportunity.

Larry Gifford: I understand the House Committee on Energy and Commerce Health Subcommittee held a hearing on high anxiety and stress legislation to improve mental health during crisis, which included a Parkinson's community priority. What can you tell us about that priority and H.R.945?

Ted Thompson: H.R.945 is pretty straightforward. It seeks to expand the number of providers that get reimbursed under Medicare, the number of mental health providers, by adding additional practitioners. One estimate is that that could add up to 200,000 additional professionals to provide mental health services.

That's the bill we've been pushing. Others have been pushing for many, many years. This is an example of, sometimes it takes time to get these things enacted.

That bill, we don't know if it's going to go anywhere yet. There was a tele-mental health bill specifically that did come out of the committee. I don't have as much detail on that.

But the good news in all of this is, for all the partisan issues out there, these are pretty much nonpartisan. Republicans and Democrats, I think they have the same ultimate goals in this area of expansion of mental health access, expansion of telemedicine. Sometimes it's not even a question of how we get there, but maybe more when we get there.

Israel Robledo: It's interesting that you say that, especially, especially not how, but when. I was thinking about that last night. I thought this pandemic... And please forgive me if this sounds... You may have heard it, as well. You can't waste a perfectly good pandemic before you can get things done. It seems like this... I'll call it a public health emergency rather than a pandemic, because this is allowing us to see things more clearly, the things that need to be done, and how they need to be done, and how quickly they can be enacted. It's a fascinating process that we're in politically, with public policy.

Larry Gifford: Israel, we know the most effective approach to any advocacy effort is an alignment of messaging. As it relates to what you're talking about right now, what's the message that we want to send to our lawmakers?

Israel Robledo: Focus on telemedicine, the mental health issue which goes hand-in-hand with Parkinson's. About half of us deal with mental health issues with Parkinson's. Again, changing the laws that are so antiquated.

Ted Thompson: I have a prime example.

Larry Gifford: Go ahead.

Ted Thompson: When we were pushing for years for the creation of a national neurological conditions surveillance system, part of the messaging was we know how many dogs exist in the country, we know how many people drive Subarus versus Fords. We know all this data, but we have no idea how many people actually live with Parkinson's, Alzheimer's, MS. Almost always, members of Congress were shocked. They're like, "What? We don't count that information?" They assume that through our public health agencies and HHS that we had all this information, and we didn't.

Israel Robledo: As we go into the August recess, one thing to remember as advocates is that our Congresspersons and their staff don't know everything about Parkinson's, don't know everything about mental health. The ability for us to actually educate them on some of these things is so important. Oftentimes, you see them just taking note after note after note, because they're going back to their Congressman to share what we've talked to them about. Don't ever assume that they know everything that we are sharing with them.

Ted Thompson: Yeah, that's a really good point. We do advise our advocates to start out with a simple question: Do you know anybody with Parkinson's? Because if they don't, then you have a great opportunity for the 25 second description of the disease. But if they do, you found a natural ally, and then passing that information on to my team so that we know those connections is critically helpful.

Larry Gifford: What else can people do to help right now? They're sitting on the edge of their seat listening to you talk, they're fired up, they're ready to go. What next? How could they act?

Ted Thompson: Well really, and I have Israel jump in too, but really, I think people are paying attention more than ever. Taking every opportunity that they can to lend their voice to advocacy efforts. Whether it's sending an email, doing an action alert, tweeting or sending a Facebook message, all of those things, as I mentioned earlier, collectively, bear weight. If people are irked that Parkinson's doesn't get enough attention at the federal level, the only way that it's going to get more attention is for those people to raise their voice, to engage more friends and family, to reach out to lawmakers. Don't be silent. Silence is what is holding us back. We need everybody who is touched by Parkinson's. Could be the nurses, doctors, caregivers. And we do have a ton of engagement so don't get me wrong, it's just to really seriously move the needle, we need everybody engaged in this. It's more than a one-step one action. It's the follow up and the consistent engagement.

I used to be Chief of Staff to a member of Congress and he got elected by around a 500 vote margin. So when you're elected with that slim of a margin out of several hundred thousand votes cast, you become extraordinarily attentive to what your constituents are saying. And the whole point in running for office, and again, whatever your political beliefs, I think people run for office primarily because they actually have a belief that they can make change, positive change, in their vision, maybe not your vision. But educating members of Congress, you can oftentimes change their position because they didn't know all the facts, they had certain assumptions. And so don't underestimate the power you have as a voter and a constituent.

But another thing I would just want to mention is that it's critically important to be respectful, even if they are diametrically opposed to you on their politics, you got to be respectful or you're not going to help the cause, it'll hurt the cause. And the other thing is we've had situations where our biggest enemy on a given issue becomes our biggest champion on the next issue. And so if we had burnt the bridges with that elected official, they would have never become the champion that they became. I mention it because in this highly politicized, highly partisan atmosphere that this country is in right now, I think a lot of people probably assume that you got to throw daggers and stuff to get attention. You got to be mean and you got to use cutesy undermining terminology. Now the same stuff that worked a decade, two decades, three decades ago, still work today. And being respectful is critically important, because you want them to respect you as well.

Larry Gifford: That's sage advice. I appreciate you saying that, thank you. Go to the show notes of the podcast. There's a link to the Michael J. Fox Foundation advocacy interest form. Once you sign up, you'll receive action alerts from us and more information on how you can get involved. Israel, how would you communicate that to folks who Spanish that may be their first language?

Israel Robledo: [foreign language 00:04:19]

Larry Gifford: And again, thank you both for being on the podcast. We really appreciate it.

Israel Robledo: Thank you for inviting us.

Ted Thompson: Yeah. Thanks so much, Larry. Appreciate it.

Larry Gifford: Ted Thompson, JD is senior vice president of public policy at Michael J. Fox Foundation. Israel Robledo is a Michael J. Fox Foundation patient council member and policy advocate. For more information on the Michael J. Fox Foundation policy priorities, advocacy resources and updates from Washington, visit michaeljfox.org. You can also sign up for action alerts at michaeljfox.org/advocacy, or click on the link in our show notes.

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