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MJFF: Welcome to a recap of our latest Third Thursday Webinar. Hear directly from expert panelists as they discuss Parkinson's research and answer your questions about living with the disease. Join us live next time by registering for an upcoming webinar at michaeljfox.org.

Larry Gifford: Well, good morning, good afternoon, good evening, wherever you are coming in from. It's good to have you here. Hi, I'm Larry Gifford. I am a member of The Michael J. Fox Foundation Parkinson's Patient Council. And this is the Third Thursday Webinar. Today, we're going to talk about telehealth. I was diagnosed with Parkinson's five years ago at the age of 45, and I am the host of the podcast *When Life Gives You Parkinson's*, and I co-founded the PDAvengers.com. It's great to be here with you and with our panelists today.

Larry Gifford: We're going to be discussing telehealth and the benefits of telehealth. It's a great option for people with Parkinson's. We'll cover access and availability of telehealth, how to make the most of a virtual visit with your doctor, and we'll also talk about the impacts of telehealth on research and care. So this webinar is brought to you by Abbott Laboratories and Neurocrine Biosciences. While their support helps make education programs possible, their donations do not influence Foundation content or panelist selection.

Larry Gifford: We've got a lot to discuss today, so I want to get started. But first, let me introduce our panelists. First, we have Dr. Ramsey Falconer. And he is a movement disorder specialist, medical director of Inova Parkinson's and Movement Disorder Clinic. Good day, sir.

Dr. Drew Falconer: Hello, hello.

Larry Gifford: Good to have you here. We have Dr. Jaime Martin. She's a movement disorder specialist, an owner and consultant of Face To Face Neurology. Hello, Dr. Martin.

Dr. Jaime Martin: Hi everyone. Good to see you, Larry.

Larry Gifford: It's good to be seen. Good to be here. And we have Ray Lapinas, board member and secretary of Neurobalance Center, NFP, also living with Parkinson's. Hello, Ray.

Ray Lapinas: Hello. How are you doing? Hi, everyone.

Larry Gifford: Great. Thank you. Thanks for being here. And next to you is Gaile Lapinas, your wife and partner in Parkinson's. Hello, Gaile.

Gaile Lapinas: Thank you for having me.

Larry Gifford: It's great. It's great to have you all here. Now, Gaile and Ray are located in Illinois. He was diagnosed with Parkinson's in 2017, and he is, as I said, as a board member of the Neurobalance Center, NFP, a wellness center designed for people with neurodegenerative diseases. And his wife Gaile works as an executive at a major banking institution. Okay, so we have everybody's names down pat. Unfortunately, we don't have name tags for everybody. So everybody, just keep remembering who each other is. We're going to get to a lot of great information here. The first is, what is telehealth? Dr. Martin, if you could join me now and just give us a brief overview of what's all included in telehealth when we use that term?

Dr. Jaime Martin: Absolutely. So as many of you know, telehealth or telemedicine is a virtual way of communicating, seeing you and your physician, your healthcare provider, using technology such as phone or video. So this can include just your standard patient and physician evaluation to discuss your condition, discuss medications, recommendations. It can be used for education, interventions, and sometimes even remote monitoring. So maybe measuring tremors or falls, or in other specialties, we might measure heart rhythms or your blood sugar remotely. And while many of us have been performing or doing telemedicine for quite some time, the COVID-19 pandemic vastly accelerated the implementation in the adoption of that. And something that... Suddenly something that only a small number of people were using became nearly universal because of the safety concerns related to the pandemic, and that insurance was now covering all of these services for everyone.

Larry Gifford: That's a really interesting point. People have been doing this for quite a while. How many years back have you been using telehealth? Because it's very new to a lot of us.

Dr. Jaime Martin: Yeah. So I first started around 2015, opened a movement disorders clinic for patients in the area in 2016.

Larry Gifford: Okay. And what do we know about telehealth? Ray and Gaile, if you could talk about your experiences with telehealth and then we'll get to the doctor's perspective. But from a patient perspective and a care partner perspective, what's the experience been like for you?

Ray Lapinas: Actually, it was very helpful during COVID. That was the first time I utilized telehealth for myself. And it just gave the access. Especially living here in Chicago, Illinois to get to my doctor's office, the travel time is over an hour. Bad traffic there, bad traffic back. You save money because there's no facility fee. I go to Rush Medical Center. And so that there's cost savings to it. So I've continued using telehealth, even though I can go to the doctor's office, just due to the convenience in the cost savings.

Larry Gifford: And Gail, how have you found it being there while he's doing the telemedicine?

Gaile Lapinas: It was very advantageous because I can be there. Otherwise, to Ray's point, we were planning on a five hour day to deal with the traffic, the parking, and coming back. So as a caregiver, it allows that flexibility to participate, especially if you have to work outside the home.

Larry Gifford: Sure. That's great. Let's bring in Dr. Ramsey Falconer.

Dr. Drew Falconer: Drew Falconer.

Larry Gifford: So Dr. Drew Falconer, tell us about your experiences with telehealth and how you see the benefits.

Dr. Drew Falconer: Yeah. Telehealth has really just allowed us to make accessibility to specialty care, such as Parkinson's specialty care, much more available to folks. Ray and his wonderful wife mentioned it. It is a journey for patients to see somebody like us. And we know, as a community of Parkinson's specialists and people who live around that bubble of people with Parkinson's, that most people don't actually see a movement disorder specialist to lead their care for their Parkinson's disease. I think the best data we have is only about 26 percent of patients with Parkinson's will see a specialist in Parkinson's disease. In the US alone, we're dealing with a million people as of today who are living every day with Parkinson's. So 26 percent isn't all that much, right? There are a whole lot of people out there that don't have a member of their team be someone who does Parkinson's disease every day.

Dr. Drew Falconer: And one of the biggest barriers that we've seen that keeps people from specialty care is exactly like Ray mentioned. There aren't a lot of us who specialize in what we do, and we tend to be kind of scattered around the US in places that make us very inaccessible. I mean, there's a big study I remember from pre-pandemic times. There's a Medicare study that looked at people who traveled outside of their hospital's referring area for care. And in the Medicare population, which again is above 65, about 20 percent of all Medicare patients travel outside of their main hospital system for care. And guess what the number one condition that made people travel outside of their care? It's actually Parkinson's disease. And in fact, that same study showed that Parkinson's patients with Medicare traveled on average across the US about 148 miles to get to specialty care.

Dr. Drew Falconer: Well, that's crazy. That's insane. That takes a lot of people and makes accessing a specialist just completely inaccessible because coming to see us involves getting ready... For a lot of patients, getting someone to bring them, getting their kids to take off, their neighbor to drive in. They fight traffic. They're in the car forever. They show up to clinic, they have to walk up to clinic, wait in the waiting room. We're always running behind, for a clinical visit, and then do it all

in reverse. Right? That is a burden of distance, travel and time that for a lot of patients makes us inaccessible.

Larry Gifford: There's the other symptoms, too. Like a lot of us with Parkinson's, if we're riding in a car, we get the anxiety and we get nervous. It brings on the other... It triggers some of the other symptoms. So yeah, I can see how that would... Yeah. I want to bring in now, Dr. Martin. Dr. Falconer mentioned it's over 140 miles round trip for most people, but it actually can be a lot farther if you're rural. How does telehealth help those folks that are maybe even a day away from seeing an MDS?

Dr. Jaime Martin: Yeah. I mean, I think it's really important. I think, certainly for people who live in areas where they don't have access to a movement disorder specialist, or in some cases, even a neurologist... I mean, I would have patients that would travel many hours, have to stay the night in a hotel, see us the next day and then do it all again. So I think this really gives people who live in areas that are rural, or sometimes even what we call medical deserts where they don't have access to this, it all of a sudden opens up a whole world of access to specialists that can really help with their care. And I think it's important...

Dr. Jaime Martin: As Drew mentioned, I think it's important. It's not just people that are far away, but people who don't want to... Can't deal with the traffic that's in the area. I mean, I had patients who would travel, but would rather drive double the distance outside of Atlanta to not have to deal with the traffic, versus coming through Atlanta traffic to get to things. And it allows family members that are working, or even patients that are working, to be able to cut down their appointment times, or maybe family members who live in other areas to be able to be involved in the visits as well.

Larry Gifford: Yeah. I find that as a person with Parkinson's who works full time, it was really beneficial for me to have the telehealth because it wasn't such a disruption of my day. I didn't have to take a half day to go see my neurologist. It was really just another hour of my day. It was really convenient.

Dr. Jaime Martin: And for what it's worth, for those of us who are able to see patients at home, there's a lot you can tell by somebody, how they were at home without getting into too much detail, I had one patient who kept falling and we couldn't figure out why because he always looked good in clinic. Didn't matter what time of day it was or where he was in his medication cycle. And he did fine with PT, but I saw him at home and all of a sudden I realized there was all kinds of stuff in the way and there's boxes and his cats weaving in and out of his feet. And it really took me being able to see him at home to realize there's multiple factors that were affecting his balance at home that we just weren't reproducing in clinic.

Larry Gifford: Now Dr. Falconer, if somebody... This is a question from the audience. If somebody does telehealth, how do you do tests with them?

Dr. Drew Falconer: Yeah, it's been a crash course for us that didn't do telehealth prior to the pandemic. But it reminded me that you can see a lot and you can test a lot without actually laying hands. Look, you still talk to a lot of docs who say, I have to touch patients to know what their tone is and their tightness and how their mobility is. But in reality, we can, we can see how your mobility is. We can see how your dexterity is, how your tone is, simply by having you do all those exercises we do in clinic. The open close, the tapping, rapid movement. But the biggest one is gait. Watching somebody get up and walk down the hallway and walk back gives me so much information about how your tone is, how your cadence is, the safety of your gait. And it gives me all that info just through visual.

Dr. Drew Falconer: That really, in my opinion, seeing still a lot of people in person gives me the exact same markers that I need to make changes. But also remember, I mean, Parkinson's disease, we're treating the patient, right? We're not treating the gait, we're not treating the tone, we're treating you. And so just talking to somebody about the cadence of their day, the limitations in their day, the things that you're choosing not to do or do because of, or despite of your Parkinson's disease, that conversation has really, because of telehealth, moved more to the forefront. And I think it's made us start to really hone in on fixing the subjective things in your day that are holding you back instead of focusing so much on tremor and tone that we see clinically. And so, because of that, it's just shifted our conversations where we get people better.

Larry Gifford: That's a great point. And I don't think it's emphasized enough, is that this isn't like, you get diagnosed with cancer and there's three possible treatments. Everybody's Parkinson's is different. And so it's important that the patient and doctor have that conversation so they can make sure that you're living the best life you can with as few obstacles as possible, and they can eliminate, or at least treat some of those more severe symptoms as they pop up over the years. And it's that conversation that matters the most because there's no guy that's going to tell you Larry Gifford's Parkinson's diagnosis and treatment schedule. You and I are both in the dark so far, right?

Gaile Lapinas: Yeah. Real quick about that. Yeah. You don't have a manual. You're not a... There's not a car manual that says 35 PSI in each tire. Right? Then it would be too easy. Don't forget, folks, in the US right now, we have 23 medications that we can use to try to adapt and adjust to fix of issues that you're having in your day. We have four pieces of technology that are magical, but that all takes treating every person as a unique person and adapting based on how they do.

Gaile Lapinas: And that's a big point that I wanted to make about telehealth. This is not something that replaces an in person visit. It's not designed to replace it. It's a tool. It's an outlet that breaks that barrier of access. And it works beautifully, especially in the patients we have to fit in quickly. Because the old way of, oh, you call up and something's going wrong, or are you having a side effect? There's a problem. The old way was, here, talk to my scheduler. Let's try to fit you in in a way that fits with your schedule in mind, given all of those logistical

challenges of clinic. Well, now it's, hey, let's just do a telehealth visit before clinic tomorrow. Can you jump on at 8:30? We'll do a quick visit, see what's going on. It makes follow up so much easier in our role too. Dr. Martin, do you see that?

Dr. Jaime Martin: Yeah, absolutely. And I think it's important to note too, so much of the decisions that we make as far as treatments and care is not dependent on just that moment in time that we're examining you in clinic. It's how you've been doing for the last several months. How are you doing when you wake up in the morning? How do you feel at the end of the day? So a lot of it is really just getting information about how you've been doing. And so that's going to be the same, whether it's telehealth or in person.

Larry Gifford: Ray, how did you find your... You never did telehealth before. How did you find out that you could do telehealth? And where did you have to go to a different neurologist? Or were you able to keep going to your same MDS?

Dr. Drew Falconer: Actually, my motion disorders... I started off directly with a motion disorder specialist, and telehealth was an option. I actually was a managing director for the Epilepsy Foundation here in Chicago, and we actually used telehealth in our offices. We were located in Crystal Lake, Illinois, which was rural, and so we had individuals with epilepsy who, either children or parents, couldn't travel. So I have experience with telehealth from the very beginning. So when I saw with COVID, it became more prevalent. It was always an option, but it became much more prevalent for use.

Larry Gifford: That's great.

Gaile Lapinas: My answer too was, when you have a telehealth something scheduled, it starts on time. So you're not in the waiting room for a long time. I think that, even if it's for 15 minutes, starting on time and ending on time means a lot. It's very convenient and very efficient.

Larry Gifford: That's great. Thank you for adding that. That's important too. Yeah, you do feel more respected, right? That you're not just hanging around wondering when they're going to come through those double doors.

Larry Gifford: Question for the doctors, how does somebody find a telehealth provider?

Dr. Drew Falconer: Well, Dr. Martin, you do this in an almost exclusive sense. How would people find you? What's the path?

Dr. Jaime Martin: I think there're multiple ways to do it. Certainly, word of mouth is one way. Talking to whoever you're getting care from now. They may provide that option or they may know somebody that does. Your primary care doctor may know as well. Looking online. Lots of patient groups have people that know who specifically in your area provides telemedicine. I don't know that there's one

central resource that would give you that information, but I think there's a lot of resources that are available to try to find that information.

Larry Gifford: Thank you. Yeah. I think the best option is to start with your current physician, or your current neurologist, current MDS, and just ask them if they have it available. And if they don't, can they recommend somebody. The Michael J. Fox Foundation has been really advocating Congress to extend the COVID-19 telehealth flexibilities, because they really help people with Parkinson's overcome the barriers to receiving care from specialists who understand their disease and treatments, especially through the COVID-19. We found out last Friday, those have been extended for another 90 days, so that's good news. Yay.

Larry Gifford: I want to talk to Dr. Falconer when we get back, about a study that he participated in, or that he was the principal investigator of. But first, I want to tell you about PPMI. The Michael J. Fox Foundation landmark study, PPMI, is the Parkinson's Progression Markers Initiative, also known as PPMI. We are recruiting volunteers right now. So listen to me closely. PPMI aims to change everything about how Parkinson's is diagnosed, treated, and potentially prevented, and you can help. People recently diagnosed with Parkinson's play a critical role. Click the link in the resource list to learn more about it. The online part of PPMI is open to everyone. Whether you have Parkinson's or not, go there. Anyone over the age of 18 living in the United States, PPMI online. You can get started in the study today, today, by clicking the Get Started button in the Take Action box on the bottom right of your screen right now. Again, it's PPMI. And there's more on it at michaeljfox.org.

Larry Gifford: Let's get into this study a little bit, Dr. Falconer. Here's what I have on it, and then you can fill in some of the gaps or give me some context here. A new study from Inova Parkinson's and Movement Disorders Center in Virginia, that's where you are in practice, explains that telehealth enabled nearly all their new Parkinson's patients seen via telehealth to meet with a movement disorder specialist for the very first time. Really?

Dr. Drew Falconer: Yeah. It was incredible. Yeah. The study came about, really because, with the pandemic, we all essentially had a forced use case experiment in telehealth. We all shifted heavily to it because we wanted to still, of course, maintain our patients and continue to do our jobs despite that whole global pandemic thing. And what we realized at our center is, so at the time we had three movement specialists, that within the first nine months of the pandemic, we actually saw, as a group of three, almost 1100 new patients. That's one thousand, one hundred new patients. And we thought, holy cow, that's a lot of people. That's much higher of a new patient referral base than I think anybody could consider, because it's crazy.

Dr. Drew Falconer: But when we looked at it, we realized that about 85 percent of those new patients were through telehealth. And of the patients who saw us for the first time through telehealth, almost a hundred percent, so 97 percent of them, had never seen a movement disorder specialist before. What it told us was, this use

case scenario this, okay, now we're going to open the flood gates to making ourselves available electronically, that it seems to have allowed us to be accessible to a whole host of folks that otherwise distance, travel, and time would've made it just not an option. It was incredibly inspirational to us because it realized the potential for what's out there.

Larry Gifford: Yeah, that's really remarkable. Dr. Martin, there're some questions in the Q and A about, what happens if I want to see a neurologist out of my state? There's some state laws and border issues. Are those being resolved or worked on? How do you go about managing that?

Dr. Jaime Martin: Yeah. So it's a work in progress. The current law is that the physician that you're seeing has to be licensed in the state in which you are located. So, not where the physician is, but where the patient or the person seeing the physician is located. That can certainly make it difficult for us to see people across multiple states. Some of us have multiple state licenses. There is, what we call, an interstate medical licensure compact, which is making that easier for physicians to obtain more licenses. But it's certainly still a barrier. It's still something that we're certainly advocating for to try to ease those restrictions and those barriers to allow us to provide care across the board.

Larry Gifford: And then there's the country barriers too. There're some questions about, is it available outside the US? I know it's available in Canada, and I believe it's available in the UK, or at least parts of the UK. Are you aware of anywhere else that it's being utilized right now?

Dr. Jaime Martin: Yeah. There're multiple countries where it's available. So you really have to look at resources within each country and the restrictions as far as who can practice. Like, let's say I wanted to see somebody, I think somebody mentioned they were in Colombia. If I wanted to see somebody in Colombia, it depends on what restrictions are available there, or what's in place there as far as, can I practice across country borders. So it's very, very country specific when it comes to that. But starting with your local resources, the Latin American movement disorder societies, things like that, might provide more information for Central and South America. There's certainly similar organizations in Europe and Asia as well.

Dr. Drew Falconer: Larry, if I could add, everyone on this call should call their Senator, their Congressman, and let them know that this is a priority and that it needs to get fixed. Just a quick example, I'm here in sunny, beautiful, 100 degree Northern Virginia. Washington DC is 10 minutes that way. Maryland is 15 minutes that way. If you're a patient of mine and you're in Roanoke, Virginia five hours that way, we can do telehealth. But if you're in DC 10 minutes that way, or Maryland 15 that way, we can't. It's nonsensical. It's crazy. It is a major barrier to accessing specialty care in our world and across the world of medicine. But the only people who can fix it is really honestly Congress, because they hold that power.

Larry Gifford: All right. We're going to move on now a little bit away from the border issues, and move towards, how do we make the most of a virtual appointment? I'm

going to start with Ray and Gaile. You talk about the importance that the doctors now are showing up on time. When they show up on time, how do you prepare to make the most of that 15 or 30 minutes that you have with them?

Ray Lapinas: That's a great question. One of the things that I do, I approach it like it's a regular doctor's visit. So I have my notes, any comments or things I want to ask the doctor, with me ahead of time. My medications as well. Sometimes I'll forget what I'm taking or how I'm taking it. It's much more helpful to have it with me. I also stage the room, as Dr. Falconer had said, gait is very important. If you put a computer like I've got in front of me right now, it's going to be hard for him to see me. So at home, I position the computer and such, so you can see me doing the gaits and such. And also, the software that's used. There're different types of software. You always want to test it out before your first appointment, because some of them don't really work on mobile devices. Some of them need to be in Chrome. So do your research before your appointment to make sure you can connect correctly.

Larry Gifford: That's great. I know there're parts of rural British Columbia where I live, where they actually have centers that people can go to where they set up the room for you, and then they dial in direct to your doctor. So it's like a virtual health center that you go to where they do all that technology stuff, especially for people that are older with Parkinson's. Go ahead.

Ray Lapinas: I was just going to mention that here at NeuroBalance, the topic of discussion that just came up, that we're going to be asking our client base if it would be helpful for us to be able to stage telehealth at our facility. Because we were seeing that there're individuals, especially when you have motor disabilities, typing, getting the computer, setting yourself up. That's something that we're actually researching right now to possibly implement next quarter.

Larry Gifford: Oh, that's great. Doctors, what do you suggest for people to do both from the personal, like, the medical standpoint, but also from a technological standpoint, how do they prepare for a virtual appointment?

Dr. Jaime Martin: Yeah, okay. I'll start on this one.

Dr. Drew Falconer: Yeah, go for it.

Dr. Jaime Martin: There's obviously some points that are here, confirming your insurance coverage, what costs would be associated with that. And as Ray already mentioned, just prepare as you would for your regular visit. Have your questions. Having a family member or loved one that's available with you is always helpful, especially for some of the testing. Sometimes it might be nice to have somebody close by, especially if there're any issues with balance. Testing the technology, we've kind of talked about a lot of these things. And I would say too, just kind of standard etiquette just as you would for any other visit. So we request that you don't do a visit while you're driving a car, or even a passenger

in a car, if possible. Dress as you normally would in public. We prefer not to be in the bedroom or while you're watching TV and things like that. And specifically for Parkinson's, when you're testing your technology ahead of time, sometimes the voice is soft, it may be helpful to have a microphone that you can put closer to your mouth as well.

Larry Gifford: Well, that's great. Dr. Falconer, any other suggestions?

Dr. Drew Falconer: Yeah. I think it is a great opportunity to not just say how we make telehealth visits more effective for you, but also how we can make just clinical visits more effective. Same ideas, and all of these things carry through, in my opinion, from in-person to telehealth. And the biggest one that we see is the best helper in terms of getting people better, faster, is number 1, 2, 3 on the list. Got to have somebody with you. Please, please, please, never go to a clinical visit or have a telehealth visit alone. I don't know if we all realize it yet, but the people around us know a lot more about us than we know about ourselves. I've been married for 10 years. My wife knows everything about me, and rightfully so. It's really important that your loved one, your neighbor, the person who sits next to you at church, who sits at the bar with you at the Elks club, whoever it is that's in your life, walking your daily journey with Parkinson's, make them part of your clinical visit. Because then we get you better, faster.

Dr. Drew Falconer: And then the other big one is, I tell folks, make a list. Please make a list. Write down the things you want to talk about. Write down the things that you wish you could do that you can't. The things that you're choosing not to do because of your Parkinson's. Write that down. And in person, hand it to the doctor at the beginning, and through virtual, send them a message ahead of time with that list. Have a guideline of what we need to talk about that matters to you, and a guideline on where to even go. It saves us from that first 15 minutes of pulling teeth, trying to figure out where we need to go today. Put it in a list, send it to us ahead of time. It helps.

Larry Gifford: I saw one of the comments in Finland, they have select pharmacies that have set up these telehealth centers where people can go and do their telehealth, which is really a neat way to do it as well. So there's lots of different options out there. And there's certainly not a solution for everybody at this point, because it is a global issue and not every country is built the same way with the same infrastructure and has the same medicines or facilities available, or technology. So hopefully over the course of time, it'll catch on worldwide, and maybe soon you'll be seeing people all over the world. That would be amazing. What has been the impact of telehealth over the course of the last couple of years on research and care of people with Parkinson's? Have we seen an increase? A decrease? How has it changed? Maybe we'll start with Dr. Falconer and then go to Dr. Martin on that.

Dr. Drew Falconer: Yeah. So we're a research center. It's part of that whole Parkinson's center mantra that we all tend to espouse here at Inova Health System. I think we are currently running either nine or ten clinical trials in the Parkinson's space, which

is really fun. It gives us a lot of opportunities with folks. But the last three years have been a real mixed bag. At the beginning of the pandemic, a lot of the research trials were very hesitant to use telehealth as an option, for all the reasons in research that we like to keep things very regimented and controlled. And so we had an incredible drop-off in our clinical research participation. We had a number of studies even just cancel and postpone, because patients didn't want to come to clinic, let alone a research study where you have to come once a month to do research things. Obviously, as someone also living through the pandemic, I get it. It's only been about the past year to two years, maybe year and a half, that companies running research trials have started to get on board with telehealth and realize that a lot of what we can do, we can do very effectively through these means. And those studies that really lean on a telehealth option have seen just this huge uptick in enrollment, because it's easy. Nothing wrong with that.

Larry Gifford:

Dr. Martin.

Dr. Jaime Martin:

Yeah. And I would say there's been studies to show that evaluations comparing in-person evaluation versus virtual evaluations show that we are able to do these same things, we're able to confirm the same diagnoses and patients that are doing these things often find that telemedicine is just as good as if not better than some of the inpatient visits. And the nice thing about a lot of studies, either having a virtual component or some of them are completely virtual now, is that it really allows you to have access to trials that are outside of your driving distance. It's not just whatever your institution is running. It allows you access to a lot of those things now and really opens up the doors, kind of removing that bias of not just, when we do studies, sometimes you have just a bias because you're only pulling people from your particular area. So really opening that door can make a big difference.

Larry Gifford:

Yeah. It is easier to participate in research. I was trying to do trials and stuff earlier on, but now I've probably participated in three or four different research projects, just sitting here at my desk, which I feel at least I'm starting down that path cause I want to participate in that process. And when you work full time and there's a lot of barriers in your way of participating and this makes it so much easier.

Dr. Jaime Martin:

I was just going to make one comment. I think it's important too because I have a lot of patients that say, well, we'll travel anywhere. We'll go anywhere we need to go. We'll do whatever. And that's great. But a lot of times that travel impacts your Parkinson's disease. If you're going across time zones, maybe your symptom control is not as good as it would be, or maybe you're more fatigued that affects your scores in the trial. So in sort of roundabout ways that can actually affect the results of the trial as well. So again, being able to see you in your environments without all of this excess travel can be helpful.

Larry Gifford:

Question here from the audience on, does this cost more or less the same as an in person visit?

Dr. Drew Falconer: That's right. Now it's on par. And that's part of that emergency that's been extended while all of us that do telehealth are really excited about it. It's a parity law. So if I, on the billing side, if you see me in person, the way billing is put through your insurance is the exact same if we do it through telehealth, just with a certain modifier that we had to let the insurance company know that it's through telehealth. Copay, on down deductible, all that it's all under in person. Is that correct Dr. Martin?

Dr. Jaime Martin: Yep. Yep. And I think it's- -

Larry Gifford: The Medicare covers it as well, right?

Dr. Jaime Martin: Yes. And I think it's an important thing while the pandemic status is continuing to be extended, that will continue. But I think it's important for us to advocate now, again, to send it to Congress about the need for this to continue long term, to not just be repeated 90 day extensions, but this is really the way we should do things going forward, because we've proven that it's beneficial, it's cost savings for patients.

Dr. Drew Falconer: Yeah. And if you're out there and you've never done a telehealth visit, try it. I find the people who, or the physician side, the docs who say, I'll never do it are the ones that have never done it. And on the patient side, a lot of the folks who are reticent have never tried it. I can't tell you how many folks have come in for once a year, let's just check in person. And then in between will do telehealth. They come in person. They're like, man, I hated that drive. I'm so excited to go back and do telehealth for our next few visits. Cause that was miserable.

Larry Gifford: Awesome. Right.

Dr. Drew Falconer: It works.

Larry Gifford: There's people that are asking about, what they're supposed to do or what they're supposed to say to their Congress people. I recommend you go to The Michael J Fox.org, click on take action. And it's the top thing there. It says, contact your lawmaker and it'll have all the language there that they can help you with that. So Michael J Fox.org, it's the take action button and you'll see it there. Who did I interrupt there? Ray and Gaile, have you participated in any research to do with telehealth?

Ray Lapinas: Not with telehealth. I've done some other in person and nothing with telehealth.

Larry Gifford: Okay. Well, here's a great opportunity for you and everybody else. I do want to say that telehealth visits help increase access to specialty care and research shows it could be as effective as in person ones. And as a patient, I feel that too. In fact, I feel like I get more attention. I feel like I have the full focus of the doctor. There's nobody coming in saying, excuse me, in a second, I got to pull

them away. So I feel like we're locked in. Specialists are able to confirm Parkinson's diagnoses via video conferencing. I think when this first started, there was questions around this part of it, whether you could diagnose from telehealth and that's been cleared up. Do you want to talk about that, Dr. Martin?

Dr. Jaime Martin: Yeah. So a lot of studies have been done to show that we are able to diagnose Parkinson's disease, Parkinsonism via telemedicine. Sometimes in the very, very early stages, there may be subtle things that we cannot pick up over telemedicine, but just like in person, sometimes we have to wait a few visits before things really declare themselves, but this has been confirmed time and time again, showing that our ability to evaluate people in person versus via telehealth is similar.

Larry Gifford: Great. The research also showing that there's improvements in depression and anxiety through the use of phone based cognitive behavioral therapy, it works for me. Somebody also ask, is a voice therapy available through telehealth? I use it. So yes, absolutely for appointment right after this one.

Dr. Drew Falconer: If I could add something very quickly, I saw some questions pop up about diagnoses. Remember out there we are not as good as we think at diagnosing Parkinson's disease. There is a very big study from about CERCA 2014 that showed that even a clinical specialist like me, who does this every day, we're wrong in our diagnoses, about 15 percent of the time. That's a lot of people. It gets even worse when you go to general neurology and then internal medicine where a lot of folks get their primary diagnoses. It is such a subjective thing. For the most part, we diagnose Parkinson's by taking your symptoms, by taking your story, giving you medicine, and then saying, tell me how you feel. Do you feel better? Do you look better? And if it's the home run ball of, wow, I feel like a million bucks, then we're pretty sure you got it.

Dr. Drew Falconer: Don't forget though, and some people have mentioned this in the chat. Here in the US, we do have a test called DaTscan, which is a type of PET imaging of the brain that for the most part tells us in color, if you have Parkinson's disease, it is a picture of the dopamine circuit. It is fully covered by most, if not all insurance providers and it's been available in the US, FDA approved in 2010, 2011. So we've got 11 years of having a test that we can order that adds something objective to an otherwise subjective diagnosis. And I can tell we order him a whole lot with telehealth, because if you're kind of close and we're not sure, why not just order DaTscan, then we can see for ourselves.

Larry Gifford: Yeah, that's the other thing my doctor can still prescribe medicine. He can still prescribe testing that facilities. And I don't have to see him in order to do that. I just get call from the testing center and they say, well, where to go and what date? And I go, and then they send him the results. It's rather efficient, frankly. And then the other impact of telehealth on research and care, online survey results, similar to assessments conducted at in-person studies. So we're finding that there's some parity there as far as how the patients are assessing

themselves and how they're filling out these surveys and whatnot. So that's great news. I mean, this is sort of a whole new world. And so as we talk about advocating for this, with your Congress, people that's really important that we get out there.

Larry Gifford: The other thing you can do is if you have questions, Michael J. Fox Foundation has a terrific policy team and you can email them directly at policy@michaeljfox.org. Policy@michaeljfox.org. Michael J. Fox Foundation is supporting the AT-HOME PD study, which asks study volunteers to complete virtual visits, smartphone activities, and online studies after completion of clinical trials to understand telehealth outcomes and conduct remote follow up. So even The Michael J. Fox Foundation is involved in really trying to make the most of the telehealth situation, there's also, and they've been doing online surveys for a long time. And so if you've not signed up for Fox Insight, for instance, that's just a quarterly questionnaire that they send out that you can fill out from the comfort of your home. And it's adding a tremendous amount of information and data to what we know about Parkinson's disease and how it develops. I'm just going to ask this. We were talking about how great it's. Are there any downfalls to telehealth? Have you found anything? You're like, oh, that's just one thing that's just not quite as good.

Dr. Drew Falconer: Yeah, absolutely. It is common, but not the norm that we just get people who we can't connect the technology, just isn't working at that moment. There's an update that needs to be run, a download, you name it. And it got made a lot harder in the world of a lot of us docs because we all zoomed for a long time. Everybody knows how to do zoom. Well, zoom is not a HIPAA compliant platform. It's not something that technically you can do within the bounds of being secure enough for HIPAA. So our system had to move away from using zoom. And once you have three or four different platforms that just gets more confusing for patients. So I think the biggest limitation is that, we just sometimes have people where we just say, forget it, let's just do a phone call and talk and then we'll work to get you in person.

Larry Gifford: All right. So there's a lot of questions about DaTscan here. And then, do we factor in alpha-synuclein, the dopamine CAT Scan they're calling it. So let's get some more clarity on the DaTscan and what it is and what it measures and how you can tell if somebody has Parkinson's.

Dr. Drew Falconer: Yeah, it's a type of PET scan and it takes a picture of the dopamine transporters in the brain. So it's taking a picture of that dopamine system and we tend to report accuracy, that someone asked about accuracy. In our world of testing, we think about what's called sensitivity and specificity. And for DaTscan, they're both over 98 percent. So if it's glaringly positive, then you're in the ballpark of Parkinson's disease or Parkinsonism.

Dr. Jaime Martin: Yeah. And I think it's important. It's ideal to get them done, or at least interpreted by an institution or by a physician that has experience with these because there are nuances in interpreting it. And it doesn't necessarily say a

hundred percent that you have Parkinson's disease, but that you have one of the Parkinsonian syndromes. So there are some atypical syndromes that would still be abnormal on this scan. So it doesn't necessarily help us, specifically with Parkinson's itself, but it certainly puts us in that ballpark of one of those Parkinsonian syndrome.

Larry Gifford: And in reality, it takes after diagnosis, maybe even a couple of years to figure that out even without- -

Dr. Jaime Martin: Yeah. Even in person. Correct,

Larry Gifford: Ray and Gaile, as far as telehealth, has it impacted your personal life and how you go about doing your daily business? Does it feel... Like for me, for instance, I'll just talk about myself without let you react to it. It was always such a day, oh, it's the Dr. Day. And so then you get ready for that day and you're taking time away from work or family to go there. Your wife's coming with you, she's got to cancel her stuff. You're dragging everything there. It's going across town.

Larry Gifford: You show up, you wait in the lobby and stay out of the nurses and you're waiting in the lobby and you're waiting in the lobby and you get back there and then you wait again for some other time. So for me, it just felt like it was a blown day. And now I feel like it's actually a very productive part of my day. And I feel like Parkinson's, doesn't get in the way of me living my life, where with those every six month appointments, it felt like my life just stopped for a day until I figured out if I was okay to continue living.

Ray Lapinas: Well, Gaile had actually mentioned when I was saying the traveling here in Chicago and such, and Dr. Falconer is right. Whenever I show up, I make sure I'm at the hospital at least half hour beforehand. So my blood pressure goes down from the commute cause it's always bumper to bumper in, it's even worse out. I think the other important thing was you can get an appointment quicker. I was put on a medication that had a definite neurological deficit impact on me, which I could tell, I felt like my IQ was just plummeting. Gaile noticed it. And I was able to have a telehealth where the doctor had me do the Montreal test and she thought I was joking. And I wasn't. And from that, I was able to transition to a neuropsychologist that said, take him off this one medication. And it all reversed. So having the ability to have a speedy appointment is really important.

Larry Gifford: That's great. That's terrific.

MJFF: A landmark study that could change the way Parkinson's disease is diagnosed, managed and treated is recruiting participants. Now PPMI, or the Parkinson's Progression Markers Initiative needs people with and without Parkinson's, especially people age 60 and up who have close relatives living with the disease. Take a short survey today at michaeljfox.org/ppmi to see if you're eligible. That's michaeljfox.org/ppmi.

Larry Gifford: I want to take some more questions from the audience here. Somebody asked about, back to DaTscan why maybe their doctor won't order one. I know in Canada, they don't do the DaTscan at all. The US uses it a lot. Where else is the DaTscan utilized and why would maybe a doctor not think it's appropriate for a patient?

Dr. Jaime Martin: So I would say, I typically only order it if I'm not sure, if there's not a clear signs of some sort of Parkinsonism, or if there's other things that might be going on. So even somebody's on a medication that causes symptoms that look like Parkinson's, or maybe they've had strokes in the same area or some other injuries that are in the same area that really muddy the water. Then, I think that DaTscan is really helpful in those situations. But I think in most clear cut cases, especially if somebody's tried medication and it's clearly been effective, then the DaTscan is not going to add anything extra to our... it's not going to change our treatment at all.

Larry Gifford: Right. That's always-

Dr. Drew Falconer: It's just an objective test.

Larry Gifford: But it worked.

Dr. Drew Falconer: Yeah. Then you're good. It's a picture, right? If you go to a doctor and they say, "My leg doesn't work and I can't walk anymore," we know it's spinal, and so we have to do an MRI of the spine to see what kind of issues are there, right? Or if you're worried about a stroke, you have to take a picture of the brain to see what the stroke looks like. That's a has to. A DaTscan is not a has to, it's just a tool. It's an objective picture that can help when things aren't clear cut. Maybe that the doctor is just very confident.

Ray Lapinas: The people that I know at the center, that I've actually done boxing and such that have had DaTscan are the individuals that don't have the tremor or the certain features, but they do have Parkinson's. And so it seems like the DaTscan really was helpful because if you don't have the tremors and it's hard when you're on carbidopa-levodopa to see that off and on time issues. And so those are the individuals I've heard that have had the scans here.

Larry Gifford: Project into the future, five years from now with Telehealth. Do you see them using more smart devices, the watch trackers and more technology as part of the overall... Because listen, you get me twice a year for 15 minutes, you don't know my Parkinson's as well as I know my Parkinson's. So those technologies could probably really bring some insights to your understanding sort of the ups and downs of your patients and sort of the flow of their Parkinson's symptoms. Is there any talk about that? Do you see that happening?

Ray Lapinas: I was part of a study initially. I believe it was [inaudible 00:47:03] biometrics out of Washington state where you're using your cell phone and it's actually

registering if you're trembling and such. And they're trying to develop the ability to use your iWatch or the apple watch and such to track that information as well. I think that would be great. And I think that if there was some way to do... Also, tie in telehealth with... Just at home, some kind of device that would be able to take your blood pressure and other information like blood sampling and such so that we could provide that information before the telehealth visit for the doctor to review would be helpful as well.

Dr. Jaime Martin: Okay. So there's a lot of research in this area, looking at different types of wearables and really trying to find what we call passive ways of collecting information. So not necessarily something where you go into an app and do something, but it just passively measures tremors, gait, your walking speed, falls, things like that. But it's a giant amount of data that comes in. And so trying to figure out how to interpret that data, make sure it really... That we're measuring what we think we're measuring I think one of the biggest barriers right now is to be able to put that into sort of an interpretable measure that we can actually use to make benefits for our patients. It's the biggest issue right now.

Larry Gifford: Dr. Falconer?

Dr. Drew Falconer: That was, I couldn't put it better than that. It's all about the right amount of data about the right thing without being data overloaded. Cause if we're already 30 minutes into a 20 minute visit talking about constipation and sleep issues and muscle cramping and toe curling and motor fluctuations, and the reason why you didn't go to your daughter's ballet recital three weeks ago. When are we going to have time for the book of here's four months of my data off of my iWatch, right? And that's what I think. There's a lot of movement in a lot of the companies that are creating these devices are trying to do is find a way to highlight their info in ways that allows for quick digestion by the doc and then implementation. That's hard.

Larry Gifford: When we talk about telehealth. Part of that is actually just a voice call that some doctors are providing. Is there a different way or a better way to prep for a voice only call without video?

Dr. Drew Falconer: Yes. Schedule a telehealth or an in person visit soon after. We've tried. Look, we are pushing and Dr. Martin might have a different opinion. Remember we're all different, but I am the biggest proponent of telehealth. You can imagine because if its ease of use, but I've got to see you. I mean, I got to be able to see you a move. I got to be able to see you a walk. In reality a phone visit is nothing more than the after clinic, you called me with a question. I mean, we can't do much over the phone with what we do. Dr. Martin, you agree or disagree?

Dr. Jaime Martin: I agree. I think if it's a quick question, like I started taking this medication, I have this side effect, or when I saw you three months ago, my meds were lasting until the next dose, but I'm starting to find that 30 minutes before my next dose, I feel like I'm starting to wear off. I think easy things like that might be okay for a

quick phone check-in, but we're really limited in what we can do as far as that goes, without being able to see you and make recommendations based specifically on what we see. Especially when it comes to something like, I changed the dose of my medication, and now I'm having this funny movement. Well no, is it too much medication? Is it side effect of the medication? Is it not enough? So, when it comes to specific movement issues we just have to lay eyes on it.

Larry Gifford: Great. Ray, I want to ask you a question, when you're going through a telehealth session. What are some of the things that the doctor asks you to do in order to evaluate your movement progression?

Ray Lapinas: It's pretty much the same as what you're doing at the doctor's office, the gait, the finger tapping, hands to the nose, everything that you do at the doctor's office, you're doing it on, on telehealth. There's no restriction. The only thing, like I said before, I would make a point to putting my computer in a position where she could watch me walk at least 20 feet forward and backwards and turn around and capture my whole body as opposed to just the upper body. I try to make it as close to the doctor's visit as possible. But everything the doctor does at the visit is the same.

Larry Gifford: Dr. Martin, if you are a new person to an MDs, if you're a new patient. You've mentioned you can diagnose people over telehealth, but how soon do you need to see somebody in person once that happens? The very first visit is telehealth. How soon after that do you want to actually lay some hands on them?

Dr. Jaime Martin: I mean, I think it really depends. I think it depends on the person. It depends on what symptoms they're having, how quickly things are progressing. You know, if it's somebody that says, "Yeah, I have a little bit of tremor. It's not really bothersome, but just thought I should get it checked out." That might be somebody, I feel more comfortable waiting a longer period of time. Or maybe checking in again in six months and saying, well, just check in, see how you're doing. You know, maybe they're not interested in medication at this point and it's not impairing their daily activity. That's somebody I'd feel more comfortable waiting, doing another telemedicine visit maybe. If it's somebody that I'm more concerned that maybe there's something else going on, maybe it's a spinal cord issue. Maybe it's... You know, there is other things obviously that can affect your movement. Then that's somebody I would want to see more quickly. So it's... I don't think there's a set time. It's really just patient dependent.

Larry Gifford: I would say that's a... It is a really interesting point that you made there. I think it's one of those things where, you mentioned earlier how hard it is to diagnose Parkinson's on Dr. Falconer and it's true. Like even at first they thought I might have MS. Then I saw an MS urologist, and then I went to a Parkinson's urologist and that's a short journey compared to a lot of people who may... if you're a young woman, it could take five, six years before they figure out, "Oh, she has Parkinson's" because they don't go there first. So you're going to want to see somebody who's... If you're not sure which it is, but what they actually have,

you're going to want to see them in person before, too awful long. You feel the same way Dr. Falconer?

Dr. Drew Falconer: Oh absolutely. I mean then again, I have patients who we have a fully virtual relationship and I have never met them in person. It all very patient dependent. And if, if we make decisions clinically over Telehealth and you're good, then you're good. Right? So at the end of the day, lean on your doctor. And if a doctor says, "Hey we really should do the next follow up in person." Do that.

Larry Gifford: Yeah. What about rehabilitation visits? Are they available virtually?

Dr. Drew Falconer: Well they are. Yeah. Especially speech therapy. That's an easy one. Even physical therapy. Look, you have every center in the U.S., every advocacy group is doing all kinds of exercise through telehealth still. Through zoom and all the other platforms. Rehab services do too.

Larry Gifford: That's great. Are you both seeing your doctors virtually?

Dr. Jaime Martin: I have.

Larry Gifford: I'm sure you have a family doctor, a physician, right. You know?

Dr. Jaime Martin: I moved east of Atlanta. My physician is Northwest of Atlanta. So if I don't have to travel all the way across or around then absolutely. I see her as often as I can via telemedicine and I have to plan the whole day around it, if I don't.

Larry Gifford: Right? Yes. You get it. Dr. Falconer, same?

Dr. Drew Falconer: Well, I'm lucky that the primary care clinic that I go to is right next door. So, and they all know us. I mean, we're all... I've been here for eight years. We all know each other. So I just run over for my clinical visits.

Larry Gifford: All right. We're running out of time here. Here's the last question. When there is some time between visits, is it helpful preparing certain events lists and some synopsis of questions and summary of experience in the doctor's portal prior to the visit?

Dr. Drew Falconer: Please...

Dr. Jaime Martin: It's very helpful how-

Larry Gifford: How is too long is too long of a list of issues?

Dr. Drew Falconer: More than half a page, try to shorten it back. Single spaced? Well just be honest with yourselves. If you send us three pages single spaced, that's going to be really hard to go completely through. So trying to keep it... I don't want to say

reasonable because that's a subjective term. But just, if you've got a top five things we can talk about, that's a good place to try to start.

Dr. Jaime Martin: Right.

Larry Gifford: How would you have them order them?

Dr. Jaime Martin: Most important at the top.

Larry Gifford: Like the thing that's giving you the biggest issues today, is keeping you from living the life that you want to live, the way you want to live comfortably or there is activities you want to do that you can't do or stuff like that, correct?

Dr. Jaime Martin: Yep. Absolutely.

Larry Gifford: So what do you want to tackle now? Then we can just sort of pack down list.

Dr. Jaime Martin: Absolutely. And sometimes [inaudible 00:55:54] that come up, that things may be related to each other. So us knowing what your questions are ahead of time, we may be able to actually even combine some of those things or address one thing with, or two things with the same treatment option. So...

Larry Gifford: Right. Ray and Gail, any final words?

Gaile Lapinas: Yeah. I'd just like to say, I think telehealth is a great way to enhance that patient doctor caregiver relationship.

Ray Lapinas: I think it's an important tool in the toolkit. To especially get people that are in a rural area services. I believe in one of the conferences I was just at, they were talking about... I don't know if it was Wyoming or a state out west that only has one motion disorder specialist. And again, as Dr. Falconer said, if you're living on the border to another state, I think the state issue is very important to tackle.

Larry Gifford: The final word, Dr. Falconer. Then to you Dr. Martin.

Dr. Drew Falconer: Well, my final word is a reminder that there's a lot of hope out there that we are a different field. We are a different condition than we were even 10 years ago by treating Parkinson's disease every day. We have therapies today that were pipe dreams five years ago. There are, again, 23 options out there medication wise, four pieces of technology. But greater than 90 percent of patients who live with Parkinson's have never touched anything, but the original medicine from 1972.

Dr. Drew Falconer: So just realize you are never at the end of the rope. You're never stuck in the alleyway without a way out. There are things we can do. There are things we can try. There are things we can implement to try to help every day in your life, but it starts with you. It starts with having the courage to be a self-advocate to

not be the good patient and to go to your doctor and talk about the things that are holding you back. And Telehealth has done nothing but allowed that process to be more accessible to all because now we can meet sitting in your living room instead of having you come on in. So just remember there's a lot of hope out there guys.

Larry Gifford: You are a big fan of this. I can tell.

Dr. Drew Falconer: Well, I'm just a fan of trying to reach people. That's all it is.

Larry Gifford: Yeah, that's great. Dr. Martin you've got the final word today.

Dr. Jaime Martin: I a hundred percent echo what Dr. Falconer said. But I would also say that as patients you have probably more power than we do as far as advocating for yourselves. Especially when it comes to healthcare, laws and regulations. You know, we can say a lot of things until we're blue in the face, but if you're sitting in front of your congressperson or your Senator and they see the struggles that you're having and they hear about your personal struggles, it's going to make much more difference than anything we have to say. So please just try to reach out and make your voice heard.

Larry Gifford: Thank you all for joining us today and being part of our community and thanks to our panelists for sharing your time and expertise. We hope you found it very helpful. And I want to thank you for being here and have a great day.

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