Rachel Dolhun: Hi, everyone, and thank you for joining us. I'm Dr. Rachel Dolhun, a movement disorder specialist, Vice President of Medical Communications at The Michael J. Fox Foundation, and your moderator for today's webinar.

Today, we'll be discussing results from our Fox Insight Survey on the coronavirus and Parkinson's disease, as well as how restrictions and distancing have impacted care and community. Fox Insight is our online study, capturing disease history, experience, and perspectives from people with and without Parkinson's disease. Nearly 50,000 people have enrolled and we're very excited to share with you today the results of the COVID-19 survey, which is the largest of its kind gathering this data from the Parkinson's community.

A couple of quick housekeeping notes before we begin. If you have a question, you can type it in the Q&A box near the middle of your screen, and we'll get to as many as we can throughout the hour.

If you want the slides for download or other helpful information, you can check the resource list on your screen. That list also contains a link to a preprint manuscript of the survey results, where you can read more after today's event.

We've got a lot to discuss, so let's get started. Let me introduce our panelists. Dr. Carlie Tanner is a professor of neurology at the University of California, San Francisco, and the director of the San Francisco Veteran's Affairs Parkinson's Disease Research Education and Clinical Center. She is also principal investigator of the Fox Insight Survey and led the COVID-19 survey. Thanks for joining us, Dr. Tanner.

Dr. Carlie Tanner: Yes, I'm really delighted to be here. Thank you.

Rachel Dolhun: Dr. Ethan Brown is assistant professor of neurology at University of California, San Francisco. He was also a lead architect of the survey and its analysis. Welcome Dr. Brown.

Dr. Ethan Brown: Thanks a lot. Thanks for having me.

Rachel Dolhun: Also joining us today is Dan Morris. Dan was diagnosed with Parkinson's in 2016 and contracted COVID-19 earlier this year. He contributed to the survey and will share his experience. Hi, Dan.

Dan Morris: How's it going? Thanks. Great to be here.

Rachel Dolhun: Great to have you. And finally, Dr. Maria Deleon, who was diagnosed with Parkinson's in 2008 and is also a retired movement disorder specialist. She too had COVID-19 symptoms and will discuss her experience and the other impacts of this time in our collective history. Thank you for sharing, Maria.

Maria De Leon: Thank you for having me here. Thanks.

Rachel Dolhun: Well, again, like I said, we've got a lot to discuss, so let's dive right in. And Dr. Tanner, I'd like to start with you. And this survey, as we said, was huge. We got a lot of data, but let's start by talking a little bit more about the motivation behind developing this survey and how you actually developed it.

Dr. Carlie Tanner: Well, as the pandemic began to really intensify, we realized we had no answers to any of our questions about how COVID-19 might be affecting people with Parkinson's. And we looked to Fox Insight as a way to reach out to the community and understand both for people who did have symptoms, how they might be affected, but also, some of the other factors that we thought might be affecting people in the community, even if they weren't actually infected with COVID-19.

And so we had this amazing, intense experience of partnering with some people who were Parkinson's specialists, a few infectious disease specialists who could help us understand a little bit more about the evolving pandemic, and then most amazingly, this really dedicated small group of people with Parkinson's and other members of the community, who many of them were partners of people with Parkinson's, but mostly people with Parkinson's. And they helped us at every stage of the questionnaire development. They helped us figure out the things we should be asking. They helped us figure out how we should be asking it. And then, as we went through iterations of the questionnaire, they also gave us feedback. They were guinea pigs, taking the questionnaire over and over again, and just worked with us all the way through.

So it was a true partnership that I think made it a lot more relevant and meaningful in terms of what we wanted to learn and what we were able to find out.

Rachel Dolhun: And Dan, you were one of the people who took this survey early on. Why did you join?

Dan Morris: For me, it was important to be able to use my feedback to contribute to kind of the datasets that they're building, as far as adding to the research in such a not well understood evolving initiative and contribute whatever I could to the program.

Rachel Dolhun: Yeah, and a lot of people contributed along with you. We got over a 7,000 responses in about a month. So Dr. Brown, this is really impressive in such a short amount of time. What does that tell you about just online research or what people want to know or how you do research?

Dr. Ethan Brown: I mean, I think it tells you a lot. First of all, it's a huge testament to the Fox Insight and the Parkinson's community. We know and we're hugely grateful to people's involvement in research in general. I think people are incredibly motivated to help with research and this is just a huge part of that.

I think, as Dan said, there's a big interest in people trying to understand the relationship between COVID and Parkinson's and trying to contribute to that understanding. And I also think that especially around this time when people were sheltering in place more and this whole experience was all very new, I think people were very eager to try to contribute in ways that they can. And so we were happy to provide ways that they could still contribute.

Rachel Dolhun: I think that's right. The online research gave this road to sort of do something while we're stuck at home, many of us still stuck at home, and to move research forward, to learn more about something that we're all learning about in real-time.

As we start to look at this data, sticking with you, Dr. Brown, we see that of this over 7,000 people, 51 were people who had Parkinson's and COVID, and 26 were people without Parkinson's who had COVID. What was the criteria that you used? You know, there's been so much about can you get a test, how do you get diagnosed, and those sorts of things. So what was the criteria you used for diagnosing somebody with COVID during this time?

Dr. Ethan Brown: I think that's a really good question and it's one that we kind of grappled with a lot in talking with other environmental health and infectious disease doctors. Obviously, requiring a positive test for COVID is not very appropriate because in a lot of situations, especially in this time period, people couldn't access the test. On the other hand, things changed from location to location. So we settled on a diagnosis from a healthcare professional, a diagnosis of COVID, that means that the healthcare professionals suspected enough that COVID was going on to provide a diagnosis.

We did also look at a more strict criteria, which was requiring a test. We did collect information on symptoms, just in case people didn't receive a diagnosis and also were symptomatic, and maybe one day we could look at that and see if we could presume a diagnosis. But in the end, for this, we really decided that a diagnosis from a healthcare professional seemed to be what other people were using and what was hopefully a reliable way of identifying people with COVID.

Rachel Dolhun: Is there a balancing what's reliable, what's realistic in this moment, again, as we're learning? And we'll talk more later about how the survey's still open and you can continue to learn more about people as they continue to respond and about the virus and Parkinson's, but speaking of having difficulty with getting a test and having symptoms and not being sure, which I know a lot of people have experienced, Maria, tell us about what you experienced with COVID symptoms, and again, difficulty kind of getting a test and those sorts of things.

Maria De Leon: Yes, my road, I'm sure, as many people have testified, that it was not easy to get a diagnosis or even to be tested. I began with symptoms that progressed over a month period, to the point that I was having severe chest pain and difficulty breathing and [inaudible] my oxygen levels dropped. So I was pretty convinced and my doctors that I had COVID, but getting the test was not as easy.

I began calling my doctors about who do I need to see in regards to what was going on with me, and also, did I need to be tested? And my physician said, "Well, you need to be tested by the center that's doing the testing," but then the testing center was only open from a limited amount of time. It was not open over the weekend. And when I finally was able to get through to the center, they said, "Well, you can't just have a test. You need to go to your doctors," but the doctors had already referred me over there. And before that, they had even asked, because I was getting so bad, to go to the hospital. And the hospital said, "Well, if we think you have the COVID, then you need to go to the center. So we can't do anything for you here." So they sent me home.

So it took about a week and a half for me to actually get tested and a month to get treatment for what was going on with me. So then once I finally got the order for the COVID test, they said, "Just go over there." And then I went to the site and they said, "No, you have to make an appointment," so I had to leave again. In the meantime, the doctor had told me, "You need to get a CT of your chest to see what's going on." And then the hospital, which was at the hospital which it's being done, they said, "Well, we can let you in if you think you have the COVID. We're not allowed to let patients in."

So it was a roundabout way to get my test. I finally got the test and it took about five days longer to get the results. So it was a very unnerving experience and persistent. I can see why people would really get sick and why people would give up if they have so many barriers as to getting the test. In the meantime, I all was pretty sick and I could barely... I was weak and wheezing and chest pain. And so, going back and forth, and I had to have somebody drive me, and so on. So that was very difficult. If you don't have anyone to do those things for you, then it's very hard to get tested and treated.

Rachel Dolhun: Yeah. A long and winding road there-

Maria De Leon: Yes.

Rachel Dolhun: And you're not alone in experience, I'm very sure of it. And thank you for sharing that and for sharing your symptoms and your experience. And we'll get a little bit more into your experience and Dan's as well. But as we move to the next slide, we start to see sort of the meat of the survey and the results. And one of the answers, I think, to a question people have been asking kind of nonstop since this began, of one is, if I have Parkinson's, am I at an increased risk for getting the virus? But then also, if I do get the virus, do I have a more severe course? Will I have a more severe course or a worse experience with the virus?

So Dr. Tanner, can you tell us what you learned about the experience of COVID in people with Parkinson's from this survey?

Dr. Carlie Tanner: Yeah, so I think the overall, with the caveat that we still have a relatively small number of people in our group, is that it seems that the symptoms are not really that different and people with Parkinson's and people without Parkinson's who have COVID. So this slide shows the numbers of people who had more severe outcomes, so pneumonia or needing oxygen, or going to the hospital, or needing to be in ICU or on a ventilator. And particularly, those last two things are very similar between people with Parkinson's and people without.

Now, this is not a population study and it's not a systematic collection, it's the people who came and told us their experience on Fox Insight. So we have to think of it with that limitation, but the good news is, of those people, it didn't seem that the people with Parkinson's were really more severely affected. So I think that that's comforting.

Rachel Dolhun: Yeah. I think again, there've been a lot of questions about ventilators or do you need to be in the hospital, or those sorts of things. So you see very low numbers is this, and were mentioning things that we see in these manuscripts, like they were not statistically significant, and those sorts of things. Can you delve into that just a little bit more?

Dr. Carlie Tanner: Sure. Well, I think overall, the numbers of people who had severe outcomes were low, so less than 10% for almost everything. And that's one good thing, a very small number of people who had the most severe outcomes of needing to be in the ICU or on the ventilator. And again, if you had Parkinson's or if you didn't, your risk of having some sort of worst form of COVID seems to be the same. So it doesn't look as if people who have Parkinson's are at risk of a more severe version of the illness, at least based on the people who came in and [inaudible 00:14:50].

Rachel Dolhun: And Dan, you sort of were able to compare in real life, right? Because you had COVID and your wife, who I don't believe has Parkinson's, also had COVID. So you sort of had this experiment going on, I suppose, in real life, of what is the experience in Parkinson's versus not with Parkinson's. So can you tell us a little bit more about your experience with COVID and how it may or may not have compared to the people around you?

Dan Morris: Yeah, that's right, my wife does not have Parkinson's, but she had COVID first. But her symptoms were very mild. In fact, she had a fever that just lasted for less than a day, and it was so mild, that we didn't think She had it. We thought it was some sort of coincidal virus. But there was a severe outbreak at my place of work, so we were definitely on high alert, and she got tested really because of that, because I had stayed home from work after she got symptoms. And then sure enough, she tested positive. And that made me think mine was going to be an easy path and it was much harder than hers. So while not severe in that I did not require hospitalization-

Dan Morris: So, while not severe in that I did not require hospitalization, I had a fever that lasted for 12 days with, really, days eight through 12 being no fun at all and being pretty debilitating. I was lucky enough to have a lot of family and friends close by to provide some support, but my symptoms really kicked in as a severe fever, kind of a lack of focus, a mental fog and a pretty nasty cough added on the back end. We were also using a pulse oximeter to keep a close eye on the oxygen levels and did not go to the hospital, but did do a couple of online visits with doctors.

Rachel Dolhun: You also mentioned some worsening of some of your movement symptoms, your tremors, in particular, which we'll get into in the next slide, and we want to hear more about that. But that's really interesting to hear about your experience and how it compares to others, which again is the goal of this survey. So Dr. Brown, I'll ask you if you have anything to add to what Dr. Tanner and Dan said about how we may or may not be capturing the full experience of COVID and Parkinson's, this being preliminary data.

Dr. Ethan Brown: Yeah, I think it's a really good point, and I think the point that Dr. Tanner made, there may be a lot of people that are so sick that they haven't gotten to the survey or were not able to access the survey. I think that's a large point of this is that this was early on. A lot of people got this during or after. So keeping the survey open and going back, and also maybe asking about different types of symptoms to try to capture a different extent, as Dan mentioned, just because two people have fever, maybe it affects people in different ways, relying on different family members, or affecting your life differently. So maybe there are other ways to capture that too, but I think that's the importance of keeping this survey open as this pandemic continues.

Rachel Dolhun: Definitely, and so that's kind of the focus of the quote unquote COVID experience in Parkinson's, but as we learned from the survey, movement symptoms sometimes came on for the first time or, in your case, Dan, worsen for a lot of people. So, Dan, I'd like to start with you and hear about how your movement symptoms were affected by the virus itself.

Dan Morris: So as you mentioned, my tremor was significantly worse as well as some slower moving part of it. But primarily for me, really, it was in addition to the normal kind of aches that you've heard about most people with COVID, severe aches, but really as far as the PD symptoms went, it was a significantly uptick in shakiness and tremor, primarily for me.

Rachel Dolhun: And, Maria, you also experienced some changes in your Parkinson's movement symptoms.

Maria De Leon: Yes, I used to have a lot of tremors, but I felt very shaky inside and I was extremely clumsy. I was dropping and [inaudible] everything. So aside from being stiffer and slower and just cognitively in a fog, I was just very, very clumsy, feel like my dystonia got worse, and I was just kind of throwing things around, spilling medicines and everything, couldn't really hold on to things very well.

Rachel Dolhun: Dr. Tanner, does that go along with what you saw from the other respondents in the survey? That their movement symptoms worsened, which ones in particular?

Dr. Carlie Tanner: Yes, we did see that in almost everyone. The actual symptoms of Parkinson's got worse and some people actually had symptoms during COVID that they didn't have before, so that was really common. I'll say, we do also see that in people with Parkinson's who have other kinds of infections, and while we don't know this yet for sure about COVID, what we do know in that situation is that over time as people recover, generally their Parkinson's symptoms improve and kind of go back to baseline. So we're hopeful that will happen here too, and, of course, having people come back and continue to give us information will help us to understand that better for the COVID infection.

Rachel Dolhun: I think that's an important point to make, and Dan, you can also speak to this about your tremor, I think is still a little bit worse now. So I guess how long that sort of temporary period may last, we don't quite know yet, is that right, Dr. Tanner you were saying that COVID may be particularly prolonged, and so this period of worsening, we don't know how long that may last.

Dr. Carlie Tanner: That's right. I know from people I know who don't have Parkinson's, but who did have COVID that the recovery period can be a really long time, as both of the panelists have said, it's a nasty disease and can take quite a while to feel that you're really back to normal again. So we would expect that may pertain here, too. This is a great opportunity for us to understand more about that and Parkinson's, and how to be able to take care of people better.

Rachel Dolhun: Dan, if you have anything to add there, you were saying that your tremor is still continuing even a couple months later, is that right?

Dan Morris: Yeah, that's correct. So I think there's definitely been a slope back, so while it ramped up significantly during that period, it has been getting somewhat better, but I feel like I'm still not back to baseline and for reference my sickness was really late March, kind of about April 1st. Here we are a few months later and I feel like that's still mostly better, but it's still more elevated than it was prior. Interestingly, I kind of saw that with my workouts, to doctor's points about how hard it is to recover. I could hardly work out to begin with, and it took a good couple of months before I kind of got back to what I felt like was baseline from that standpoint as well.

Rachel Dolhun: But encouraging that you're back to your baseline from that standpoint, I suppose, but not helpful to have to go through that long of a period to get there. Dr. Tanner, you mentioned that whether it's COVID or a urinary tract infection or whatever it is, we often see that Parkinson's symptoms get worse during the infection, but Dr. Brown, I guess I'll ask you, why does that happen? Do we know, is it the virus itself? Is it something related to the virus? Is it how medication isn't working as well?

Dr. Ethan Brown: Yeah, I think that's a really good question. I think that we don't fully understand and whether or not it has to do with the severity of the virus. I will say there are a lot of theories about the inflammation and its relationship to Parkinson's and there have been a lot of discussion on COVID and a cytokine storm that occurs and a lot of inflammatory response. So, could that somehow be tied? On the other hand, whenever anyone is feeling bad for anything, a lot of different types of symptoms, both neurological and non-neurological may get worse. Maybe just our ability to compensate for a lot of things is impaired when our body is focused on fighting off an infection. There're some theories about alterations in dopaminergic signaling and certainly alterations in medication absorption as well that have been brought up with past reports of infection and Parkinson's symptoms.

But I think that we don't really know, we don't really understand, and like others have said, I think it is important and it's a very practical question for a lot of patients. I will just say that this is certainly the largest study to date in terms of who's evaluating these types of issues. There have been other small reports of people with Parkinson's and COVID that have reported similar things, like worsening motor symptoms or adjustment of medications. I think that's another very practical question. Do you adjust your medications when we think these issues are going to be reversible? So I think this is really trying to get at some of those and see if we can help answer some of those questions.

Rachel Dolhun: Along those lines of medications and things like that, a question just came in and Dr. Brown, I'll stay with you about do we know if people were taking medication for COVID, or if they had changes in their Parkinson's medications? So I guess perhaps that could be one reason for worsening, if you lower your Parkinson's medication, your symptoms could get worse. So do we know anything about if and how people's medications changed or if they got treatment for COVID during this time?

Dan Morris: Yeah, that's really good question. We did collect information about whether or not people were treated for COVID. At this stage, and still perhaps now, there are not a lot of standard treatments for COVID. So we did ask people about what types of treatments they may have received, if they were any investigational treatments, and listed a number of potential treatments at the time. Obviously, it's changed over the course of time. We asked people a little bit about Parkinson's medications, more probably supplied throughout Fox Insight, but those are really good issues to look at as well.

Rachel Dolhun: Absolutely, and good questions from our listeners. So moving on now, that's motor symptoms that we thought people with Parkinson's had new or worse motor symptoms, but we see in the next slide, the same thing happened with the non-motor symptoms. That people with Parkinson's and COVID had worse or new non-motor symptoms, and Maria and Dan, I know that you both experienced these on different fronts. Dan, you talked about your fatigue, particularly with exercise. I think there was also some anxiety, which I'll raise my hand to somebody who's without Parkinson's who's having anxiety during this time. Dan, can you tell us a little bit more about your experience with any other non-motor symptoms or expand more on the fatigue and anxiety you experienced, and why during this time?

Dan Morris: Yeah, I think you hit the nail on the head. There is anxiety just for a lack of understanding, especially given the time period of late March, of a lack of understanding of what was going on with COVID in general and then really having no kind of insight as how that might affect me with PD. So it was just a very uncertain time period with so many unknown factors and it was hard to get definitive answers. It was hard enough to get in touch with doctors at the time.

My general practitioner was great and I had felt like almost too concerned with the Parkinson's disease, where that kind of made me a little bit more anxious and he seemed to be... It was during the time period when we were really being advised not to go into hospitals unless you need to, and I think he was getting a little uncomfortable with how long the COVID symptoms were lasting, and was almost pushing me towards that end, where I'm not sure he would be if I was a non PD person, which kind of led to, again, more of the anxious feelings about whether to just sit at home and ride it out or to go in and seek help during a time when hospitals were overrun and it didn't feel like a safe place to be.

Rachel Dolhun: Yeah, absolutely. And, Maria, I think you were saying some of the same things about being nervous about going to a hospital and we've seen people who've avoided care during this time for strokes and heart disease and other things, because they're worried about going in to see their doctor, or going into the hospital and things like that. So certainly a lot of anxiety around that and anxiety around the unknown, as you mentioned, and Maria, you were also saying anxiety around not being sure if you can take care of your family when you're so sick and things like that. What else did you experience?

Maria De Leon: Well, it's funny because I definitely had a lot of sleepiness and usually with any kind of infection, whether it be a UTI, dehydration or anything, I know there's something going on when I started becoming very sleepy and that certainly was the case again. I just couldn't sleep enough, sleeping for hours and getting mental fog. But also I had change of taste. I lost about 10 to 15 pounds because nothing tasted right. I was real congested and nothing was tasting right.

But autonomic problems, blood pressure was dropping, and heart rate was going up really high, and so there was a lot of changes and some of the sleeping problems and that, that's usually common with any kind of other underlying illness, but certainly not the autonomic problems and the taste loss, but also had severe headaches that just would not go away, and talking to other colleagues that have treated a lot of people with COVID and they were positive, and even after, there seems to be a lingering headache, and I certainly experienced that, but even after I started feeling better normalizing [inaudible] for any of the other sleepiness or other issues, my headache still lasted for another couple of weeks.

I was still having a chronic, severe headache, kind of like a migraine where you're just light sensitive, and noise sensitive and things like that. I don't know if anybody else has seen that, but when I got to the point where I was having... Oxygen was dropping, heart rate was going up, and I could barely walk or anything, and everybody was sleeping. I'm deciding, do I need to go to the hospital? You're scared, I'm going to be admitted. You got to be intubated, that kind of thing. So that just didn't make my symptoms better, of course, it made everything worse. My anxiety made, of course, my heart rate go up and the cognitive changes just kind of get more irritable and things like that.

So decided, fortunately, my doctors put me on... I was taking Plaquenil, and they put me on steroids and things, and then I also, because of the Parkinson's, and I don't know if this has anything to do with it, I have been taking Amantadine and I kept thinking this about the flu of 1918, how amantadine helped with that. So I don't know if that has anything with that, but I'm just glad that I ended up not having to have any kind of admission to the, with respiratory failure or anything like that, the outpatient treatments worked fine. So...

Rachel Dolhun: There are so many things in there, Maria. I don't know how to get to all of them but you mentioned [crosstalk] I think we can talk about later, but this big thing and what we've talked about in the last two slides about movement symptoms worsening, non-movement symptoms coming on or worsening, and Dr. Brown so much concern.

Rachel Dolhun: Are worsening and Dr. Brown's so much concerned, rightfully so about how do I know if this is COVID or not? How do I know if I should go in and get tested or talk to my doctor? Maria mentioned that fatigue or getting sleepy is often a harbinger of illness for her. So she kind of knows herself in that way, but how do you know if your tremor is getting worse, that you should go and see your doctor, if you should go and see your doctor? What are you telling people right now?

Dr. Ethan Brown: I mean, I think that it's really a good question and challenging, and I think it was more so at this time, when a lot of people didn't know anything. I think that now we are certainly telling people not to seek care if they feel sicker, even if they think maybe it's just Parkinson's symptoms getting worse or normal fluctuations. And if they would normally seek care from their doctor, I think they should. I think more and more there are ways that people can do so remotely either through telephone or video. So there is a large risk or people that are worried about that, then they can do it through that way remotely, if possible, I think. I mean, I think one of the silver linings or realizations of this pandemic is we've really found how effective we can be remotely for those that we are able to do and how much we can get done over the phone and counsel people. So I think really trying to reach out if people feel that symptoms or anything else is getting worse.

Rachel Dolhun: Yeah. I think that's a great point. And if you're concerned, if your symptoms are getting worse, certainly you should speak with your doctor. And as you mentioned, Dr. Brown telemedicine is much more widely available right now. So hopefully that's a point where you can access care more easily, even for mental health care providers, if anxiety is spiking for you. But certainly getting in touch with your doctor, keeping those open lines of communication. Dr. Tanner, anything to add there?

Dr. Carlie Tanner: No, I think Ethan really covered it. I think just being aware, the changes in Parkinsonism and especially sort of really dramatic changes might be a signal and it would be really important to reach out to your doctor to make sure you're taking good care of yourself.

Rachel Dolhun: So sticking with you on a completely different question. Dr. Tanner, Maria mentioned taste loss, which it can often go with smell loss. And I think we've heard a lot in the news about those being potential symptoms of COVID, but we also know that smell loss can happen in Parkinson's. So lots of questions around this. What did you see in the survey? What do you tell people about this right now?

Dr. Carlie Tanner: Yeah, so many people with Parkinson's already have a reduced sense of smell. That's a really common experience for people with Parkinson's. And as you point out, sometimes you're not as aware of the smell, but smell and taste go together and so your ability to perceive tastes or to enjoy a certain taste, may go down. So, that's common in people with Parkinson's. What was remarkable to us was that people notice even a change that it got worse, and we're able to report that even if they already had a reduced sense of smell. And then some people who didn't have it, or hadn't been aware of it also noticed it when they were affected with COVID.

Rachel Dolhun: And something also to kind of another reason to keep the study open long-term, right? So that we see more, if and how this evolves and changes over time.

Dr. Carlie Tanner: Yeah, absolutely. Yeah. I mean there also were people, I think it may be on our slide, that's coming up who noticed this, who hadn't been diagnosed. And as Maria mentioned getting diagnosed, wasn't all that easy. And so it will be interesting to us, as we look forward to try to understand whether some of those symptoms that people experienced may have been undiagnosed infections or not too.

Rachel Dolhun: So all such great information and information is I think so helpful at this moment and what we're learning, what we know, what we don't know. And we talked about the impact of COVID on people or the impact of COVID on people with Parkinson's who actually got the virus. But we saw Dr. Brown in the survey that the impact extended pretty broadly to people in the Parkinson's population who didn't even have the virus itself, or didn't test positive per se, or didn't have a physician diagnosis. So tell us a little bit more about those broad impacts that the pandemic has had that you saw in the survey.

Dr. Ethan Brown: Yeah. I think this is really important. And while the question is about people with Parkinson's and COVID is obviously very interesting and very important there were obviously a huge number of people, a lot more, at least in the survey that were affected by the pandemic. Virtually everyone has been. And we really wanted to understand how people with Parkinson's who rely so much on outpatient care, exercise, really a whole system of ancillary services that often involve leaving the house and interacting with other people. And that we have really found can help all of the people with Parkinson's in terms of their symptoms and their overall wellbeing. So that was part of the inspiration for trying to understand how the pandemic effected these people that were not infected by COVID, we presume, but still obviously had done to go all the shelter in place guidelines and restrictions from the pandemic.

So we found a large number of people that had impact obviously to their healthcare, to exercise activity, to social activities. We asked about a variety of different types of social activities, like support groups, community gathering, volunteer experience, religious gatherings. A lot of those were either postponed or canceled and a lot of impact on the central daily activity as well. So, disruptions of things like getting essential services, home care, other types of support in the house. And a lot of this also kind of was associated with worsening symptoms in people who didn't necessarily have COVID, but were in the pandemic.

One other kind of, there's a lot to talk about this. And we talk about a lot in the manuscript tutorial, which we're working on, but the important point too, is how many people were able to find other avenues of doing these types of things. So from everything to hold types of social activities and exercise activities, there was a decent number of people that were able to find different ways presumably through telemedicine or other types of virtual visits and continued these activities. And the hope would be that, that would be even more accessible and more available in the future as this continues.

Rachel Dolhun: Yeah, that's absolutely right. And we'll talk about this in the next slide, but something that we need to continue to advocate for in the future is more widespread and continued access to telemedicine. But as you detailed really nicely, there were such broad impacts on things that are so important to Parkinson's care that the cornerstones of care. Not only just seeing your doctor and getting in touch with your doctor, but exercise, you getting support, seeing your family and friends. And when these things were sort of cut off, people really did have to find alternative ways to keep their activity going to maintain their social connections. And we're still in that moment in very many ways, but Dan, I'll start with you and then Maria, I'll ask you to add in. How did you experience these changes? How did you adapt and overcome? Are you still working through them?

Dan Morris: Yeah, so it was obviously highly disruptive to routines I think that everybody in the world had, regardless of whether you're affected or not. For me, exercise and working out is a central part of my approach to managing Parkinson's disease. And so, from a standpoint of the symptoms of COVID made it impossible for a while there. I was fortunate enough to have my garage kind of outfitted it partly as a gym. So once I was able to get up and moving, I was lucky enough to have a outlet for that rather than like so many friends who couldn't get to a gym or wherever they might've done their exercise before. But then it was, as I mentioned before, just a very slow start to getting things going again. So it was hard to say what part of my uptick and tremor and some of the other symptoms were due to COVID or due to just losing my usual routine of working out and having that kind of pronged my approach.

Rachel Dolhun: Absolutely. Again, just being adaptive, finding other ways to exercise, be social, maintain your community. Maria, anything to add there?

Maria De Leon: Well, it's funny because for me, I think that having Parkinson's for a number of years, I'm pretty well adapted to doing things because there are so many fluctuations and a lot of times I'm not able to get out or do things. So I think I have already a good support system and routine that I can do things from home. And actually having been in this pandemic has actually improved my social activities because now I'm able to do a lot of this dancing and art therapy and things through teleweb with the various foundations that are working a lot with the Hispanic community, with the Mohammad Ali and with the Parkinson's Foundation there and their extended. So we've been teaching the patients how to access telemedicine and Zoom and things like that.

So I've been a lot more active and doing activities with them. And having my daughter back from college now we have a weekend exercise or do things together here at home where before I was alone. So for me, it's been more of a blessing that I've been able to do a lot more than I usually do, and not feel guilty when I'm not out. Because a lot of times that guilt of you're not well and you want to go socialize and do things in person. But now since everybody's home, we can still talk to each other and do things together without having to feel that guilt of not being able to go out and so totally different experience.

Rachel Dolhun: Yeah, more family time, a lot more family time for a lot of us, especially in small apartments in New York City.

Maria De Leon: Yeah.

Rachel Dolhun: You're mentioning a lot as you always do, Maria, you're talking about being optimistic and looking for the benefits and the silver lining. Dr. Brown, you mentioned silver lining before. But we got a question from the audience and Dr. Brown I'll start with you, but about any benefits reported and the slowing down at society during this time? And you can keep that broad in society or you can keep it focused on the Parkinson's community.

Dr. Ethan Brown: Yeah. I think that is a really good question.

Dr. Carlie Tanner: For me it's [crosstalk 00:44:20].

Dr. Ethan Brown: I don't know if we've looked in enough detail at that. As Maria mentioned, we did capture those, we were able to conduct these activities in other ways. And that seemed to be helpful for a lot of people in terms of preventing worsening of symptoms. But I think in terms of are there new benefits to that? I think that's a really good question. I don't know if Doctor Tanner can comment, but I'm not sure if our survey really addressed those questions as much. I think that's something we're realizing more and more as the pandemic continues.

Maria De Leon: May I say something about the new benefit? I think the new benefit for me as a patient is access to the physicians. Because my physicians are three, four hours away. And so now I don't have to worry if I'm not well or having to keep that appointment, I still can have access to them. So that's been the biggest benefit of this for me.

Rachel Dolhun: And before we move on from this slide, I want to mention something really important that you saw patterns in Dr. Tanner. We're talking all about being adaptive, looking at benefits, people finding work around and those sorts of things.

But you saw some patterns of disparity, is that certain groups had more difficulty obtaining medications or finding other ways to get care or to exercise? Tell us a little bit more about that and how we can use that information to be more inclusive in our care and our research.

Dr. Carlie Tanner: Yeah. So I think opportunities for advocacy are the take home from the prior discussion. And then these findings that we had, that people who were in lower income, who had lower income or people who were not white, had more difficulties obtaining access to medications or other things, access to alternatives, such as telemedicine or other online opportunities like exercising or medication or support groups were reduced. And so we've been advocating for making these services available to people in general. I think Maria makes a great point that this reduces burden and improves the opportunities for care for people with Parkinson's in general. And I think the next step of our advocacy is to be able to continue that post COVID, but also to expand that access. And it's an opportunity for all of us to kind of pick this up and move it forward so that everybody with Parkinson's has these opportunities.

Rachel Dolhun: Yeah. I think that's right. Opportunities to expand in care and in research to be more inclusive. And we're certainly working on many fronts, not only with the survey, but across research and as you said, across care. As we move to our last slide before getting into even more questions, we're getting a lot of questions about the survey respondents themselves. So Dr. Brown, I'll start with you and Dr. Tanner, you can add in, but can you tell us a little bit more about who took this survey? Was it all people from the United States? Was it across all stages of Parkinson's, different ethnicities? Tell us-

Rachel Dolhun: - different stages of Parkinson's, different ethnicities. Tell us ... again, just give us a little bit more insight into who actually was responding to this survey.

Dr. Ethan Brown: Yeah, that's a great question and we do go into detail on that in our report. So out of the people that responded, it was ... I don't have the exact numbers here, but it was somewhere around a little over 5,000 of the respondents did have Parkinson's and the rest did not. Mostly in the US, but it was global. We had a pretty wide presentation. There were other large countries where places like the UK, Canada, some other countries in Europe like Spain, but there were representations from a number of different countries, Australia. The distribution within Parkinson's disease was actually a lot wider than we expected. There was a large distribution in terms of duration of disease. So there were some people that have had Parkinson's for a relatively short amount of time, but a good amount of representation from people that have had it for more than six years, or even more than nine years, that have had Parkinson's for that long.

So we felt ... and there was, as you may have mentioned, the disparities in care that we saw, and it's a problem in Parkinson's research in general, those are the small minority. So we don't have a large number of ethnic diversity or racial diversity or income diversity, but the fact that we were still able to see these disparities, I think is a real testament to the advocacy that we need, as Dr. Tanner mentioned, and a future goal certainly with Parkinson's with our online efforts are to try to make these types of assessments more diverse, because I think we have a real opportunity to be able to recruit people from a lot of different types of backgrounds.

Rachel Dolhun: Absolutely, and such an important point and such an important learning that we do really need to work on. A couple more just to ... people are so interested. Did you know that ... Ethan, can you tell us the age range of people in the survey, with and without Parkinson's, who did and didn't have COVID, and then also expand on if you know anything about where people actually contracted COVID? Dr. Brown?

Dr. Ethan Brown: Oh, sure. I can take ... yeah, sure. I was just looking at the numbers. The age range ... so for people with Parkinson's disease and COVID, the age range was 40 to 89 and the average age was 65. With people in general with Parkinson's disease, the age range was as low as 33 and as high as in the 90s. We know some details in terms of locations and where people ... I think you maybe mean geographic in terms of where people contracted COVID, or in terms of specific exposures, like work. We know geographically, certainly in the US ... most of the cases came from the US. Within the US, I believe most cases came from New York and California, but there was wide representation across the country. Were there other questions? I'm sorry.

Rachel Dolhun: Nope. I think those are ... probably more will come through, but as I said, people are just very interested, and I think the age question, that's certainly one that we've heard for a long time, is that if you are older, you are at higher risk of getting COVID, Parkinson's or not, and so I think that may be where that question is coming from, of understanding ... and maybe you can tell us, Dr. Brown or Dr. Tanner, if you saw, was there any discrepancy in age? Did it seem like people who were older and had Parkinson's were more likely to get COVID or were you not able to see that?

Dr. Carlie Tanner: So I think it's important to note that the youngest person with Parkinson's and COVID was 40 and the youngest one with COVID who didn't have Parkinson's was 30, and so I think being cautious, irrespective of your age, is important, and the average age was 65 for people with Parkinson's and 57 for people without in our group. So again, this is a little bit limited by we're only reporting on the people who came and gave us information, but I think even in general, we're recognizing that maybe popular press suggested in the beginning that you were immune if you were younger and I don't think that's playing out at this point.

Rachel Dolhun: And Dr. Tanner, sticking with you, you're very clear about what the survey can and can't tell us, and that one of the questions, again, that comes up over and over is with Parkinson's, in and of itself, am I at higher risk for getting COVID? But more specifically, we're getting a question about if I have Parkinson's, should I consider myself vulnerable? When you hear on the news that vulnerable populations are more likely to get COVID or to have a more severe course. So can you tell us more about that or how you think about that?

Dr. Carlie Tanner: Yeah, so I'll say that from the survey that we did, because we didn't go out and look at everybody in the population, we can't really say are you at greater risk because you have Parkinson's than someone else? But from the perspective of taking care of yourself, I think it would be reasonable to take precautions and not put yourself in situations of risk, and do all the things we talk about in terms of wearing masks and washing hands and avoiding places where you might just be too close to other people and not have control over that. So I think that's good advice for people to follow.

Rachel Dolhun: And you were talking about some other advice on keeping ourselves safe. So we're really not out of the woods here yet, but again, with or without Parkinson's, it's wearing mask, making sure you're washing your hands frequently, social distancing, all those rules still apply. Dr. Tanner, anything that you would add there more specifically for people with Parkinson's?

Dr. Carlie Tanner: I think the only thing would be to reemphasize what we said earlier when we were talking, that if you do find yourself feeling not well or you're a little concerned about yourself, don't wait, and be in touch with your physicians and make sure that you're in a relationship with your health care provider that you can get the best care possible.

Rachel Dolhun: Absolutely. An interesting question, Dr. Tanner or Dr. Brown can take this one from our audience. I've heard temperature recordings from people with Parkinson's may be unreliable, and that's due to that autonomic dysfunction, that involuntary network of nerves that controls our temperature, our blood pressure, our digestion, and so is there anything that we know or don't yet know about how temperature may or may not be a reliable indicator of COVID in people with Parkinson's?

Dr. Carlie Tanner: As far as I know, people with Parkinson's, if they're infected and they have a fever, you can measure that. Ethan, I don't know, do you have any other information?

Dr. Ethan Brown: No, I think that's it, and we did look among people with COVID, and again, small numbers and a special population, but there were no differences between the temperature recorded or frequency of fever in people with COVID, with and without, but I agree with Dr. Tanner, I think as far as I know, that should be reliable, although keeping in mind, I guess, that people may have other presentations.

Rachel Dolhun: Definitely, and -

Dr. Carlie Tanner: I wouldn't use the fact of not having a fever to be a reason not to go, to be in touch with your doctor if you're otherwise feeling ill, for sure.

Dr. Ethan Brown: Right.

Rachel Dolhun: Yeah, that makes sense. So if you have other symptoms but you're not having a fever, make sure you still get those other symptoms evaluated.

Dr. Carlie Tanner: That's right.

Rachel Dolhun: Another question. Dr. Brown, maybe you can start with this one about genetic subgroups that may or may not be at a higher risk. Did you look at people with genes that are associated with Parkinson's, like LRRK2 or GBA? Do you know anything about that in COVID?

Dr. Ethan Brown: So yeah, that's a good question. There was some suggestion of some genetic risk in another study, actually with the [inaudible] allele, which is more related to Alzheimer's, but it also may have some relationship with Parkinson's and symptoms in Parkinson's. There were some people that had genotyping through Fox Insight, which is possible for people with Parkinson's disease. So we were able to look at that in a very small group of people, and we didn't find any differences in terms of risk, to what extent we could look at or changes in symptoms. So it's hard to say with such small numbers, but we didn't detect that.

Dr. Carlie Tanner: And just to emphasize, not only [inaudible] there was no association, but we did look also at the people who did have GBA associated, Parkinson's associated mutations and LRRK2 mutations and there was no difference in those people either.

Rachel Dolhun: Well, we could talk for another hour on this topic, on this survey, but we're amazingly already at the end of our hour together. I would like to give each of you the opportunity to give a couple of last thoughts or words about your experience or the survey. So Dan, if you'd be able to start, just tell our audience, again, maybe what you'd like to leave them with today.

Dan Morris: Yeah. I just think that the Fox Foundation is doing such great work and conducting this survey with obviously the two esteemed doctors on board here. So it's really an honor to be able to contribute and to be a part of the data that hopefully comes up with some answers that can help guide people who might be affected in the future. So thank you again for having me and super excited to be a part of this project.

Rachel Dolhun: We're so grateful for your participation. And Maria, how about you? We also, I should say, got a comment that somebody in our audience has your book and recommended it to their Parkinson's support group. Maria, are you still with us?

Maria De Leon: Oh, I'm sorry. I just wasn't sure if you were talking to Dan. Thank you. Where are you talking about my book? I'm sorry.

Rachel Dolhun: Yes, your book.

Maria De Leon: Oh, thank you very much. I appreciate it. Thank you for allowing me to be here and share a part of this experience, trying to figure out how things impact, not just Parkinson's, but neurologically, and I think as Dr. Tanner and dr. Brown, thank you for doing this, but also realizing that if there's any changes in any of the Parkinson's symptoms, whether it's COVID or not, I think that they need to be in touch with their physician right away to make sure that there's nothing else going on, and the only thing that I would love to see this in Spanish so that we can get more information about disparity and how it's affecting the communities outside of what we have so far. So I'll be glad to work with you guys if you guys are interested in doing that.

Rachel Dolhun: And you're already helping us with that. Yep, and you said thanks for allowing you to participate, but we can't do it without you, Maria. We can't do it without -

Maria De Leon: Thank you so much.

Rachel Dolhun: - all of the people who participated in the survey. So thank you all, and Dr. Brown, anything you'd like to leave our audience with?

Dr. Ethan Brown: I think just reiterating how grateful we are to the Parkinson's community, both for participating in the research and the survey. I can't imagine a community that could provide us with such information so rapidly when information is important to get quickly in this setting, but also on the design side and really continuing to help us understand the right questions to ask and what matters to the community. So I think just really thanks to everyone and looking out for more opportunities to inform us on this subject.

Rachel Dolhun: Yep, they're with us every step of the way, and Dr. Tanner, any last words?

Dr. Carlie Tanner: Yeah. Sorry. I just echo everything that has been said by that the panelists before. This is I think a great demonstration of the partnership and how powerful that can be in terms of really rapidly advancing understanding and being able to move forward to make change, and I encourage anybody who hasn't yet signed up to sign up and provide us with information and be part of that, and we look forward to learning more as we go forward. So thanks a lot.

Rachel Dolhun: Yep. Thank you, and the survey is still open, as you mentioned, and people can join now and in the future. So thank you all for being here, for sharing your experience, for sharing your expertise. Thank you to our audience for joining us and for being part of our community. We'll be sending a link to the webinar on demand to listen again or to share as you like and we hope you found it helpful. Please stay home, stay safe, but most importantly, stay connected.