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Speaker 1: 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.

Maggie Kuhl: Hi there. Thanks for joining us. I'm Maggie Kuhl, Vice President of Patient Engagement at the Michael J. Fox Foundation and I'll be our moderator for this discussion. I'm thrilled to be here with you and our panelists. And today we're going to be talking about tech tools for living with Parkinson's disease, the apps, devices and technology that support people living with disease today and that scientists are looking to, to have better tomorrows. We're also going to discuss how to find the right options for you, what you should think about when you are considering which tech tools to use or pursue.

We have a lot to discuss, so let me introduce who's here with me today. First we have Richelle Flanagan, who is joining us from Ireland right now. She's a dietician and was diagnosed with early onset Parkinson's disease in 2017. Richelle is the CEO and co-founder of the app, My Moves Matter. Richelle, thanks for joining us.

Richelle Flanagan: Lovely to be here. Thank you for having me.

Maggie Kuhl: And next we also have Claire Meunier who has a vast experience as a health executive and health technology advisor. She was also a colleague here at the Michael J. Fox Foundation for seven years before leaving us for other ventures in 2016. Claire, great to have you back.

Claire Meunier: Thanks for having me, Maggie. Great to be back.

Maggie Kuhl: And finally we have Dr. Siegfried Hirczy, a movement disorder specialist and assistant professor of neurology at University of Texas Southwestern. He researches tech tools for Parkinson's. Siegfried, thanks for lending us your experience today.

Dr. Siegfried Hirczy: Thanks for having me and I'm excited to be here.

Maggie Kuhl: All right, with that we'll kick off our discussion. Siegfried, maybe you could just ground us in a little bit of an education or a 101. When we think about tech tools for Parkinson's, what type of things come to mind?

Dr. Siegfried Hirczy: So this is an amazingly broad thing that when we all get the experts all together, we have to set what are we really talking about? And I like to think mostly about wearable devices, software on computers and phones, and that's things that are accessible to people and that they can try, and assistive devices as well. I think we try to remove things that are technology for sure, DBS, drugs. Those are other things that are helpful, but I think we have to limit our discussions.

Maggie Kuhl: It looks like maybe behind you you had some virtual reality goggles or such. That's the sort of fun stuff we're talking about.

Dr. Siegfried Hirczy: Yeah.

Maggie Kuhl: Richelle, how about you? What does the term tech tools mean to you?

Richelle Flanagan: I think for me it's basically, obviously there's the technology-enabled, using tools that might help with freezing of gait or a tremor, but I also think there's probably innovative design. So it might be spoons that help people eat better, but they're not necessarily tech enabled, but they actually are designed to help counter the impact of having a tremor. So I think it's both ends of the scale. It's basically innovation.

Maggie Kuhl: Yeah, certainly. And so many of these tools are in some way related to movement and as a movement disorder, Parkinson's and some of its aspects are uniquely positioned to benefit from some of these tools. We do want to just set a couple guardrails for our discussion today. If we do talk about specific apps or technologies or devices, we are in no way endorsing one thing over another. This is a general conversation about how to evaluate and utilize these tools. And we also know that some of these may not be available for everyone on the call. There's a lot of different regulations and even just creating these and making them available in different geographies and with different governmental oversight sometimes limits their use.

So Claire, maybe I'll ask you to speak on that. How do we think about regulation of these tools both geographically or just in general?

Claire Meunier: Yeah, it's a great question, Maggie. And I think the first thing that's really important to remember is that not everything that's out there is necessarily regulated. And so you may find apps in the app store that don't have that kind of regulation. You may find devices being marketed to Parkinson's patients and for Parkinson's that haven't gone through a regulatory agency. And when we say regulatory agency we mean places like the FDA, the EMA in Europe, et cetera.

And I think the other important thing to remember is that when things are regulated, they go through country-specific processes. And so what that means is you might find something that is approved in the United States but that is not approved in a European country or in China and vice versa. And so different populations are going to have access to different things based on where those approvals have gone through.

And so when we think about things that get approval more broadly, of course drugs, devices, think of a pacemaker, those kinds of things. In the tech category, there are a few different pathways and now I'll speak more about the US where I'm the most familiar with the FDA. But in the technology category there's something called software as a medical device. There's also something called a digital therapeutic, which I think of as it's a treatment just like a pill is a treatment. But instead of taking that pill, you're actually using an app or technology, not hardware but more software, to help you treat your disease.

And so there are pathways that exist for some of these things that attempt to treat and provide care. And so that alone is a huge advance to have our regulators really thinking about these things and where there are clinical-grade solutions, providing that regulation.

Maggie Kuhl: Great. So that's one piece of the puzzle of what you could be evaluating if this is regulatorially reviewed and endorsed. Well, maybe that, and you also touched on how different tech tools can help us, whether it's therapeutically or managing daily life or I know some diagnostics, we also look at how tech tools can be helping us identify disease perhaps earlier. With that, maybe we'll move on and we'll dive a little bit deeper into how some of these tools can be advantageous or helpful to people living with Parkinson's today.

So symptom and med tracking. Maybe Richelle, why don't you just tell us more about your specific, your app or how others that you have used or that your community has used are related to certain symptoms?

Richelle Flanagan: Well, I suppose in terms of the My Moves Matter app, it was designed basically out of an unmet need of women with Parkinson's in terms of identifying that women's Parkinson's symptoms worsened around their menstrual cycle. And when I tried to find an app that allowed women to do the tracking across their menstrual cycle of their Parkinson's symptoms, there wasn't one there. And that's basically what led me to design or develop that app. And it's been used in two pilot trials, one out of the University College Cork in Ireland and then one through a grant through France Parkinson's in four neurological centers in France.

But I think that's one of the things about apps is a number of them have been developed by people in the community when they've seen an unmet need. And I think that's probably one of the most powerful because you're really developing on the basis of the patient being very much at front and center of the app. There are many different types of tracking apps out there. I was actually having conversations with people before this webinar and there is a sense that there's so many, it's hard to know which to choose.

And I think it's about not getting confused but looking at what you need it for. So is it, you just need it for a medication reminder or do you want to track? Are you a woman who's really struggling with your symptoms around your menstrual cycle and you need something to basically prove that this is a problem for you to your neurologist, for example? So I think it's depending on what your need is.

Maggie Kuhl: Siegfried, picking up on that point, how do you counsel your patients to look for or evaluate specifically tracking apps? Again, I feel like that we just hear so many of those. And then how do your patients show up to their appointments with the readouts from some of these tools?

Dr. Siegfried Hirczy: So I want to echo what Richelle was saying and I think that there are three main steps. One is assessing yourself and understanding what am I trying to get out of this, what are my symptoms, what am I trying to track? And then seeing what the app can do and what is it saying that it will be capable of providing you with? Is it medication reminders, is it symptom tracking? What kinds of symptoms? Do I have to write in everything or is it already an easy option or choose it, that it's already there? And then does it track extra things? Does it integrate your walking data, how fast you're going? Does it integrate your tremor or dyskinesia or other factors?

So the tracking apps, they can do lots of different things at this point and it's expanding day in and day in. But I encourage my patients also to review and think about, okay, what are the benefits and what are the risks of using this and how much time and effort am I going to put into this endeavor? And then talking with your care provider, are we going to come and agree on this? Are we going to use it together? Is it going to be meaningful? Because we want to make sure that technology is integrating and helping and not putting burdens without causing real impacts that are beneficial.

Maggie Kuhl: Siegfried, you had just spoken about the participant experience, what one needs. Richelle, you said many of these are created by patients themselves. Claire, how do tech developers think about the experience of the user and really integrate that into the development of some of these tools?

Claire Meunier: It's a great question. And before I get to that, and this is sort of contrary because I've spent the better part of the last decade working on these tech tools and really thinking about how do we incorporate user experience into those and really meet meaningful needs, but I think the first question that everyone should ask is really, do I need tech to solve this problem? We don't want to be just playing whack-a-mole with tech to try and solve our problems when really that's not the right solution. So I think that's a first important filter.

But when we recognize that going from paper, writing down your medications, to going to an app, where maybe we can share that with family members, maybe we can better track and timestamp things in a more useful way and tech really is going to be helpful, I think the burden is on the technologists creating the technology, whether it's a patient, whether it's a clinician who comes up with a solution or whether it's, I don't know, a large tech company that is developing something to really be integrating the voice of the patient and that patient experience. But multiple patients' experiences because we know that those can really vary from person to person, from day to day, from stage of disease, et cetera.

And so I always encourage the tech companies that I work for to get on the phone with a big group of patients, the ones that are easy to find and the ones that are hard to find to make sure that they're integrating those preferences and really thinking about that. And then it's not just a one-time thing, it should be over the life of the development of the tool and even after the tool is out there and making sure that some mechanism for user feedback is built in so that improvements can have that in mind.

Maggie Kuhl: And I'll just make a plug that the Fox Foundation plays the role often of connecting developers, drug developers, tech developers with people with lived experience. And so if you're on this webinar and you'd like to be part of that work to share, again, your experiences or your use with a specific product, we have a Share Your Story forum on our website where people can raise their hand for those options.

I just want to pick up on something that, Siegfried, maybe I'll ask you if you can recommend. I think we already got a couple questions about fall prevention or fall alerts. I think that that is understandably a really big concern for people living with disease or their loved ones. How can tech help mitigate, prevent, alert if it happens, falls specifically?

Dr. Siegfried Hirczy: So I think that it can be very helpful and there's a lot of passion and research about it and it's a really challenging topic, but we're very interested in, one, knowing that falls happen and the accelerometers that are based in the devices seem like a reasonable way to collect that, though sometimes the data's a little bit mixed. So it doesn't catch everyone's falls, but it provides us with more data. But two, the devices help us understand why falls are happening.

So why was it, was it a freeze? Was it an off state? Is it something that my doctor can fix by giving me more levodopa? Is it something that I'm going to make worse by giving more levodopa because it was actually autonomic dysfunction, I was orthostatic at that time, I'm dizzy? Or is it something independent that really doing a medication or changing it, that's not going to really make an effect, we really need to focus on physical therapy?

And so right now there's some amount that you can get from just tracking your symptoms, seeing when did those falls or those near falls happen with consumer apps, with medical device apps. But then there's a lot of passion about what's coming next about, okay, how is that going to help instead of trial and error with providers and just let's see if this is going to make things better? No, but this shows that this is the direction we should go next. And then there's even more fancy things that I think we can go into.

Maggie Kuhl: So it's perhaps not so much actually impacting the falls themselves but giving you more information on the root cause to then perhaps take other interventions?

Dr. Siegfried Hirczy: We definitely don't want to have the fall, we want to get ahead of the fall. And then there's things that helpfully reduce the fall once it happens, fancy belts that deploy airbags and whatnot, but we want to get ahead of it.

Maggie Kuhl: Fabulous. And just before we move on, just this last category of daily living, we got some questions around magnetic shirts for example. Richelle, you brought up the spoon that absorbs tremor. Do you use any tools in your daily living with PD to help adjust or just benefit day to day?

Richelle Flanagan: In terms of tools like spoons and that, I don't, but I do know that I have to use a heavier glass in terms of drinking water. So I think weight helps in terms of tremor, in terms of an action tremor. And I think it depends. In fact there was just a paper that Michael Okun actually shared and it was about looking at different spoons for people with Parkinson's. And one of the points in the paper was that it depends on the type of tremor and this is something that obviously others can speak to better than I, but I think that's where the personalization comes into.

I mean for example as well, I have problems with micrographia. So I saw this tool, it was a weighted pen. I said, "Oh, that sounds good." And it said it was good for tremor and micrographia so I bought it. But unfortunately for me it really didn't help my micrographia at all, but it possibly helped someone with a tremor. So I think that's where it depends on your individual situation.

I think the other thing as well in terms of falls, there's actually a friend of mine with Parkinson's called Sara Riggare and she uses a rollator and she's about the same age as myself, but she was sort of saying that she had a fear of falling. But actually what she did then was she got knee pads and put them on her knees and it basically took away her fear of falling, so she doesn't actually worry so much. I'm not saying that people shouldn't fear it, but I think there is a psychological and I think there is I suppose looking at things differently. So an app may not be the only answer. There needs to be other creative ways of helping you in terms of managing your symptoms.

And I think just the other thing is in terms of symptom tracking, for some people it can actually make them feel worse because they're focusing on themselves more and it almost highlights the issue. So I think there's almost an understanding of the person and the personality in terms of what the right tool is for an individual. I suppose that's where the relationship with the movement disorder specialist or neurologist who really understands that, the person, the patient, I think is really important.

Maggie Kuhl: That's great and we're going to move on to have some more conversation about those sort of factors and what you use to decide, but I just want to underscore two things I heard. One, Claire, as you said earlier, tech might not be the answer and we tend too often to have a shiny new object and want to try it out. And sometimes it's okay if you do want to try it, but that's not the solution or if it's not for you. And then, Richelle, as you said, really knowing yourself and being, again, I don't think any of these are all or nothing. You might take a break, you're just too much in your disease, you're too much tied to your phone or tech and you can set something down and pick it up and really take what serves you and leave the rest such.

So with that we're going to move on to just have a little bit more of a conversation about choosing your best option. And I want to call out, we got a lot of questions already about where folks can go for some of this information, how can you see what other people are using or is there a rating system? I know I don't buy anything on Amazon before seeing how many stars it has and reading those reviews.

So there actually is a review of sorts for Parkinson's tech tools. It was put together by the Parkinson's UK group, Park Tech is the name of the program. I think it's linked in the resource list. As we were discussing, some of these tools are available only in the UK but some are also available in other regions and it can give you an idea of people's experiences with them. They are all tested very thoroughly with a group of council members and then also collect some ongoing feedback from people who are using the tools. So the Fox Foundation has supported that and we're continuing to look at perhaps expansion into the US.

In the meantime, we do also have our Buddy Network, which is another online system or community where you can definitely talk about tech tools and your experience but also all of these other methodologies, something like wearing knee pads to really just deal with the anxiety of falling. I think that that's really valuable. I don't have to tell those folks on this webinar that the community sourcing is really critical in Parkinson's. And so that's also a place where you can ask questions but also share what has worked for you.

So moving back to our discussion, perhaps, Richelle, I'll just toss to you first. We see some questions on here, credibility, options, cost, for example, what are some other things someone might want to think about when they're looking for or evaluating a specific tool?

Richelle Flanagan: I think one of the core things I think going back to the point of regulation, obviously things that are regulated, they've had to put a lot of massive funding under doing randomized control trials and things like that and they're involved in giving advice. But you've got different apps that don't give advice, that don't have to go through the same rigorous testing as such. But I think I've got a lot of people asking me different questions about different tools.

I had a woman asking about a red light therapy there recently and I said, "Look, I think what you've got to do is go to the community and ask people in the community, so in some of the closed Facebook groups," this is an Irish woman for example, "to ask in terms of how did they find it." Because it hasn't been proven in terms of a randomized control trial yet, but people are finding that it's benefiting them. Whether it's placebo or actually having a benefit, I think at the end of the day, it's about first do no harm and ask in the community how did people find it because some tech can be quite expensive. So I think it's important to have a sounding board and also very much so, talk to your healthcare team about it as well.

But what I would say is that even if your healthcare team says, "Well, there's no evidence yet enough for that," I think there is benefit sometimes using tools. For example, I was having low blood pressure problems and I wanted to track my blood pressure. There was a wearable device that tracked low blood pressure and I found it really helpful. But when I brought it into the hospital, they sort of pooh-poohed it and said it wasn't medical grade. But I actually found it useful in terms of being able to see the patterns myself. So I think there needs to be a recognition that when you've got a progressive neurodegenerative condition then it's causing you day-to-day problems, you will look for things, solutions. And I think people need to be open to that.

Maggie Kuhl: Siegfried, how do you counsel your patients to look for or use these tools?

Dr. Siegfried Hirczy: So I mean similar statements would come out. So again, I think that it's important to know what the evidence is and of course, we want our double-blind trial showing that this is beneficial. But sometimes it's very hard to do blinding for these kinds of studies. You can't blind people to data collection really unless you create fake data and that's hard anyways. And the fact is Parkinson's is different for everyone. Everyone has different symptoms that bother them. There are different stages. And so, even when you do a controlled study, you're just seeing what the average response is and that doesn't mean that some subgroup within that isn't responding or benefiting from something.

So I think the most important thing when I counsel patients is, okay, well, what are we seeking from this? What are we trying to improve? What are the benefits that are supposed or hoped for here and what evidence supports that? And then what are the risks? What could happen if I do this? Is it monetary? Is it, again, effort, time wasted doing this that I could be focusing on some other aspect that has more data that supports its usage? And it's challenging, it's hard and it's hard for providers as well.

I don't like pooh-poohing people's ideas. I think that we should experiment and see as long as it seems safe. And then does that cross-validate? Does what I see adhere, does that converge with what the lived experience is, what everyone else is seeing is happening? Are things going in the right direction? So a lot of the nice things that these tech options, they'll let you do free trials. If they really believe that it's helpful, then they should be giving a free trial because if they don't believe it, then they're just trying to stick you with it. And so I think just testing it yourself is the most important part.

Claire Meunier: Hey, Maggie, just two things to add to that. I do think it's important. I know we all love to scroll through terms and conditions and just be done with it, but I do think particularly for some of these apps where you're giving a lot of personal information or you're putting a lot of data in, really understanding how are they using my data and who are the people behind this? Is it a company that's going to go sell my data to someone? Is it going to be tied back to me in any way? I think those can be really important questions to ask.

And then the second part is usually, at least for me when I download an app, I'm like, "Oh, this is really exciting and I'm using it every day for the first two or three weeks." But taking that moment three weeks in and sort of saying, "I'm spending a lot of time now doing whatever's being asked of me in this app, is it still serving me? Is it solving the original problem that I set out to solve?" And Maggie, you made a good point before, you can put it down. It is not a requirement. So I think remembering that is important and making sure that it aligns with what you thought it was going to do in the first place.

Maggie Kuhl: So what I heard in what you shared is just be really aware of who has made the app. A lot of these are coming from academic institutions or companies that are supported by patient advocacy orgs or such. There's a lot of good out there, but there may be some more for-profit companies that you just want to be aware, make an informed decision, really. Sorry, Richelle, I cut you off. You were going to jump in?

Richelle Flanagan: No, I was going to say one of the things that I find about the apps that are out there at the moment is obviously most of them focus on motor symptoms and the non-motor symptoms often cause us much more problems. So I think that's something that's missing. And I suppose in terms of remembering to include the lived experience of the patient reporting through these apps, I think is important as well.

Obviously I know as well, the burden of having to log stuff all the time. So there's passive apps as well, which are great, but as I said, I think they tend to focus more on the motor. So I think that's a gap in terms of the non-motor side of things because I'd actually prefer to suffer from some of the motor symptoms than some of the disabling mental health symptoms of Parkinson's.

Maggie Kuhl: That's a great comment too on what are you getting back from some of these? Especially in the research space, we use a lot of apps. It can be very hard to ask you to travel to a medical center, and so technology is allowing us to capture a lot more information day to day. Parkinson's is different hour to hour, and so this is giving us a clearer picture of Parkinson's disease, but it's also as we've been discussing somewhat of a burden too. And so how are we giving you back some sort of information either a cumulative report on how your answers have changed over time or the aggregate from the full group and where you may fall across others who are doing the same? So it's something that we talk a lot about and that you should also be using in your evaluation of if you are doing this altruistically to advance science, what are you also perhaps benefiting? What's the ratio of that?

Okay, I want to leave a lot of time for questions because we have a lot, which I think we can keep diving a little bit deeper. We have a large study called the Parkinson's Progression Markers Initiative, which Claire actually launched at the Fox Foundation and I've had the pleasure of working on for the last decade or so. It's really a large scale study to learn more about, as Richelle was just saying, all the different parts of Parkinson's. And the goal is to be able to have this really deep profile of the disease and better tools to advance toward cures. So if you are interested in participating, it's recruiting people with and without Parkinson's. You can learn more at that website, michaeljfox.org/PPMI. And I should say, as we were just discussing, we do capture some data using tech tools in that study as well.

So turning quickly to what's ahead and how we are thinking about the technology of tomorrow, maybe I'll just, Claire, generally, again, as you said, you've been working in this space a lot, where do you see technology going for disease management specifically in Parkinson's or just general health and wellbeing?

Claire Meunier: Yeah, it's a great question. It's a very exciting time, I would say in tech. We've done the low-hanging fruit and the things that are kind of basic interfaces and we're seeing a lot of acceleration in terms of the sophistication of the tech, which I think is really exciting. Lots of customization and personalization as well as what I would call smart technology that remembers your last reaction or your last responses and meets you where you are instead of starting at zero every single time.

In terms of the kinds of solutions I'm seeing lots of tracking and reminders and things that are going to help you be compliant with your routines that are working. Also, virtual care, and I think this is not an area that we've touched a ton on today, but the recognition that not everything requires an appointment that you have to wait multiple months for with your doctor. Some of it could be handled via video visit with a nurse or a nurse practitioner. And also some of those virtual interactions may accelerate the need to see the doctor or may slow down the need to see the doctor. Rather than going in three months, maybe you could wait six months if you have the opportunity to check in with a nurse.

So I don't think we should underestimate the value of that. And it's virtual care, not only for your physician and clinical interactions, but also your physical therapy. I heard about a speech therapy solution the other day. People are doing PT and OT virtually. And maybe for some Parkinson's patients where it's hard to get out of bed and get in your car three times a week to go to your PT appointment, maybe doing it in the comfort of your own home is both easier and also helps you create a home routine to do your exercises more regularly. So I think those kinds of solutions are extremely exciting.

And then last but not least, I hate to even bring it up and we'll time box this conversation, but artificial intelligence, AI, we're seeing it in headlines everywhere. I think we're certainly seeing use cases for it across healthcare and medical research. Categorically, I'll say a lot of those are more administrative than they are care in terms of being ready for prime time and actually integrated into your doctor's visit. But that's not to say that patients and clinicians alike aren't going on ChatGPT and asking it questions.

And so we can talk more about that. Maggie, I'll let you control that conversation. But eventually you can envision a ChatGPT companion to someone like Siegfried who's co-managing your care and it's technology plus a clinician kind of super power to be able to be more available to you, get you information when you need it, and to know that that's trusted information. And I would say that last part of know that it's trusted information is the big hurdle that I think is preventing AI from fully being there for now.

Maggie Kuhl: A lot on the horizon is what I'm taking away. Richelle, where do you see maybe some of the biggest unmet needs that you think?

Richelle Flanagan: Well, I think actually care, access to care is one of the huge big unmet needs. In Ireland, we have the worst ratio of neurologists to patients in Europe. I know talking to people all around the world that they're often not getting to see, not being diagnosed by a neurologist, getting to see a movement disorder specialist, it's like a needle in a haystack. People don't have access to a Parkinson's specialist nurse. So access I think is one of the biggest problems.

And as a dietician, we know that 90% of people with Parkinson's don't get access to dieticians. And the reality is there's only two dieticians to a hundred thousand people in the world, so it's not going to suddenly change overnight. So that's actually something that we've been working on in terms of developing online nutrition programs to scale access. And I think that's where technology in terms of mentioning about physio, OT, other ways of using, there's a technology in the UK that it's not a real physio, it's a digital physio. And the people report that they were actually more happy with the digital physio than the real physio. Now I know the physio is probably jumping up and down in the audience going, "No!" But I think the point is there aren't enough physios either.

So it's about actually what I call dealing with the low-hanging fruit and giving people access to the information. It's going to make them be able to live better with their condition in between appointments and also allow them, the people who really need to see the clinicians, to get triaged to see a dietitian one-to-one because they need to be on a tube feed or they've got really severe gastroparesis and they need much more input. So I think that's for me, obviously as being a health professional and I see it day to day is people cannot get access to speech, OT, physio, dietitians, and the other most worst accessed is mental health services. So I think that for me is the area that needs to really grow.

Maggie Kuhl: I just want to clarify, we got a clarification question and we're using different international terms. So physio or Claire said PT, physical therapy, physical therapist, OT, occupational therapists. And I just want to call out there, so underscoring, if those listening are not aware, many medical centers offer telemedicine visits. And Siegfried, I'm going to turn to you too with a similar question or just to build on. But there's also a company called Synapticure that started out with ALS tele care and has expanded into Parkinson's disease. I'm not sure if it's US only. Yeah, I think it's at this point. But if you're interested, you can pursue that. It's S-Y-N-A-P-T-I-C-U-R-E, Synapticure.

Richelle Flanagan: I think there is actually, I just saw on LinkedIn that there is a number of Parkinson's nurses I think in the States who've put together an online telehealth services to be able to access Parkinson's nurses as well, which is really great. Sorry, I can't think of the name of it off the top of my head, but it was really great to see that happening.

Maggie Kuhl: We can all Google Parkinson's nurses tele care. Siegfried, same question to you-

Claire Meunier: I was just going to build on something Richelle said, which is we don't have enough providers at the end of the day. And in some respects, the fact that your cadence to go see your Parkinson's doctor every 6 months or every 12 months is a bit arbitrary, right? Because we know every patient's progression is going to be different, their symptoms, when they're struggling, when they're not struggling. And so the opportunity I see with virtual care is for people to get the care they need when they need it instead of just being on this kind of standard routine that is set because it's our best guess.

And so I think between the virtual care and some of the wearables and sensors that can monitor what's going on with patients, think of a world where Siegfried can pull up every morning a panel that shows all of his patients and there's a red light, a green light, and a yellow light next to his patients that sort of says, "This is how everyone's doing." And maybe someone had a fall last night and instead of spending his days with people who scheduled six months ago, he spends his days with the person who fell last night and checking in with them and saying, "How are you doing? Maybe we need to bring you into the clinic." And I think it has the possibility of creating a much better way to provide Parkinson's care and make sure that those who need it most are getting it in the right timeframe.

Maggie Kuhl: I think this is why Claire's in the right position with health tech innovation. Siegfried, before we go over to questions, just same question, or if nothing's been said yet, where do you see us going? Where do you see the biggest needs?

Dr. Siegfried Hirczy: I think there's a lot of excitement and there's a lot of development that's going to be happening. And I think same thing of non-motor symptoms really needing to be tracked, but also motor symptoms that are more challenging to understand. Dexterity is something that, like we were talking at the beginning, oh, the weighted pen didn't really help with micrographia. Well, what component of that is a levodopa responsive tremor as opposed to what is dexterity loss or motor learning? There's so much more going on in Parkinson's than the typical features, I would say, tremor and slowness and stiffness. No, there's even more features.

So I think the wearable devices and data in general is going to be very much better and we're going to find new things that we didn't know about. And hopefully that will lead us to interventions that are beneficial and understanding, especially a lot of interest is in disease progression. How do we slow progression and can digital biomarkers, which are based off of wearables and whatnot, can that help us? Because trials are short and clinical exams are imperfect, I'll go with that. And so can we use things that will pick up on smaller signals and clearly say, "Oh, we're on the right track. This is a drug that's going to work or another intervention that's going to work," and then we can follow it out for longer. So I mean there's a lot of excitement, a lot of things.

Maggie Kuhl: Absolutely. And again, just a plug for trial participation and collaboration with scientists to help us test these technologies and test the therapies using these technologies and also help us keep making them easier for you to use, more reflective of your full Parkinson's experience.

So with that, we're going to move to our question answer. I'm going to say that a lot of people are giving us some flak in the Q&A for not being more specific with which apps and such they should use. So we're going to do a little bit of a lightning round where someone's either asked about a specific app or tool and I'm going to ask if you have any experience or thoughts on it, or someone has a specific issue and would like some suggestions of specific apps. Again, we're not endorsing anything and there's so much out there, it's hard to actually give super specifics and that's why the Park Tech program from Parkinson's UK, Buddy Network, your local Parkinson's support group, your doctor is a great place to go. But we are going to try and service our audience here a little bit so you can pass, but we'll just run through this quickly.

So okay, first one we got is the BeechBand, which is a wearable band on your wrist that gives you a pulsing prompt and can help with motor symptoms, anxiety, depression, et cetera. This is open round. If you've got an opinion, jump in.

Richelle Flanagan: Well, I know Carl and I've watched basically the beginnings of this development and watched it go from literally him understanding that tapping actually helped to improve his speech in particular, kind of a stutter. And it was a friend of his who sort of said, "Well, maybe we could make that into something that you can actually wear that does the beat for you." And it basically iterated in terms of to a BeechBand now that basically, I think it works off potentially around the vagus nerve, but they're looking at the research behind it through Parkinson's UK as I think a collaborator there.

But I've seen a few other devices coming along and doing a similar approach. But one thing about the BeechBand is it's a very reasonable cost. It's only available in the UK at the moment. And it depends, some people find it absolutely transforms some of their symptoms. Others haven't had as immediate, but they found that it benefits once they used it a bit longer. So I think they're still trying to understand what is the actual underlying process that makes the benefit happen, but it's been quite transformative for a number of people.

Maggie Kuhl: Siegfried, were you going to jump in?

Dr. Siegfried Hirczy: Yeah. I haven't had any experience with it among my patients, obviously US, but speaking towards vibrotactile stimulation in general. So again, like stated, it can help some people, but on the class as a whole, I think we have to be a little bit cautious about how much is it helping everyone in general. Should everyone be on this? So there's been some nice data looking at vibrotactile versus laser light for freezing of gait and some small studies there and seeing that the effect seemed smaller for vibrotactile. But I think a lot of people are very interested because it can be achieved with relatively low costs and it does help some people it seems.

Maggie Kuhl: Again, I think the answer for many of these might be it works for some people, it doesn't work for others. We got questions on exactly how to spell it. It is Beech like the tree, B-E-E-C-H, Band. Red light therapy?

Richelle Flanagan: Well, I suppose there's a company called SYMBYX Biome who has been using red light therapy in Parkinson's patients for a good number of years now. And I think they are certainly, they've launched a randomized control trial to see to actually prove the outcome. But they have done a trial along the way that seems to have shown that people have been stable along a number of years that they've used it. But again, I think it needs more randomized controlled evidence. But in terms of people in the community, some people have reported again that it's been beneficial, others maybe not so much. So I think again, it's up to the individual.

Maggie Kuhl: Consider the cost, how long? Is it one of those fun masks that's also at the same time tightening your face, maybe two birds sort of thing. This one is really interesting to me. We're talking about tech, our lives, we're on computers. I've got my cell phone constantly within reach. Tech for tech. People with Parkinson's disease can have trouble using a keyboard, using a mouse, swiping on their phones, holding a finger in a specific area to use that phone. How do you deal or are there other complementary, supplementary tech to use tech?

Richelle Flanagan: Well, I'll come in on this one as well because it's something that's my biggest, it's always been my biggest problem is micrographia and typing. It's a real frustration in terms of keyboards and using mouses. I've tried everything. There's a thing called a roller ball, which is quite good. It has a, I don't know, I can actually show it to you here. I don't know if you can see it there. So basically it has a roller ball in the middle. Because the problem is when you've got rigidity and stiffness in your arm, sometimes it's hard to move the mouse. So this is in front of you so you can just flick the roller bowl to move your mouse.

I think then in terms of my phone, I find it really frustrating on my iPhone, when I'm sort of going off, I just find I'm hitting the buttons and missing. And what it does is it actually interferes with you communicating with people because you stop. You go, "This is just too much hard work." But for example, I've seen now the Samsung Pro actually it has a lot more accessibility options on it. Now, it's expensive, that's the only problem, but it also allows voice.

You can actually record calls and it'll transcribe calls for you. So from a working perspective, that's really important. And in terms of voice recognition, I've used various different, and it's really poor what's out there in terms of if you're trying to work in terms of some of the voice recognition tools. So I think there is a need for really someone to really delve into that area to help people who are still working, or people who still want to communicate because that's a big part of being human.

Maggie Kuhl: And in our world today, it's increasingly more required to use these tech tools for such. Okay, an area of interest, Siegfried, put together a funding proposal, come up with something great. Maybe speaking of doctors, we talked earlier, symptom tracking. What tools would you recommend to track your symptoms so that when, to Claire's point, you've got that scheduled appointment six months out, you have some more real data on how you're doing.

Dr. Siegfried Hirczy: I'm not supposed to hype any brand or company?

Maggie Kuhl: No, go ahead. You can share what you have seen work.

Dr. Siegfried Hirczy: I use Strive. I like their UI from a clinic perspective.

Maggie Kuhl: User interface.

Dr. Siegfried Hirczy: Yeah.

Maggie Kuhl: User interface.

Dr. Siegfried Hirczy: I think it lets us communicate better, clinicians and patients, about what's going on because it synthesizes the data in the way that a clinician is trained to understand it. It's not perfect and if someone comes with a similar thing, great, but it's the one that I've utilized and I find it to be reasonably helpful.

Maggie Kuhl: Great. Okay. That's the StrivePD app and they also are getting more into research and using that data. So we as a foundation are always glad when that comes together. Richelle, you maybe mentioned voice recognition, but are there apps or technology for help with voice strengthening or to improve voice?

Richelle Flanagan: Yeah. So there's a number of technologies. There's one called Beats Medical, which has a number of tools on its app, but one of them is helping with speech and it gets you just do your ahs and do all those exercises and check in how you're doing over a period of time. There's also teletherapy is actually a tool that actually enables speech therapy through telehealth online using an app as well as access to speech therapists. I'm trying to remember the one, there's another speech app, speechify I think it's called.

But the other thing then is in terms of tools, there's a thing a called an EMST, expiratory muscle strength training. So basically it's something that I was diagnosed with very early, dysphagia, because people with Parkinson's can have this problem where their swallow in terms from their mouth to the back of their throat can be affected. And it basically helps to strengthen the breathing muscles, and there's actually quite good research behind that. I think they might've now developed an app to go with it, but that's something that I found very beneficial as well. And obviously then, in terms of just speech, there's the likes of LSVT LOUD. And there's another provider, I'm sorry to them, I can't remember their name.

Maggie Kuhl: Oh, no, that's eight. Again, I think you're giving us a lot. Next one, maybe Siegfried or again, Richelle, I love how educated and informed you are on this topic, mental health. And we've talked a lot about telehealth counseling with providers, but are there certain apps that can help people deal or to connect with resources or community, what have you, around mental health challenges?

Richelle Flanagan: I actually don't think there is anything that I'm aware of specific to Parkinson's. I think from a mental health point of view, it probably at the moment it sits in the realm of community support where people get that mental health by sharing. So we were just talking about a number of us use an app called Marco Polo, which is a video app that you can leave video messages for each other. And so I know during lockdown, after I had met people at the World Parkinson's Congress, young onset women, it was really supportive in terms and we were able to share our ups and downs with people who really understood what we were going through. So that I think is really important, community.

But I think there are apps, there's one called Woebot, which was developed for depression, sort of a general app. I think it was actually targeted originally at postnatal depression. So it actually is a bot that is trained to have conversations with you and I think to alert when there's any issues. But I'm not familiar of ones like that in Parkinson's and I think it needs to happen.

Claire Meunier: Maggie, I think potentially that's a good reminder is there may be some solutions that aren't Parkinson's specific that are quite helpful for Parkinson's patients. And that's something I think for people to consider.

Dr. Siegfried Hirczy: I would echo that Parkinson's specificity is nice, but people with Parkinson's have anxiety and depression and other things, and that came before and Parkinson's contributes. But as far as we know, we don't have a lot out of pimavanserin, that most things work. They work in the healthy population, general population, Parkinson's population, those things work. So the apps that you see for BetterHelp and whatnot, those can be helpful, very helpful in people with Parkinson's.

Maggie Kuhl: And I love, Richelle, too, your point about connection and that that is indirectly so beneficial. I'm going to upvote Marco Polo, which if you're not familiar with, it's like a FaceTime, but on your own schedule and also with the problems of using your fingers or thumbs to text. You can send a video message to anyone and then they watch it when they can and they record back when you can. So there's probably a lot of other tools like that. Social media has a lot of its downsides as well, but it also can help you feel more connected and stay just engaged and up to date with your loved ones, no matter geographic or other limitations. And so just another underscore for using tech tools to promote connection because that's really important when dealing and living with Parkinson's disease.

Maybe, Siegfried, again, general question, you could probably all give different perspectives, is placebo a impact of consideration when evaluating or using app or device? And sometimes I like to also ask, does it matter?

Dr. Siegfried Hirczy: Yeah. So you preempted it for me. So placebo is a strong and good thing. It's an effect that we doctors make just by sounding confident and being there for people too. So I think fundamentally going to the root of the question, placebo responses are present with apps, with wearables, with all of these technologies. You can tell people this is a placebo and they will still have that reaction that it seems like it's helpful, but that's not necessarily a problem. If it helps you, if it makes you feel good and it's not causing any significant harms and the benefits outweigh that, then continuing on with it. And then the science about whether it's helping or not, that's another question, another realm.

Maggie Kuhl: Okay. Well with that, I'm going to ask us to go around and just have maybe a general last comments or thoughts for our audience about technology both in their daily life with Parkinson's today and maybe how they can be part of a future with or without technology towards a better tomorrow. So Claire, maybe I'll start with you.

Claire Meunier: Yeah, [inaudible 00:52:30] opportunity. And Richelle, it's something you mentioned is just like as you're vetting these things, ask, is this too good to be true? Does this feel legit? What am I missing? Just as you would vet the decision to make a large purchase. I find myself doing this with my parents at times actually as they get older, just sort of like, hey, just take an extra beat and then I think sometimes you'll get a different perspective and give you things that you didn't think about.

I feel I've devoted my life to this health technology or my career life to this tech health technology space over the last 10 years. It's come a long way. There was a lot of tech developed without patients in the early days, 10, 15 years ago. And I'm encouraged to hear and see that so much of that has changed, and I certainly spend a lot of my time encouraging companies to do that. And I think what we have now is extremely exciting, but that curve of what's possible is only going to accelerate. So I think continue to watch this space and stay engaged with it.

Maggie Kuhl: True. We really didn't touch on just how fast these things can change in new apps. So it could be a full-time job to try and evaluate which tools. So Siegfried, same question. What do you want people to walk away with?

Dr. Siegfried Hirczy: So number one, be excited. Things are happening, things are getting better. Number two, be a little skeptical. Make sure and check in and see and do the steps that we recommended and talked about for validation. And then three, we really need people who are very interested in this technology, people with Parkinson's, people who take care of people with Parkinson's, everyone in the community at large to be interested in this space, to get involved in research studies, to bring their feedback about what's going right, what's going wrong with these things. And then hopefully all together, we'll move and hopefully eventually cure Parkinson's.

Maggie Kuhl: Right. And Richelle, the last word's yours.

Richelle Flanagan: I think the N-of-1 is really important, which is you are the expert in your condition. And often when people are maybe more advanced, the care partner is the expert in their loved one and I think they need to trust their gut. I think we have to be very careful that there isn't a digital divide in terms of technology for the haves and the have-nots. So I think there's an element of sometimes, for example, I do a callback service, a dietitian one for Parkinson's Ireland, and a number of people don't want to do a Zoom call. They'd prefer to do a phone call. So we can't leave out these people as well. I suppose we have to look at that as well.

But I think it's looking at what works for you and not to regret not trying something as long as it doesn't do you any harm. I think that's the most important thing. And then taking a punt if you can afford it to try something, but being aware that there is a placebo effect. And I didn't realize, obviously it boosts our dopamine, but if it boosts our dopamine, it makes us feel better. Is that such a bad thing? I don't know. I don't think it is.

Maggie Kuhl: Great. Well thank you to those listening for being a part of our community and for joining us today. And thanks to our panelists for sharing your time and expertise. We hope you found today's discussion helpful. Thank you and have a great day.

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