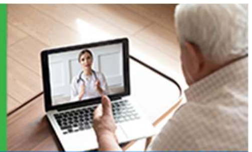


Transcript

Welcome and Introductions

Rebecca Gilbert, MD, PhD

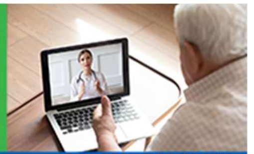
[Slide 1] Thank you so much. Welcome everyone. Thank you so much for joining us today. **[Slide 2]** My name is Rebecca Gilbert, and I'm APDA's Chief Scientific Officer. I am pleased to welcome you to this Web/teleconference education program designed for people with Parkinson's, their care partners, family members, and healthcare providers. And I would like to thank, at this point, Neurocrine Biosciences for funding this important program. And I want to acknowledge Neurocrine's appreciation for the critical need to provide educational programs like this one to people impacted by Parkinson's disease as well as their loved ones.

Now we know that you have continued concerns regarding your Parkinson's treatments and you want ways to identify how to live your best life with Parkinson's disease. American Parkinson Disease Association, or APDA for short, is the largest grassroots network dedicated to fighting Parkinson's disease, and we work tirelessly to assist the approximately one million Americans with Parkinson's disease. APDA distinguishes itself as a national organization working one on one with the Parkinson's community to make each day better.

And now to our program. **[Slide 3]** We welcome our distinguished presenters today. We have Dr. Chantale Branson, who is Assistant Professor, Movement Disorder Specialist, and Sleep Medicine Specialist at Morehouse Healthcare located in Atlanta, Georgia, and she's also Assistant Adjunct Professor of Neurology at Boston University Medical Center in Boston, Massachusetts. She is joined by Dr. Drew Falconer, Director of the Inova Parkinson's and Movement Disorder Center and Associate Professor of Neurology at UVA (University of Virginia) School of Medicine at Inova Campus in Falls Church, Virginia. And they are here to discuss with you and share their expertise on telemedicine in Parkinson's disease.

After the presentation, we'll open the program for questions from both telephone and Web participants, and we encourage everyone on the line to complete the evaluation after the program because your feedback is instrumental in helping us plan for future educational offerings, including Web/teleconferences like this and other programs.

It is now my pleasure to turn the presentation over to Dr. Falconer.



Presentation

Drew Falconer, MD

[Slide 4] Thank you, and thank you to everybody who's joining us on this beautiful afternoon. I hope the weather, wherever everyone might be, is as beautiful as it is here in beautiful, sunny Northern Virginia.

My name is Drew Falconer. I am the Director of the Inova Parkinson's Movement Disorder Center here. And it's a real pleasure to be joined by Dr. Branson and everyone else to have a really important conversation today around the subject of telehealth.

These are our disclosures on the screen. It is an important part of all that we do to disclose where we consult as well. And, with that now done, I do want to jump into our topic for today.

[Slide 5] Now telehealth is something in our world that we actually have really loved. Many of us physicians have really enjoyed the ability for our patients to reach us through telehealth. That being said, you will see a lot of discerning voices out there questioning the need or the use of telehealth, especially in a discipline like Parkinson's disease and movement disorders. And so, we want to spend today talking about why, at least in our opinion, this makes sense; telehealth that is.

And I think the biggest reason why telehealth has a real role in our world is not as a replacement to an in-person visit, but simply as a tool that we can use to improve one of the greatest barriers to getting better with Parkinson's, and that is access to specialty care like that which we deliver.

And I mean it, it's on the screen and I'll try to back it up, but telehealth and Parkinson's disease has always been a fine pair. It's something that has always made sense to us who strive every day to make people's lives living better every day with Parkinson's. The reason why telehealth makes sense is that there aren't a whole lot of us. There are not a lot of movement disorder specialists, that being neurologists by training, who do extra training to become specialists in Parkinson's disease.

And for those out there living with Parkinson's or with somebody in their lives who they're caring for or on the journey with them during their walk with this, that Parkinson's is complicated. Parkinson's is a condition that affects every system of the body, and it affects different systems at different times and the hardest part is it changes over time.

The challenges, what we face every day, is that we have a million people in the United States with Parkinson's disease today, a million people. That is going up by the month, by the day, and by the year. But the vast majority of those patients, by recent data more than 90% of those patients, have only tried one medication for Parkinson's disease, and the vast majority of those patients have limitations in their daily living that holds them back.

Well guess what, folks, if you haven't heard it yet, let me be the first to let that as of today, we have 23 medications indicated for the treatment of Parkinson's, 13 of which are new in the last five years. We have four lifechanging pieces of technology. We have tools available today that ten years ago seemed like a pipe dream. But we have all of this advancement, all of this development, all of this

better that we can offer to our patients, but yet very few patients with Parkinson's will have tried anything that we would consider new.

And a big reason why that happens is the data you see on your screen. Only 28% of patients with Parkinson's disease will see a specialist like me. And the reason why that is, is multifold. And if you live with Parkinson's, you can most likely relate to this. Getting to a specialist takes time, it takes logistics, it takes travel, usually, and the cost to that can be big. And so, one of the greatest barriers we see for patients to seek specialty care is distance, travel, and time. In fact, there's a big study that came out in 2020 that looked at Medicare patients – all of Medicare not just Parkinson's – and they said, "Okay, how are we doing for access?" And in that study, it found that 20% of all patients with Medicare traveled outside of their hospital region for care; 20%, that's a lot of people. And the average distance people traveled was 148 miles to seek care.

Now out of all of Medicare, guess what the number one condition was that traveled for care? It was Parkinson's disease. So, within the Medicare community, those over 65, the most common neurological condition where people traveled at least 150 miles to seek care was Parkinson's, right? And so, for us that has always set up a use case for telehealth. If you can come and see me through your computer, through your iPad, through your computer, through your cell phone, then we don't have to worry about travel. We don't have to worry about the logistics of getting someone to bring you or to have your kids take off work and come pick you up. We don't have to worry about distance, time, cost. We simply log in and we can meet with the great technology that we have to advance your care to, hopefully, a better place.

And guess what, telehealth has always made sense for Parkinson's, too. Because as those who have tried to get in with movement specialists, there's a lot of wait time for us. This is another study on the screen you can see that says in the United States as of today the average wait time for a new patient visit for Parkinson's in the U.S., at a movement center like ours, is 2.2 months. But that range is huge depending on where you live and the resources in terms of specialty care that are available. There are some regions in the U.S., especially the Midwest, where the distance to a movement center is hundreds of miles and the next visit that's available is anywhere from six to eight months out. That's not access. That is not easy access. That is not a path to better. And so, that's why telehealth makes sense to us as a tool, not in place of an in-person visit, but to make access easier for those that a traditional visit might leave behind.

[Slide 6] And guess what, prior to COVID, we've actually been able to do telehealth for a long time. In 2018, there was a study in Parkinson's patients in terms of telehealth, and this was in the U.S. prior to the pandemic, that showed that in the Parkinson's population in 2018, only 38% of patients with Parkinson's could complete a telehealth visit. And the reasons why they couldn't were numerous and there are things that seemed to make a lot of sense in retrospect. So, to do a telehealth visit, you have to be very comfortable with technology, you have to be able to interact with technology, and follow detailed instructions to log in easily. Some people said no to telehealth because of privacy or security concerns. The platforms we were using were kind of junky. And then for a lot of folks the availability of good Internet connections was really limited prior to the pandemic.

Now there was a glimmer of hope that came from this data. and that hope was, and this was a study that came out before the pandemic started in early 2020, so pre-everything. It showed that the patients who in the U.S. did end up doing telehealth visits that 80% of those patients said it was the bee's knees. They said it was fantastic. They said it was great because they didn't have to worry about distance, about travel, time, logistics; all of these things that have classically been barriers to accessing specialty care like ours.

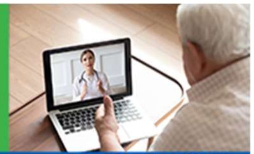
[Slide 7] And then the pandemic happened, and we all got better at doing what we do every day. If nothing else, the pandemic allowed us – by us I mean us as healthcare and you as patients and their care partners in their world – it allowed us to become a lot better at telehealth. The technology advanced very quickly, the platforms became a lot easier, and we all became much more comfortable with technology, using technology, and the awareness of the access of telehealth just exploded overnight. And in many ways that is a good byproduct of what's happened over the last few years is that we have been able to take a tool, telehealth, that allows us to reach patients that otherwise a traditional visit would leave behind. And it's allowed us to meet them where they are.

And, in fact, our center here at Inova Health, we looked at the first nine months of the pandemic, so the last nine months of 2020, and at that time we had three movement specialists. So, at that time we were at three of us movement disorder docs (doctors). Now we have five of us. But at that time, we saw in nine months 1,097 new patients. And of those patients, 85% were via telehealth. So, the vast majority of our new patients during the first nine months of the pandemic were through telehealth.

And we have all kinds of data from that study that talked about the benefits that that telehealth experience gave to our patients. But the biggest one is that almost 100% of those patients who we saw via telehealth had never seen a movement doc before. So, that's evidence that telehealth is a tool, and it's something that we all need to realize is available for the most part and we need to use it for the tool that it is, which is to make access easier.

[Slide 8] Now there's some pros, there's some cons to it. So, I want to run through those very quickly and then I'll pass the baton to my good colleague, and we can talk more about how to get prepared for those visits and how to maximize that opportunity. But as you could guess, the benefits for telehealth are what people who do it every day can tell you: it is rather easy. It's like riding a bike. Once you figure out the process that goes into being part of a telehealth visit, it tends to flow easily into the future and all of a sudden, you don't have to worry about distance, about travel, about time. We meet anywhere. We've done telehealth visits on the golf course. I've done telehealth visits in a parking lot. I've done lots of telehealth visits where patients are at work, and they simply close their door, and we do their visit, or very easily, I can't tell you how many people I've enjoyed watching eat breakfast as we talk about their Parkinson's disease sitting at their dining room table because it's that convenient.

There's a lot of data coming out, so feel comfortable that the telehealth experience is relatively on par with an in-person visit. Those of us doctors that do a lot of telehealth have really gotten good at using tools that we have available and physical exam maneuvers that don't require us to touch you to see how you're doing. I can't tell you how much better I am at looking at how people walk now than I was before the pandemic. Because you can tell a whole lot about how someone's doing with Parkinson's



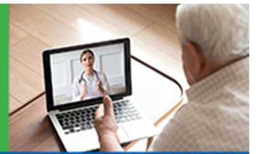
and how their medicine is, how their mobility is, just by watching them walk up and down the hall. And we have data that supports that the outcome measures of telehealth-based services, even in Parkinson's, are relatively on par with that of an in-person visit. And the final is that a real benefit is it's just so much easier.

So, if you call us up or message me and say, "I really need to see you, something's going wrong", finding a time for you to come in in person to do a sooner visit is kind of a game of moving the ball in the shell, right? I have to find a time I can fit you in that works well with your transport and your logistics, and it tends to be a real challenge. A telehealth visit though, is easy to add onto the schedule. Usually I tell folks, "Okay, we'll do a telehealth visit at 8:45 in the morning before clinic starts. We can go through what you need and slip you in a lot easier". Follow-up visits, fit-in visits, even DBS planning, deep brain stimulation planning, is a whole lot easier now, for us, because of the option of telehealth.

[Slide 9] But then there's some challenges, and we still are trying to figure out how to overcome these. And we can talk about this in the Q&A and I know Dr. Branson is going to hint on these as well, or hit on these as well, but there's a lot of red tape and rules that get into the way of telehealth. You still need technology, and you still need the Internet to work. Every now and then we run into a situation where it's just not going to work. The Internet signal is flipping in and out, maybe they're on their cell phone and the cell connection isn't that good, or someone's on, they get all set up for telehealth and then they have a Motorola Razor from 2002, an old flip phone, and it just won't work. So, the technology and the Internet needs to be in place to really allow it to work.

And then another challenge we have, and we run across this all the time, there are still physicians and institutions who are really uncomfortable with the idea of telehealth visits. They think we have to lay hands to truly be able to tell what's going on and fix things. And I always push back a little and say, "Sure, in-person visits are where it's at. That's what we need to do, but if we can see each other in person once or twice a year and fill in in between with telehealth visits, then we're getting that touch point while also utilizing the tools we have just to make it so much easier."

And then a big one is licensure. If you haven't heard this one yet, during the pandemic for the first 10 or 15 months of the pandemic – even I think it was a little later than that – Medicare and CMS (Centers for Medicare & Medicaid Services) passed a rule where physicians could practice outside of their state of licensure through telehealth, and it was okay. And then all of a sudden, about a year and a half to two years in, all of the state licensure rules, the boundaries, started to get put back into place and you would end up in a situation like mine here in Northern Virginia where I'm licensed to practice medicine in the state of Virginia, but if you are ten minutes that way in Washington, DC, technically we can't do a telehealth visit because I'm not licensed to practice medicine in D.C. If you're 15 minutes that way in Maryland, we can't do a telehealth visit because I'm not licensed in Maryland. But if you're four and a half hours that way on the other side of Virginia, we could do a telehealth visit. It's arbitrary, it's stupid, everybody knows it and it's ridiculous. But it's a licensure thing and so, it requires these licensing bodies to come up with agreements to allow for cross-state telehealth and there's a lot of advocacy going on behind the scenes to try to fix this significant limitation to this wonderful tool.



Then the final challenge that you'll hear is that there really isn't a physical exam. We can't lay hands on you through telehealth. We can't do Botox injections through telehealth. We can't adjust a DBS through telehealth except with the Abbott system which can. So, there are certain things in our world that we still need you in person to do, but it takes thinking about this a little differently. It takes realizing that the tool of telehealth is there not to supplant an in-person visit, but to be an option in place of if the logistical reasons make sense.

And so, I challenge everybody to think about how telehealth might fit into your world and how it might make your daily life easier and then to find those people and those partners that can help you make it happen.

And with that, I am pleased to pass over the baton to my colleague. **[Slide 10]** Dr. Branson is going switch spots with me and then take you through the second half of our day.

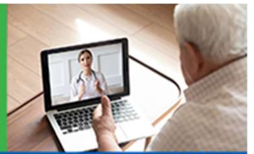
Chantale Branson, MD

Thank you. Thank you, Dr. Falconer, that was fantastic. Everything that he stated is so true, especially when talking about at the beginning of telehealth. So, our institution, luckily, we were able to transition to telehealth prior to COVID. And what we've heard over time is that mainly people who have challenges with using the platform, or using the Internet, or using the hardware of some sort that's the main challenge or burden. So, the most important part is to talk about the pre-visit. Once you become comfortable with the platform that your particular physician or clinic uses, it can be a bit easier and less cumbersome, if you find it to be cumbersome. As stated, with COVID, it kind of pushed us forward a little bit and that was the one positive thing that we can possibly talk about as well.

So, the pre-visit, basically, we want to make sure that you have an understanding of what is expected of you during the visit. You want to kind of review whatever information the clinic or the physician or the staff support team has provided to you. Some places will email you something. Others may provide you with a printout and sending that over to you. Reviewing that making sure that your software is compatible with what they need to have in a successful visit. You want to make sure you understand if you can use it on your phone or if you need to have a laptop. Going back, again, to talk about the Internet connection. Sometimes, that can sometimes be a challenge, but these days a lot of the systems that we use are compatible with both either a laptop or a cell phone, so that can be good. You can switch easily to a cell phone, if needed.

But just finding out that information and sometimes even using it, going through their preliminary steps prior to the visit, is important and essential. It makes you feel more comfortable with using the equipment if you have not done a telehealth appointment before or if their hardware or their platform has changed since your last visit, it is important to try to use that and maneuver it to make sure that you feel as comfortable as possible.

So, the instructions should include the type of device that you need to use and sometimes it may include the Internet browser that you should use. Sometimes one browser works better than another one. They may have a preferred browser, so just looking at that and making sure you understand it prior to the visit. Even calling the clinic or the support staff team prior to the visit is really beneficial



because you want to make sure that you have a grasp and understanding of what is going on. And if you don't, maybe they can walk you through it.

Other times, we've had loved ones, family members, friends, neighbors to kind of assist with that as well. So, if for some reason, there's issues with connecting with the provider or the clinic prior to the visit, reaching out to someone you feel comfortable with who wouldn't mind walking you through that is also beneficial.

Hopefully, you will have received your instructions, including a link, that you will use on the day of the visit. And you should just go ahead, unless the instructions say something else, go ahead and try to use that. Try to see what it's like to log in. Try to just make sure that you have everything set up the way that you like it prior to the visit.

[Slide 11] On the day of the visit, you want to be able to log on early. You want to get into the system. Once again, you should be comfortable, or at least more familiar with it, even if you're not comfortable with it. You want to be familiar with it and have a basic understanding of how to use the software. And then you want to maybe possibly be patient. Be patient with the technology because there can sometimes be glitches. Once again, the unknowns, the unpredictable parts of it is usually the Internet service or the connection. Sometimes those can be a challenge. If you have the capability to have another device available, if needed, that's always good and/or the provider or the team of people that you will be seeing may be running slightly behind. So, logging on early, being prepared, understanding that we're going to kind of go with the flow a little bit with it.

You also want to try to make sure, to the best of your ability, to not perform any other activities outside of the visit. Some of the things that I've seen in my clinic, and I'm not sure if Dr. Falconer can attest to some of this but sometimes people are driving, which can be not only a distraction but a hazard; it could lead to an accident. So, typically if I see that, I try to ask them to not drive. What we do in our clinic is we have the medical assistant reach out to them first and tell them the instructions, make sure they understand them and that they've used it and then ask them to log in within five to ten minutes prior to the visit to make sure there are no issues.

And during that time that they're having that conversation about the logging-in process, they say, "We really want to take this time to focus on your concerns and your needs during the visit, so if you cannot do anything that's just not distracting such as driving, using the bathroom, sleeping in the bed or eating breakfast." It's fine to eat breakfast. Dr. Falconer mentioned that. That's okay as well, but, as long as you're not like out in a busy restaurant at breakfast time. And it can be hard to really focus on that. You want to limit your distractions as much as possible. Also, check your lighting to make sure that myself as the provider or anyone else can kind of see you clearly.

[Slide 12] During the visit, it is your time. It is your time to discuss your concerns, your questions, your medical problems, anything that is going on with the provider. And to have a really intimate conversation because most commonly my patients are at home, so I get to see some of their surroundings. I get to see if they have someone with them who's helping them, a family member or something of that nature. So, really being able to have that conversation and that's why you don't want to be distracted with other things that are going on.

And while there are certain parts of the physical exam that we're not able to do, there are parts of the exam that we can do and that's why lighting can become important. There are parts of a memory test that we can do. We can evaluate memory, parts of it, through telehealth and that has been very instrumental with the prevalence of the telehealth system. There's certain types of what we call cranial nerves, so these are examinations of your cranial nerves of the face and potentially the hands. These are different parts, so sometimes people can ask you to test for your sensation and that's your senses of your face or your hand, using your hands or test your own strength, how fast. We have fast finger movements. We can also evaluate you or watch you walking. So, there are different parts of the examination that we can and do test during the visit.

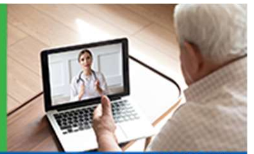
[Slide 13] So, what has telemedicine, and Dr. Falconer have already addressed this at the beginning, so I don't want to be redundant in this, but particularly the impact of the community particularly with certain underrepresented/underserved communities, how has this telehealth impacted this part of the community? We do know that about 23% of self-identified respondents using a survey used telehealth during the COVID-19 pandemic. And we have seen studies that show that it has been very beneficial and helpful with access, getting access to telehealth. Particularly with the software and the platform being a little bit easier to use on the phone. While some people may not have Internet to use on a computer, they may be able to use their cellular data or something of that nature to still have the visit. So that has been just very helpful with regard to improving and streamlining that support and access to care to our patients with Parkinson's disease.

Also, we noted that telehealth visits, of course, are preferred to no care at all. They can be that bridge or bridge that gap between not being able to see, as Dr. Falconer said, your clinician in a year or being able to get them in a little bit quicker because it's a telehealth visit. So, having that connection and bridging that gap between the long wait times or not being able to see a provider in person due to COVID or other issues has been tremendous.

Also, telehealth visits for video were comparable in quality of care to in-person visits among people with Parkinson's disease, as Dr. Falconer already mentioned. And that is pretty new. I think, as stated before, there have been some providers who just want to really, like Dr. Falconer said, just really touch you, really have that personable visit with you where you're in-person together. But I push back on that, and I challenge that a little bit that I feel that our telehealth visits are even more personable. I get to see some of your family members, some of the patients' loved ones, some of the people who are in their home with them, so I can really connect. They can see me. I'm not wearing a mask. I'm not standing back. And so, you really want to consider giving it a try, if you haven't already done it, because what it can do is it can really bridge that gap and it is a lot more personable than I think we thought in the past, if that makes sense.

Finally, telehealth provides an alternative form of communication and connection with people in the community. Living in Georgia, we have different parts of that area that can be a bit more rural and the travel time, as Dr. Falconer has already stated, and the wait time can be a bit cumbersome. So having that different form of communication where you can do a video visit and really have a conversation with them and examine them on different levels can be very beneficial to the community.

And with that, I will hand that over to Dr. Gilbert.



Question & Answer

Rebecca Gilbert, MD, PhD

[Slide 14] Thank you very much, Drs. Branson and Falconer, that was excellent information, and I know everyone listening has learned already a lot and are now ready to ask a question. So, it's time for our Question & Answer session.

One moment please while we poll for questions.

Rebecca Gilbert, MD, PhD

Okay. So, we have a bunch of questions that came in as our presenters were presenting and please feel free to ask your questions now as well.

So, our first question, either of you can answer this, "Is there a directory available by state listing movement disorder specialists who provide telemedicine services and their fees?" Anyone want to take that one?

Drew Falconer, MD

Dr. Branson, do you know of one because I don't think there is.

Chantale Branson, MD

No, but that's a great idea for MDS (movement disorder specialists) to do that. We do have a list of providers who are MDS members on that website, but they do not state if they provide telehealth or not.

Rebecca Gilbert, MD, PhD
It's a great question, yes.

Drew Falconer, MD

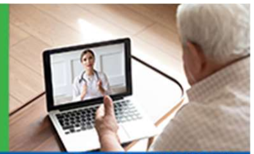
And to that point of fees, in the eyes of all CMS providers, Medicare on down, a telehealth visit is on par with an in-person visit, so it's not a separate fee schedule. So, whatever your in-clinic copay is for an in-person visit, it works the exact same way, cost-wise, for a telehealth visit.

Chantale Branson, MD

The exception with that is people who are uninsured, so if they are uninsured, there may be a fee or a cost and that will be just dependent on each individual provider.

Rebecca Gilbert, MD, PhD

Okay, great. Thank you. So, information to take back to our movement disorder society to perhaps come up with such a list, so thank you for that.



We have another question, and this is sort of stating a little bit of uncertainty with the whole topic of telemedicine and it's stating, "Will this be the new normal, having telemedicine even when it comes to the administration of medications?" And I'm going to editorialize a little. I think what the question is asking is if a medication change is necessary or something's going wrong, is a telemedicine visit really, really good enough?

Drew Falconer, MD

Dr. Branson.

Chantale Branson, MD

Yes. I think that it is our new normal and it is really, really good enough. I think we've been doing this two years, some longer, depending on when it really started for them, that we have become comfortable. There are DBS companies that are allowing us to change their settings with remotely. So, yes.

Drew Falconer, MD

Yes, and back to one of the earlier points, it is so much easier. Think about without telehealth, if you think you have a medication problem, you're going to either call my nurse and go through a loop of trying to find an answer, or you're going to message me through our portal, and I might reply back with - I'll reply back with guidance, but if we needed to see each other, it would be, "Okay, I can maybe fit you in at this point a week or two out and with my PA here, there, or the other." But with telehealth, it literally can be as easy as, "Let's just meet up virtually tomorrow morning" because it's just so much easier logistically.

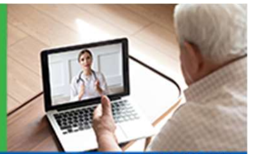
Rebecca Gilbert, MD, PhD

Okay, great. Thank you so much.

We have a question directed to Dr. Falconer. "We are in Maryland. What can we do to permit a telemedicine visit with you in Virginia?" Who makes the decision here in Maryland?

Drew Falconer, MD

Yes. Well so it sounds like some cheeky thing that people said for 100 years, but you really do need to call your congressman or your senator and let them know that this is a problem. This has affected millions of people across the U.S. where during the pandemic, we established a relationship, a treatment pattern and help for folks at home and then all of a sudden very arbitrarily in February – I'll never forget it – all of a sudden, we got a message saying, "You can only do telehealth in the state." And we were having people with appointments scheduled where we had to tell them, "We're so sorry, legally we can't see you anymore." And so, it's a state licensure thing, and it can be remediated or at least helped on a federal level. And there's a lot of advocacy going into it. But if you think it's as ridiculous as I do, call your local senator or congressman. That's really the recourse.



Rebecca Gilbert, MD, PhD

Fantastic. This is a related question. You brought up the concept of advocacy of actually exercising our voice in a democracy, and people on the call may know that there is a National End Parkinson's disease bill (HR 8585 – National Plan to End Parkinson's Act) that's going through Congress right now. And the question is, "Is the issue of telehealth part of this bill?"

Drew Falconer, MD

Oh, I don't know. Dr. Branson, do you know?

Chantale Branson, MD

I do not know.

Rebecca Gilbert, MD, PhD

I can at least speak to this if you are okay with that. And just to clarify, the bill, whosever asking the question, is a very, very generic bill. It's basically saying, "We are going to form a plan to end Parkinson's disease." And so, the answer is yes on sort of any issue that touches Parkinson's disease will hopefully become part of that bill. So, back to Dr. Falconer's point, definitely raise your voice, get that telehealth information so that the congressmen know that that's a big issue for you.

Drew Falconer, MD

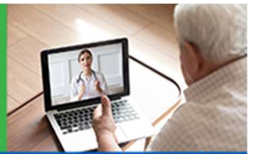
And if your voice is quiet, don't forget speech therapy; it works fantastic to make that voice even louder.

Rebecca Gilbert, MD, PhD

Very good. So, we now have some additional questions that came in earlier before the webinar. So, someone asked, "We have a three-hour drive to see our neurologist in person and that can be very stressful. Is that three-hour drive worth it? Do we keep doing telehealth? What are the benefits of in-person visits? Should we do some visits in person, some visits telehealth? How should we proceed from here?"

Chantale Branson, MD

Yes, I can take that. Yes. I think a combination is really good. You know, you don't want to not go in. It just depends. It will be an independent decision because it's just based on the care and some of the problems or some of the problems you may or may not have. So, therefore, I think the best part of telehealth is that you can do both. You can come in and do that three hours or you can do the telehealth. And there's no either/or; you can do and. You can do both if you need it.



Drew Falconer, MD

And ask your doctor, right? I get questions all the time through MyChart, "Hey, do you think we can do our next visit through telehealth?" And I'll honestly tell you, "No, no, you really need to come in," or "Yes, absolutely! Just don't drive while you're doing it." Dr. Branson mentioned it. I can't tell you how many people who we will log into the virtual visit and I'm on their lap looking up at their nose as the world is whipping by. And I'm like, "This is not safe. You need to reschedule or pull over because, no." It's crazy. Don't be driving.

Rebecca Gilbert, MD, PhD

Don't drive. Don't see a doctor and drive, that's the lesson.

Drew Falconer, MD

Yes.

Rebecca Gilbert, MD, PhD

I have a great question here. "I live by myself, and I don't have anyone to film me during my telehealth visit. Will telehealth still work for me?"

Drew Falconer, MD

Yes, I can take this one. Yes. We see a lot of folks who live alone and don't have let's say a camera person there to help. As long as you can get logged in on a computer or your phone, we can still see a move, right? We can still angle the camera and watch you walk up and down the hallway. I think being solo wouldn't be a reason not to do telehealth. Though it does bring up a good point that I know Dr. Branson always speaks on, and we all do, is that no matter who it is that's in your world with you, whoever that partner is that goes through that journey of the day with you, always invite them to come. In person, on telehealth, we get so much good information from that person who's on this journey with you. It's most likely a spouse or a child, but for a lot of people it's their friend who sits next to them at church. It's their person they go to dinner with. I had a guy yesterday that he brought his Elks buddy that he sits at the bar with three days a week. You know, bringing that person into the clinical environment is incredibly helpful, and it's helpful especially with telehealth because they can help too.

Rebecca Gilbert, MD, PhD

Excellent. We have a great question that just came in about speech therapy. So, "Can ancillary services also be done by telehealth and what about platforms such as Luminosity, where you're engaging a virtual sort of therapy?" What do you think about those two issues?

Drew Falconer, MD

What do you think, Dr. Branson?

Chantale Branson, MD
Yes, and yes. Yes, definitely. At least where I'm at they were doing that during COVID, speech therapy virtually. There were groups. I'm not familiar with Luminosity, so I might have Dr. Falconer speak on that one, but absolutely.

Drew Falconer, MD

The example of Luminosity is a good one. That there are a lot of things we can do virtually to help issues. Luminosity is a little bit of an odd one though. There's data that maybe it doesn't help to the cost of what your subscription requires, but, again, all tools and all things are good, if used in the right context, but a lot of these things are also virtual. Look, our center alone, we offer 50 some odd programs a month of some kind, including exercise and speech therapy. And we get 2 to 400 people at every one because people love the ease of doing technology. So just look for it; it's all out there.

Rebecca Gilbert, MD, PhD

Great. Thank you.

Chantale Branson, MD

And just going back to that, talking about one or the other, it can be a hybrid. Some places are doing in person and telehealth. So, making this our new normal provides you with some convenience of, if you can't make it, if something happened suddenly, you can still attend. You won't miss out on that therapy.

Rebecca Gilbert, MD, PhD

Great. We have a great question that just came in. "I live in Ecuador" So, we're talking about international Parkinson's patients, "Can I get a telehealth appointment with a Parkinson's disease specialist in the United States and what would be the cost?"

Drew Falconer, MD

Dr. Branson, go for it. I need to distill what I've been told. Here, and I'm sure Atlanta too, here in DC, we're a huge international destination, but I have to figure out the easiest way to explain how that's happened over the last three years.

Chantale Branson, MD

Yes, I know, and it's changed, right.

Drew Falconer, MD

Yes.

Chantale Branson, MD

So, the rules were really relaxed, as Dr. Falconer's already stated before, and we were like, "Sure, yes, absolutely." Now I think it just depends on if some people live in Ecuador and the United States and they have residence in both locations and so that would be if you have some sort of residence in the United States in a certain place, then absolutely. There may be a cost if it is international, but I don't think that people have released those fees because it's just going to vary state by state, provider by provider. Like if it's in a hospital versus an outpatient clinic, that will vary.

Drew Falconer, MD

That was a great answer because the honest answer is we don't know. Ask. If you're in Ecuador, call up who you want to see and ask, and they'll be honest. We've had people where we've done international and it worked out, but usually in our center they send in a request and it goes through like a special, I don't even know what it is, and they tell us if we can do it or not or if it's cash or insurance. But I think the counter is we can do it. Like it's doable. The technology works great.

Look, Dr. Branson mentioned one of the DBS providers has the ability to do tele DBS. We can adjust the DBS platform remotely. I had a patient who went to Spain on a vacation, landed, because of the time change and the stress, was just a mess. We connected to her DBS device on the cell network in Madrid, adjusted her DBS, her tremor stopped, and she had a great trip. So, it's all doable, but I think that's an important point of all of this is that the cat it out of the bag. We've built the infrastructure, we've made the awareness, telehealth and our ability to connect remotely is there. We have to keep using it, we have to keep talking about it and we have to keep promoting new and novel ways to increase access. Otherwise, there is a chance it just goes away if people don't find utility at it. So that's an important part of that awareness part too.

Rebecca Gilbert, MD, PhD

Great. Thank you. We have another great new question that came in. "Is Rock Steady Boxing available through telehealth? And I benefited greatly from that program. Not available now where I live. Can I access it remotely?"

Chantale Branson, MD

I think we both are nodding our heads yes.

Drew Falconer, MD

You just have to find the group. There are a bunch of groups that are still doing it remotely.

Chantale Branson, MD

Yes.

Drew Falconer, MD

I know there's a big group in the Boston area that's still doing remote Rock Steady, yes, because it's important. That left hook is a good one.

Rebecca Gilbert, MD, PhD

Very good. Here's a great question. "How technologically safe is a virtual visit using technology? How can I know for sure that unauthorized people won't have access to the visit?"

Chantale Branson, MD

So, that's going to be on the provider side of things. You may not see that, but all of our platforms are supposed to be HIPAA (Health Insurance Portability and Accountability Act) compliant, so we are ensuring that this is a safe visit, that your information won't be released. Now I have seen people have issues on their end and things of that nature, but the software or the platform that all providers are supposed to be using are supposed to be HIPAA compliant.

Rebecca Gilbert, MD, PhD

Okay, great. So, not too many concerns about that, although understandable why people would have concerns in this day and age.

I want to go back to the previous question, who had asked about Rock Steady Boxing. If the person who submitted that question calls the APDA hotline, which is 1-800-223-2732, they will reach someone who will be able to connect them to a Rock Steady Boxing virtual class. So, hopefully, you will do that. That's 1-800-223-2732.

Okay, next question. "Will my televisit be recorded properly in my record like a regular visit?"

Drew Falconer, MD

Sure. I can give a quick answer to that: Yes. The video itself is not recorded, so we don't keep recordings of our visits just like we don't record you when you come to clinic. We, as the physician, when we're doing telehealth, like you're here on my screen, but the rest of the screen is still the medical record and we're entering all the usual info and data that we do in an in-person visit. So, it's the same documentation that we use for both.

Rebecca Gilbert, MD, PhD

Okay, great. Next question, "My doctor suggested that we do a visit over the phone, so presumably just audio, any thoughts on doing it that way?"

Chantale Branson, MD

So, I have done that, but I don't do it as a visit. It's not considered a visit if it's over the phone and you can't see the person. That's a telephone call. And so, I may call them if they have any questions, but

if it's a visit, there has to be video and you have to see the person so that you can speak with them and do some sort of an examination, if needed.

Rebecca Gilbert, MD, PhD

Okay, great. But better than nothing I suppose.

So, someone asked, "Can you repeat the number to call?" in this case for not Rock Steady Boxing but really any reason to call our help line, which is 1-800-223-2732. So, just wanted to repeat that number for the questioner.

We have another great question. "I have had both telehealth and in-person visits, and I find that my doctor is much more willing to make changes in my regimen when I'm in person as opposed to keeping things the same when I do telehealth. Do other people find that to be the case?"

Drew Falconer, MD

That's very provider based, I think, and experientially based. I would challenge everybody on the call because you can't control your doc. As I tell my eight-year-old, "The only person you can control is yourself." Especially his five-year-old sister, can't control her. But it's just a reminder to folks that what you bring to the table is extremely important and so, you can't really tell your doc to do things different. So, think about how you approach the virtual visits. I find that patients tend to be a little more 'everything is fine' through telehealth. So, just a reminder to everybody that how you start the conversation, how you go into that visit is extremely important, and to lead with the things that are bothering you. Lead with the things you want to talk about. And, if you feel like you aren't doing your best, have the courage to ask for a change because it's all about you. And it takes being a confident advocate for yourself to really sometimes move the conversation forward.

Rebecca Gilbert, MD, PhD

Okay, great.

Chantale Branson, MD

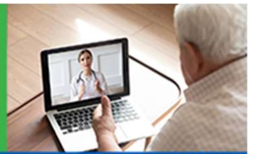
Absolutely.

Rebecca Gilbert, MD, PhD

So not so much about telehealth versus in person, but how you advocate for yourself.

Drew Falconer, MD

If you feel like things need to change, if you feel like you're not able to go to dinner with your friends and you want to, talk about it. Don't just say, "I'm doing fine." Because in the U.S., the average neurologic visit is seven minutes. Don't know if you know that, but it is. And so, what you say upfront counts. If the doc says, "How are you doing?" and you say, "I'm fine." Then that doc, as well meaning as they are, is going to go through their mental checklist and say, "Oh good, this is a quick one." And



then, "Come back in six months." If you lead with, "I'm doing fine, but I really want to do Zumba at 4:00, but I feel like I can't," then we're going to talk about Zumba at 4:00 and how we can get you back doing that. So, have the courage, you can do it.

Chantale Branson, MD

Yes, just to add to that, and that's what we were talking about with the visit, preparing for your visit, that was a part of that. Preparing, things happen, people forget things. Writing down what you want to talk about and having that agenda set so that you can have those conversations. Now you may not get through everything, but just the top three, the top two things that you want to talk about and making sure that you're being heard on that.

Rebecca Gilbert, MD, PhD

Great. We have another question. "Would you recommend that the first visit, as opposed to follow-up visits, be in person versus telehealth?"

Chantale Branson, MD

Dr. Falconer. I mean personally I think it's going to depend. It's going to depend like, I also do sleep, so some of my first visits in sleep are fine with doing telehealth. It depends on the complexity of the nature of the problem, the symptoms, some of the movement problems. It's going to vary.

Drew Falconer, MD

Yes. I'd say don't rule it out. I still see a ton of folks through telehealth for their first visit. They get just as better as the people coming in person. The beauty of what we do is that there are so many options and therapeutics that we can employ to try to help the things that are bugging you. Really, for a first visit, the history is what's important, which we can do over telehealth or in person. And then seeing how you're moving is the second important thing. And then we pair that with your treatment regimen. And for most people how you're being treated, the medicines you're taking, tend to reflect the limitations in your day. And so, coming up with a better, more targeted plan is something I find we can do in person or through telehealth and so I find it to be okay.

Rebecca Gilbert, MD, PhD
Fantastic. Well with that, we have come to the end of our Question & Answer session.

Closing Remarks

Rebecca Gilbert, MD, PhD

[Slide 15] I wanted to, once again, thank Drs. Falconer and Branson for joining us, for your fantastic presentations, for your very thorough answers to the questions. And I apologize if there are any questions that we left unanswered. And if you have a question and would like to speak with someone from APDA in our Scientific and Medical Affairs Department, I encourage you to visit our website at apdaparkinson.org or, again, call our toll-free help line 1-800-223-2732, and you can access even more information then.

[Slide 16] And if you enjoyed today's webinar, we hope you will consider supporting APDA with a donation because with your help, APDA can deliver more programs and services like this one.

[Slide 17] I want you to remember to check out the APDA Symptom Tracker App which is an app that helps you or your loved one track their Parkinson symptoms. The Symptom Tracker is available in English and Spanish and can be downloaded from the Apple Store or Google Play.

[Slide 18] And I want to emphasize to everyone on the phone that we really do appreciate your feedback and comments, and we want to make sure that you complete the program evaluation form.

To join us in this fight against Parkinson's, to learn more about the support APDA provides across the country through our network of chapters and information and referral centers, as well as our national research grant program and our centers for advanced research, please visit us at apdaparkinson.org. We all agree that being informed about your disease and treatment options is the best way to empower yourself and take control of your care.

Have a wonderful rest of the day.