

Dave Iverson: Hello everyone and thanks for joining us. I'm Dave Iverson, contributing editor at The Michael J. Fox Foundation and an Emeritus member of the Foundation's Patient Council. I'll be your moderator for today's webinar. And of course we're here to discuss one of the most important things going on in our lives these days, which is of course the election. We're going to take a look at sort of various things that are on the ballot. What voting will be like this year and how it's of course different from many elections past. And then we're going to drill down into some of what this means for those of us in the Parkinson's community.

What some of the policy priorities are, from access to care to eliminating those things in the environment, which we think may trigger the disease, federal research funding, and a variety of other issues. So we've got a lot to talk about and let me introduce who's going to be with us today to join in our conversation. First of all, Ron Elving, who is a Senior Editor and Washington desk correspondent at NPR news, of course, also a faculty member in the School of Public Affairs at American University in Washington. Ron, welcome, always a pleasure to have you join our conversations.

Ron Elving: Good to be with you Dave.

Dave Iverson: Joining us as well is Dr. Allison Willis. Dr. Willis is at the University of Pennsylvania where she's a neurologist treating people with Parkinson's disease. Her research in particular focuses on disparities in care and disease outcomes. And she's going to be talking about how some of these policies impact people with Parkinson's and some of what government may be able to do to address the current gaps in our care access. Dr. Willis, good morning. Happy to have you join us as well.

Dr. Allison Willis: Good morning. I'm happy to be here. Thanks, Dave.

Dave Iverson: And joining us also is Ted Thompson, who is the senior vice president for Public Policy at The Michael J. Fox Foundation. He'll be able to give us a sense of what the current policy landscape is as it particularly impacts the Parkinson's community and the particular programs that The Michael J. Fox Foundation are advocating. And as importantly, how you can get engaged with those issues. So that will be really helpful for all of us. Let me mention before I get started though, a couple of housekeeping things, which is you'll see on your screen the Q and A box, you can type in your questions for us. We'll spend the last part of our webinar today, the last 20, 25 minutes or so, trying to respond to as many of those questions as we can. We also want to let you know that you can download these slides for future reference and also we have a variety of other resources for you on our resource page, which you can see on our screen.

And that's something that you'll be able to, some of the things that Ted in particular will be talking about, about steps you can take if you want to get involved in some of these issues. On that resource page are a lot of useful things that will help people get engaged in our conversation and in those issues that

matter to us. So let's begin and talk about what's on the ballot this year. Of course, we're going to be choosing people for both national, state and local issues and there are a variety of things that you can do to be engaged in this election. And we also want to note before we begin that the Fox Foundation itself of course cannot and does not campaign for or against any candidate. Instead we advocate for policies and programs that support the Parkinson's community and Parkinson's research.

Before we dig into the specific issues though, I'd like both Ron Elving and Dr. Willis to sort of set the scene for us. And Ron, let me start with you in the sense that we've all seen a particular scene on our television news recently of long lines in various places, particularly Georgia and Texas. People are clearly engaged with this election, but voting is more challenging perhaps this year, particularly for people who want to vote in person. We have many options, including of course something we've all heard about, mail-in voting. So give us your sense, Ron, at this point of what things are looking like around the United States as far as how voting goes and any thoughts you might have on how people can put this in the right context in terms of definitely voting, but voting safely.

Ron Elving:

Thank you, Dave. Thank you. And I will say one thing with confidence about this election and that is that people are more aware of voting and how it is done and how they themselves may need to adjust their behavior in order to vote than there has ever been in our country. Not only is the franchise wider now because women this year are celebrating a hundred years of being enfranchised to vote, but we have gone a number of different miles in different directions to make voting more possible for more kinds of people, whether that was race or expanding the franchise to 18 year olds, lowering a lot of the barriers by which people were prevented from voting in the past. And many of those barriers, as you know, are physical barriers where it was more difficult for people who had any kind of a health condition to get to the polls, to get there in timely fashion, and then to endure what oftentimes has been a truly challenging, standing up, line experience, sometimes worse than anything else people have experienced in just to shop or go about their normal business.

So when confronted with something like this, even a person who is completely healthy and 25 years old might very well decide they don't want to stand in line for hours. And as Dave mentioned, we have seen people standing in line for hours in Florida and in Texas. Not coincidentally, those are two states with a history in recent years, as well as in the far past, of making voting a little more of a challenge, of making it a little more of a privilege and perhaps trying in some aspects to limit the franchise somewhat by making it, I think, a little more difficult for some groups to vote. Now, without getting into all of the politics of that, it is clear that these are states where people have been talking about whether or not you will be able to vote. And that's why so many people are going out early and trying to get their vote recorded.

That's also why you have record interest in mail-in voting this year, and people are really concerned about it. You hear people talking about make a plan, be sure you know your vote's going to be counted and there is going to be more mailed in vote and it's going to be harder to count. And I think we all know that by now. Polls indicate more than half the people in the country realized there probably won't be a result for the presidential result or for many others as of election night as there usually is, because of this later count. So that's the one thing I would say with confidence, as far as the availability of voting, there are more ways to vote. Most states are expanding the possibility of voting early, voting remotely and drop boxes are becoming very popular. Obviously there are controversies around the edges of all of that, but the basic thrust of it is trying to get people involved in an election that is sure to see very high historic turnout, perhaps the highest ever.

Dave Iverson:

Ron Elving, thank you. Dr. Willis, you see patients all the time at the University of Pennsylvania. I know today is normally one of your clinic days and you're sequestering yourself away a bit so you can participate in this conversation. But I imagine this may have come up with patients that you talked to about what should I do, Dr. Willis about voting. Any general thoughts you want to observe about people with Parkinson's particular or their care partners as far as voting. Should you be particularly concerned about voting in person, vote by mail if you can? Just, what's your perspective on that as someone .ho works with Parkinson's patients every day,

Dr. Allison Willis

Those are great questions. So I have been telling, and I've been hearing those types of concerns from my patients and most of the concerns revolve around questions like if my handwriting has changed, will my ballot be disqualified because the signature doesn't match if I mail in a vote? Or if my handwriting is changed and I vote in person, am I going to have an unpleasant or embarrassing experience with one of the poll volunteers because my handwriting has changed? That is a problem that is not unique to Parkinson's. We know that adults who are older adults who have problems with their muscles or their joints can have changes in their handwriting. And there are policies to protect people from being challenged, their handwriting or their signature being challenged excessively because of that. But it highlights the importance of the advice that we've been hearing for months now, which is have a plan for how you're going to vote and try to vote safely by mail.

If you find that you are unable to vote safely by mail, what I've been recommending to patients and their care partners is that they plan for being at the polling station or waiting to enter the polling station for longer than they would have in past years. So there's some practical things to think about such as what you're wearing, having layers in case some of that time is spent outside, making sure you have doses of your medications so you don't accidentally have wearing off of your medications just as you're at the front of the line, your medications wear off and you feel uncomfortable. What I have seen and what I have heard from people doing early voting is actually something that's wonderful. And it highlights for me that we're all Americans and in this together.

And that is what I have heard is that people waiting in line who have had physical disabilities, there have been others who have volunteered to hold their space in line and allow them to sit so that they're not standing, they're not uncomfortable. And so I'm hoping to see that these long lines are all of us exercising our civic duty and responsibility, but I'm also encouraged to hear that there's some glimmers of humanity and kindness. And so if you can have someone go with you who can hold your place in line while you sit comfortably, or if you have a wheelchair or you have a walker with a seat, that may make you more comfortable, but those are things you can do. Dress for all of the weather you might encounter, bring your medications and be encouraged that there are many of us who are trying to do the right thing and take care of each other, no matter how we're voting.

Dave Iverson:

Those are all really excellent points Dr. Willis, thank you. I think we've often thought of voting as being something we can kind of take for granted. And this is a year when that may not be the case. And so having a plan and thinking through exactly how you want to approach it makes all the sense in the world. And it's worth noting that you want to direct people to our resource page again, where there's the Washington Post put together an excellent site where you can just put in what state where you live and it'll tell you all the kind of rules and regulations about how you vote in your state from there's some states where you can still register to vote. There are some states that have early voting, as Dr. Willis was describing. There's some states as in California, for example, where they're going to be remote places, not your usual polling place, where you can actually drive up and vote curbside.

So for some people who have issues with walking, that may be advantageous. So do take a look at that site on our resource page. But Dr. Willis, one quick follow-up question, and then I want to bring Ted Thompson into our conversation to talk about specific issues. But do you generally feel, Dr. Willis, without getting into the politics of this, because we all know that mail-in voting has become sort of a debate politically in and of itself, whether or not people who have serious issues with mobility and Parkinson's, or just because of the prevalence of the Coronavirus. And we know that people with Parkinson's who get the virus, that it poses real problems. Are you urging many of your patients to consider voting by mail?

Dr. Allison Willis

I am encouraging many of my patients to vote safely by mail, as governed by the laws in their states. This is something that we need to think about moving forward. It has probably been problematic for some time where adults who are older or who are ill or individuals who have mobility problems have been shut out of the voting process because of their physical impairments. And so we as a country have to have an enduring safe solution for this because no one should lose the right and privilege of voting because of a physical disability or a physical impairment. So I am encouraging my patients and my loved ones to vote safely by mail, following the rules laid out by their state. And I agree that the link for the Washington Post site is excellent for giving individual state information on how to do so safely.

Dave Iverson: Great, thanks. Thanks Dr. Willis. We're going to move us along to talking about some of the specific issues that are either on the ballot or indirectly at stake here in this election. And a lot of those have to do with the question of access to healthcare. And so I want to bring Ted Thompson, the Senior Vice President for Public Policy at the Michael J. Fox Foundation into our conversation, noting that you'll see at the bottom of the slide for those of you who have the slides in front of you, sort of the big elephant in the room, which is the upcoming Supreme Court hearing of arguments over the constitutional reality of the Affordable Care Act that comes up a week after the election.

Well, we'll come to that in a bit, but I want to start with some of these other things because Ted Thompson, one of the things that Allison Willis was describing was that there may be opportunity in our experience of the last six months to realize that some things like expanding access really matter, particularly for people with healthcare and finding new and creative ways to do that, not just with voting, but we have-

Dave Iverson: So many creative ways to do that, not just with voting, but we have our first item on our list here Telehealth. We've found during this time that being able to connect with a movement disorder specialist, like Alison Willis, can be sometimes done. There're challenges with that, that I'll ask Dr. Willis to describe, but it can be really helpful. There are a variety of things like that we need to think about in order to provide care. So, Ted on that question first, we've seen some of the benefits of Telehealth flexibility, but we want to make sure that that's something that continues on into the future. Give us some thoughts on that in particular please?

Ted Thompson: Definitely Dave. Although I'm going to pretend I'm a candidate and answer a different question first, just real quick. On the absentee ballot or voting by mail issue, we also have a blog that we wrote. Because, 31 States have some sort of signature requirement, 25 of them for verification purposes. What we found and the advice we're giving is, if you have a concern and Alison stated this, but contact your election officials. We have a web page in the blog that gives you all 50 States election officials. We're advising you to call them, don't just rely on their website, because things have been changing so quickly during this that the websites may not be up to date. And we have had several reports of people who have had signature issues. Generally, they've been able to resolve them, but it is a real concern and we've been putting a focus on it. So, be sure to check that blog out. To the Telehealth [crosstalk 00:17:51] possibilities-

Dave Iverson: Yeah, it's a great point. Because we know that cramped handwriting, that can still happen often in Parkinson's, plays directly into that issue. So, thanks for pointing that out. But yes, Telehealth.

Ted Thompson: Well, I feel like we all should maybe do it, because I know my signature doesn't look like it did 10 years ago. On the telehealth, one of the silver linings obviously of what's been going on is, a dramatic expansion of Telehealth. That has been very helpful for the Parkinson's community for a variety of reasons. It's easier,

it's less stressful, you don't have to worry about the travel and things like that. But we've also heard that there are people who have never been able to visit a movement disorder specialist. Because they don't have access to one until the pandemic.

Those people have reported that they've gotten a better care plan, their medications are better in terms of the timing and dosage and things like that. So, we definitely want to keep Telemedicine and Telehealth flexibilities. Just yesterday, we actually found out an item that we were advocating on with CMS, the Center for Medicare and Medicaid Services, we've been pushing them to allow programming of DBS through Telemedicine. Because, what was happening was a doctor could do it remotely, but they couldn't get paid for it. And so a patient would have to like drive to the parking lot of the doctor's office and then it would be remotely programmed. Anyway, we just got word yesterday that CMS is covering that under Telemedicine, under the Telehealth flexibilities. So CMS, and I think this is very bipartisan, there's a broad almost universal support for continuing Telehealth into the future.

Dave Iverson:

Dr. Willis, you were telling me in our conversation we had the other day, that for all the benefits of Telehealth, it works for some and not so much for others. Fill that in a bit more, if you would please?

Dr. Allison Willis

Sure. I absolutely agree with Ted Telehealth is important. It is vital to being able to continue to care for our patients when it is challenging or not as safe to obtain inpatient care and that it should absolutely be continued. It's important for the listeners to understand that Telehealth is not being guaranteed indefinitely at this point. So, there is an expiration for being able to obtain paid Telehealth services. Again, these are non-partisan issues that are important for individuals with Parkinson's disease.

But I think we also, and I'm sure Ted you would agree, we need to go beyond what we currently are doing and what we began to do when the pandemic hit. And that is to make Telehealth and Telemedicine available to even more people. The best description I heard was, we were building the plane while it was already in the air in the spring. What we found is that, we were able to get Telehealth going for many people, but there were lots of adults and patients in my practice who lived in rural areas where they didn't have good internet coverage. We literally couldn't connect easily because they didn't have good internet coverage in their area. Or they had a computer that wasn't compatible with our software. Or they still needed support from a care partner in order to dial in.

There are still some challenges for being able to use Telehealth for most people safely. It would be ideal for us to be able to provide Telehealth to people whenever they need it at every stage of the disease. As we have so much data which shows that we can deliver excellent care via Telehealth. There are some remaining issues with that, and I am hoping that future policies will support, allowing that rural patient with internet coverage problems, that individual with

some cognitive impairment who needs Telehealth support. All of those things are non-partisan policy issues that need to be addressed in order to be able to support our patients.

Dave Iverson: I think one of the ironies of [crosstalk 00:22:56].

Ted Thompson: [inaudible 00:06:57].

Dave Iverson: Sorry Ted, go ahead.

Ted Thompson: I'm sorry. Yeah, I completely agree with that, because we've said for a long time that expanding telemedicine is the goal, providing Telehealth is the goal. But if you're a rural state that doesn't have broadband coverage and you need that movement disorder specialist, telemedicine doesn't really matter if you don't have access to the internet. Hopefully, when Congress finally gets around to doing an infrastructure bill, broadening or expanding broadband internet coverage will be a priority. I just want to know also, in terms of the permanence of this, the Public Health Emergency that enabled the expansion of Telehealth, it has been extended until January 20th of 2021. So, you don't have to worry about anything until that time.

Dave Iverson: Yeah. Good to know Ted. Thank you. We look at a number of things on our list of access to care issues here on the screen. Many of them include the word Medicare, Medicare Coverage, medications that are covered on Medicare, broadening Medicare coverage. And so, one other thing I want to ask you to give us a wider perspective on the status of Medicare right now. Alison Willis mentioned ago, that some of these things should be, and are often non-partisan issues.

But we also know these days that it's very hard to be non-partisan about anything. When it comes to Medicare, something that's enjoyed wide bipartisan support for the 50 years or more now that it's been an existence, where do we stand with that? There's been debates about, for a while, this idea of cutting back on the payroll tax. Having central employees not pay us, concerned about how that would impact the funding support for Medicare.

Give us your big picture look, Ron, at where support for Medicare stands and the possibility of extending some of these things that Ted and Alison Willis are talking about?

Ron Elving: Medicare remains the third rail of American politics, and you've heard that cliché, any politician who touches it risks being electrocuted. That is something that has been doctrine now for several decades. It's ironic to think that Medicare was actually regarded as somewhat radical in 1965, when it first became the law. It was perhaps not as controversial as the affordable care act that came along so much later. But it was controversial, nonetheless, many of the same socialized medicine arguments were lodged against it.

Medicare is not politically, utterly bulletproof, but for any politician in any kind of a competitive situation. And no, I'm not talking about primaries, I'm talking about November elections. It is possible that just by showing less than total fealty to full funding for Medicare. And that includes things that people have come to regard as part of Medicare, [inaudible 00:26:09] been talking about. Anything that is Medicare supported has been considered, in a general election environment in November, to be absolutely toxic. You're not to do that. We didn't hear anything but promises to expand Medicare and expand Medicaid in the democratic debates or the democratic primary debates earlier this year.

But we also know that the federal government has been operating increasingly on deficit spending in recent years and this year we've really blown the doors off. Because of the coronavirus, passing trillion dollar and multi-trillion dollar supplemental appropriations bills, in dollar amounts that would have been unthought even a decade or two ago when we started paying more attention to the deficit.

Social security, while that's supposed to be sacrosanct, Medicare while I believe it does remain sacrosanct, are under pressure in the long run. One party at least is saying that those things can ever be cut and most Republicans feel that way. But depending on which part of the Republican party prevails, in the next several years, it is conceivable that still in power the Republican party is going to come under pressure to restrain at least the growth in what they like to call the entitlement programs. The social security Medicare and some of the pension programs that fall into that category as essential spending, and that are usually not even debated in the appropriations process, that could come under pressure as the federal government finds it more expensive to borrow.

It's very cheap right now, which is a big boon for all concerned. But if down the road interest rates increase, that's the moment, when interest rates start to increase that's the moment when great pressure is going to be brought on both social security and Medicare. At least in terms of the growth, and of course as we know, the prices continue to go up. So, growth is an absolute essential to maintaining current services.

Dave Iverson:

Ron, I want to get your views on what we're going to see in the week after the election, in terms of the oral arguments on the constitutional [inaudible 00:28:13] of the affordable care act in just a moment. But before we get to that, have one more question to you on these various things that have to do with Medicare. From extending Telehealth services, to the cap on how to pocket poss medications, to broadening Medicare coverage for mental health in particular. People want to engage on that particular issue, if you would direct people to how they can have that impact. Again, on our resource page, there's a way to get engaged and advocate on some of these issues. But say a little, if you would Ted, on what you'd like to hear from people in the Parkinson's community who care about those issues in particular?

Ted Thompson: Thanks, Dave. Yeah, we absolutely encourage everybody on this call to go to our policy page. There are a number of different action alerts where you can communicate through a couple of buttons pushed with your lawmakers about the issues we're talking about today. The telemedicine expansion and a number of other issues. If you aren't part of our policy network, you can also sign up to join that on our resource page, that's one way to engage. Actually, a more effective way to engage, beyond email and social media, is by contacting your lawmakers by phone, trying to set up a meeting with a staffer to talk about these issues. And critical to having impact is, telling your personal story, weave in why these policies matter to you. That's the type of thing that will catch the eye of an office holder or a staffer is, knowing why these things matter. Rather than just the broad, "Hey, telemedicine is great, let's keep it." Tell a story about why it's so important to you or your loved one.

Dave Iverson: Great, thanks Ted. Ron, couple things to you, before I ask you to preview the Affordable Care Act, a Supreme court debate. A question came in from one of our participants today, who's concerned about what's going on with the Postal Service. There was a story in the, either the New York Times or Washington Post this morning, about how there are still delays and when things are being delivered through the Postal Service. The person who asked this question was concerned not only about its impact on the election, but Ron as you know, an ongoing issue. Which is worrying about people who get their medications delivered through USPS. How do things stand right now at the United States Postal Service, Ron, and what are the prospects for it's continued support and survival?

Ron Elving: The post office has, like so many other aspects of the election process, become highly controversial. There was a new appointee to run the Postal Service, and he was a major Trump donor, but not a person with a background in the Postal Service. Should it be someone who has made his way or her way up through the post office over the years rank by rank, or should it be someone brought in with a career success in business, organizing logistics?

I think they're good arguments on both sides for that question. But the person who was put in place immediately began taking out some of the sorting equipment that the post office considers no longer necessary. Partly because a lot of what the post office used to do has been taken over by other kinds of delivery services as we all know.

Ron Elving: ... By other kinds of delivery services, as we all know, people order so many things now from Amazon and a little truck pulls up that says Prime on the side. And we know that obviously FedEx and some of these other services have eaten a lot of what had been the post offices main business. So perhaps there was some justification for trying to reduce the substantial deficit that the post office runs by looking at some of that equipment, by looking at some of the union rules. But suddenly the pandemic increased not only the reliance that many people have on the post office, but the reliance that the election system might have on the postal service.

Now, we have lots of other ways of voting besides mail-in, but for people with a health condition, that is by far the safest way. For people with any kind of remote issue, whether it's caused by health or whether it's caused by transportation or age, any issue of that kind, clearly, if they can get a ballot in the mail, either because the state send it out automatically as in some states or because they requested one and got one, that's a great solution for people in those dilemmas.

The post office cutting back on its capacity and saying, "Gee, we don't know if we can handle all that volume in October and November," led to a lot of disputes that went all the way to some courts about whether or not ballots coming in after November 3rd or how long after November 3rd could be counted. I fully anticipate there will be lawsuits and complaints and angry arguments about counting balance that arrived in some States after November 3rd. Some of that maybe, could be theoretically the fault of some of the changes the post office has made to save money. It's also possible that it's just such a big volume that whatever the post office had done, they were going to have a challenge they don't usually have that particular week of November. It's going to be like Christmas very early, and that is not a gift from the standpoint of the post office.

Dave Iverson:

I'm going to turn now to the Affordable Care Act, which has been so much in the news, of course, recently, particularly as the confirmation hearings are going on now with Judge Barrett and Ron, before I get your forecast on that, I want to ask Allison Willis for your perspective, not as a pro and con on the Affordable Care Act Per se, but on the importance of access to care. One of the things that you have a particular interest in, I know, and I've done research in is in disparities of healthcare. And whether you're a fan of the ACA or not, one thing it has allowed is greater access to health care for those who could not afford it, perhaps before, some 20 million people gained access to healthcare through the ACA. And of course, there's the whole question of pre-existing conditions, as we know.

As someone, again, who treats people with Parkinson's, can you just outline us... Again, not so much what's at stake with the loss of ACA, but what's at stake in terms of making sure we are a country that provides access, all people access to care, particularly with conditions like Parkinson's?

Dr. Allison Willis

Sure, certainly. Speaking as a physician in care of my patients, I don't care what you call it, but it is important for us to have enduring laws and policies, which allow older adults and individuals with health conditions to be able to access equitable, excellent care. And regardless of your overall feelings about the Affordable Care Act, there are a few things that it did for older adults, which I think need to stay in place. And the first thing is that it... As you said, it expanded access to lots of services for adults and for children, but generally it expanded access to care. Number two, the Act did begin to close the donut hole. It began the closure of the donut hole, which President Trump then continued to close in a bipartisan agreement in 2018. Again, these are

nonpartisan fundamental issues that affect everyone, and we should view them in that way.

Dave Iverson: Sorry to interrupt. But just for those who aren't familiar with the donut hole, of course refers to particularly what can happen as far as the cost of medications, depending on the kind of health coverage you have.

Dr. Allison Willis Yes. I'm sure everyone, almost everyone is familiar with the donut hole, where when you get close to the end of the year, you enter the coverage gap and you are responsible, or were responsible for 100% of prescription drug costs during the coverage gap, which was around this time of year for many people. Again, the Affordable Care Act began the closure of the donut hole, which then President Trump helped to close completely and a bipartisan agreement in 2018.

Another thing that the Affordable Care Act did, which is fundamental and needs to be retained is that it allowed for preventative care to be provided at no cost to Medicare beneficiaries. Depression screening, diabetes screening, cardiovascular disease screening, mammograms, colorectal cancer screening, nutrition counseling, and annual wellness visits, and Welcome to Medicare Preventative Care Visits. Those are now all covered free of cost to Medicare beneficiaries. And that is something that is important for individuals with Parkinson's disease, important for maintaining the health of their care partners.

There are absolutely some elements of the Affordable Care Act, which were not there before, were not benefits that we had before and should be retained and have been important and beneficial for individuals, especially those with Parkinson's and their care partners.

Dave Iverson: Indeed. And Ron [inaudible 00:38:50], in the interest of time, because we have much more ground to cover. I want to just ask you for a brief observation along the lines of what Dr. Willis was just describing, which is that as concerning as this is, I think there's also a sense that the sky is falling, the Supreme Court is going to hear arguments on November 10th and what's going to happen then. Just because arguments are heard on November 10th, doesn't mean that the Affordable Care Act is going away on November the 11th. And there is, as Dr. Willis also suggests a broad sense of how whether you like the ACA or not many of its provisions from preexisting conditions, onwards or protection for people with preexisting conditions are quite popular. So just give us kind of a quick synopsis, Ron, of how this will likely play out in the months ahead.

Ron Elving: If you were watching any of the Amy Coney Barrett hearings, the last several days, you probably heard more about the Affordable Care Act than you'd ever heard from Congress before, or at least since it was passed initially in 2009. And this was a big focus because of that November 10th date, just one week after the election and who knows, we may still be counting ballots on November 10th. She is going to be part, and she is going to be confirmed. This will be done. And she will be part of a nine member court that will hear this particular case.

It's called California versus Texas. And you hear quite a bit about it, and it essentially asks whether or not you can have this law stand.

If the individual mandate is unconstitutional, this is having virtually everybody pretty guaranteed that they have health insurance, we're all familiar with it from the long time debate over Obamacare. And if you take that out, does that mean the rest of the laws unconstitutional? The Trump Administration has already succeeded in eliminating the penalty tax that people had to pay if they didn't follow the mandate, but the mandate is still there, and it's still important to the entire construct, really of the bill, because it has to do with making of the base broad enough so that insurance companies get enough money in that they can afford to cover things like preexisting conditions.

If you take the mandate out and you pressure the insurance companies and they need to do something about preexisting conditions, the Democrats conclude and you saw all those pictures during the hearings, that many people who depend on the Affordable Care Act will lose their care. So we don't know whether or not even that is true because soon to be justice Barrett was telling us that she thinks there's a possibility you could take that one part out. It could be declared unconstitutional, but it could be severed from the rest of the law, that's the severability argument lawyers talk about and that the rest of the law could remain. And then you had people like Senator Roy Blunt who's very important on the Appropriations Committee for Health. He's the chairman on the Senate Appropriations Committee for Health. He said, "Look, a lot of Obamacare has already baked in..." Well, of course, when they like it, they call it the Affordable Care Act.

But he said, a lot of that is baked in and as Dave was saying, the court's not going to rule the day after this hearing. The court might have a conference on the Friday of that week in which the attitude of the court might become clear, but only to members of the court and their immediate clerks who will start working on opinions. We may not hear the conclusion of the court on that issue for several months. It could be well into 2021 before we even find out what the vote is in the Supreme court on those arguments that we will hear on November 10th.

Dave Iverson:

Thank you, Ron. I'm going to push us forward to some other topics as significant as obviously the things we've been talking about are, there are also a number of more Parkinson's specific, I guess, issues that are in play during this election. And given that our time is short, I'm going to make sure we address some of these and turn to some good questions that have come in as well.

The next topic that you can see on your slide has to do with the elimination, what we're saying of something called disease triggers, meaning those things that are in the environment or that man has added into the environment that we think play a pretty direct role in making people more vulnerable to Parkinson's. And one of the specific triggers is something called a Paraquat, which is a widely used pesticide. The foundation has had a foundation, which

has had a petition rather, you can see it on the screen. You can sign it by learning more about that on our resource page to try to urge a ban of this. But Ted Thompson, this has not exactly advanced with lightning speed. Where is that right now?

Ted Thompson: No, it has not. It is widely used in the United States and it's use is increasing even though over 30 countries, including the countries of the EU and China have banned it. So this is a big market and it's widely used in the United States. Obviously that means that there are some vested interests who don't want to see it banned regardless of the health consequences. To be fair, there are a lot of restrictions on the use of Paraquat and the protections that have to go into it for the workers using it and everything, but that doesn't negate the fact that it is known to trigger Parkinson's and we believe it should be banned. We have a bill that was introduced in both the House and the Senate.

Very broad based bill, well beyond Paraquat, but it does include a specific Paraquat ban, but we're pushing and the community is very activated around these issues. The petition, at change.org has over 114,000 signatures. And we've just noticed a real spike when we talk about environmental issues from a policy perspective or a research perspective. The patient community is deeply engaged and very interested in helping us eliminate some of these.

Dave Iverson: And again, if you're interested in getting engaged as Ted is suggesting again on our resource page, there are ways to do that.

Briefly, Dr. Willis, this has been a long debate in the Parkinson's recent world about what causes Parkinson's. Is it the environment? Is it genetic? Is it perhaps most likely a combination of both? We often say that it's really hard to determine a specific smoking gun, if you will. A specific thing that absolutely causes Parkinson's because environmental triggers are so widespread and it's hard to discern whether it's this one or that one or some combination they're in. But is there now some consensus within the field Dr. Willis, that these pesticides, along with some other environmental triggers. Well, it may be hard to say that Paraquat causes Parkinson's, we do know that exposures to some of these tests makes people much more vulnerable, increases the odds of that possibility. Is that a fair way to put it? Just give us, I guess, a sense of the state of our knowledge in this arena?

Dr. Allison Willis Sure. That is a fair way to put it. You're absolutely correct, we don't know what exactly has triggered Parkinson Disease for each individual person, but that is not that different for many diseases. We don't know exactly what triggers cancer for each individual person or high blood pressure or cardiovascular disease. And we don't have great ways of predicting how a person's individual conditions will progress. Having said that, we no longer need to keep waiting for the day to come, which we have all of the answers for all of the people at the same time.

And my only response to what should we do about Paraquat at this point in time, follow the science. Not knowing all the answers or not knowing the answer for every individual person shouldn't be a barrier to us doing something that could help some people. And there is very reasonable, well executed research that has shown strong associations between high dose occupational Paraquat exposures, and Parkinsonism or brain injury that resembles what we see in Parkinson's Disease.

Follow the science and we should seek to be proactive. If you want to see fewer Parkinson disease cases, you have to take a population level neuro-protective and neuro-preventative action, and that means considering population level exposures-

Considering population level exposures to some of these chemicals that have been shown to strongly associate in study after study with Parkinsonism and Parkinson disease.

Dave Iverson:

Well-put. We can act without knowing absolutely every single thing and when there is a preponderance of evidence, it's certainly motivation to take some of the steps that Dr. Bellus thinks. I want to move us on to the question of Parkinson's registries. One of the things that makes population studies possible is just knowing who has the disease, and in Parkinson's, that's actually not always easy. It seems like it should be obvious, but it isn't. And so the Fox Foundation and others have been active in trying to make sure we collect information and collect actually more information about the prevalence of the disease. And that's done through these registries.

Congress has passed something called the National Neurological Conditions Surveillance System, which sounds a little scary, but it's basically just a big registry. But we need to keep providing ways that that can be funded. Ted, again, sorry to ask you to be a brief on this point too, but tell us where we are, and what you'd like people to do.

Ted Thompson:

Yeah. With the national surveillance system, it has been funded over the past two years, I believe, and funding is in play for the coming year. So we feel very good about that. We feel even better about the partnership that we've been able to create with the CDC and building this out. As a lot of you know, MS and Parkinson's are the two diseases that they chose to do first as a pilot to just enable a proof of concept to make sure that what was fashioned in the law is possible.

So we're feeling good about that. And I'm going to take the opportunity and dovetail immediately into the state registries, because one of the reasons the state registries are so important is the data collected in those states will flow up into the national surveillance system, because the surveillance system, as enacted only has funding that would pretty much enabled the CDC to determined prevalence with specificity or with confidence, but because of the

state registries, that data is going to be able to flow into the surveillance system, making it a much more powerful research database.

So we're excited about that. In terms of other states, I'll just let you know that Nebraska has had the longest Parkinson's registry. Utah did create one as well, with California being the biggest one that is generating by far the most data. Given the financial situation with the coronavirus, the state was not going to fund the registry anymore, even though they had invested \$3.7 million to build it out. But we ended up issuing a grant to the state of California in order to keep that registry going. And I'll mention too, that in Ohio there's a state Senator that has drafted a bill to create a registry. He's going to introduce it next year. And that happened because he knows one of our advocates in Ohio and made the connection to Parkinson's and what can I do? So that's an example of how an advocate connection is enabling us to possibly get another registry in one of the largest states in the country.

Dave Iverson:

It's a great point, Ted, and a good, I think, motivation for all of us to be engaged at the local level, because that's where some of these differences can begin to be made. And as Ted suggests, by creating these registries at the state level that then will make the national registry that much more robust. And I think it also speaks well of what the Michael J. Fox Foundation can do. One of the things, one of the many good things the foundation does, is to step in when needed. And this was a case where the Michael J. Fox Foundation stepped in and helped sustain the effort in California during a time when California, and of course, so many states are deeply challenged by the pandemic.

I'm going to move us on to the state of overall research funding and ask Ron Elving for a sense of this. NIH funding is actually another place where there's largely been bipartisan support, National Institutes of Health funding over the years. And during the last four years of the Trump administration, NIH funding for Parkinson's disease in particular has gone up, and those are positive things you can see on the screen now, this slide that indicates that funding for Parkinson's in 2019 from the NIH is about at 225 million dollars. Now that pales in comparison to how much is spent on Alzheimer's disease, for example, but money has been creeping up.

Ron, just give me your brief sense, if you would about, Alison Willis said a moment ago, follow the science. Would that we could all be supportive of science and see it as a nonpartisan issue, but that's difficult these days. Where do you see that going in the year ahead and whether or not there will continue to be broad-based support for the funding of fundamental research?

Ron, are you there?

Ron Elving:

Yes. Dave, I'm sorry. I was briefly muted there for a moment. I wanted to begin by saying that I do believe there will continue to be broad-based support, bipartisan support, for fundamental research on health questions, and that I think that will include Parkinson's. I think there may be some easing down the

road with respect to the handling of STEM cell research. That has been a political football, sadly, for a very long period of time. Some people probably already know that the President's treatment, the cocktail that they talked about when he was diagnosed with coronavirus, included some treatments that were derived from STEM cell research. And perhaps that will begin to break some of the log jam on that issue and the confusion between that and issues of abortion.

So that is a hopeful sign, perhaps, and I do believe that there will be bipartisan support, but there are two big competitions going on. One is the overall competition for federal resources conducted in the trillions, hundreds of billions, and billions of dollars. And then there is a somewhat more micro competition, competing in millions of dollars between different diseases. And that's just the reality of it. And we all realize that. So fundamental research that can help multiple disease conditions and multiple needs is really the focal point that Congress should have on this. We will probably be seeing some turnover with respect to appropriations. We will see some turnover with respect to the health committee. As we know, Lamar Alexander is retiring. He's been a member of the coalition, a member of the task force for Parkinson's in the Senate, and that will make some difference.

But I think the really important thing here is to continue to make the case for fundamental research that can apply to multiple diseases and also to raise the profile of Parkinson's disease. We all know that Alzheimer's has had a tremendous amount of attention, in part because of Ronald Reagan, in part because of a number of other individuals. This really needs to be mounted as a campaign for each other competing need.

Dave Iverson:

Thank you, Ron. Ron mentioned STEM cell research is also of course on the ballot in California, statewide ballot Proposition 14 is about renewing the state support for STEM cell research. So again, more on our research page if you'd like to get engaged in some of those issues. Here, again, I'm putting up on the screen now or our review of the ways in which you can get involved in all of these issues. Again, on our resource page, you can find out about how to get active, whether that's joining the Parkinson's network of advocates, or sending out, getting action alerts from Ted and others about how to tune in and support various things that are before us that support the Parkinson's community.

We only have time for a few questions. We've had so many big issues to dig through, but let me get to a couple of those. One person raised the question about whether or not that with new medications being approved, hopefully, that there may be a lag time, Ted Thompson, between the approval of new Parkinson's medications, and what's on the formulary for various of healthcare plans. Can you just give us a very quick thought if you would, Ted, on where that stands and what the Foundation is doing to try to make sure that new medications are included within people's various healthcare plans?

Ted Thompson:

Sure. I think everybody on the call probably knows that the vast majority of our population are on Medicare, our economic burden report estimated 90%, may

not be quite that high. So the Medicare formulary is of particular importance. And given that there are roughly 1200 private health plans in this country, it's just not feasible for us to do a strategy to touch all 1200. So what the recommendation is, well, two things. One, we do work with companies in order to try and help get new medications on the formularies. We don't endorse any medication, but we do endorse access to all medications that have been approved. But the other thing that you can do, if you're having a problem is talk to your doctor and see what he or she would recommend. You can also self-advocate by contacting your insurance company and asking them if they will look into adding a new medications. There are things like that that you can do on your own.

Dave Iverson:

Ted, thank you. Just have a minute left. And so I'm going to pose the last question and ask you just for a brief thoughts from each of you. And that is, we live in a time where the words American community almost seem like an oxymoron. We are so divided, often over partisan terms. And it strikes me that, that there is however, a real Parkinson's community, that the Parkinson's community provides for those of us, with the disease, or for those of us who are care partners to people with the disease, a way to really commune, a way to be together. When we're together we don't talk about each other's politics. We talk about each other's medications or about new advances in research. I'm just wondering whether or not there is a way, and I'll start with you, Allison Willis, that as a community, we can perhaps model what it means to work together to find solutions for those common concerns rather than being so divided. Dr. Willis?

Allison Willis:

Sure. Well, I think what we're doing right now today is a great example of how we can begin to have meaningful dialogues about policies and laws that are important to individuals who have Parkinson disease, those who care for them, and those who've love them, and see that our shared concerns, our shared struggles, are nonpartisan. And work together to try to alleviate those concerns, to address those concerns, by following the science, by advocating for healthcare policies that expand access and allow for prescription drugs to be affordable, and allow for us to see providers who have the expertise to make our lives better. Those are nonpartisan issues.

Dave Iverson:

Dr. Willis, thank you. And I'm going to let that be the last word, because we are indeed out of time, but that's a wonderful way, I think, to end our conversation and to motivate us for what we can do going forward. I want to thank Dr. Alison Willis, as well as Ted Thompson, our Senior Vice President for Public Policy and Ron Elving at NPR for participating in our conversation today. I also want to thank my colleague, Maggie Kuhl for putting together this webinar. I haven't done one of these for awhile, and it's fun to be able to do one once again. So thank you, Maggie. And thanks to everyone at the Foundation.

We'll be sending a link to the webinar in case you'd like to listen again or share it with others as well as to take a look at all those resources on our resource page. On behalf of everyone at The Michael J. Fox Foundation, thank you for being

part of our conversation today, and thank you for being part of our community.
I'm Dave Iverson.