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

Carol Blymire: Hello, and thank you for joining us today for this Third Thursday Webinar. My name is Carol Blymire, and I'm a policy consultant for The Michael J. Fox Foundation. And I'll be your moderator for today's webinar. Today, our panelists will discuss Parkinson's policy priorities that advance research toward a cure and support people and families with Parkinson's. We'll talk about how you can reach out to your state and federal elected officials to help influence change on behalf of the Parkinson's community. And we'll discuss the National Plan to End Parkinson's Act, which was recently introduced into Congress and is the first legislation of its kind that will create a comprehensive, coordinated approach to ending Parkinson's. We've got a lot to discuss today, so let's get started.

Carol Blymire: Let's meet our panelists. First, I'd like to introduce Dustin Watson. Dustin is the director of government relations at The Michael J. Fox Foundation, and he played a pivotal role working with Congress on the National Plan to End Parkinson's legislation. Also joining us is Amy Lindberg. Amy is a retired Navy officer and she lives in Wilmington, North Carolina. She was diagnosed with Parkinson's in 2017 and she's an active Michael J. Fox Foundation policy advocate and ambassador. And let's welcome Dana Richter. Dana is a senior policy advisor and general counsel in the office of Senator Shelley Moore Capito of West Virginia.

Carol Blymire: All right. Let's get started. Dustin, I would like to have you get our conversation going. Could you tell us why the Foundation has a government relations team and what role public policy plays when it comes to Parkinson's disease?

Dustin Watson: Sure, sure. Thanks, Carol. So, at our core, The Michael J. Fox Foundation is a research organization. We're looking to enhance treatment for Parkinson's and ultimately, to find a cure. Our approach is aggressive, it's comprehensive, and it takes multiple paths. One path is through public policy created by the federal and state regulations. So, our policy team makes it a point to focus on issues related to things like this is where we engage on issues related to Medicare. And so, we advocate for legislation to make medications and treatments affordable and services accessible, such as things like telehealth.

Dustin Watson: We look at health research funding and we continue to encourage the federal government to invest more, for example, at the National Institutes of Health, Centers for Disease Control and Prevention, the Food and Drug Administration, and Department of Veterans Affairs. We dig into policy issues around environmental triggers for Parkinson's like exposures to dangerous toxins, such as pesticides, insecticides, and herbicides like Paraquat, plus policies for soldiers who are exposed to toxins from burn pits, jet fuel, coming out of battle situations with traumatic brain injury or head trauma.

Dustin Watson: We cover research freedom issues such as access to and the use of medical cannabis, clinical research, and we're working on long-term care issues related to nursing home, hospice, and palliative care services. Finally, and in the spirit of getting closer to a cure and supporting our families, when you wrap up all these issues together and you work with so many different stakeholders, we figured it was time for the federal government to step up and create a National Plan to End Parkinson's, and I know we'll be covering that issue soon so I'm going to pause here and, Carol, I'm going to turn it back over to you.

Carol Blymire: And in addition to the federal work that the Foundation does, I know there's also a lot of activity going on in terms of reaching out to state legislatures and governor's offices in almost all 50 states. Is that right, Dustin?

Dustin Watson: Yes. Our state government relations program is up and running. It's new. Lots of wins this year, which I can cover now or in a few. Carol, I'm going to turn it back over to you.

Carol Blymire: We'll talk about that in a minute. I would actually love, Amy, you have been incredibly active in terms of reaching out to your members of Congress about the issues that matter to you and to others who are living with Parkinson's. Could you tell us a little bit about why advocacy is so important to you?

Amy Lindberg: Well, as a TCE-exposed veteran from Camp Lejeune's contaminated water back in the 80s, I'll tell you, when I finally found out that I had a disease such as Parkinson's and it was related specifically to TCE in the water that I drank and bathed in and breathed from plumes underground, I became very, very committed to wanting to help people learn about the hazards of this toxin and other neurotoxins. I became very much involved with what was a red letter campaign after I read the book Ending Parkinson's Disease. Your former CEO, Todd Sherer, was one of the authors and Dr. Ray Dorsey and others, but I learned about how to advocate through letter-writing campaigns and things like that.

Amy Lindberg: And then, I found out, in The Michael J. Fox website, that you can just go and use pre-formatted emails that can effectively target specific topics to our legislators. And I found out that it's very easy to do that and I started to utilize those approaches and tell my friends about it. And before you knew it, we had hundreds of people writing to our legislatures and getting good advocacy work done with a very easy approach. So, I'm currently in The Michael J. Fox working group for veterans and I'm in the ambassador training. I'm not one that wants to be a spokesperson or is very good at that anymore. I have some mild cognitive issues, so what I found helpful is just knowing that the organization has tools that we can use and simply complete forms, click buttons. I mean, anyone can do that and be an advocate without necessarily getting out and being on TV or a webinar like this for instance.

Carol Blymire: That's a really good point. Dana, who I will tell all of you is coming to us live from Capitol Hill in Senator Capito's office, Dana, you and your colleagues on Capitol Hill are on the receiving end of advocacy and constituent outreach on every issue under the sun, including Parkinson's disease. Could you tell us a little bit about why it's important for people to reach out to their federal and state elected officials and share with us just what some of the most effective ways are to do that?

Dana Richter: Sure. Thanks so much, Carol, and thanks, everyone, for having me join you today. As Carol mentioned, I am coming live from the Russell Building on the summit side of the capital. Well, first of all, one of the reasons that advocacy's so important is we can only act on what we are asked to do and what people and what we know is going on. So, I often tell people that, when I'm meeting with them, there can be some wonderful, wonderful bills and some wonderful, wonderful things going on, but unless I know it and my boss knows it, we really can't be effective in working on it.

Dana Richter: Right now, we are getting at the end of a Congress. A Congress is the technical term for the two-year period. Each Congress is a two-year period. So, we're getting to the end of the 117th Congress. And there are about 6000 bills in the Senate and I'm guessing about 8000 bills in the House. So, as you can tell, really, really good bills can get lost in that mix. And obviously, there's some bills that everyone's working on. There was just a really big bill and the president signs it, but then there's also a lot of really good bills that we just don't know about.

Dana Richter: I mean, one thing I always tell advocates is it's not important to know every fact and figure about Parkinson's. We'd much rather hear your story and hear about how this has impacted you and why the bill or the resolution or whatever action you're talking to us about, why it's so important to you, and how it's going to impact your life than knowing however many advocates there are in West Virginia or North Carolina and prevalence rates and mortality rates. We can all find that on the computer. What you are bringing to us that we can't get anywhere else is your experience and your lived knowledge. So, that's what we really, really appreciate.

Dana Richter: I have worked in both the House side and the Senate side, and I can tell you that makes the most effective advocate. And then the other thing I always tell advocates is follow-up. Think of it as you're forming a relationship. So, the first time you talk to someone, you're introducing yourself, you're introducing the issues that you care about and The Michael J. Fox Foundation cares about, but that's just an introduction. I'm not saying call every day by any means or email, but you're going to want to maybe at the end of your meeting, say, "Would it be all right if I follow up in a couple of weeks? Is there a good time for me to follow up?"

Dana Richter: That way, you're giving them some accountability. And I can tell you that, Hey, I love a meeting that ends with no ask or no request and no follow-up, but there's a chance that I'm going to move on to the next 14 things that are coming across my plate and I might not remember, but when you reach back out, I go, "Oh, yes. Let me talk to the Senator about that again." And the other thing I will tell you, and then I will wrap up, is that a lot of the age you're going to meet, I'm actually on the older side of most of the age you're going to meet on Capitol Hill. A lot of times people come and they're upset if they're not going to meet with a Senator or your member of Congress. And of course, I'm biased because I have been staff for a long time, but the staff are pretty invaluable in, they decide what the member hears.

Dana Richter: So, certainly don't think you're wasting time by talking with staff members because they're the ones who are going to ... their job is to triage what the Senator or the representative sees. So, you want them to understand your issues so that when they're talking to the Senator and giving them a recap of what's going on and what's important that they pay attention to, that your issue's there. So, I always tell people that because people all of a sudden go and meet with a 24-year-old and think, "Oh my gosh. What am I doing?" But that person has the ability to really get your issue moving.

Carol Blymire: Well, and what you said in the beginning of this part of the conversation is that there is so much activity on Capitol Hill, that it is really important for our community to raise these issues with you so that they can be prioritized and that we can add voices and advocates can tell stories about why these bills and pieces of legislation and laws matter. I would imagine that advocacy has changed given COVID and a lot of the changes in all of the ways that we communicate with one another.

Carol Blymire: Could you talk a little bit about the importance of or the best ways for people to reach out? Amy talked about doing some of the action alerts and sending emails. Could you talk a little bit about phone calls or when members of Congress are back in their states or back in their districts, they hold town hall meetings or you could even-

Dana Richter: Exactly.

Carol Blymire: Call their schedule or schedule in something. Could you talk a little bit about some of the best ways or some of the more effective ways to make that personal contact?

Dana Richter: I think it's all of the above.

Carol Blymire: Okay.

Dana Richter: I think, obviously, in-person meetings or, to be honest, virtual meetings. We're doing a lot of virtual meetings. As some of you probably know, the congressional office buildings are still closed to the public. We can do some meetings, but we're not doing a ton of them in person at this point still. And some of that's because of, obviously, the COVID pandemic. Some of that's because we're short on Capitol police officers, and so for security purposes, the buildings have remained closed. But having said that, we have found that you can be extremely effective over different platforms to reach virtually.

Dana Richter: And one of the nice parts about that is I feel that a lot more people have access to their members of Congress and their staff than before. Amy was talking about having some mild cognitive decline, I know there's other people with Parkinson's who have much more severe symptoms that don't make traveling or doing an in-person day where you're walking from building to building the easiest thing. So, this is a great way to be able to talk to your members of Congress and their staff without leaving. As far as letters and phone calls, those are very effective. They also keep these issues alive. They let the member know that it's not just you or you and your husband or partner or neighbors. There's a whole lot of people in the state or district who care about this issue.

Dana Richter: So, I think, as I said, it's all the above you want to ... and then, as you continue going forward, whether it's the ambassador program or other things, look at all the ways that you can be an effective advocate.

Carol Blymire: Well, the advocacy committee-

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Carol Blymire: Ways that you can be an effective advocate.

Carol Blymire: Well, the advocacy community within our Parkinson's community is strong and we have a lot of collective energy that has moved a lot of policy work forward in the past year to a few years. Dustin, what I would love to have you do next is kind of share with everyone watching what some of these most recent progress moments have been on policy issues that matter most to the Parkinson's community. Would you mind sharing some of those with us?

Dustin Watson: Sure. Carol, thanks again. Yep. So we're making great progress with federal research funding. And when I say we, I really mean the collective, we, which includes the thousands of advocates who are lobbying their lawmakers for positive change. So in addition to maintaining funds at the Parkinson's research program at the Department of Defense, Congress gave the agency funding for two new programs. So one is a toxic exposures research program and that's funded at $30 million dollars. And a second is the traumatic brain injury and neurodegenerative disease program. And that was actually established at $60 million, but Congress has actually upped it again this year, another $5 million for a total of $65 million. So when you combine the two new programs, that's $95 million in new research funding. Now some of that money, not all of it, is going to be allocated for Parkinson's research. So if there's researchers that are tuning into the webinar today, we encourage you to apply for the federal funding. And if you need our assistance, we can point you in the right direction.

Dustin Watson: We're also doing very well with the department of veterans affairs. The U.S. Senate is proposing a 50 percent increase for the V.A.'s Parkinson's Centers of Excellence to hire some additional staff and expand the number of sites beyond the current six. So there are three Parkinson's Centers of Excellence on the west coast, there's two on the east coast, and there's one in Texas. And securing this additional funding is going to be important because currently there's no sites really serving middle America nor in the deep Southeast region of the country. So these specialty care centers, they were established 20 years ago with very limited funding from Congress and with the intent to provide comprehensive care for our military veterans living with Parkinson's.

Dustin Watson: Now over the same 20-year period, the number of veterans diagnosed with Parkinson's has increased by a whopping 37 percent. So from 80,000 veterans 20 years ago to now over 110,000 plus today. But the annual operating budget for the specialty care centers has risen just a tiny bit over those 20 years. So this proposed extra funding, it will represent the most significant budget expansion ever for the V.A. Parkinson's centers. And so we're going to continue to advocate for that very hard.

Dustin Watson: Okay. So as part of the recently passed inflation reduction act, we have lobbied for years for key provisions that were ultimately included in the approved bill. So one was the establishment of a $2,000 dollar out of pocket cap on prescription drug medication, not reimbursed under V.A.... [inaudible 00:19:59] and relatedly, allowing Medicare beneficiaries to pay those year versus having to pay the bill all at one time. And that's referred to as a... President Biden signed the bill into law this week and our team does sending an update to our advocates today.

Dustin Watson: We also continue to advocate for legislation that would reduce barriers and allow scientists to expand research related to the use of medical cannabis. The purpose here is to assess cannabis as a possible treatment option for managing symptoms of Parkinson's. Politically, the U.S. House of representatives recently passed a bill we support, and it's awaiting final action in the Senate. And since the Senate approved very similar legislation in the spring, we expect this slightly revised bill to be passed again this year.

Dustin Watson: And then as you mentioned previously, and last, but certainly far, far from least, the Foundation state government relations efforts this year, which are led by my colleague, Julia Wooster. She just continues to have an incredible legislative season working alongside local advocates. Bills to establish Parkinson's registries were passed in three states this year. They include West Virginia, South Carolina and Maryland, and a fourth registry bill in the state of Ohio is expected to have a final vote later this year. The registries will collect patient population data and this will feed into the federal database housed at the Centers for Disease Control and Prevention, which we also support at the federal level. Data that is collected, that's going to result in more research. The more research that we do, that's going to get us closer to a cure.

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

Carol Blymire: Is really interesting. A lot of progress this year and this might be the first time that some of our friends in the Parkinson's community are learning about what role federal and state governments play when it comes to Parkinson's research and care. And all of this progress certainly sets the stage for what I'd like us all to talk about next, which is the first legislation of its kind in Congress. The National Plan to End Parkinson's Act.

Carol Blymire: Dustin, could you walk us through what this legislation is, what it does, and then we'll also have Dana and Amy share their perspectives on this as well. But Dustin, if you could just give us a top line of what this bill does, and then let's dig into it and we'll all talk about how advocates can get involved and get this passed.

Dustin Watson: Great, great. I'll try and touch upon all points in the next few minutes. Yeah. So the National Plan to End Parkinson's Act, it is the most comprehensive, it is the most robust piece of legislation specific to Parkinson's ever proposed in the U.S. Congress. It is bipartisan, it's supported by both Democrats and Republicans. It is common sense. It is non-controversial and it comes with no cost to the federal government. It was recently introduced in the U.S. House of Representatives by Congressman Paul Tonko, he's a Democrat out of New York, and Congressman Gus Bilirakis, Republican out of Florida. The bill number in the House is H.R.8585. Kind of rolls off the tongue very nicely. Senator Chris Murphy, Democrat out of Connecticut and senator Shelly Moore Capito, Republican out of West Virginia, they are planning to introduce a companion bill in September. And this is where Dana has been extremely instrumental in supporting us and working with us very closely to get this done.

Dustin Watson: Each of the congressional sponsors I just mentioned, they're all longtime supporters of the Parkinson's community and we are extremely grateful for their leadership. With the bill itself, we are not shy about acknowledging that the legislation is largely modeled after the success of the Alzheimer's Plan, which Congress approved 10 years ago. And fast forward to today, that has resulted in a quadrupling of federal funding for Alzheimer's research at the federal level. Parkinson's is now the fastest growing neurological disease in the world and yet the U.S. federal research investment has largely remained stagnant. There are currently one million Americans living with Parkinson's, including 110,000 military veterans.

Dustin Watson: The annual cost to the nation for caring for individuals with Parkinson's is now $52 billion dollars. That's $52 billion with a B. And we know that number is going to grow and by the year 2037, we expect that annual cost will be a whopping $80 billion dollars. And yet the federal investment for Parkinson's research has been stuck at around $250 million dollars a year. So the U.S. funds Parkinson's research at $250 million dollars, but it spends, right now, $52 billion to care for those living, with park, with Parkinson's. And so we need to flip that equation. We know that the more funding we put towards research, the faster we're going to get to a cure and we can wipe away the financial impact on government, on families, and change lives for the better. So we think it's time, once and for all, for the best of the best federal and non-federal stakeholders to come together through a national plan to end Parkinson's.

Dustin Watson: And so at this point we can ask ourselves, okay, so what does the bill do? It proposes a public-private effort centered on creating a plan to treat, cure and prevent Parkinson's. The bill itself requires the Secretary of Health and Human services to do an assessment that are all things related to Parkinson's across the federal government. Secretary will also create a Parkinson's advisory council. This council will include over a dozen federal agency representatives who work in that Parkinson's space. It will also include about 17 non-federal members. And these will include patients, caregivers, researchers, clinicians, and representatives from nonprofit organizations like The Michael J. Fox Foundation and others.

Dustin Watson: The council will be responsible for creating a report. That report will go both to the Secretary of Health and Human Services and to Congress. And within that report there will be recommendations on improving federal programs dedicated to Parkinson's, reducing the financial impact Parkinson's has on government and on families. It will look at and make recommendations for enhancing health outcomes, eliminating environmental triggers, and ultimately recommendations for preventing the disease. The Secretary of Health and Human Services will also be asked to produce a similar report to Congress. So, in a sense, we have a system of checks and balances in place to ensure Congress hears directly from the Parkinson's advisory council and from the Secretary of Health and Human Services.

Dustin Watson: And I know we'll be talking about ways to engage advocates, but as we take steps to lobby our lawmakers, it's going to be just as important to raise awareness about the legislation and get many more people involved. And we all know Parkinson's takes folks on a journey that includes so many different stakeholders and so many different touchpoints with a variety of different people and professions. We need to let all people know about the National Plan to End Parkinson's legislation. So as part of the webinar, for those who are listening, for those who will be tuning in on their own time and downloading the webinar, please tell your friends and your family members about this legislation. Tell your doctors, your neurologist, your movement disorder specialist, your pharmacist. Tell your physical therapist, your occupational therapist, your speech-language pathologist, tell your social worker, your mental health provider, your nurse care coordinator. If you're involved with clinical research, tell the clinicians, tell the researchers about this bill. We need all of these people and their voices to get this bill passed this year. So I'm going to stop there, Carol, and turn it back over to you.

Carol Blymire: Dana, so the bill was introduced in the house at the end of July.

Dana Richter: Yes.

Carol Blymire: So the next step, I'm not going to do the Schoolhouse Rock, "I'm just a bill, Capitol Hill." So it gets introduced in the house with both a Republican and a Democrat sponsor. And then the Senate, there's also a bill intro with a Republican and a Democrat. Will you tell us a little bit about kind of the process of what this bill goes through and then how it gets to where it could be passed and talk a little bit about the Senate's involvement in this as well?

Dana Richter: Sure. No. Well, and first I have to give a shout out to George Manahan, who's an exceptional advocate in West Virginia, and his advocacy is actually what brought this to the senator's attention. The senator's been involved in the Alzheimer's Plan and was very familiar with the legislation so this made a lot of sense to her, but he did a great job of advocating to the Senator. So he's a great example of why advocacy's so important. As both Carol and Justin, said it will be introduced. I'm joined by my counterpart in Senator Chris Murphy from Connecticut's office. Jackie is wonderful and we are very excited to work together on this. And we looked at the calendar and the cen...

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Dana Richter: And we looked at the calendar and the Senate's been very busy working on a number of the bills that Dustin mentioned. And so we determined that for us, the best time to introduce was in September. Congress will be in session for most of the month. And it gives us a chance to really use that opportunity to talk to a lot of our champions. We're depending on all of you and all of the people that Dustin mentioned to get the word out on the bill, because how it works is, we will introduce hopefully with what we call up here, original cosponsors. That simply means the people who go on the bill the day it's introduced. We'll introduce with some folks, hopefully, and then we're going to add folks. Because the Senate's 50/50 right now, we will probably at the beginning at least add in bipartisan pairs.

Dana Richter: This is very common in the Senate right now, because we want to show Parkinson's couldn't care less whether you're a Republican or a Democrat or have no party affiliation at all. And that's the important thing here, it doesn't matter. But because we are divided, it is good to continue that message by showing that this is something that both parties care about. So we are going to hopefully have a rush of wonderful co-sponsors from all of your great advocacy work. And at that point, when it's introduced, this bill will go through a committee in the Senate called the Health Education Labor Pensions Committee, which has the very useful acronym, HELP. And so at that point when we introduce, I will make sure the committee's aware of the bill and aware that the Senator would like to see this bill move forward.

Dana Richter: The more co-sponsors we can get, the more they're going to pay attention, for lack of a better term. They're going to, because the more people they hear from and the more traction this bill is getting, and as our co-sponsor numbers build up, they have more incentive to move forward with this. And so at some point our goal will be to get the bill into something we call a markup, which back in the day, they used to actually take out their pencils and pens and actually make changes to the bill to make it something that the majority of the committee could approve. To be honest, at this point, it's mainly a done deal by the time it gets to a committee markup, but the terminology stays the same. And once it gets through that process, it's ready to go to the floor of the Senate. And at that point we're hopeful that it will overwhelmingly pass.

Dana Richter: And then, hopefully by that point, the House bill has gone on a very similar journey from being introduced to gathering co-sponsors, to going to... Over there, it's the Energy and Commerce committee. And then hopefully it has already passed the floor. And at that point, our bills as written are identical. But as I said, there's a chance that there could be changes made. They'll look at the two different bills that have been passed, figure out any differences through something called a conference committee, and come up with a final bill that, if there were changes, will need to be passed. And then hopefully we will see a bill go to the President to be signed into law. Having said that, that's the path. There are always a lot of fits and starts. It's not unusual for a bill to go through this process for several Congresses.

Dana Richter: As I said, we're in the 117th Congress. We'll finish that at the end of the year. And at the end of a Congress, what happens, which is the two-year period, it's sort of like Monopoly. You go to back to the start and all your co-sponsors get wiped out and have to be reintroduced and you have to start again. But the good part is the momentum that you've built doesn't have to start over. So the more co-sponsors we can get, even if we're not able to get done by the end of the year, it's much easier to what we call rolling people back on, because you're like, "Okay, you already have vetted this bill and decided it's something you support. So we just need you to sign back on."

Dana Richter: So if that's the case, then that's how we'll start back up. And then we have two more years to get it passed. Remember there are also in the Senate about 6,000 other bills going through this same process and all trying to do the exact same thing. So that's why there's a glut trying to get bills marked up and to the floor. So it's important to show as much support as possible so your bill stands out and that you can show... We all know how important this bill is. And it's just important to share that with members of Congress. So we can really make this bill stand out from the masses.

Carol Blymire: Well, and let's also be super clear with everyone listening and watching that this is a bill for and by the Parkinson's community. This is a bill that every Parkinson's nonprofit organization, every Parkinson's group and chapter and association, we are all working together on this bill and on making those phones ring on Capitol Hill. I know there was a question submitted in the chat, "Is MJFF working with other Parkinson's organizations?" And I will answer that directly by saying, we all work on this together before taking anything anywhere. This is the voice of the community. The energy and the excitement around this bill has galvanized the communities, such that this is a bill that voices will and do need to weigh in on to get this passed this session. Amy, we're going to show a video in just about a minute that can show advocates and all of you, how to get involved and use your voice on this. Amy, you are living with Parkinson's disease. When you heard the news that there is a bill introduced in Congress, that's going to create this national plan to end Parkinson's, what does that mean to you?

Amy Lindberg: Well, Carol, like Dustin said, PD is the fastest-growing neurological disease in the world and it's doubled since 1990. It's going to double again in the next generation, certainly by 2040, if we don't make changes. So there's an impetus upon us and this bill gives us hope. It lets us know that there's a dedicated plan with several agencies, not just one, that can basically funnel and make efficient the efforts of so many different organizations and people. It's just incredible. I'm excited to be a part of it and to get all those thousands, over a million of us, involved in supporting the effort because we can. And because Michael J. Fox Foundation has given us the tools. No matter whether or not you have certain handicaps due to the disease, there are different ways in which you can advocate from home. Phone, text, email. So thank you to the Foundation and to the speakers today for making this so abundantly clear that we do have hope.

Carol Blymire: Thank you. Amy, you and the more than one million people living with Parkinson's and family members and friends and caregivers, you are the reasons why we do this. Christina, will you roll the video that we have that can show all of our viewers how easy it is to complete a message to your members of Congress?

MJFF: Completing an action alert is easy. Click "Take Action," then Contact Your Policymakers on our homepage. Scroll down to the National Plan action alert, click "Take Action." And here it is. You'll enter in your contact information and the system will auto-populate a pre-written message you can send directly to your Representative. It'll ask them to become a co-sponsor on this important bill. It takes about a minute or less to do. You'll enter your name, your address, phone number, and email address. And then after that, it'll ask you to share your connection to Parkinson's disease, your interest in government advocacy, any military service, and then your interest in receiving communications from the Foundation. And once you're done filling out all the information, you'll click "Preview Letter." And there it is, a pre-written message to your legislator. Click "Submit," and you can rest assured your message has gone successfully to your Representative.

Carol Blymire: It really is so easy to do. In fact, I did mine right before we started this webinar and it did take less than a minute and it was easy. What's great about the form is that I literally started entering my street number and the first few letters of my street name and then it auto-populated my address for me because I believe it's synced with the Google street address system. So as long as your address appears in that window and you make sure your zip code is there, it's super easy. I will also say that this action alert is only available to people in the United States, because this is an issue that is happening only in the United States for right now. Those of you living outside the US, please tell all your friends, relatives, family, colleagues, coworkers, who do live in the US that they can fill it out.

Carol Blymire: Before we continue our conversation about the National Plan to End Parkinson's Act, I'd like to shine the spotlight on the Foundation's landmark study, the Parkinson's Progression Markers Initiative. It's also known as PPMI. PPMI aims to change everything about how Parkinson's is diagnosed, treated, and potentially prevented. And the study is looking for volunteers to participate. So those who have recently been diagnosed with Parkinson's, they can play a critical role in this important work. So you can click on the link in the resource list to learn more. And the online part of the PPMI study is open to anyone over the age of 18 living in the United States. To join that study, you can click the "Get Started" button in the "Take Action" box on the bottom, right hand side of your screen. Let's get back into our conversation about the national planned End Parkinson's Act, and let's talk about all the ways our community can get involved.

Carol Blymire: As we have this part of the conversation, I am going to scan the chat and the questions that are coming in. We're getting amazing questions about this. To sign up for the latest and greatest updates... Because we will be emailing the community quite a bit about this. There will be moments where we might need some of you to apply a little heat, apply a little pressure to your members of Congress.

Carol Blymire: You can go to michaelJfox.org/advocacy. Go ahead and sign up there. You can also email us at policy@michaeljfox.org. Tell us you want to be involved. We'll get you all roped in and we'll get you involved in this incredible movement. Dana, you shared earlier in our conversation about the effective ways that people can reach out to members of Congress to advocate on an issue and this issue in particular. We have some questions in the chat of people wondering, is a phone call better than a meeting, or should I do the action alert only? And what about a separate email? And I think you said earlier, all of the above. All of it, anything else you want to add about ways in which people can professionally and appropriately reach out? You don't want people emailing you six times a day on this I'm guessing, right?

Dana Richter: Exactly. No. I think one thing that you can do, if you can personalize it, I mean, I talked a little earlier about sharing your story. I think that's really important. If you're comfortable with sharing your story, I think that's very impactful. The other thing is, while everyone I know is incredibly enthusiastic, you really want to stick to your district and your state. It's not that, "I know my office doesn't care about other people from other states." It's just that's our job is to really reply to our constituents. So a lot of times we have to triage and just reply to our constituents.

Dana Richter: So really stick with those who represent your state, because I hate to say it, but you can say "I'm going to go and do all 50 states." Well, that's going to be a lot of work that's not going to get a lot of return. So stick with your state and stick with your two Senators and your Representative as your focus. But feel free. Let people know about your specific story. If you feel like you're up to it and want to set up a meeting, I think meetings are incredibly important and useful. But if not, emails, fax... Well, I guess we're not doing faxes anymore. I'm aging myself. Calls. They're all fabulous because they're really building the momentum. And that's what we want is to get the word out there.

Carol Blymire: Dustin, you have been in meetings all year with our Parkinson's community and all of the work and all of the conversations that have gone on. How would you encourage our community to best channel the energy and the excitement and all of the questions that I know that we're getting on this.

Dustin Watson: Yeah. Be comfortable with whatever choice of advocacy you would like to pursue, because I'm sure the audience today, it's probably a mix of people who are hearing about advocacy for the first time to some folks who are very familiar with emailing their members of Congress or their state legislators, or putting those phone calls in, to some who may know their lawmakers on a first name basis. So I would say no matter where you might be in the advocacy journey, I'd only like to stress kind of two things. One, know that you have a team at The Michael J. Fox Foundation who is ready to support you. And two...

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Dustin Watson: ... Foundation who is ready to support you. And two, meeting with your lawmakers at home, just like Dana was just describing. Back in those local communities, that's extremely effective. And I think much more effective than making the costly trip to Washington DC, especially at this point where Capitol Hill is largely just still too secure to maneuver through and get the meetings that you want in the most effective ways.

Dana Richter: I just wanted to make one point too. Each office on Capitol Hill is kind of its own little kingdom, imagine. So each office makes their own policies, rules, and this goes for everything. But what my office does and the meetings that we're willing to do in person might not be the same as 99 other senators. So just because you hear from one person that, oh, she had an in person meeting, or oh, they're only doing virtual, that's one office. And that goes for the House side as well. So I just did want to say that because I didn't want anyone to think that what we're doing or what any other office doing is what every office is doing, because they really are all separate little kingdoms.

Dustin Watson: I will piggyback on that and just continue to stress, our team is ready to support any advocates who want to have a meeting, virtual or in person, preferably, again, in district or in state. We are happy to do that. We can supply talking points, advice, and guidance. We can organize the meetings, we can join you for those meetings, we can help prepare for those meetings, we can handle the follow up. The point is, wherever you want our help, we can insert ourselves. And if you're not already a member of the Parkinson's Policy Network, and I know it's posted right here first at the top bullet on the slide, please register with us. michaeljfox.org/advocacy. Again, through that video, it only takes about a minute to sign up with us. Once you do, you're going to get regular updates. You're going to get those calls to actions and we're going to mobilize folks at the times when they are needed most to contact their lawmakers.

Dustin Watson: Right now, the US House and Senate, they're in recess. They're back home in their districts and states. So now is a perfect opportunity to attend a town hall meeting or work with us to schedule a local meeting. We would be happy to do it. Again, it can be virtual or in person. It's an opportunity to raise the national plan to end Parkinson's. Ask them to co-sponsor the bill. If they're already a co-sponsor, thank them and discuss other important issues related to Parkinson's. And again, I just want to stress, we can help with all of that. If you're interested in meetings, or you just want to do the phone calls, or you want to utilize social media, we can help you with all of those as well. Or if you just want to share your story, whether it's written or you'd like to capture it in audio or video, we would love to work with advocates in that area as well. So whatever your flavor of advocacy is, just know that it's greatly appreciated and we will support you every step of the way. So again, please use this as a resource. Contact us anytime at policy@michaeljfox.org. That's our email address. Policy@michaeljfox.org.

Carol Blymire: In the follow up email that you will get from having attended or registered for this webinar, we'll include links to everything that we're talking about. So please, again, check your email inboxes. But I want to be cognizant of time because, again, we know we've got some folks in our audience who advocacy is new, and you might think, oh gosh, I could actually pick up the phone and call my member of Congress? How do I do that? That seems weird. Am I really allowed to do it? Yes, you are. And Amy and Dana have very kindly volunteered, they're going to do a sample phone call. So Dana is going to pretend that she is Senator Burr's staffer because one of Amy's senators is Senator Burr. So Amy is going to pretend that she's calling Senator Burr's office and Dana is going to play the role of the staffer of Senator Burr. And we're going to do this live right now so you can kind of see what a phone call might go like for you. Amy and Dana, take it away.

Amy Lindberg: Okay. If it were me, I would write down my notes, I've got some right here. This is a sample. And what I would actually do is I'd call Dana and say, "Dana, this is what I'm about to say," or I'd email it to her and ask her to edit it for me, which would be nice because it's a little bit verbose. I'm going to just read it kind of quickly. But anyways, I might say something like this.

Amy Lindberg: My name is Amy Lindberg and I'm from Wilmington, North Carolina. I'm a retired Navy officer that was stationed at Lejeune back in the '80s when the water was contaminated with TCE and other toxins. As you may know, Parkinson's and other neurological diseases have long latency periods, often decades. In my case, I was misdiagnosed several years before diagnosis was finally confirmed. The gold standard for treatment and even confirmation of a Parkinson's disease is a medication called levodopa and it's over 50 years old. It doesn't stop a disease, it only treats symptoms. Over time, the side effects destroy the quality of our lives. We need effective drugs and a cure. To do this, we need better funded research that keeps up with the demand of the population that's growing and growing. There's over some 200 Americans that will be diagnosed with PD, and tomorrow, another 100 will die of it or with it. We've got to get ahead of this. I'm calling today to ask Senator Burr to support the National Plan to End Parkinson's Act.

Dana Richter: Amy, thank you so much. First of all, thank you for your service and thank you for telling me your story. I know it's not always easy to share your personal experiences, but it's very helpful for me and I'll be happy to share that with the Senator. I had a chance to look at some of the materials you sent and I know one thing the Senator's going to like a lot about this bill is that we're going to really make sure that we're using all of our resources in the federal government wisely by looking at everything that's doing, making sure we're not duplicating. So I think that's something that I think he'll really like. What I can do is I will definitely talk to him about this and I can get back to you and let you know if he's willing to be a co-sponsor of the bill.

Amy Lindberg: That sounds wonderful. That's exactly what I wanted to hear. Just that we have your support and that you'll move forward. And the favor of a response after that is greatly appreciated so thank you for volunteering to do that, to get back with me.

Dana Richter: Of course. I will do my best to get back in the next week or so. If for any reason you don't hear from me by that point, feel free to reach back out. But no, I just really appreciate learning about it because we didn't know about the bill before. So thank you.

Amy Lindberg: Thank you. Have a great day.

Dana Richter: You too.

Amy Lindberg: Go Navy.

Carol Blymire: And look at that. In two and a half minutes, three minutes, that is all it took Amy to make that phone call. You can see that congressional staff, even as busy as they are and as many issues as they juggle day to day, they're friendly. They don't bite. They're there because their boss, the member of Congress, represents you. You are the constituent. Again, you can go to michaeljfox.org/advocacy. You can sign up there to receive email updates on the national plan, all the other policy issues. You can always reach us at policy@michaeljfox.org, and someone will get back to you as soon as humanly possible with whatever question you have, whatever need you have, or whatever policy issue is burning and making you concerned or that you think we can get our community rallied around. We've got two, three minutes left. Dustin, Dana, Amy, any other inspirational words of motivation, go get them, we can end Parkinson's with this legislation?

Dana Richter: Definitely. And any of the actions you do are going to make a difference and that's the important. Nothing is too small. And I think it's a lot of something people get bit by the advocacy book. But we're just very grateful for your support.

Dustin Watson: And I'll add, Carol, in the spirit of rallying and advocacy, I want everybody to know there will be a National Day of Action on this legislation, where we will be mobilizing all of our advocates. So I strongly recommend if you are not registered with us yet, please do so at michaeljfox.org/advocacy, and help us up with this National Day of Action that will be coming up in September.

Carol Blymire: We're very excited about that. Amy, you are proof that every voice matters in advocacy. Anything you want to share with your fellow advocates out there who are watching and listening?

Amy Lindberg: Keep moving, keep learning, keep the hope. We've got it here with Michael J Fox. This is a great testimony. Thank you all so much.

Carol Blymire: Thank you to Dustin, Amy and Dana. Thank you everyone for watching and listening. We've covered so much information today. We hope you found this helpful. Thank you all so much and have a really great day.

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