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MJFF: Navigating Parkinson's disease can be challenging, but we are here to help. Welcome to The Michael J. Fox Foundation podcast. Tune in as we discuss what you should know today about Parkinson's research, living well with the disease, and the Foundation's mission to speed a cure. Free resources like this podcast are always available at michaeljfox.org.

Carol Blymire: Welcome to The Michael J. Fox Foundation podcast. I'm your host for this episode, Carol Blymire. Today, we'll talk about how state and federal governments fund research and care for people with Parkinson's. We'll also talk about how you can play a role in educating elected officials on what the Parkinson's community needs, and how much your voice matters. We'll start today's episode by hearing from Israel Robledo, from Midland, Texas. Israel lives with Parkinson's disease, and he's been using his voice on behalf of our community since he was diagnosed in 2007. Israel tells us why it's important to get to know your members of Congress, and help them work better for you.

Israel Robledo: Not soon after I was diagnosed, I asked for a meeting with my Congressman at the local level. And I'd written a letter and said this is who I am, this is what I do, and this is what's going on with me and my life and what has changed dramatically. And it was interesting to watch him as I was talking, because you could see a change in his demeanor, because once I was done and then he would ask questions, he said, "You're the only person that I know with Parkinson's." He says, "I know one other gentleman," he says, "But he's older." He says, "You're young, and you have Parkinson's." And through the years, it was interesting, because as we would meet with him, he would say to me, "Whenever anything about Parkinson's comes in on the floor or meetings," he says, "You're the one that I think of. And that helps me to know that what you're doing is helping us in our meetings." And so that was eye opening.

Carol Blymire: Welcome back to The Michael J. Fox Foundation podcast. I am here with Ted Thompson, who is the senior vice president for public policy, Dustin Watson, who's the director of the organization's federal work, and Julia Worcester, who is the director of the organization's state policy work. Welcome, everybody.

Ted Thompson: Thank you.

Julia Worcester: Thanks for being here.

Carol Blymire: All right, Ted, I'm going to kick this off with you. What role do state and federal governments play when it comes to Parkinson's disease?

Ted Thompson: Thanks, Carol. They actually play a pretty significant role. For example, the federal government is the world's largest government funder of Parkinson's research, so that research funding investigates the various aspects of the disease. The federal government also has a key role to play around things like data collection. Well, I should say state and federal governments, through a surveillance system at the Centers for Disease Control, and at the state level, state based population-wide registries. Another component for the government is identifying environmental triggers of Parkinson's. We do know that there are several, including Paraquat and trichloroethylene. So there are many different ways in which the federal government can inform and help lead, from a research and scientific standpoint. But beyond that, of course, many or most people with Parkinson's are on the Medicare program, so quality, affordable access to healthcare is another really important role of the government. And at the state level, there are similar opportunities to engage.

Carol Blymire: So, Ted, we have, in the United States, it's approximately 1 million people living with Parkinson's disease, correct?

Ted Thompson: Yes.

Carol Blymire: So I imagine that carries a significant economic burden. There's a significant cost of Parkinson's disease, since you mentioned Medicare, both to the federal government and to American taxpayers. Can you talk a little bit about how much Parkinson's costs, since we don't have a cure?

Ted Thompson: Yeah, absolutely. And you're right. There are about a million people. We think that's a conservative estimate. And we also think our estimate of the cost of the disease is conservative, but that cost is at about $52 billion per year. And about half of that is paid for by Medicare and social security disabilities. So the federal government has a financial incentive to be involved in this, because they are spending huge amounts of money, every year, simply to care for people with Parkinson's. Unfortunately, their investment in research isn't reflective of that. The federal government puts about $240 million a year into researching Parkinson's, whereas they spend about 26 or 27 billion caring for people with Parkinson's.

Carol Blymire: So $52 billion every year is what both the government and families and other programs pay to cover the cost of Parkinson's. Do you have any idea what that number might look like in the coming years, as the baby boomer generation ages?

Ted Thompson: Yeah. In just what seems to be a few short years from now, in 2037, the estimate is that's going to be up to $80 billion a year. And for the portion that's not paid by the federal government, it's paid by people with Parkinson's, caregivers, lost wages, state governments, local governments, different organizations. So the cost really affects a wide swath of society. And if we could just prevent Parkinson's from happening to a subset of the population, due to what I mentioned, the environmental triggers, that would save billions of dollars a year. And of course, if we could slow the progression of the disease, keep people in the workforce longer, that would tame the costs as well. And ultimately, a cure would eliminate that cost altogether.

Carol Blymire: That's incredible. Thank you. That was a great overview, and that really explains why the government does have a role and a responsibility to be involved in finding a cure. Dustin, I want to toss to you for a minute. Could you share one or two of the federal priorities that the Foundation is working on right now?

Dustin Watson: Sure. And, Carol, as you know, the Foundation is primarily a research organization. So what we do in the policy space at the federal level is to advocate for additional research dollars, especially for federal agencies working in the Parkinson's space. So, of course, this includes the National Institutes of Health, but more specifically, as it relates to Parkinson's, there are new federal dollars at the Department of Defense, to the tune of $60 million. Some of this is going to go towards brain injury and disease prevention. Some of it is going to go towards toxic exposures. The total amount of funding isn't all for Parkinson's, but some of it will be, and we'll be advocating for that. And we love funding at the Department of Defense, because it allows researchers some flexibility to do cutting-edge research, and using innovative technology, to really hone in on techniques and tools and abilities to address what's really needed in the Parkinson's space.

Dustin Watson: So we love those dollars at the Department of Defense. And, in fact, the only program at the federal level with Parkinson's in its title is at the Department of Defense, the Parkinson's Research Program, which has now been in existence for over 24 years. We're going to continue to push for increased funding in that space. And then there's a 20-year program at the Department of Veterans Affairs, which a lot of folks don't know about. The true title is the Parkinson’s Disease Research, Education and Clinical Centers, for short. The intent here is for neurological centers of excellence to provide holistic care to veterans with Parkinson's. Unfortunately, it's been operating on a shoestring budget, so we're going to be asking for significant dollars to be increased there. And another example is with the CDC. They run a national data registry. It's called the National Neurological Conditions Surveillance System. We're going to be asking for increased dollars in this space, because data is going to be driving research, and research is going to get us closer to a cure.

Carol Blymire: That's a lot on the federal government's plate. And I'm glad you made the connection between research at the Department of Defense and Veterans Affairs. I think that might be illuminating to our listeners, who may not have understood that sometimes defense budgets are big, because we're helping to find a cure for disease. And I'm sure Parkinson's will take any amount of budget increase that we can get. We all know that members of Congress work for us. We are their constituents. So while the Fox Foundation has this team of incredible lobbyists and employees, what can our listeners do, the general public, people with Parkinson's and their family? Can they play a role in talking to their member of Congress about any of these issues, Dustin?

Dustin Watson: Absolutely. And we would encourage folks to check out our website, michaeljfox.org/advocacy, and join our Parkinson's policy network, and our growing list of advocates who are sharing their stories, because it's their stories that is going to make a difference. They're the most impactful, effective ways to reach lawmakers. When lawmakers hear the stories being told by our patients, by their caregivers, by family members, by researchers, clinicians, healthcare workers, that's what's going to resonate most. We need people to join us in that effort. Going to Michaeljfox.org/advocacy, it would be a great first start.

Carol Blymire: We'll talk a little bit later in this episode about how specifically our listeners can get involved and the ways in which the Foundation makes it easy for them to do that. Julia, you head up the Foundation's state efforts in terms of public policy. Can you talk a little bit about what that means? What are the kinds of things that state governments do to either help cure Parkinson's or support people with PD?

Julia Worcester: Sure. Thanks, Carol. There's so much that can be done on the state level. There are 50 state legislatures and they go in every year. Each year in the beginning of the calendar year, they all meet for 30 days, 60, sometimes the whole year for a period of time. Every year you get the opportunity to work on annual funding, new programs, updating laws, state funding for research. There are nearly 8,000 state legislators in their house and Senate. When you break that down on average, a state with a couple million in their population that gets down to about 150, on average in your state legislature, that's deciding your state budgets, your state education. And then also your state Parkinson's opportunities. There's a lot of opportunities for your state government folks to really get with our community members, and work out a piece of legislation through that process on a yearly basis. Or start a process that can be done quite quickly.

Carol Blymire: We are going to talk with you a little bit more directly in our next segment of the podcast about some state efforts and ways in which advocates can get involved. But first, let's hear from two of our friends in the Parkinson's community about their experiences with being an advocate. First, you will hear from New Jersey's Myra Hirschhorn, whose grandmother, uncle, and husband all lived with Parkinson's. Then you'll hear again from Israel Robledo in Texas.

Myra Hirschhorn: One very special event happened when I responded using one of the action alerts and we were told, "Add information that's important to you, to it, as well as just putting your name in." This was going to Senator Booker and lo and behold, I get this call. I think it was a Friday afternoon saying, "This is Senator Booker's office. He read your letter and really would like to use some of the information you put in there. Is that okay?" "Okay? Certainly it's okay." I was thrilled. Just to see that what we do really matters. It's so important to take part and do those action alerts because they all say that it's what we say, and what information we give to our senators, in this case to Senator Booker. It's so important to move things along. That was a really exciting point for me, and it's something you could do, too.

Israel Robledo: I got involved in advocacy when I was being treated for Parkinson's by my movement disorder specialist and taking part in clinical trials. What interested me about the trials was, "Where does the funding come from that allows this to happen?" Once I realized that the majority of the funding for Parkinson's research was federal, that's when I started looking at advocating with the organizations who would help move the needle forward, to create the chain that was needed. So much has been done within the last few years that it's an amazing thing to watch. I look back on those years and think, "I knew very little of anything." And now I'm like, "I'm actually helping vote on $16 million worth of grants from the Congressionally Directed Medical Research Program."

Carol Blymire: Welcome back to The Michael J. Fox Foundation's podcast. I'm Carol Blymire, your host. In this segment of the podcast I'll talk with Julia Worcester, the director of state government relations and public policy for the Foundation. And George Manahan from West Virginia, about what it means to be an advocate and all the different ways that you can become involved. George Manahan is a Charleston, West Virginia small business owner who was diagnosed with Parkinson's in 2010. He wanted to put West Virginia on the map as a state that can help researchers more closely identify Parkinson's hotspots, and learn more about what triggers the disease. I'd like us to talk about advocacy, and then we'll go right into the story about what you all did together in West Virginia. Julia, let me start with you first, about kind of what it means to be an advocate? We talked a little bit about it with Dustin in an earlier segment. What does it mean to advocate? Do you need any special training? Do you have to be a lawyer? Can you talk a little bit about what it means?

Julia Worcester: That's a great start, Carol. Anyone can be an advocate, and you are your best advocate when you're passionate about a cause, or reason, to go to your state legislature. Or to Congress to speak about something that you care about. All you need is to be passionate and be able to communicate your issues. And usually short spans your meetings with legislators are typically on the shorter side, they're quite busy. But when you connect on that human level with your legislators on a local level, all the way up through Congress, via emails, coffees, meeting them in a town hall. Writing to them, or even testifying in person in your state, you really can get so much done. It's such an impact to the people of your entire state, or across the country and in the federal government.

Julia Worcester: With regards to any special training, no, you are your best advocate, but something that The Michael J. Fox Foundation is working on is providing resources. And tools to better help folks that want to go advocate in state and federal governments. We can give you those toolboxes, and those talking points and work with communications and be that resource. And net in as we have those connections across the country. What you really want to do is just be involved in the first step as Dustin mentioned earlier, is becoming part of our Parkinson's policy network, emailing our office and working with us going towards the future. Like we said, there'll be elections, they have consequences. Next, you go back and you talk to your legislators each and every year.

Carol Blymire: You can email policy@michaeljfox.org to get involved, but we invited George to join us on the show because the two of you collaborated on something pretty big that happened in West Virginia in just 27 days. George, would you like to kick us off with a brief synopsis of the story, and how you were able to work with your colleagues in West Virginia to establish a Parkinson's disease registry for the state? Julia, you chime in on that story as well.

George Manahan: Carol, thank you. Ultimately, it came down to strong partnerships and a great relationship. We had strong partners with The Michael J. Fox Foundation, the West Virginia University Neuroscience Center. And the Parkinson's community in the state, which is very active. In West Virginia we jokingly say there's only one degree of separation from anyone because being a small state, we know who to talk to get things done. Only days after I'd received the model legislation from Julia, I was at a luncheon honoring a friend of mine, and coincidentally sitting at my table was the head of the WVU Neuroscience Center, and the chief lawyer for the House Health Committee. By the time the lunch was over, we had a commitment from WVU to manage the registry, and the lawyer for the House Health Committee to take the legislation that Julia sent to me and localize it to West Virginia.

George Manahan: He was also going to talk to his boss, the chairman of the House Health Committee, to be the lead sponsor for the legislation. We had a handful of legislators too, as doctors, so they rallied behind ours. It was great because two of the doctors were heads of both the Health Committee in the House, Health Committee in the Senate. The third doctor was the majority leader in the Senate. As anybody knows, those are probably one of, well, probably three most influential people in the state. We were able to get the bill passed in 27 days, which doesn't really happen that often.

Julia Worcester: George is pretty awesome with that. He pretty much combined almost an entire year's of effort into two months of effort going into the legislature and then getting it done in 26 days. You don't see that often, but we definitely would love to clone George, and replicate this all across the country if we could.

Carol Blymire: Well, and I think what's great about George's example is that I'm sure many of our listeners and those who are already advocates on behalf of the Foundation, you know your local legislators that report into the statehouse. You may have gone to a fundraiser at the local diner when they were running for office, or maybe your cousin's dentist is their brother. So, like George said, in West Virginia, it's one degree of separation. I'd be willing to bet in every state, there can be one or two degrees of separation at that state level. And at the federal level there are opportunities to reach out to your members and tell those stories and introduce people, which is what it sounds like George was a big part of, how you helped make this happen. The right place, the right time. But also just making sure the right people were talking to one another. Is that about right?

George Manahan: Yeah. I mean, I think what you should do is, well, the one thing you can do is put yourself out there. I mean, by telling your story, your personal story, you make yourself more human to the legislator. I carry a notebook with me, and I write down every legislator's contact or their connection to PD. And so, that means the next time I talk to them, I say, "Senator, how's your brother doing?" Or, "How's your wife doing?" And that really helps with the conversation. PD is not Republican, it's not Democrat, it's everybody together. So, we were able to bring both sides together and pass this legislation quickly.

Carol Blymire: George, do you have any advice for anyone out there who might want to become an advocate, or learn how to do what you did?

George Manahan: Well, I'm going to sound like a broken record. I think they should talk to The Michael J. Fox Foundation, which we've talked about. But I think you need to develop your story, and then start developing relationships. In some cases, it's just start, pick up the phone, call your local legislator, go up to the Capitol, just talk to them. Obviously, we want to talk to them about pieces of legislation that's important to the Parkinson's community. But once we have that, then we can start a conversation.

Julia Worcester: That's right, I echo everything George says. It's all about the developing of the relationships on your local level.

Carol Blymire: And to work on ways we can help to eliminate the fear that may come up for some people who think, "Oh my goodness, I couldn't reach out to my member of Congress. They are so important, and I'm just me." Your voice has power.

Julia Worcester: And you're the voter, and you're a constituent, and you may have even grown up with them and then helped them on their campaign, or babysat their children. There's so many connections, and it's never too early or too late to get started. They're always going to be there, and that's what's the great part about politics is you just keep pushing and keep developing those relationships, year after year.

George Manahan: And Carol, can I say something about the three legislators who are doctors, who helped us? We call them the Doc Caucus. Dr. Rohrbach, Dr. Takubo and Dr. Maroney were the three legislators in West Virginia that really helped us get that passed.

Carol Blymire: But hey, we will always take a shout out to members of the state legislature who did something great for people with Parkinson's. So thank you, George, for helping us make that happen. And in the spirit of you saying about the connections and how this was an important effort in these relationships, we're going to hear again from Myra Hirschhorn about how advocacy brings her a sense of feeling like she belongs to a community.

Myra Hirschhorn: You matter, number one. You matter, you matter. It counts, everybody doing their part is so very important. And whether it be writing and sending an action alert, whether it be picking up the phone and calling the office of your representatives, your senator, your congressman. It's so important, it makes all the difference in the world. And you're part of a wonderful group who's doing it. It's been a wonderful journey for me to take part in working with other people, to approach our senators and representatives, and get the information to them and let them know what it personally means to people, what's happening, why we need their help. So please, it'll make you feel really good if you take part, I really encourage you to do it.

Carol Blymire: Welcome back to The Michael J. Fox Foundation's podcast. I'm your host for this episode, Carol Blymire. And we are going to talk with Dustin Watson, who heads up the federal policy and government relations efforts for the Foundation. And we're going talk about an issue that is hot right now, which is expanding healthcare for veterans with Parkinson's. Dustin, we talked a little bit earlier in the episode about research that is happening in the VA system. Could you tell us a little bit about veterans and Parkinson's disease? Help us understand kind of the connections there and what that looks like?

Dustin Watson: Yep. So let me start with a quick stat, Carol. During the past 20 years, we know that the number of military veterans in the United States diagnosed with Parkinson's increased by 37 percent. And so you may want to say to yourself, "wow, how is this happening?" Well, it could be because of exposures to very dangerous chemicals, like insecticides, herbicides, pesticides. We know that soldiers are exposed to dangerous chemicals coming out of burnt pits, where they're ingesting these terrible solvents. And then unfortunately, and after 20 years of war, soldiers are coming out of battle conditions where they receive severe brain injury or head trauma. Everything I just mentioned, they're all triggers of Parkinson's disease. So the number of military veterans diagnosed has gone from 80,000 20 years ago to 110,000 plus today. And we do expect that number is actually low. And it's probably much higher than we think.

Carol Blymire: 110,000 veterans living with Parkinson's disease. That's something to pause and think about. You mentioned in the earlier part of our conversation, that one of the areas of funding that you're working on is funding for what you called a PADRECC. I know that in the government, boy do we love a good acronym. Could you tell a little bit about what a PADRECC is, what they do and why we care about them?

Dustin Watson: Yeah. So the longer title is the Parkinson's Disease Research, Education and Clinical Centers. These were established just over 20 years ago by Congress with the operating budget of about 6 million, which is divided among six sites. A couple are located on the west coast, there's a couple on the east coast, and there's one in Houston, Texas. Currently, there's nothing in middle America to provide a high level of care for our military veterans living with Parkinson's, nor is there one in Florida where we know there's a high prevalence rate of people living with Parkinson's, including a correlating rate of military veterans living with Parkinson's. So what are these specialty care centers do? They provide a high level, comprehensive approach to care for military veterans. They are veterans living with Parkinson's. They need access to their neurologists, to movement disorder specialists, but a whole host of other specialties, which these neurological centers of excellence provide.

Dustin Watson: And they include, and because of the nature of the disease and the way it progresses within individuals both from a mobility standpoint and from a cognitive standpoint, patients often require access to a speech language pathologist, a mental healthcare provider, a psychiatrist, a social worker, a nurse care coordinator, an occupational therapist, and the list goes on. And what these neurological centers of excellence do is they provide that holistic approach.

Dustin Watson: What's also nice about the PADRECCs is they do operate on a hub and spoke model, which means there are about 50 plus other VA health centers throughout the country that do provide some level of care for military veterans living with Parkinson's, but not at the level that these neurological centers of excellence provide. So going forward. Yeah, we're asking for additional funding for these neurological centers of excellence. One, to maybe establish a couple more throughout the country, and particularly in those underrepresented areas: middle America, maybe state of Florida, but also to provide that human resource infrastructure, that additional support for the 50 consortia sites around the country. These are the VA health centers that cooperate with the neurological centers of excellence, the six located throughout the country. We hope to provide them with additional support so they can begin to provide higher level of care for our military veterans living with Parkinson's.

Carol Blymire: So yes, people with Parkinson's need specialized care. And it sounds like, as you said, that care is only available on the east coast, the west coast, or Texas. So there is a need for sure to increase that availability in other parts of the country. How did we know that this was an important issue for us to focus on? Do you work regularly with veterans to help counsel you on the right things to pursue?

Dustin Watson: I do. And out of full transparency, I joined the Foundation in the summer, and it was about 30 days into my working for the Foundation where Congress issued a directive. And the directive was for the VA, the Department of Veterans Affairs, and particularly the secretary, to in congressional words significantly increase the investment and support for the Neurological Centers of Excellence, including the PADRECCs.

Dustin Watson: So being in this legislative arena, we took it upon ourselves to leverage from this new directive and put together a working group of veterans, of researchers in the PD space at the Federal level, and healthcare professionals, patients, and some caregivers. And we started to ask tough questions about what is really needed in the space for these Centers of Excellence to provide that holistic, comprehensive approach to care.

Dustin Watson: And together, and quickly, the working group worked over a good six month period and came up with very specific recommendations for the VA to take up, which essentially serves as our case for Congress to back up its words with additional funding for these Centers of Excellence, all in the context, provide a greater level of care for our military veterans living with Parkinson's.

Carol Blymire: That's incredible. What a way to ensure that our community, that that voice is not just present in advocating for things that we know are part of the government's regular calendar, but on special issues, such as this one to elevate that voice and make sure that they are driving the solution. That's remarkable. What a great way to do that. Now, I'm guessing I know the answer to this, but I'm going to let you answer it. Do you have to be a veteran to weigh in on this issue with your member of Congress?

Dustin Watson: No. And in fact, over the past several weeks, we've been lobbying on this issue specifically. And part of our model obvious is to bring in the experts, but also the patient voice and the caregiver voice. And in addition to military veterans living with Parkinson's, we've had researchers, we've had healthcare professionals, we've had caregivers, we've had family members. We have had friends who have participated in this effort who tell their story from their perspective. So, no, you don't have to be a veteran to advocate with us or on this issue. If you are familiar with Parkinson's in itself, there's a story to be told. And if you happen to be a veteran, so much the better, but absolutely we can hear from a variety of different voices on this issue.

Carol Blymire: Thank you for that. So today we covered a lot of territory. We talked about the role of the Federal government in helping find a cure for Parkinson's disease, as well as the programs that support people living with the disease. We talked about state government relations opportunities and the ways in which states play their special role in helping find a cure and helping elevate sources of data that otherwise wouldn't be found. And of course, we talked about a very important group of Americans, our veterans, 110,000 of them, who are living with Parkinson's disease and the ways that we can increase access to care.

Carol Blymire: Thank you to all of our guests today, Ted, Dustin, Julia, George. Thank you to our advocates, Israel, Myra, and you'll be hearing from Leslie shortly. Thank you for your stories. And to all of our advocates out there, thank you for doing the work that you do. I don't think the Foundation could advance their policies without you. And I know that we are all grateful for everything you do.

Carol Blymire: If you need more information on how to become involved or all the different areas in which The Michael J. Fox Foundation works on your behalf in Washington, D.C. and all the state capitals across the country, you can go to michaeljfox.org/advocacy. And now we're going to let Leslie Peters from Colorado close out our podcast episode for today with some of her words of wisdom about being an advocate.

Leslie Peters: My name is Leslie Peters and I'm from Aurora, Colorado. My husband and I were caregivers for my mother-in-law who had Parkinson's. And shortly after she passed away, my husband Steve was diagnosed with young onset Parkinson's. My reason for advocating is because it kind of helps me feel like I have control of kind of uncontrollable illness. I've met with Colorado representatives, both on Capitol Hill and locally. I've been able to develop a relationship through consistent communication. Advocating for policies that are important to the Parkinson's community has been beyond rewarding for me. The work that we do is making a difference and it has helped me channel some of my fear for the future into something positive.

MJFF: Thanks for listening. Community members like you are bringing us closer than ever to a world without Parkinson's disease. Learn how you can support The Michael J. Fox Foundation in its mission at michaeljfox.org.

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