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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.

Larry Gifford: Hi everyone. And thank you for joining us. I'm Larry Gifford, a proud member of the Michael J. Fox Foundation Patient Council, the founder of pdavengers.com and the host of a podcast called *When Life Gives You Parkinson's*. Today, we are discussing how to navigate new Parkinson's diagnosis. We'll cover how to build your care team and ways to connect to the community and opportunities to participate in research. We have a lot to discuss today, and so let's get started and let's introduce our panelists.

Phil Alongi is a journalist who left NBC News in 2009 to start his own production and consultancy program, Alongi Media. He was diagnosed with Parkinson's in 2019, and quickly jumped to action. When the landmark Parkinson's Progression Markers Initiative, or PPMI, began recruiting again late last year, Phil was the first newly diagnosed person to enroll. We'll talk more about that decision later this hour. Phil, welcome to the panel.

Phil Alongi: Thank you very much, Larry Gifford. It's good to be here.

Larry Gifford: Dr. Jerome Lisk is a movement disorder specialist practicing in Texas. He sees people with Parkinson's at a range of experience with the disease from recently diagnosed to later stages. He's also been a primary site investigator for multiple Parkinson's clinical trials. Dr. Lisk, welcome to the panel.

Dr. Lisk: Thank you, Larry Gifford. Appreciate it. Glad to be here.

Larry Gifford: It's great to have you. And Dr. Marie Saint-Hilaire is a professor of neurology and director of the American Parkinson Disease Advanced Center of Research at Boston University. She is involved in direct care of people with Parkinson's and a range of research interests. Dr. Saint-Hilaire, thank you for being here.

Dr. Saint-Hilaire: Thank you for inviting me.

Larry Gifford: All right. We have a full panel and a lot to get to. And for the newly diagnosed, we're going to try to keep this as top-line as we can, but informational because we can get into the weeds and we don't want to do that, but we will promise you that there will be many takeaways. I encourage you to take notes because you'll want to follow up maybe with some questions with your own neurologist or movement disorder specialist after this webinar.

What is Parkinson's? What a great question. You hear Parkinson's, you hear Parkinsonism, and what is the difference and what do I have? I remember when I first got diagnosed, they're like, "Yeah, you have probably Parkinson's," and I'm like, "I have no idea" ... In my head I'm like, "I have no idea what that means." I knew Michael J. Fox had it and I knew Muhammad Ali had it, but what did they have? I don't know. My hand didn't do what theirs does. Why don't we go ahead and define Parkinson's disease? Dr. Lisk, what are some of the common symptoms and what exactly is Parkinson's?

Dr. Lisk:

Parkinson's disease is a neurological disorder of the brain that affects primarily movement. And so Parkinson's disease affects multiple chemicals in the brain, but the one that is most popular is dopamine. And when you have that lack of dopamine, you could have slowness of movement, which is really how Parkinson's will start for a lot of people in the beginning.

The second can be tremor and also stiffness, and this usually will happen on one side of the body or the other. A lot of times it happens on your dominant side. Parkinson's disease is different for everyone. And the importance is that you get to a neurologist movement disorder specialist, which we'll go in later, but as Parkinson's develops, there could be more new symptoms you can develop that the other chemicals that the brain becomes deficient in can start to manifest and that's why it's really important to educate yourself and get in early, see someone.

Larry Gifford:

I think one of the surprising things is, at least it was for me, is I was collecting symptoms, but I didn't realize they were related. I just thought I was getting older. How does somebody know that it's not just aches and pains or, "Oh, it's an essential tremor. It's nothing to worry about"? People, at least I kind of just sort of dismissed them all until there was enough of them, I'm like, "Something's wrong here." Do you have encounter that quite a bit?

Dr. Lisk:

Yeah. Frequently, what happens with Parkinson's disease and other Parkinson disorders is that you could have non-physical signs that start to happen before the physical signs. And if you're not aware of this and you're not educated on it ... Programs like yours have done a great job in educating people and social media and the community. There's a disorder called REM Sleep Behavior Disorder that could be a warning sign where people will fight out their dreams, and some people get them confused with nightmares are sleepwalking. This is where the person is asleep and they are actually swinging or kicking or yelling at someone and they can even roll out of bed. This can happen 20 years before you have your first physical sign of Parkinson's disease.

If you all of a sudden lose your smell and there's not an explanation, that could be a sign of not only Parkinson's disease. Sometimes it happens in Alzheimer's too, but Parkinson's disease is probably more popular for that to happen in. And also, other things such as ... There are softer signs like constipation, depression, and anxiety could happen as well. But the big thing that we know is abnormal is if you're acting out your dreams because 60 to 80 percent of those patients will

develop a Parkinson disorder like Parkinson's disease, multiple system atrophy are Lewy body dementia.

Larry Gifford: Great. Thank you. Let's talk about the path of navigating Parkinson's disease. Everybody's journey is so different and I know early on, Dr. Saint-Hilaire, it's hard not to go, "Well, that person has this symptom or was on that pill," and there's a lot of comparison going on, especially between the newly diagnosed. Can you talk about how unique everybody's journey is and why it's important to really just focus on your own health?

Dr. Saint-Hilaire: Yeah. Everybody has a different progression and is on different medications, but for most people, it takes at least two years to get to a diagnosis. It's not unusual that patients have seen an orthopedic surgeon before or sleep specialists because they're acting out their dreams, like Dr. Lisk mentioned. People can get to the movement disorder specialists to different pathways. Some people, it's their physical therapist who said, "You should go see a neurologist." It might take a while to get diagnosed because we still don't have a specific test for Parkinson's. The diagnosis is made clinically, so it's important to see somebody who has experience in diagnosing Parkinson, like a movement disorder specialist.

And initially, when we see a patient, we might not be sure it's Parkinson's disease because there are various causes of Parkinsonism. Parkinsonism, if you hear the term Parkinsonism, it's an umbrella term that covers Parkinson's disease, but other causes of Parkinson's symptoms, like sometimes it's caused by medication. Sometimes it's caused by a condition like multi-system atrophy, which Dr. Lisk mentioned. The movement disorder specialist's role is to try to tease out really what is the cause of your Parkinsonian symptoms. And initially, it might be difficult because we still don't have a test. That's why Michael J. Fox is doing that PPMI study is trying to find a bio marker, so it might take a little while to get to the diagnosis. And when you get a diagnosis, then you have to discuss with the person about the treatment. At this point, we don't have any treatment that slows down the progression of the disease, but there's plenty of opportunities if you're interested to get involved in research, and we'll talk about that.

But also, discuss with the physician what are the symptoms that bother you the most, if you feel that you need treatment for those symptoms or if you feel you can function well enough without treatment for a while, and everybody is different and the type of treatment you will start really depend on the age, on your degree of disability, the type of work you do. It's a process with your doctor and it's not like you're going to go see a movement disorder specialist get a certain diagnosis right away and get the medication right away. It might take a little while to the diagnosis and the right treatment for you.

Larry Gifford: I was going to just add to that that when you are first going to a movement disorder specialist, as far as the medication is concerned, I know in my case, they started me at the lowest dose possible. And then every time I saw him as I

talked to him about my symptoms and about what was bothering me, what was holding me back from living my life the way I wanted to, he would increase that. And after a while, it felt like my disease was getting worse, but then I later realized he was just trying to give me a little bit of a time in order to get to the level I needed rather than pushing me too far. Is that a pretty typical plan for progression of medication?

Dr. Saint-Hilaire:

Yes. Usually we start with the medication that is the lowest dose that is helpful for the symptoms without causing side effects. And all of these medications can cause some nausea or certain other types of side effects, so we start with a very low dose and build it up very slowly and see if you can get at a good level where you have good control of your symptoms without having too much or having no side effects. And as time goes on, you might have to add other medications, a combination of medications, but you can speak to many people who have Parkinson's and everybody can be on a different combination or different dosage. It just depends on how they react to the medication or they respond to the medication, what side effects they have, or just a unique lifestyle can influence the medication we use or the age of person also.

Larry Gifford:

Yeah. And just to double up on that, I mean, you think about somebody like me who is pushing 300 pounds, if you weigh 125 pounds, it obviously takes more medicine to put down a larger person than it does a smaller person. And if you're more active, you may ... It just depends on your lifestyle.

And the other thing that you said that I want to just reemphasize is that when you go to a movement disorder specialist or a neurologist or your general practitioner and you are a person with Parkinson's, this is your time. This is not the doctor's time. This is your time with the doctor and the doctor is part of your care team. And so what you really want to do is make sure you go there with an agenda that you go there with a list of things that you've talked about with your partner about what's holding you back from living the life that you want to live, what are the things that bother you the most, because they won't be able to tackle everything all at once.

But if you go with the most important things to you, so whether that's ... Maybe you want to continue running and you've got a gait issue, well, then they can help you work towards that. And I think it's important to understand that it's not just you just showing up going what next. You're part of the team and you're the leader of the team. You have to communicate pretty aggressively with your care team.

Dr. Saint-Hilaire:

Yeah. It's not like being treated for hypertension, like the doctor measures the blood pressure and say, "Oh, you have to increase your medicine." It's really a constant discussion with your care team, your physician and physical therapist about your symptoms and what bothers you and what's important to you. Some people come and might want to discuss their sleep problems because they really have a lot of sleep problems or other people it's more the tremor that prevents them from playing golf. I mean, everybody has different goals for their

treatment, so that's why it's really important for the physician to know what's really bothering you and what are your goals in your treatment.

Larry Gifford: And one of the other things when you're newly diagnosed that really kind of plays with your head, and I know I did for me for a while, is who do I tell, when do I tell them, what kind of reactions should I expect? I want to bring Phil Alongi in here, who is fairly newly diagnosed. Phil, what was your process for sharing your diagnosis?

Phil Alongi: Like everyone else, Larry Gifford, I initially took the approach like I was ashamed of it and I was embarrassed by it and I was keeping it as a secret, but I slowly realized that, especially with the Michael J. Fox Foundation help and people I was talking to there, that there was nothing that I did wrong and I shouldn't be ashamed and actually I should take a more active role because hearing from someone, another person that has it, I found already is helpful not only to me, but to them. And when I found out about the PPMI program, that's why I raised my hand as high as I could and I said, "If there's any way I could help find whatever it is that causes this disease or how it manifests itself, I want to be part of it. Perhaps it'll help me, perhaps not, but if it will help someone down the road, I'm happy to be there to be part of that process as well."

Larry Gifford: How did you tell your family?

Phil Alongi: What was interesting, when we ... I'm very fortunate I have a very good primary doctor and the neurologist that I went to, the neurologist was ... Immediately, that was the first thing he said he wanted to check. And it's not that my symptoms were that obvious. At that point I didn't have tremors or whatever. It was just, he was very perceptive in doing this. I did tell my wife very quietly and then we spread it around first to siblings. And I have two boys that are really fine young men, and I've started sharing it even more with my extended family. By extended family, I mean colleagues from my work, people that we were in the trenches together for many years and everyone has been extremely supportive.

But what has also been extremely helpful is to hear about the different types of programs that are out there. Just very interestingly enough, one of the one Sunday at church, I noticed a person that I never really spoke to before who was sitting there and I saw tremors and this was shortly after I was diagnosed. And I said to the wife, I said, "May I ask you what this is?" And when she told me, she immediately started spilling out about what I should look into and what I should do. So that further cemented in my mind that you need to be more vocal about this and you need to be more proactive about this. And there is no reason to hide it.

Larry Gifford: I was about nine months post-diagnosis listening to a Michael J. Fox Foundation Parkinson's podcast, and I heard Dr. Ray Dorsey say, "If people with Parkinson's don't start sharing their stories, we'll never get enough attention to raise enough resources to do enough research to find a cure." And I thought about

that, and I've been in media my whole life and telling stories because I'm a storyteller, and I'm the national director of talk radio here in Canada for a company, and we have TV stations and a huge website. And I thought, "Well, I have the platform. I've got the ability to tell a story. And here I am hiding my disease from even my colleagues and my co-workers." And so I thought, "Well, if I don't do it, who will?" And that's how we started the podcast When Life Gives You Parkinson's. And it's really a platform to share the stories.

And what I found was, the fears that I had were unwarranted, because the support that I get back now from, not just my family and friends, but my colleagues and my workplace, is just unbelievable. And they're pretty much like, "Whatever you need, let us know." And they've been there at every turn, everything I've done, including they distribute the podcast and give me promotional time on radio and TV to talk about it and to raise awareness of Parkinson's. And so obviously not everybody has that opportunity, but whatever that is for you. Some people put it on Facebook and some people don't. Everybody's different. So whatever you're comfortable with, there's no right answer. You don't have to tell your work, but if you feel comfortable enough, you can. But you can ask, there's a lot of people here to ask.

Michael J. Fox Foundation has a lot of great resources. There's a guide for the newly diagnosed. There's Parkinson's 360. So just check out the resource area of the Michael J. Fox website, and you'll be able to get some more information on that. We're going to transition now into building your care team. We've talked about the neurologist and the movement disorder specialist. And Dr. Lisk, maybe you can define the difference between a neurologist and a movement disorder specialist. What are the differences in their roles as it pertains to Parkinson's? And what would you prefer, or what's the preferred role? Do you see just a basic neurologist, or would you rather somebody with Parkinson's see a movement disorder specialist?

Dr. Lisk:

Okay. Great question, Larry. So let's start off by saying that when a doctor does go to neurology residency, they get general training. And then you decide that you want to be a general neurologist, or you want to do something called a fellowship. A fellowship is something where you do focused training for one to two years on one thing such as epilepsy or stroke or movement disorders. Movement disorders comprises Parkinson's disease, essential tremor, cervical dystonia, Huntington's disease, and other movement disorders. Okay? So usually people will find a general neurologist initially because they don't know the difference, and they don't even know movement disorder specialists exist or know what the term means. And so if you do know that, and you think you're having symptoms of Parkinsonism, or a Parkinson disorder, or Parkinson's syndrome, which those are all synonymous, then what you want to do is you want to initially seek out a movement disorder specialist. Okay?

Because that person, as Phil was saying, that person is going to, if your symptoms are not very obvious, that movement disorder specialist is going to be able to tease it out easier than, usually, than a general neurologist. And so

everyone presents differently. Some people may present with tremor. Some people have come in my office and said, "Well, I don't even think I have Parkinson's because I have no tremor." You don't have to have tremor to have Parkinson's disease. So when someone does this every single day of their life, that's important to do. Now, the important thing also to know is that any general neurologist could call themselves a movement disorder specialist based on them saying, "I just see a lot of patients." So what you want to do is you want to add, because there's no board exam for the movement disorder fellowship, that's sub-special. So what you want to do is you want to ask, "Have you done a fellowship in movement disorders? Is that doctor fellowship trained in movement disorders? Are they just calling them this because it's based on them just seeing a lot of people in their clinic?"

So the other thing I want to point out is that a movement disorder specialist, as you go through your journey with Parkinson's disease, we say that there's no cookie cutter treatment, everybody is different. You go to support groups, online forums, what works for you won't work for someone else. Some patients come in, they want to avoid medication. Some patients come in and they want medication now, and they want a more aggressive therapy. So we're in tune to really getting to know our patients, and knowing kind of how to implement that therapy, and try to do ... We know all the programs, such as there's a lot of exercise programs out there that we can do. As you progress through Parkinson's disease, there will be things that may come up, such as blood pressure changes, orthostatic hypotension, bladder problems, dementia later on in life within 10 years or 15 years or so, psychosis, sleep problems. And we tend to treat those things as well, instead of sending you to a psychiatrist or urologist or to a cardiologist.

So it's almost like a comprehensive one-stop shop. And it's an educational resource for patients, where if you don't know all these programs or the Michael J. Fox or the PPMI, a movement disorder specialist is going to be going to national conferences, research conferences, and they're going to know all the things available for you to get your resources, and the things that treat you naturally without medication.

Larry Gifford: Right. Yeah. That's great. And we'll get into some diet and exercise coming up here in just a minute, because it's important. Let's talk about some of those treatment options, Dr. Saint-Hilaire. Taking a high level, what are the latest techniques for treating a newly diagnosed Parkinson's patient?

Dr. Saint-Hilaire: So everybody comes to the diagnosis from a different point. Some people have read a lot about Parkinson's and might have already made their opinion. Other people have family members who've had Parkinson's or know people who have Parkinson's. Other people don't know anything about Parkinson's. So one thing first, when we give a diagnosis or discuss a diagnosis, is we have to gauge where the person is along the path. And just have them think about what they are doing now that they cannot do now when they could do in the past. So having difficulties in doing activities of daily living or hobbies or functioning at work

would all be reasons to start medication. There are patients who are not very disabled by their symptoms and prefer not to start medication. And that's also a good choice for them, if it works for them.

Usually the way we start medication, if you need to start medication, is we look at the primary symptom and the age of the person, and the other medical condition. In general, I mean it's really very general, the younger patients, so people who are diagnosed before the age of 60, we tend to delay the use of levodopa because it can cause abnormal movement. So we would start with another medication, like a dopamine agonist. And eventually the symptoms progress, eventually add levodopa. But in older patients where the [inaudible 00:24:35] high, we might start right away with levodopa. There are other medications like rasagiline taken once a day and very well tolerated. Or another medication called amantadine which is a medication that [inaudible 00:24:58]. So really, it's a discussion with the patient about whether symptoms are bothering them, if we feel they need the medication, or if they [inaudible 00:25:10] medication.

And if they want to wait I would encourage them to just [inaudible 00:25:20].

Larry Gifford:

Dr. Saint-Hilaire, I'm going to pause you for a minute, because you're breaking up a little bit. I just want to repeat what you said. So what Dr. Saint-Hilaire is saying is that if you decide to delay taking medication, you are a prime candidate for research. And I think that's really important to understand, because once you start taking the medication, there are some research opportunities that close off to you. But like for case, the micrographia and the typing issues I was having made it so I went on the levodopa right away. And it almost instantly allowed me to type again and to write better. And it was a miracle for me. I thought I'd lost that ability forever. And I think that's another thing that people feel like if they ... I had a horrible walk, like a foot drop. And through physiotherapy and through the levodopa, I mean, I'm able to make that better.

And so I think one of the things that people need to understand is once you have a symptom, it doesn't mean that that's symptoms there forever, or that you can't treat it and get better. Even though it is a progressive degenerative disease, there are ways to address these issues so you can continue to live a productive and happy life with Parkinson's.

Dr. Saint-Hilaire:

Absolutely. And your work, so some for some people, the ability to be able to work, it's really important, and would be one of the reasons why you would want to start with the effective medication.

Larry Gifford:

For sure. But let's talk about the care team. I was never a doctor guy. No offense, but I didn't like doctors. I never went to a doctor. I didn't have any regular medication. I was living a great life and then 45 came and now suddenly I'm seeing a neurologist. And 47, I get a urologist, and I have a physical therapist and I'm seeing my pharmacist every week. I feel like I see them more than my

brother's. Like he's part of the family. And so how do you decide who's on your care team, who should be on your care team? We can just do a round-robin. Let's start with Phil. Phil, what's your care team look like today? And then what do you think is maybe missing from it?

Phil Alongi: My care team today is, I do fortunately have a movement disorder specialist in Manhattan that I see every three months, and we check in with one another periodically as needed. But I also have a very good local neurologist, as I already mentioned, who was very quick in figuring out what my issue was. I also spend two days a week with an occupational therapist to work on my motor skills to make sure that I can continue, because I've taken a different road. I've opted not to start the drugs as much as possible, to kick them down the road. And my family supports that decision, as do my doctors. So I feel I'm able to control what I need to do in order to accomplish my work goals and my family goals. I also have a physical therapist for two other days. I'm very active outside as well of the sessions that I have with my therapist.

I generally walk somewhere in the two to three mile range on a given day, when the weather is even nice so longer. I had been hoping to start a Rock Steady Boxing program, but as we all know with the pandemic, everything is shut down. But what has been a great tool for me, and I would highly recommend this, is look at YouTube. There are some amazing, amazing videos on YouTube that you could actually work on your own to keep your skills and your motor skills practice as best as possible.

Larry Gifford: Yeah. There's a lot of great free resources out there. And many of them are listed on The Michael J. Fox Foundation website, michaeljfox.org.

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Larry Gifford: Dr. Lisk, let's talk about the care team. What would you suggest people, how would you suggest people build their care team?

Dr. Lisk: Well care teams are different for everyone. So I'll tell you my clinical experience is that I've had patients come to me from a general neurologist, as Phil was saying, and I want to be respectful to that neurologist. So sometimes I will see the patient and they'll see their neurologist as well. But I think it's important to find your movement disorder specialist. That may be your own neurologist. And that's fine. I think [inaudible 00:30:26] okay with that. I think that, because we know that there's a lot of research and exercise, and exercise secrete chemicals that help Parkinson's disease. So getting with a physical therapist in physical therapy center, where you find a good physical therapist, occupational therapy. And then really, your movement disorder specialist is then going to start guiding your medical care team. Because Pasadena, California is different than Dallas, Texas.

So when I was in Pasadena, California, I had a really good urologist that I could send all my Parkinson's patients to because we talked, I told them about the challenges, we spent several phone calls together. And so I trusted him. I've been in other communities where the other medical specialties don't really know anything about Parkinson's disease. The patients know more than them. So like an orthopedic surgeon or urologist or psychiatrist may not, and they may even give a Parkinson's patients [inaudible 00:31:30]. So sometimes your movement disorder specialist will help guide your care team. I think it's very important to find somebody in your personal life and get a good support group around you. Those people that you care, you love, your friends, family. You need a good personal support team as well as a medical support team.

Larry Gifford: And that might even include a pet.

Dr. Lisk: Yes. Pet therapies are as ... I think that helps a lot of depression anxiety. I mean, having a little cute animal with you, who could go wrong? I think it's important. I've had so many Parkinson's patients that I've said, how can I get this guy, this woman to exercise? I say, "Do you have a dog? Do you have an animal?" They say, "Yes, it [inaudible 00:32:22] walks the dog. My wife walks the dog." I say, "Okay, now you're walking the dog. When you walk that dog, I want you to try to keep up with that dog but walk safely."

Eventually one guy said, "Now the dog's trying to keep up with me." He's getting out the house, he's talking to people on the sidewalk and he's socializing more. His depression is better. His anxiety is better. Some of these little things that we try to think of ... Like Dr. Saint-Hilaire said, there's some of these personal things with lifestyle, how active you are, that we want to learn about our patient. A lot is about learning about your patient and then implementing those therapies that your patients will be receptive to.

Larry Gifford: Dr. Saint-Hilaire, what's your experience with building a care team?

Dr. Saint-Hilaire: I don't have too much to add. I totally agree that you have to get physical therapy involved in the exercise, that your neurologist or movement disorder specialist can guide you to specialists to help you, if you have certain symptoms like urological symptoms. The only thing I would add is get a good primary care physician. Somebody who takes you seriously when you come in and you have, for example, fatigue, which is very frequent in Parkinson and say, "Oh, it's your Parkinson. Don't worry about it." Somebody who's a good physician would say, "It couldn't be your Parkinson's, but let's be sure you're not having problems with your thyroid. That you're not anemic." A primary care who will be happy to collaborate with the movement disorder specialist, if they notice something on the exam or your blood pressure is going down. They're concerned that your blood pressure is too low. I think that would be the last person I would add to your care, a good primary care.

Larry Gifford: Go ahead, Dr. Lisk.

Dr. Lisk: [crosstalk 00:34:33] Add and piggyback on that. You were telling patients about coming in with a list before. I think every patient needs to know that healthcare providers are very busy, clinics are packed, everyone's running, trying to take care of patients. It is very helpful for you as the patient to tell your primary care, tell your movement disorder specialist or running from room to room, your physical therapist, "Please communicate with my other doctors." It's always on my mind, but when patients tell me that, it gets to the forefront of my mind. That is really important. Tell your doctor. Urge your doctors to communicate with each other.

Larry Gifford: I think this is probably the best advice that I've found. I keep a diary of odd things, whether I start tremoring in the middle of the day and I'm not sure why or whatever. I put down the date and the time when I took my last medication and I try to keep track of that. Then by the time it's time for my doctor's appointment, I can look through that and see if there's any trends that I should be talking about. I also put down all my medications in here in case I'm in an emergency and or I go to a new doctor and they want to know what medication are you on? I can just forward them this list. I have all my doctor's information on here too, the same page. It's just one sheet that I update and I send to my doctors and my wife, anytime it gets updated. I think that's really important.

Dr. Lisk: I'd love to have you as a patient, keep it all together. My patients don't even have a computer.

Larry Gifford: I would say the other thing that ... My wife is a huge part of my support team. She is my partner in Parkinson's. We have a son who's 11 and it can be tough with kids. What we did with my son is ... His job ... We gave him a job and we were given that advice. Kids, they want to help, but they don't know how to help. His job for probably the first year and a half was to just, whenever you see daddy tremor, let him know that he's tremoring. He was on the lookout for it. For him, he felt like he was helping because ... "Hey, dad, your arm's moving," and then he'd hold it or whatever to help try to stop it. He felt like part of the process.

Then we'd have him on the podcast to talk about what he's feeling about, dad having Parkinson's and what questions does he have? Why can't we rough house as much as we used to or things like that. Just involving him in the whole thing has been great. I feel like he's a more empathetic child because of that.

Dr. Lisk: That's beautiful. I didn't think of getting the kids involved. I didn't even think of that. That's beautiful.

Larry Gifford: It can be any job. I take pills every two and a half hours. A lot of people when they're first starting, maybe take those in the morning or take pills at night and you can say, "Hey, make sure you remind me tomorrow morning to take my medicine." Just give them a job so they feel like they're part of this big thing that's happening to the family. Speaking of big things, I want to talk about PPMI. We're going to take a break and be able to give the panelists just a minute to

breathe, but I want to talk about PPMI. This is the foundation's landmark study that is speeding treatment breakthroughs. Now this is so important and they're going on to their next phase.

We'll talk about some opportunities to participate in it a little bit later, but I wanted to call out the PPMI also known as the Parkinson's Progression Markers Initiative is recruiting now. This is a study that could change everything about the doctor's diagnosis, how they manage patients, how they treat Parkinson's disease. I know that sounds like, "Whoa it can change everything. That seems a little hyperbolic." This could change everything. If you have not started your medication yet and you want to participate in research, we encourage you to volunteer for the PPMI. You could be part of the key that unlocks the mystery of Parkinson's. People with Parkinson's are diagnosed within two years. Sites are open until you've ... Within the last two years, we've been diagnosed. The sites are open now ready for you. You'll find the list of the sites and their contact information on the resource list. The study also needs parents, brothers, sisters, and children of Parkinson's to take a short survey to see if you're eligible. You can do that michaeljfox.org.

You can get the whole family involved. Michaeljfox.org/PPMIsurvey. Michaeljfox.org/PPMIsurvey. It's also in the resource list. There's no other group of people. It's on us. They can't do research without people volunteering. A lot of people are like, "Hey, when are they going to come up with that cure for Parkinson's." We have to say, "Test me. I'll be part of the process." If we don't volunteer the research doesn't get done because the doctors are only one half of it and we're the other half. I encourage you, if you are diagnosed within the last two years and you have not started on levodopa, please just investigate the PPMI. Thank you.

Let's get back to the panel. My ranting is over, but it is really important. There's a lot of things you can do. You can advocate in a number of different ways for yourself. I think advocating for yourself is really important, whether you're advocating at the doctor's office for sleep help or advocating at your office for ... One thing, they put a new door on my office, and it was a turn handle instead of a lever. I said, "Guys, it'd be so much easier if it has a lever instead of a turn handle." There are times when I'm off on my meds and I cannot turn the door knob. Little things like that, that nobody else thinks about, you have to ask for it. What are some other practical tips and stuff that we've discovered? Dr. Lisk, Dr. Saint-Hilaire, what are some recommendations that you have for just let's start with living a healthy lifestyle?

Dr. Saint-Hilaire:

I think it's really important to exercise regularly. As I mentioned, we don't have any treatment to slow down the progression of the disease. Although there is some research going on to see if regular exercise does slow down progression. We know that people do better if they exercise. It has to be at least 150 minutes a week and it has to have a combination of strengthening, balance, stretching and aerobic exercise. That's why consulting a physical therapist who has experience in Parkinson is really important that he can tell you, which are the

exercise that are good for you and follow you regularly, and be sure you're challenging yourself. It's important when you exercise that you challenge yourself. If an exercise is too easy, it means you have to ramp it up a little bit.

I think it's important to educate yourself about Parkinson. For example, we have some good start program for early or recently diagnosed patients where we discuss about ... It's a couple of evenings where we discuss about Parkinson more in detail and medications and the role of exercise in Parkinson's. We talk also about having a healthy diet. There's no specific diet that is recommended in Parkinson's, although there's some data that the Mediterranean diet might be beneficial. I'll let Dr. Lisk [crosstalk 00:43:00]

Larry Gifford: I'm hearing that more and more. What is it about the Mediterranean diet that we're like, "Yeah, that's probably a pretty good thing to do."

Dr. Saint-Hilaire: It's just that there are some studies showing that people eating a Mediterranean diet had a lower risk of Parkinson. When people ask me, "What is the best diet," I say, "Follow the Mediterranean diet." It's also good for your heart. It's good for your weight. It is a healthy way of eating.

Larry Gifford: ... Less carbs. It's more pescatarian style. It's a lot more fish. It's just a little more vegetables and fruits and it's more of a balanced that way, I think.

Dr. Saint-Hilaire: Yeah. I think also the important thing to remember when we talk about diet is that if you're on levodopa, the food in your stomach can decrease the absorption of the medication. We tell people to take their levodopa away from the meals.

Larry Gifford: Let's talk about that. They're talking mostly about proteins. When do you suggest people eat before? How long do they wait before or after taking a pill?

Dr. Saint-Hilaire: I usually say, wait 20 to 30 minutes after taking your Levodopa to eat. If you have eaten, wait at least an hour after having eaten to take your medication, if it's possible.

Larry Gifford: Yeah. Dr. Lisk, how important is it to take your Levodopa at the same time every day?

Dr. Lisk: I think it's very important to take at the same time every day. When patients come into the clinic, they don't know what [inaudible 00:44:46] is. They don't know what dyskinesias are. Dr Saint-Hilaire talked about education. You talked about keeping your information on your phone. If you're not technologically savvy, write this stuff down. Get support from people in the home children, the wife, cause people with Parkinson's aren't always aware that their symptoms are occurring. It's good to have someone let you know that. When you come in with this information, it makes your visits so much faster, for me anyway. I think for all of us so much easier, when you say this is the time. I'm having trouble

during the day, this is the time my medication's wearing off. I'm turning off. My symptoms are worse.

Then your movement disorder specialist can say, "Then I'll take this medication. I'll move it here. I'll switch this immediate release medication to a longer acting medication." We're trying to plug the holes in the boat. We're trying to cover the gaps in your day so you have more functional on time during the day.

Larry, I want to bring up one thing you mentioned, when you talked about the PPMI. I had one patient tell me, "Why should I be interested in biomarkers? I know when I have Parkinson's because you can see it." People are under [crosstalk 00:45:58] People are under that misconception, that when you see your first very tiny symptom of Parkinson disease, that's when it begins. Parkinson's disease will start in your brain. We know from looking at these imaging studies [inaudible 00:46:15] 20 years before you have your first physical symptom. That's why this PPMI is so important to find a biomarker. By the time you have your first physical symptom, your brain is halfway in the disease process. We want to get early.

You think of any time that you lose more than 30 percent of nerve cells in a population. If you hit a city with a bomb and you destroy more than 30 percent, you're doing damage control now. We want to get that neural population when it's just starting to degenerate so we can save nerve cells. You can only do that with a biomarker jumping in early. There's no disease on the planet that benefits from jumping in late.

Larry Gifford: Yeah, you're right. When you're first diagnosed, you don't realize ... It's not like, we just found a tumor and you now have cancer. This has been taking a toll on your body for years and years. Now it's done so much damage that it's starting to affect your movements or your depression and anxiety. It's interesting that you talked about how family members can see different things. I realized I was having some anxiety or anger issues, I'd anger quicker ... When my son goes, "Dad, why are you so mad all the time?" I was like, "Oh, I didn't realize I was." It can be a real check and it can be a gut check sometimes where you're like, "Sorry, son. I didn't mean to yell at you."

Dr. Lisk: I'll talk to a patient and tell them about their depression, anxiety they've been experiencing for the past three or four years was the Parkinson disease probably and not really them, their personality. They're blaming themselves for how they're behaving and they're acting for their depression, anxiety. And it's a relief to know, it's not me. It's the disease, and I can get treatment for it.

Larry Gifford: It's not a reaction to the diagnosis. It's part of the disease.

Dr. Lisk: It's not who you are. It's the disease and the chemicals. There's more than one chemical in the brain that is decreasing.

Larry Gifford: It's really exciting. There's a new program that The Michael J. Fox Foundation is beginning to launch, and you can sign up for it now, it's in beta testing. It's a Parkinson's Buddy Network and it's online. Anyone can sign up for it. It's designed to connect members of the Parkinson's community, and there are resources and a group for the newly diagnosed.

You can connect up and just so you have somebody if you're not ready to share it with your friends and stuff. Here's a safe place you can go, talk to other people that are going through the same thing or similar situation that you're going through.

You work together. I've created my own buddy system over the course of the years around the world now. I've got friends. I went to the World Parkinson's Congress in Kyoto, a couple of years ago. And met just tons of people that are just great.

This community, people think it's weird, but I oftentimes say Parkinson's has been a blessing because I would have never met such an awesome community of people. I would have never had that opportunity, and I feel so fulfilled having had that opportunity. Get to know people, because this is a really interesting group of people that have Parkinson's and we're all in this together.

It's a big group. It's the fastest growing neurological condition in the world. We're trendy too. Hey Phil, welcome back. I know you dropped off there for a minute, technical issues from the senior producer of the program, nice.

Phil Alongi: Thanks, I know. I really appreciate that. But unfortunately I do have a backup laptop standing by all the time. I just needed to get it going very quickly.

Larry Gifford: Because you are a pro my friend. Let's talk about symptoms. How are you managing some of your symptoms?

Phil Alongi: Like everyone else has been saying, the support network that you have is critical to all of this. I fortunately have a great life partner in my wife. When she was even listening last week to the prep meeting we did and picked up immediately. We have now switched over to the Mediterranean Diet in this house since she started cooking, in that regard. My wife has been very responsive. In terms of managing the symptoms, I've tried my best to push through. I've never been one in life to just take things lying down. In terms of talking to others within the community, you find out about things that you should do, and you should try. But what, the two therapists that I work with between the two of them, plus my family, my wife makes sure that I get my butt off the couch and do what I'm supposed to do. She reminds me, "I haven't seen the YouTube videos lately. Let's get going on that." It's very good to have someone who's going to push you, especially on those days when you just don't feel like doing anything.

Larry Gifford: There's a lot of great groups out there. There's Dance for PD, I actually started Improv for Parkinson's, in Vancouver. We do improv online every week. It helps

with just paying attention and listening, and you're creating new neural pathways. Lots of great programs out there you can research. I do want to move on to the participation of research. Dr. Lisk talks about the importance of participating in research early in your journey with PD. We've kind of touched on that. Dr. Saint-Hilaire, what's the difference between an observational study in a clinical trial?

Dr. Saint-Hilaire:

There's research for all types of different research, depending on what you want to do. An observational study, which is like the PPMI study, we'll be talking about, which is the biomarker study. We don't do any intervention. The person comes to our center every six months and we just examine them. We do some blood tests, urine tests, test the spinal fluid, do an MRI or DAT scan. We do the usual physical exam that you do. You have what you see your neurologist. Taps your fingers, open and close your hands, and your gait. It's really getting data on how Parkinson progresses. It's putting a big database that can be accessed by any researcher. Trying to find a biomarker, trying to find some links about progression or risk factors.

This is an observational research. It's just gathering data without doing any intervention. Then clinical trials, means that there is an intervention. Which means that somebody is doing something to you to help those symptoms of Parkinson's. For example, there's a big trial that we'll start funded by NIH called the SPARK study, where they will get a group of people who have Parkinson disease. They will have them do intensive exercise and compare if the disease progresses more slowly in this group of patients compared to who doesn't do as much exercise. It's really an intervention because the group of people who will do intensive exercise, it's an intervention. They will be under the supervision of physical therapist and neurologist.

There's also clinical trials of medications. There are trials now of medication to slow down the progression of the disease. There's also many trials of medications to help certain symptoms of Parkinson's. Trials of medication to help depression and Parkinson or cognition and Parkinson's. There are even trials of intervention, such as cognitive behavioral therapy for depression and Parkinson's. There are all kinds of trials. You have to really find a trial which you feel comfortable with, a clinical trial, an observational trial, it could be a medication trial, an exercise trial. There is for all every taste, but definitely we will not find any cure or any better treatment if the people have Parkinson's, don't participate at trial. Really the participation everybody's really important.

Larry Gifford:

At this point, I'll mention that there is on the Fox website, The Michael J. Fox Foundation, and there's also another website called Fox Trial Finder. If you sign up for that, they'll show you different trials that are coming up in your area, Fox Trial Finder. I do want to talk to Phil here. Phil, what's it been like enrolling in PPMI?

Phil Alongi:

It's already been an amazing journey. I've met some unbelievable people that have been extremely supportive. I've been up in Connecticut, at the main facility

site twice already. We've gone through a whole series of tests and they exposed me to what PPMI can offer. In terms of doing DAT scan and developing our baseline and AV133 machine. But they've also told me about some other research projects that are going on.

And by learning about this, it gave me the opportunity to broaden out, as well as, my reach in terms of participating in the research projects. Because it's not a lot of work, but it's meaningful work, and it's very rewarding work. But it's a great team of professionals that are a part of PPMI. Anyone who's interested, I'd be happy if they'd like to just bounce some questions off me. I'm a big fan. I'm actually scheduled to go back in April for the next round of tests and see how things are progressing or not, hopefully. Anyone who has any questions about it, first of all, reach out to any one of the folks at Michael J. Fox Foundation, or feel free to try to find me and I'd be happy to answer any questions they have as well.

Larry Gifford: Phil, let me just say on behalf of the Parkinson's community, thank you for what you're doing. Appreciate it.

Phil Alongi: We're all in this fight together.

Larry Gifford: I do have some questions. I'm going to fire them off. We just have a few minutes left. Dr. Lisk, does stress trigger more tremors?

Dr. Lisk: Yeah, any type of anxiety, emotions, the answer is, yes. In your brain, there's a system for your movement and there's a system for your emotions. The system for your emotions is called the limbic system, the system for your motor functions called the motor system. These two systems are interconnected. When people get angry, or nervous, or upset, they basically that feeds into your tremor. You can think if you were in summer camp or something, and you're trying to do a task, or you're in some type of race, to do some type of fine motor skill, the more nervous you get, the harder it is to do it. For us in motions, we'll make any movement disorder that where there's movement involved, worse. The thing is treat those emotions.

Larry Gifford: I find when I'm in a stressful situation, my arm will move like this, and I'll start to start to stutter anymore. It's hard to get things out. It just sort of enhances all of the...

Dr. Lisk: It's careful not to go, see that's where the education part in this whole, I think program. We're saying, education and being involved, and you don't want to go to your doctor because you're having stress and anxiety and say, "Give me more Sinemet." That's not what's making your tremor worse.

Larry Gifford: Dr. Saint-Hilaire, what is DAT? You mentioned DAT earlier? Can you explain that?

Dr. Saint-Hilaire: Can you repeat the question?

Larry Gifford: DAT scan? What is a DAT scan?

Dr. Saint-Hilaire: A DAT scan is a dopamine transporter scan. It is a way to differentiate primary Parkinsonism from other forms of Parkinson's. It's not specific to Parkinson's disease. Any type of Parkinsonism such as multi-system atrophy or progressive supranuclear palsy, will be positive. It just tells you that you have a primary Parkinsonism versus a secondary Parkinsonism. For example, drug-induced Parkinsonism caused by medications. Certain medications for depression can cause Parkinsonism. Then your DAT scan, would be normal. It also differentiates between primary Parkinsonism and another condition called, essential tremor. Sometimes when people have a complex type of tremor, it's difficult clinically to know if this is really Parkinson tremor or essential tremor. The DAT scan is useful to differentiate those, but it will not be useful to differentiate between the different forms of primary Parkinsonism.

Larry Gifford: Great. I'm going to get to the last word to our buddy, Phil. Phil, wrap this up for us.

Phil Alongi: This has been extremely helpful. I just wanted to make one last, very important point. As already mentioned, what's important about when you go to your doctors to bring a list of your questions and track things. As you've talked about Larry Gifford, what you do in all. But the other thing that I found extremely beneficial is bringing my life partner with me. Me and my wife, who sleeps with me every night, because she fills in the blanks about things. And the doctors have said to us, this is great because of course you are sleeping and you don't know. But she obviously monitors what goes on during the day and points out those things. That would do to the last point I would like to make to the newly diagnosed person. Again, life partners are critical.

Larry Gifford: It's really important. They have a different perspective that the doctors really appreciate. I want to thank all of you for being here and for being a part of our community. It's great talking to you. We could go for hours, I think. Thanks to our panelists for sharing your time and your expertise. We'll be sending a link to the webinar on demand. You can listen to watch again, and share as you like. We hope you found it very helpful. Stay safe, stay connected, and be well.

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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