Michael J. Fox: This is Michael J. Fox. Thanks for listening to this podcast. Learn more about the Michael J. Fox Foundation's work and how you can help speed a cure at michaeljfox.org.

Speaker 1: In this episode, you'll hear a recap from our latest third Thursday's webinar. Expert panelists will discuss the latest in Parkinson's research and answer audience questions about living well with the disease. We hope you find the discussion helpful.

Soania Mathur: Hi everyone. I'm Dr. Soania Mathur. I'm a retired family physician, writer, speaker, Parkinson's advocate, and co-founder of the PD Avengers. I'm also a very proud member of the Michael J. Fox Foundation's Patient Council. I was diagnosed personally with Parkinson's in 1998 at the age of 27. I would first like to extend my gratitude for all of you joining us today, and it's my true pleasure to be here with you and our really esteemed panelists. Today, we're going to be talking about sleep and as it relates to Parkinson's. Sleep is part of our daily routine. It provides some reprieve from the symptoms of our disease. But this disease itself and the treatments that we take can often make restorative sleep difficult to find, which can significantly impact our quality of life. In today's webinar, we'll be talking about sleep issues in Parkinson's, treatments that can help, and the ongoing research into this challenging problem.

We've got a lot to discuss, so let me first introduce our panelists. Wanda Kim Lilley is a friend and a fellow member of the Michael J. Fox Foundation's Patient Council, and we're definitely better for it. She was diagnosed with PD in 2012 and is an avid Team Fox member. She lives in Europe with her husband.

Dr. Emmanuel During is a neurologist, psychiatrist, and board certified sleep specialist at Mount Sinai. His primary interest of study is REM sleep behavior disorder or RBD, something that we'll be talking about during our time together. Dr. Okeanis Vaou is a movement disorders division chief at University of Texas Health in San Antonio. She also is a sleep specialist and her research is directed mostly towards deep brain stimulation, sleep, and Parkinson's. Welcome everyone. So we all know that sleep is good for us and it's really important for our health, but why is it important? How do we benefit from a good night's sleep? Dr. Vaou, let's start with why a good sleep is important. How do we benefit from one?

Dr. Okeanis Vaou: Thank you, Soania.That was a wonderful introduction. And thank you, Michael J. Fox, for having me. This sleep is near and dear to my heart. After I trained for movement, I had a fellowship, I did feel that my training wouldn't be complete if I didn't train in sleep. So I further moved along and did another fellowship in sleep because what I realized is that I was seeing patients with Parkinson's and they all had sleep problems and they were very complex for me at the time and didn't know how to treat them. And that really bugged me. So I feel more comfortable having had that sleep fellowship to understand sleep as it's one of the biggest one-third of our life we spent sleeping. So why is it important? Yes, you hear that sleep is important, but if only people knew the true importance, I think they would sleep better.

First of all, sleep, you reset. It's like you're plugging your phone to recharge before you go to sleep. That's what sleep does to your brain metaphorically, obviously. It is a reset. It clears, we now know through the glymphatic system, it clears a lot of the, as I tell my patients, the impurities or the toxins that they accumulate over the day. So it's like the resetting of the brain, but it's not just the brain. It's of course Parkinson's. And neurologists, we're neurologists, we talk about the brain or psychiatrist, we talk about the brain. But there's all other benefits. It does support physical recovery. So if someone is injured or has an infection or even has overexercised, sleep is important for recovery, for muscle recovery, for physical recovery. We do know that it boosts immune function.

So as we're talking about inflammation, could this be an inflammatory disease? Sleep does improve immune function, therefore decreasing inflammation. And then protects metabolism, protects heart health in so many ways. And the list goes on and on and on. It's overall very beneficial. However, too much sleep is not good for you either. So it shouldn't be too little, it shouldn't be too much. So anywhere between seven to eight hours is allowed. However, if you exceed that, then it's problematic. It could actually harm you. There have been studies that show that it can accelerate dementia and cognitive dysfunction. So sleeping too much is a concern for us. So I have multiple patients who come and say, "Oh, I love sleeping." I actually had one who was referred to me for hypersomnia. He was late hypersomnia, he's in the 80s and he has Alzheimer and he just said that, "I love sleeping." He sleeps basically 20 hours a day.

Soania Mathur: Oh my goodness.

Dr. Okeanis Vaou: Such a huge problem, but neither his family nor himself thought that this was a problem because, oh, well, he's sleeping. So we have to recognize what is too much and what is too little. I have patients say, "Oh, well, that's how I've been all my life. I sleep four hours. I'm good." These are some of the myths that we need to crack in the society. I know that obviously when you're living a very fast and active life, you consider that five or six hours of sleep is good for you and you can get along, but it really isn't. So we are one of the most deprived nations in the world.

Soania Mathur: I believe that. So it sounds like it's a fine balance, like most things in Parkinson's, there's a fine balance between the amounts of sleep that we get. So that's why sleep is important, but the whole process of sleep is much more complicated than we think. So Emmanuel, I was wondering if you could walk us through what a healthy night's sleep is like. What goes on in the brain and body in a healthy night of sleep?

Dr. Emmanuel During: Right. Well, again, thanks for inviting me. This is very exciting and I'm really passionate as well about sleep and Parkinson's. My story is a little bit different. I trained as a psychiatrist first in France back 20 years ago, moved to the US, trained as a neurologist. And at the end saying, "Sorry, I was very interested in Parkinson's and movement disorders, but also in sleep." And I figured, well, sleep provides a lot of answers and solutions to people with Parkinson's. You asked me about what's going on in the brain through a healthy night's sleep. It's very interesting. There's like a clock that really [inaudible 00:06:56] showing that

we go through several cycles. And the typical night would be falling asleep and then quite quickly going in the deepest stage of sleep, which we call slow wave sleep, slow wave sleep, or deep sleep. And that's probably the most restorative and almost probably the most vital or critically important for health because we never skip that cycle.

So the deepest sleep is really the first hour or 90 minutes of sleep. After which, we enter first cycle of REM sleep. And rapid eye movement sleep, REM sleep, is the part of sleep where we may dream, we may remember or not our dreams. But if we remember them, those dreams are typically quite vivid and complex and just like a real awaking experience almost. And after which, after a few minutes, we start over a new cycle and we cycle through those deeper sleep and REM sleep every 90 minutes to two hours. Depends on people. And like that over six or seven or eight hours, we go through three, four, five cycles. As we get the deepest sleep early in the night, sleep becomes a little bit more shallow towards the end. And at the same time, we have more and more of this rapid diet movement sleep. So we dream more.

When we wake up in the morning, often, not always, we may remember a lot of dreams because that's after which cycle we typically wake up. So every part of sleep has a function. There's not a better or worse stage.

Soania Mathur: Right.

Dr. Emmanuel During: All are important. Like I said, the deepest sleep is probably very important for survival and restoring the energy for all the organs and clearing up a lot of the toxins like we discussed. But REM sleep is important too because that's when we reset sometime emotionally and it's very important for emotional health. And the lighter stages of sleep are important too. So I always tell my patient, "Even if your sleep is light, feels light, well, you're still resting and that's normal."

Soania Mathur: And we'll get to talk about what's going on in these brains that might be a little bit different and not allowing that to happen. But we've talked about that sleep is necessary, but achieving a good night's sleep can be difficult, particularly when it's complicated by a chronic disease like Parkinson's. And I know for me personally, sleep has always been a struggle. Initially, I had difficulty falling asleep and then I wake up frequently. More recently it's changed where I sleep a little bit better, but I'm struggling with pain secondary to not spontaneously turning over again, which we often do without waking. And so even though I have to wake up to struggle to turn, that can be certainly disruptive. Can't sleep in for the eight hours like I used to, or certainly as luckily my kids do now. So it definitely impacts quality of life and it impacts functioning the next day. Wanda, what has your sleep been like and how has it changed post Parkinson's diagnosis?

Wanda Kim Lilley: I have to say, I'm delighted to be here with these wonderful presenters. I'm learning so much already. I wish I weren't qualified to be on this call today. Until literally two or three years ago, I was a champion of sleep. I was a gold medalist in sleep and I could get to sleep, I could stay asleep. If I had to get up, I would get back to sleep. But then something started to happen with my own symptoms.

I started to get the very painful, prolonged muscle cramps during the day and dystonia in my hands and in my feet.

And then I noticed that at night I would start getting leg cramps, mainly my ankles and my calves. And I started to deal with that by just saying, "Okay, fine. I'm getting leg cramps. I've had them before as a child, not many, but I'll just get up and walk it out." That's okay. The pain woke me up, but what kept me up was fear because then I would start to think, oh my goodness, does this mean this is another symptom that I have to worry about? Is this a progression of my disease? Does this mean I'm entering another phase? And that voice in my head made sleep very, very difficult. So yeah, it was a pain that woke me up and it was a fear that kept me up.

Soania Mathur: Yeah. The fear thing can have a webinar all to itself. I understand what you're saying. Dr. Vaou, when people come to you with sleep concerns, what kind of symptoms do they experience? Is this something like Wanda and I have discussed with you today or are they different or what kind of symptoms do you normally have them discuss?

Dr. Okeanis Vaou: So Wanda, I'm glad to hear, I mean, I'm not glad to hear, but I'm glad to hear that you're recognizing and sharing all these sleep problems, which are very common in patients with Parkinson's. Just to set the stage, I do see patients with Parkinson's in my movement clinic, but I also run a sleep clinic for the movement division, but as well as the Alzheimer's Research ADRC center that we have. So I see sleep from two different angles from neurodegenerative disorders in general. What people need to understand is that you need to tell your doctor about your sleep because what I find a lot of the times is that sleep is never discussed in a movement disorder clinic visit. And this is really important. So just like Wanda was saying, she has painful cramps or you were saying Soania that you can't turn over in bed. My patients don't tell me that unless I ask them specifically. I believe not because they don't want to, but maybe they don't think it's related.

So the first thing, when I start having a relationship with my patients and establishing relationship, I let them know that anything that's bothering you most likely is related to Parkinson's. Please let me know and I will tell you whether it's related or not. So back to the sleep, yes, one of the most... Sleep maintenance is a big issue in patients with Parkinson's. Less of them have trouble initiating sleep, but on the most part is maintaining sleep. And they can go even as far as six, seven, eight times, waking up at seven or eight times during night.

Our job is to understand why, because there's a myriad, multiple reasons as to why this is. Is it the brain itself, like the disease affecting the brain's ability to sleep? Is it your body discomfort, the turning over, the painful, the muscle cramps, painful muscles, muscle cramps? Or is it if you wake up to go to the bathroom that a lot of people do, you don't have to have Parkinson's to do that, coming back to bed, if you're off and you don't have enough dopamine in your system, you might have resting tremor that keeps you awake and prevents you from falling asleep. Do you have restless leg syndrome? We should never also forget that patients with Parkinson's get sleep apnea. So is that what's waking you up?

So many, many, many more things. But the most common that I find is insomnia. I mean, of course REM behavioral disorder is a concern, but again, a lot of the patients who are new to Parkinson's or have not been diagnosed yet don't know what REM behavior disorder is, acting out your dreams, kicking, yelling, screaming. So these are all issues that we pull out in the visit and we have to ask our patients to get that information. And of course, medication. So there's also medication that affects sleep. For some patients, dopamine is stimulating. So I had patients who woke up in the middle of the night and started cleaning because they don't-

Soania Mathur: Right. I've been there. Been there.

Dr. Okeanis Vaou: Yeah. So once [inaudible 00:15:17] them or stop, their sleep improved.

Soania Mathur: Right.

Dr. Okeanis Vaou: So there's so many things to think about.

Soania Mathur: Well, you just touched on this briefly, but you mentioned that people sometimes aren't going to be asked about their sleep. So what are maybe three kind of things that you think people should be prepared to discuss about their sleep? You mentioned duration and how the duration is important to mention. What other things do you get from the patient or the care partner that are important for you to know?

Dr. Okeanis Vaou: So the care partner is the one who's going to report a few things such as obviously acting out our dreams. Snoring is another one. So if the patient is snoring or having apnea as meaning gasping for air or witnessed apnea is when they stop breathing, that's something the patient will not know unless it's very severe. So they wake up from an apnea. The bed partner, the caregiver will be reporting that. So that's a good point, Soania. So I always involve the caregiver in the discussion because they're the observers. When we sleep, we don't know what we're doing. And that's sometimes the problem because you tell the patients that you have, I don't know, REM behavior disorder and they're like, "But I'm asleep. I don't know that this is happening."

Soania Mathur: Yeah.

Dr. Okeanis Vaou: Or you have apneas and they're like, "No, I sleep well." So when you're sleeping, we don't know what we're doing. So if you have a bed partner to objectively, you report what's happening, it's very helpful.

Soania Mathur: Dr. During, Emmanuel, why does Parkinson's affect us? We know all these symptoms that we've been discussing, but what's going on in our brains versus someone who's getting a good night's rest that may not have the challenge of Parkinson's?

Dr. Emmanuel During: Right. So it's complicated and our job is really to distangle the intricacies here is one is it's true that Parkinson's and a lot of neurological disease, but all the

cardiovascular disease affect sleep and that's biology that they may disrupt sleep and they may disrupt wake. So we feel tired, we feel sleepy, and that's part of it. But a lot of it, and I would say most of it is due to other things. And a big one is really lifestyle, what we do. And others, like we just mentioned, are very common things like sleep apnea. The snoring is always a red flag. [inaudible 00:17:50], restless legs, restless legs, really very much underdiagnosed, very common, and probably more common in Parkinson's, very much manageable most of the time. So saying insomnia is a symptom of Parkinson's is true and not true. And I always tell my patients, "It will get better. It may not be perfect, but it will get better." And that's really the good news.

The other thing now is really on the patient. We all have a responsibility as well is doing what's healthy, trying to not nap if we can avoid napping because the more you nap and the less physical activity you have, the less time you spend outside, the worse the sleep will be typically at night, which is then it becomes insomnia. So now my sleep is a little bit more shallow, more fragmented. I don't sleep solid. There's a couple of things we have to remember is as we get older, sleep typically fragments as well. Our brain doesn't have the same ability, capacity to really take sleep for extended hours. So that's one.

Two, let's try to not fixate on sleep because if you start really wondering, thinking there's something that can't be fixed, that is almost part of the disease, then you start fixating on that and really that creates anxiety and a sense of [inaudible 00:19:22] and that makes sleep worse. So now you're stuck in a vicious cycle. And that's where you want to keep in mind, I have to do certain things during the day, keep a healthy lifestyle, but also report anything abnormal about my sleep to my doctor and then worry as little as possible because part of it is also getting older. Unfortunately, I'm part of that. So it's complicated, but it always gets better.

Soania Mathur: That's a good thing to know. Well, one of the more unique disorders that we get with sleep is something we alluded to before RBD, a REM behavior sleep disorder that Okeanis had discussed a little bit. And that's something I would also like to hear your thoughts on because about two to three years ago, I began to call out in my sleep or some my husband says, which is again, another reason the care partner is important to have in on the history, but I know this is your special area and we have got a lot of questions about it, but how is that linked to Parkinson's?

Dr. Emmanuel During: Well, it's tightly linked because it's one of the earliest symptom for many, many patients. Many patients will start acting out their dreams and moving, twitching during a specific part of sleep, which is REM sleep. So in REM sleep, we've mentioned we dream actively. So the brain is very much active, but the muscles are supposed to be locked. There's a lock so that we don't move, otherwise we would act out our dreams, and that can be dangerous, of course. So with REM behavior disorder or REM sleep behavior disorder or RBD, this system, this lock, fails. So we start twitching and at times we may act out dreams, scream, yell, punch, kick, depending on the dream. The reason is this system is really deep down in the brain, we call it the brainstem, and that part of the brain is affected very early on for many people with Parkinson's.

I would say about half of them will start developing symptoms before they have the tremor, the shaking, and difficulty with movements. Well, we call it these Lewy bodies or synuclein, a marker starts depositing in many areas in the body, in the guts, in the nerves, in the skin, and in this brainstem that controls movements during sleep and coordinates these cycles of sleep. And that's the reason. And then later on, people develop other symptoms, then they have the tremor, the shaking, et cetera. So the connection is very close. And for some reason, we don't know why these Lewy bodies tend to really hit and affect these areas very specifically compared to people with Alzheimer's disease, for example, which really rarely, only very rarely will develop these kind of symptoms.

So there's a close connection and that's part of the disease. At the same time, it's very interesting because if people start developing those symptoms and are otherwise healthy, it can become an indicator that their risk of Parkinson's is elevated, is increased more than other people. So that a lot of interesting opportunities in terms of for the scientists to understand Parkinson's better, especially these earlier stages, also to get care really early and hopefully and slow down potentially the disease progression.

Soania Mathur: Right. And that actually leads in great to the next point I wanted to make. I wanted to take a moment to call out that PPMI or the Parkinson's Progression Marker Initiative is recruiting volunteers. And for those that may not be familiar, PPMI is a landmark study collaborating with partners around the world to create a robust set of data and biosamples to speed scientific breakthroughs in new treatments. People from all backgrounds with and without Parkinson's can help move the research forward. So we know that there's sleep troubles. And Wanda, when you first noticed that sleep troubles were an issue, where did you turn? What did you do?

Wanda Kim Lilley: Well, the first thing that I did was to try to figure out what was triggering the sleep issues. So one thing that I have done regularly since my diagnosis is that I keep a journal of how I feel that day, what's been going on with my life. I feel that there might be a reason that there's something within my control. And it was very interesting when I heard Dr. During say, "Lifestyle issues that can affect sleep," because I found if I eat too much sugar and I should say sugar in the form of alcohol as well, if I don't drink quite enough water, I will get cramps. If I'm a bit cold when I go to bed, I like sleeping in a cold environment anyway, but if I'm actually cold when I go to bed, I will probably wake up with cramps.

And I also spoke to my doctor about this, but funnily enough, he was less concerned about my sleep and more concerned about my cramps. So he started to give me things like magnesium and bed socks. Bed socks work, but I decided that if there's something I could do to improve things, and I did this through observation, and then also a few lifestyle changes. I miss the wine, I don't miss the cramps.

Soania Mathur: Well, that goes without saying, I think we're all experts in our own disease, which is something that's really important. But Dr. Vaou, when should someone see a specialist? Wanda noticed that she was having difficulties and she discussed

it with her physician. When should someone see a sleep specialist and what should they know about preparing for that meeting?

Dr. Okeanis Vaou: Thank you for mentioning sleep specialists because when they feel that their sleep is not good, if they're sleeping less than seven hours, if they wake up in the middle of the night multiple times, if they're sleepy during the day, that is when they need to see a sleep specialist. Well, their movement specialist can also have obviously some suggestions about sleep, but they definitely need to see a sleep specialist because I find a lot of the times there's a big discrepancy, especially from the primary care provider to the movement specialist, how they treat sleep. Now, I happen to be sleep trained, so I'm a little biased, but the approach in the treatment is very different. I rarely, for patients with Parkinson's, go directly to sleep aids because that is not the problem if that is a bandaid. So I do agree with Wanda and Soania. Lifestyle is huge. That's what must come first. What we call sleep hygiene, this is what we really need to work on.

And then as we've been talking about all these multiple problems that can affect sleep in Parkinson's, this is really what we need to tease apart and find out what is the root cause of cramps or RBD or sleep fragmentation, meaning waking up multiple times at night. Is it frequent urination? Is it anxiety? Is it medication? And then we treat the symptom that is causing that. And that is something that a sleep specialist really can go through, a sleep specialist, especially one who knows about Parkinson's disease and all these complexities and very specific reasons to cause sleep problems in Parkinson's.

Soania Mathur: And I think just to round out the figuring out of sleep troubles or what's troubling your sleep, I think Emmanuel, actually, maybe you could take this question. It's something I've wondered about even since medical school, to be honest. My husband's gone for a couple of sleep studies. I'm not really sure how you get information from patients who come in for a sleep study when they're in a foreign environment and hooked to all the monitors, et cetera. But what exactly is a sleep study and how do they work and what do you learn from those?

Dr. Emmanuel During: That's a good question. And even for sleep docs, sometimes it's tricky because there are two types of sleep studies and we always have to decide which one we go with. Both have pros and cons. There's the old fashioned, extended, comprehensive test, which is done in a sleep lab, so not at home. They invite you to come early in the evening and they hook you up with a number of sensors, wires, and record brainwaves, respiration, oxygen, heart, muscle movements. There's a camera, there's a microphone. So it's amazing because it's such a comprehensive test. We can answer a lot of questions. The one being is, does someone have REM behavior disorder or not? We can pick up on that. We need that test for that. We can detect sleep apnea, of course. So that's very comprehensive test, but it's not very comfortable. It's costly. Sometimes there's some weight depending on the sleep lab.

And in the end, sometimes the test fails in a way because it can be difficult to sleep in a sleep lab sometimes. Not always. Now, the alternative is a home test, and that's a much easier test for our patients. We give you a little device to take home, usually goes to your fingertip. Sometimes there's a watch with it, and then

you take it home and you wear it for one night at home and in your own bed, which is more comfortable. This test, however, only answers one question is whether someone has sleep apnea or not, which is important. Sometimes that's the only question we have. So these are the two types of sleep tests. I don't know if it answers your question.

Soania Mathur: It totally does. Yeah. If we move on to treatments for the sleep issues we've been discussing, we won't spend too much time on sleep hygiene because I think we've actually answered a lot of that issue, and there are also many great resources out there on it. But I guess maybe we'll start with you, Dr. Vaou. What should people be keeping in mind to set themselves up for the best sleep possible, including your top diet and movement activities and lifestyle choices and that sort of thing? What would you say the top three things are that you would recommend to your patients?

Dr. Okeanis Vaou: So as if coincidence, I saw the poster patient for sleep this morning. She was a patient with Parkinson come to me waking up five to six times at night. She was very anxious. And I gave her suggestions how to improve her sleep. I gave her an anti-anxiety medication. I did tell her to sleep at the right time, at the same time every night and wake up at the same time every morning. Don't nap. Increase her exercise levels. Avoid alcohol or large meals before bedtime. And I also asked her what was the temperature in her room when she sleeps and she had it set up at 74. So I suggested that according to Sleep Academy suggestions, it's around 68. So she did everything by the book. And honestly, she comes in and she says, "I've been sleeping seven hours, maybe sometimes eight with all these changes I made. Thank you. I've been struggling with sleep medications be given to me by my primary care provider, by other doctors. This is all it took for me to be regimented, to follow a good sleep hygiene."

Obviously her anxiety decreased, not just by the medications, but by also sleeping better and then also believing that she sleeps better. And that's the other thing that you get caught into this cycle where you start believing that you can no longer sleep well. So it's an expectation that you will not sleep well. And that adds to the insomnia or the trouble initiating or maintaining sleep. So we also did some cognitive behavioral therapy with her to eliminate this belief or this expectation, which also helped very, very much.

So she also found that exercise, which is true exercise, helped a lot with sleep initiation and maintenance. When you really, exhaust is not a good word, but increase your physical activity and your mental activity. You're tired. You want to be tired before you go to bed at the same time. And then that's what she did. And she had the best sleep. And that's what I find with most patients. The hard part is for patients to stick to this plan. It's almost, as I tell my patient, sleep or adhering to sleep hygiene is like starting a diet. It's not easy. And it's also a habit forming. So once you get into that habit, eventually you're successful with your sleep. Now that may sound very easy.

There's obviously other things like pain, nocturia, meaning waking up to go to the bathroom frequently. But sleep timing, also light. I didn't mention about that. Lack of light will help you sleep. If you have light or if you have a TV on, you'll

be surprised how many people are struggling to sleep. And they have their TV on in their bedrooms without sound. And they're like, "But it makes you sleep." But actually it doesn't. Light will wake you up. That's how we function. That's how mammals function, like any living species function. We wake up with light, we go to sleep with lack of it. So cool bedroom, lack of light. Make sure it's dark curtains and there's not much light coming in in the morning.

The other little caveat is, again, with sleep hygiene, if patients are going to wake up in the middle of the night to go to the bathroom, don't turn all the lights on because that will wake you up. So use a nightlight, make sure it's safe, of course, so as not to fall. So little tricks of the trade, little tricks like that. Being mindful of these stimulants such as light. And the flip side, if patients are very sleepy, light will help you stay more awake. So if you're having trouble waking up and starting your day, maybe you want to... If you can't go outside, like here in San Antonio, the weather's perfect most of the year, you can go out for a walk even in the morning, you might want to use one of those 10,000 lights, we'll call it happy lights, for seasonal depression. It really works well with waking you up during the day or keeping you more awake.

Soania Mathur: Yeah, that's very, very helpful. Thank you. Wanda, I'm sure you've mentioned a few lifestyle things that you've changed, giving up your wine and other things. But what are some of the things that have worked for you? And I also want to know, because you mentioned that kind of cycle of waking up and then keeping yourself up with anxiety and that would keep you up then afterwards. So how did you break that cycle as well?

Wanda Kim Lilley: Well, I approached it three ways. The first is I wanted to minimize the triggers, and that is the lifestyle changes that I've discussed. Sure, if I'm celebrating and I have a glass of champagne, I understand I might pay for it, but it's a conscious choice. So I try to minimize the triggers, increase the hydration, don't eat so much sugar right before bed, et cetera. All the sleep hygiene that we've heard. But then the second thing is I have discovered that heat directly on my cramp helps. And I've discovered an old-fashioned hot water bottle. This is about as analog as you're going to get, but it's wonderful because what it does is that the recurring cramps, and those are the ones that I was so afraid of. I would get rid of a cramp by standing up, stepping on it, flexing my toes, get back to bed, and then start feeling something happening again, something in my toe going up.

And it was so frightening that I would either not get to sleep because I was so vigilant or because another cramp would come. And so having that little hot thing in my bed has really helped. And on the occasions when I don't have a hot water bottle, my husband is pretty warm. So just knowing that there's a heat source close by has really helped. But then the third thing is, and this was very deliberate, I decided to stop thinking of lack of sleep as life limiting. I decided to stop thinking of it as something I needed to fear. I just had a little shift in my brain and I just said, "This can be fixed. We can improve our sleep. With everything that you read, there are things that can make it better." So I decided to be optimistic about it and it has helped.

Soania Mathur: I have a couple of very quick questions. First for Dr. During, we mentioned medications. Are there certain medications that you think are helpful? And Dr. Vaou, also to you after that, has DBS something that you've found will help patients' sleep? But Dr. During, you first.

Dr. Emmanuel During: Right. The medications, I'm not opposed to medication. It's true that it's not necessarily the first thing we recommend or we suggest. There's so many other things that can be done, but sometimes when we're doing everything right and it's still a struggle, well, there are a couple of treatment options that are, I would say, safe and often quite helpful. There's a new class of drugs. We call them the orexin antagonists. And now there are a few that we've used for a few years and they can be quite helpful. They don't cause addiction. They're not habit forming. They're very safe in the short term and data suggests they're safe in the long term. So they restore sleep quality, certainly. They improve sleep a little bit. And again, that's a good option. So these orexin antagonists.

The other one I use a lot. I'm just citing another one is Trazodone. Trazodone is a drug that's been around for decades. Interestingly, it doesn't help everybody, but when it helps, it helps. And it's certainly very safe. It gives you the deep sleep early in the night that is important and reduces arousals and it doesn't make people groggy and there's a lot of safety data as well. So I mean, there are options. There are other ones, but these are just to list, name two.

Soania Mathur: That's great. So there are treatments that we can discuss with our neurologist-

Dr. Emmanuel During: Absolutely.

Soania Mathur: ... or movement disorder specialists or sleep specialists. Great. And Dr. Vaou, does DBS help at all?

Dr. Okeanis Vaou: I will answer this question. If I may add a few more things from the Parkinson's movement standpoint in terms of medications, and that also is the same mindset with DBS. So some of the symptoms such as we talked about cramps, we talked about RLS, we talked about painful muscles or trouble turning over in bed. All of these, the majority is symptoms of wearing off. So what that means is you may be better controlled during the day, but maybe not at night when you're sleeping. So the best and easiest way, and I find this all the time, is to give treatment to patients, whether that's carbidopa-levodopa, dopamine agonist, through the night. I know you're sleeping, but we still need dopamine when we're asleep. So when I hear cramps, when I hear trouble turning over medication through the night, and my favorite is carbidopa-levodopa extended release, there's different formulations.

Dopamine agonists are very good because they also have that sleepiness effect that I like to use, especially the extended release. But coming to DBS, it's the same concept. So DBS provides continuous therapy for motor symptoms day and night, so you don't turn it off at night. So this is why we found over and over again, there's been multiple studies that DBS improves sleep, improves deep sleep as well. I'm not saying it's a tremendous change where from people who are

not sleeping, now they're sleeping, but it definitely improves it tremendously because it treats the motor symptoms much better.

Does it have a benefit to the actual sleep center in the brain? That is something that I'm interested in finding out in research, and this is something that maybe, but maybe in a different target, that remains to be proven. But we certainly do know that it does improve sleep. Oh, I program a lot of patients. And one of the things when they come back from the second time after I programmed them initially, I always ask, "How is it? What did you do better?" They're all excited. "I worked out better. People saw the difference in me. I'm able to do things I have never been before, to do before." And then I ask, "How's your sleep?" And they're like, "Miraculously, it's better." So by and large, we see an improvement.

Soania Mathur: That's very interesting. And you talked about that being a focus of research is lead placement and how that affects sleep particularly. But Dr. During, you're also very much involved in research. And what's exciting for you? What are you looking at that a big part of your research being directed towards?

Dr. Emmanuel During: Yeah, a lot of things. I'm very interested in how to enhance deep sleep, what we call slow wave sleep. I think that's a very hot area in research because it's probably beneficial for healthy aging, the deep sleep. Interestingly enough, the thing you can do every day to get more of these deep sleep is exercise. We're back to exercise. So physical activity. You don't have to be extreme there, but a good amount every day, something you enjoy and can be different every day. And if you have no drive for anything, just go outside for a walk. So that's one. Now, really going back to science, what I'm really passionate about is how to detect Parkinson's much sooner in many more people. And that we discuss REM behavior disorder that made people move in their sleep sometimes for years or decades until finally they develop other symptoms and we understand they have Parkinson's.

So this condition is very common, affects about one million in the US. We don't know how to diagnose it at scale because we can't do sleep tests in everybody. So there's an access issue and there's an awareness issue. So I really work on that and I've developed a new way to diagnose this. And now around the world, we try and really develop that because wearable devices, these devices that track sleep that you put at your wrist or at your finger can detect those little movements in REM sleep. And they could make a diagnosis of Parkinson's many years before people are usually diagnosed in many more people. So that's a very hot area as well. This is really expanding very fast, especially with AI, how to analyze with algorithms these little twitches that these devices can detect. So that's a very active area I'm really interested in.

Soania Mathur: Right. And that's amazing. I mean, there's so many questions and we can only answer them through research. And so one of this is something that always comes up at our council meetings, but having patients participate or people participate in research. Well, what do you find the value is in participating in research? Why have you participated or why do you feel we should?

Wanda Kim Lilley: Well, obviously we heard research works. So for all of us who want a cure and to have treatments that are better for us, we need the research. But from a very personal point of view, I just remember when I was diagnosed in 2012, I remember feeling utterly powerless. My body wasn't doing what I thought it should be doing. I kept hearing incurable, progressive. I thought, what is it that I can do? Then I started to read about it and I realized there was so much in 2012 that we didn't know. And I thought, gosh, the experience of people with Parkinson's needs to be documented. We need this data from everyone if we're going to understand more about this disease.

And now we know. We know that some of the recent research breakthroughs has been because of the mass of data that has been collected. We know that we are making a difference. I know that there have been studies that show lifestyle changes can help me to ameliorate my symptoms. And I know that the research brings us a science that gives us the hope, realistic hope that we will end this disease. That's why I do this.

Soania Mathur: That's amazing, Wanda. Thank you so much. And like you mentioned, there's so many ways people can get involved in research based on your own capacity that you have. You can find a way to contribute to finding better treatments in that elusive cure for our whole community. PPMI is one great way, so is Fox Trial Finder, and you can talk with your local medical center or movement disorder specialist to find local studies you may be eligible for. And I would gently encourage you to look into an opportunity that's right for you. I think that the cure is within us somewhere and we need to participate in order to find it.

I'm going to now go on to our Q&A. The one question that is coming up a lot is the use of melatonin and magnesium supplements. I know Wanda, you mentioned magnesium, but who wants to take on the melatonin? I find it helps me personally. Dr. Vaou, do you want to take that one? What's your experience with melatonin and magnesium?

Dr. Okeanis Vaou: Sure. And Soania, I will answer with a question to you. When you're saying it helps you, what does it help you with?

Soania Mathur: I find it helps me get to sleep a little bit quicker and not as frequent wakings, but yeah, duration is still not the best.

Dr. Okeanis Vaou: And this is why I ask because what I find is melatonin is very weak if you're having sleep problems as in maintaining your sleep or initiating your sleep. So I rarely go to that. I use melatonin by and large for REM behavior disorder, and that certainly does help tone it down. There are some instances that it doesn't, but I don't really find a lot of help with melatonin for treating insomnia. Interestingly, I do tell my patients, "I'm giving you melatonin for REM behavior disorder for acting out of your dreams." And they come back and they say, "I stopped taking melatonin because it didn't help me." And then that's why I asked you, I asked the patients, "What did you expect it to do?" And they always think that I'm giving melatonin to help sleep. And I tell them, "No, I gave it to you for REM behavior disorder."

Soania Mathur: Well, I haven't hit my husband yet.

Dr. Okeanis Vaou: Okay, good. Maybe that's fine. Maybe it's working.

Soania Mathur: Maybe it's working. The other question that's come up, and Dr. During, maybe you can answer this, is people hear, "You should nap, you shouldn't nap if you have excess of daytime sleeping issues." What's your recommendation when it comes to naps?

Dr. Emmanuel During: Listen, I'm not dogmatic and I always work with my patients and every situation is different. So I always tell my patients, "Well, if you nap during the day, you will sleep less at night. Don't expect to sleep eight hours at night if you sleep an hour or two during the day, it doesn't add up." So the total amount is not infinite. That's one. Napping is not a bad thing. And what I recommend is if you feel really you can't help but you need to sleep during the day, try and keep it short. We like to say 30 minutes and less is good because you will wake up more refreshed as opposed to a two hour long or one hour long nap. You may be a little bit groggy when you wake up because you'll enter too deep a sleep. So short naps, when you can't help can recharge you, give you a boost, but remember, expect to sleep less the following night. That's fine.

Soania Mathur: Should care partners wake somebody up if they're in a deep sleep during the day? If they're napping on the couch and it's been more than 30 minutes, should they be woken up?

Dr. Emmanuel During: It's tricky, right? I think in general, as you practice shorter naps, you become good at it and just keep that in mind. And I think a gentle awakening and then maybe going outside for a walk. That's a wonderful way to move on to other activity and wake up and feel good. So don't stay inside, try and go outside as much as possible.

Soania Mathur: And also for you, Dr. During, there's another RBD question that's come in, but they ask, "Do vivid dreams and nightmares have to do with RBD or is it something different?"

Dr. Emmanuel During: Well, it's interesting question because we see with RBD, it's not just acting out dreams. The dreams themselves are often different from before. There's a lot of... People experience really negative dreams being attacked, a lot of fights, arguments, and that's probably part of this symptom. There's something wrong about the dream experience itself. So certainly that's something that often can be relieved with melatonin. And I like to add one point with melatonin, it's not more is better. Even low amount, but what matters probably more than anything else is taking it at the same clock time, same time every evening.

Soania Mathur: This last one can be for you, Dr. Vaou. This audience member says that they have sleep related problems with their PD, but they're the result of the fact they wake up in a sweat one minute, then they wake up freezing cold. And is there any way to... Well, for me, that's menopause and that happens to me, but is there any way to lessen these temperature issues?

Dr. Okeanis Vao...: I was going to say, is this a woman who was asking or a man? Because there's also other things going on. It can be menopause, so you have to think about that as well. But if that's not the case, and wearing off can sometimes manifest as sweating or... What sweating or freezing cold is, it's basically an autonomic dysfunction. The thermoregulation, like your body's ability to regulate changes in temperature is not intact. So that happens with Parkinson's. And we do see that when you wear off, medications are wearing off, you do have these changes a little bit more prominent.

So again, treating your Parkinson's symptoms at night, taking a little bit more of an extended release carbidopa-levodopa can be helpful. What I do find a lot, patients tell me that they have trouble sleeping because they have very cold feet or hands, so their limbs are very cold. And that is, again, it's another manifestation of autonomic dysfunction, dysregulation of temperature. So for them, I do recommend warm socks or with the... I can't remember what it's called, what they wear for skiing in very cold temperatures.

Soania Mathur: Yeah. Yes. Those hot pads.

Dr. Okeanis Vaou: Pocket. Hot pocket.

Soania Mathur: Yeah.

Dr. Okeanis Vaou: So these can be very helpful that patients find it helpful as well.

Soania Mathur: And Wanda, that weeds into you because I really wanted to ask you for any last words you have of support for people that are going through these issues, experience this struggle to change your shift in mindset because you mentioned you had a shift in mindset.

Wanda Kim Lilley: I think that when I was first diagnosed, I felt so alone. And what has helped me is to know there's a community of people, there's a community of really wonderful people all trying to do the same thing, trying to live with the disease better now, but also to find a cure. And I think that my finding optimism helped me to shift the mindset. I love when I hear, "Look, we can improve your sleep." But that can be true for everything that we're going through. Our symptoms, we can improve how we're managing them even with what we know now. We can get better.

Soania Mathur: Wise words, my friend. I'd like to thank you all for being part of our community and for joining us today, and thanks to our great panelists for sharing their time and expertise. And I really hope you found today's discussion helpful. And remember, we often don't have control over our diagnosis and we certainly can't stop the passage of time, but we do have control over how to face the challenges that life brings, so face them with knowledge and optimism, and that's my wish for you all. Thank you and have a great day.

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