

Soania Mathur: Good afternoon. And thank you everyone for joining us for today's Third Thursday's webinar. I'm Dr. Soania Mathur and a Parkinson's patient for about the last 22 years, co-chair here at The Michael J. Fox foundation Patient Council and I have the pleasure of being your moderator today. Today we'll be discussing practical tips and personal viewpoints on being diagnosed with PD, as well as ways to connect with the Parkinson's community. Throughout our discussion today, you are able to submit questions which our panelists will try and answer later in our presentation. You should see a Q and A box in the middle of your screen. Type your questions there, and we'll do our best to get to as many as we can.

Also, we're providing slides from today's webinar for download. You should see a box called resource list below the Q and A box. And just double click on the document you want. In this case, webinar slides and it should open up in another browser window and you can print or save them from there. Slide two. Even though, it was a couple of decades ago, I still remember like all of you the day I heard those four words, you have Parkinson's disease. After the initial shock settled, questions naturally started to race through my mind. What did the future hold? What treatments would be most helpful? How is this diagnosis going to affect my functioning and relationship? What could I personally do in order to give myself the best chance of optimizing my quality of life? In other words, I've got Parkinson's disease. Now, what.

Next slide please. Helping us today to explore these initial concerns that come after diagnosis of Parkinson's disease is a great panel. As a lifelong entrepreneur and sports fan, Bill Rasmussen Rasmussen is the founder of ESPN and now faces a different set of challenges having been diagnosed with Parkinson's in 2014. But as I read the quote from you Bill Rasmussen, "Life isn't about the obstacle you may encounter. It's how you try and figure your way around them." Happy to have you here.

Bill Rasmussen: Well, thank you very much. Soania, happy to be here.

Soania Mathur: Thank you, Eric also is joining us. Eric is an advanced emergency medical technician who was diagnosed with Parkinson's in 2018. He has since started a foundation, the Gray Strong Foundation that is focused on helping individuals and their families to move forward with Parkinson's, all while raising awareness in the community. We'll hear more about that in depth later. Welcome Eric.

Eric Aquino: Welcome, thank you.

Soania Mathur: And lastly, but certainly not least. We have Dr. Amy Amara, movement disorder specialist, and associate professor of neurology at UAB Medicine with a special interest in sleep disorders and Parkinson's disease and the influence of nonpharmacologic intervention versus exercise on non-motor symptoms. Thank you for joining us, Dr. Amara.

Dr. Amy Amara: Thank you. Happy to be here.

Soania Mathur: Great. So why don't we get started? Next slide please.

Dr. Amara, although I'm sure we all have a sense of what Parkinson's disease is. For those of us that are newer to this diagnosis, could you describe in general what it's Parkinson's disease and what's symptoms it's defined by.

Dr. Amy Amara: So, typically, Parkinson's is defined by a resting tremor, as well as slowness of movement and rigidity or stiffness. And then some people also experience balance trouble. There are also other non-motor symptoms or, or non-movement symptoms that can affect people. And sometimes those are even more common than the motor symptoms or have more effect on quality of life. And so those can include sleep disorders, which I'm interested in particularly, but also cognitive changes over time, changes in mood like mild depression or anxiety. And also trouble with things like constipation, loss of sense of smell, and sometimes getting lightheaded when standing up and that's called autonomic dysfunction.

Soania Mathur: Right? So what type of-

Dr. Amy Amara: So as the webinars-

Soania Mathur: Go ahead. Go ahead. No, I was just going to say, what is happening in our brains that causes these symptoms?

Dr. Amy Amara: So, the main change is that there are dopaminergic cells, mostly located in part of the brain called the substantia nigra and those get damaged. And, actually by the time we develop motor symptoms or the tremor and rigidity and stiffness, usually about 80% of those cells have already been lost. So, it's a long process with many changes happening before we even become aware of the symptoms. And there are other areas of the brain that are affected as well. And the change related to Parkinson's disease in the brain that we see on autopsy is called a Lewy body. And those have even been found in neurons near the gut. So it can be a full body disorder and we're learning more and more about that.

Soania Mathur: Is that why we have symptoms, like you were describing earlier, the non-motor stuff like the constipation, mood disorders and the autonomic dysfunction.

Dr. Amy Amara: Exactly. So the constipation, right, and the constipation can be related to those changes in the gut. And then things like mood problems can come from changes in other parts of the brain that secrete certain neurotransmitters that help us feel good or have more positive outlook like serotonin, norepinephrine, and then other areas that affect sleep can also be changed.

Soania Mathur: It's a little bit more complicated than we initially thought, I guess.

Dr. Amy Amara: Yes, definitely. So, the discovery that dopamine was involved really changed the treatment landscape for Parkinson's disease and allowed the motor symptoms to be better treated. But, after that happened, we've been discovering more and more that it's not just dopamine.

Soania Mathur: Right. I have to say, in most diseases, genetic loads the gun and environment pulls the trigger. Can the same be said for Parkinson's disease. Dr. Amara?

Dr. Amy Amara: Yes, absolutely. So there are only rarely cases of Parkinson's that are completely inherited with a single gene mutation. Although that can happen, but it's unusual. But typically there's sort of a constellation of a genetic background that put someone at maybe a slightly higher risk for developing Parkinson's. But then something probably has to happen within the environment, like some exposure and one that's well established is certain types of pesticides and there are others that we probably haven't identified yet. But some environmental trigger might lead someone with the genetic landscape to end up developing Parkinson's. And, as the slide mentions there, age is certainly a risk factor. It typically is a disease that is associated with more risk as you get older. However, there certainly are people who develop it at a young age.

Soania Mathur: Right. And Eric, that was your situation. Eric do you have a family history of Parkinson's disease?

Eric Aquino: Yes. My grandmother on my mother's side had Parkinson's. She had it later and I think she was in her 60s when she was diagnosed.

Soania Mathur: Oh, I see. Okay. And Bill Rasmussen, do you have any relatives with this disease or did you-

Bill Rasmussen: Yes, my mother also had Parkinson's and I don't know if there was any other family history on her side of the family but it was very pronounced by the time she was in her mid to late seventies. She didn't last much longer after that.

Soania Mathur: Right. Oh, that's too bad. My goodness. Dr. Amara, what are the chances that someone in your family will get PD? If you're the first one to be diagnosed? I think this is especially concerning for those of us with the disease that have children or siblings or other younger family members in our lives. So what are the chances?

Dr. Amy Amara: So the exact percentage is hard to predict, especially since, you often do have to have those environmental factors come into play. So we think that probably there's an increased risk of family members developing Parkinson's, probably around 1%. Whereas, in the general population, if you don't have a family member affected that risk is much lower. So, there is some increased risk, but it's not anything like, for example, Huntington's disease. If you have enough of a family member that's a parent, you would be 50 percent likely to develop Huntington's disease. But Parkinson's risk is much less than that. So, if you have

one of those rare genetic mutations, there might be a higher increased risk. But it's not very common to have a huge increased risk just because your family member is affected.

Soania Mathur: Right. And is there a point where someone should ask for genetic testing? Is there a time where that would be a good thing to do?

Dr. Amy Amara: Well, if you have multiple family members affected or even one affected family member, and if that's ... It's sort of a personal decision. If you want to know about that, or if your children would want you to know. But there are a lot of research studies that are specifically looking into the risks with genetics and The Fox Foundation sponsors some of those. So there are a lot of research opportunities and to get involved and get a better understanding of Parkinson's and future risk. So, like I said, it is a personal decision and sometimes or always very important to discuss with your doctor and really get an understanding of what it might mean if you find out that you do have genetic risk. And what it might mean for your family members, if that's something they would want to know or not.

So, those are important discussions to have, but there, like I said, are a lot of research opportunities that can tell you those things and also contribute to the overall knowledge that we have about how Parkinson's might develop and progress.

Soania Mathur: Right. And I think an important point you made is that just because you have a genetic mutation or risk for getting the disease doesn't mean you'll actually get it necessarily. Is that true?

Dr. Amy Amara: In most situations? Yes.

Soania Mathur: Most situation. Okay. Next slide please.

So there's a common thing that I heard numerous times since I started working with the foundation. And that's, "When you've met one person with Parkinson's, you've met one person with Parkinson's." And what this means is essentially there's such variability in terms of how we experience this disease. We all vary in terms of our symptoms, our progression, our response to treatment, our prognosis. We're really truly unique in our own disease. I'd like to hear a little bit from Eric and Bill Rasmussen. We'll start with you, Eric. Could you talk a little bit about your story? When you were diagnosed? What symptoms you're experiencing? What's happened since? If you could speak up a little bit?

Eric Aquino: Can you hear me?

Soania Mathur: A little bit louder would be great, if possible.

Eric Aquino: How about now?

Soania Mathur: That's good. It's getting better. Yes. Thank you. Go ahead.

Eric Aquino: So, I got my first symptoms looking back and after being diagnosed, were in 2016. I thought I had a stiff shoulder, I was getting therapy for my shoulder. And then, in the process of getting physical therapy. I got tremors starting on my right leg. And I thought it was just tiredness, I didn't think much of it. But it progressed into my hand and my wife knows so she advised me to get checked. And I don't argue with her a lot so [inaudible 00:12:23] that checked. And, I went through a year of trying to figure out why was I having tremors and being in the healthcare profession I kind of was leaning towards Parkinson's. But, it took me a year, almost a year and a half to actually get the diagnosis for Parkinson's.

So, by that time, I was ready to move forward and I really didn't actually ask questions at first because I was just like, okay, what meds even are there to literally take. And then my wife, when I got home, had a lot more questions that I didn't have answers for. So I went back for my second visit, I had more questions. Yeah. So, I think like you said that one way, my path was different. Because I know most people that I've talked to had a bunch of questions at the beginning, I was writing [inaudible 00:13:22] the symptoms and just getting nowhere with nothing. Because I was just ... They kept doing tests and not finding anything. So at the point, I got diagnosed, I was really frustrated. Right.

Soania Mathur: Sorry, Eric. Could you just speak up a little bit more please?

Eric Aquino: So, I was a little frustrated by that point. So, I was ready to move forward because one of the ... And then I slowly started telling people. And since then I've started the podcast, started the foundation, just kept moving forward with the diagnosis.

Soania Mathur: Right. I think your story is really easy to relate to. I think when we go in for initial diagnosis or initial appointment with our physician, that's giving the diagnosis, we often don't know what questions to ask. And so that's a really important experience. I'm sure a lot of people have shared. Bill Rasmussen, can you also share a little bit about your experience, as well, when you were diagnosed and what brought that about?

Bill Rasmussen: Sure. Let's see, it must've been ... Excuse me, my wife passed away in 2011 and sometime after that and 2012 or early 2013, I noticed my left hand had a bit of a tremor. So I just talked to primary care doctor and said, "Should I be doing something about this?" I didn't really even think about Parkinson's at that point. I just wondered if maybe I had pulled a muscle or some such thing. I didn't have any idea. And he said, "Well, I think maybe it's an essential tremor. Let's watch it for a ... you know, come back in a couple of months." And when I went back, he

said, "I think we'd better send you off to see a neurologist and there might be something going on that we're not aware of."

And so my daughter is an oncology radiation nurse. And she said, "I'm going with you because we want to find out." What can I do, mean my daughter, to help whatever it might be? And so, we went in and we talked, we met the neurologist and we went through the standard tests that they give you. And he said, "I have some thoughts on this. Let me do something else." He said, "Let me send you down to." I went down and had a CAT scan and a couple of different tests that they did. A month or so later, my daughter and I went back and he said, "Well." He said, "I think-

Bill Rasmussen: Couple of months or so later, my daughter and I went back and he said, "Well," he said, "I think I've confirmed my belief." It's probably not going to be good news is the way he put it. Well, my daughter as an oncology radiation nurse had a whole different reaction.

Soania Mathur: Oh no.

Bill Rasmussen: Her immediate thought was, "Oh no." And he said, "You have Parkinson's." And she said, "Oh good." From her point-of-view. I didn't have some cancerous problem. And so, he smiled and he said, "Well, that's a good thing. I guess it's a good thing." And then, he said, "Here's ..." And then, he explained a bit about it. What we want to do and get started with an exercise regimen. Eventually, we added the Levodopa and I've been active. I exercise all the time. From that moment in 2014, I was still traveling quite a bit and living in Florida and Seattle. So, I would see him every time ... Whenever I had an appointment scheduled for him, I made sure that I was in Seattle.

Once we got well into ... I went through all of the physical therapy, occupational therapy, speech ... Did all of those things. Started the medication and I don't know if it's just good fortune or if I'm really doing something with the exercise. So far, it hasn't really changed very much. The problem that I have of course is sleeping, which is a major issue with lots of Parkinson's folks, but really I'm just trying to be positive and do all the things I can. And I couldn't emphasize ... I know a lot of people who may or may not have it. They don't know and they're afraid to go get diagnosed, I guess, because they don't like the word "Parkinson's." But we have it and we have to deal with it. There's so much good research happening around it now. I don't know when it's going to be solved in my lifetime, but I'm only going to be around till I'm a 100, so we've got some time left, which is a good thing. I'm planning that anyway.

Soania Mathur: Absolutely.

Bill Rasmussen: But I think, yeah, recognizing it, facing it and exercise. An interesting thought came to me and maybe it's because of the way I approach things. I think that if you not only do physical exercise, but keep your brain active. Don't fall into

some, "Oh I can't do anything because I have Parkinson's." You can do a lot of things with Parkinson's. It's not quite a normal life, but it doesn't mean you shouldn't be positive. So, I try to keep a positive approach every day.

Soania Mathur: Those are great words of advice. As you can see, I guess, between your experience and Eric's experience in terms of age of onset and symptom wise, we all do differ. We share some common symptoms, but we do differ in other way. So, it might be difficult to predict progression. Dr. Amy Amara, what's your answer when a newly diagnosed patient asks you about their future and what to expect as the disease progresses?

Dr. Amy Amara: So, we do frequently have this similar discussion where we talk about how it is a very heterogeneous.

Dr. Amy Amara: There's a lot of heterogeneity. Yes, thank you. So, each patient is a little bit different and not only age, but some people come in as Bill Rasmussen did with mostly tremor at the beginning and others, like Eric, experienced the pain in his shoulder, the stiffness in his shoulder. And I've seen several patients who've had shoulder surgery prior to diagnosis because it gets mislabeled as a shoulder problem. And then, there's some people who start with some balance difficulty. And so, there are some features that we can help say what might be predictive. So, if you start out with balance problems and you're having ... [inaudible 00:20:20] in things that is certainly more disabling than having a tremor because you are at more risk for injury. So, that can give us some clue about progression.

But overall, Parkinson's itself is a slowly progressive disease and while that speed of progression might be a little bit different from person to person, it usually is slow. We don't see things happen too suddenly to change things in Parkinson's. As the disease moves forward, I tend to tell people that if you sort of look back a year ago at how things were then and how much you have changed from one year ago, you'll probably have changed about that amount one year from now. So, it is a slow progression, but it does change over time. And then, of course there is the medications that we use to control the symptoms so that sometimes the progression can actually look like an improvement over time once you start medications.

Soania Mathur: Right. And we'll discuss the medications in just a moment. So, you're saying basically that the measurement of progression is really done in years as opposed to weeks or months.

Dr. Amy Amara: Oh absolutely.

Soania Mathur: Yeah, great. Next slide please. And here we're going to look at ways to get the best care. And depending on where you live and what medical institutions you have access to, you may receive your initial diagnosis from any variety of doctor, family physician or primary care physician, neurologist or movement disorder specialist. We do know that movement disorder specialists are true experts at

managing diseases like Parkinson's. Dr. Amy Amara, just one more question about this. What can a movement disorder specialists do specifically that perhaps another physician may not be able to offer?

Dr. Amy Amara: Well, the movement disorder specialist typically have two years of specialty training in movement disorders. Some fellowships are only one year, but more often they're two years. And so, there's a lot of clinical experience specific to Parkinson's disease. And then, also, there typically is a better relationship with research that's going on. So, some general neurologist would have that knowledge as well, but the movement disorder specialist are really just focused in on that aspect of care. And so, might be more aware of the most recent developing treatments and have a little bit more nuanced understanding of specific things that are important to know, such as encouraging exercise, the prominence of the non-motor symptoms and not just using the medicine only to treat the motor symptoms. I think one of the most important things about the physician ... Sorry, go ahead.

Soania Mathur: No, no, go ahead please.

Dr. Amy Amara: Oh just going to say I think one of the most important things about the physician that you interact with is your rapport with them. So, there are primary care doctors and general neurologists who are excellent caretakers of Parkinson's patients, but there is more training among the movement disorder specialists. And so, if you have an opportunity to see one, it can really help with better understanding the diagnosis and getting the best treatment.

Soania Mathur: Right. I think part of that, Dr. Amy Amara, if I'm not incorrect, is that we really don't have a test for Parkinson's disease. One of our listeners was asking were there any diagnostic lab tests that can be used to determine that, but it's really more of a clinical judgment, is it not?

Dr. Amy Amara: That's right. The diagnosis is still made based on the clinical features, so mostly the motor symptoms, the tremor, rigidity, bradykinesia or slowness, and then, the balance. And so, putting that all together is something that movement disorder specialists do every day. There are imaging tests that can help us understand if this is more likely to be Parkinson's or not, but the actual diagnosis is still based on the clinical features.

Soania Mathur: Right. We also know that part of optimal care for those of us with Parkinson's disease is sort of a team approach. We do our best when we're surrounded by a group of allied health professionals and support system that have our quality of life in mind. And Eric, have you gathered your Parkinson's support team and who's included in that team?

Eric Aquino: Yes, I have. I have slowly started my ... When I first got diagnosed I started my team and I figured I was going to need them, so I started with the physical therapist ... the movement disorder specialist, and then, the physical therapist. I



added occupational therapist because the advice of the physical therapist. I was having some issues. Like, "I think you need occupational therapy." And the minute she said it, I was like, "Of course, makes sense" because I was having problems with writing and picking up utensils and pens. I've had a urologist and I previously had a cardiologist. So, once I got diagnosed with the Parkinson's, I went back to him, said, "Hey, I have Parkinson's now. Can we talk about the meds and the interactions and stuff like that?" [crosstalk 00:25:51] I've made generally collaborate with each other because we all have doctors and we have them for different reasons. But the point is to make them collaborate and talk to each other.

I've sent messages to my movement disorder specialist and to my physical therapist because I was not going to see her till couple of months from now, but you usually forget what you were going to say. So, I go to physical therapy [inaudible 00:26:21] and say, "Hey, can you put a note in my chart that I'm having issue with this so when Dr. Diaz looks at it, she can see that I was having issues and ask me about it?" Or vice versa. I have Dr. Diaz once she wrote a prescript for physical therapy, said, "Hey, he wants to work on this" or "Can we do this?" Stuff like that. So, they can collaborate. And then, it gets you better care.

Soania Mathur: Right. Yeah, absolutely. I think that's key. And Bill Rasmussen, what about you? Who's on your team of specialists or health professionals? I guess your daughter for sure is a great source of [crosstalk 00:27:07].

Bill Rasmussen: Oh yeah absolutely. She observes every single day and she'll say whatever. One day I might be a little slow moving, so she'll call it to my attention. "Is there anything wrong? Stand up straight. Do this." And obviously, "Are you still doing that exercise?" She'll prod me, which is great. Unfortunately, I think it happens to old ball players. When they're finished, they get traded away. My neurologist is retiring on June 30th, and so, the team that I've put together with him and the therapist and so on at the hospital, I'm going to ...

There are a couple of movement disorder specialists here at the hospital where my daughter works. The Swedish Medical Center in downtown Seattle. And so, I'm going to ... I have met the one doctor who I think is probably going to be the next in line for me, but I'm at the in between stages. So, I'm continuing all the things that we have built up to this point with exercise and so on, and the medication. I'm not quite sure how this transition goes, but I'm being traded away so to speak due to the retirement of the man who diagnosed it.

But that's okay. I'm an optimist and I look forward to it. And I've had several conversations with this doctor just informally. He volunteers a lot in the area. When the local Parkinson's folks put together a seminar or meeting, he's spoken several. I have an appointment coming up later in the summer and we'll start down the path. I honestly don't know. The different doctors have different approaches, but I assume they've taken into account everything that's gone

before we'll see. So, I'm recruiting a new team in effect. Or about to meet a new team will be a better way to put it.

Soania Mathur: Right. That's right. And [inaudible 00:29:23] repeat of the question, Dr. Amy Amara. Who is responsible for putting that team together? Is it the patient or is it you as movement disorder specialists?

Dr. Amy Amara: I think it can be approached by both, so the physician should be in charge of making suggestions for that. So, Eric mentioned physical therapy and occupational therapy. Both of those are very important. There's also speech therapy. We have social workers on the team and there are geneticists. There are a lot of different people can get involved. I think Eric also mentioned urologist. That can be very important. But then if there's a need that the patient has, sometimes they bring it up to me and we can make that work and put it together as well.

And then, as Bill Rasmussen has experienced, his daughter has very special expertise in nursing, but he brings up a point that family and friends and other people who you know who have Parkinson's, all can be very helpful as a support system and also in giving you additional ideas. So, all those things can be important.

Soania Mathur: Right. Well, I have a urologist for husband, so I've got some in-house [inaudible 00:30:43], which is not too bad. Nice slide please.

So, as we know, Parkinson's disease is currently a progressive and terrible illness, but there are ways to manage our symptoms and optimize our quality of life. What that management will include is of course individualized to each patient. A unique regimen that each of us follows and just much like our disease presentation is unique. Dr. Amy Amara, could you please broadly outline how medications work in Parkinson's disease and how does one decide what medications to try?

Dr. Amy Amara: So, most of the medications for the motor symptoms do work through the dopaminergic system. Bill Rasmussen mentioned earlier, Levodopa. This actually converts into dopamine in the brain to replace what is missing from our loss in dopaminergic neurons. And then, there are also medications called dopamine agonists that bind to the dopamine receptor to make the brain think that there is more dopamine. And then, there are other medicines that slow the breakdown of dopamine to keep it in the brain longer, so that it's more effectively and also has a more potent effect. And then, there are other medicines, like we mentioned earlier, some of the other neurotransmitters that are involved. So, if someone is having the non-motor symptom of-

Dr. Amy Amara: Or transmitters that are involved. So if someone is having the non-motor symptom of depression, we frequently use antidepressant medications if needed. Although sometimes those things can improve with dopamine as well.

And then there are medications for other symptoms like urinary symptoms or constipation. So there can be a broad range of medications that can be used.

And then also, we've mentioned exercise a few times, but there are other non-pharmacologic things that are important. So for constipation, making sure that you're drinking enough water and having enough fiber.

Soania Mathur: Right.

Dr. Amy Amara: Exercise helps with constipation as well. And different measures to help with sleep, like sleep hygiene, and using safety measures if you have REM sleep behavior disorder, or acting out your dreams.

Soania Mathur: Right. Mm-hmm (affirmative).

Dr. Amy Amara: So there are many different things that come into the equation of what medications are needed.

So sometimes our doctors focus on the motor symptoms. So it's important as the patient to advocate for other symptoms that you're having and make sure to bring those up. I recommend always bringing a list of questions with you to your appointment, so that when those questions do come up, you can remember to ask them.

Soania Mathur: And a term that many of our listeners have heard, and is an important symptom to bring up with your physician, is dyskinesia. Can you explain briefly what dyskinesias are, who tends to get it? How does it influence your decision regarding medication choice?

Dr. Amy Amara: So Parkinson's is typically a slowing of movement, which is, we call a hypomotor or hypokinetic disorder, but dyskinesias are actually an increase in movement. So, while the tremor of Parkinson's is rhythmic, the dyskinesias are more like a flowing, dancing type of movement.

And for some people they feel more comfortable than the slowness of the Parkinson's does, but for others, it can be disabling. It could lead you to have trouble with walking, or it can be socially embarrassing for some people.

So the way that we develop dyskinesias, is after longer term use of Levodopa.

Soania Mathur: Right.

Dr. Amy Amara: It is a risk of long-term use of Levodopa. Seems to be a higher risk if you're taking higher doses of the medicine. However, we do have lots of different ways to suppress dyskinesias. There are different medications or surgical therapy, like deep brain stimulation. Those things can ward off the dyskinesias if they do develop.

So, while dyskinesias are a concern, a lot of people... like I said, we do have ways to treat them. And from my viewpoint, it's more important to treat the symptoms at the time that you have them. So, if you're having trouble walking-

Soania Mathur: Right.

Dr. Amy Amara: ... and feeling very slow and stiff, it's more important to treat now so that you can maintain mobility and be more active. Because if you're feeling very slow and stiff, you might be more likely to sit on the sofa and not exercise.

Soania Mathur: Right.

Dr. Amy Amara: Whereas if you start taking the medicine, even though there's a future risk of dyskinesias, it will keep you more active now and be better in the long run.

Soania Mathur: Well that's great to know, because I know a number of listeners are wondering whether they should hold off on taking medication, or is it best to get medicated at the beginning, managing their symptoms as soon as possible. So that's a great piece of information.

Next slide please.

So this kind of-

Bill Rasmussen: Hello.

Soania Mathur: ... hits what you were talking about in terms of what else you can do. And the diagnosis is frustrating, because currently there is no curative treatment. The challenges that it brings into our lives are not controllable.

But there are, however, certain variables that are within our control, certain lifestyle choices that can be made in order to optimize our life experience. Because until there is a cure, it really is all about quality of life.

This is where regular exercise, healthy diet, decreasing stress [inaudible 00:36:12] to support that marker, so very important, it can make a real difference.

Bill Rasmussen, what lifestyle modifications have you found that have made a difference in how you feel? I know you mentioned exercise as being one of those?

Bill Rasmussen: I'm sorry. I just missed that last part.

Soania Mathur: Oh, I was wondering, you had mentioned exercise as being one lifestyle modification that you found made a difference in how you feel. I can tell from what you said before that attitude is certainly... your optimistic attitude is

certainly another thing that you work on keeping as well. But are there other lifestyle modifications that you found that made a difference?

Bill Rasmussen: Not really. I've been pretty active all my life. And I think that... one question that I always have, and we talk a lot as we have here today about the impact on the brain, and so on.

Soania Mathur: Mm-hmm (affirmative).

Bill Rasmussen: And, I was talking to my neurologist several months ago. We were talking about always asking questions, what can we do? "How can we...?" And he said, "One thing is to keep your brain active. We can... we, meaning the medical community, can give you medications. We can do things, but it's really up to you to manage your life. You have to be active and so on.

And so I've started asking the question and talking to different people about brain exercise, for want of a better phrase. What I mean by that is, if you wake up every day and you say, "Well, I don't know, this isn't going to be a good day." Instead of waking up and saying, "I've been thinking about doing X," whatever it might be. "I've been thinking about reading this or reading... learning more about that."

Come up with something to, I guess you would say, augment the physical exercise that you do. But being active, and my phrase, brain exercise, what I mean by that is being optimistic. Do things.

A diagnosis of Parkinson's doesn't mean you have to stop and turn around and go back and start over again. It means you have Parkinson's. As you mentioned earlier, if you've met one, you've met one.

And I try to get up and write something every day, silly things.

Soania Mathur: Right.

Bill Rasmussen: My kids... my grandchildren say, "Mr Excel over here, he'll do a chart about anything," Just because it's fun and it causes me to think and try to figure things out. And I don't know whether that's medically true or not, but certainly psychologically it helps me get through every day. I'm a pretty happy guy walking around with Parkinson's.

Some days are down days, of course, but the positive attitude and thinking about creating something, look up something in history, whatever it might be to keep my brain... I use brain exercise as well as physical exercise, when somebody talks to me. That's my regimen. I do it every day.

Soania Mathur: That's awesome. And that kind of answers some of the people who are questioning, how come you're so optimistic? How do you have that attitude? You've answered that question quite well.

Eric, I understand that you've started a nonprofit foundation to help those within your community to do stuff. To help themselves get better, to move forward with Parkinson's through a variety of initiatives. Would you like to tell us a little bit about your work?

Eric Aquino: Yes. I started the foundation back in fall of 2018. We've been in this organization for about a year now. And it started because once I got the diagnosis, I went looking for better services and just community support for the Parkinson's. And aside from major foundations like the Michael J. Fox foundation, there was really nothing in my community to say, "Hey, let's do this. This is what we're doing. This is what's going on in our community."

I was fortunate enough or I am fortunate enough to be on a nonprofit organization for cancer with an amazing support... board of directors, and then they were like, "Let's tell your story. Let's do the same thing we're doing for the cancer community."

Soania Mathur: Mm-hmm (affirmative).

Eric Aquino: [inaudible 00:40:27] The Parkinson's community when we started, a very strong foundation.

And quickly in my journey with Parkinson's, I realized that exercise is so beneficial, it's one of those things that with many [inaudible 00:08:44] there's no one size fits all approach to Parkinson's.

Soania Mathur: Mm-hmm (affirmative).

Eric Aquino: With physical therapy, it's one of the things that is so beneficial to anyone with Parkinson's, no matter what age you are and what symptoms you're having, it can be tailored to anyone that best fits their needs.

So once we get funding and we get the program [inaudible 00:09:08], we're going to help people with-

Soania Mathur: Right.

Eric Aquino: ... exercise, meeting the cost of Parkinson's. Whether it be a gym membership to a hospital gym that has Parkinson's programs. Or whether it be getting boxing gloves to take the boxing classes.

Soania Mathur: Right.

Eric Aquino: Or you're just taking a gym class or a dance class. Just something we can get the community to be active.

Soania Mathur: Well, that's a fantastic program you're running that I'm sure makes a huge difference to those in your community.

Both Eric and Bill Rasmussen mentioned exercise as being an important thing and other lifestyle changes, but in these sort of strange times with this pandemic, it may be difficult for patients to engage in the regular resources to achieve their self-care goal such as exercise.

Dr. Amy Amara, what suggestions do you have for patients during this time?

Dr. Amy Amara: Well, there are lots of exercise things that can be done in the home. If you have access to a computer at home, which probably most of us do since we're on this call, but there are a lot of online shows that can have different exercise regimens during this pandemic. Stretching is extremely important for Parkinson's, so certainly that can be done. There are online yoga programs.

And then, just even walking through your home, or sitting in a chair and marching in place, there are a lot of different things that you can do to be active and get your heart rate up.

Sometimes I'll tell people to grab some hand weights and lift them every time a commercial comes on, if they're watching TV-

Soania Mathur: Right.

Dr. Amy Amara: ... just for a few reps to get started. So there are lots of different ways that you can be active in the home.

And then if you feel safe to go outdoors and are able to continue social distancing, certainly an outdoor walk in the sunshine is excellent for exercise.

And, as you mentioned, maintaining a healthy diet and reducing stress, which exercise can contribute to that as well. And continue to-

Soania Mathur: Be creative, I think, is key.

Dr. Amy Amara: ... speak with people-

Soania Mathur: Right.

Dr. Amy Amara: Correct, yes. That's what we-

Soania Mathur: Yes. Don't lose that social connection.

Dr. Amy Amara: Mm-hmm (affirmative).

Soania Mathur: The last point on the slide, is about research participation. So the other thing I think to keep in mind is something that would be helpful to all of us within the Parkinson's disease community is research participation.

One of the biggest factors that holds back medical research is patient recruitment. We just don't have enough patients that are willing to participate. It's particularly difficult to find fairly newly diagnosed patients, some of you who may be listening, many of whom have not been started on medications. And without our involvement in clinical research, there'll be no better treatments or cure.

So we'll give you some information at the end on how you can learn more about clinical research and consider participating.

Next slide, please.

This next slide deals really with the process of disclosure. Now this is such a personal decision, about when, and to whom you disclose your diagnosis to. Sometimes you have to be in a place of true emotional acceptance, kind of wrap your head around it, before you can discuss things with others.

While others will benefit from having people around them, initially, to support them as they process this diagnosis.

For me, it was the former. It took me a good 10 years before I told people beyond my most inner circle of a few individuals. Until that time, I had not told my colleagues at work, my patients, extended family or my broader social circle. And I could do that because initially my symptoms were fairly mild and manageable.

I held back for a number of reasons. First I wasn't sure how my patients would feel. And that was based on an ill-conceived feeling that they would find my medical skills as being weaker, post diagnosis, which was completely false.

And also, I didn't want a pity party, which actually, once I disclosed, never actually happened. So Bill Rasmussen, I read a piece on the ESPN website where you disclose your diagnosis to the world, so to speak. Can you share with us what inspired you to write that post?

Bill Rasmussen: Yes. I have been concerned personally, but talking to other people about Parkinson's, and I have it, that's it. I mean, it's like, I'm wearing a green tie. It's a fact that's the way it is.

Soania Mathur: Right.



Bill Rasmussen:

But I've had a long relationship with several of the people back in Bristol at ESPN, and one young man, we hired as an intern back in 1979, 40 years ago, he's now a senior official, a senior communications official. And he and I have talked about it, and is this the kind of thing... can we help somebody if we go public? Is it going to be embarrassing... in some way or not?

And the embarrassment part didn't bother me. But I started to think about the people who may have Parkinson's and are fearful of going to the doctor. They don't want to hear about it. They don't want to know. That's not a good thing. They ought to know, and so they can get some help.

And the other thing is, as you mentioned, people who have Parkinson's don't like to talk about it. But it's not like catching a cold. It doesn't mean that it's bad to talk about it.

So I was talking to this gentleman and he said he had a very serious kidney problem and almost died, because he did not go in in time to talk to his doctor. And when he came out... being in the public relations and communications department, and he's the vice president, he said, "I decided to write a piece on my problem," this is him, about his problem.

And he said the response was overwhelming. And he said, the one thing that he would tell me... one of the responses was from a gentleman who said his brother had the same thing that Mike had been experiencing. And because of Mike's writing about his own problem, his brother finally went to the hospital, and now he's hale and hearty and healthy, and he had been facing death.

And so Mike felt-

Soania Mathur:

Sounds [crosstalk 00:47:22].

Bill Rasmussen:

... if you feel you can save or contribute to saving even one person-

Soania Mathur:

Mm-hmm (affirmative).

Bill Rasmussen:

... just get one person to go and be positively diagnosed and to get started on the path to extending his life and recovery or whatever it may be, we don't know what the future is. That that's a good thing.

And so I said, "Mike, let's do it." And so we put together that story, we got a writer to help, and took down all the information.

And I frequently speak around the country on other things about business. And I always say, if we can just... one person goes out that back door with a positive thought and an idea and...

Bill Rasmussen: ... out that back door with a positive thought and an idea and carries it through to success, then I've been a success because I delivered the message and motivated someone. And I think Mike and I talked about that, and that was really what led to the writing of that story and to the going public, so to speak, on ESPN. And if we've encouraged one person to get started earlier, to get started on an exercise program, to talk about it, to go to a doctor... Maybe they haven't even been diagnosed. If we can make an improvement in one person's life, that's great.

Soania Mathur: I think you're absolutely correct with that. I think that's why most of us talk about it so openly, because I think shared experiences is a really powerful thing for sure. Eric, what was your disclosure process like?

Eric: My disclosure process was... It started off with my family, but I ran into the problem of how I disclosed it. Because I was slowly disclosing it to friends, and with my symptoms being the tremor, a lot of people noticed that in certain situations my tremors were being exacerbated. So I would tell them at the moment... But I would tell them, like Bill Rasmussen said, "I'm wearing a blue tie." I'd say, I have Parkinson's. And because it was such [inaudible 00:49:22], they laugh and not believe me, or wait for a different response. And I'd stand there, and I'm like, "I'd just wait for you." We'd stare at each other for five seconds, and they're like, "Wait, you're not joking. You really have Parkinson's."

So my problem is more of how I disclosed it because of my [inaudible 00:49:48]. And then [inaudible 00:49:51] started with... One of the first people I told is my sister. I remember disclosing to her what's going on and what's my new situation. She was like, "You should start a podcast." And I was like, "A podcast. Why?" She's like, "Because you have a compelling story and people need to hear it." And I thought it was crazy but I figured, "Why not?" I had nothing to lose. And slowly found out that, like Bill Rasmussen said, one person called me and said, "Thank you. Now I know what my dad's going through because he's never spoken about it." And it took me by surprise because I've known the person for almost all my life. So just to have that, to help someone and they just say, "Hey, thank you for telling your story because now I understand it better," it makes a huge difference.

Soania Mathur: It does make a huge difference, for sure. Thank you, Eric. The next slide, please? Next slide is to quickly remind you of the resources the foundation has to keep you in the loop. Of course, there are a variety of ways to connect by social media with the foundation. You can engage in online research by Fox Insight, of which I think, Eric, you're a part of, or more hands on with clinical research through Fox Trial Finder, which matches you with possible studies, two initiatives that are really easy to join and I feel are great ways to contribute to the search for better treatments.

The last resource was just launched earlier this week. It's our new patient guide, "If I Knew Then What I Know Now," a guide that was developed and written with members of our patient council, trying to give some insight, answer some

common questions, and practical suggestions to navigate life with Parkinson's disease. And it can be downloaded for free on the foundation's website. And I think we have a couple minutes to take a few questions that have been submitted by those of you that are listening. One of the first things is, how often, Dr. Amara, should people be seeing their Parkinson's disease physician?

Dr. Amy Amara: I think that can be different from person to person. I have some patients who prefer to only come once a year because they feel like they're doing well and prefer not to make the trip. Others need to be seen more often, especially as the disease progresses and there are more symptoms and more issues that need to be discussed. I also have a lot of interactions by phone or patient portal with my patients, because we can do a lot of things that way as well. But yeah, somewhere between every three months to six months is the most typical, I think, but it is also important to really advocate for what you feel you need. If there is a new symptom that you don't understand and need to discuss, definitely call your physician. We don't know if you're having troubles and we don't know until the next time you see us. So if you call and let us know ahead of time, being seen earlier is usually an option. So it's important just to let us know.

Soania Mathur: Right. That makes sense. Eric, how long did it take you to find the right set of medications since your diagnosis? Or have they not been changed?

Eric Aquino: Well, when I first got... In my process of getting that diagnosis I actually went for a second opinion, because one of my feelings when I first went to a neurologist... I went to a neurologist and they were trying to figure out what it was. And they thought it might be Parkinson's, and they actually wanted to do the DaTscan, but that wasn't approved. After them doing months and months with the insurance company, I called them up and said, "What do I do now," and surprisingly, their response was, "You can continue dealing with the tremors or take the [inaudible 00:54:02] Levodopa." And knowing the side effects for longterm use, I was like, "I'm in my forties. There has to be other options."

So I found a mood disorder specialist, and they were like, "These are your options." They gave me five [inaudible 00:00:54:16]. The nurse practitioner was great. She was like, "There's five medications you can take." I'm only going to mention four because there's a fifth one and she explained why. And so we [inaudible 00:54:28] and I started with [inaudible 00:06:32]. And just recently I added [inaudible 00:54:36] to my [inaudible 00:54:38] just because there were certain situations I wanted to manage it a little better than [inaudible 00:54:44] and [inaudible 00:54:44] would.

Soania Mathur: Right. So I mean, I guess that just shows, again, that you have to find that fine balance between medications that will work for you. But as Dr. Amara mentioned that it's often in her approach to start medications early enough when you have the symptoms, as opposed to waiting when you're quality of life becomes more severely compromised, would that be a fair assessment, Dr. Amara?

Dr. Amy Amara: Well, there are certainly situations when it's okay to delay starting treatment. If you have tremor and it's not very bothersome to you, and it's not keeping you from being active and doing the work that you need to do, then certainly, waiting longer to start medicines is an appropriate choice. And it does also open you up to some of those clinical trials, as you mentioned, that are actively searching for people who are not yet on medications, because that is such an important time of the disease to research because it tells us more about the natural history of Parkinson's, and also what happens before the medications begin to influence things. So those people, before they're on their medications, very important area of research.

And there are even exercise studies that will be starting soon that look for only people who are not yet on medications. So it's certainly sometimes appropriate to delay starting, but as I said before, and as you emphasized too, if you feel like your symptoms, or if your doctor feels that your symptoms are keeping you from doing the things that you need to do to stay overall healthy, or to maintain your work, or to continue, as you mentioned, the quality of life that you need to achieve, then certainly, starting medicines, there's no reason to delay that.

Soania Mathur: Right. So as we wrap up our time together, I'd like to pose one final question, first to you, Bill Rasmussen. What is the one piece of advice you'd give to someone who just found out they have Parkinson's disease? Is there, sort of, any one thing you wish someone had told you when you were in that position?

Bill Rasmussen: When I talk about the positive side of life, face it, take the medication, start whatever regimen that your health professional puts forth. But I think, for me anyway, it is maintaining every single day. You just get up and face the day, and you have Parkinson's and go through whatever your regimen might be and be positive. I think a positive attitude toward life and toward Parkinson's and toward the common cold should all be the same; take it on in a very positive vein and... We only have so many days on earth. Let's use them all to our advantage. And that's just my approach, not very medical, but it's very practical from my point of view.

Soania Mathur: Oh, you're absolutely right. I mean, optimism is a choice, not an easy choice at times, but a choice nevertheless. Absolutely. Thank you for those words. Eric, the same to you, what is the one piece of advice you would give to someone who just found out they have Parkinson's disease, based on your experience?

Eric Aquino: Build your team early and develop them quickly. Build your team both professional and nonprofessional, especially your care partners, whether it be at work or at home or friends that you hang out with. Talk to them. Be honest with them and tell them, "Hey, I'm going to need your help with these things, or these are my symptoms," so that when you're having trouble where they know what's going on and they don't assume that you're okay or that you're not okay. Just communicate with them. But develop your team, I think [inaudible 00:58:46] my advice for people when they first get diagnosed. [Inaudible 00:58:48] your team.

Soania Mathur: Absolutely. I'm glad you mentioned those non-healthcare members of the team because I have a great deal of deep respect for those people that kind of weather this journey with us. Dr. Amara, do you have any one piece of information you wish people who are newly diagnosed would know?

Dr. Amy Amara: I think that it's very important to gain information with the caveat that, remembering that something that worked for someone else you know who had Parkinson's may not necessarily work for you, but gaining the information and learning everything you can about Parkinson's. And again, as Eric said, looking for your resources and who can help you through the process. And I completely agree with Bill Rasmussen that a good attitude is important and helps you face each day, but it is also okay to grieve sometimes because it's a big change. So that's okay too, but [crosstalk 00:59:51] that important attitude.

Bill Rasmussen: Some tough days. [crosstalk 00:59:56] I was just saying, some tough days will come along.

Dr. Amy Amara: Yeah. And then, just really do try to stay active and exercise. I think that's so important.

Soania Mathur: Excellent. Well, thank you kindly everyone for joining us today. I hope you feel that your time was well spent and that you found the discussion informative and valuable. And thank you, Dr. Amara, for sharing your expertise, and Bill Rasmussen and Eric for sharing your experiences. We'll be sending a link to the webinar on demand to listen again or share if you'd like. And mark your calendars for our next webinar, which will be held on June 18th, where we'll be talking about the environment in Parkinson's disease, something we talked about a little bit earlier in this discussion. And remember, those of us with Parkinson's have no choice in our diagnoses, but how we face the challenges is ours to determine. So empower yourself by educating yourself as much as you can about this disease. Until next time, stay home, stay safe, and stay connected. Thank you.