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

Soania Mathur: Hi everyone, and thank you for joining us. I'm Dr. Soania Mathur. I've had Parkinson's for about 24 years and I'm co-chair here at The Michael J. Fox Foundation Patient Council. And I have the pleasure of being your moderator today.

Soania Mathur: We're well into the beginning of a new year. It's a time for reflection, a time to commit to new healthy habits, and a time for resolutions. So it seems appropriate for us to dedicate our first Third Thursday Webinar of the year to discussing strategies, healthy eating, exercising, building your care team, and boosting your brain health, those things that will help you to live well with this disease and really as we age in general. Well, we've got a lot to discuss today. So let's get started.

Soania Mathur: It is my privilege to introduce our panelists. Dr. Gregory Pontone is an Assistant Professor in the Department of Psychiatry at John Hopkins University School of Medicine in Baltimore, Maryland, where amongst a lot of things, he's also the Director of the John Hopkins Parkinson's Disease Neuropsychiatry Clinic, which focuses on treating and diagnosing the neuropsychiatric aspects of Parkinson's disease and related disorders.

Soania Mathur: Ben Rossi is also here today. He's an ACE Certified Personal Trainer, Founding Member and Chief Program Officer at a favorite place of mine, InMotion, which is a wellness center for people with Parkinson's in Cleveland, Ohio. He's also the owner of Ability To Perform training center.

Soania Mathur: And rounding out our panel today is Rose Truby. Rose is a retired accommodation officer from Bicester, United Kingdom. Her husband, Peter has Parkinson's and she's a control participant in the Foundation's landmark study, the Parkinson's Progression Markers Initiative, or PPMI. And we'll talk a lot about that later. So a warm welcome to all of you.

Ben Rossi: Thank you.

Gregory Pontone: Thank you.

Rose Truby: Hi. Thank you.

- Soania Mathur: More than welcome. So after the gluttony of the holidays, it seems appropriate to start with talking about diet, and this is always a hot topic for those of us living with Parkinson's. And I think that's because eating is so central to our lives, and it's really one of those variables that we actually have control over in this disease. So I'll start off with this very common question for you, Dr. Pontone, and I've seen it in the Q&A as well. Is there a specific diet that can be recommended with someone with Parkinson's disease or brain health in general?
- Gregory Pontone: Yeah. So right now there, isn't a lot of scientific evidence about a Parkinson's specific diet. That said, the best evidence diet in general is the Mediterranean diet. And that's one that has a lot of the features that you list up there on the slide. Now, although there isn't a Parkinson's specific diet, there are many Parkinson's specific issues that may influence your dietary needs. So one of them is, people with Parkinson's are on average, likely to have a vitamin D deficiency. And so you want to make sure that you're either supplementing vitamin D or eating foods that are high in vitamin D.
- Gregory Pontone: The other issue that comes up quite a bit with Parkinson's related diet questions is protein can interfere with the absorption of the Parkinson's medications. So what do I do to be mindful of that potential confound to my medication efficacy? Eating certain foods that have high fiber is also very important because I often joke if you don't have constipation, you probably don't have Parkinson's. And I think that's true for all of us. A high fiber diet with fruits and vegetables is really important.
- Gregory Pontone: And then finally, hydration is an issue that comes into play for many people with Parkinson's because there can be blood pressure changes that increase your risk of falls. And so, one of the things that we recommend is that each time you take your medication, instead of just sipping water with the medication, take the whole cup, and then if you do that with each administration, that'll put you off to a good start. So I think those would probably be the first things that I would comment on in terms of diet.
- Soania Mathur: That's great to know. You mentioned the diets that are listed on the slide, just to remind people, the Mediterranean diet is actually made up of plant-based foods, a lot of whole grains, vegetables, legumes, fruits, nuts, seeds, and they're sort of the foundation of the diet. And then olive oil comes into play, fish and seafood, poultry, dairy in moderation, and very little red meats and sweets, which is hard for some people, but that's what it says. And the MIND diet, Dr. Pontone, do you know much about that? It's supposed to have been developed for healthy brains?
- Gregory Pontone: Yeah, absolutely. So yeah, the MIND diet was developed really to decrease dementia risk in general. And so it's a combination of the Mediterranean diet and something called the DASH diet, which is a diet to sort of naturally help control hypertension or high blood pressure. And so, I think the MIND diet

probably would be a good choice for people with Parkinson's in general, as long as you don't have other health conditions.

Soania Mathur: And that's where the wine comes into play, is it not? There was a couple questions in Q&A about alcohol and whether that's okay for people with Parkinson's to take.

Gregory Pontone: That's one we get a lot. Any chronic disease, there's this issue of quality of life. And for many people in many cultures, having wine or alcohol with meals is a quality of life issue. And so the two caveats there are alcohol in excess can certainly increase your risk of falls. So you always want to be mindful of that. The second is that the studies that show that wine is helpful possibly mediated through this compound called resveratrol, it turns out that you'd need a whole lot, I mean, more than you could drink in an evening, maybe more than you drink in a week. So don't overvalue the benefit. If you're going to have wine or alcohol as part of your sort of diet, just make sure you do so in moderation, especially given the fall risk.

Soania Mathur: So if you eat a healthy well-rounded diet, Dr. Pontone, so you stick to something like the MIND diet where you have a lot of green leafy vegetables and berries and nuts and olive oil and a little bit of fish and that sort of thing, do you actually need any supplements? Is there any clear evidence beside the vitamin D that you mentioned, of course?

Gregory Pontone: Yeah. So for the most part, we do recommend that people with Parkinson's certainly when they're diagnosed and then maybe as often as annually, get their vitamin D checked and that should be supplemented if it's low, but otherwise really, there's maybe some evidence that vitamin C can facilitate the absorption of levodopa. But again, at this point the probably best guidance is to have that sort of well rounded, healthy diet that is high in fiber and low in saturated fats and the things that sort of get us all in the end in terms of our cardiovascular risk.

Soania Mathur: That's important to know as well, but what about probiotics?

Gregory Pontone: There's certainly been a number of studies looking at the microbiome in Parkinson's. Just in case anyone's interested, I recently read just an amazing book called I Contain Multitudes. It was one of the first books out for the lay public about the microbiome. And it turns out that there may be implications regarding the microbiome and probiotics, and even what's called prebiotics in Parkinson's. We just don't currently have full knowledge of what those implications may be, but certainly to the extent that it helps move your bowels and keep your gut healthy, that would be a reasonable thing to do.

Soania Mathur: Very good. Ben, is diet something that you discuss with your clients at the wellness center?

Ben Rossi: It is. It's always a top question that comes up in terms of nutrition at InMotion, but it is something that we've recently hired a registered dietician to take a strong stab at with our community. And it's something that we'll be implementing going forward this year. So we're super excited to roll that out. So I really appreciate your great information, Dr. Pontone. It's terrific.

Soania Mathur: That's excellent. Yeah. Like I said, it's a very, very popular question. Rose, where you are, has your healthcare team recommended any dietary changes for your husband?

Rose Truby: No, just eat healthily, which he does. He tends to have done it himself. He doesn't drink a lot. He used to. He's never drunk a lot anyway, but since Patty's had Parkinson's, he seems to have drunk less. He won't bother, he'll just have a Pepsi or a glass of water, occasionally. The water's another problem with him. But he sort of seems to have done it himself. And he's lost weight since he's had Parkinson's. He's naturally eating what he should, I think.

Soania Mathur: That's good. Sometimes though, Dr. Pontone, weight can become an issue for patients with Parkinson's disease. They can be sort of underweight or poor nutritional status. Can you comment a little bit about that?

Gregory Pontone: Absolutely. So I was actually part of a group that published a finding in Parkinson's on weight loss over the course of the disease. And it turns out that for the average person with Parkinson's, the bigger problem is maintaining their weight over the course of the disease. And on average, lower weights or being underweight tends to be associated with worse outcomes. And so that sort of makes the importance of a healthy nourishing diet even more important in the disease, because we want people to be able to maintain their strength over the course of the illness. And one of the things that really can burn calories that people aren't aware of is dyskinesia. So they'll say, I feel like I'm eating as much as I've always eaten. I'm not having any trouble swallowing and yet I'm dropping weight every week. And so there are certain things in Parkinson's that cause this sort of almost insensible loss of weight. And so if you have a situation like that, you definitely want to talk to your neurologist about why you might be losing weight.

Soania Mathur: That's a great point. I think also you may want to ask for a referral to, like Ben was saying, a registered dietician to help you with that because things like butter and margarine, cheese, red meat, fried food, pastries, these are not ways to gain weight. You need to do it in a healthy fashion.

Rose Truby: Luckily Peter isn't underweight. He's just lost a bit of weight and that's where he seems to be maintaining. But I'll take a note of what you've said. Thank you.

Soania Mathur: That's great. There's a couple questions on ketogenic diet.

- Gregory Pontone: Yeah. I can comment on that. I actually have it up in front of me on another screen. So there's been a couple of studies of ketogenic diet and it turns out that, again, this isn't something that we would generally recommend, but at least in this initial study, it looks as if ketogenic diet did improve some of the non-motor symptoms in Parkinson's disease. And so it probably won't end up being a broad recommendation for everyone with Parkinson's, but possibly people who have a certain profile of non-motor symptoms that might have a role in the future, but there is ongoing research on that particular diet.
- Soania Mathur: You're right. I mean, it's probably going to be, we're sort of on a whole spectrum of diseases, really, when you look at Parkinson's in terms of our symptoms and what makes us feel better and what works for us. So perhaps diet will be a little bit on that spectrum too, when all is said and done. But before we move on to the next slide, I just wanted to bring your attention to the publication on the right-hand side, Parkinson's Disease and Diet, A Practical Guide. You can find a link to it in the resource list and it's a very helpful resource to have.
- Soania Mathur: Our next slide is on a topic that we hear over and over again, and rightfully so. And that's exercise. Now, undoubtedly exercise is good for you. We can't deny that. Parkinson's disease or not, it's good for our hearts, our lungs, our muscles, bones, and even, yes, our brains. Ben, let's just start with the work that you do. Say someone who's newly diagnosed with Parkinson's or hasn't exercised before and has been told that exercise will help and they come to you, where do you start?
- Ben Rossi: Well, that's a great question. What we've learned from the beginning of time with InMotion is on education of our clients. That's number one. We have to educate someone, we have to help them understand what they're dealing with, but when it comes to how do we get started in exercise, first and foremost, we help them understand what the major value of exercise is. And that is in turn, that really translates to your activities of daily living. We want to make sure that you understand that you're going to improve your posture. You can lengthen your stride. You can become less rigid, less fearful, increase your endurance, have better cognitive ability, improve your balance, develop more confidence, better voice volume, less falling. These are all things that to develop those areas through exercise, that you can live a safer life and you can have a better daily life, day-to-day life. I mean, that's really what it needs to translate to.
- Ben Rossi: In 2021, the Parkinson's Foundation, the American Council of Sports Medicine, and just excellent panelists of health and fitness professionals, which I was fortunate enough to be involved in, we developed the Parkinson's Exercise Recommendations. And we know that exercise and physical activity can improve many motor and non-motor Parkinson's symptoms, but how do you get started? And that's really where this question came from, Soania. And really, it's important that you see first a physical therapist or a qualified health professional to truly get a full functional evaluation of where you are. We have to understand your benchmark. Secondly, safety. Safety is really a top priority when it comes to exercise. It's important that you do this during your on periods

or when you take your medications. It's not safe to exercise on your own. When it comes to InMotion, we are a community and we do this together. So to work out with a care partner or to work out with a care partner or to work out with other friends that are going through the same situation, that's very, very important. It's important to work with qualified exercise professionals so that they can modify and/or progress your programming as you go, based upon where you are. A professional should be able to regress or progress to keep you in a continuous improvement situation.

Ben Rossi: The big one, you should participate in 150 minutes of moderate to vigorous exercise each week. Now, this is broken up into really four specific categories. So there's your aerobic activity. So you can... This is your continuous rhythmic movement, cycling, walking, if you're capable to run and do that, swimming, that type of situation. Strength training is your second area. This is working your major muscle groups, your upper body, your lower body extremities. And yes, weight lifting is okay. Resistance bands are okay. Body weights, handheld dumbbells, these types of things are terrific to use with proper guidance and with proper support.

Ben Rossi: The third category is balance, agility, and multitasking. So multi-directional stepping, working on weight shifting, dynamic balance activities. And balance is always a big, big question. Balance is huge. And how do you get started on balance? Where do you go? We have to start slow and controlled and do things properly, not just jumping onto imbalanced [inaudible 00:16:34] shoes, or these things that make you lose your balance like crazy. That's not the goal. We really have to crawl before we walk when it comes to areas like balance and doing it properly. Classes like yoga, Tai Chi, dance, boxing, these things that are forcing you to multitask, to weight shift, to put you through excellent range of motion, taking you away from your center of mass is super, super important.

Ben Rossi: And of course, the fourth category is stretching. Stretching, this is... Beginning of workout, it's very important to do dynamic stretching, active stretching, where you're pumping blood to muscles and getting things flowing, ready, and preparing you to exercise. And then post-workout, you should be involved in what we call static stretching, where you're holding your muscles and allowing your muscles to properly cool down.

Ben Rossi: So I said 150 minutes of exercise, and that's a lot of areas, aerobics, strength, and balance, and multitasking, and stretching. You can do these individually. You can join classes like Ed in motion, or other area of organizations that allow you to... They use all of these areas in one class. But the goal really is to, how can I achieve my 150 minutes a week?

Soania Mathur: That's a wealth of information you gave, Ben. Now, I've heard a lot of talk about the intensity of the exercise that you have to achieve in order to reap the benefits of doing it, optimally, I guess. It's always beneficial to do whatever you can. But do you know anything about that?

Ben Rossi: Intensity of training, no, absolutely. And when we talk about exercise and Parkinson's, or aging population, we're really talking about the amplitude of your program when we talk about intensity. Intensity, you should be able to exercise, and we've heard this since the beginning of time, to where you're able to talk comfortably with someone next to you when you're exercising. You push a little more than you think you can do, which is really the basis of the training that we do here. But everything that we do in terms of intensity has to be large movements, overdone movements, a louder voice, bigger moves. And that's the way we approach it, because when you're talking about Parkinson's and the slowness of movement, we need to work against that, and we need to counter that type of stuff. So, that's how we monitor our intensity.

Gregory Pontone: Right.

Soania Mathur: Thank you. So, Dr. Pontone, as Ben has described, exercise has a lot of value for people with Parkinson's disease and brain health in general, I think, but what does the science tell us?

Gregory Pontone: Yeah. So, first of all, I think there was a ton of incredibly important information in what Ben just said that I sort of want to reinforce. First of all is, exercise of the big three, sleep, diet and exercise might be the single most important in Parkinson's. And I think when we think of exercise, we sort of focus on the physical benefits of exercise and what it'll do for us physically, which is all great and wonderful. But it turns out that in Parkinson's disease and other neurological diseases, and in people who don't have neurological diseases, physical exercise may also be the single most important thing you can do for your brain health.

Gregory Pontone: So let me just tell you some of the specific evidence for exercise and different types of exercise in Parkinson's. Ben mentioned that there are different types of exercise, so aerobic, anaerobic, or resistance training, and then flexibility, a range of motion, mobility type movements. And all of them are important. All of them have a role. But it turns out that they also specifically benefit different parts of your brain function. So looking at over 18 articles in Parkinson's, specifically, aerobic exercise, things like walking on a treadmill, just walking outside, stationary bike, anything that gets that heart pumping seem to help processing speed, attention, reaction time, executive function, which is probably the single most common problems that people with Parkinson's have, and that's problems with organizing, sequencing type tasks, and language. So they've shown this specifically, "And oh, by the way, aerobic exercise also seems to lift mood and help depression in Parkinson's."

Gregory Pontone: And then although there's less specific research on it, resistance training, whether it's with bands or lifting weights, there are a few studies that looked at this specifically in Parkinson's, and they also showed that it improved performance on measures of executive function and attention. And the physical benefits clearly showed that it improved balance and gait. Now, while flexibility and mobility are very important, we know physically, they haven't been studied

as formally for the cognitive benefits. But certainly when combined with things like mindfulness, meditation, and yoga, there's clear benefit to quality of life in the Parkinson's population.

Soania Mathur: Wow. So I guess we can't get out of it. Exercise is necessary.

Gregory Pontone: Well, Ben mentioned that, doing it in groups. I think there's a couple... I have many of the people that I work with in my clinic, who do group Parkinson's exercise, whether it's in places like In Motion, or we have something here in Maryland called Rock Steady Boxing. And they love the community, and it helps keep the intense the up, because they're cheering each other on.

Soania Mathur: Right.

Gregory Pontone: And I think that sort of gets two birds with one stone. You're getting the socialization, you're getting the intensity, and there's an accountability, right?

Soania Mathur: That's right.

Gregory Pontone: Because if you don't show up on Thursday, then what am I doing here?

Soania Mathur: Someone's going to call you. Yeah.

Ben Rossi: That's right.

Soania Mathur: Rose, is your husband involved with any exercise classes or routine?

Rose Truby: Yeah. So, there's a clinic not far from us. And it's The Bosworth Clinic, and they do exercise for Parkinson's called PD Warrior. So again, it's doing everything that Ben was saying you have to do, you've got the resistance bands, you've got the stretching. And they all go out for coffee afterwards, so they get the social thing as well.

Ben Rossi: That's great.

Rose Truby: I mean, that's about the only thing he does do. He used to walk to go to the gym, but he stopped doing that when lockdown happened here in England. And he's not got back to it, he keeps saying he's going, but he does walk out every day and meet friends. And he goes into town, which is about a 15 minute walk for him, 10, 12 for me. So we very rarely walk together. And he's doing that every day, so he is getting his exercise, I'm pleased to say.

Soania Mathur: That's excellent. And we're actually going to touch on the challenges you just mentioned in our next slide. But before we leave this slide, the family doctor in me just wants to emphasize what Ben already mentioned, that you should really consult your healthcare professional before you start on an exercise regimen. Particularly, if you have mobility issues or balance problems, or any other



illnesses like cardiac disease or heart disease, then that may require more cautious or supervised approach.

- Larry Gifford: A landmark study that could change the way Parkinson's disease is diagnosed, managed, and treated is recruiting participants now. PPMI, or the Parkinson's Progression Markers Initiative, needs people with and without Parkinson's, especially people age 60 and up, who have close relatives living with the disease. Take a short survey today at [michaeljfox.org/PPMI](http://michaeljfox.org/PPMI) to see if you're eligible. That's [michaeljfox.org/PPMI](http://michaeljfox.org/PPMI).
- Soania Mathur: Onto the next slide, which really speaks to me, because even though I've been living with this disease for close to 24 years, and I know that exercise and other self-care habits are important, it's a struggle sometimes to get motivated some days. And that's my greatest challenge. Ben, how do you motivate your clients to keep up their exercise routine? What seems to work?
- Ben Rossi: All right. Well, I love this part. Mentality, to me, is the name of the game. I am a performance coach by trade, IMG Academy in Florida, and one thing we always talked about was motivation and mentality. So, what I teach and preach in my community is the power of 212 degrees. So at 211 degrees, water's hot, but at 212 degrees, water boils. When water boils, it produces steam, and steam can power a locomotive. Just one degree difference can create so much change.
- Ben Rossi: So at In Motion, we focus on becoming one percent better every day. And our mantra is "Good, better, best. Never let it rest until your good is better, and your better is best." Now, we wear this as a patch on our sleeve. It's like armor for us in here, and we all know it. It's almost like we have a little chip on our shoulder around this place. And it's important that you have that, it's exciting, and to kind of bounce off each other. We all are here fighting the same fight, doing the same thing.
- Ben Rossi: It's important that we help our clients understand, or our participants understand, that they need to embrace their situation and not hide from it, number one. They need to take charge of making a difference in themselves. It's important that, self-efficacy and the belief in yourself is a huge, huge thing. And we always talk about being a warrior versus a worrier. But when a community of warriors come together, it's powerful, and it's hard to beat that. And it's really what you need to work against this isolating disease.
- Ben Rossi: In my mind, some strong tips to get started, I suppose, for those that it's very tough for, I think it's understanding where you are now is really what matters to help you determine your benchmark to go forward, determining like... To develop strategies for your specific and personal journey, success journey when it comes to exercise and wellness. We always say it's one thing to be in motion, but it's another thing to really take action. And Parkinson's doesn't stop, so neither can you when it comes to developing your action plan to really attack it and address it head on.

Ben Rossi: So like I said, it matters about your personal exercise story, and then you need to identify a few action steps in my mind to do that. Number one would be identifying your current level of exercise. Are you someone that exercises regularly? Or you don't exercise, but you stay active during the day, or you're just mostly sedentary? We know that 75 percent of the day for someone with Parkinson's is typically sedentary. So, it's important that you add that action in. So how about determining your barriers to exercise, what's holding you back? What's holding you back? Is it time? Do you need an accountability partner? Are you lazy? Maybe. Or, and I've heard this, "I just don't like exercise." Well, listen, this is something that's so massively important to your life. Whether you like it or not, it's something that you need to do.

Ben Rossi: So what about determining the extent to which you currently exhibit your self-efficacy, your belief in certain areas? Do you accept the responsibility of your own wellbeing? Do you set goals for yourself and work towards them? Do you replace unhealthy habits with healthy ones? All things to think about. Do you follow a regular Parkinson's specific exercise routine? One of amplitude based, like I mentioned before, right?

Soania Mathur: Right.

Ben Rossi: Do you persevere in the face of difficulties? And do you focus on the positive? Are you A, use it to improve it person? And these are things that I think about, and we like to preach to our community, for sure.

Soania Mathur: Yeah, those are all very important, Ben. That sort of self-reflect, honest self-reflection is really important to developing a plan. But Dr. Pontone, you know very well depression and apathy, lack of energy. These are very real issues that people of Parkinson's face. And they can really interfere with that person's motivation to take care of themselves. Do you have any advice when somebody should maybe seek their healthcare provider's assistance?

Gregory Pontone: Yeah, absolutely. I mean, I think if you have noticed that your mood is low more often than not, and that you lack initiative, and your less interested in the things you usually enjoy, or even if someone... Let's say, your care partner drags you to an event that you'd usually like, and you don't enjoy it, those can be signs of depression or apathy, and they need to be treated. The other one we see is people are so anxious about everything that might go wrong when they leave the house that they avoid activities. So those are barriers that can be addressed. We have good treatments for those sort of things. So if you recognize those, be proactive and go talk to your healthcare providers.

Soania Mathur: I think that's great advice, actually. Rose, have you faced challenges getting your husband motivated to exercise? It sounds like he's been doing a fairly good job.

Rose Truby: He can be lazy, but generally, he does his walking every day, and sometimes he's out all day. They go somewhere on the bus, walk around, and then come home.

They usually find lots... He's got about three or four friends that are really good, who take him out and they understand, and they're there supporting him. If he can't drive, which may happen in the next six months or so he might have a problem getting to his Parkinson's class, but I will do that every time I can, but sometimes it isn't possible. And if I suggest he get a taxi, he gets upset. That's how do you try and encourage somebody to do that? I know it's a minor thing, but it's useful if anybody can help me with how to encourage him to try that.

Soania Mathur: I think that brings up a really good point and that's the... It's not just mindset sometimes that acts as a barrier to pursuing this part of your management. Sometimes people can't get to a center or group class either due to external circumstances like COVID or the centers themselves have closed because of government restrictions or due to lack of transportation or mobility issues, advanced disease. What do you recommend, Ben? For instance, how has InMotion been able to pivot their work and what do you recommend for patients to do if they're stuck at home?

Ben Rossi: The biggest thing within InMotion is, like I mentioned before, we know that Parkinson's doesn't stay up so neither can we, in terms of our care that we provide or the participants that are involved. And when this crazy time hit us and COVID hit us, we had to pivot immediately to a recorded video platform. That's number one. There are so many great organizations and on our website, you can access [inaudible 00:31:42] InMotion and participate in programming for all levels of individuals. That's first and foremost, find recorded programming. Number two is, if you're comfortable, if you were to participate in something like this, you could participate in a Zoom workout. We have a full, active Zoom workout schedule going on. We just pivoted back in January. We are back on Zoom again in our community.

Ben Rossi: Not that any of us are happy about it, but it is what we have and it's what we do. And we bring the best of the best that we possibly can to our individuals. Those are always two amazing opportunities. Yes, access to care is a huge, huge topic that we always talk about, developing remote services and working with those don't have the access that some do, looking into local transportation. All these things are a huge topic right now. And then we're all trying to tackle them. Those are my main two that we focus on for sure.

Soania Mathur: Yeah. It's pretty multifactorial what goes into getting someone to an exercise class actually.

Ben Rossi: Absolutely. [crosstalk 00:32:43]

Soania Mathur: Rosie mentioned [inaudible 00:32:44] Warriors. I believe they have an online class available as well. Is that true?

Rose Truby: [inaudible 00:32:51] he was doing that, but he can't... He does have... He's been diagnosed with [inaudible 00:32:58], so he is also struggling to do the

technology. Again, if I'm not here that makes it very difficult for him to get onto anything like that. For us, the walking is his main [inaudible 00:33:13] I suppose. Yeah. He has done it online, but I've had to be here to help him get on in the first place.

Soania Mathur: Right.

Ben Rossi: That's a good point on doing what you can Rose. You do what you have access to and what you can accomplish. That's the truth too. We go [inaudible 00:33:29] we can. Absolutely.

Rose Truby: [crosstalk 00:33:32] I'd love for him to do more, walk faster, but he's 71. He's quite set in his ways, but he still is doing as much as he can do. I will give him that.

Soania Mathur: That's really important. And that kind of will tie into a couple slides from now when we talk about building a care team that will help you in the management of your loved one. The next slide... I'm just going to move on... Is about PPMI because we're talking about changes in behavior and habits to adopt, and I would really encourage you to consider participating in research in some way, because without our participation as a patient community, the search for better treatments and a cure, it can't be successful. The Parkinson's Progression Markers Initiative also known as PPMI is the Foundation's landmark research study.

Soania Mathur: This is a study that we say could change everything about how Parkinson's is diagnosed, treated, and potentially prevented. And the study recently expanded. Thousands have already taken the first step to join PMI, thousand more volunteers with or without Parkinson's are needed.

Soania Mathur: And the online part of the study is open to anyone over 18 in the United States. And hopefully we'll go international so people like me up here in Canada and other parts of the world can sign up. You can get started in the study or learn more about the study by clicking the get started button in the take action box. And there's also some information and resource as well. Now, Rose, I know you were involved or you are involved in the original PPMI [inaudible 00:35:08] still ongoing. What made you join and what has that experience been like for you?

Rose Truby: I suppose I joined not because so much Peter had it, but a friend of mine who I used to see years ago and lost touch with moved to Vista from Oxford. And we met up and she'd been diagnosed with it and she was doing the course, the study as somebody with Parkinson's and she just said, would I be interested? I thought, yeah. I couldn't run a marathon to raise money for it, but this is something I can do. And I thought, well, it's not going to hurt me. And in fact, as a little bit selfishly, I know that my brain is reasonably okay, because I'm still a control subject and I just felt my son ran the marathon. I trained with him to

encourage him to do it, but I can't do something like that. I thought this would be the way for me forward.

Soania Mathur: That's [inaudible 00:36:04].

Rose Truby: [Crosstalk 00:36:04] and then the first six, you do it every six months where you do... I have the [inaudible 00:36:12] puncture and the [inaudible 00:36:13] scan and the MRI and all the cognitive and smell test next week. I'm on my second part where I just do the cognitive test, the smell test. And I think there's one other bit, but my memory's failed me.

Soania Mathur: Rose. Thank you. That's such a selfless action. You're literally giving of yourself for the betterment of our Parkinson's community. I really extend my gratitude to you for sure.

Rose Truby: That's fine. It's something I can do.

Soania Mathur: We all can do something, but it's really heartwarming when we see that action take place as Ben was talking.

Rose Truby: Thank you.

Soania Mathur: Our next slide talks about building your healthcare team. And that's what I mentioned earlier. Living well isn't a solo endeavor in my mind. We're not islands unto ourselves. We do best when we're surrounded by a team of people that are committed to helping us optimize our quality of life. And the members of that team will vary from person to person. And so to go back to you, Rose, because you were discussing about not being there all the time, not being able to encourage your husband in ways that he may need at certain times when you're not around. Have you sort of built a care team for his health management?

Rose Truby: Not really because we seem to be doing okay as we are. As I say, I've got friends who will come over and help me if I have a problem with the house, which Peter can't deal with. I've got my sons who will help out when they can. And he's got his friends who are really good with him. They make sure they see him once a week. And that, I suppose, in a way that is his care package, isn't it?

Soania Mathur: Right. Yeah. You are the most vital part of your husband's care team, but you also have to remember is you have to take care of yourself and build your own support network.

Rose Truby: I walk every day with one of my neighbors who incidentally has also done the PPMI thing.

Soania Mathur: Oh wow.

Rose Truby: We walk every day... Morning. We get up at 7:30, we go [inaudible 00:38:16] a walk, come back and I'm home by sort of half eight, nine. O'clock when Peter's getting up. I've done that. And then we walk into town again a bit later, [inaudible 00:38:26], and I just make sure I walk a lot and have friends. I've got friends who I see on a Friday that I used to do a martial art with. I still meet with them. I've got that.

Soania Mathur: I think that's important for the care partners who are listening to understand that they need that respite. Ben, at InMotion, how important is a team approaching improving the quality of life of people that come there?

Ben Rossi: Everything. Only everything. I think there's... At InMotion, we're fortunate to have all of the forms of exercise and wellness under one roof. We have our [inaudible 00:39:01] boxing class. We have our signature better every day exercise class, which is our large amplitude movement, multitasking, cognitive work, mindful movement, yoga, spinning. We have our [inaudible 00:39:14] class, drums alive in our facility, Tai Chi. The idea, I think the point of saying that is that it takes all forms of care. They're all evidence based.

Ben Rossi: It's important to participate and expand your care team of exercise specialist. I think that there should be a major... As far as care-apy with Parkinson's, you need to focus on neurologists, movement disorder specialists, seeking a physical therapist, you have that one-on-one attention and then finding community exercise to build that socialization and to expand outside of that one-on-one approach and to work your abilities from all angles. Very, very important. The expansion of care team is everything. That really is what you need. You can't, like Soania said and everybody else is saying, you can't do this on your own. And why would you? Don't do that to yourself. Expand, expand, expand, broaden your horizons a bit and get involved in something that maybe you haven't done before. Something that may make you a little more uncomfortable, something that you're not used to doing. Step out of the box a bit.

Soania Mathur: Absolutely. And as I mentioned before, the members of your healthcare team will differ from patient to patient. You mentioned physio, there's also OT. There's social work. There's massage therapists, depending on where you are in your stage and age of disease, it will make a difference. Dr. Pontone, I'm fairly lucky. The people that attend InMotion are fairly lucky. Rose's has been... That we've been able to build a fairly solid team of health professionals, allied health professionals, to help with the challenges that come our way, but not everyone is as lucky. And do you want to elaborate on that disparity a little bit?

Gregory Pontone: Yeah. We're fortunate, at least in the American healthcare system, that insurance covers a lot of these important services. For us, you need that movement disorder specialist neurologist. That's invaluable. Okay. And that sort of works almost like the primary medical doctor does in the traditional medical model. They're the ring leader. In addition, referral to physical therapy is really important. Okay. Occupational therapy. The way I like to think of these, and this is a little bit reductionist, is physical therapy is going to work with you on sort of

being as strong and as able, best balance, risk mitigation for falls on the individual. Occupational therapy is going to help you modify the environment to decrease all those same risks. And then one that we don't talk about much, I think, in public forums, but we should... In the hospital, they're very important... Is something called speech language pathology.

Gregory Pontone: And they're a type of therapist that helps facilitate communication, effective speech, but also in later parts of the disease addresses things like trouble with swallowing. That is... If you were to think of the number one and two biggest risks for people over the course of Parkinson's, it's the risk of falls and the risks of what we call aspiration pneumonia. And so this care team covers all of those bases, not just in avoiding bad things, but also living the best that you can while you have the disease. And ideally, fighting every day, because that's the thing that Ben keeps mentioning is every day you wake up and it's I'm going to win. And that's the point here is that have that focus and it gives you a reason to do this. But I want to plug one more specialist that's often left off this list and that's the mental healthcare specialist, whether it's a therapist or a psychiatrist, keeping your head right. If you're not motivated, if you're depressed, none of these other things happens. Keep that there too as an active strategy.

Soania Mathur: Absolutely. And that's sort of your ideal healthcare team for sure. Unfortunately, there are more underrepresented populations that don't have access to that. And the Foundation is actually working to address these issues and resolving these inequities in access to care. They're advocating to expand Medicare coverage for dental, hearing and vision care. And actually, if you'd like to add your voice to these efforts, there's a link in the resource list.

Soania Mathur: And another effort by the Foundation is to fund research study that will look into the challenges, diagnosis, health outcomes, and disease experience in underrepresented populations I think is really, really important. Our next slide is kind of a fast fire discussion because we've focused on diet and exercise and building your care team all which are very, very important. But there's a couple things on here that I particularly want to talk about. And the first is sleep because as we age our sleep patterns change, you add Parkinson's disease to the mix and sleep issues can really become very bothersome. Dr. Pontone, what do we know about sleep and brain health?

Gregory Pontone: Again, I want to mention another book because this is probably the best summary of the importance of sleep in general to people. It's called *Why We Sleep* by Matthew Walker. It's a book that sort of details all we know about sleep and its importance and in Parkinson's it's particularly important. Getting a good night's sleep, there's no magical number of hours you need, but for most people somewhere more than six hours and less than nine or 10. There is such a thing as too much is a good number in terms of promoting ideal health. It's good for your physical health. It's good for your mental health and in terms of emotionally and it's good intellectually for keeping you as sharp as possible. Unfortunately, Parkinson's attacks your ability to sleep in several different ways. And so, probably the best thing you can do is establish a healthy habit of sleep

where each night you have a routine where you basically get ready for sleep. You're not getting involved in things that are mentally taxing in the hour or two before sleep, you're sort of winding down. And so there are definitely books about sleep hygiene, and I would say that's the first place to start before you even think about medications.

Soania Mathur: That's great to know. I got to take some of that advice. I give it all the time, but I rarely take it, unfortunately. And what about training your brain? Do you have any advice about that, Dr. Pontone? What does that mean exactly?

Gregory Pontone: Yeah. So one of the things that I think is really important is if you have good sleep hygiene, your brain and body will naturally learn to sleep more efficiently each night. And so, as you get ready for bed and you have this ritual or routine, if you don't fall asleep right away ... Let's say it's more than 20 minutes. We actually recommend you get up out of bed and do so something that isn't stimulating and doesn't involve ideally technology. So maybe reading a book, or just listening to soft music. Do that until you start to drift off again and then get back in bed. And although that may take several days, eventually people find that they're able then to sleep more and more.

Gregory Pontone: Now, if you run into a problem, let's say you have REM sleep behavioral disorder, restless legs, or other things that might interface with your Parkinson's. Some people's medications wear off in the middle of the night and they're stiff and rigid, and they can't sleep because they're uncomfortable. Then you need to start bringing in health professionals to help with the sleep.

Soania Mathur: What about during the day? How can we help train our brain during the day in terms of brain health in general?

Gregory Pontone: Yeah. So staying active and connected. It turns out that just being social and engaging in structured activities, physical exercise, absolutely, probably one of the most important things. People often ask, "Hey, are brain games important?" Sure. Anything that it engages your brain is important. Are they more important than exercise or socialization? At least not so far that we can tell through formal study, but you really want ... Even if you're retired, you really want to keep a sort of vigorous social calendar. I know it's hard during the pandemic, but you really want to have things to look forward to throughout the week.

Soania Mathur: Rose, has Peter been able to incorporate some of these sorts of activities to help keep him occupied and motivated?

Rose Truby: Yeah. No, let me think about that. I'm not really sure. He's bets on the horses. He goes to the betting office every day and he picks horses. He looks and he thinks about it and he does that. And he quite often wins quite a lot of money, other times he doesn't, but he doesn't lose a lot. That's his way of motivating himself to walk. The other thing I do worry about is he sits on his iPad and plays



games, but he will do that right till he goes to bed and then he can't sleep. So you say one to two hours before is very useful. I can now tell him.

Soania Mathur: That's a good thing to take away from this, for sure. And then when you were talking about exercise, you were talking about things like directional change. Are there certain exercises that are more useful for brain health and that sort of thing that you know of?

Ben Rossi: Well, let me spin off of what everybody else said. I think one of the things that we preach a lot about here is the importance of taking a nap. I think that naps are important. I think this is where mindfulness, the mindful movement practice, that type of approach in terms of winding down and getting your mind to relax and calm you is very important.

Ben Rossi: The value of static stretching before we go to sleep at night to calm our body down is of utmost important. But brain health and that type of work, that's why we talk about exercise for brain change. We tie in that vigorous exercise component, plus some type of skill to go with it. When we tie those two together and there's a synergy of brain and muscle working together, that's exercise for brain change. It's not just pumping weights, doing that type of ... It's beyond that. And it's very specific. It's important that if you're going to embark on an exercise program, which we want you to do 100 percent, that you are focused and doing an evidence-based practice in that way for sure.

Soania Mathur: Excellent. Well, I think we have a few minutes to take some audience questions. One that seems to have come up, goes back to our diet. And I think you mentioned this, Dr. Pontone, but they're wondering about the timing of the protein consumption related to medication.

Gregory Pontone: Yeah. So that's really tricky because most people who have Parkinson's disease have to take medications throughout the day, maybe every 3, 4, 5 hours. So if that's the case, when are you going to eat protein? Because you need to have a certain amount of protein. So what we tell people is for the most part, unless you're having clear problems with sudden offs or early wearing off, don't worry about it too much. Obviously you wouldn't want to have a protein shake with your medication. If you can separate it by an hour or so would be ideal. But I always tell people, once you get into those intervals that are less than four or three hours, it's just eat what you have to eat to maintain your weight. And the neurologist can help you sort it out using other augmentation strategies.

Soania Mathur: Great. Ben, this one's for you. What are top exercises for people with Parkinson's? Anything that can hurt or harm?

Ben Rossi: Right. That's a huge question. Well, safety first, like I said before. So if it's done right with proper guidance and the right type of coach in the room with you, you can be just fine. The things when it comes to harmful, what can damage me? I think of balance training and someone progressing too quickly. We are

encouraged to focus on base of support. And a proper balanced program should be one that we are slowly narrowing base of support and adding different components in so that we are challenging balance before we get on to things, like I said before, imbalanced surfaces and that type of stuff. So being very mindful about how we do that. But the best exercise is one that is large amplitude, that's helping you move bigger and faster with higher effort and better intentional focus. Building the foundations of function are huge. Any of those types of things.

Ben Rossi: Exercises like power moves. Parkinson's Wellness Recovery out of Arizona have some of the best stuff, because they really focus on amplitude and working big and exercises that focus on rotation, getting out of a chair, weight shifting, that type of work, big, large steps. These are exercises that you need, and you can find those in all of those great programs that are out there. Like I said, our Better Everyday Program, Tai Chi, dance, mindfulness or yoga type practice, spinning. So they are valuable to you. They're all evidence-based and it's just a matter of getting started.

Soania Mathur: That's the key, getting started. There is one question more that I've actually gotten a lot of myself, I've heard people ask and that's on milk and Parkinson's. And is there any association with milk consumption and onset of Parkinson's, or severity of Parkinson's that you know of, Dr. Pontone?

Gregory Pontone: Yeah. So in looking through the literature on diet leading up to this talk, there is some evidence. There's a study by Gao, he's the senior author. G-A-O, is the last name. And it does appear that in some cases when there's contaminants in the milk, it could increase the risk of Parkinson's in some cases. Now this isn't something where we're saying, "Hey, don't drink milk if you have Parkinson's." But, I can tell you that heavy milk consumption is not part of those mind or Mediterranean diets. They really want you to decrease dairy. So again, hopefully more research will bring that association a bit clearer. But right now, it looks like it's contaminants rather than the milk itself.

Soania Mathur: That's good to know. Great. So as we come to the end of our time together, I would like to ask each of you one final question. And so as we start out this new year, what is the one resolution that you think will benefit someone with Parkinson's disease, or someone aging in general? What is the one change that they can make in their lives that will help them live well? I know there's a multitude, but if you had to pick one change that someone makes today. Who would like to go first? How about you, Ben?

Ben Rossi: Oh, you came to me first. I would go and download the Parkinson's exercise guidelines, and I would have those at my fingertips. And I would focus on setting goals for myself, writing things on a mirror, use sticky notes, something that you see every day and find your best friend and start exercising together. That's what I would do.

Soania Mathur: That's great advice. Dr. Pontone?

Gregory Pontone: Just from what I've seen and the people I work with, you have to get connected. Because if you're on an island and you think this is just happening to you, it's so much harder to wake up every day and fight. You need to get a community around you. And I think it's going to inspire you and hold you accountable to exercise and follow up visits, and all the things you need to do to stay healthy. You really need that community. And it turns out that that interaction, that social interaction is also nourishing. So if you were going to do one thing, that's what I would say. Get connected with a community of people just like you, who are suffering from the same disease and put your effort together to fight this thing.

Ben Rossi: Yeah. Well said.

Soania Mathur: Great piece of advice. Rose?

Rose Truby: I think for me, it would be to ... I tend to take it over when Peter's struggling and I think my resolution should be to make him do it himself more. Because sometimes it's too easy for me to step in and do it. So, I think that's mine and that's I think quite an important one for a lot of people, because sometimes it is easier to do it yourself than try and explain.

Ben Rossi: That's right.

Soania Mathur: Very, very important point. Absolutely. I think mine would be to tell people that they can't, they have to take an active role in their management. You can't be a passive bystander and expect to live well with this disease. It takes you looking at the variables that you have control over, such as the ones that we talked about today. We don't have control over the disease, but we have control over certain variables and being proactive in that, for sure. So, a big thank you to our panel. Did anyone want to add anything else then?

Gregory Pontone: Yeah, they asked about me repeating the titles of those two books. So one is *Why Do We Sleep?* by Matthew Walker. And then the other one, if you have any interest in the microbiome in general, it's called, *I Contain Multitudes* by Ed Yong, Y-O-N-G. And they're just outstanding, they're sort of ... Hopefully, if you have an interest and they'll have some impact on Parkinson's down the road as well.

Soania Mathur: Very interesting. Thank you for those resources. So, a big thank you to our panel again, Rose, Ben, Dr. Pontone for taking the time to share your expertise and your experience with us today. Your advice and discussion I know were invaluable for a lot of people listening, and for myself as well. And thank you to those that joined us today. It's a pleasure and a true privilege to have you as part of our community. And remember, those of us with Parkinson's really have no choice in our diagnosis, but how we face the challenges is really ours to determine. So empower yourself by educating yourself as much as you can about this disease. And until next time, be well, stay safe and stay connected.

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