



**Live Well Today Webinar Series:
Exercise, Freezing of Gait, and Postural Instability**
with Jay L. Alberts
Davis Phinney Foundation

Melani Dizon (Director of Education, Davis Phinney Foundation):

My name is Melani Dizon. I'm the director of education at the Davis Phinney Foundation. And today we're going to be talking about exercise, freezing of gait, and postural instability in Parkinson's. And I am here today with Dr. Jay Alberts. So, we're gonna have a really great conversation. I know this is a topic that is important to many of you and you have a lot of questions. I have a lot of questions, so hopefully we're gonna get those answered today. All right, Jay, you have done so much. You've been involved in our community for so long. Can you tell people a little bit about who you are and what you're up to now?

Jay L. Alberts (Researcher, Biomedical Engineering, Cleveland Clinic):

No, absolutely. For sure, Mel, thanks for having me. It's great to see all the people coming in. It's fantastic. So, you know, we've been, like you said, you know, doing this for a while and been part of the community for a while, and we're doing a lot of work still in the exercise domain as well as really, I'm sure we'll get into it today, but talking a little bit about how do we address postural instability, gait dysfunction, freezing of gait, and really try to understand the mechanisms and potentially even use some of this for early diagnosis. So that these interventions that we've been talking about with exercise and other things we could potentially deploy them even earlier, which is critical. So.

Melani Dizon:

Yeah, absolutely. Okay. That's great. I have a ton of questions that are gonna lead to all of these things. And I apologize, Amneal is our other Peak Partner sponsor, so it's Amneal, Kyowa Kirin, and Sunovion. And thank you so much. And I am sorry that that went out of my brain. Okay. So postural instability is one of the four core motor symptoms of Parkinson's and it's a pretty broad term. So can you give us, let us know what it is, how doctors look for it and diagnose it, and then physiologically what's happening in somebody's body with Parkinson's that is causing that to happen?

Jay L. Alberts:

Yeah, no, that's a great question. So, you know, postural instability and gait dysfunction is considered one of the four cardinal symptoms of Parkinson's. So how do we get to that? Or how do we see it? Well, if you look at pictures or images, right, that's the classic line drawing of an individual with Parkinson's sort of a stooped posture, right? And I think that's probably where most of it comes from, but it's really much more than just having a stooped posture. Clearly you wanna have ensure that your posture's upright, but it's this instability and gait

dysfunction. And where does it come from? So that's a great question in terms of, oh, I just see a little question from you there. I'm from the Cleveland Clinic, sorry, originally from Iowa, but that's where I come from now, we're talking about where does P I G D come from you know, it there's certainly potentially, or there's certainly periphery, right? Changes in muscle mass that are associated with just sarcopenia associated with aging. And as I'm hitting that age 55 and older mark, we all experience that. So, there's some of that. And then there's also some of it's related to pathophysiology, right? So, much of this instability comes when individuals are dual tasking, right? And we think of, you know, what's dual tasking? That's really processing cognitive information and monitoring motor function simultaneously. Right? So, you think about you're in a grocery store, that's a classic dual task. You're walking through the grocery store. You have to be checking your item, your list, you know, do I have this spread? Do I have that, whatever, you also have to be aware that someone else is coming down the aisle or that there is, you know obstacles and things like that.

So, you're processing information and there are a number of different hypotheses associated with, you know, why individuals then have either freezing of gait or postural instability under these conditions. And there's four sort of predominant hypotheses. I won't go into each of them, but fundamentally, we think that there's probably a level of attentional resources that are being disrupted by Parkinson's. And because you have diminished attentional resources, you either have to attend more to your motor component, the gait let's say, or the cognitive component, and that potentially causes problems in terms of doing these two things at the same time.

Melani Dizon:

All right. So, let's say somebody is not dual tasking. They're actually just, they're just walking, and they freeze. What has happened there?

Jay L. Alberts:

Yeah. So, unless you're walking in a space that's completely devoid of any stimuli you're still probably dual tasking. Right? So even as you're walking in your home, right, there's still information that you have to process, you're processing visual information and so there could be an overload there. But it could also just be related to sometimes there's a physical environment, right. A narrowing of a hallway. So again, you would say, you're not doing anything dual tasking, but that information has to be processed by someplace. Right? It has to be processed by in the brain. And so that processing of information is most likely then causing some disruption in the motor circuitry or motor activity and that's causing this freezing of gait.

Melani Dizon:

Okay. So, essentially, you're saying we are always, no one is never not dual tasking?

Jay L. Alberts:

Well, I mean, not never, but it's pretty rare, especially when you're walking, right? Unless you're, even if you're walking with your eyes closed, I think you probably, you've got other things going on there. So, it's very rare and that's why I think it's so important to be thinking about these things, right? We historically, always want to think about cognitive function, motor function, and that they are in these nice, beautiful little silos. Turns out they're not right? Even walking across the street. Right? You gotta process, at least in Cleveland, you have to process information of cars coming, do I avoid the pothole? How do I do that? Right. And so yeah, there's a lot of low-level dual processing going on.

Melani Dizon:

Yeah. I mean, and I think it speaks to the importance of making sure that you are, you know, to what extent that you can continuing to build your cognitive, you know, abilities and to not let that go, because that is going to come into something you might not normally think of as a cognitive thing that you're doing. It actually, the better you're able to keep that going, you might be able to process things better.

Jay L. Alberts:

For sure. Yeah. That's exactly right. They are intimately linked. Right. The challenge is that we don't always evaluate them using methods that are intimately linked.

Melani Dizon:

Okay. So, let's talk a little bit about that. What are some things that you do that does assess those things as a link and then what are some practices that people can do?

Jay L. Alberts:

Sure. So, we are right now, we're doing what I think is a super cool research project, looking at individuals with Parkinson's as they are walking through a virtual grocery store. And we are, that's why I used the grocery store example earlier, but what we do is we have an omnidirectional treadmill. So, there was a movie ready player one, a number of years ago, not that great of a movie, but had great technology. Anyway, with that treadmill, what you're able to do is you're able to walk and turn and you can turn in any direction. And so, we also think about, right, when do PD patients have problems? It's generally not just walking straight, but turning, right? There's a lot of data out there that suggests that turning causes problems. So now we can monitor them as they're turning through this virtual grocery store.

So, the real point of this is to create an environment that is very similar to what they experience on a daily activity. And it's under those conditions where we can start to identify when do patients freeze, right? And have these postural dysfunctions. Because if you think about it, most hospital systems, Cleveland Clinic being one in particular, most hospital systems want to have a very sterile environment, right? Very clean, not a lot of stuff around because I don't want people falling. I don't want people tripping and it doesn't look very pretty, right. The problem is that doesn't necessarily replicate how patients are reacting or responding and walking or living

in daily life. And so, the goal here was to create a virtual environment that we could safely replicate real life activities, and then observe the freezing of gaits and other dysfunction.

And if we can observe it, then that can help us treat it right? Because if you think about many people will talk about how medication is only marginally effective for addressing freezing of gait and postural stability, deep brain stimulation, I'm a huge fan, but again, right now it's only marginally effective at the treating postural stability, instability and freezing of gait. And so, I think we have a tremendous opportunity there because right now we still program, you know, DBS patients kind of the same way we did 20 years ago, despite some great advancements in engineering from a DBS electrode perspective and everything else. So, there's a tremendous opportunity there. So, what can patients do? We actually published a study in 2019 that showed that a type of physical therapy called multimodal therapy was actually very effective in treating, freezing of gait and reducing the number of falls.

So, I think, so what is multimodal therapy? Well, that's really practicing dual tasking, right? So, we had patients walking and spelling the word cat or some random words backwards. Right? And so, what it does, it gets you, as I talked about before you have these intentional units, if you will, and it gets you to practice under those conditions that, you know, are a little bit more challenging than a typical physical therapy session that may only focus on strength or range of motion, et cetera. So, I think that's one thing you can do is, you know, really practice doing some dual tasking in a very safe environment. And we, right now, we have a clinical trial that we're conducting that is looking at, you know, can we use augmented reality, which is, you know, different than virtual reality to help facilitate this training and treatment approach. And in that situation, we would send some augmented reality goggles home with a patient, and they could potentially do this remotely. So, we're a little bit away from there yet, but that's where I see it going, you know, and I think quite frankly, we are obligated to do that because we have to get, we have to get these treatments and therapies out to more patients than those who live in our zip code.

Melani Dizon:

Right. So, one of the things that I've noticed several different times is, this was very, very clear when we did an event with Sunovion called Little Big Things in Austin. That was, it had to have been 2019, but one of the things that was really interesting was a man came in and he was in a wheelchair and he couldn't walk really, like, he just, he couldn't get going and it was very dangerous for him to walk and one of the vendors that we had there were using poles. And he went literally from being in the wheelchair the whole day to standing up, getting poles in his hand, and walking back and forth, like with no problem. What... was it the poles sort of providing a focal point, like what what's going on there in terms of the freezing wasn't happening, the postural instability, he wasn't, what was happening?

Jay L. Alberts:

Yeah, no, that's a great, so yeah, maybe they were magic poles, like Jack and the bean stalk. Right. But I doubt they were magic poles. So, I think probably what was going on there is if you think about the poles, what he was able to do is he was able to increase his base of support, right? So, you normally, when you're on, you know, your two feet, you have a base of support and it could be relatively small in PD patients because of a whole host of reasons, both neurological, as well as more on the periphery. So, what those poles could be doing is just increasing that safety base of support for him, and could allow him to take those steps in terms of the freezing. That's a hard one to know in terms of what might be going on there.

Now, one thing that has been shown is that sometimes people will freeze when they're maybe off their meds, and then if they take their meds, they don't freeze as much, but they also have these potentially these levodopa induced dyskinesias. Right.? And there's certainly some data out there to suggests that even when people are walking while under these levodopa-induced dyskinesia, they're actually sort of, let's say, walking on the ragged edge in the sense that they're just moving. Right? And they just keep recovering and catching themselves the next step. And then when they turn, that's when they get into trouble and then will have a fall.

Melani Dizon:

Okay. Yeah. That's interesting. The other one that I've seen a lot is when they play music, they don't freeze like if they use headphones, right. They'll move more smoothly. And then sometimes, you know, you'll see people, I can't walk, but I can dance. Yeah. So, what's happening there?

Jay L. Alberts:

Yeah. That's a fantastic question. And that seems like you're probably pulling back some old memories somehow from employing the hippocampus or something there, it's a very interesting phenomenon. And I know there are folks who have tried to replicate that, and it's been challenging to then replicate it consistently. So, it seems like it's this epi-phenomenon, but I'm not sure of the exact mechanism there. However, what it does is it does suggest that there's something there and now what we need to be looking at is trying to figure out, right, this is that paradoxical kinesia right. So, what we need to be thinking about it, is there a way to understand that, and if we can understand and identify that mechanism, then maybe we can replicate it, whether it's through DBS or understand that circuit that's active, and then we could, you know, activate that circuit as well. So, even though that's an area that we don't know much about, it's an area that is certainly ripe for investigation and advancement.

Melani Dizon:

Okay, great. So, I wanna go back a little bit to DBS. So, for those of you who are, might be new to the community, DBS is deep brain stimulation. And I wanna talk about how deep brain stimulation does or does not impact postural instability or any of those freezing of gait, walking, any of that because I know people are gonna have questions about it. So obviously it's not a primary thing that that's gonna help. And you're not gonna go into your doctor and say, I want

this to be fixed and they give you deep brain stimulation, but what you said that we usually use the same, you know, the same triggers and stuff, what's happening, why is it helping some people, but not helping other people?

Jay L. Alberts:

Yeah, well, we still don't know the exact mechanism associated with deep brain stimulation. There are different hypotheses out there and we're getting close, but I think you know, as one of my, you know, mentors taught me, he said, when you've seen a hundred PD patients, you've seen a hundred PD patients, right. There's a lot of variability and a lot of uniqueness there. So, I think that's one thing. And the other is it's dependent upon the symptoms, right? Typically, DBS is very effective for individuals who have tremor, can be very effective for bradykinesia as well, and even rigidity probably in that order. And then the challenge is because gait, as we talked about before gait and postural instability is such a complex physiological and environmental situation, right? So, you've got the cognitive function, you've got the motor function, you've got the environment and you've got all levels of, you know, predictable, unpredictable, et cetera. So, we're sort of asking it to do a lot of things to control that. But I am an optimist and I think we can ask it to do that. We just have to use better or more clever ways to program the devices.

Melani Dizon:

Okay. great. Let's see. Why is it so important to focus on postural instability and freezing of gait in people with Parkinson's?

Jay L. Alberts:

Well, because people fall, and falls are bad right? Generally you, again, as we age our bone density diminishes, and we potentially become, I don't wanna say frail, but more frail. And you break a hip or even a collarbone. And what that is going to do is it's gonna be problematic by itself. Right. So, you have to treat that, et cetera, but it's the ripple effect, right? Because, okay, so now let's say you were exercising three times a week, whether you break your hip, you're not exercising three times a week, you break your clavicle, you're also not exercising three times a week. So now it just puts you on this path or this trajectory to almost accelerate the effects of the disease. I mean, it's probably not literally accelerating, but it's doing nothing to slow the disease. And so, I think that's where it's the activity, you know, the actual treatment of the broken bone or the whatever, but it's in these side effects or these you know, other issues that they're also problematic.

Melani Dizon:

Right. So, that gets me thinking about all of the different potential aids that people use. It could be a cane, it could be poles, a walker, all of these different things. And can you speak a little bit about the value of them for people who, you know, maybe they haven't fallen yet, but they're like terrified of falling and they do have a lot of freezing of gait. Is there a downside to using

them? And what's, you know, how do you determine what's the best thing for you and then what are the upsides?

Jay L. Alberts:

Yeah. So, I think there, you know, the first thing you should probably just consult, obviously with your physical therapist or a trusted occupational therapist to really have an evaluation to see. So, I'll give you my general impression there. So, you know, from a convenience factor, having a cane or a walker is always less convenient. You have to manage it. You have to remember it, right. You got a father-in-law who forgets where his cane is. And it's like, oh, well it's over here. Right. So those are things you have to do. But from the upside is it does give you that increased base of support. And it can give you a little bit of, can reduce the fear that you may have in terms of falling. And I wanna say that, you know, despite the fact that we were just, you know, lamenting the falls, you know, fear of falling itself, you know, I get it, right? But we also don't need to let the fear of falling sort of control our life.

And now I'm not suggesting to go hike, you know, up and down some Boulder mountain or whatever, but, you know, doing things that you can safely do is critical. And you know, if those, you know, assistive devices allow you to do that, then I think that's great. But I think probably the best way to evaluate it is to have a conversation with your physical therapist or occupational therapist to really get on the same page. And I think you have to advocate for yourself, not just looking at and just expressing or showing them what you can or can't do, but what you also want to do and what you want to maintain.

Melani Dizon:

Great. So, I'm gonna take a couple of questions from the chat, because they're related to what we're talking about. Somebody says, how does intent affect instability? Do you have any insight in working what you've worked with?

Jay L. Alberts:

Yeah, I guess we haven't measured intent. It's such an abstract psychological factor. But yeah, I would imagine, I don't know. That's a great question. We haven't really looked at that so.

Melani Dizon:

Well, there it is. It's out there, do some research, does LSVT big exercise program help with freezing?

Jay L. Alberts:

There are some, again, I haven't seen any data necessarily to show that but there are certainly some vignettes to suggest that they or people reported that it's helpful for that. And I think obviously they're focused mostly on, you know, big movements and amplification of voice. So.

Melani Dizon:

Yeah. Somebody says... in the mornings, I walk like a drunk sailor bouncing off the hall walls for the first five minutes. Is that what you're talking about or something else? I wonder maybe if that's like if it's the first thing and you woke up, you haven't taken your meds right? That could create some issues?

Jay L. Alberts:

Yeah. It could, it could be a med issue as well as some people get up and they have hypotension, right. So, if you ever get up quickly and this is more common in individuals with Parkinson's even if they're not getting up quickly, they may have this experience. And so, you get up and you're a little like that, that could also be orthostatic hypertension. So, I recommend you tell your neurologist that and let them let them know because there are things that can be done. One of the easiest, one of the things is ensure that you are really well hydrated.

Melani Dizon:

Right. Okay. Yeah. And drink cold water right before you get up and make sure you're well hydrated throughout the day. Somebody says, diagnosed with festination of gait. My feet just start running and I can't stop, diagnosed with Parkinson's 20 years ago. So, I'd love for you to talk a little bit about what that is, what festination of gait is. I know we get a lot of questions about that.

Jay L. Alberts:

Sure, sure. That is, you know, as I was sort of describing some of the levodopa induced changes associated with gait, very similar to festination, really it's these rapid small steps, and it's like, you're trying to keep you center of gravity in between your feet while the trunk is going forward and your center of gravity keeps going further and further. And so, you're like trying to catch up. And so that can be a real problem, obviously, especially because some people freeze and then they have festination. And so, you can imagine going from, you know, frozen, like your feet are glued to the ground to now they're, you're going like crazy trying to basically catch up. So that is, that's a real issue and a real problem. And I don't think we fully understand what's going on there. So, I would lump that into this postural instability and gait dysfunction that we need to continue to study it and really evaluate, if DBS or how we can optimize medication to prevent it.

Melani Dizon:

Yeah. What can somebody do? I don't know. Is that an aid? Is that...

Jay L. Alberts:

Yeah, that's a great question. I mean, the challenge generally is they, so, their normal, when they're not having festination, their normal gait may be good enough that you wouldn't think you would wanna give them a walker. Right? But when these episodes occur, a walker may be very helpful, right, to allow them to stabilize and to stop them slowing down, et cetera. But that's a very, it's a very difficult symptom to treat and can be very problematic.

Melani Dizon:

Yeah. Somebody said that they fall 5 to 10 times a day, because of freezing of gait. That's a lot, and so she wears knee pads a lot of the time, she's been wearing 'em for the past two years. She said her posture's great. And she's not super slow. It's just that you know, this freezing of gait happens and she's asking about, and someone else asked about a laser cane. What experience have you had with lasers, whether on shoes or a cane or that kind of thing?

Jay L. Alberts:

Yeah. Again, there are different studies out there that have looked at this and in general having a laser or even some people have a ball tied to the wrist or in their pocket or something. And so, what it does is it just provides some visual stimulus or stimuli that allows the patient to then start walking again. So again, the exact mechanism I think is under debate, but I think as a compensatory aid, it probably works like champ for many patients.

Melani Dizon:

Great. I think it's a great idea. This whole conversation is a great reason why working with a physical therapist is a really good idea. Even if you think, you know, everything else is going great, this is one of those things where if you are having freezing of gait, if you're worried about postural instability, you can work with a physical therapist and you can try out different things, right? So, you can be in a situation where you've got somebody who's got your safety in mind and when you're walking, hey this is sort of when this usually gets triggered, they can help you use a walker. How does that work? You know, they can teach you how to use the walker effectively, they can teach you how to use a cane most effectively or walking poles. We're gonna share a bunch of links in the post event email.

We have, we did a whole video on urban poling. We've got a lot of people that are using poles to help with freezing of gait and really to help continue to exercise when they're worried about falling. This is just something that helps them keep going. Somebody did put a question in about Parkinson's ability, does it ever inhibit healing for people? Does Parkinson's play a role in that versus you know, their non-Parkinson's peers?

Jay L. Alberts:

That's a great question. So, I mean, certainly there are data to suggest that overall life expectancy for individuals with Parkinson's is less than a healthy peer. Some of that could be due to let's call it a lack of healing or it could be a, some microglial response or even some other inflammatory response or issue. So, but let me go back to your PT comment as well. I think I, one hundred percent agree, but what I would definitely encourage people is they still have to advocate for themselves and really push to make sure that your goals are clearly communicated to the therapist so that they can treat you in a very specific way as opposed to right, a general, oh, okay, here's our general therapy for PT that we're using today, that everybody uses today.

Right? You have to get very specific, and you want to say, hey, I'm a new patient. I want to do X, Y, and Z. How do we get there? And you have to advocate for yourself.

Melani Dizon:

Great. Somebody has a question that I think you're gonna love, can cycling help address gait and postural instability? And he says, I'm on Dr. Albert's EVCC Pedaling for Parkinson's team.

Jay L. Alberts:

Ah, very good. Excellent, great to see you virtually. Yeah, no. So that we have data to suggest that cycling does, in fact, improve gait, certainly gait speed. One of the, you know, people report that it comes back and improves freezing of gait. We are measuring that objectively in our current cycle trial, cycle two trial, where we have a Peloton bike in the patient for a year. And so, we're looking at all of these measures in a much more rigorous manner now. So, for sure.

Melani Dizon:

Great, great. Somebody says Nordic walking works very well for a number of PD individuals I work with. Yeah, absolutely.

Jay L. Alberts:

The other thing on Nordic walking and slightly, sorry, I don't wanna derail, but you know, we've heard different individuals say they will walk with their spouse and each one of them will hold the end of a golf club and they'll be, you know, walking one behind each other. Right. And then that person helps facilitate the arm swing. Right. And so that's another thing you can do that's just, you know, with the poles or with some old random golf clubs. Again, to keep these arms moving. Right. Because your arms are driving the legs or are certainly in parallel with legs, so.

Melani Dizon:

Right. Yeah, absolutely. And somebody else said something about a metronome. I forgot to mention that some people have found success, they'll put a metronome in their earbuds or something. And then it helps them move. It's not a hundred percent, but some people have found it really, really helpful. Somebody is a general physical therapist, or do we need one specific to PD? And my saying is always, hey, if you can find somebody who specifically knows about Parkinson's the better. I also know that not everybody with Parkinson's lives in a community with somebody who's, you know, specific, but the really great thing is, you know, most physical therapists, which is true of occupational therapists and speech therapists. If you come to them, they're there to, they wanna help people and they will read up and they will do research and you can send them to the Davis Phinney Foundation, to Dr. Jay Alberts, there's lots of different people that are working with people with Parkinson's. And you can educate them if you're willing to put in a little effort and help them help you. So obviously it would be great, but I wouldn't stop seeing a physical therapist just because they're not a specialist. If you feel safe

with them, if you feel like you have an open door to communication and if they're open to learning. Any suggestions for a hunched back?

Jay L. Alberts:

Ooh, that's a great one. So again, I would start with core exercises, right? Our core is critical for maintaining the good posture. It's also very critical for moving in bed, getting in and out of bed, all of those things. So, I would start with the core and then I would very much again, it becomes a bit practice and trying to just remind yourself, and again, we talk about attention units, right? You're going to have to have cognitive attention units to remind yourself, to try to have a straight posture there or upright posture. But, I would start with the core work because without a strong core, you know, your posture, you're just gonna collapse in on yourself.

Melani Dizon:

Yeah. Okay. And speaking of core, have you done much research around strength, weight training, and strength training for people with Parkinson's?

Jay L. Alberts:

Yeah, we haven't done a lot of that. We've been mostly doing the air over training mostly because Charco the grandfather of neurology probably rightly very early said that, you know, Parkinson's people, it's not generally having a deficit in strength. Right. And I see a lot of PD patients and I, you know, you shake their hand and they have very strong grips. Right. So, it's not like they can't grip it. But they have a challenge controlling it, right? So, you think about when you button your shirt, you never are buttoning your shirt with your maximum force. It's the control, it's the smoothness. And so that's where we haven't seen a lot of changes in, the literature would probably support that, but the core I would argue is a different situation there.

Melani Dizon:

Yeah. and I think one thing is while they're probably not, I mean, we are all losing muscle mass as we get older. And whether you have Parkinson's or not, the stronger you are, if you fall, you'll be in better shape. You'll be able to catch yourself better. So those kinds of things are better. It's not necessarily gonna be like, oh, I'm gonna do that. And it's gonna eliminate all my problems, but downstream, it might have some...

Jay L. Alberts:

Yeah, same with flexibility.

Melani Dizon:

Right.

Jay L. Alberts:

Trying to have some flexibility.

Melani Dizon:

Yeah. And when we were talking about the, kind of went down through the healing and you made a lot of those points and then the other point is that if you get hurt by falling through freezing of gait or postural instability or something like that, and then you hurt something, it's also another downstream effect, right? Like if you can't do your exercises, then yes. You're actually, like, I know if you fall and like hurt your knee or your back, and you can't do the exercises to get better, then that's just not gonna heal. That's true whether you have Parkinson's or don't. And so, because people are with Parkinson's are, you know, more compromised than other people in terms of moving it's even more important. So more important to kind of do everything you can to prevent falling and to prevent those injuries. Let's see. Can you retrain your brain to address freezing, and is it better to exercise when you are on OFF time to address freezing? That's an interesting question.

Jay L. Alberts:

It's a very great question. So, can you retrain your brain? You certainly can retrain your brain, right? Because there's plenty of people who have had a stroke and then they re-learn how to tie their shoes or something. Right. So, there's plenty of data out there to suggest that there's neuroplasticity, and remodeling of the brain. The question is, can you do that then to overcome freezing? I think we've shown a little bit in some of our data that you can certainly improve gait and postural stability with this training. And we think that we're actually changing brain function with those interventions. But I think to me, that's a great question because before we can start to train, to overcome freezing of gait, we need to better understand it and figure out when it's being triggered so that we can then create that intervention. And so that's what we're also doing here. We have a study that is actually, we'll be recording from the brain while people are walking through our grocery store and a home environment. And then we'll potentially, we're hoping to elicit some freezing so we can evaluate the, really characterize the neural signature of freezing. And then we can start thinking about how do we change that signature?

Melani Dizon:

Great. Thank you. Gosh, we have so many questions coming in here. Let me see.

Jay L. Alberts:

I saw someone ask, can we define freezing? A quick way to define freezing is really just it's the feeling that your feet or your foot feels nailed or glued to the floor and you can't move. It's really a combination, it's similar to akinesia, which is the difficulty initiating movement.

Melani Dizon:

Great. Thank you Kimberly. She says, Parkinson's Wellness Recovery maintains a directory on our website of therapists and fitness professionals we have trained. We have access there. So, you guys can look at that. We'll also share that in the show notes as well. Let's see, we talked a lot about the key strategies. Oh, this is a question that came up earlier. It's a very common question. First of all, when we talk about exercise to improve Parkinson's and probably freezing

of gait and postural instability, how much is enough and then is there such a thing as too much?

Jay L. Alberts:

Yeah, great question. So, we're always looking for the minimum dose, right, to get the maximum gain and I get it, I do the same. So, I think, you know, for what we would suggest as well as others around three times a week for high intensity or moderate intensity exercise, and then, you know, sprinkle in those other days. Some flexibility training or strength training, again, to maintain or to decrease the effects of aging and PD on loss of muscle mass. But, and that sounds, so I think it's like 150 minutes a week, so that's a lot and it sounds overwhelming. And I get it right, and guess what, the vast majority of healthy Americans don't even come close to meeting the exercise requirements either. But this is what I would say is I would say what you have going for you as an individuals with Parkinson's is that, you know, that exercise is actually going to be beneficial.

And so, you are taking this exercise as medicine and it's actually going to be beneficial for it. And I guess maybe the other people know it. But they don't, aren't quite as motivated. And so, I think it does take time, block it out, figure out the time, have a partner and, you know, some accountability in the community, cetera. Then to your other question, is there too much exercise? Certainly there could be, right? So, the biggest issue there isn't necessarily what we think of like high endurance athletes to overtrain, it would be more of like a musculoskeletal issue. Like you're overdoing it and you're having some joint problem because maybe you haven't been cycling or doing the walking, et cetera as you have in the past. Also you may have preexisting conditions or age related conditions right, because now you're starting to, you've got asymmetry in your gait, so you have a hip issue and it's only making it worse. So that, so there is that balance for sure.

Melani Dizon:

Great. And then high intensity, is this perceived high intensity? Is there a very objective mark people should be looking at?

Jay L. Alberts:

Yeah. Yeah. So, there's probably, there is some objective marks, but those are data that you probably aren't ever gonna collect. Right? Like your heart rate or things like that. So, what I say is, if you can have a conversation with your partner, then you're not working hard enough, but if you could answer questions, you should be able to answer a question, but you shouldn't be able to recite the Gettysburg address. Right. You should be able to say, you know, who delivered the Gettysburg address, Lincoln, and let's move on. Right. So, like two- or three-word answers. So, yeah.

Melani Dizon:

Great. What are some things aside from, let's say too many stimulus, too many inputs, what are some things that people might be doing unknowingly to increase their fall risk?

Jay L. Alberts:

That's a great question. So, we have data now that we're collecting. And I think it's probably what we actually see is a high incidence of falls. While people are doing everyday tasks in the home, as well as getting in and out of a car. And so maybe you are, you're very comfortable in those situations. You're very comfortable in those environments. And that could sort of put you at a little bit of risk because of just how you have this perceived comfort. And again, you're not paying attention to things. Interestingly enough, our data right now, we're suggesting that, you know, we think intuitively we thought, oh, I bet people are gonna fall a lot during the use while they're showering and using the bathroom. Right. Cause it's in the slippery area and everything else, turns out there's not many falls during that because, and I would argue that either we've done a really good job of teaching people, how not to fall there, or people are aware. Right? So, I'm very aware when I am getting out of the shower in some hotel or something, is this floor different? Is it slippery? What's going on here? And so, I think that level of awareness, now, hopefully you don't need that level of awareness for everything, but I think certainly in some of these routine activities need to be a little bit more aware.

Melani Dizon:

Yeah. That makes perfect sense. Somebody's asked about, I don't even know, I feel like I heard this when I was younger, but are there people that can teach you the right way to fall?

Jay L. Alberts:

Oh, for sure. Look at the karate people.

Melani Dizon:

Right.

Jay L. Alberts:

No, seriously they fall, right, so my wife did ki-do, but they really learned how to fall. And so that actually is a great idea is that you think about, and maybe you go I haven't thought of it until then, but till now, but maybe you learn how to fall from a Tae Kwon Do or karate type instructor. Right. I think that's very valuable. That's a great idea.

Melani Dizon:

Yeah. Great. Let's see. Somebody says, there's running marathons and completed triathlon at age 77. Now at age 80, I can't get to 80 rotations a minute in pedaling for Parkinson's. Should I find something else to do?

Jay L. Alberts:

I don't think so. I would still go, I don't, you know, we also have to realize that you know, we came up with 80 to 90 RPMs, it was really based on our experience on the road. And then some of our other data, you know, help support that. However, now, as we see more Pedaling for Parkinson's programs and some of our other data, it turns out there's probably not a magic cadence between 80 and 90. It's probably a bit lower, probably closer to 73 to 75. That seems to be the ideal cadence. So, you know, again, this is part of science we just learn and it evolves. And so, we hope to, with our new trial have a much more precise prescription for that.

Melani Dizon:
Great.

Jay L. Alberts:
But don't, don't get off the bike.

Melani Dizon:
Right. Don't get off the bike. Another bike question, but real quickly, Erin says, yes, learning how to fall is amazing. You can use poles or blow-up mattresses to practice, or you can go to a trampoline park. Yeah. There's trampoline parks all over the place. That's kind of fun. Someone says, is road cycling dangerous or beneficial?

Jay L. Alberts:
So, I never encourage someone to necessarily go out on the road because I mean, I ride on the road and it's dangerous, inherently dangerous because you have cars, potholes, other things. In Ohio, you have deer and raccoons to watch out for in the morning. So, I wouldn't recommend that because unless you're very skilled at cycling and have a history, whatever, but I think you can get the same benefits without the risk by doing indoor cycling.

Melani Dizon:
Yeah, absolutely. A couple people have talked about boxing as helpful for obviously for, you know, balance and those kinds of things. Somebody said that they were boxing three times a week and they were falling so much that they were told not to come back. I think in that case maybe working with a physical therapist or finding some avenues to box that are not gonna impact another person, right? Like you can also use just the stationary...

Jay L. Alberts:
Well, you could lower the speed bag down and you could sit on a chair. I mean, I think boxing is fantastic in the sense that, you know, and it's very humbling. I have a speed bag in my basement, and I thought, oh, I can do like Rocky. Right. You know, we've also the Rocky movie and that's easy. And it's very humbling. Right. And so, I think it's a great thing in terms of being able to you know, have that coordination and it sort of forces you in some ways to go faster.

Melani Dizon:

Right.

Jay L. Alberts:

So.

Melani Dizon:

Go ahead.

Jay L. Alberts:

Find a different gym. Don't let him kick you out. Tell him to figure it out.

Melani Dizon:

Stairs. What about stairs? Is this something that might increase the chance of freezing, decrease it? Anything happening there that people should be aware of? I mean, I think it's one of those things that people are gonna be like, I don't wanna keep going up and down the stairs. I'm gonna look for a place that's a one level, because I don't wanna deal with the stairs. But just in general.

Jay L. Alberts:

Yeah, sure. I think the most common time when they freeze around stairs is at the top of the step. And then just before going to that first step down the stairs I don't know of a lot of freezing going up to steps necessarily. It's usually down because there's also an emotional and excitability component that's associated with freezing, right. As your emotion or as your excitability increases, probability of a freeze also increases. Right. So, it's the classic even like if you, the doorbell rings and you're trying to get to the door quickly, that will sometimes trigger a freeze. So again, I think you have to be very aware of stairs and certainly use the railing, et cetera. Yeah, that's the big thing.

Melani Dizon:

Yeah. Use the railing and make sure there's good lighting.

Jay L. Alberts:

Yeah, for sure.

Melani Dizon:

Yeah. I wanted to just, oh, shoot something, oh you touched on it that when somebody's anxiety or when they start to start getting worried about something or excitability about I'm going up here, then things can get worse. Can you talk a little bit about that in terms of not just the person with Parkinson's, where they're starting to feel anxious and so they're falling more, they're freezing more, but also the care partner who's with them, what are some things that both of them can do to, you know, kind of get them to a place where they can calm down and start walking a little bit more smoothly?

Jay L. Alberts:

Yeah, sure. So, I think the first thing is understanding your environment, right? Trying to do things in a common environment. And, but you can't always do that. Right. So, you're going to go to the grocery store and that will be potentially anxiety provoking. So, what I would recommend is that it sounds odd, but it's okay to be a little selfish in the sense that it might take you a little more time to run the ATM or not the ATM, but the credit card checkout thing or whatever than some 17-year-old. But that's okay. You've earned that time and don't feel that anxiety. You know, you're probably more internally anxious about that than external because you know, that 17-year-old behind you, they're checking their Instagram or some other goofy social media thing, so don't worry about it.

Melani Dizon:

Right. So, a couple of you have asked about theracycle. Can you talk a little bit about what it is? How is it different than some of the other cycling things that we've talked about and its effectiveness?

Jay L. Alberts:

Sure. So, theracycle is a semi recumbent cycle that has a motor on it, has an electric motor on it. And that electric motor helps facilitate your movement and you can set it at whatever RPM or cadence that you would like. I haven't seen the most recent version of the theracycle in terms of what it's monitoring and measuring. I know earlier versions didn't really have good feedback in the sense that you put the motor on and you set it for 80 RPMs and it would just jiggle your legs about at 80 RPMs. And that's not really forced exercise and that's not really exercise. Right. That's like those old commercials with the heavy woman who had that belt and they tried to shake her, right? That wasn't effective. So, I'm not sure about any new data that's come out from theracycle.

Melani Dizon:

Okay, great. We'll also share the link and so that you guys can find out what the latest and greatest is on that. Okay. So, we've talked about so many different things. I would love for you to share some of the best success stories you've seen in working with people who've had bad postural instability, a lot of freezing of gait, and now they have it under control. What are some of the things that they're able to do actually in their life now that they couldn't? And then what are some things that they were like, oh, this is what helped me. This is what I do.

Jay L. Alberts:

Yeah. So, you know, there are a couple. One, you know, there was a woman who was having a lot of problems going to the grocery store and she was, in some ways was an inspiration for us to develop the virtual grocery store. And then after this multimodal therapy where we were able to help her, you know, dual task better, she had a much more enjoyable experience or not an anxiety provoking experience at the grocery store. And I think the other one that comes to

mind more recently is with our augmented reality trial, we've created an avatar, a digital physical therapist, if you will that's presented in the goggles for the HoloLens, and we've named her Donna after my mother. And I think what's really cool is that you said, you know, as I'm walking down my driveway to get my mail, you know, well, I'm able to get my mail now. And I hear Donna's voice saying, you know, long steps are, you know, move your arms or things like that. And so, these little cues are reminders. And I think that those are probably the two that are most top of mind.

Melani Dizon:

That's great. Yeah, that's something we haven't talked, we talked about them but not with a specific word of cuing. And I think that's something great for people to check out, you know, you can use tape on your floor as a cue to like, oh, I'm gonna step over this. Or we talked about cue in the laser in the shoes, in a laser cane, we talked about the metronome, trying music. So, these are all great, no cost things that people can try to help with their freezing of gait. And I think that's really exciting. Does anybody have a final question before we take off? We'll talk about PD stiffness and rigidity and joints as sort of the more general topic, we'll talk about that at another time. We also have lots of webinars about that, but anything around one last question on freezing of gait or postural instability? Okay. Yes. Great. I've heard about this. What about a gait belt?

Jay L. Alberts:

Yeah, so gait belts are very common in physical therapy or any type of intervention, and they're just simply a belt that someone wears and the, it gives the therapist or even a care partner, quite frankly, the ability to hold onto it pretty well to assist them in terms of maintaining a posture or if they are starting to fall, back to our conversation of falling, helping them to have a more controlled fall. So, it's not a potentially injurious fall.

Melani Dizon:

Great. Dr. Alberts, I so appreciate you taking the time. I know that people really appreciate answering all these questions. They don't get a lot of time with a real expert like you, so it's super helpful and we'll share the recording of the audio, video, and transcripts and everything with everybody. So, thanks all for being here and thank you to our sponsors, Amneal, Kyowa Kirin and Sunovion for making this possible. If you have any questions for me, or if you have any questions about this topic that you wanna make sure that we do a follow up, or we share more information about, please just email me at blog@dpf.org, and we will see you at the next one. Thanks everybody.

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