

**The Latest and Greatest on Boxing and Parkinson's
Live Well Today Webinar Series**

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Davis Phinney Foundation

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We are here today to talk about all the things related to boxing and Parkinson's. We're going to talk about what is boxing for people with Parkinson's, like what a class might look like. If you're new and boxing curious, we're going to talk about the research that's been done, some of the research that hasn't been done, research in the pipeline, and all of the things that would help you if you're just getting started or if you want to get even more out of boxing. My name is Melani Dizon, I'm the director of education and research at the Davis Phinney Foundation. I am here with Josefa Domingos. She is a member of our Science Advisory Board, and John Dean who is also a member of our Science Advisory board and they are married. Hello! We're so glad to have both of you here. And Sara Riggare, who's from Sweden, and she's calling in from Sweden, and she's going to, she's done a lot of work in this world of boxing and Parkinson's, so she's going to have a lot to share, and we're really excited to share that work.

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Okay, I'm excited to get started, I would love for you guys, for the three of you to introduce yourself just tell us a little bit about you know who you are, where you work, and how you got involved, or interested in the world of boxing in Parkinson's. I know that it's not the only thing that all of you do, but sort of where your interest comes with that. So, Josefa, let's start with you.

Josefa Domingos, MSc (Member of Davis Phinney Foundation Science Advisory Board, Physiotherapist, specializing in Parkinson's):

Okay. Hi everyone, I'm very excited to do this talk because we can see all the responses, so I am a physiotherapist specializing in Parkinson's and I'm working at the Portuguese Parkinson Association in Portugal.

I do travel and obviously have the international connections, because I think it's very interesting if you work in only Parkinson's that you know what's happening in the world. I would say that boxing came into my life in a very particular and funny story which is I actually had an argument with my former boss.

So I go down to the gym. And I was so irritated, that I started punching the equipment that we just bought right so, and suddenly it hit me it was like my aha moment for boxing it's like wow this is such a queuing kind of training strategy right, so I just immediately fell in love with it. So I think in terms of how it can help me as a physiotherapist in what I'm already doing, it's really interesting, so I'm happy to share those experiences with you.

Melani Dizon:

Excellent. Thanks. John?

John Dean, MA, CCC-SLP (Member of Davis Phinney Foundation Science Advisory Board, Speech Language Pathologist, specializing in Parkinson's):

So I'm John Dean and I'm a speech language pathologist and I also specialize in Parkinson's. I split my time between the states and Lisbon with my wife and I actually, I remember the first time I saw or heard anything about boxing up close I had been aware of, you know, the Rocksteady program but Rick Schwartz who was on the board at the Parkinson association of the Rockies was talking about walking out the door from a meeting and said I'm going to go with my boxing instructor.

And a couple months later that turned into a class that we all went to on Saturdays with Anthony Moor on just started growing from there and it turned into a program that's actually locally, pretty popular in the Colorado area. A lot of our people we know teach it. And it's been great. I do agree it's a very great motivational and it's good queuing and there's a lot to it. We enjoy it a lot, it's not all we do, but we enjoy it a lot.

Melani Dizon:

Great, thanks John. Sara?

Sara Rigarre (Engineer, Doctoral Student at Karolinska Institute, Person with Parkinson's):

Yeah, so I am a person with Parkinson's disease, and I've had Parkinson's for over 35 years. I had my first symptoms in my early teens around age 13 in 1984 I turned 50, in February, so I've been, I've been having it for a long time.

And I met John and Josefa, I actually don't remember who I met first but around to 2013 2014 somewhere, different meetings. In Montreal, yeah, so that was 2013 yeah and that's also actually where tried boxing for the first time for Parkinson's because the Rock Steady Parkinson's people were there.

So that was fun. And I wanted to, I live in Stockholm, Sweden, and I wanted to get to start having boxing here as well, but there wasn't anyone doing boxing for Parkinson's. So I sort of lost hope a bit but then one of the boxing clubs in Stockholm actually contacted me, via the Parkinson's Association and wanted to get a boxing class started and so I contacted Josefa and said why you don't you come over and we'll teach them how to do it. Actually before then I had

been through some Rock Steady boxing classes on my travels, I'd been to one in San Francisco a few times, it was if it was really really fun.

Melani Dizon:

Okay, great. Um, before we get too far into the research, I'd love to help set the stage for people who are curious about boxing it's something that maybe their support people in their support group their friends have talked to them about, they go to Rock Steady boxing or another boxing class during the week and they're curious, but they're just, they don't know what to expect.

Can you talk a little bit about what is it, you know, I don't want to say like level but like should somebody be in good shape? Does it matter? Is it all levels? What happens when you walk in the door? What does a typical class look like?

And, yeah, let's just start with that. Does somebody want to jump in, somebody who kind of loves talking about that piece.

Josefa Domingos:

Yeah, I wonder if Sara if you want to explore maybe what took you to do that, the boxing, and when you did your first class because I think all three of us will have different experiences on that? And then I might build on it.

Sara Rigarre:

Sure.

So what attracted me to boxing is the, the craziness about it really, I mean it's so counter intuitive, you get boxing, you get Parkinson's from boxing, so why would you do boxing for Parkinson's? And the sense of doing something that's not expected from a person with Parkinson's. And I've heard that for many people saying, when I'm doing boxing, I don't have Parkinson's, I'm a fighter, so it changes the mindset.

It really does because if you get the confidence to achieve something that you didn't think you wouldn't be able to achieve. You grow. So that's what attracted me the sort of the contrast of it all.

Melani Dizon:

Yeah, that's interesting. I've never heard that before. So what is a class like when you walk in, and you're somebody with Parkinson's? Let's say you walk in and you know you're, you're alone. You are going into a gym for the first time, what is likely to happen?

Sara Rigarre:

So for me, it's been very different in different places, so my first thing would be you need to find a trainer that that knows a bit about Parkinson's, otherwise it won't be any good. They also need to know a bit about boxing but it's more important to know about Parkinson's that they know about boxing because boxing, they can learn.

Parkinson's is more difficult to understand I think if you if you don't have a background in in physiotherapy or similar. What would you say about that, Josefa?

Josefa Domingos:

Yeah, I'm already biased by what I've learned from these experiences in the way I'm doing it now so it would might it might not be the typical class right. So if we go to, I would say the only research and we have we have a 15 minute warm up that's usually based off movement and stretching. So, for people to get an idea of what would happen.

And then you have circuit training where people go around in different stations doing exercises. And then you have about 15 or 20 minutes of cooldown. This is usually the normal format of a boxing class.

And I'd say, I'm biased by the experiences that I've had. I tend to see that the places and the research that we did, we actually found out that the part of the classes that people like most was actually the warmup and cool down, which is an actually an interesting discovery, because like what's happening there. Oh, that's the moment where they're all together. Right, so it's really the group is the glue right and the bonding and that's where you all going through it together.

So what I've done with that knowledge is basically the section of boxing that I'll do will also be in a group, which makes it really hard on me right. Because, of course I have smaller groups and I think that's that's the difference, it really depends on, what happens in a class really depends on the people that are doing it the instructor the knowledge that they have, and their goals.

Melani Dizon:

So, one real specific question.

Some people ask, does it hurt? So can you talk a little bit about, is it contact? Are you punching a bag? Are you punching another person? What's happening in the class specifically?

Sara Riggare:



So you're never punching another person, you're punching against, their sort of mittens or in some cases, but not against other people with Parkinson's because then things might happen. So you punch against this sort of, whatever they call it. Pads, right, that other people hold.

Melani Dizon:

So, you're punching the coach's hands?

Sara Riggare:

Yeah, and bag. And the air of course, punching air is also fine.

John Dean:

Shadow boxing

Sara Riggare:

Yeah, shadow boxing

Melani Dizon:

Yeah, I just wanted to make sure you know since people have asked, does it hurt?

Josefa Domingos:

I can comment on that which is if you have those true boxing, you know, Boxing Club, which was the example of the program that we implemented. The boxing bags are really hard. And so they might hurt. It's not supposed to, no therapy no exercise is supposed to hurt right.

Sara Rigarre:

Except afterwards. Muscle soreness is fine.

Josefa Domingos:

So I would say so we actually saw what people preferred and the pads were the preferred ones because the instructor can meet you halfway, so you actually think you really bunch really hard.

But so you can engage people and even if people are having a lot of difficulty, to not get frustrated, we can meet them halfway. So even like situations of MSA or other Parkinsonisms, we can motivate them with boxing.

Melani Dizon:

So one of the things that I went to like over three years ago when I joined the Foundation, one of the first Parkinson's classes I went to was a boxing class at the corner boxing gym in Boulder, and I was amazed. I was like, oh gosh this is incredible. One of the things I noticed though was that there were a lot of volunteers there. So a lot of the people who went to go take the class, their, their care partners came with them their sons, daughters whatever and then they were volunteering in the class they were helping people put their gloves on. They were, you know,

letting people punch them, is this something that's normal in boxing classes, you know everywhere?

Because I just imagine somebody going by themselves, and being like, how am I going to, how am I going to manage all of that stuff if I have difficulty? So can you talk a little bit about that?

Sara Rigarre:

So the club in Stockholm is actually a regular Boxing Club, but they had started with something they called the Gray Panther, so they had over 60 boxing for non-Parkinson's people.

So then they want to start Parkinson's boxing and then these Gray Panthers actually are the volunteers in the Parkinson's class. So some of them are sort of extra coaches and help with that. They then learn a lot about Parkinson's in doing it as well.

Melani Dizon:

So in a Rock Steady boxing class, are there typically a coach and like volunteers or is it, no, it's usually just a coach and the class?

John Dean:

We gotta be careful, because I'm not trained in Rock Steady but what I've seen is they do have a lot of help, in the same way in the center of boxing. I have to say I went to that boxing program quite a few times back when I was living in Boulder and I think their pedagogical, their training and instruction is quite solid, but they do need to have a lot of volunteers to be able to handle the quantity of people and some people need additional attention. So yeah it's big part of that I think. We definitely had it down in Power Punch with shield down in Denver.

Melani Dizon:

Yeah, somebody, one of the coaches says, our Rock Steady classes we split our groups into two levels, one two and three and four. So I guess it's going to depend. I just wanted to make it, you know, possible for people who are curious about it and to give them all information we can. So you'll be taken care of. If you're going to a Rock Steady boxing class, the chances of that you're going to be taken care of and they're going to be aware of your level and they're not going to push it too hard, is really important. We're going to talk a little bit about safety a little later on and we're also going to share some tips on how to make sure that you're vetting the place that you go so that you feel safe, and it's a safe environment. So we'll talk a little bit about some of the questions that you can ask the trainers to make sure that you're in the right place.

Sara Rigarre:

If you want to see what it looks like, you can check Josefa's background when she's in the spotlight because those are pictures from the boxing class in Stockholm.

Melani Dizon:

Somebody asked if you need your own gloves or other equipment, or is this typically something that are at the gyms for people?

Josefa Domingos:

I would probably suggest it. I'm sure the boxing clubs have them. But if you go, once you try it and you like it and you're going to stay, I would probably recommend in terms of hygiene and safety, that you have your own.

I don't know how much they cost in the US but I'm sure it's feasible to buy one. I usually tell my people that I work with to buy theirs.

John Dean:

You're supposed to bring your own wraps.

Melani Dizon:

Right. Let's talk a little bit about the benefits to the motor a non-motor symptoms of Parkinson's and if you could speak a little bit to dystonia, a lot of people have talked about how they have such terrible cramping, in their hands and feet, that this just seems really difficult. So can you talk a little bit about those benefits and then some of the things to look out for?

Josefa Domingos:

So we would be referring to the fact that they do it and then they have these cramps? Just to clarify?

Melani Dizon:

Part of it is the cramps getting in the way.

Josefa Domingos:

Because I would imagine that whatever you're going to do in the boxing club has to mimic something that you're going to do in daily life right so it's like if you're going to walk, you're going to sit and stand, you are you are using your arms, and if that brings on the dystonia so I think it really deserves an assessment on his own to understand in what situations does it come on? Then it's distinguished between, you know, dystonia is a complex, it could be morning dystonia, right, it can be exercise induced. So I'm not sure if I can answer and we what we know is from subjective reports that people, their tremor tend to decrease but there's no official publication on that, results on that.

So and this might be an influence maybe on the information that we are receiving in our hands and have an influence that might also, I would say, have some influence over dystonia but we have no data on it so I can't really base that on any experiences. I think if I had someone that, that he was cramping up I probably wouldn't be boxing with that person, I'd probably try something else.

But you know, working in this area, you get surprised. So I never like to say no.

Sara Riggare:

And also it can be related to, if you improve medication, you might be able to reduce the cramps and you might be able to go boxing, it's a mix of everything I would say.

Melani Dizon:

Right, yeah. So let's talk about some of the benefits.

Sara Riggare:

It's fun, which is the most important, important factor for doing it for doing it.

Josefa Domingos:

And going off of the fun actually, the fun means that you will do it, ongoing, and what I think what I like about the boxing, it's actually a nice ongoing strategy for exercise, it motivates people to continue exercising.

Because we know that people can have periods of rehabilitation physiotherapy speech therapy, but we need people to be able to continue active in their communities close to their homes, because one of the barriers of people dropping out from this from any exercises is if it's too far away from their houses right. And this is actually the solution that Sara was finding an ongoing problem that she needed to do exercise, so it's I think that's the best benefit of it.

What we need to realize is how can we make it better so that we also have clinical benefits right and clinical benefits that have been shown in one RCT only as we were talking earlier. The research is still not there. That doesn't mean it won't have benefits, but we can't prove it yet in terms of of clinical studies, but they are coming.

And I would say that the benefit would be obviously the aerobic component was the strongest benefit that we saw so the fatigue, rate of improvement in endurance, and you can see the component of how boxing is so aerobic right?

It grabs onto everything; it grabs onto the aerobic component it grabs onto the balance as well because you're challenged at all times of changing directions as well.

The transfers, negotiating all these busy environments, the dual tasking is obviously very present in the boxing that's also one of the great reasons why I like it. And then the overall benefit of the ongoing exercise will probably have some connection with the non-motor symptoms like sleep and and so on. Right.

Melani Dizon:

Sara, can you talk about that research, the RCT? The one that we were talking about, can you give a little bit of background what it was, who was in the study?

Sara Rigarre:

I don't think I know about that study, in particular, but Josefa and I, we did this small study out of the program in Stockholm that we that we started, so it's more of a pilot or a feasibility study.

Melani Dizon:

Okay. Can you talk about that?

Sara Rigarre:

Sure. And Josefa, you'll probably have to fill in because I probably don't, but it was based on assessments that we did prior to starting as well as follow up to see the feasibility and the acceptability of the program in the community-based program. I think we had about, 20/25, people participating.

Josefa Domingos:

26 people that registered for the workshop, so we had two sections which was the workshop, and which was the teaching component, and this study was about implementation of the program.

So testing feasibility and satisfaction and the one that I was mentioning before was actually the first RCT that was published in 2013, so it's the only one we have at this moment. Stephanie Combs.

And then we did an implementation study, so it was really to highlight these types of components these questions of do people, why do they register, what needs in terms of educational needs do the boxing trainers need?

The amount of people that would register the adherence. We had, the outcomes were more subjective in terms of that, so our focus was really how to to implement it and give it as an example, and also create some educational tools that come along with the paper and I think that's probably the most important contribution of this paper is the outline where we make some recommendations about who you should be choosing, things that you should be adapting in boxing, identifying red flags, identifying fluctuations. So if somebody comes in and they suddenly they have an OFF period, what are you going to do, you're going to send them home?

You know, so how are we going to manage these situations? How to help someone to get out of the OFF period to assess it, to understand if it's medication related, if it's just anxiety related and then maybe use some strategies to bypass that.

So this is all components that are in an outline that comes with the paper. I think if people are interested in it, I think it was a positive contribution.

Sara Riggare:

And that program is still ongoing in Stockholm as well as it has spread to I think at least 20 other places in Sweden. So it's really taken off.

Melani Dizon:

Great, we will share that paper with everybody too. So, Josefa, can you talk a little bit about the RCT? Do have information about that that we can share?

Josefa Domingos:

Oh yes, I think I mean anyone that's the first publisher on any area is really breaking ground there, so they have the merit of always being the first to be able to prove that we're not all mad that everybody likes us.

And the first time I discussed this with the neurologist he literally looked at me like I was mad because I was talking about boxing and obviously boxing is associated to violence.

And so, people tend to look at it, and I think there's still a resistance in bringing it maybe into the scientific world because of that. But because people are enjoying it so much.

This is making a lot of noise right so I think now there is a clear need that we need more research in it so that we can improve these programs. So that first study, it was also in a community setting but they actually completed they did a pilot study with six people in 2011, and then in 2013 they did the RCT, which is very excellent work in terms of piloting and then doing it more effectively.

And they were comparing it to university. So people would be at the community boxing gym, or they would be comparing with the group that was under supervision of a physiotherapist and and students at the University.

What was interesting about this obviously both groups improved in terms of outcomes of balance, of endurance as well, step size, walking parameters. These whole outcomes that they assist. But what was interesting to highlight here is balance confidence was actually greater in the group that did the physiotherapy supervised program.

Melani Dizon:

The balance confidence in their balance?

Josefa Domingos:

Yep, because the program had a component where it focused a lot about bypassing obstacles. So people clearly understood that they were training balance.

So there's an influence if you think that you're training in balance and if you're not. It was interesting results, but both programs, had benefits, the boxing program showed a little bit more benefit it wasn't clinically significant, but it showed improvement in terms of the endurance and the aerobics so that's where it won more.

So when you're looking for a program, it's really deciding on what you're looking for, which which area or which domain, are you looking for flexibility you're not going to go to boxing right?

If you're looking for an aerobic component, or you're looking for, you know, for balance. And this actually guided to one of the studies that I'm currently doing we're writing up the paper, and it's where we're comparing boxing, and my PhD is on community-based therapy and integrating implementing these programs at Radford University and ILMegan. And so one of the studies that we are doing at this moment was to compare if we added in the kicking if that would increase this perception that you are training balance, right, and the results were negative.

So it was the same. So adding in the kicking or not kicking. Basically we had the same results in terms of balance outcome.

John Dean:

No MMA cage fighting for Parkinson's.

Josefa Domingos:

You know we all desperate to find things for falling right so it's the balance of relating directly to falling. So, part of that random control trial, what, how many classes a week were the participants taking and how long was the duration of the study?

Josefa Domingos:

So they did 24 sessions, which was twice a week. And so, 24 sessions for was it 18 months? I'm sorry I don't...

Sara Rigarre:

Twice a week for three months.

John Dean:

12 weeks.



Josefa Domingos:

But I think the intensity really depends on how people are combining with whatever programs they doing as well.

Melani Dizon:

I mean for most people, this is complimentary to other things that they're doing, whether they're doing cycling or, you know, yoga, dancing, other things like that.

Somebody had said, who believe is a Rock Steady boxing coach said that three sessions is sort of the suggested sessions a week. I think that obviously depends on where you live, if you have access to three sessions a week, a lot of times you know a boxing gym will have a couple of classes a week they won't have three but certainly you know something to try out. I think that, I asked this question earlier, I'd love for you guys to address it because I think people are curious about it, we see a lot of research on lots of other exercise, related to Parkinson's. What do you think is holding up the research on Boxing and Parkinson's?

Sara Rigarrre:

So doing randomized control studies on research, on exercise is really really really hard because how can you know that people aren't doing other stuff?

And if people are in a study that assesses exercise, they will do more exercise than they would if they weren't in the study anyway. So it's really hard to the randomized control studies and for boxing specifically, I think there is some hesitation as to safety I think in most cases and I think it's in some cases it can be justified.

But it's perfectly feasible to do it in a safe and sort of environment in a safe way, but there's a hesitance because it's new as well.

Melani Dizon:

Okay, great. A lot of people in the chat have said that you know my rock steady boxing gym customizes to individual needs. They do assessments you know before the classes to make sure everybody's there. One of you mentioned, I think it was you Josefa, you talked about what to do if somebody walks into your gym and they're OFF, you know, and they're really maybe they got into the car and they're feeling fine and then they got to the gym and they're really feeling OFF. What are some things that you do in a class when somebody has that situation?

Josefa Domingos:

Yeah. So because I'm using this format where we are all together in every activity that we do, I'll probably manage it differently right, because if you have groups and you're organizing people in circuits, you will probably have someone that can be with that person for a while, and I think the simplest way to handle it is to ask the person how he usually does handle it in his daily life. And that will guide you.

Because I do deal with it daily right. And then, in the format that I'm using, everyone is aware that everyone has Parkinson, and we are very, maybe I'm using the wrong word, but solidarity to each other.

And so if someone is not feeling so well, we might change the exercise, so I automatically change the exercise. So, maybe I can sit down and do some boxing, or change it or walking, sometimes walking alleviates, I would say OFF, if it's related to to anxiety, so just relax, let's walk, let's walk, everybody let's walk, so I'll change the exercise without even highlighting that that person is in OFF.

But that's because I know the group really well, and because it's a group of eight people max. So, and I can see that maybe sometimes we have boxing and the person is having more difficulty than usual.

He's becoming slower. I can see that he's probably having back pain and so I'll change the exercise again up, you know, so maybe one, two, up. One, two, up. So that they're rotating. So I'm addressing the problem without highlighting that he's having a problem.

Melani Dizon:

That's great. And you did speak to something about sitting, you know you can do this in a wheelchair, right, there were a lot of people in the classes in a wheelchair and you can box you know with your hands and your instructor should be able to, especially a Rock Steady boxing instructor is understanding that people have mobility issues, and they might need to be sitting down and boxing, that's definitely possible to do.

Josefa Domingos:

If someone is coming in sitting and they, so you have specific goals about, you know, being able to be mobile in your chair, I would imagine that's one of the goals that the person wants to achieve.

So using the boxing is actually quite clever, if you use the pads right, so because if you are in normal rehab, people will have you reach out for things so that you can train your trunk mobility.

And this is what you'll do right, so if you're punching out, you are just queuing that person to also do it with more effort. So that's the additional benefit of using the boxing in that type of situation being that most of the, I would say recommendations, is to use the boxing with early stage more

Melani Dizon:

So, John, one of the things that things that you're really involved with is dual tasking and cognition and how exercise can sort of improve cognition, can you talk a little bit about how boxing does that and what you do that you could incorporate dual tasking into boxing?

John Dean:

Well you know it's interesting because Josefa just highlighted something very, very interesting in that respect because I think the way that the dual tasking happens at least in the sessions that I do with her, a lot of times, she's looking at the goals and these are people that she knows well and she might modify it on the fly so she'll have somebody who comes in and starts to have trouble and instead of highlighting like you need to have this change we're going to do this, but she'll make a dual task, little activity out of it, without being like, oh, you're having trouble with that and I think, you know, the ways that we incorporate it, we obviously use a lot more voice I think

I mean I'm a speech therapist so we like to do that and we use that either to put the framework that we would do another dual task that would be boxing related whether you're sequencing or counting or highlighting, I'm trying to get some of the better videos I've seen Josefa do where she had someone, I remember that the older gentleman sitting and standing in and hitting the bag that she put on the wall and then going through two different words, so she's basically doing a trail making test, but it's trail making with two different words that we're not hurting you, next time you go to your neuropsychologist to get tested to them for not getting in trouble with that but those are the kinds of things that you can do and it's not a very traditional approach I think people would be very ... when they would see one of our classes, it's not going to look at all like even what we did at

Denver Richfield, The Power Punch, Rock Steady or some of the many other Brandon approaches there's a whole, I mean Josefa got trained in boxercise in Germany I believe there's a number of ones around there and I don't think it would look like that.

So, use of voice, use of the way that we do some of the sequencing but again I see with Josefa, it's always a framework that she can apply to whatever situation we can be swimming and dual tasking is going to happen, you know we could be sky diving and dual task is going to be happening.

Josefa Domingos:

I can add that it's a way to bring people together. So if you do have someone that's struggling it's like okay now we're going to focus on our voices and so if you're sitting down and you're like, this is, Boom, stop, boom, stop, whatever you know so it's you distract people quickly into something else. Sara has that experience so it's like um.

Sara you want to share your experience with dealing with freezing and boxing you know the experiences that we did was very interesting.

Sara Riggare:

Yeah, so there's, I would say that for boxing I would say if you're interested in boxing for Parkinson's I would say, you should find a rock steady boxing person, trained in that if you're after this specific boxing.

But as you say, as John says there are many approaches to exercise and the best thing is to mix it up I say, and with the boxing, my freezing has been a challenge for sure. And Josefa's has been helping me finding different ways to deal with that. And that has been successful.

Melani Dizon:

Great, I know that was a big issue for our community. Can you talk a little bit about what that looked like in your boxing classes when you were freezing and then what are some of the strategies that you've tried to?

Sara Rigarre:

Yeah, so, freezing is a very personal concept as well. Freezing can look very different to different people for me, my freezing is very much related to anxiety and sort of these kind of emotion of sort of racing I have a lot.

So, that's something that happens if something unexpected happens. Unexpected sound, unexpected movement, very frustrating even sometimes an unexpected thought in my own head that was just extremely difficult to be prepared for.

Josefa Domingos:

Can I interrupt you to give an example? Do you remember the story of three?

Sara Rigarre:

Yeah yeah yeah.

Josefa Domingos:

Do you want to tell it?

Sara Rigarre:

You go ahead.

Josefa Domingos:

We have numbers on our boxing bags. And there was one there was two there was four. And then suddenly, Sara comes into the gym and she's like, where's three? Where's three? So just that thought was enough to bring on freezing.

Sara Rigarre:

And there's a very funny videos as well of me running on a treadmill.

So actually I can't run, I can't run on flat ground but I can run on a treadmill which is a bit of a mystery as well but it makes sense for me but I wouldn't have guessed it before Josefa challenged me to do it.

So that's also encouraging for me to know that I can do it and I'm trying to understand that the implications and what what the mechanics with that is. But, and that's that's actually a challenge for me with this floors on on in boxing because they're often sort of sticky in a bit, which makes it more I mean more prone to freezing actually, which is something I need to think about.

But there's a lot of things with boxing because if you if you go to a place where the boxing is stronger than the Parkinson's, they will often stress the fact that you should have a proper boxing stance, which is the same foot forward all the time which can be the wrong foot forward for somebody with Parkinson's, for example, if the other side is more effective.

So that's something worth checking for if you're shopping around for a class to join, how adaptive they are to people's individual needs and challenges.

Josefa Domingos:

Okay. I think that's a good point Sara because our professional convictions which we can understand that we all take our courses and our educational and then we we know what we know. And so to sometimes to let that go so that we can be open to listening to people is critical, it's, I think even a things like posture like the crunch posturing in boxing, that I know that all the physiotherapist will, you know, we look at that. So, obviously you have a vertical stance. So, it is possible. It's also possible to adapt and it's not in boxes.

So these small adaptations make a big difference right because if you are bending forward you're bringing the weight forward so you're freezing will also be worse if you have one foot in the other you are less balanced. So it's details like this that sometimes really increase the discomfort, and people feeling unsafe.

Sara Rigarre:

So, in fact I don't go to the gym in Stockholm anymore for a number of reasons, not since I've started using a walker outside because they had, I don't mind stairs, but there's nowhere to put my walker when I go downstairs into the gym, which is a sort of a structural issue in terms of logistics and this.

And also, that there they are more boxers than they are Parkinson's knowledgeable. So, which to me with what I want to optimize for myself, it's not the right fit right now. Of course they



closed down as well during the pandemic. But now I actually attend a weekly online class with people from around the world actually for mixture with boxing included.

Melani Dizon:

Yeah actually somebody was talking about that. There are Rocksteady boxing classes online. There are other boxing classes online, definitely check those out.

And we'll share some links as well. John it looked like you were going to jump in. Were you gonna say something?

John Dean:

Just to say that as they're talking about the stance and you know whether it's one foot in front of the other we often just do match because it gives us better rotation and posture, as a speech therapist many times I've gone into a class and I'm like oh my gosh we're all, you know, punching slabs of meat and it's really very vocally abusive so I was just trying to get people to like hey, you can use a louder voice and you don't have to grind your vocal folds together so I'm just out there in boxing land, more air less tension.

If it sounds like you know if you're Rocky Balboa then you're kind of doing it wrong because you've got a lot of great qualities, but his voice is not where I'm heading, when I'm trying to improve your ability to communicate, many other places he's great. I want to be careful, but I want to say, often I see the same kind of thing when we get in this position that we may get one foot forward and all that kind of stuff.

It happens to the voice as well.

Melani Dizon:

Oh yeah that makes sense, make sense. Somebody says we sing a lot in our RSB class.

John Dean:

That's great. I saw that in spin class to that you guys go too and I was like that's a great way to add some stuff and it's hard to sync with like tension.

Melani Dizon:

That's true. So we have so many comments in here, I would love it if you all could throw your questions, if you have any questions. There's a lot of comments in here. "We run a Rock City class, five days a week but several times a month we try to include other things like dancing and yoga," "RSB customizes to individual needs."

Let's see John, what were you talking about the gyms in Denver -what was it?

John Dean:

It's called power punch for Parkinson's, and the only one I know of in Denver and I'm sure there's more than one now was the one at the Denver Red Shield and that's where it started with Anthony Maura working with Rick Schwartz, but I know that a friend of ours, Emily Munchpesky teaches one down in Colorado Springs. I believe Bob Walton was teaching one for a long time up in the Fort Collins area, so I think you will have to look around, but there are a number of them around. I actually don't think there are a ton of rock steady but there might be a couple out there by now, there weren't when I left like four years ago.

Melani Dizon:

Yeah, Yeah, for sure.

John Dean:

That one center in Boulder is excellent, again, they trained a lot of Olympic athletes but their so strong on their educational side I really loved it.

Melani Dizon:

Yeah, they really are pretty amazing ladies. So, Leigh put up a link about how to find a Rock City boxing class so you could go there and then look at the places in your area.

And you can also look online for Rock Steady boxing online, and go to YouTube and just search through YouTube there are actually some classes I mean I would highly recommend that you, now that we're opening up to the chance of opening up, either work with your physio/physical therapist or at a Rock Steady boxing class, those initial sessions I think are important for you to understand what's good to do, what's not great to do and how it's different for people with Parkinson's.

Somebody says, "I newly diagnosed, Rock Steady boxing is taught with our Parkinson's group online zoom, how will this work without gloves?"

Sara Rigarre:

So if you do this online you don't need gloves.

Melani Dizon:

You're just punching the air.

Sara Rigarre.

Yeah.

Melani Dizon:



Yeah and you could I mean technically you could get a bag like the bag you have in your office, like a big, round one, for yourself

Josefa Domingos:

Get a soft one so you get the impact right, if it's too hard it doesn't feel good.

Sara Rigarre:

One thing that's good about gloves is it adds a bit of weight to your hands, so that's added weight, but you don't need to them really.

Josefa Domingos:

I have another suggestion. Also challenge you know your health professionals to try it out because there's also some resistance there, and it's a pity, again, our convictions as professionals and I think if there's a key message here it's like boxing in the community is important as an ongoing strategy for exercise.

But if we do use it in our therapy, it makes it much richer. It doesn't mean I'm always doing boxing, but I can really use boxing to highlight even all the amplitude, the speed, the aerobic and it's not rocket science, my key message to my fellow colleagues, it's not rocket science if you took other courses, you can take this one. It's learning a bunch of movements, I don't want to reduce it, but I don't think that people should say oh it's because I don't know it. It shouldn't be a limitation.

Melani Dizon:

Yeah, someone said, "Who would I contact about trying to bring Rock Steady boxing to our area, PT and neurologists?" I would definitely start with PTs in your area, you know, Rocksteady boxing trainings are happening all the time.

You could definitely talk to somebody about that and like John said there are other organizations too, I'm just most familiar with Rock Steady boxing but there are lots of other organizations you could check out.

John Dean:

I think they're doing the training online now too I believe Rocksteady boxing has a program that you can do over the internet. I would start with Rocksteady boxing themselves because they have just so many affiliates, you may not be aware of the affiliate that's nearby and you might they might point to somebody, if not, then you can start talking to your professionals and get your PT involved one way or another and your speech therapist for that pattern, I mean I really enjoyed the process. It was great.

Melani Dizon:

Yes, someone says you can put a pillow on a chair for online boxing, wearing boxing gloves increases the cool factor, agreed.

Sara Rigarre:
Especially if they're pink .

Melani Dizon:
Yeah Josefa show yours, pink and like little sparkly. Yeah.

Josefa Domingos:
These are actually from kickboxing because it allows you to keep your finger so in case you need something. It's more practical.

But it could also be that more dangerous but.

John Dean:
I think that's something to be careful of is that you want to be sure that when you're doing this that you have people that are giving you the, A) the right protective equipment, I've had a number of patients that have gone into something and had a shoulder issue or something here, or came out and said, afterwards I got done and it's like I had to nap for four hours and it's like, I've done a lot of exercise in my life but if I have to nap for four hours I'm not gonna do that one again.

Melani Dizon:
Right, right. Yeah, that brings us to a great point around the safety and sort of expectations as you're doing this so what do you think is important for, let's say somebody who hears that a boxing gym not necessarily a Rock Steady Boxing gym, maybe a Rock Steady boxing place or something like that. What are some questions to ask the coach to, to make sure that they understand what they're doing, and you're going to get a good, safe class?

Sara Rigarre:
So I would say you could go watch your class before you join yourself to see what it's like and see if it's if it seems safe if the coaches to know what the, what people are doing it can support them in a good way.

Melani Dizon:
That's a great idea.

Josefa Domingos:

You know, we are, we are struggling at this moment to find out like inclusion criteria as whoever is delivering it, how we glue people how we separate people into groups. So it's, we don't have the right answer at this moment. There is, highlighting the recommendation that obviously earlier stages will probably benefit more.

But I think so it's a challenge to get those right questions if we don't know why are people joining, why are people dropping out and so I actually I did a social experience last week. An experience that's what I'm call it, there's no way we can publish this this stuff but it was just a simple question on Facebook and I want to thank everyone that answered, trying to understand why people drop out because this was actually one of the limitations in the study that we published, we had no reason why people were dropping out so the program 18 months after we had 40 people that were in the program, but people, everyone that was lost it wasn't the same people that entered and we didn't know why. Why do people go out? And so I just asked a simple question on social media and Facebook, just to get a glimpse of what people are saying, besides the experience that I've had, and obviously the results are really in line of the safety issues the injuries in the shoulder, in the hands with the hands was, was a particularly interesting one. And then, transportation, was a limitation as well. Cost was another issue that came up, often as well.

Sara Rigarré:

I think in the case of Stockholm as well we have that very, very narrow and very steep staircase.

Yes, which was one of our adverse events which was a black staircase, all the way down, and people with Parkinson don't usually have difficulties in stairs, right.

Sara Rigarré:

With no contrast, no contrast on the steps.

Melani Dizon:

So if you find if you find a gym it's actually a good idea to maybe do a little reconnaissance with somebody, maybe your care partner or friend and drive over there and see what you're looking at in terms of getting into the place, and the parking and all of those kinds of things. The other thing to do, like Sara was saying if you go and you want to observe a class, you know, it would be really helpful if you could say to the coach, "Hey, I want to observe this class, I'm interested in it, but I just want to see how it goes." Maybe and then maybe the coach could kind of announce to the group, "hey there's somebody here watching, she would love or he would love to talk to you if you're open to talking about your experience after the class," and then you could talk to some people, maybe various ages, various abilities, and you get a chance to talk to those people about their experience in that gym, and they'll probably also tell you about if they live in a bigger city about other gyms they've been to and why they're at this gym and you can get a lot of great information with that.



Someone says I use gloves in the shadow boxing portion of my zoom RSB class as added weight, among other things, but our participants are all boxers who are in our gym class pre covid.

Okay. Rocksteady boxing promotes an exercise protocol called forced intense exercise which helps delayed onset of PD symptoms.

Well, how is this forced intense? How is boxing forced intense? It's just intense.

John Dean:

Yeah, I think it's high intensity not forced use per se.

Melani Dizon:

Right, okay. Boxing was great, you need to stress you have to learn the correct form to throw the punch or you will have shoulder injuries and wrist injuries. Yes, completely. In Atlanta we're fortunate to have the resource of boxing for Parkinson's.org.

They offer different levels of PD boxing yoga and optimizing classes in person and virtual so you could probably check those out if they're offering the virtual.

John Dean:

Yeah, I'm not familiar with that group so that's cool, I'll check it out.

Melani Dizon:

BoxingforParkinson's.org.

Each station should have a safe exit, a chair to sit on, balance bars to grab, etc. Yeah so those are good things to think about when you go visit some sessions. Oh, Pete, hi Pete, I'm so glad you're here. I know Pete's a big boxer, he says Rocksteady uses a standardized assessment to determine level and then does assessments at every six months to gauge improvement.

That's great. Probably built into the trainer curriculum, and somebody says we have all potential boxers, watch our class speak with at least one of our current numbers and undergo a full assessment prior to becoming a member, that's great, that's, you know, very sort of peace of mind for people who are interested, you are if you walk into a rock steady boxing gym, the chances of you getting an assessment and making sure that things are safe is great and please if you are on this on this and you're not Rock Steady boxing or somewhere else please feel free to put the organization that you work for, so that we can share it as well.

Josefa Domingos:

Now, I would just like to highlight your point about the assessments, because we can do as many assessments as we want. It's the fluctuating characteristics of Parkinson, increase the

need of us to gain this expertise and expertise is based on experience right. So if no matter who's delivering it, if you have a certain amount of time working with people Parkinson's you will learn, right, you will get that, at least until the research catches up and can guide us better right.

But it's important for the assessments that you do in the day in the hour. Right. And I think we have to be mindful of that because I can give you an example of someone that I was following in our boxing class last week, and I was understanding that he was hyperactive for some reason, but only because I took him home, did I realize that he had taken double his medication by mistake. Right. So when we assess these things it's really about if we can have time, we need time with people. So, if you have 40 people it's going to be very difficult to do that.

Melani Dizon:

Right. Yeah, I think you make a point I mean people's Parkinson's changes from day to day. So it's just having that awareness and being able to notice, notice things that, you know, you'll get better at with time, you know, the more classes you teach, the more people that you have, you'll get that.

Josefa Domingos:

So let's say the baseline is if you at the end of each class, if you have learned something that's the criteria if you are growing in terms of expertise. So even though I've been doing this for some time, in every single class there's a learning point, this was my turning point from last week is like, why didn't I go and ask him if, why was he so agitated and you see, if we learned something it's all based on error right the learning point.

Sara Rigarre:

Speaking of learning, I'm not sure if you've had this on your programs before, Mel, or not, but Josefa has this bouncing for Parkinson's.

Melani Dizon:

Bouncing?

Sara Rigarre:

Yeah, trampolines.

Melani Dizon:

Ohhhh, we don't have that yet, Josefa.

Sara Rigarre:

We've done boxing and bouncing at the same time. But actually that's the best thing I've ever had for my freezing gait.

Melani Dizon:
Is the bouncing?

Sara Rigarre:
Yeah, yeah. That's good to know, for everybody else watching.

John Dean:
It's totally amazing to watch.

Melani Dizon:
Somebody was just saying, they pay \$80 a month for 12 sessions per month. Some people, \$50, three videos a week so it's going to vary, it's also going to vary by community and city and that kind of thing.

One person just said, Okay this is the tip that I think is a very great point to end on, I always feel better after leaving my rock steady boxing class and when I came in, and I think that one of the things that we certainly hear at the Davis Phinney Foundation is how much community, how important the community is, and people, no one's really talking about how they miss the boxing or the punching they're missing all their friends at the Rock Steady boxing so I think it's definitely spoken to that aspect of how important connection is to people with Parkinson's and this is a great way to do it in a fun environment, and you can watch people grow and advance and, you know, reduce their symptoms and still stay active as their Parkinson's progresses.

Josefa Domingos:
I'd say even though we promote that it should be more specific to the needs right so you should have exercises that are approaching your specific problems. I think we should be careful to never change the environment of enjoyment. And so, let's not make this clinical, it's not a clinic. So I think we have to be mindful of that because that's why people are going there, so they're not reminded that they have Parkinson's.

Melani Dizon:
Yeah, they don't have it for that period right?

Josefa Domingos:
I can be doing everything I want as a physiotherapist, and I don't have to be reinforcing that the person has a disease.

Melani Dizon:
Right. Oh Angie's here and she says I would love to do bouncing in Michigan. Yes.

John Dean:

We will come. We will come there to do it.

Josefa Domingos:

It's just like boxing, we're still getting evidence.

Sara Rigarre:

Remember all those years ago, Josefa, we talked about bouncy castles in the yard of the clinic. And here we are, bouncing, but there's always a way around it, right?

John Dean:

Well and I think the bouncing is better than the bouncy castle.

Josefa Domingos:

And let me clarify, it's walking on trampolines, it's not so much about the bouncing, it's more about the balance information you're getting, the very intensive balance training.

Sara Rigarre:

That feedback to your feet and joints and everything. That really reduces my freezing and improves my gait.

Melani Dizon:

That's really great, are there any such classes like that online Josefa?

Josefa Domingos:

Regarding the bouncing, no. It's a pilot program that we are testing.

Melani Dizon:

Well you heard it here first.

John Dean:

Yeah, let me get some camera equipment for Josefa and we'll get it together.

Sara Rigarre:

I have my own trampoline, small trampoline at home so we can do it online.

Melani Dizon:

So, Bailey says our programs are all free if you're ever on Vancouver Island, Parkinson's Wellness.

John Dean:



Yeah, she's great. That's a great nonprofit up there.

Melani Dizon:

Absolutely, we, we definitely have a lot of links, and we will share them all and post email along with the recording, along with the audio, the video, the transcript.

If you have any questions, please feel free to email us at blog@dpf.org. Thank you so much Josefa and John and Sara for being here today. We really appreciate it; I know a lot of people could talk about this forever and boxing has big fans. So thanks so much for sharing your expertise.

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