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

Stephanie Paddock: Hi everyone and thank you for joining us. I'm Stephanie Paddock, Vice President of Community Outreach & Events at The Michael J. Fox Foundation, and your moderator for today's webinar. Today we'll discuss loneliness, apathy and isolation that can happen in Parkinson's disease. We'll cover ways to manage these issues through community connections, and share information on the Parkinson's Buddy Network. We've got a lot to discuss, so let's get started.

Stephanie Paddock: Let me introduce our panelists. Lynn Hagerbrant is an MJFF Patient Council member who was diagnosed with PD in 2010. She heads a support group called ""Shakers Anonymous"" and an exercise and wellness program called Parkinson's Body and Mind Program. Both are in Connecticut.

Stephanie Paddock: Hi Lynn. It's great to see you.

Lynn Hagerbrant: How are you. It's nice to be here. It's an honor to be here.

Stephanie Paddock: Thank you. Next we have Ned Neuhaus, joining us from Peoria, Illinois, who was diagnosed with Parkinson's in 2013. He's a Rock Steady boxing coach and an active member of our Team Fox community and the Parkinson's Buddy Network. Hi Ned!

Ned Neuhaus: Good morning. Great to see you.

Stephanie Paddock: Good to see you. We also have Dr. Indu Subramanian, a Movement Disorder Specialist, Clinical Professor at UCLA Department of Neurology, and Director of the Department of Veterans Affairs, Southwest Parkinson's Disease Research, Education, and Clinical Center. She has studied loneliness and isolation in Parkinson's disease. Welcome Indu.

Dr. Indu Subramanian: Hi, nice to see everyone.

Stephanie Paddock: And last but not least, with an equally long title, we have Lance Wilson, a Neuroscience Medical Social Worker at the Jefferson Health Comprehensive Parkinson's Disease and Movement Disorder Center at the Vickie and Jack Farber Institute of Neuroscience, a part of the Thomas Jefferson University Hospital in Philadelphia. He helps people with Parkinson's and their care partners navigate the disease and resources available. Welcome Lance.

Lance Wilson: Hi everybody, thank you guys for having me.

Stephanie Paddock: A huge thank you for all of you for joining us today. So, let's dive right in. Indu, I'm going to start with you. We hear often from people with PD and their loved ones that a lack of motivation can be really frustrating. Told to exercise, reach out, take action, get involved. But apathy is part of the disease. What can you tell us about that part of Parkinson's?

Dr. Indu Subramanian: Yeah, so apathy is very common in Parkinson's. I think the numbers are about 40 percent of our patients complain, or, we recognize 40 percent of our patients have apathy, but I think it's a lot more. It's part and parcel of the disease. It's something that's terribly disabling, and I think we really have no real health treatments or any sort of other therapies outside of sometimes behavioral modification. So it can be very frustrating. And I know for family members as well, it feels like sometimes caregivers are trying to motivate their loved ones to get going, and they feel like they're nagging them, and it can really cause distress within the family dynamic too. So, it is important that people recognize that it is part of the disease.

Stephanie Paddock: Mm-hmm (affirmative). And along with apathy, there are different types of isolation. Lance, can you talk to us about those, and what advice you give patients and their care partners?

Lance Wilson: Sure. So I think one of the, in regards to this talk, I think the most important ones to point out are emotional and social isolation, which has been of course impacted by our pandemic. So I think the biggest things to pay attention to, any advice I give to patients are kind of pushing those limits, kind of assessing those micro-system type relationships you have with friends, family members. And I think that, especially within the quarantine, that people have had pushed through some of those, pushed through some of those boundaries or pushed through some of those comfortable boxes that they might be in to make sure that they continue and maintain their healthy relationships.

Stephanie Paddock: And we know that these factors don't just affect the social and emotional well-being, isolation can worsen others Parkinson's symptoms and Indu, why is that?

Dr. Indu Subramanian: So in our study, we were looking for modifiable risk factors of how, different things that you can do in your life affect the disease. And we found, we went into it looking to see that exercise was beneficial and we did find that. But what we found is that the negative effects of being lonely and isolated were as bad for people with Parkinson's and their symptoms and their quality of life, as the beneficial effects of exercising seven days a week, 30 minutes a day was good for you.

Dr. Indu Subramanian: So it really is a profoundly important thing that is modifiable, and hopefully we can talk a little bit about strategies that can help. And one of the things that ends up happening is that people get isolated, they get withdrawn, they don't

feel so well, their motor symptoms get worse, their non-motor symptoms get worse, they get more stressed out. That leads to this cascade then of getting more isolated and more withdrawn. And so we really have to figure out ways to break that cycle.

Stephanie Paddock: Yeah. And we will definitely dive into some of those strategies. I'd love to hear from Lynn and Ned. We know that it's been a challenging year in so many different ways. Lynn, for you, how has the pandemic and social distancing impacted both you and your community?

Lynn Hagerbrant: Well, what I did is I, it had a huge impact on the community. I think, people with Parkinson's tend to, a lot of times, isolate because they're embarrassed at their symptoms, and they feel uncomfortable being in social situations, so this all magnified the whole situations.

Lynn Hagerbrant: So, what I did is, I focused on my PD community and instead of having meetings live once a month, we started Zoom meetings every week. So we reached out to the community more on a frequent basis. And that made, I think that helped to make a big difference, helped people with, overcome isolation.

Lynn Hagerbrant: And we encouraged, we also started Zoom exercise classes. And so, we kind of encouraged one another through the pandemic over the last year.

Stephanie Paddock: Did you see a great response from your community in joining those?

Lynn Hagerbrant: Yes, a significant response. You know, it brought us closer together and you know, Zoom meetings, we, moving forward, but probably going to do a hybrid of live and Zoom because we saw the benefits of the Zoom meetings. We had researchers from Stanford University talk to us about stem cell, we had nutritionists talk about Parkinson's nutrition, and it was just, and then plus we had support from one another and networking, and it just, it was a lifeline for me, during the pandemic.

Stephanie Paddock: That's great. And Ned, how did the pandemic impact you and make changes for you?

Ned Neuhaus: Well, as a Rock Steady coach, it took away our outlet. You know, we had, we're used to getting together multiple times a week with the same people. We build a social network there and all of a sudden the network was gone. And what we did is pretty quick into the pandemic, we started doing Zoom classes and I was a bit apprehensive because, this wouldn't be the prototypical group of people you would want to be putting in front of a Zoom camera, but we've got people in their mid-eighties that are coming to class on a regular basis. They're nailing the technology. We opened up classes a half an hour before time, so they could socialize with their friends. It was almost like we didn't miss a beat. And it was really great to see. And now that we're back in the gym, it's almost like we didn't really ever leave.

Stephanie Paddock: Mm-hmm (affirmative). That's great. And, we all know that it can be hard to make connections as adults, let alone as part of the Parkinson's community, and really where to start. Lance, I'd love to, you know, start kind of talking about some of those strategies and, how can a social worker help people and families with Parkinson's to build connections and manage relationships?

Lance Wilson: So, to help build connections and kind of maintain those relationships? So, a social worker and the first side of things would help identify if there are any issues that would stop someone or block someone from maintaining or making those types of connections. So, if we can identify a cause that might lead back to that apathy that we were speaking about earlier, then we can try and build some tools or strategies to help interrupt that cycle. Like Dr. Indu had mentioned earlier, interrupting the cycle is usually the first thing we need to do if there's something, stopping someone from making those connections. But then, typically it's just usually giving insight to what a healthy dynamic or a healthy relationship looks like. And some of those things are, of course, this expands outside of Parkinson's specifically, things like being all authentic in your approach, being empathetic, things like that.

Lance Wilson: And also, the other thing that social workers can do is kind of tie people to existing platforms that already exist. So, things like Rock Steady boxing, or other community center programmings, or different support groups. I have a lot of patients that find their support group based off of trial and error. You might not like that support group, but there's another one over here I might be able to refer you to, and you might make a connection with one of the community members that way, that exist outside of the actual disease state.

Stephanie Paddock: Yeah. And we'll talk about the Parkinson's Buddy Network a little bit later, but, I think that will be another resource that you could provide. Have you seen, or did you see in this last year, an influx in people, patients, care partners, needing your services and needing to talk to social workers?

Lance Wilson: Yes. I think that typically when people hear "social worker", they have a preconceived notion of what it is that we do or what we can assist with. I have seen a huge influx of people who need mental health resources, as well as being able to kind of talk through some of the things and the challenges that have been kind of exacerbated by the isolation of COVID-19, as well as not being able to connect to individuals, or go and do the things that they would typically do. So kind of a lot of the kind of work I've been doing has been some primarily around coping strategies and getting people connected, or thinking about connecting with individuals in another way.

Stephanie Paddock: Mm-hmm (affirmative). That's great. Ned, how do you go about building community connections and how has the pandemic changed this?

Ned Neuhaus: Well, very early on, I was anxious, maybe borderline depressed, and I met with a professional and she helped me realize that Parkinson's didn't have to define me.

Ned Neuhaus: And that got me thinking that Parkinson's was out there trying to take away the things that I felt made me who I was. And I quickly began to realize that you need to do the things you love to do because Parkinson's will take it away if you let it. Even though I've made PD advocacy a big part of my life, I don't dwell on having PD.

Ned Neuhaus: And what I found is, I put myself out there. Whether it's social media, it's in local media, it's whatever, I'm out there and I'm telling people what I think and what I've experienced, and I'm finding that people react very well to that and it's allowed me to build connections that I would have never had without having had PD, as weird as that sounds. But it's to the point that I'm actually a much more outgoing person now than I was before. I was very private. And people that didn't know me before I knew I was living with PD would never believe that, because I'm constantly out there. I'm telling very personal things to the world and seeing how that reacts. And I'd have never believed that I would have made this change.

Stephanie Paddock: Wow. And I think both you and Lance just hit upon something about mental health. And I think this pandemic has really opened up the conversation about mental health, and for everyone and knowing that we all need different resources, we all need different things through this time of isolation, whether we're living with Parkinson's or not. So I'm glad to hear that, Ned, you sought help, and got the help that you needed, and that the conversation is becoming more natural and de-stigmatized.

Ned Neuhaus: Yeah. And you know, I talk a lot about PD obviously, but I do a lot of things that have nothing to do with PD. You know, I get together with a friend from high school once a week, we restore cars together, I'm out there. I still play guitar. I do the things that make me happy, because if I don't, I'm afraid PD will take over.

Stephanie Paddock: Mm-hmm (affirmative). You don't let it define you, which is...

Ned Neuhaus: Absolutely.

Stephanie Paddock: Yeah. And Lynn, I'd love to hear about your support group, "Shakers Anonymous", that you started. How did it get off the ground, and how has it evolved?

Lynn Hagerbrant: Through Michael J. Fox. Michael J. Fox is, has been incredibly valuable for me, personally, and for so many people. It was an Ambassador who came to my house that turned my life around. I was not open about having Parkinson's for two years, and the Ambassador from Michael J. Fox...

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Lynn Hagerbrant: It's for two years and the ambassador from Michael J. Fox [inaudible 00:15:04] visited me and turned my world around. That I'm very grateful to this individual and Michael J. Fox for that, but it was through that, that I spoke, I had the honor to speak at Partners in Parkinson's in New York City. And, through that event, I met a gentleman and his wife that I connected with and we co-founded "Shakers Anonymous" and that was over seven and a half years ago. We started by meeting in a library in Connecticut and we almost got kicked out because we were too noisy and we stayed too long. [crosstalk 00:15:39] We eventually moved to the local YMCA and it's been fabulous. We have over 375 members and it's just incredible. It's a peer led support group and it's just, it's unbelievably fabulous. The connections that we're making is tremendous. It's just, it's wonderful.

Stephanie Paddock: That's incredible. And you point out that you met a gentleman at Partners in Parkinson's event, which was an educational series that the Foundation hosted a couple of years ago. So, even educational events can be ways of making connections with others [crosstalk 00:16:20]. In due, one more question on this topic. What advice would you give patients who are looking to find support groups or form other types of connections?

Speaker 2: So one of the things that I think just taking a step back, that's important to help people to understand about loneliness is that, when you're looking at relationships in your life, if there are various spheres that you have to kind of think about, so there's a sort of intimate sphere where you might have a spouse that's, with you at home, you're sheltering in place, you interact all day, every day. As for your doctor, maybe calling you on zoom and having a patient visit, and that's one aspect of your social connection, but there's also these other connections that are kind of important in our lives that I think we also sometimes don't realize. So one is a sort of friends circle. So there's outside of just that partner in your home, a circle of friends that you have a relationship with that maybe outside the home, maybe a friend that you can go for a walk with, maybe a friend, or a few friends that you meet up with that are from your high school or whatever that are in your neighborhood.

Speaker 2: And that's another sort of sphere. And then there's a sort of community sphere of connection that I think is kind of what people have been talking a little bit about here that may connect you to a bigger purpose and it might not be around just the Parkinson's disease. You know? So for some patients that may be Parkinson's disease, that that is their sort of advocacy area or brings them meaning and purpose. But outside of that sphere, sometimes it can be things like you mentioned guitar playing or a car restoration for my veterans as being a veteran. So really think about those things that bring you meaning and thinking about the people maybe in your community or society that can kind of speak to that and really bring that side out of you. And so I think it's important to realize that you can still be lonely just with that intimate sphere being that, and that a couple can actually be lonely together.

Speaker 2: And so I think we're thinking about these other sorts of relationships and what brings us meaning and what brings us connection, think a little bit about, do I have people in these other spheres and how can I kind of foster those relationships and really with apathy, I think it's about sort of getting outside that box, kind of pushing that comfort zone. You may not wake up in the morning and feel up to calling a friend, but really put it on your calendar, schedule these things every day, every week. I think so far we've heard about people who met once a month, but then felt the need to meet weekly and people look forward to that. You can kind of make that a regular part of your schedule and that way, you'll be more inclined to do these things.

Speaker 2: I think, you know thinking about meaningful connections with people that may not just be in your home may not just be in your regular day-to-day sort of things that you would normally have interacted with. Thinking about people, maybe on your Christmas card list, your neighbors, maybe high school friends that have been mentioned. We're thinking about those sorts of things and I think we can probably find a lot of people that bring you joy that you may not have ordinarily interacted with.

Ned Neuhaus: Yeah. I think that is such a great point to make. And I know for myself personally, I, with both this job and the work that I do, and also just for fun, I travel quite a bit and I get these opportunities to see friends and people through the Foundation at different times of the year and that all stopped last year.

Ned Neuhaus: And those moments to interact kind of stopped, but I can still text them. I can still pick up the phone and I started making more of a habit of doing that. Trying to reach out to somebody different once a week and even just the idea of sending a text message, brought me some joy. It was always, it's always great to hear from someone out of the blue as well. So I like that that point that you distinguish about the different spheres of connections that we can make. I also think that you've queued up a video that we want to share very perfectly about different people to lean on in our lives. A few years ago, we put together a video to talk about the importance of connections and how people in our community have found different friends to lean on. Ned actually participated in this video and we're going to share a short clip now from that piece, if you're interested, the 10 minute full video is linked in the resource list.

Dr. Dolhun in Video: People who are newly diagnosed often approach us at The Michael J. Fox Foundation for advice on their symptoms or where they should go next. In Parkinson's, it's really important to build connections because this helps you build your support system and take control of your disease.

Ned Neuhaus in Video: Like a lot of people that, that get the diagnosis, the first thing you want to do is just run and hide, curl up in a ball and don't come out of your room. Judy and I weren't expecting that at all. It was a real unknown for us and it was just overwhelming. I remember hugging each other in the parking lot, shed a few tears and then I went back to work because it was the only thing I knew to do. Shortly after I was diagnosed, we met Claudia, low and behold we lived about a

half mile away from each other, had no idea who each other were, or the fact that we were both about the same age and both had PD.

Claudia Revilla in Video: And we went out for coffee. I talk a lot about the Foundation. I told him what I do and I told them all the things that are out there. Go to the website, you're going to find everything. If, you need anything just give me a call. I'm there.

Ned Neuhaus in Video: Claudia and I really clicked well together. She's had Parkinson's a little longer than I have. So she became a mentor to me. She encouraged us to go to a Fox Foundation event that was held in November of 2014. I met two people that day, that really changed my life.

Eric Johnson in Video: I met Ned Bauhaus through The Michael J. Fox Foundation. Ned really was inspired by the therapeutic benefits of boxing to combat Parkinson's disease. He wanted to start his own program in Peoria. Since then, he's built this program up.

Ned Neuhaus in Video: Meeting Eric that day was one of those points in life I can look back to and say, that was a day where my life changed. Funny thing was that, wasn't the only thing that changed on that day. I didn't actually meet Jimmy and Cheryl that day, but I saw them speak.

Jimmy Choi in Video: I met Ned in 2016 at a research seminar with The Michael J. Fox Foundation. Ned came up to me and he told me a story about how he had heard myself and my wife speak and how it helped him along in his journey. And then a year later, he signed up to participate in the, Shake It Off 5K, which is our fundraiser for The Michael J. Fox Foundation.

Stephanie Paddock: Thanks again to Ned for being a part of our very special video. Before we jump back into our conversation, we'd like to take a short break, to call out the foundation's landmark study, PPMI that is now recruiting. The Parkinson's Progression Markers Initiative, also known as PPMI, is the study that could change everything about how Parkinson's is diagnosed, managed and treated. Right now the study needs parents, brothers, sisters, and children of people with Parkinson's. Get involved today by taking a short survey, just click get started in the take action box on your screen. The study is also recruiting people diagnosed with Parkinson's in the last two years, who are not yet on PD medications, learn more about PPMI by clicking the link in the resource list and help spread the word that PPMI is recruiting. The link to share is michaeljfox.org/ppmi — that's michaeljfox.org/ppmi.

Stephanie Paddock: Now, while you may not think of research participation as a way to really build connections, PPMI has built a community since it launched in 2010 with annual events to connect both study leadership and participants. That's just one avenue for making connections in your community. You may find great connections in your neighborhood or a local support group, even through a hobby like car restoration, like Ned mentioned, or in your gym. There's also

ways to connect through the Fox Foundation. Our public policy team hosts an annual policy forum and is currently building out the Parkinson's Policy Network. Anyone interested in getting involved in grassroots advocacy can learn more by visiting michaeljfox.org/advocacy. Let's turn it back to our panel. Lance, where else would you suggest that people try to connect with others? I think there's a great list up on the screen, but any other suggestions that you could provide?

Lance Wilson: So I think that it's, you have to be a little creative. So I think that these are great places to start, but I think that even something as simple as, I mean, not that we're doing this as openly as we were before, even those simple conversations that you have with your neighbors or going to the grocery store can just open up. I think we underestimate the ability of just having a connection with someone, even if it is kind of those one on types of interactions. So I would just say, be open to those other places. So you have the gyms, you have the support groups, you have the exercise groups, you have research studies.

Lance Wilson: I think even physicians, I know that my physicians here at Jefferson will, you know if they know that two of their patients might really do great kind of building a rapport with each other, then they'll get consent from the patients and to have them connect that way. So it really is kind of thinking about those things that are outside of the typical, Hey, you go here and you meet that person there. Sometimes it's about saying, Hey, I think you have some really similar interests with someone else that we might see. So I'm going to see if that's something that would be open to having more of a conversation or a dialogue about.

Stephanie Paddock: Definitely and Lynn outside of "Shakers Anonymous", have you found community in other ways?

Lynn Hagerbrant: Outside of "Shakers Anonymous"? Yes. You know I actually, through the zoom meetings that we have every week have connected with interestingly enough women with PD, from other states in the country. And we've, we've formed like, like a group together that there's like six or seven of us and we were all around the same age and that has been very special and that's a silver lining of the pandemic that has been very positive for me, so that's occurred and that's been very special.

Lynn Hagerbrant: And then also like you were saying, Steph is that I'm trying to reach out to some of my high school friends and it's made me really think about my connections with people outside PD and like Ned, there's more to me than Parkinson's and I tried to work on that also because that makes you know, that there're other things I'm interested in besides, PD and I tried to develop that myself. So with other people.

Stephanie Paddock: Yeah. We're all kind of feeling, I'm sure the fatigue of zoom meetings and feeling zoomed out at this point, but it has been this opportunity to, for people to log on from wherever they are from home. Like you mentioned people are joining

your zoom classes because they don't have to actually leave the house or even feel embarrassed about going out in public. So, there are small silver linings to this I'm sure. Indu, I'm curious for people that are feeling zoomed out or, not wanting to engage anymore in this matter. Do you have any suggestions or strategies for folks?

Dr. Indu Subramanian: You know, I think it's been a long year and a half for all of us and it's been, a time of grief for some of us. We haven't had a chance to see each other. We're grieving occasions that have been missed. If you lost a loved one or somebody that means something to, you know it is a long time. And when bad things happen, we're used to connecting through social situations, hugging each other, holding each other's hands. I knew as a physician, it's been tremendously difficult for me not to give that sort of physical connection to people. But I think in small ways now, as we're sort of in some parts of the world emerging, from the pandemic, hopefully people are getting vaccinated, if they feel comfortable to do that.

Dr. Indu Subramanian: I really urge people to get out into nature. I think that that can be very therapeutic and sometimes that connection to the environment, to the world, in your garden, if it's available to you, or if you can go for a walk in a park or in the forest and just be around nature. I've used the beach a lot, just to sort of connect me with other sorts of elements. So I think that connection doesn't necessarily just have to be with a huge group of friends at a party. It could be these small ways to connect, in other ways. Maybe grab a friend and go down to some sort of nature elements that can restore you a little bit together. Go for a walk, maybe in your neighborhood, say hello to, your neighbor or if you go to the store, even in your daily life activities, you can incorporate, as other folks were saying, into these small social interactions can actually add up to something quite meaningful. And so it doesn't have to be.

PART 2 OF 4 ENDS [00:30:04]

Dr. Indu Subramanian: Interactions can actually add up to something quite meaningful and so that can actually add up to something quite meaningful. And so it doesn't have to be two hours on a Zoom meeting, actually, this sort of little smiles, little sort of hand waves can actually be very, very therapeutic. And I think getting out in nature as the summer's kind of approaching, people have kind of started to fall out from the winter in many parts of the world. And hopefully, we'll be able to connect a little bit more outdoors, I think would be a really good way to get over that Zoom fatigue.

Stephanie Paddock: Mm-hmm (affirmative). Yeah. I've found that even some of my colleagues and I, instead of taking another Zoom meeting where we're all sitting and looking at each other on a screen, we'll make it a phone call and people will be walking outside while they're talking and listening. And so mixing it up and finding different ways to interact. And I love now that the weather is getting nicer and we can all be outside a little bit more,

- Larry Gifford: A landmark study that could change the way Parkinson's disease is diagnosed, managed and treated is recruiting participants now. PPMI or the Parkinson's Progression Markers Initiative needs people with and without Parkinson's, especially people aged 60 and up who have close relatives living with the disease. Take a short survey today at michaeljfox.org/PPMI to see if you're eligible — that's michaeljfox.org/PPMI.
- Stephanie Paddock: Another way to build connections that I want to happen too is through the Foundation's grassroots fundraising program called Team Fox. Believe it or not, that's how I actually got involved with the Foundation over 12 years ago in support of my dad who was living with Parkinson's. I signed up to fundraise for the New York City triathlon and then became a member of the New York City young professionals group that was just getting off of the ground. There are now eight different YP groups across the country that actively connect, meet, and fundraise together and similar to all Team Fox time fundraising a hundred percent of the proceeds that come in through events that are held, go directly to the Foundation's programs to speed a cure for Parkinson's disease.
- Stephanie Paddock: And, Ned, I absolutely love this photo of you showing your guns. How did you first get involved with team Fox back before meeting Jimmy Choi?
- Ned Neuhaus: Well, actually in 2016, which is right before I met Jimmy, we did the inaugural Star Wars 5K at Disney. Our older daughter works at Disney and she works some of the run Disney events and she really wanted to participate in one. And so my wife and daughter and I ran that 5K. And quite honestly, I was a little reluctant to ask people for donations. So we just put a couple of notices out on Facebook and the response was overwhelming and we raised \$3,000 with not even really trying. And it really opened my eyes to this.
- Ned Neuhaus: And then as Jimmy mentioned in 2018, it was my fifth anniversary of being diagnosed. So I said, it's five years, I'm going to run a 5K and I'm going to raise \$5,000. And the \$5,000 came pretty quickly and Jimmy called me up and said, you need to double it. And with that motive, with that little bit of spurring which is very, if anybody who knows Jimmy knows he does that. I did and we raised about \$12,000 that year and I ran it a couple more times and then I started hosting my own events and the one we did last year, I'm very proud of how it just expanded on itself. A friend of mine and I decided we were going to roll a million meters on the rowing machine to raise awareness and raise money for research. And we put it out there on January 1.
- Ned Neuhaus: And before the end of January, 20 people from all over the place joined up with us and we wanted to have an in-person rowing day, but we couldn't do that with the pandemic so we're going to do that in 2021. And the road is slow, Parkinson's has really introduced me to some amazing people. In fact, one of our members is at the US Olympic training camp right now, trying to qualify for the Paralympic team. And he's got a really good shot and it's just so amazing. You know, the people you meet, he lives in Portland, I'd have never met him otherwise. And I've got a little insight into what it's like to be training for an

Olympic event. Now it's just so cool that the people we met through Team Fox are just amazing.

Stephanie Paddock: Wow, that's incredible. And I remember when I first met you actually at a Jimmy Choi's event. And so yes the Team Fox community definitely brings people together. I'm curious, you said that you were reluctant to go out to people with your fundraising efforts, what kind of got you past that and what kind of advice would you give to people?

Ned Neuhaus: Well, I guess what finally got me past it was this, what I referred to before is I'm now the guy that does stuff he's not comfortable with. And I take more chances and I just decided it was worth it because we wanted to do something to give back to the community. I think Lynn mentioned how much Michael has done for her, reading his books early on, really [inaudible 00:35:28] and I wanted to do what I could to give back and that got me over that hump. And I think the advice I'd give people is you're not gonna hurt yourself by asking people for help or for donations. The worst thing that can happen is everybody ignores you and that's probably not gonna happen. You've got people that care about you more than you realize, and this is a way for people to be part of your journey. And it's been very rewarding for me.

Stephanie Paddock: It's amazing. I think I need a new mantra, which is to be more like Ned, which is to get out of my comfort zone and try new things. And so forget about, what is it, be like Mike, it's be like Ned.

Ned Neuhaus: I'll take it.

Stephanie Paddock: Lynn, I'm curious. Have you participated in any Team Fox events and what has your experience been like?

Dr. Indu Subramanian: So I have participated in team Fox events. Mostly I was in a 5k at Battery Park in New York City and it was just amazing. It was so much energy. It was just wonderful. And I thought I finished the race but I was only halfway through, I almost came in dead last, but it was amazing through "Shakers Anonymous". So we have always had speakers come in representatives for Michael J. Fox and we basically all send weekly emails about what's going on in Michael J. Fox. And through "Shakers Anonymous" through our group, we have had teams that have come about Chris Tracy, Chuck Hendrix from Mt. Kilimanjaro and he was the only person with PD with his wife gone. So we basically promote Michael J. Fox and his clinical studies for Fox trials so we are advocates of Michael J. Fox in a big way.

Stephanie Paddock: Amazing. And I think you touch upon something that Team Fox is, it's a lot of things. So people can host events, people can show up to other people's events. You know, it can be as much as hosting a thousand person bike ride or a lemonade stand with your kids, your grandkids in your driveway. So Team Fox is a lot of different things and there's different ways to get involved. And there's

more that you can all find out on our website as well. I'm wondering, there's obviously I can tell just by hearing you Ned and Lynn, there's a lot of joy and happiness that comes out of these connections, but into how something like this improves someone's quality of life overall.

Dr. Indu Subramanian: Yeah I mean I think that a lot of what we've done as Parkinson's docs is find a pill to help with motor symptoms historically and refined surgeries. I've really spent a lot of time in the pandemic trying to explore a little bit of the secret sauce of what makes people do well. What is the secret that really makes people thrive? But that you can meet two patients on the same day with Parkinson's that are exactly the same. And one because of positive attitude with focus with great purpose with great meaning can really do well. And others with maybe not some of those things may not thrive as much and really look very different five years later. So I really have been trying to figure out sort of what brings people that passion, meaning, purpose, and trying to refine that a bit.

Dr. Indu Subramanian: And I think what we've realized in the pandemic is that these sorts of social connections that we've all been missing. It's not just our patients. It's really all of us, even as healthcare providers, I don't get to see my team nearly as much. I don't get to get advice and hugs and connect nearly as much with the rest of the people that I've grown to love. You mentioned the meetings that you go to that bring you joy. I've missed that and the camaraderie that we really have and all of the sort of fabulous travel and connections and collaborations. So I think that re-kind of purposing that and trying to figure out how to bring those sorts of things to yourself on a daily basis is really important. And I think that we can't also forget about the cultural context that this is around for each and every one of us.

Dr. Indu Subramanian: So I know I have friends right now that are really interested in social justice and really learning about their heritage and figuring out forefathers brought to this country and how to really change that other people, it's about sort of seeing their grandchildren for the first time and playing with them and re-sort of establishing those connections. And so for each of us, it's going to be really different. And I think that we have to kind of just take a moment and forget about necessarily tremor rating scales and how fast you can walk from point A to point B and say what is it in my life that really brings me a good quality of life? What is it that makes me wake up in the morning and brings me joy and meaning and try to focus honestly on those sorts of things and figure out in your own world, who are those people that support that, that help be your cheerleaders, are your tribe, are the people that really, you reach out to, forge meaningful relationships with those people.

Dr. Indu Subramanian: And I think, it may be somebody that you do need to ask for help from, and that's okay. I mean, I think many of us have sort of our mantra historically, has been like be independent, be you're your own person and we don't need each other. And I think I have really sort of spent some time really rethinking that and understanding a little bit more about how we are all completely connected on this planet to each other, right. A virus that starts across the world is affecting

my family and how I wear a mask that's gonna help you protect yourself from getting this. And so I think that sort of feeling of social connection, but sort of altruism of doing things for each other is so meaningful. I think we really have to kind of I think pause and try to reinsert that in our lives.

Stephanie Paddock: Yeah, definitely. And I think, we're all eager to get back to those hugs and things that we've been missing so much, but we've also been able to really hone in on some of these connections that we have made online. And during this period of time, we at the Fox Foundation really saw a need for a tool to be able to connect the community virtually. So the Parkinson's Buddy Network is a new online network to connect members of the Parkinson's community virtually. Think of it kind of as like LinkedIn meets Facebook. The pandemic really solidified the need for this tool. And as a way to provide a way to combat isolation and loneliness in our community. Now that we have gotten through a few months of testing, we are really excited to open this platform to everyone and you can find the link to join in the resource list.

Stephanie Paddock: We encourage people living with Parkinson's as well as their loved ones and care partners to join and find others that are going through similar experiences during the signup users will answer onboarding questions that pertain to their experience and what they hope to learn and who they hope to meet. Then users can search for others with similarities, some private messages, join groups based on different topics and engage in open form dialogue. There's also a way to find others that can help you kind of forge that mentor relationship. If you're looking like you said into that, you need to reach out and ask for help. Ned, I know that you have been a part of the network since day one. What has your experience been like with the Parkinson's Buddy Network?

Ned Neuhaus: Well, I think you explained it very well. I'm a member of I don't know how many Facebook groups related to Parkinson's. You know, young onsite groups, exercise groups, you name it. I'm chairing some of them, I'm participating in some of them, but the real weakness with Facebook is it doesn't have the profiling that you go through the onboarding questions that you can on the Buddy Network and you know right away if somebody wants to have something more than an online interaction on a Facebook group, they say "Hey, I'm interested in meeting people. I'm interested in meeting other young onsite, whatever it may be." And I on the first week it was out there. I met a couple of people and it was that quick and we don't interact every day, but we touch base from time to time.

Ned Neuhaus: And we talk about things that are going on in our lives. Things may be going on with Parkinson's, maybe things not related to Parkinson's. And it really is a great way to meet people from literally anywhere. There's great subjects out there. I get email notifications of "Hey, there's something on the young onsite group or there's something in the exercise group." and it spurs me to go back out and look and see what's out there, learn from what others have to say, put my two cents in and kind of watch the interaction as this thing grows, I'm excited about

what it has the potential to become it's already great, but it has potential to really be a game changer for the Parkinson's community.

Stephanie Paddock: Yeah. And like you mentioned, people can join. You've met people from all over the place. We currently have individuals from 49 states, we're waiting for our first user from North Dakota to join. And I think 45 different countries represented so people can join and connect with others from all over the globe. It is obviously a way for people with PD, their loved ones, care partners, to connect. Lance, why is it so important to meet with others that are part of this Parkinson's community?

Lance Wilson: I think that everybody on this call would agree that I think one of the biggest things is a sense of community. I think, not to go back to the title of this entire presentation, but ultimately letting and informing people that they're not alone. I think that sometimes people can get caught up in their heads, all people, in and outside of the Parkinson's community. And then what happens is, is that no one experiences the way I am experiencing, no one else is having these issues the way I'm experiencing these issues. And I think that one of the biggest things, and specifically about the PD community, is that there are alliances and there are friendships, and there are lifelong relationships that are built. And the commonality that brought anyone together was the fact that they were affected or had some type of tie back to Parkinson's.

Lance Wilson: So I think primarily there's an empowerment that happens when people are able to identify other people that are going through the same experiences. Sometimes people call it a trauma collaboration or something, there's a thousand different ways to call it that. But ultimately, people who identify and share your experiences are people that you begin to build bonds with. And that's important, and especially with dealing with a lifelong disease such as Parkinson's.

Stephanie Paddock: And I think something you just touched upon... Ned said earlier that Parkinson's doesn't define him, but there is this common thread. There's obviously this thread that weaves through everyone that is part of this community. But then especially within the Buddy Network, there are ways to search for others based on hobbies or interest areas. So you can connect with others that are also into knitting or boxing and, and connect on that level. And yes, there is the thread of Parkinson's, but you can talk about other things and bring other aspects of your life together.

Ned Neuhaus: Yeah, just to add. Something we started saying, my wife and I, early on in the process as we started to meet people with Parkinson's, only good people get Parkinson's. We haven't met somebody we didn't want to have another interaction with and I think there's some truth to that. Maybe it's somewhat those are the people that are more outgoing, whatever, but we've made some really good friends that we would have never have met otherwise.

Stephanie Paddock: Yeah. I couldn't agree with you more. Everyone that I have met through my time working at the Fox Foundation has been incredibly warm and inspiring and all good people. I guess one last question before we turn over to official Q and A is regarding the Buddy Network. Ned, what advice would you give someone who's considering joining?

Ned Neuhaus: Put yourself out there. It's as simple as, the worst thing that can happen is you don't like it. The best thing that can happen is it could change everything for the positive. Think about what you want out of it. You can alter your profile at any time. If you're young onset, you want to meet other young onset people, that's a great way to do it. Talking to people about exercise, just put that in there and join the forum on exercise. There's a lot of flexibility.

Stephanie Paddock: Awesome.

Dr. Indu Subramanian: One other thing that might be kind of interesting to people. So I think that the Buddy Network sort of fits into this sort of new, kind of a concept of what we call social prescribing, which is sort of literally that we're taking social support and prescribing it to our patients through, either it could be a person like a social worker that links that person to another organization, or a support group like this. And so I think it's really kind of an exciting new wave of the future. And I think we have it in our midst. And I know at the VA we have a similar kind of system where we're trying to pair people with like interests really through this sort of [inaudible 00:49:31] people kind of connect. And I think it's a really a beautiful thing to use technology in this way to really prescribe this intervention, which I think is a basic human nutrient.

Dr. Indu Subramanian: So I think for patients out there, for people out there that are living, we talk about food and shelter and water and sleep as basic human nutrients. Exercise maybe as well. I think social connection is a basic human nutrient. And so when you're feeling lonely, you're not alone. It's very a normal thing to feel that, to sort of crave human connection. And so I think getting out of your comfort zone and using something like this, it's kind of a beautiful way to connect. And I think you also told me that you've connected people, even in their own backyards almost, through this sort of network, is that you were able to connect people geographically to other people that were in their community, that they may never met them.

Stephanie Paddock: Yeah, and thank you for bringing that up. There is a way to search within the network in a map view. So you can search people based on where they're located. And I've now heard multiple stories at this point of people that have connected with folks that live the next town over or a two minute drive away. And so, people that they would've never met otherwise. So while as well it's an online network, there's still that opportunity to then meet people in person. And as things open up a little bit more, hopefully more people will be able to meet through the network and then become friends in real life. I thank you all so much. I'd love to transition over to Q and A. We have been getting some great questions that have been coming in already. I'm going to start with a

question for Lance that came in, how do I find a local social worker and support group?

Lance Wilson: Great question. Especially if you are not in a heavy area that has a lot of academic medical institutions, you have to get a little creative. I've gotten this question a few times. I typically tell people, one of the things you can do is contact your insurance. A lot of people are not aware that there are typically care coordinators and social workers at the insurance company that can kind of navigate you to some additional resources, as well as finding those local institutions. So finding those Parkinson's and movement disorder centers that even though it might not be local to you, I promise that I have gotten and received all types of emails, phone calls from people that are nowhere near Philadelphia, just asking and interested in connecting. And if I don't have the best answer, I can tell them what I do have access to. And if I don't have the answers, I probably am in contact with someone who has a better answer for them to make that connection directly with them.

Stephanie Paddock: Great. And this next question that came in is for Lynn. How did you find your small group of women with Parkinson's?

Dr. Indu Subramanian: Good question. It was through Michael J. Fox again, because I'm on the Patient Council. One of the women that contacted me wanted to talk to another woman that was much like her and I'm a retired nurse, and so she sought me out. She found me through the internet and through that, we developed this woman's group. So I think that the Buddy Network is fabulous for people who are newly diagnosed, because a lot of times that's where they want to start. They want to meet somebody else like themselves. So that's how I did that.

Stephanie Paddock: Yeah. And I definitely think that we'll see more people connecting through the Buddy Network as it continues to grow. This next question is for Indu or Lance, I'll let you guys decide. How do I explain to others who matter to me, my husband's apathy towards my attempts for my own social life?

Dr. Indu Subramanian: I can take a crack at that. So I think apathy is, as I mentioned, tremendously distressing. And I think that a lot of the times, when you have a family sort of circle of people and you're used to getting together for birthdays or friends circle, and there was a dinner happening, and a person is totally withdrawn and looks bored. And it's kind of embarrassing sometimes to the loved ones to say, hey are you not interested in this? Do you not want to be with us? And I think it's important for people to realize that as part of Parkinson's, sometimes there's a lack of facial expression and the apathy is just part of the disease. So it's not an insult, they shouldn't take it personally. So that's number one.

Dr. Indu Subramanian: Number two, I think we really have to give a shout out to our caregivers out there. We realize that this year has been horrible in terms of you being able to get breaks. Many of our caregivers have been tirelessly alone and isolated themselves with their loved one. Sometimes two people in a home for months and months and months, and not without any other interaction.

Dr. Indu Subramanian: So I think that getting breaks for yourself as a caregiver is absolutely something that we have to encourage and prescribe. And I really spend time talking to my caregivers and making sure that they're getting time for themselves. So I would say that if people are giving you a hard time about your own trying to get out and get a break and socialize, I think that you [inaudible 00:55:02] to do that for your own wellbeing and wellness and that that they shouldn't take it personally if the other person, the person living with Parkinson's, does not seem to be interacting. I still think though that it is important to make efforts every day to try to do something on the calendar, because often patients with apathy will say, it's hard for me to get started, but once I'm in the sort of setting, I kind of enjoy myself and it's actually great. So just make that step to put something on a calendar and get out the door. Once you're there, I think you'll be feeling like you're kind of more into it.

Stephanie Paddock: Yeah. And it's a great reminder that we encourage loved ones of people with Parkinson's and care partners to also be joining the Buddy Network and have that as an outlet to meet others and have discussions and talk through some of the things that care partners and loved ones are going through as well. I will throw this one over to Lance, how to deal with isolation while not being able to publicly disclose my diagnosis at work.

Lance Wilson: So that is actually quite common. So first of all, kudos to you for doing what you need to do to make yourself feel safe in the work environment. That sometimes can be a very slippery slope. But I think primarily how you can make sure that get it is... I'm sorry, can't talk today. But to do what you need to do in regards to the isolation is something that we've said multiple times on this talk today is connecting with people, with things that have completely nothing to do with your diagnosis. If you need a certain adaptive things that needs to be done, then that's fine. But I think ultimately, remembering that you are a person with Parkinson's, not Parkinson's in an entirety. And I think that that's something that we've echoed today a few times. So making sure you do whatever you need to do for you to protect yourself and your wellbeing, but also not allowing that to kind of corner you, because you are somebody outside of your diagnosis.

Stephanie Paddock: Definitely. This next question, I'm going to throw over to Ned. How to manage being embarrassed about your diagnosis and how can you gain confidence in going out with Parkinson's?

Ned Neuhaus: Great question. And I lived that. I was terrified of letting anybody know. It relates a little bit to the question about work as well. What I found, what really worked well for me, is take baby steps. I went to a support group, safe zone. I met some people there I could talk about having Parkinson's and kind of get over that in a friendly environment.

Ned Neuhaus: You could go to an exercise class, a Rock Steady class, whatever, and make it very clear, I'm not public with my diagnosis. And you've got built in people that are there to protect you because most of them went through the same thing. You don't have to go rip the bandaid off and make a public post on Facebook or

on YouTube or whatever, and say, I'm here and I've got Parkinson's. You can take small steps. And as you gain more confidence and you get positive reinforcement from people, it gets easier and easier the more people you tell.

Stephanie Paddock: I love that. Take those small steps. There are small steps that we could take every day. And I will end with that question. I want to thank you all for being a part of our community and joining us today. A huge, special thanks to our panelists for sharing both your time and expertise. We hope that you found it helpful. Please mark your calendar for our next webinar on June 17th. Stay safe and stay connected.

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PART 4 OF 4 ENDS [00:59:40]