

Michael J. Fox:

This is Michael J. Fox. Thanks for listening to this podcast. Learn more about the Michael J. Fox Foundation's work and how you can help speed a cure at michaeljfox.org.

Michael J. Fox Foundation:

Navigating Parkinson's disease can be challenging, but we're here to help. Welcome to the Michael J. Fox Foundation podcast. Tune in as we discuss what you should know today about Parkinson's research, living well with the disease and the foundation's mission to speed a cure. Free resources like this podcast are always available at michaeljfox.org.

Larry Gifford:

Hi. Welcome to the Michael J. Fox Foundation Parkinson's podcast. I'm Larry Gifford, a proud member of the Michael J. Fox Foundation Patient Council, executive director of PD Avengers and the host of another podcast called, When Life Gives You Parkinson's. As we've all learned from our COVID-19 experiences, isolation, quarantine, masks, social distancing, it can make for a lonely existence. Who misses hugging friends more than me? Nobody. That solitude can amplify symptoms, exaggerate emotions and lead to a realization that it's dinnertime and you're still in your bed clothes from the night before. At the Michael J. Fox Foundation, the realization actually was everybody in the community needs a buddy. People with Parkinson's, care partners, family members, we all need someone. It's always been important to build social connections with others in the PD community, but never so desperately as the last year and a half. While the Michael J. Fox Foundation was founded on funding research, engagement with the PD community was almost immediately a complimentary focus.

Michael J. Fox:

The Michael J. Fox Foundation launched in 2000 with a singular goal to cure Parkinson's disease. We focus on raising vast sums of money to fund the most promising research but a funny thing happened on the way to cure Parkinson's. The foundation grew into more than a research organization. Our forums, events, even our website became a nexus for a Parkinson's community to form. One that offered support, advice and mentorship. PD patients discovered the best way to connect to other patients was often through us.

Larry Gifford:

You meet this need, the foundation created the Parkinson's Buddy Network, an online network designed to connect members of the Parkinson's community, allowing them to make meaningful connections, engage in important dialogue, find PD resources and build long lasting relationships. The Buddy Network is available online at parkinsonsbuddynetwork.org And we'll share that address in the podcast liner notes too.

Larry Gifford:

Well, I would like to introduce you to our panelists today. Stephanie Paddock is the vice president of community outreach and events at the Michael J. Fox Foundation and the lead on the Buddy Network. Hello, Stephanie.

Stephanie Paddock:

Hi, Larry.

Larry Gifford:

Bob Harmon, person living with Parkinson's and Parkinson's Buddy Network member. Bob joins us from central Florida. He's 73 years old, an active Team Fox member and a long time. MJFF community member. Hello, Bob.

Bob Harmon:

Hey there, how are you doing?

Larry Gifford:

Oh, I'm doing great. It's good to have you here. Thank you for taking some time for us. Chris Kester-Beyer, a person living with Parkinson's diagnosed in 2017, like me and a Parkinson's Buddy Network member. He lives in Nebraska. 64 years old, he joined Team Fox in 2020 and is a little bit newer to the MJFF community. Hello, Chris.

Chris Kester-Beyer:

How you doing?

Larry Gifford:

I'm good. Thanks for joining us today. I love that we're doing this Buddy Network. Everybody's like, I wish there was a social media platform for people with Parkinson's where we could just talk about things and I didn't have to hide things from my friends that don't know about my Parkinson's yet or my colleagues. And this is really, Stephanie, this Buddy Network is a blossoming into this great community online.

Stephanie Paddock:

Yeah, we have seen such a great response. People signing up. The Parkinson's Buddy Network really is designed and I like to think of it as kind of Facebook meets LinkedIn, but without all the other noise, as a way for members of the Parkinson's community to connect. And so it's for people with Parkinson's, their loved ones, their care partners and is a way to really make connections. Whether that's a one on one connection through messaging, share different stories or questions or comments in a public discussion, join different groups based on different interest areas and just a way for people to connect. We know that those feelings of apathy and isolation and loneliness can be apparent in people living with Parkinson's.

Stephanie Paddock:

And so the Buddy Network kind of stemmed from an idea and we very quickly got things up and running. When we launched our beta product in December of 2020, we had just a couple hundred people in the platform, but it gave us an opportunity to work out some kinks and learn from them and see what was missing. And now we have nearly 2,500 people in the platform and are looking to have 5,000 active users by the end of 2021. It's an ambitious goal but we're halfway there. And we are just so pleased to see that connections are being formed. People are engaging in open discussion and Chris and Bob are just two of the incredible people that have connected through the platform so far and we're excited to see what comes. We also are promoting events through the network, our third Thursday webinars series and some of our upcoming community events.

Larry Gifford:

Chris, how did you hear about the budding network?

Chris Kester-Beyer:

Got the email from Fox Foundation that they were testing this new beta platform and asked me to join it and I did. Put out my profile there and started searching and through my searching of connections of exercise and time diagnosed and things like this and Bob's name came up and I thought, oh, sounds like a good person to try. And I messaged Bob and we started connecting.

Larry Gifford:

Oh, that's amazing. Bob, how did you get connected to the Buddy Network?

Bob Harmon:

Well, I've been around the Fox Foundation for a number of years and there's this saying that we've got about you're not alone, that we've used forever. And with the pandemic, when it happened, I immediately said, "This is something I want to be in because I really want members of our community to know that we're out here." And I think this is a great way to be there for them to find us.

Larry Gifford:

When Chris reached out, what did you think?

Bob Harmon:

I didn't know what the think. It was just a reaching out. I think we were talking originally about things that were similar to us or I was trying to help him get some information on a support group. And so we went from the emails back and forth to a video call and started from there.

Larry Gifford:

And was he the first connection you made?

Bob Harmon:

Yes.

Larry Gifford:

What was your intention joining the network and meeting with Chris? What did you think your role in that was?

Bob Harmon:

With being diagnosed for it's 15, 16 years now, I thought I could impart some of my experiences and knowledge to those who needed it. I'm like anybody else, I need contact, I need support. I said, "What the heck? I've got nothing to lose."

Larry Gifford:

Right. And Chris, when you reached out to Bob, he seemed like a pretty good guy then?

Chris Kester-Beyer:

Yeah, Bob really did seem like a great guy. And I just wanted to find out a little bit more about him. And he kept wanting to find out more about him and especially, I had a selfish reason for kind of joining the network is I wanted to find somebody who was been down the road a little bit further and doing it somewhat, what I see as successfully. And Bob has met those kinds of requirements. And so I was pleased to learn more about him and to find out that you can have Parkinson's and you can deal with it.

Larry Gifford:

Oh, that's great. Chris, that's what you learned. Bob, what did you learn from Chris?

Bob Harmon:

Not to pick up the phone? No, I got the opportunity to talk to Chris about my journey and kind of the way I dealt with it. We talked about similar symptoms that we both had early on and how we're doing now and how that's changing.

Larry Gifford:

How often do you guys still talk?

Bob Harmon:

Usually every month.

Larry Gifford:

How long have you been doing that?

Bob Harmon:

Since December.

Larry Gifford:

Wow.

Bob Harmon:

Yep, that's when the first contact happened and we both came away after having spent an hour on the...

Bob Harmon:

We both came away after having spent an hour on Zoom with each other. We said, "Let's talk again." And it just seems to become something that we both enjoy and because we enjoy it, we probably need it. It's a great resource.

Larry Gifford:

How has this helped you, Chris?

Chris Kester-Beyer:

Basically it's given me a lot of hope. And as I look at Bob and hear his experiences and his dealing with it and living with the symptoms and doing things like golfing and all those experiences, I go, "Wow." I can

possibly look forward to living with Parkinson's in a way that does not... challenges your life, but it does not need to stop it. It encourages me to keep going forward. I consider myself somewhat active. I bicycle, I run, I'm still employed full-time and I look to Bob to give me the hope and the energy to keep going.

Larry Gifford:

I imagine with once you establish a friendship, a buddy-ship over the course of six months, you're able to start diving into some deeper topics.

Bob Harmon:

That's true. I know when I came to the relationship, I felt that I'd be the mentor and help this person down the journey. And as we got to talking and Chris is very comfortable to talk to, and we talked about things that I don't talk to other people about for whatever reason. One was depression. I just don't talk about it because I don't have time to, I want to be positive and keep going and do that. But that's an anchor and I was comfortable almost immediately talking with Chris to be able to talk that kind of an issue. So I became the the needy, not the need-er.

Larry Gifford:

So suddenly the Buddy Network became more than just you being able to offer what you know, it's also now serving you.

Bob Harmon:

Absolutely.

Larry Gifford:

Yeah. That's amazing. Stephanie, when you hear this story, how's that make you feel?

Stephanie Paddock:

I mean, this story is quickly becoming one of many that we're hearing from community members. And I remember getting on the phone with Bob probably a couple of months ago now. And he said, "I met this gentleman and we set up a call and we got on the phone and we said, 'okay, now what do we do?'" Blind date style, I guess. But I think knowing where that started and hearing this story that they're both being able to learn from each other and lean on each other, I think that's what the Buddy Network is all about. And I'll say one thing, when people are signing up, there is not a lengthy, but a decent onboarding process to ask specific questions that are... it's one set of questions for people with Parkinson's and other set for care partners and loved ones.

Stephanie Paddock:

But it really digs into what you're looking to gain from the network and what some of your interests are, hobbies are, your stage of disease. And I think through that onboarding process and within the Buddy Network, you're able to really filter in and meet the right people. This was, I think, Chris's first outreach to Bob and it clicked. That might not always happen, but through the Buddy Network, you're able to really dive into finding that right person or people to make these meaningful connections. And we're hearing, as more and more people are joining, that more and more people are reaching out and saying, "Hey, I connected with someone and we had a great conversation. And I found out that we live two

miles from each other." So these things are happening and it just reiterates how important this network is.

Larry Gifford:

When I signed up for it. So you first, you put in your name and your email, it asked me for my cell phone number so it can send me some SMS messages when I get a new message or whatever. I can put in my interests. I said how long I've had the disease, they give you ranges of how old you are, and you can put your city in there or any number of cities, in fact. Maybe you have a Florida home and a New York home or whatever. And so you want to meet people in both places, or maybe you're just in the car all the time, just driving around and just you're everywhere. But I like to meet people everywhere. What I was surprised to find out is I immediately, when I looked in my little area, there was people from some of my original support groups that I've lost track of. And so I was able to reconnect with people, which is really cool. I'm like, "Oh, I haven't seen Les in forever! I wonder how he's doing." For me, that was a surprise of it.

Speaker 2:

A landmark study that could change the way Parkinson's disease is diagnosed, managed, and treated is recruiting participants now. PPMI or the Parkinson's Progression Markers Initiative needs people with and without Parkinson's, especially people age 60 and up who have close relatives living with the disease. Take a short survey today at michaeljfox.org/ppmi to see if you're eligible. That's michaeljfox.org/ppmi.

Larry Gifford:

Now with the social media and with the Parkinson's community being mostly on the older end of the demographics, I'm sure they're concerned about security and about it being too complicated. And so what has the Michael J. Fox Foundation done to make sure that everything is safe and secure?

Stephanie Paddock:

It is a safe platform that we have vetted. We are not going to be spamming the community. People have to opt into our emails if they'd like to receive them. There is also some basic terms and conditions. There's also a code of conduct that people sign off on when they are registering. We want to make sure that it's a safe space, that people feel comfortable, feel comfortable sharing. First name, last name and email are required to sign up, but then you can actually change that name if you'd like to, or post things anonymously in the platform. Because if people are not yet out with their diagnosis or still trying to gauge things a little bit, you can post anonymously. We're also here to support.

Stephanie Paddock:

So there is info at parkinsonsbuddynetwork.org, and people can email us. We've been answering questions, some about the onboarding. Some people have emailed in and say, "I signed up, now what do I do?" So providing help and support. There's also resources in the network to help people navigate a little bit better. And again, we're here to support. We want to make sure that people are having a safe and supported time in the platform.

Larry Gifford:

Well, yeah. And you mentioned the resources, it's a great connection to the Michael J. Fox Foundation because oftentimes we'll get emails or whatever, but it's all in one place. So you can go look at some of the videos, you can look at some of the resource guides, you can... everything that you guys have.

Stephanie Paddock:

And I think along with the resources, I think everybody that's in the network is a resource. There are discussion topics popping up left and right about learning more about DBS, or "Has anybody tried this type of diet?" Or "I'm thinking about this medication." And I think not only can we provide MJFF resources, but the community is providing resources to each other. We do not want people sharing medical advice necessarily, but if it's your own experience and what has worked for you, and you're providing that in a truthful and honest manner, then I think that can provide a resource for the community as well.

Larry Gifford:

I just want people to hear what I heard, which is everybody who is part of the Buddy Network is a resource to the community. And I think that's really important because it gives us all that sense of value, which is oftentimes what we lack when we get diagnosed with Parkinson's is we feel like we've lost our value to most of society. So what you're doing is a real service to the community. Chris, I'd be interested in, have you shared the Buddy Network with anybody that you know, or have you met other buddies online?

Chris Kester-Beyer:

Yeah, I actually just met another buddy online. And it happens to be in Nebraska, small town in the middle of Nebraska, I'm on the edge of Nebraska and been talking to him a little bit, not developing quite as fast as it did with Bob, but that's okay. Just send a couple emails back and forth a little bit. And I think that's kind of the beauty of the, again-

Chris Kester-Beyer:

... back and forth a little bit. And I think that's kind of the beauty of the, again, The Buddy Network is, I can send a message to him, he can send a message to me, and we don't have to give a lot of personal information yet. We can kind of explore it and go, "Okay, is this person somebody that I really want to connect with?" And then kind of like a dating relationship, you have to take the next step, and be comfortable with it, because if I find out that this person, for whatever reason, is not somebody I want to continue with, I haven't given them my email, I haven't given them my phone number because we connect through The Buddy Network, and so all of that is secure. I don't have to give it to the other person until I feel comfortable.

Larry Gifford:

That's great. And then, Bob, did you know he was cheating on you?

Bob Harmon:

No, I didn't. I knew something was up because it was my turn to call and he wasn't there. [crosstalk 00:19:00] any minute, but no, I know now.

Larry Gifford:

Have you had any other connections on The Buddy Network that you'd like to share?

Bob Harmon:

Yeah, I've had a number of issues that are presented by people to me, "Where can I get to a support group?" And those kinds of things. And, "Where can I get information?" And I try to steer them in that direction. Some folks, I found somebody who went to college when I was there, we were near each other, but he was still living near the college. So some people, I don't want to talk to them. I've got 10 or 12 golfers I'm trying to put together to see whether we could do something.

Larry Gifford:

Oh, that's great.

Bob Harmon:

Yeah. And that could lead us into the other side of Fox Foundation where we could do... [inaudible 00:19:50], some are hot topics. Some are cold. And if it's a hot topic, I engage. If it's a cold topic, I say, "I just really don't do that. I do this. But if I can help you in the end just don't hesitate to get back to me." I've had a number of people.

Larry Gifford:

For folks who've never used a social media platform, or maybe just only Facebook, how would you compare the experiences? And, I'm guessing a lot of people are just nervous to join another social media, even though it's run by Fox. It's like, "It's another thing I've got to check." Or, "It's another thing I've got to do." How would you talk them through the process?

Bob Harmon:

Well, the thing that I found was that it was more secure than I'm capable of breaking. And I felt that if I couldn't get to something, it was hard to get to. And I could get back to the foundation and get resources, engage to get answers. So I just right away became comfortable with everybody else who's out there. They're suffering, like we all are.

Larry Gifford:

Yeah.

Bob Harmon:

And the platform itself by not being perfect in the beta, gave me a little trouble moving around. And I thought, that's good. If you can't find me, that may be a very good thing.

Stephanie Paddock:

Yeah, we learned a lot through feedback from Bob and our other beta testers on ways to improve the platform. And we're continuously, even now that we have launched more publicly, still making updates, still trying to change a couple of things to make it more user-friendly. One thing that I think both Bob and Chris kind of touched upon is this idea that people are looking for people in like life situations, but also looking for that mentorship or mentee kind of relationship as well. And so we're building out an actual mentor group that is going to be a better way for people like Bob, who wants to mentor others,

to formerly raise his hand and say, "I'm here, reach out. I am really eager to talk about X, Y, Z." And for people like Chris to say, "Oh, that's exactly who I'm looking for."

Stephanie Paddock:

So it is happening organically already. Obviously they found each other, but as a way for people, not only to meet people in like areas, but also this kind of mentor, mentee relationship. I know we have our new, not new, but our PPMI study is going to be recruiting once again. And we've got lots of people in the platform that are already part of the study, and are eager to talk about it, and talk about some, demystify clinical trial participation. So I know, we're really excited and eager just to get that up and running. So we have that added layer of people being able to connect.

Larry Gifford:

Well, what's really interesting as you say that, Steph, is when the foundation was founded by Debbie and Michael, it was really research focused, and we accidentally, along the way, found our way into the community. There's this whole big Parkinson's community. And now that Parkinson's community is fueling the research, which I don't think anybody anticipated 20 years ago.

Stephanie Paddock:

No, I think we know that clinical trial participation is just as important as dollars for research. Research can only go so far without people in the clinic being able to donate their time and energy towards research. So anytime that we can promote some of these trials, or help connect people so that they can understand more from somebody that's been down that road, or tried this, or tried that, we're just excited to have those opportunities.

Larry Gifford:

Now are people only meeting on The Buddy Network and then meet in person, or the post COVID, or on the phone?

Stephanie Paddock:

Great question. We are so hopeful that people will take their relationship outside of The Buddy Network. While it does provide an online platform for people to connect globally, we've got all 50 states represented and over 45 countries represented in the platform. But like I mentioned, we're learning about people that have said, "I met somebody that lives two minutes down the road." Or, "A couple of miles away." And we're hopeful that as things are opening up again, people are going to say, "Hey, let's go grab coffee and get together in person." Or like Bob said, "Let's get this group of golfers together out on the golf course." So while the network does provide that safe opportunity, and Chris mentioned, "You don't give your phone number. You don't give your email. It is a safe place to start a conversation." But then if you want to take it outside of the platform, by all means, we're hopeful that people do.

Larry Gifford:

Okay. Now I've got a serious question for your Steph.

Stephanie Paddock:

Okay.

Larry Gifford:

Is the woman who's joining every Facebook group about Parkinson's there, who posts about how she was cured by herbal remedies? How do you keep those people out?

Stephanie Paddock:

Great question. I have not seen such a post yet, but as part of that code of conduct that I mentioned earlier, we have the right to remove any content, or people from the network that are not adhering to that code. That are promoting that they have the magic cure, or that they want to try to sell you a product. We are in the network every day monitoring. We have ways of capturing keywords or phrases that are popping up. And we're definitely taking that seriously. We do not want to turn the platform into everybody trying to sell this, or that. So, yeah, great question, but it is very important to us.

Larry Gifford:

Okay.

Chris Kester-Beyer:

[crosstalk 00:25:41] jump in there? Again, I think that's what I found is that it gave me confidence that when I connect to somebody, I'm not going to just stumble into somebody who's going to try and sell me a herbal product. If I find that thread, I can just kind of leave the connection and go, "Well, they haven't got my contact information, so I don't need to deal with them anymore." I can come on The Buddy Network, and since it's powered through the Michael J. Fox Foundation, it's linked in there, and they won't give out my email, then my phone number, but I can still make connections.

Larry Gifford:

Which is great.

Chris Kester-Beyer:

Can I just jump in? One more thing.

Larry Gifford:

Oh, sure. Go ahead.

Chris Kester-Beyer:

Talking about the social network thing, follow a couple of Facebook feeds, and The Buddy Network discussion pages and stuff like that. But I'm just not a person, I read them, I find good information, but I just don't comment on them. I don't type in a response and join the conversation. Where with this part of The Buddy Network, I talked to Bob, I ask him questions, I jump in. And it's kind of a neat thing about The Buddy Network, the unique thing about The Buddy Network, that...

Chris Kester-Beyer:

The unique thing about the buddy network that separates it from Facebook pages and stuff, which are great, I follow them, but, I don't connect to, I don't communicate through.

Larry Gifford:

It gives you a little bit more, sense of security and a little bit more confidence that, everybody here is in the same boat.

Bob Harmon:

It gives you power of enforcement. You can cut off something that you don't want to deal with. And I had someone who was asking for help finding a support group in their local area. Well, I've got to go find that. And, so I said, I need to know where you live, give me the town and that's all on the state and I'll go from there. And if you don't want to give it to me, that's okay. I just need that to go try to get this information for you. And next thing I knew I had an address and was able to help them.

Larry Gifford:

Is there anything else people should know about the buddy network, why they should join?

Bob Harmon:

I think that we've all faced the challenge over the pandemic in this last year or so. And, when we were able to deal with it on an individual basis and feel comfortable that we were vaccinated and things are going back to normal, things would get better. And, what I found was that during that period there was this cloud over everything, when's it going to get better? And when I was able to get in and talk to folks who had the same challenges I have, above and beyond the normal person in society, to help them, help me get through that and move on to the other side. And that was really empowering and really important to me.

Chris Kester-Beyer:

I lead a support group. I have connections with other people with Parkinson's. As a leader of the support group, I feel constrained not to dominate the talk and at the same time, lead it. And don't necessarily, just jump in and explore the things that I want to talk about and share. Because kind of the leadership role there, I want the group to feel comfortable and not be dominated by me. Again, the buddy network allows me to talk to Bob on a conversational level and connect and I love to hear Bob's stories about being in trials, research trials, not-

Larry Gifford:

Oh, I thought he was being convicted.

Chris Kester-Beyer:

I thought I better clarify that.

Larry Gifford:

Stephanie, why should people sign up for the buddy network?

Stephanie Paddock:

How else would we have connected a gentleman in Florida to a gentleman in Nebraska? I mean, I think that their story resonates. Also, a part of the PD community, my dad had Parkinson's for 16 years. I've connected with other loved ones that have someone that is living with Parkinson's or has passed and have built connections with those people. It's kind of a virtual young professionals network almost of ways to connect with others and just talk. Sometimes it's easier to talk to a stranger than it is your best

friend. And, Bob even said, he's opened up to Chris about certain topics. And, I think the opportunity is there to make these connections, to learn more, to really take charge of your diagnosis or take care of yourself. Whether you're a person living with Parkinson's or you have a loved one with PD. It is a great tool to really give you that power.

Larry Gifford:

Yeah. I was just looking here right now, live in motion here. The discussion page, has anybody been on Sinemet? So there's that question. There was somebody else asking about DBS. I love this question. How do you see yourself in five to 10 years? Do you visualize a healthy you or a compromised you? There's all sorts of great things for people. People asking about where you can find free meditation online. And so this is a great resource. So I encourage everybody to go there. It's the parkinsonsbuddynetwork.org. Parkinsonsbuddynetwork.org. There's an 's' on Parkinson's. Oftentimes it's either a Parkinson or a Parkinson's. This is the parkinsonsbuddynetwork.com

Larry Gifford:

Thank you, Chris and Bob and Steph for joining us on the podcast today.

Stephanie Paddock:

Thank you, Larry.

Bob Harmon:

Take care

Larry Gifford:

And thank you for listening to the Michael J. Fox Foundation Parkinson's podcast. If you like it, please leave a rating and a review on Apple podcasts. It really helps to raise awareness of the podcast and the cause of Parkinson's disease. And please share this episode with your friends and followers on social media. A personal endorsement goes a long way. For everyone at the Michael J. Fox Foundation, who is here until Parkinson's isn't. Thank you for listening. I'm Larry Gifford. You can follow me on Facebook, Twitter, and Instagram. It's the same handle, @parkinsonspod.

Speaker 3:

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