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MJFF: Navigating Parkinson's disease can be challenging, but we are 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, founder of PDavengers.com, and host of another podcast called *When Life Gives You Parkinson's*. Today's show is themed *From Diagnosis On: My First Days with Parkinson's*. Today we're going to hear different experiences from a diverse group of people living with Parkinson's and a care partner about the early days and years after receiving the diagnosis. Hopefully, by the end of this, we'll be able to infuse some hope and positivity, reinforce that there are many, often conflicting, emotions during this time which are normal and understandable and common and many different approaches and paths through this disease. No one has the right answer, except for you, for your journey. We also have a 360 look at this topic in our Third Thursday Webinar, which took place earlier in September, and it is now available on demand at www.michaeljfox.org/webinars.

Larry Gifford: We have a great panel for you today that I'm going to introduce now. Barry Grey was diagnosed in 2021 at the age of 66, is a writer, non-fiction TV producer, book editor from Los Angeles, also is a participant in the PPMI Study. Hello, Barry.

Barry Grey: Hi there. Hi, everybody listening.

Larry Gifford: John Lipp is diagnosed in 2015 at the age of 49, Parkinson's advocate, writer, and nonprofit executive based in the San Francisco Bay area. He refers to revealing his PD diagnosis as his second coming out, a not so veiled reference to his coming out to his family as a gay person at the age of 16. Hello, John.

John Lipp: Hi, Larry. How are you?

Larry Gifford: Great. Great. Thanks for being here today.

John Lipp: Thank you.

Larry Gifford: Tim Hague Sr. And his wife and a partner in Parkinson's, Sheryl, are also here with us from Winnipeg. Tim was diagnosed with Parkinson's in 2011 at the age of 46. As a registered nurse and son of an adopted father with Parkinson's, he

has cared for many people with PD. Tim is the founder of U-Turn Parkinson's and co-founder of the PD Avengers. Tim and Sheryl, welcome to the podcast.

Sheryl Hague: Thanks, Larry. Good to be here.

Tim Hague Sr.: Hi, Larry. Good to be with you.

Larry Gifford: All right. Now that we're through that, let's get to the nitty gritty. So we've all heard about the time it can take to diagnose somebody, but let's skip to the day of the diagnosis. Barry, that day when they said, "You have Parkinson's," what was that like?

Barry Grey: Well, that moment was almost cinematic, and it was almost absurd, and it recalled *Pride of the Yankees*, the 1942 film. It's about Lou Gehrig. And my doctor said the same thing to me. He comes in the room and he says, "Well, I think I have some ideas." I said, "Yeah?" And he says to me, I swear he said this, "Do you want it straight?" This is right out of *Pride of the Yankees*.

Larry Gifford: Wow.

Barry Grey: I said, "Yeah." And he says, "I think it's Parkinson's or Parkinsonism." And naturally my jaw dropped to the floor, and I didn't believe it. I thought he was wrong. He was mistaken. He was in error. He was being ridiculous. That kind of thing never happens to me. And I went home and I told my wife, and the weird thing about my situation is that I had just gotten over a case of cancer, and a few months before that, I was diagnosed with an autoimmune system problem that was pretty serious. And so this was just another slap across the face, and I didn't believe it because it just seemed surreal.

Larry Gifford: Wow. Thank you for sharing that. What a string of luck. John, I'm going to move to you now. Day of diagnosis, what was it like when you heard those words?

John Lipp: So for me, it was about a year long journey, Larry, and when I finally heard those words, and my doctor was a lot more direct, he said, "You have Parkinson's." And for me, it was almost a sense of relief. I knew what I had. There was a label, there was a name for it. And in my mind, knowing that, I could immediately jump into my savior mode and save myself. And so I was actually pretty upbeat about it.

John Lipp: And then I remember driving home about an hour from San Francisco to the East Bay where I live and thinking about it and going through this whole roller coaster of emotions - up and down. And do I want to stop and have a drink and process or am I going to go straight home? And my husband was home that day and I said, "Guess what. I have Parkinson's." And he just looked at me, and my husband's a physician, and he said to me, "You don't have Parkinson's. I don't believe it." So I immediately crashed in that moment. And it was a long, probably about a month process of up and down in research and taking my

husband back with me to my neurologist and having him walk him through the diagnosis and how he got there. But ultimately, for me, the first month was pretty much strangely a high because I could wrap my arms around the disease.

Larry Gifford: Interesting. Okay. Thank you for sharing.

John Lipp: Yeah.

Larry Gifford: Tim, what was it like for you?

Tim Hague Sr.: Hey, Larry. Thanks. A little like John, I have these competing memories about that first day. It was a little over 11 years ago now for me. And I remember feeling like, "You know what? I've got this." Because on the one hand, I was a nurse, and I'd been nursing for 18 years at that point. I pretty much had self-diagnosed myself. I knew that my dad had Parkinson's like he mentioned, and so I knew what Parkinson's looked like. I had a half-sister with MS, knew what MS looked like. So I figured it was one of those two, and I figured it was most likely Parkinson's.

Tim Hague Sr.: So by the time the actual diagnosis came around, which didn't take long, I saw my first tremor in August 2010 and was diagnosed in February 2011. So that's pretty quick for a lot of people. I was pretty like, "Okay, this is what it is, but I'm young, I'm healthy, I'm still doing lots of things, so I'm just going to go on with my life. I'm going to ignore this." But then there was this other kind of juxtaposition in my head who was saying, "Oh God, this is going to suck. Is my wife going to leave me? Is my kids going to fall apart? Is my life going to fall apart? What's going on?" So I had these competing emotions and thoughts going on at the same time, but we hit the ground more or less running and just kind of went with it.

Larry Gifford: Sheryl, did you know that he was having these tremors before the diagnosis?

Sheryl Hague: He kept it from me for about three months. He didn't want to scare me, and he thought might go away, and he didn't really know what it was yet. So finally we were on a trip for our 25th anniversary, and he said, "I've been having these problems and it seems to be getting worse." And so we just said, "Okay, we'll go and see your doctor when we get home." And he didn't tell me in that meeting with his doctor, that his doctor right away said, "It's likely young-onset Parkinson's." He didn't tell me that yet. He just said that the doctor wanted to send him for a bunch more tests.

Sheryl Hague: So at some point he said, "Well, it could be Parkinson's." And all along I was like, "No, that can't be right. It must be something else, and it'll be something that we can work on or fix or whatever. It's surely not Parkinson's. He's so young. There's no way." And I didn't really believe it until we sat down with our neurologist and he said, "You've got young-onset Parkinson's." And at that point, of course you're still wanting to deny it. And really, it took me a while to

truly accept it because nothing much changed. I mean, Tim was still going to work. Our life carried on. So it was a whole process of accepting it, I think.

Larry Gifford: Yeah. Let's talk about acceptance because it's not a linear line from not accepting to accepting. And probably the two of you went back and forth on who accepted it better at a certain time.

Sheryl Hague: Yes.

Tim Hague Sr.: Absolutely.

Larry Gifford: What was that like in the house and how you finally got to the point where you're like, "Okay, there's a third thing in our marriage we got to deal with"?

Tim Hague Sr.: I'm not sure how that really went. It's like you said, it's nonlinear. For me at the very beginning, I was like, "All right. Whatever. I've got Parkinson's. I've got it by the neck and I'm going to hold it down and I'm going to make it do what I want it to do. I'm going to carry on biking, I'm going to carry on running. I'm going to do my thing. So I'm just going to be in control of this. Put it on a shelf and ignore it." Well, you know how that goes. That didn't go so hot. And I don't know when we really, really came to terms with it.

Sheryl Hague: I think it's a slow acceptance because it slowly takes your life, and so there's a whole process of, "Okay, this is what it's going to be now. This is what Parkinson's looks like in our life right now." At the onset, I remember Tim telling me, "Well, the neurologist thinks I have five, maybe six, good years of work left." Well, I thought, "That's ridiculous. You're completely healthy. It'll be a long time before you have to leave your job." But sure enough, I think it was...

Tim Hague Sr.: Five years.

Sheryl Hague: ...five years later where he had to leave. He couldn't, for various reasons, couldn't function as a nurse anymore. So I mean, it's a slow progression of accepting it because you're faced with reality and as new symptoms appear, you're reminded again that, oh yes, we have Parkinson's that we're dealing with.

Larry Gifford: And did you grieve the old life and grieve what you thought was going to be your future?

Sheryl Hague: It's more of the old life, and it's a constant grieving because you're constantly losing little pieces of your life. And I think it's a healthy thing to grieve. You have to admit and realize that that's not going to be your life anymore. And you can't stay there. You can't mourn forever, but you have to grieve and to sit with that for a little bit before you can move on and get to that place of acceptance.

Larry Gifford: John, I'm going to move on to you. What was the trigger that said, "Okay, this is real, this is staying, I got to deal with this"?

John Lipp: I came out to my friends through a Facebook post probably about a month after the diagnosis, and I was very positive. And I signed up to run the marathon for Michael J. Fox Foundation, and I was going to conquer this disease. And I found that that energy I created around me with my friends and my sense of community was really helpful and very healing for me. But then as the months went on and I was training and I was limping a lot and some discomfort and pain and trying to find the right medicines and the medications I was on at the time were very unhealthy for me personally, I kind of hit a low point because I realized I had set the bar so high for myself in terms of being "Mr. Positive" and "I'm going to solve this disease" and it's not a disease we can solve, right? Every day is different. You have good days and bad days, good hours and bad hours and so it was the realization I kind of put myself out there too high, too far and then I had to figure out how to walk that back a little bit, that I'm a human being. I'm allowed to have bad days and I think fortunately, having my husband there, he took the brunt of the bad days and the good days. He saw me cry and he was there to hold me up and keep me moving forward. But it's still, I got to be honest, it's what, seven years in my diagnosis and there are some days where I get really low and depressed and I have to force myself to keep moving.

Larry Gifford: I hear you. I hear you. Barry, how about you? What was the point of acceptance for you?

Barry Grey: I'm not sure that I've reached it yet. In all candor, I can tell you that I was on board with it in effect when I finally had to break down and tell my daughter who's extremely sensitive. And she was in the middle of her college career and I did not want to throw her into the ocean with this so my wife and I kept it quiet in the family until six months later. And it was just before the holidays last year that Anna and I sat down with Lulu and said Lulu was home from winter break. And I said, "Lulu, you know Michael J. Fox?" She says, "Yes." I said, "You know he has this really disturbing disorder?" And she looks at me, she says, "Parkinson's?" I said, "Me too."

Barry Grey: It's painful to see your own kid trying to grapple with something that she cannot do anything about. Not that I can do much more, but I can do things to mitigate some of the symptoms and the progression I suppose. But to see her hurting like that was the worst part, that's been the worst part for me, is knowing that she's walking around, the other day I had a slip of memory which is happening a lot more lately, and she remarked to my wife, "I'm watching my dad lose his mind." She meant nothing bad by it, but it just stabbed me because I don't want her to hurt and I know that as time goes on, she's going to be hurting more.

Larry Gifford: I have a 13 year old son now but he was eight when I was diagnosed. And he's actually the catalyst for why I ended up going to the doctor cause I was collecting symptoms but ignoring them like a good person in his forties just as I do can't be too bad for me, I'm young. I never went to doctors, never took

medicine so I just assumed it meant nothing and then I started trembling and he noticed that, and I would try to hand him a glass of water and the water would spill out. And he finally said, "Dad, why are you shaking so bad?" I'm like, "I don't know." He goes, "Well, shouldn't you go see a doctor?" And so he was in the loop pretty early on, even probably before I was that there was something more going on. And so we told him from the beginning, and I'm glad we've included him in that.

Larry Gifford: We gave him little jobs. If we go out in public, I'd say, Okay, now your job is to watch, to let me know if my hands start to tremor. Now I knew when my hands were going to tremor, but it gave him a job. And I think that was really important for him to always feel like he had something to do to help his dad. And he still does today. He'll give me a massage or whatever and he feels like he's helping. What about for Tim and Sheryl, you had four kids at the time. What point did you tell them and bring them into the loop?

Tim Hague Sr.: Well, we told him fairly well right away and they all did varying degrees with it. They were around 20, 16, and 12 at the time. We have four kids, two twins at the 12 stage at that time and the oldest one probably took it the hardest, he was old enough to go get himself online and start hunting for things. He'd get himself a little freaked out and we maybe didn't keep quite as close tabs on him as we should have early on. So he probably took it the hardest, the 16 and the 12 year olds, Well, the 16 year old, she's into her teens and the world's all about her and the 12 year olds... they were a little too young to kind of grasp it yet, so they didn't do too bad with it. They've grown up with it, if you will, but the oldest one took it fairly hard.

Larry Gifford: Sheryl, do you remember their reactions and is it different? Is your memory the same or different than Tim's?

Sheryl Hague: Pretty much the same, yeah. The 12 year olds, they just wanted to know basically how it was going to affect their life and nothing was really going to change so they were okay with that. I think it has been a progression of, as they've gotten older, because they have spent most all of their teenage life living with this disease, they've sort of come to understand it and be more aware of how it affects Tim as they've gotten older.

Tim Hague Sr.: You see them grow in the progression, like we were talking about ourselves growing in the progression of it. It's not a matter of accepting it all at once, like we've said. And I think for them as well it's been an ongoing acceptance of this reality for dad because dad's at a certain place one day. Dad used to run all the time and suddenly dad's not running anymore, can't keep up with his kids, his little girls. You never had a prayer of keeping up with dad and leaving him in their dust now. So things change and they start to see that and they grieve and they mourn and they move through the disease alongside us.

Larry Gifford: Yeah, it's interesting. So now we've talked about the diagnosis and the journey of acceptance and I think part of accepting it is when you have those

breakthrough moments, when you realize there's still things you can do. When you realize you still have some control when you stop fighting to the disease and you sort of embrace it and say, Okay, let me leverage this, kind of like Tai Chi where you leveraged the disease to your benefit as opposed to attacking it or fighting it off. And I felt that, it's given me permission to do things that I've always wanted to do that I never made time for, like I'm doing improv comedy. I always loved being on the stage and I haven't done it in 30 some years, but we're doing it. So what are some of the things in your life that you've realized, Oh, well I can still do this or I can do this now, or I didn't even know this was possible and some of the positives or the silver linings maybe of Parkinson's that you've discovered? Yeah, go ahead, Sheryl.

Sheryl Hague: One of the things that we have been very grateful for from almost the very beginning, and when Tim had to leave his job so early, it was really hard at first, but now we're realizing that it's actually a blessing that we're... Because he's still relatively healthy, I'm a self-employed and so I can kind of work around my own schedule and it's given us extra time during these good years for us to spend together with our kids, our grandkids, and with each other and to have just opportunities to do things that we might not have until Tim retired if he didn't have Parkinson's. So we've always been very thankful for that aspect of it.

Larry Gifford: Yeah, a job.

John Lipp: Well, It's funny, I'm still working full time, probably about another three or four years. I'm the director of an animal shelter, the big nonprofit. And I think I've become the best leader I've ever been in my career because of this disease, because the things that used to drive me crazy or I perseverate on it forever, I let them go. I'm able to see the big picture, I'm like, people are upset about something, you know what? I've got Parkinson's, it could be worse. And that usually shut them down pretty quickly. But honestly, I think this disease, the gift is seeing the big picture and realizing how lucky I feel.

John Lipp: I think a lot of us are, we have time still from diagnosis. There's a lot of great research, a lot of great treatments out there, and I don't suffer folds anymore. So that's been a roughly positive thing, the one thing I had to give up was skiing and my husband and I used to ski a lot together and I just didn't feel safe on the slopes anymore. I couldn't turn anymore and I would fall a lot and I thought, you know what? I can give that up. But the good side is now I just hang out in the lodge. He skis all day, I have a couple cocktails, I can read my novel and I still have fun on the slopes.

Larry Gifford: Tim, one of the things you got to do the opportunity to be on Amazing Race Canada after your diagnosis.

Tim Hague Sr.: Absolutely.

Larry Gifford: That must have been amazing.

Tim Hague Sr.: I continue to say that Parkinson's has given me far more than it's taken. About a year into the diagnosis, we started talking about applying for the race, second year into the diagnosis we were planning to be on the race, was on the race, won the race and after that it was just insane. Suddenly you're in this whole different world, traveling everywhere, speaking, traveling for fun, from winning stuff on the race and it was just incredible and from there it's launched us into a whole unanticipated life of being able to be advocates on behalf of people with Parkinson's to be the Avengers through U-Turn Parkinson's.

Tim Hague Sr.: Hence have met so many people and been able to do so many wonderful things that we would've never had the opportunity to do if I hadn't been diagnosed with Parkinson's. So I mean, there really is a huge for us silver lining that would never have existed in our lives had we not come down with this disease. And so it really is a double edged sword. It's difficult to wheel some days because some days you get down and depressed and that's real. Those bad days are real. They're really real and they're really bad some days. But there's also days that are so phenomenally good that you get a little crazy some days trying to figure it out. What am I today? Am I happy? Am I sad?

Larry Gifford: Right. Yeah, Barry.

Barry Grey: Yeah, I just wanted to say that I had a clue that something was really wrong when I was in a five and 10k walk/run and had to keep myself from tipping forward and face planting about a half dozen times and I couldn't get my balance at all. And at the end of the race wouldn't what I came through it unscathed, but then I tripped over a curb and broke my two front teeth.

Barry Grey: So I thought, I think this whole Parkinson's thing, I think there's something to it. And my wife was doing some research online and found out about a program for Parkinson's patients boxing because it helps pump blood into your brain and it helps with coordination. And so I've been doing that for about the last eight or nine months, once a week and then I try to mimic as much as I can in our modest little home gym, the same kinds of things. So I mean, I'm working it, at the same time that little voice inside of my head says, "Oh, this is all for naught." I mean, it's nice to be working out and then the reality of it, remembering face planting so fast that I had no time to react, actually feeling and hearing my teeth break. And I thought, it just reminds me that this is a very real thing. I

Larry Gifford: I actually had a similar instance, I wasn't doing a ck, because look at me I could never do a ck, but I was running towards the bus before it ran away. And I went to run and my left side went and my right side said, Stop! And I went catapulting into the air and I fell face first and scraped myself up. But the bus stopped and I was able to get on.

Tim Hague Sr.: This guy throwing himself in front of the bus somehow made it stop.

Larry Gifford: So this disease and dealing with this on a daily basis can have emotional, physical, and mental health consequences. What has helped you and your partner deal with your Parkinson's emotional, physical, and mental health? I'll start with you, John. And what's your care team look like and who are you depending on the most these days?

John Lipp: Yeah, I talk a lot about my husband, which is a good thing, but I've got a really great supportive group of friends as well. And there was a period about a year ago where I was having a hard time moving and walking and I was trying to run and I couldn't run anymore. And my good friend Pete, who's a neighbor, he said, You know what? Let's go for a walk. And it has turned into a daily three mile walk pretty much every single day, which has been great for me. Exercise helps a lot as well, so that's been really helpful.

Larry Gifford: That's great.

John Lipp: Yeah, Barry?

Barry Grey: Well, my support staff as it were, is my wife and daughter. I had posted on Facebook about a week after we told Lulu about everything that was happening. And people have been, especially kind, even people who are Facebook friends that I don't really know, but I have not made an issue of it since then really with people. And people are kind enough to call me up out of the blue and say, It's been a long time since we spoke. I wanted to tell you how I was thinking about you and wishing the best and that's like gold, you know, can't beat that. But the things that I do to try to deal with it are nothing unusual. It's just being aware of the symptoms and trying not to let them interfere too much with my everyday life. And I'm a writer by trade and I pretty much just retired when I got the diagnosis because I wanted to write stuff that was important to me rather than editing somebody's book. So that's what I've been doing and that's been kind of a saving grace for me too.

Larry Gifford: That's great. Yeah. The creative outlet's important. Tim, you were going to say something?

Tim Hague Sr.: Yeah, I going to say, much like John there, I've got a group of folks that I cycle with now. I loved running for years and I just came to hate it because I couldn't do it. So I finally gave myself permission, don't run, do something else. So pulled up my bike, which I'd been on for years anyway, commuting to work and we started a little club. We get together every Saturday and we ride year round. So now, if you know Winnipeg, that's quite the statement to say that we ride in February, but we do. And it's been just a great support group that keeps me active, keeps me going, and I noticed a huge difference when I'm exercising hard.

Larry Gifford: Oh, that's great. Sheryl, what do you do to deal with the emotional, physical, mental toll that it has on a care partner?

Sheryl Hague: I think one of the most important things is that I have also a group of friends that Tim and I both, I have my own girlfriends, but we have also have some really good friends that walk through our entire journey of Parkinson's and have been there for us and just hold us accountable and check in on us and let us know that they're there for us, which is so important. And I also work. I love my work and I take time to get out away from Parkinson's, if you will. And I know that sometimes it's hard for Tim to see me go, but he knows that I'm a better person when I come back. So he is all for it.

Tim Hague Sr.: She's never gone that long.

Sheryl Hague: And he knows I'll always come back. I think one of, we mentioned the kids earlier in their growth, one of the things that we have both really enjoyed is that they have become our champions. They're our cheerleaders. They have just really cheered us on. They encourage Tim and his exercise and both of us actually, and they check in on us to see how we're doing. And it's just been a real blessing to see how that has pulled our family together in that way.

Larry Gifford: Has Faith played a role in your dealing with Parkinson's? I'll start with Tim and Sheryl,

Sheryl Hague: Absolutely.

Tim Hague Sr.: Yeah.

Sheryl Hague: We...

Tim Hague Sr.: We both have brought up with fathers who were pastors, but beyond that, as adults made a decision regarding our faith. And it's just continued to be a very real, deep and abiding part of our lives. It provides security, stability, a sense of belonging and a sense of where we're going with us. And ultimately for me, I've always wanted a bit of an out. I don't have to feel like I have to be in control of this. I feel like I've got somebody who's bigger than me, smarter than me, that's got my back and that I can rest in that when I let myself.

Larry Gifford: Good.

Sheryl Hague: And for me, I mean very much the same. The one thing is that I feel like God's not just a big person in the sky for me. He's a friend, a father that I can go to and he can handle my pain and my frustration and my anger, all my questions. And it's just a constant comfort and encouragement to me when those dark days do come.

Larry Gifford: The dark nights of the soul.

Sheryl Hague: Absolutely.

Larry Gifford: Yeah. Hey John, how about you?

John Lipp: I don't identify as a person of faith, but I have faith in people and I'd say 99% of the people I've met are fantastic. I have faith in science, I have faith in research, I have faith in the future. And that's been a beautiful thing. And that gives me hope.

Larry Gifford: Yeah, hope is actually one of those things that once you can see it, you start seeing it everywhere, and whether it's in science or whether it's in people or whether it's, Hey, my pharmacist knows me by my first name. Not everybody can say that.

John Lipp: A lot of my friends would send me things, they would see online clips about people riding bikes with Parkinson's or a miracle cure. And they thought, Have you seen this? That used to drive me crazy at first and I thought, You know what? Good for them. They're thinking about me and so if it doesn't work, the fact is they're reaching out and they're trying to help. And I made an attitude adjustment around that. And not that I want tons of posts to me, by the way, but want to clarify that. But it's sweet.

Larry Gifford: Barry. Where do you find hope and faith?

Barry Grey: John? Ditto. I don't have conventional faith. I put my faith in people because I can't think of any better place than other people and how they treat other people and how they want to be treated themselves. And I try to be as respectful as I can. Sometimes I slip a little, but to me it's all internal. I mean, the little voice that I hear in my head, to me that's God, because there's somebody in there trying to tell me what's the right thing to do here and the right thing to do as far as Parkinson's is to not give up hope and try new things like the boxing I tried, and be open to the meds because I'm not on meds yet, but I know sooner or later I will be. And I've been warned about them. They have side effects. You're on them the rest of your life. You need progressively larger doses, that worries me, but suffering badly from Parkinson's worries me more.

Tim Hague Sr.: And you know what, Barry, I'll give you the counterpoint to that. I was in the same boat when I started. I didn't take meds for three years. And when I looked back on it, now for me, I want to kick myself a little bit because I think I lost quality of life that I could have had. Now that's not to say that that would be the same for you, but I just want to throw the other side of the argument out there. When the levodopa works, it rocks.

Larry Gifford: First. I'll answer that question. I'll talk about the medicine a minute. I'm kind of in between all of you. I'm a spiritual guy and so I have a meditation practice and I like to believe that we're all connected and so that with the proper intentions, you can manifest what you want in your life. And so I do a lot of reading and we're listening to books and I feel that Parkinson's has made me more conscious of who I am and how I treat people. I feel I've become a better person, just in a

better leader. I'm the national director of talk radio for a company in Canada, and I feel like I'm at a better place in my life, mentally, physically, emotionally. And a lot of that has to do with just working through these issues with my wife and our friends and the support I get from everybody.

Larry Gifford: But just knowing that I'm not alone, I think that's key. And then seeing everybody hope, I talk about how hope is the binder of everybody that has anything to do with Parkinson's. The reason The Michael J. Fox Foundation exists is because there's hope that there's a cure out there. The reason that there are people that go into medicine to be near a movement disorder, a specialist, is because they have hope that they can make our lives better. All these people that are dealing with Parkinson's, whether they're home healthcare or their therapists, they all have hope that they can help us. And you have to have hope in order to allow them to help you. That's kind of how I see it.

Larry Gifford: As far as medications concerned, I was never on a regular medication before my diagnosis. I did not like doctors. I've avoided them at all costs. I now have a really strong relationship with all of my doctors and therapists of many different persuasions. And I enjoy them. And I tell you what, I am an advocate of pharmaceuticals because without them I would be, I'd be a lump on the floor.

Larry Gifford: Well, I take 24 pills a day just to be able to continue to do what I do. Some of it's levodopa, some of it's helping me with sleep and some of it's helping me with depression and everybody's on their own as far as what they should be using. But it's taking me five years to get to the point where I feel like I'm finally balanced, where I have consistently good days and I have bad moments, but good days. And Barry, I know when I was first diagnosed before I was on the medication, I could barely use my right hand to type and I could barely write my name or take notes. And the levodopa change that overnight. And so you just because you've lost function of something, doesn't mean you've lost it forever. The levodopa will bring good back. Some of that and exercise can help bring stuff back as well.

John Lipp: Yeah.

Larry Gifford: All right. So what do you wish you knew from day one about this disease? You look back on your journey so far. Would you do anything different knowing what you know? Or would you encourage somebody to do something different if they just get diagnosed? Start with you, John.

John Lipp: I don't think I would do anything different, but what I would say is be kind to yourself. Just give yourself a hug because you're going to have good days and bad days and it's not going to play out like a TV movie of the week. There's not going to be an end credits for everybody's happy and it's all solved. It's a journey. And just be patient with yourself and give yourself a lot of time to grieve and to have bad days and have good days and not want to blame

somebody. Blame somebody, and then get over yourself. Right. It's just a journey. I don't know how else to say it.

Larry Gifford: How about you, Tim? What do you wish you knew then that you know now?

Tim Hague Sr.: I struggle with this question for a number of reasons, but actually, as a nurse, I like to know where I'm going. I like to know, if you come and tell me I have cancer, I want to know everything about it. So Parkinson's, want to know everything about it. I wish I had dug a little deeper and that somebody would've sent me down and said, You know what, there's 40 different symptoms that can come with this thing. Here are the things that can happen to you. And to have had that information, so that for me, I could go dig into them because I hate surprises. I don't want to go down the road and hit a pothole, not see it coming. I want to know that that pothole is a potential so that can be aware of it and watch for it. And that gives me peace. What takes my peace away is not knowing. So I wish I had just known more from the get go. And then from a personal side, I wish I had kept running more, cycling more. Exercise is the next best thing we can do for ourselves. And I wish I had been even more active than what I was. And I've always been very active, but I find now that if I let a day or two slip of activity, I feel it in every way. And I just wish I had kept going harder from the get go.

Larry Gifford: Sheryl?

Sheryl Hague: I wish I had read up a little bit more about it as well. And I wish that there had been some support or some information about dealing with kids because we were in the middle of raising our teenagers and there were some difficult days. And I think that it would've helped to have known the symptoms that were going to come. And also we had seen some things already for years that we didn't even realize that's part of Parkinson's. And that would've been helpful to have known that in dealing and working with our kids in this whole process.

Larry Gifford: How about you Barry?

Barry Grey: I guess I wish that I would've listened to my body more carefully. Because the clues in retrospect were all there, but I didn't recognize them at all. I remember at least five or six years ago walking through a shopping mall and my feet were barely lifting off the ground as I walked. And I was shuffling like crazy and I kept thinking, why is this happening? And I just thought, Eh, it's a fluke. I'm having a bad day. I don't know, maybe the gravity has been stronger today. I really don't know. But I knew that I had very minor tremors several years ago that I ignored. I thought, Oh, well it's just the price you pay for getting older. There were all kinds of little gimmies that I should have done something. But nothing seemed so terrible that I couldn't live with. And that's what was going through my head is, okay, so my thumb shakes a little bit. So what?

Barry Grey: All these things added together, it's like Sheryl just said there's a million symptoms. And I realized when I read the list of them, there's nine of them right in a row that I have. And that's when I knew this thing has got to be real. And this couldn't just be happenstance. So I wish I would've listened to my own internal concerns better.

Larry Gifford: Yes that's good advice, I was the same way. Hey, I've never been 40 before. Maybe that's what this is all about. I'm just getting old. I think the one thing that I wish I would've known was that when they put me on the Levodopa and they would put me at the lowest possible dosage and every time I visited they'd give me more and more and more. And I thought my Parkinson's was getting worse, but in fact they were just slowly bringing up the medication so they could get it to where it needed to be. And I was like, Ugh. I feel horrible every time I go they're giving me more and more medication. I must be a bad case of Parkinson's because they say it's slow moving. And that was all in my mind. So I just wish I would've known that was the course of action that was going on at the time. And maybe that'll help somebody else.

Larry Gifford: Here are six tips for your first year with Parkinson's. We'll go through these quickly and then we'll wrap up the show. See a Parkinson's specialist, go to a movement disorder specialist. It's really important, it's a neurologist with additional training of Parkinson's. Their best position to give a second opinion on your diagnosis and care and really develop an individual plan for you.

Larry Gifford: Learn about Parkinson's. We've talked about this a lot. Knowing the facts about the disease can help you really understand it and make informed decisions about your care. Can also make you realize that, especially if you're a care partner, that the mood swings are not personal. It's the disease. I know I got a quicker temper and it wasn't expected. And we were like, oh, is that part of the disease?

Larry Gifford: Build a support system. Know that you're not alone. Some people find support by talking with a loved one. Many find it helpful to connect with others through support groups, online forums, the Parkinson's Buddy network. There are classes, there's all sorts of things. So build a support team.

Larry Gifford: Eat a healthy, balanced diet. I just recently changed my diet. We've cut out most fatty red meats and we're eating a lot more vegetarian. And I tell you, that's part of the reason why I feel so good. There's no one specific diet you should do for Parkinson's. But nutritious diet that's high in fruits and vegetables and whole unprocessed foods is good for your body and your brain. You can talk to your doctor about what's good for you.

Larry Gifford: As Tim said, exercise regularly. Exercise can lessen movement and non-movement symptoms such as depression and anxiety which are common in Parkinson's and increase around the time of diagnosis. Any type of exercise is beneficial. So find something you enjoy and do it regularly. The last month and a half I've been cleaning out my garage and I've been sweating and I've been

working, going up and downstairs and that's been my exercise. It doesn't have to be a full blown aerobic workout. Whatever makes you sweat and gets your heartbeat up. That's your exercise.

Larry Gifford: And then join a research study. Taking an active role in research can be a way to take control when you feel like much of control is out of your hands. The Michael J. Fox Foundation's PPMI study needs volunteers who are recently diagnosed and not yet taking medication. Travel costs are covered for participants and a loved one. Call 877-525-PPMI. 877-525-PPMI or email joinppmi@michaeljfox.org to connect with the team.

Larry Gifford: So those are six things you can do in your first year. I hope that helps. I want to thank John and Barry and Tim and Sheryl. You guys have been great.

Tim Hague Sr.: Thank you.

Sheryl Hague: Yeah, thanks Larry.

Barry Grey: Thank you Larry.

John Lipp: Thank you.

Larry Gifford: You get one sentence for the final goodbye, one piece of advice you'd give people as we're saying goodbye. Let's start with Barry.

Barry Grey: Listen to that inner voice. It's telling the truth. It doesn't lie.

Larry Gifford: John?

John Lipp: You nailed it. Have a good partnership with your physician. Movement disorder specialist. If it's not working, let them know. Communicate. Because they have tons of tools and they will make it better for you.

Larry Gifford: Sheryl?

Sheryl Hague: Embrace the good that can be found in this stage in your life. Because there are things that can be a positive thing in your life.

Larry Gifford: Tim?

Tim Hague Sr.: And stay active. That's my mantra. Stay active in every way. Keep your mind active. Keep your body active. Look after yourself and make this all about you. Make sure you take care of-

Larry Gifford: And laugh. Find a way to laugh because there's some situations you can cry at or you can laugh at or both. But I laugh a lot. We laugh a lot in this house and what are you going to do? This is our life. So I'd rather laugh. Makes me feel more

positive. If I could make people laugh with my Parkinson's even better. And buy lots of extra dishes. Because you're going to need them.

John Lipp: I just say something really quick?

Larry Gifford: Sure, yes go ahead.

John Lipp: Participating in groups like this is amazing. I just, being with Tim and Sheryl and Barry has been very inspiring for me personally.

Sheryl Hague: We feel the same.

John Lipp: And Tim and Sheryl, I told my husband you guys did the Amazing Race. He's like, we should audition for the Amazing Race. So I'm like, No.

Sheryl Hague: Absolutely.

Tim Hague Sr.: Do it.

John Lipp: Okay.

Larry Gifford: That's great. I will encourage people to participate in research. It is the great way to feel empowered and make a difference. So again, the PPMI study, you can learn more online, michaeljfox.org/podcast-newlydiagnosed. It has got a lot of links there in the notes.

Larry Gifford: On behalf of all my guests and the hardworking people at The Michael J. Fox Foundation who are here until Parkinson's isn't, I'm Larry Gifford. I'll talk to you next time.

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