

- 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.
- Rebecca Gifford: 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: Welcome to another episode of The Michael J. Fox Foundation Parkinson's Podcast. I'm Larry Gifford, a Parkinson's advocate, the co-founder and president of PD Avengers, a global, patient-led advocacy alliance, and a member of The Michael J. Fox Foundation's Patient Council. I was diagnosed with Parkinson's in 2017 at the age of 45.
- Rebecca Gifford: And I'm Rebecca Gifford. I'm a writer, workshop facilitator, communications executive, and a Parkinson's and care partner advocate. I also happen to be Larry's partner in Parkinson's and in life. You may know us from the podcast, When Life Gives You Parkinson's. Today we have the privilege of co-hosting this episode of The Michael J. Fox Foundation Parkinson's Podcast together. You're going to hear from us and a little bit about our journey with Parkinson's, but most of the voices you're going to hear today are from The Michael J. Fox Foundation's Patient Council.
- Larry Gifford: The Fox Foundation exists for one reason, to find a cure for Parkinson's disease. Patients are at the very center of that pursuit. That's why the Foundation's Patient Council came into being, and that remains its central purpose today. Our goal is to make sure the patient voice helps inform, support and fortify the fight against Parkinson's. We engage in a wide variety of activities to support our broad Parkinson's community, including the development of educational resources and outreach programs, and perhaps, most importantly, we focus on efforts that can help speed research progress in the development of better treatments and, ultimately, a cure.
- Rebecca Gifford: From young onset individuals, through those who have had Parkinson's from more than two decades, the nearly 40-person patient counsel understands the reality of living with Parkinson's disease, and works with The Michael J. Fox Foundation to always have the patient voice in mind.
- Larry Gifford: Recently, I was at the Foundation's home office in New York City, and had the privilege of moderating a discussion between fellow members of The Michael J. Fox Foundation's Patient Council, along with a few of their care partners. I asked them to think about their experiences at diagnosis and what they would want to share with people who've recently learned they are living with Parkinson's.
- Rebecca Gifford: The result was a conversation filled with a lot of collective wisdom, a lot of shared experiences, and really valuable advice, and today you get to listen in.

Larry Gifford: Diagnosis is one of those memories seared into your brain. By the time I got to see the correct doctor, I was already on dopamine replacement, and it was working, so I kind of knew I had Parkinson's, even though no one officially told me; however, actually sitting in the office and hearing the MDs say, "You probably have Parkinson's" really hit me harder than I expected. I remember, honey, we were sitting there, and I was asked for a test so he could be certain, and we were told that the only test that would confirm the diagnosis was an autopsy. God.

Rebecca Gifford: You want certainty in that moment.

Larry Gifford: Yes.

Rebecca Gifford: And with Parkinson's, there is no certainty.

Larry Gifford: No.

Rebecca Gifford: Sadly, not yet.

Larry Gifford: Soon afterwards, I was doubting everything. Would my job want to keep someone with a degenerative brain disease? Would you still want to be with me, Beck? Would our sons still love me if I were broken?

Rebecca Gifford: Well, and I remember having a lot of those same questions, fears, and worries. How is this going to affect our life? How is it going to affect you and your quality of life? How is it going to affect your job? We didn't have a lot of perspective on what the future might look like, so all of that uncertainty settled in pretty quickly. We just didn't have the knowledge and perspective that comes from informing yourself, getting connected to community, and meeting other people in your circumstance. As a result, I think we were really overwhelmed, so much so that I think there was a bit of denial happening, where we just weren't ready to face the full reality of what could be, what we were looking at, and the uncertainty of not really knowing what we're looking at. We still don't, a lot, and it took us at least a year to really kind of get into a space where we were ready to get more information, really get connected, figure out what we wanted to do and how we were going to face this.

Larry Gifford: At the beginning there, you kind of got choked up and started to cry a little bit. What happened?

Rebecca Gifford: Because you've referred to yourself as broken.

Larry Gifford: Yeah.

Rebecca Gifford: Because in the beginning, you felt like you were broken. It's like, "Oh. I used to be this strong, robust, energetic guy, and now I feel so broken," and that really, I've never heard you refer to yourself that way. All these conversations that we've had, privately and publicly, and I'd never heard you refer to yourself that way, and I would never consider you broken. This is just something else that you're

facing, but in the beginning, I understand why you felt that way, because it was such a shift and such a big deal to consider, "Oh my goodness. This is what my brain is doing right now. This is all the things that I may not be able to do in the future, all the things that I can't do right now," and it probably does feel like-

Larry Gifford: For sure

Rebecca Gifford: ... You're broken.

Larry Gifford: It's like a broken bone, but it was my brain.

Rebecca Gifford: Yeah.

Larry Gifford: That's how our journey began. Now we turn to the council members about their initial reaction or emotion after they were diagnosed with Parkinson's. It's a big ask to boil a lot of strong feelings as you can see, and very human reactions down to a few words, but it was a very revealing exercise.

Rebecca Gifford: People talked about many different reactions, as many as there were people in the room, really.

Margaret Sheehan.: I'm Margaret Sheehan. My first reaction was, "You're joking, right?"

Michael Fitts: My name is Michael Fitts. It just hit me like a ton of bricks.

Fiona Davis: I'm Fiona Davis. I was panicked. I Googled it online. I saw someone in a wheelchair drooling, and I thought that would be me in a couple of days.

Claudia Revilla: My name is Claudia Revilla I did feel relief, because unbelievably, I've been struggling with symptoms and visiting so many doctors before you have Parkinson's disease.

Allie Signorelli.: I'm Allie Signorelli, and I'm a public crier, so my first reaction was just fear for my kids.

Israel Robledo: I'm Israel Robledo. I remember my first reaction was, believe it or not, "When does the house get paid off, and how am I going to get two girls through college?"

Matt Peck: Matt Peck. First thing that popped into my head was, "Will I be able to walk my daughter down the aisle?"

John Seibel: My name is John Seibel. I had worked with 20 years as a brain imaging researcher. I realized that there's something ironic about me getting Parkinson's disease. I think the universe has a sense of humor, but then so do I.

Jim McNasby: Jim McNasby. I sort of wanted to hide my symptoms, so I came out of one closet and went into another.

Jimmy Choi: My name is Jimmy Choi. My initial reaction when I was told that I had Parkinson's was, unfortunately, to go into isolation and to put everything on the back burner and forget about the disease.

Anna Cohn Donnelly: I'm Anna Cohn Donnelly. I went home that day, and feeling just so alone, so isolated, so unsure.

Larry Gifford: Oh, boy. So I wish there was only one reaction that you could have, but as you can tell, there are a myriad of reactions that people have, and I relate to quite a few of them. I mean, it's kind of like going through the stages of grief. You're bargaining, and you're feeling like it's over, and then you feel like, "Well, I'm sorry," and then you start punishing yourself, and there's all sorts of stuff that happen.

Rebecca Gifford: And a lot of denial.

Larry Gifford: Tons of denial.

Rebecca Gifford: And that came up several times, and that came up with us as well, with both of our experiences. Then, you've got the deep sadness, but you've also got that just, "I'm not ready to face it yet," so that denial, and including right at diagnosis. Several people mentioned that they thought their doctors were crazy and, of course, wrong and, "How could you think that? That's got to be a joke." They start laughing, all of that denial that comes in. And then, for some, it leads and it's quite common for that then to kind of lead to secrecy and not telling people about it, not telling employers about it, really keeping that information close to the vest until they're ready to deal with other people's reactions and having it be really real.

Larry Gifford: Yeah. There were a lot of questions that came up like, "How will I be able to?" or "Will I die? Will it be like X, who has Parkinson's?" A lot of comparison.

Rebecca Gifford: Well, and those are all the questions that we asked too. How is this going to affect us? And somebody even asked, "Well, am I going to lose my hair?" There were a lot of people asking, "Is this going to affect my longevity?"

Larry Gifford: Right.

Rebecca Gifford: And I thought it was really interesting as well that there's several people, and we have heard this over and over again, a sense of relief and that relief comes from just having the diagnosis. It's so common for Parkinson's to be misdiagnosed or for it to take a long time to get to that diagnosis, that once you have it, there is a sense of relief because then at least you know what you're facing, and you can find information and have something to address. The patient counsel ranges widely in age and years since diagnosis, but what was interesting and heartwarming to hear was when you asked the group to offer advice to people who have recently been diagnosed, there were some really consistent and helpful themes in their answers.

Larry Gifford: A few people talked about the importance of getting the right healthcare team around you as quickly as possible, especially a neurologist or movement disorder specialist. Here's Brett Parker, Richard Huckabee, and Denise Coley's advice

Bret Parker: See a movement disorder specialist immediately.

Richard Huckabee: I wrote this poem since I've been here. I wish I knew I needed a medical team. I have a primary care doctor, a movement specialist neurologist, a movement specialist therapist, a sports injury therapist, a pharmacist, a urologist, an ankle neurologist, a social worker, and a psychologist. Oh, I wish I knew.

Denise Coley: If you have questions about the doctor, you're going to, don't be afraid to get rid of them.

Larry Gifford: So after we got through all of our depression and our denial, we began to build our team. From our MDS, who's great, to our general practitioner who we had to sort of rope into what we were doing and get them up to speed, and pharmacists, and there's all these people that become part of your regular group, and you can also include pets, you can include family, you can include your core circle, and I think what's key is you're at the center of that, as a person with Parkinson's, and it's a job to make sure that they're all informed that they all have the same information.

Rebecca Gifford: And to keep them at the ready so that when you need them, because you don't always need your occupational therapist, you don't always need your speech therapist, but when you need them, they're informed. You have a rapport and a relationship with them so that you can pull them in and use them as necessary. That's something that, it took us quite a bit to warm up to getting that full team together. Once we did, we recognized the value of that, and also recognizing the value of me being in the loop with them and having contact and information from them and about them, and them about me, so that I can help to advocate for you and that I'm informed about things, so that if I need to pull in somebody in a situation when maybe you're unable to or I need to help with communication there, then I can as well. So as care partners, I think that's important, that once you're ready to engage with the healthcare team and really get that team around you and inform yourself about what resources are available, that the care partner be involved in that as well.

Larry Gifford: Yeah. Don't be afraid to ask questions, challenge, advocate for yourself, and change a neurologist if it's not working for you. It's like finding a wife. It's a life partner, so this disease is currently not curable, so you're going to be seeing this neurologist for the rest of your life, and so if there's no chemistry, then dump them for somebody else. It's like swipe right and get a new one.

Rebecca Gifford: Well, and it has to do, I think that's what you said, which it's about chemistry, because they can be a very good neurologist, but if you don't have the right connection with them, you communicate differently, or they just deal with people differently than how you would like to be dealt with, then you have the opportunity to look for someone else. I think that's great advice.

Larry Gifford: My friend and frequent guest host of this podcast, Soania Mathur, summed up what several people said.

Soania Mathur: I wish I knew that knowledge is power with this disease.

Rebecca Gifford: Knowledge is power, so I think that collecting information, gathering information, that's one of the ways that you can dispel a lot of the fears, misconceptions, and lack of information, the uncertainty that comes from lack of information in those early days and months. So when you're ready, there's so much information out there, and that information can be empowering, not just give you knowledge and perspective, but can feel really empowering because you have better information, you have a better idea of what you're in for, and then what are the ways to address symptoms and situations?

Larry Gifford: And along those lines, our friend, Becca Miller, offered a critical reminder that when it comes to taking in information early in your Parkinson's journey, take it slow.

Becca Miller: I think one piece of advice I would give to people newly diagnosed is that you don't need to do it all at once, that you can take a break, wait to learn everything, and do it on your own time, because I think that you can also overwhelm yourself and you need to leave time for things that are not Parkinson's, and sort of take it little by little.

Rebecca Gifford: That's great advice. It can be so overwhelming, all the information.

Larry Gifford: Yeah. The Patient Council, not just a group of wonderful people, positively impacting the Parkinson's community. Also, a group of people who enjoy each other, and see the value and connections that we make during those meetings and events. Lynn Hagerbrandt said it well.

Lynn Hagerbrandt: What I recommend is somebody who's newly diagnosed is to not start the journey by themselves to find a support group, to find a group like what we have here, to learn as much as you can about Parkinson's, to become knowledgeable, and to share the lifeboat.

Rebecca Gifford: Dave Iverson had some perspective for people who may not think they are the support group type. He received some perspective from a friend during a patient council meeting.

Dave Iverson: Not everyone is a joiner for different things, and I remember one day saying to my dear friend, Soania, "I'm not a support group kind of guy."

And Soania looked at me and said, "Well, what do you think this is, David?"

Larry Gifford: And I think Dave's right on there. I mean, there are so many different ways that you can have a support group, and whether it's through the patient council, which is a great one for me, or sometimes we do a wild PD dinner night, where we go out to eat or we go to somebody's house or whatever, and we just share in that

community, and it doesn't mean you have to talk about Parkinson's all the time, but you get together with the people you like, and you have discussions about life and whatnot. It's just good to get out and socialize.

Rebecca Gifford: And there are lots of ways to do that. I think that's the lesson there, that sometimes it's at a committee meeting and sometimes it's because you organize something on your own, or maybe you just happen to live near a lot of folks and you get together for dinner every once in a while. I think there are lots of ways to create and curate that "support group environment."

Larry Gifford: You can do a Zoom hangout if you don't live near people.

Rebecca Gifford: For sure, and workshops and other things that are offered online. That's a good way too.

Larry Gifford: Yeah.

Rebecca Gifford: I really appreciated something that Wanda Kim Lilley said about not ignoring the symptoms that are less obvious.

Wanda Kim: What I wish I knew was that the non-motor symptoms can be extremely strong, especially the ones that relate to emotion: the volatility of emotion, the swings, the inability to understand why I was being a certain way and reacting a certain way. I think it would've been a lot easier for me, as well as my loved ones, if I had known about those.

Larry Gifford: If we would've known about the non-motor symptoms. I mean, they call this a motor symptom disease, but it is really a full body disorder, and the non-motor symptoms are actually more bothersome to me and a lot of other people than the motor symptoms.

Rebecca Gifford: Yes. I mean, the ones that you've experienced are anxiety, depression, sleep disturbances, urinary issues, executive functioning issues, a little bit of masking, and those are all considered non-motor symptoms. If those are the ones that have affected our collective quality of life the most and are less simple to address in a lot of cases, sometimes they are, and less simple to recognize for what's really happening, why it's happening, and ways to address it. So informing ourselves about that, and even just recognizing when that's coming up, that took us a little bit of time, so I wish that we had known about those and had paid a little bit more attention to them earlier in your journey.

Larry Gifford: Yeah, and the thing about them is they come and they go, and you don't know, when they come, if it's going to be there forever, if it's just a today thing or this hour thing, and that's the problem with the symptoms with people with Parkinson's, is you could experience 30 different symptoms in a day, and then the next day you'll have a good day, and then the next day you won't, and there's no rhyme or reason.

Rebecca Gifford: Which makes it hard to recognize the patterns, and whether this is something that needs to be paid attention to or not.

Larry Gifford: Right. Some very sage advice came from Hadley Ferguson.

Hadley Ferguson: The other thing that I would say is that none of us are alike, and so the best thing is not to compare yourself to someone else, because you may never even end up on the same path.

Rebecca Gifford: I agree. The comparison thing is so easy. Our egos want to do that. We naturally go to that. That person seems to be dealing with things so much better than I am or the opposite. Then, just doing that constant comparison thing, and everybody's journey is so different. You've met one person with Parkinson's, you've met one person with Parkinson's. It can become really, it's very natural, but it's a futile exercise. Be easier with yourself.

Larry Gifford: Well, and a lot of people do this with medication as well, where they say, "How many pills are you on? Oh, why are you on so many pills? Maybe I should be on more pills or less pills," and you can't do that. You can't play that game, because everybody's so unique and so different.

Rebecca Gifford: Well, and care partners, it's easy for us to compare, "Well, this care partner seems to be doing great, and look how supportive they are of their partner all the time," and it's so easy to do the comparison thing as care partners too.

Larry Gifford: Speaking of care partners, there were a few in the conversation, along with patient council members. I asked them for advice to partners of people who have been recently diagnosed with Parkinson's.

Rebecca Gifford: And what great advice they gave too, so here is Angela Huckabee, wife to Richard Huckabee, who we heard from earlier, and Pamela Krys, wife of patient council member, Sebastian Krys, with similar words of wisdom.

Angela Huckabee: The advice I would give is to take care of yourself. Also, for me, don't let your whole world be Parkinson's, so find something for you or for the two of you that's not associated with Parkinson's.

Pamela Krys: The advice I would give is to make sure that you put your own oxygen mask on first, I guess, and to steal a comment yesterday that was told to me, you are your own person. You are not the wife, the daughter, or the child of someone with Parkinson's.

Rebecca Gifford: Yes, care partners often need to be reminded to take care of ourselves, our own health and wellbeing, our own mental health, and social health. It can be difficult to make time for exercise, doctor's appointments, spending time with friends, all of the things that we do to take care of ourselves when those around you need so much care and attention, so I had to learn this over time, and frankly, I'm still learning it and have to remind myself constantly, but I intentionally make self-care a priority, and if I find myself resisting it, "Oh, no. I'll push that off until

tomorrow," or "That's not really important. I'm going to reschedule that," and then it never gets rescheduled, whatever, however that may manifest. If I start telling myself those things, I remind myself, "I need and deserve the same love and care I offer to you and to our son," so self-care is harder to do because of your Parkinson's, but reminder to self, "I'm human, not superhuman, so my own wellbeing deserves time and attention too."

Larry Gifford: For sure, and you have 100 percent of my support on that. You need to take care of you.

Rebecca Gifford: I know I do, and I appreciate that.

Larry Gifford: I also appreciate Pamela's words about making sure you're caring for your sense of self and your own identity.

Rebecca Gifford: And that has as much impact on our wellbeing as whether we get exercise and enough rest and meditation that day, or not, really. It's so easy for me and other care partners to lose ourselves in our partner's disease or in the caregiving role that we play. So in our case, in all the ways that you're engaged in the Parkinson's community, I could probably spend 100 percent of my time supporting that. But I can't forget that I have needs, pursuits, and things to offer outside of the Parkinson's in our family, and to me, to you, and to everyone around me who wishes me to be a nice, balanced, well person, it's important to nurture those things too. As Angela said, also nurture our relationship by giving time to those things that we enjoy doing together, and most of them have absolutely nothing to do with Parkinson's, so we need to remember those are things that we do together and enjoy doing together as well, and nurture that part of our relationship.

Larry Gifford: For sure, for sure. We like to go to the movies.

Rebecca Gifford: Yes.

Larry Gifford: And we like to hold hands as we walk, which wasn't always easy for me to do, but I've learned.

Rebecca Gifford: Yeah. We've been doing a lot of hiking together, which has been really nice.

Larry Gifford: Yeah. Bernard Coley, Denise's husband, also talked about connecting with other care partners.

Bernard Coley: Go find another care partner and talk to them as soon as possible.

Rebecca Gifford: I think it's important to remember that being a care partner or a family member of a person with Parkinson's can be quite lonely. It's really easy to begin to believe that you're in this all by yourself. So even like me, if you have amazing friends and strong support around you, most of the people in your life can't understand the unique journey that you're on. That's definitely been my experience, so there are many care partners out there who are also seeking connection and understanding.

This took me a little bit of time to recognize and really get connected with it, but when you're ready, there was so much value for me with connecting with local organizations, curating the folks that I met at different meetings and different events, and really kind of getting that care partner support group around me, but there are other ways to do it too. So you can get connected with a local support group or organization. You can join the Parkinson's Buddy Network, maybe attend a Parkinson's IQ+You educational event in your area, as well as other events and workshops. And trust me, you'll discover you are not alone, and there are fellow care partners out there who understand what you're going through.

Larry Gifford: That holds true for people with Parkinson's as well. I mean, it's one of those things where it can be very lonely. It's a very lonely disease, because everybody is so different, that even when you do hook up with people, it's like, "Oh. I don't have that. I don't have that. It's like, "I can't find anybody who's going through what I'm going through exactly," and so it can feel like, "Oh, boy. This is a weird disease," and it feels exotic and rare at times, and you're like, "Oh, man. How did I get this?" At the Michael J. Fox Foundation research is key, and research participation is always an option we encourage. So I asked the council members what they would want people who are newly diagnosed to understand about research participation and what their options are.

Gary Rafaloff: Gary Rafaloff. It allows me to feel that, as a patient, I have the ability to make an impact, to help change what the cost will be, if not for me, for my children and grandchildren.

Dr. Karen Jaffe: I'm Dr. Karen Jaffe. I understand the importance of research, but many of the studies that I would've wanted to be in, I couldn't be in because I was already on medication. I asked my husband whether he would participate, and he categorically said no, because he had had a previous bad experience with a spinal anesthetic and he didn't want to go through that again, and then for my anniversary, he surprised me with the papers that he had signed up for the PPMI study.

Brian Roberts: My name is Brian Roberts. I'm a Mets fan. I can't control that. By participating in research, it gives me agency in the disease and gives me a sense of empowerment. That's why I participated.

Hadley Ferguson: Hadley Ferguson. I think it's important to say, on the research topic, that research is very personal. Not everybody feels comfortable in participating, but there are a lot of ways to participate, and you can help fund research, but you can also help be an advocate for research, so I wanted to say that as well.

Larry Gifford: Ah, what great advice, before you start medication, you do have an opportunity to participate in trials. People recently diagnosed with Parkinson's play a valuable role in research. The landmark PPMI study is recruiting people of all backgrounds that have been diagnosed the past two years and have not started Parkinson's meds yet. Visit michaeljfox.org/newlydiagnosed for more information, and the link is in the show notes if you choose not to participate in the trials, then you have the opportunity to take the medication, and you may just go, "I just want the meds. Just give me the meds," because the medication, the

dopamine replacement, is magical and wonderful, and I didn't find that out until after I had to go off of it for 12 or 14 hours.

Rebecca Gifford: In preparation for DBS, we should say, perspective. So, both valid choices. I think that's important to say, and also I appreciated Hadley Ferguson's comment about, it's also a valid choice to not participate in research. It's a very personal choice, and there are a lot of ways to support research without participating in it. You can raise money, raise awareness, advocate for, do educational seminars as other patient council members do, recruit people in that way, and make sure that people know what their options are. I think it's also important to remember that family members who don't have Parkinson's can participate too. There's a way to do that through Michael J. Fox Foundation's PPMI study, as Karen Jaffe mentioned and it's also important to remember, do you want to talk about Fox Insight? You know a little bit more about that.

Larry Gifford: Yeah. I actually take the Fox Insight polls every quarter. Just took one the other day, and it takes up 15 minutes of my time every quarter, and it's tracking my symptoms, and it's tracking my development and whatnot, and what's bothering me at that moment in time. Then, they take all that data, and there's thousands of people that are involved in this over the course of, this is a longevity study, and so they're going to be able to track that, and they're already using it for some stuff, and it's easy, because you just do it from your home on your computer.

Rebecca Gifford: And there may be opportunities in your own community, at the academic institutions and research organizations.

Larry Gifford: You may remember we started this conversation with The Michael J. Fox Foundation patient council members by asking them what their initial reaction was after diagnosis, we ended our conversation with our thoughts on where they are today.

Rebecca Gifford: I found this really moving, because there were more than 30 people with Parkinson's in the room, anywhere from 2 to almost 30 years after their diagnosis, and almost across the board, people express that they now feel more fulfilled than they did before their diagnosis. So let's start with Sebastian Krys, and then we'll go to a few other voices you've already heard today.

Sebastian Krys: Today, I live life a lot more vibrantly than I did prior to my diagnosis.

John Seibel: You have to adapt, change, accept. I think Michael talks a lot about acceptance, getting there and moving forward with your life.

Israel Robledo: I've done some things I never would've tried to do. I made some incredible friends that I never would've met. When I walked into this room, I looked around and I felt like I was coming home again.

Dr. Karen Jaffe: I finally figured out that I wasn't put on this planet to just have Parkinson's disease. I was here to do something about it.

Fiona Davis: I have found many silver linings. I've never been so busy in my entire life, advocating for Parkinson's.

Dr. Karen Jaffe: I'm more optimistic than I've ever been.

Michael Fitts: I'm 50 pounds lighter, I'm stronger, I'm faster, and I just have a fantastic time with life. Go.

Larry Gifford: Yeah. All right. Can we talk about Richard Huckabee and his poem? Hello.

Rebecca Gifford: I know.

Larry Gifford: How did you write that during the meeting? I don't get it. It's like, dude is a savant.

Rebecca Gifford: It was very efficient and productive.

Larry Gifford: Oh, yeah. It was great. It was great.

Rebecca Gifford: And encouraging.

Larry Gifford: I found a lot of hope in those words, even just seven years after my diagnosis.

Rebecca Gifford: And I think we understand a lot of that concept too, of feeling like there are things to gain from a Parkinson's diagnosis or having Parkinson's in the family, things like perspective, maybe greater gratitude for good days and health. Opportunities. We've tantamount experienced that with opportunities to connect with communities, go on events, speaking engagements. We did this podcast that connected us to a community in a really meaningful way that I now find really valuable, and if you weren't diagnosed with Parkinson's, I wouldn't know all of these amazing people and be connected to this wonderful community.

Larry Gifford: The other day somebody asked me, they go, "Now you're retired, right?"

And I said, "No, not retired. I've been repurposed, meaning my purpose has changed, and so my purpose is now Parkinson's, and really, it's about the gratitude, the purpose, the connection to the community, and all that stuff," and so I found that really helpful way to describe what I'm doing now versus what I did before.

Rebecca Gifford: I think it's important to remember, for newly diagnosed, that having Parkinson's can mean so much more than you have a disease, or your partner or your family member has a disease, or they have a disability or you have a disability. You can make it mean something more than that. There are many opportunities to do that.

Larry Gifford: Kathy Holden shared a touching story that brought home how you can be surprised by the ways your Parkinson's can affect you or the people around you, and perceptions can change over time.

Kathy Holden: I do remember the most terrifying part of it for me. I remember sitting at our kitchen island that first night and scrolling through the Fox information, and I told my husband, "I'm afraid."

He said, "What are you afraid of?"

I said, "I'm afraid my grandchildren will be terrified of me." Well instead, my grandchildren, who at the time were little, but now are teenagers and down to three, they fought over who got to hold the shaky hand when we would go walking around.

Larry Gifford: Aw.

Rebecca Gifford: Thank you to everyone on The Michael J. Fox Foundation Patient Council and their care partners for your honesty, enthusiasm, and vulnerability during this recording session.

Larry Gifford: You are a wise and wonderful group, and we are grateful for your generous participation in this episode. If you or a loved one have recently been diagnosed and you're wondering where to start, visit michaeljfox.org/newlydiagnosed. On that page, you can access many resources including an educational guide, support groups, videos, and information on The Michael J. Fox Foundation's Landmark PPMI research study. There will be resources and links available in the show notes. Please rate and review the podcast. For everybody at The Michael J. Fox Foundation, who is here until Parkinson's isn't, thank you for listening. I'm Larry Gifford.

Rebecca Gifford: And I'm Rebecca Gifford. Did you enjoy this podcast? Share it with a friend or leave a review on iTunes. It helps listeners like you find and support our mission. Learn more about The Michael J. Fox Foundation at Michaeljfox.org. Thanks for listening.

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.