

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.

Speaker 1: 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.

Jimmy Choi: Welcome to an episode of the Michael J. Fox Foundation Parkinson's podcast. I am your guest host, Jimmy Choi. I am an athlete, an activist, some would say a foodie, a father, and not always in that order. I was diagnosed with Parkinson's disease in 2003. I also want to introduce my friend and co-host today, Hadley Ferguson. Hadley is a patient, activist and artist, and she was diagnosed with Parkinson's in 2010 and then three years later diagnosed with multiple systems atrophy or MSA, which is atypical Parkinsonism. We're both members of the Michael J. Fox Foundation's Patient Council. So Hadley is here. She just raised the IQ between the two of us in the room, the average, and I'm glad you're joining me today.

Hadley Ferguson: Hey Jimmy, thank you so much. It's great to be here. And that's a lot of pressure you just put on me.

Jimmy Choi: The pressure is on me because I've got to keep up with you. In this podcast we're all going to hear not only from us about how we took that first steps towards engagement after our diagnosis, but our listeners will also hear from other members of the Patient Council. Now, patients are at the heart of everything MJFF does, which is why the Patient Council was created. It's made up of more than 40 people living with Parkinson's, with really diverse backgrounds, experiences, and disease journeys.

Hadley Ferguson: That's right, Jimmy. And we all got to meet up at the end of April in the Michael J. Fox Foundation offices in New York City. We had the pleasure of spending a couple of days together. We learned more about the latest research and we had a chance to offer our perspectives and opinions to the Michael J. Fox Foundation staff, which was, it's always a true honor and pleasure to be a part of.

Jimmy Choi: Yeah, I always look forward to these meetings. Now while we were at the meeting, I also sat down with the entire group and I asked them about the impacts of engagement and how it has affected them in their own personal journeys. And the result was a beautiful mix of, there was wisdom, there was experiences shared, and advice that we're excited to share with our listeners. So Hadley, I think we should kick this off by telling our listeners about how we first started and what drove us to take more action. So you want to kick us off?

Hadley Ferguson: Sure, I'd love to, Jimmy. For me, I had a year of trying to get diagnosed and then when I finally got a diagnosis, I was so excited to know what I had and get some tools to feel better. And so that's the first thing I thought about. But because I live in the state of Montana, it was recommended that I get a second opinion in

Oregon at OHSU where they had a movement disorder specialist because we don't have one here. And I just remember getting the diagnosis and then after getting it, I had, oh, several pamphlets and things that I could sign up for, a conference, a newly diagnosed get together, and I thought, wow, this is, what great support. And I said, "Yeah, this is great, but I don't live here, so I'm going to go back to Montana and see what they have." So I went back to Montana and it was like radio silence. There wasn't anything.

We did have the APDA at the time in the state trying to do a conference here and there, but our state is so vast and wide that the chances that I was going to have it in my town was pretty slim. So I thought at the time I'm young, I have energy, I think I have a responsibility to create something for Montanans like I experienced in Oregon. So that was my first involvement. Within about 10 months, I started an organization called Summit for Parkinson's, and we had a 10-day wonderful conference and art auction. But part of that too wasn't just starting something in Montana for Montanans, but I really wanted to connect Montana with the outside possibilities. So I got involved with the Michael J. Fox Foundation in those first few weeks and with the Brian Grant Foundation. And then a lot of what I do is try to bring information from big organizations back to Montana. So it's been a real pleasure and people really look forward to it and I'm happy to be involved.

Jimmy Choi: Every time I hear you tell that story, it's really inspiring to me because I live in a big city. I live in the Chicago area, and it's complete opposite. We have access to just about everything here. So for you to do that, not only for yourself, but for the Parkinson's community in Montana, it's amazing.

Hadley Ferguson: Thanks, Jimmy.

Jimmy Choi: Oh, of course. The way I got involved with being active in the community is a little different story than yours. When I was diagnosed with Parkinson's, I launched into an eight-year-long denial and pity party for myself. So you were glad that you have a diagnosis so you know how to attack it. Me, I put it all on the back burner. I didn't want to do anything about it. And after those first eight years, I spent the next two years when I finally woke up and it was because I fell down the stairs with my son. And I finally woke up and it took me two years to build up to the point where I can start running again and I wanted to run my first marathon. And when I had decided that I was going to run my first marathon and I wanted to sign up, it was four weeks before the Chicago Marathon in 2012, and there was no way in because it was sold out.

So that's when I found Team Fox and they told me that they had one bib left and they told me, "Jimmy, we've got one bib left. If you want it, it's yours. All you got to do is raise \$2,000 for Team Fox and we're good to go." So in that four weeks time, I started telling my story. I connected with other people who are like-minded, and at the end of the day and the end of that four weeks, I raised \$5,000, just over \$5,000 for Team Fox. And the moment that really changed my mindset and really changed the way I thought about how I was going to be active in the Parkinson's community came was I was actually standing at the start line. I realized that I've already raised \$5,000 and I've connected with other people, I've

shared my story, I've brought others closer to me. In that moment, I realized that I did more in those four weeks of fundraising than I did in those first eight years combined. So that in itself was the moment for me.

Hadley Ferguson: Jimmy, that's an inspiring story. And isn't it amazing how certain events in our life kick off life-changing moments? And you've always been an inspiration to me and to so many.

Jimmy Choi: Oh wow, thank you. And yes, you're right, but as we just, from the difference in our stories, engagement can look like many different things, right?

Hadley Ferguson: Yeah.

Jimmy Choi: Marathons or you taking the bull by the horns, so to speak, to bring more resources and awareness into your own state. Or other people can get involved by just something as simple as writing a letter to the congressional representative, right?

Hadley Ferguson: I agree. And I think that just that act of being involved, it just feels so proactive and you do feel like you're doing something and it takes you outside of your own body and your own illness and you're working on something toward a greater good.

Jimmy Choi: Yeah, absolutely. So now I want to talk about the why. Why do we get involved? One of the most interesting takeaways for me from the conversation that we had with our Patient Council members is there were so many whys that inspired people to start to take action and get involved in the community. Here's a few words from our Patient Council co-chair, Bret Parker.

Hadley Ferguson: Wonderful.

Bret Parker: I was diagnosed in 2007 and after sort of denying it for a few years and not telling anyone, not doing anything, I decided two things. I needed to figure out selfishly how to make sure Parkinson's didn't define me, and then secondly, how could I make a difference?

Jimmy Choi: Bret took that moment, and he started small, and he was running short distances here and there to fundraise, but over the time that something small became something really epic. When he ran, get this, I'm always in awe when I say this, when he ran seven marathons in seven days, and that's not all. He did it all, he did it on all seven continents.

Hadley Ferguson: It's just incredible.

Jimmy Choi: Yeah, it's crazy.

Bret Parker: Sharing my journey with people has allowed me to help make a difference and help myself selfishly to prove that Parkinson's is not going to control me.

Jimmy Choi: And that's why Bret is co-chair. He's pretty amazing. And here's a few words from Israel Roberto who was diagnosed in 2007.

Israel Roberto: Mark Twain said, "The two most important days in your life are the day you were born and the day you find out why." Once I came to terms with the diagnosis, everything changed for me. I literally was on the ground crying my eyes out. I was like, why am I feeling this way? I've got church, I've got family, I've got insurance, I've got a job. I've got everything that I need and I'm so focused on me. And from that day forward is that second day where I said, "I've got to stop thinking about me and think about others that I can help along the way." And I haven't looked back since.

Jimmy Choi: Yeah, I got to say, when I first met Israel, I always say this, and every time I see him, he is to me always the smartest person in the room. He always knows what to say to make someone feel better. He always know the right answers. And today he's helping drive forward the next waves of treatments by encouraging others to volunteer for studies. That's very important because studies often go unstaffed in terms of volunteers. And next here is a few words from Wanda Kim Lilley. She was diagnosed in 2012. She found her inspiration just looking out her window at a mountain.

Wanda Kim Lilley: I was looking at Mont Blanc, that big mountain that everyone needs to climb and conquer when they're in Chamonix. And I saw that mountain taunting me, "You will never come up here. You will never even set foot on me. This is not the place for you. Chamonix is a place for the able-bodied and you are not." And I remember looking at that mountain and I just sort of said, "F that. My mountain is bigger than you are. And I'm climbing my mountain every day."

Jimmy Choi: Yeah, and she certainly has. And she decided to start to host a virtual cycling fundraiser from her exercise bike. And that event has grown over the last couple of years to something really amazing.

Wanda Kim Lilley: We raised a bit of money, but what it also did was to show me the power of community.

Jimmy Choi: Yeah. And people ask me all the time, they ask me, "Jimmy, why do you put yourself out there? What's your why?" And it's simple. It all started very selfishly for me. I was doing things because it made me feel better. It made me feel empowered. It made me feel less alone. But somewhere along the way I realized that it is also making others feel better. With my words I'm also helping others feel empowered and also helping others feel less alone. So if me being me is going to help someone else, why the hell not? I think it's a win-win.

Hadley Ferguson: Yeah, I agree, Jimmy. I mean, I think that is the power of the why. It's you just realize that you have an opportunity to step outside of yourself and motivate other people, inspire other people, and give people access to tools they may need. And I could say deep down, yes, selfishly, that keeps my disease probably at bay because I'm not focusing on my disease process. I'm focusing on how can I carry into the next day to help other people. But it really was a true feeling of I feel like I have a sense of responsibility and I know there are people that are more

advanced in the disease and maybe they're getting it at a different time period in their life, and can I be an example and can I help other people? So I think that becomes a why for a lot of people.

But what I love is hearing from all these people about their different motivations and how different they are and really the importance of sharing our stories. Because didn't you find it interesting how many people in the conversation did bring up the importance of sharing their story publicly at the beginning of their engagement and journey? But not everybody that was the appropriate thing, but for some people, like for myself, I actually ended up, because I'm a local artist and a lot of people know me, there was an article in the paper very early on, Artist Diagnosed with Parkinson's. But I felt it was an awareness opportunity to be able to share my story. And let's not be afraid of this.

Jimmy Choi: Right. Absolutely. You got to be a voice.

Hadley Ferguson: Yes. And here's Larry Gifford, diagnosed with Parkinson's disease in 2017.

Larry Gifford: I was kind of spiraling after my diagnosis, afraid of whatever was to come and wasn't really exercising or doing anything. Being a radio guy, I listened to a lot of podcasts and I was trying to find a podcast from somebody who had Parkinson's and there wasn't any. I was listening to the Fox Foundation podcast with Dr. Ray Dorsey, and he said, "If people with Parkinson's don't start sharing their stories, we won't raise enough money to do enough research for any of this to matter." And I thought, well, I'm a storyteller and I've got all the audio equipment you could possibly want at my fingertips. So I started a podcast.

Jimmy Choi: Yeah, and Larry set the bar high. And then there is Dr. Soania Mathur. She was diagnosed with Parkinson's in 1998.

Dr. Soania Mathur: My story actually began when my husband got me tickets to the gala for the Fox Foundation, and I sat by a gentleman named Bill Wilkins. I hadn't told anybody that I was diagnosed with Parkinson's disease, and this was like eight or 10 years into my diagnosis. He taught me a lot. He taught me that no contribution is too small. We all can participate in some way, whether it's generosity of funding money or time or energy or spreading word about the foundation itself, that no contribution is too small. He said, "Sharing your story is important to inspire people and to enlighten people in terms of what this struggle is like." And I started sharing, and I haven't really stopped since.

Hadley Ferguson: Yeah. She is such an inspiration to the community. And we also have Richie Rothenberg. He was diagnosed in 2004 and he was just starting a financial business with his father, but his involvement started with a phone call from Michael J. Fox himself.

Richie Rothenberg: So I decided when I talked to him that I would tell everybody I ever knew and we would throw a fundraiser for the foundation. And I went down to my dad's office and he said, "I just want to talk with you about something. We got to be careful about who we tell about your diagnosis because we're getting people to invest

money and people might consider it too risky to give you money if you have Parkinson's." I said, "Well, I just told Michael J. Fox. I would tell everybody I ever knew and throw a fundraiser." And my dad said, "You have my full support. How can I support you?"

Jimmy Choi: Yeah, it's beautiful to have the support of your family members. I had that right from the start with my parents and I couldn't tell you how important that was for me. Karen Jaffe, who was diagnosed with Parkinson's in 2007. Karen is a mentor of mine. And here's a few words from her.

Dr. Karen Jaffe: Because I'm a physician, I decided to keep my diagnosis a secret. And about a year after I got diagnosed, I found my way into New York at my first Michael J. Fox Foundation Research Roundtable. They gave the people from Team Fox an opportunity to speak and person after person stood up to tell their story about how they had raised a lot or a little bit of money. And I sat there with tears rolling down my cheeks knowing that I didn't have a voice. I didn't have a voice like that. And I introduced myself to Michael J. Fox that day, and he gave me a warm hug, a hug that sent me home and said, "Who was I meant to be?" And I asked myself that question and I started raising money for Team Fox. And then after about a couple of years, I thought, why am I hiding this? I don't need to hide this. So I took the brave step and told my medical community and my patients that I had Parkinson's disease, and that was the beginning of my advocacy work.

Jimmy Choi: I love this story of Karen because it really shows the ripple effects from getting involved. When I was just starting myself, she was a person that gave me so much encouragement and she helped me set my way down my own path. And I'm not the only one. She founded InMotion, which is in CleRevilland, Ohio, which was where she touched another Patient Council member, Richard Huckabee, and he was diagnosed in 2013.

Richard Huckabee: A friend picked me up and drove me to this place called InMotion, a wellness center for people with Parkinson's. I walked in with my cane, not realizing my life was about to change with that community. And one of the things I'm proud of is that I got involved talking to Case Western Reserve medical students, and it's three things I always leave with those medical students. I tell them, it took me nine years to get diagnosed and I don't want nobody else to take that long. Then I tell them, it's all of us that could get Parkinson's. It is just not an older white man stooped over. It's black, white, young, old, male, female. And then I tell them to leave your patients that you've diagnosed with anything with hope, because there's always hope.

Jimmy Choi: There is, absolutely. And that's the ripple effect, right? Because Karen shared her story, she took action. Richard had the chance to access the care that hundreds of other people will eventually get as well. Now, when I first started to share my story with everybody, I mean, to really share the story, I brought everyone in my various orbits much closer to me. I have family members in my most inner orbit, and I have friends in my next layer, and then I've got another orbit that's comprised of my care team. Now because I was sharing now, I removed the elephant in the room every time I see my friends and family and everybody else because we're not worried about dancing around topics relating to Parkinson's,

right? So I removed the stigma and I removed that elephant in the room, and it has brought everybody closer to me.

Hadley Ferguson: Jimmy, that is so true because when it's unspoken, people know something's going on. Some people may not know what it is, they just know something is. And it is, it's a huge elephant in the room and it creates even a negative tone over everything. But if you feel like you want to take charge of your disease and how people respond to it, that's the best way is to share your story and make it come from your voice, not from other people saying, "Well, I hear Hadley has Parkinson's and I hear it's XYZ." It's your story to share. And that's what's so important.

Jimmy Choi: Yeah, I always tell people that if you're actively hiding your symptoms or anything like that, they already see it. If you feel like you have to hide it, they already see it and they're not saying anything about it. And would you rather be the one to tell them the real story about you or would you want them to make up their own rumors and stories behind your back?

Hadley Ferguson: It's so true, Jimmy. And then just the physical impact of trying to hide your symptoms, they can make your symptoms worse to have to deal with, and it is so freeing to be able to just be yourself with this process. For Claudia Revilla, she was diagnosed in 2010. It started with education.

Claudia Revilla: I really, really feel that education, if it's not the cure, it's part of the treatment. It makes you a better person, it makes you a better patient, it makes you a better human, and it makes you a great advocate because you help people that don't have access to information.

Jimmy Choi: Yeah, and other people with information felt more drawn to participating and supporting in Parkinson's research in some way. For example, Kevin Kwok, who was diagnosed in 2009.

Kevin Kwok: I come from a lifelong career path in the biopharma industry, and the one thing that always impacted me was volunteers in that space. Then I went to my neurologist when she diagnosed me and said, "How do I get involved?" And it set me sort of on this course of what could I do given my background and given my interest. When you get involved, there's something that you actually gain. I find that the more you give, the more you get back.

Jimmy Choi: And Kevin is giving a lot because he participates not only in clinical trials, but he's a key community advisor for the foundation's landmark study, the Parkinson's Progression Markers Initiative. And then now let's hear from Denise Coley who was diagnosed with Parkinson's in 2018, and she also talks about research.

Denise Coley: I found out that I could work with researchers and I could take part in research studies. So I decided if I was going to work with researchers and participate in studies and tell people about it, I had to learn. So I made sure that I made contacts with different organizations, with different communities and brought

them together to give them the knowledge of what's going on and empower to advocate for clinical research.

Hadley Ferguson: Yeah, medical research, as we know, is such a key part of this, and we're going to hear from Gary Rafaloff, he was diagnosed in 2012, who also focused on research.

Gary Rafaloff: I very quickly made a decision that I was going to get involved in research. Selfishly, it was because I wanted to try to find something that would slow, halt or cure disease.

Jimmy Choi: Yeah, that was me too. When I first started getting involved in research, it was very selfish. If there was a cure, I wanted to be the first one to get it. And let's hear from Julie Ocko. She was diagnosed in 2018.

Julie Ocko: I also was very focused on finding opportunities to contribute through research. And I live in Boston, so I had a lot of opportunities in my backyard to explore.

Hadley Ferguson: Isn't that wonderful? She had opportunities in her backyard to explore, but I just want to reach out to people like me who live in a rural area. There are still ways to participate in research or find other ways to get involved. There is the Fox Trial Finder that you can get on and see where you can participate in research. A lot of local places, you'd be surprised. They might be running a little research project. It's not necessarily even going to be a Michael J. Fox Foundation Research Project, but you'd be surprised with how many neurologists have access to research. Unfortunately, what I find is you often have to ask, and they're not going to necessarily offer up the information. So I really highly recommend for people in rural areas to be proactive. Ask your neurologist. If you don't have a neurologist, ask your physician, do you know if there's any research being done? And there are some wonderful research projects online that are simply surveys, so you don't even have to leave your own home. So there is a way for anybody to get involved if they would like to.

Jimmy Choi: Yeah, oftentimes your neurologist, your movement disorder specialist, or your general practitioners or doctors, they get all this information in their emails or literature that they receive. Sometimes they won't even remember they received something or remember that they've actually read something unless you remind them, say, "Hey, have you heard about X, Y, and Z? Or do you know of any research in depth?" They're searching their brains like, "Oh yeah, I remember seeing this." And you just never know what kind of information that you can get. So that's another way to get involved, right, is to really become your best advocate for your own care.

Another big topic that comes up is the impact of getting involved in the community, whether that was through a support group, an exercise group, a friend group, or even a fundraising group like the Michael J. Fox and Team Fox Community Groups. So I talked about my orbits, but I have also have an entire community that exists all over the world, right? Orbits are people that are close to me and around me every day and a real person in real life. But I also have this entire network. I have access to Zoom meetings or social media or other virtual

forms of communication. Now, we keep in touch and we keep each other going because we can bounce ideas off of each other. We can have questions that we can ask each other, and more often than not, we end up challenging each other to some pretty crazy either fitness challenges or fundraising challenges or whatever it might be. Hadley, do you have experience with communities like that?

Hadley Ferguson: I don't know about the challenges specifically, Jimmy. I think that's more in your wheelhouse because I'm not that athletic. But I definitely feel what you're saying that this camaraderie of being able to bounce things off of each other, and for me, it might be more project based. I might feel like this is something that's really important and there are a couple of people that feel like they want to also be involved in the same project, and we work together toward a common goal. So I think that that's really important that just the involvement, how you involve one another, how you involve your community and you bring back this information. I'd like to introduce co-chair of the Patient Council, Lynn Hagerbrant. She was diagnosed in 2010, and she was actually advised by her neurologist not to attend a support group. And here we're saying how vital that is. And this neurologist told her it would make her feel depressed. Let's hear from her.

Lynn Hagerbrant: I was stunned and bewildered, and eventually through the Partners in Parkinson's, I met several people and one man, Jeff Butchen, and we started a support group called, Shakers Anonymous, based on our connection to that event. And we basically at one point had 80 to 90 people that used to come to our support group at a YMCA in Connecticut. And eventually through that whole experience, I started Parkinson's Body And Mind in 2018. That's become a nonprofit, and we basically train instructors to work with a science-based exercise program to help hold back the progression of the disease. And we have support groups, we have speaker series, we have mentorships, and it's just amazing. I just have to pinch myself every so often. We're stronger together.

Jimmy Choi: Yeah, she definitely created an environment that was more surrounding herself with people like her. I remember my first support group experience. I did walk into, remember I was 27 years old when I was diagnosed, so I walked into a room full of 60, 70 and 80 year olds, and it just wasn't for me. So next, let's hear from Yvonne Jackson. She was diagnosed in 2014.

Yvonne Jackson: I started with Rock Steady Boxing. I kind of became the go-to person in our community, both in the desert Palm Springs area and on Martha's Vineyard because I had researched this so much and knew so much. And of course, I believe that exercise was the route to solving this to the degree you could. And I recruited people to Rock Steady Boxing. More people that would call me and say, "I have Parkinson's. My friends tell me to talk to you."

Sebastian Krys: And I've just tried to dedicate my time to raise awareness, especially in the Latin community. I was surprised about when I told friends how many people were affected by this disease, especially all Latin American, Columbia, Peru, everywhere down there.

Jimmy Choi: Now that second voice you heard was Sebastian Krys. That's right. The Grammy winner, Sebastian Krys. He was diagnosed in 2018. So let's hear a little bit more, this time from Kathy Holden. She was diagnosed in 2011.

Kathy Holden: So my main connection is through Team Fox, and I find in that group my own support group. I find strength, I get energy when I go to different events. It's where I've met a number of people who I can turn to if I need support.

Hadley Ferguson: You know what I love about these stories, Jimmy, is that they're not specific to support group stories. They're very different ways of thinking about your support group. And here's another one, Bill Bucklew, he shares his story. And Jimmy, you are a feature in that story.

Bill Bucklew: I learned exercise was important, so I thought of the most difficult thing that I would try to do, and that was I signed up for an Ironman a week after my diagnosis with Team Fox. I did this Ironman, I ended up completing it, sending in my check. I think I raised \$3,000, got a T-shirt in the mail and said, "Okay, great." That was really it. But then Jimmy reached out to me and said, "Hey, I saw you're with Team Fox." And I connected with Jimmy, started doing more Team Fox events and found people that were like myself. I didn't think, I didn't know anybody with Parkinson's. And that gave me a great connection. And now seeing what that's turned into, it's been very rewarding for me. So these kind of little iterative things in the beginning turned out to be really profoundly impactful to my journey with Parkinson's.

Jimmy Choi: You know, it's funny, Bill said in the beginning of that clip, he said that he found the hardest thing that he can do, and he did it. And if you follow Bill, you'd know that the Ironman was not the hardest thing that he's ever done. The man is crazy. He's one of those people that we'll challenge each other. But his story inspired me, right? He didn't know who I was back then, but I too was still looking for my community and I found him. We were the same, but we're different. We were determined, but we went about it in slightly different ways, which is why the Patient Council has impacted me so much. We are a group of determined, and let's face it, stubborn individuals, but we all learn from each other and because we all do it in different ways.

Hadley Ferguson: Jimmy, it's so true. And for people listening here who are not part of the Patient Council, because we are very fortunate to be part of this group, you have your own patient council in your community somewhere. And I just remember before I was part of the Patient Council, before I was part of these organizations, I just met up with a group of people in Oregon of all places. I hadn't really connected with people in Montana outside of the organization. It's sort of like a teacher becoming friends with their students. I felt like I had to remove myself.

But in Oregon, I had this group of friends and for me, that was my support. And I didn't really necessarily, that was my support group. I didn't really need to have anything else and we all encouraged each other. And I think that everybody out there has that group that they can bounce things off of, and you can get encouragement from one another and inspiration from one another. Oftentimes we find in life that one opportunity will lead to yet another and another and

another. And here are a few words from Anne Donnelly, who was diagnosed in 2010, and Leonard Chandler, who was diagnosed in 2017.

- Anne Donnelly: Joining the Patient Council gave me an opportunity to do that as a patient researcher on a really interesting study that the Fox Foundation was involved with, with the federal government. And also to do some things more private that I like doing. I love to write, something that professors love to do. So I wrote a book about Parkinson's. Actually, I wrote two books about Parkinson's and illustrated them both. One is about Rock Steady Boxing and its benefits for people, and the other is about ping-pong and its benefits for people with Parkinson's. So it's been a wonderful opportunity for me to give back while also getting.
- Leonard Chandler: I got an email saying, you've been accepted to join the patient care group at the Fox Foundation. And that has been a very eye-opening experience for me. For all of you that I have come to know and listen to and hear and grow from, it has been a blessing to me. This has been a very pleasant, aside from having to deal with the progression of this disease.
- Jimmy Choi: I think Peter DiBiaso summed it up well. He was diagnosed in 2015.
- Peter DiBiaso: I really feel that I've gained more than I've given, and I'll spend the rest of my life giving back and advocating as much as I can for all the great work that's done. I have a new family now, and the journey continues.
- Jimmy Choi: I love hearing all of these clips from our Patient Council. They all have something to share. And the last thing that we asked of the Patient Council during that conversation when we met in person, was that we would go around the room and just, everybody would just give us just a couple of words of what their life was like before they got involved, and then what it's like after. So just a couple of words. So let's go ahead and run that tape here.
- Dr. Soania Mathur: Before wrong priorities. After, enriched, blessed.
- Bret Parker: Fine and epic.
- Israel Roberto: Naive. Now informed.
- Peter DiBiaso: Scared transformed into hope.
- Kathy Holden: Living large and living better.
- Richie Rothenberg: Apprehensive and blessed.
- Julie Ocko: Shocked and empowered.
- Lynn Hagerbrant: Full of goodness and better now.

| | |
|--------------------|---|
| Bret Parker: | Work and purpose. Before too self-righteous. After still self-righteous. But hopeful, and part of a wonderful community. |
| Hadley Ferguson: | Before disconnected. After filled with love of community. |
| Kevin Kwok: | Before narcissistic, after slightly less narcissistic. Work in progress. |
| Richie Rothenberg: | Before all about me. After all about others. |
| Peter DiBiaso: | Before selfish. Afterwards grateful. |
| Julie Ocko: | Before selfish and afterwards, selfless. |
| Richard Huckabee: | Before blissfully ignorant. Afterwards blissfully blessed. |
| Leonard Chandler: | Before it was a good life. After it's a meaningful life. |
| Bill Bucklew: | Before tired. After inspired. |
| Leonard Chandler: | Before lost. After rewarding. |
| Dr. Karen Jaffe: | Before grateful. After grateful and hopeful. |
| Wanda Kim Lilley: | Before happy. Afterwards, joyful. |
| Claudia Revilla: | Before learning. Afterwards just beginning. |
| Sebastian Krys: | Before hopeless. After optimistic. |
| Gary Rafaloff: | Before fearful. Afterwards hopeful. |
| Dr. Soania Mathur: | Before busy. After busier. |
| Larry Gifford: | Before busy and stressed. After empowered. |
| Anne Donnelly: | Before busy. After engaged. |
| Denise Coley: | Before understanding. After empowerment. |
| Bill Bucklew: | I don't have anything for you guys other than before I was still numb, shaky. |
| Jimmy Choi: | I love that last part, just going around and listening to everybody. We heard from you during that. For me, before, I felt alone and after I felt like I was part of a team. |
| Hadley Ferguson: | Isn't that true? We feel like we're part of something bigger than ourselves after. And you heard a lot of that in these answers. There was a lot of people would use the word, selfish, or they were very alone words. And then after there's hope, |

there's being grateful, there's empowerment. And it's just really, it's amazing how something that can sound so scary can really change your life that way.

Jimmy Choi: Right. And I've always said that when it comes to getting more involved in anything in the Parkinson's community, for every one person, like yourself, like me, like everybody in the Patient Council, for every one of us who are vocal, there's probably a hundred sitting at home who have not yet ready to share their stories. So we just want to encourage everybody to just step out and do whatever it is, right? Once again, it could be something as simple as filling out an email to your representatives. It could be something as simple as telling your loved ones more about how you're living your daily life with Parkinson's.

Hadley Ferguson: Yes.

Jimmy Choi: But be more vocal. I think that's what we can ask for.

Hadley Ferguson: For sure.

Jimmy Choi: So I want to thank you, Hadley, for taking time and joining me in this conversation. The entire Michael J. Fox Foundation Patient Council, I want to thank them when we were there in person having this great discussion. Hadley, any final words for our listeners?

Hadley Ferguson: Well, I also want to thank you for including me in this conversation, Jimmy. I thought it was so engaging when we did this podcast in the meeting. I do want to just reiterate to the community listening that engagement is really going to look different for everybody. And it's just that first step. That first step will be different too. It's where you are in your life and the community that surrounds you, but there just are so many ways to get involved, and I highly recommend you take that step. It's liberating, it's freeing, and it is so worth it.

Jimmy Choi: Great advice, Hadley. Thank you. And for our listeners, if you are looking for ways to get involved, you can check out our website. There are tons of resources from ways to contact your representatives, to research studies to join online, and also support groups that are available in person and of course, online, like The Buddy Network. You can also visit the show notes for links to those resources. Now don't forget, please rate and review this podcast. It helps listeners like you find our show for future. And until next time, with Hadley Ferguson, I'm Jimmy Choi. Cheers.

Speaker 1: 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.