Timothy Lockhart: Every little thing makes a difference. There's strength in numbers that way, too. Don't just sit in a room thinking that, "Oh my God, I have Parkinson's disease. What am I going to do? Nobody understands. I'm all in this by myself." You're not. And you'll find out you're not when you start joining organizations like the Fox Foundation. My name is Timothy Lockhart. I'm from Jackson, New Jersey. I was diagnosed October 12th, 2021. So I immediately reached out to the Fox Foundation and I wanted to see what I could do to help.

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.

Maggie Kuhl: Welcome to the show. This episode is part of our award-winning Parkinson's Science POV series, where we dig a little deeper into the science and research. I'm Maggie Kuhl, Head of Patient Engagement here at the foundation, and I'm joined by our chief scientists, Brian Fiske and Mark Frasier.

Mark Frasier: Hi, Maggie.

Brian Fiske: Hi, Maggie.

Maggie Kuhl: This year, we're going to release four episodes throughout the year that dig deep into MJFF's four key areas of focus, our strategic research agenda. Brian, what do we mean when we say strategic research agenda?

Brian Fiske: Well, when we talk about our agenda, it's obviously something we've had really since the foundation launched in late 2000, and really just represents the direction we're going with all the work we're doing. So our mission to deliver better treatments for people living with Parkinson's, what does that look like? How do we turn that into action? And so that really is what our strategic research agenda is trying to define. And so over the years, of course, that has evolved, as it should, with the science and the progress that we're seeing in Parkinson's disease. And so today we really think about it in four key, important areas. So we're thinking about it in the context of how do we better define and diagnose Parkinson's disease given all the biological insight we know about the disease today and some of the tools that we have to measure that biology?

And then how do we turn that biology into actual therapeutic ideas? So to translate that biology into the language of therapeutic development is often the way I like to talk about it. Then how do we speed the testing of those ideas? And especially when you get into clinical trials, how do we speed that process? Not just in the traditional idea of speed, like how many days does it take, but actually in the context of how do we speed informed decisions? So really good quality data-backed decisions so that drug makers know that they're testing the right ideas and the right people and getting the answers that can inform whether to continue to develop that therapy or not. So those being really key three objectives in our strategic research agenda.

But then a fourth really important one is how do we work with the entire community of people involved in Parkinson's from obviously the people living with the disease and their families and loved ones, but also all the scientists and the researchers and the drug makers and the policymakers, the whole ecosystem of people who make up the Parkinson's community? So how do we best work with them and catalyze them and coordinate the work that they're doing on the most important problems and barriers for making progress?

Maggie Kuhl: Yeah, I think in our case, it takes much more than a village, or many, many villages to get this done.

Brian Fiske: Exactly.

Maggie Kuhl: Later this year, you'll hear us talk about those other three pillars of the strategic research agenda: clearly define and diagnose Parkinson's disease, create a better treatment pipeline, and speed clinical trials. But today we're starting with the one, as you said, underpins those others, which is catalyzed community. Mark, let's start with a definition. What do we mean by catalyzed community?

Mark Frasier: We mean a lot of different things. There's multiple communities that we're trying to energize and motivate to participate in what ultimately will look like a world without Parkinson's. So we'd like to have the patient community, people that are living with Parkinson's, motivated, participating in research, educated on what's happening in the world of Parkinson's research, volunteering for studies. We'd like to have biopharma invested in Parkinson's disease research and therapeutic development. We'd love to have neurologists that are treating people with Parkinson's disease aware of what's happening in research and encouraging their patients to explore opportunities to participate in research. We'd love to have policymakers around the world, and particularly in Washington DC, aware of the challenges of people living with Parkinson's, and developing and recommending pro Parkinson's policies. So it's a whole community of different sub-communities that we are trying to motivate, energize, and coordinate the activities around this world without Parkinson's vision that we have.

Brian Fiske: And connect, I think is important too. We need all these folks collaborating with each other and working together.

Maggie Kuhl: Patient-centricity has been a core value of the foundation from our start. So I want to start our conversation there. Here's our founder, Michael.

Michael J. Fox: The patient experience and the patient struggle and hopeful outcome of our work is essential to everything we do. It starts with me, being that the foundation was created by someone with Parkinson's, that has a personal stake in it.

Maggie Kuhl: And here are a few voices from our community of people living with the disease or at risk for it, sharing how they see their role working with MJFF as part of this community. Take a listen.

Donna Rajkovic: I researched on the website of Michael J. Fox Foundation that they were doing a PPMI study. I enrolled, and I'm still part of the study today. So I wanted to do my part to help not only myself and my family, but other people. Science is the key to a cure. That's the way we're going to get there and we need everyone to participate.

Maggie Kuhl: That was Donna Rajkovic, diagnosed in 2012. And here's Kevin Kwok, 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 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.

Maggie Kuhl: Here's MJFF Patient Council member, Hadley Ferguson, diagnosed in 2010 with Parkinson's and then later with multiple systems atrophy.

Hadley Ferguson: 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: I am Jimmy Choi, diagnosed in 2003. 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, 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.

Allie Signorelli: I'm Allie Signorelli, and I have young onset Parkinson's disease. Advocacy is great. It's tangible action items that we can do to make a change in the course of Parkinson's disease. So it feels good. It's hopeful, it's actionable, and it's exciting to meet with our members of Congress. We need to keep our voices loud to make sure that the Parkinson's legislation stays at the top of everybody's minds.

Maggie Kuhl: Our community includes people like PPMI participant Allen Dance, who is living with a risk factor for Parkinson's called REM sleep behavior disorder, or RBD, when people act out their dreams.

Allen Dance: I got a diagnosis for RBD last September, and I joined PPMI the next week. One of the things that I found out before I was in this study is that a lot of the research studies in this area have a shortage of African Americans participating in it. If you're doing research, you need to have people from all backgrounds. So I look to be an active participant.

Maggie Kuhl: Here's Tim Lockhart again, whom you heard at the beginning of the episode.

Timothy Lockhart: I have never gone to a Fox Foundation or a Team Fox event where I haven't left more motivated leaving than I was when I came in. Every time I go to one, I'm like, "Turn the chapter. Well, what's the next thing I could do? How else can I help?" And the hope is that that becomes contagious and that we all start doing it and it leads us right to a cure.

Maggie Kuhl: So Mark, Brian, we just heard these members of the community talk about why it's important for them personally to be part of our efforts and why we need to all work together. Can you just say more about that why? What is the importance of prioritizing this work? Why is this a full pillar of our strategic research agenda to build community?

Mark Frasier: I think

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Maggie Kuhl: ... Pillar of our strategic research agenda to build community.

Brian Fiske: I think, again, we can't really succeed if any one group trying to solve everything. So the problems that we're trying to address through our strategic agenda, again, whether it is figuring out how to define the biology at a point where we can better tell somebody, here's what you have, not just that you have symptoms of Parkinson's, but biologically that we think you have this biological form of disease, whether it's turning that into drugs and developing those drugs to reflect that biology. And then, of course, how do you get that through clinical testing? All of that requires just this ecosystem of people working together and connected to each other and learning from each other and listening to each other.

And so, I think why this fourth objective for us around community is so important is because we can prioritize how we work and operate to make sure that we're working and collaborating with all these different community stakeholders and bringing them to the table and making sure their voices are heard and that their ideas are being considered. And I think you can't succeed on the other three objectives if you don't have that connected community.

Mark Frasier: Yeah. I think of Michael's quote here where he said, "There's no department of cures," and we are the department of Parkinson's cures. And in order to enable that to happen, we need all of these different groups. We can raise all the money in the world, but without scientists and motivated research volunteers and pharmaceutical companies involved in this vision, we're not going to make any progress. And so, having this catalyzed community is really important to our mission and being that department of cures.

Maggie Kuhl: I think too, sometimes what comes out of collaboration is so important, but collaboration in itself, feeling like you are part of something bigger, that connection, not just for what it breeds, but also how it sort of inspires is so important. And I do think a term that we use at MJFF is unique convener, that we are in this unique position to be able to bring all these people together. Why is it, Mark, that you think that the Michael J. Fox Foundation is successful in being that nexus?

Mark Frasier: There's probably a lot of reasons. I think being neutral, as you said, and we're cheering for every program to succeed, every intervention to work in people with Parkinson's, so being neutral is important. And I think related to that, building trust and credibility with these different communities that we have one singular focus is to go out of business. And with that very clear mission, I think that trust and credibility with the different communities, the patient community, the scientific community, the industry community, the policy community, I think it's a very powerful organizing principle that enables and encourages and incentivizes these different communities to work together and with us.

Brian Fiske: Yeah. In many ways, almost as important as the funding and resources we can provide to people who are trying to tackle Parkinson's is that credibility. I think you're right. It really is. That is what people come to us for, too, just to know that they're part of a community that is really thinking about this. And, again, I love the department of cures concept, too, because I think without that, I think you're right, that you lack that central hub, that nexus for getting things done. And I think that's such an important part of the way that we can bring and connect those communities together.

Maggie Kuhl: Yeah. And I think the more that we do it, the more that we have this view of what different people need, what's coming up next, and how we can really be making those connections. I think that it's literally the job of the foundation to hold that bird's eye view to really know everything that's going on, such that we can be bringing the right resources, the right people to this sort of collective effort. I want... Maybe we've talked a lot at high level about why this is important and what we mean. Maybe it would help to illustrate a little bit and to talk about our own pockets of work. And we've named a lot of different partners. So what does it look like? What are some success stories? Brian, maybe I'll start with you. You work a lot in the drug development space. We bring companies together a lot. We bring large global cohorts together. What comes to mind in your own portfolio when you think about catalyzing community?

Brian Fiske: Yeah, for me, it really is about catalyzing around, we often like to use this word pre-competitives. So what are the big questions and the big challenges that everybody faces, in this case in the drug development space, that we can, again, use our power as this sort of unique neutral convener, bring these different, in this case, drug maker industry people together to the table and ask, "Okay, you all are interested in developing therapies against this particular biology, but we're struggling with this similar question that you're all going to have to deal with. And so, how can we work together to try to address that?" And using that connected community, they're all very motivated. They want to try to develop these types of therapies, but they individually can't address some of the big questions. Maybe it's a biology question or a measurement tool question or some other, how are we going to find these people who have this particular biology type question?

And we can then work with them to understand what their needs are, understand what challenges they're facing, and then actually work with them then to try to address and answer those questions. And I think that just is a core aspect, that sort of pre-competitive collaboration that we can bring to address those questions that really I think keeps them motivated, keeps them involved, keeps them excited about Parkinson's as an opportunity to continue to pursue.

Mark Frasier: One exciting example of that is this focus on LARC-2 drug development. And I just can't emphasize enough how rare it is to see the level of collaboration between companies around a particular target. So we have a consortium of over 20 groups that are developing... We have 20 biotech and pharma companies that are developing drugs against this Parkinson's target that are working together, sharing information all through the foundation that are facilitating these collaborations. And the expectation is that progress will be made a lot faster through these collaborations and sharing of information. And this is pre-competitive, as Brian said. We'd like them to all eventually be competitive once they get over the hurdle and into clinical trials, but to have this level of collaboration, I think is just going to accelerate the therapeutic landscape and develop these treatments quicker.

Brian Fiske: Yeah. Maybe another good example is we just launched earlier this year, an initiative called Targets to Therapies, which was sort of an evolution of work we'd been doing for many years to try to advance promising biology that could become future therapies for Parkinson's disease. And this was an attempt to refresh that approach through the lens of this idea of this more pre-competitive stakeholder community connection where we've brought in not only the basic scientists and researchers who understand the biology, but a lot of companies as well that are very interested in understanding what some of this emerging biology might look like for future therapeutic development. And so, they've been really key part of this discussion, this initiative to, again, try to not only offer advice and thoughts and considerations about what makes a good biological target for therapeutic development, but actually then contribute to some of the studies that need to be done to increase confidence around some of the biology that could become these feature therapies.

So again, I think this idea, if you can define the right pre-competitive space for these groups to work in, they're very eager and very hungry to want to work together and then be a part of that community.

Maggie Kuhl: I want to address, we're talking about companies, we're talking about industry, and sometimes in the patient, the Parkinson's community, general population, there's this feeling that industry and companies are the bad guys and that maybe we shouldn't be working with them. So I wanted to ask you to address, and just sharing, companies are the ones who make therapies. This is how we are going to get new treatments. And so, they're not a boogeyman for us to not engage with. And I think the examples that you're sharing, and I can talk...

... Engage with. And I think the examples that you're sharing, and I can talk, too, about how we try and work with the companies to think about how what they're focused on is really meaningful to patients, it addresses the needs that they have, how they're designing studies, how they're evaluating the impact of those therapies is really rooted in the patient experience and what's meaningful to them to change, not just biology in a test tube. But can you say anything, Brian, about how we look at collaborating with industry and why they need to be? And they have been very good partners in this realm.

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Brian Fiske: Yeah. No, I think it's important to remember that to deliver therapies for any disease, let alone Parkinson's, you have to work with companies in the industry who are going to be able to ultimately make and deliver and distribute those therapies. I think we often get immersed in Hollywood concepts of the scientist working in his basement lab who no one listens to, and he or she discovers the cure for some disease, and somehow that just miraculously leads to a world without that disease, but isn't, of course, reality, and you really do need to be working with these companies who have the resources and the will and the interest and the desire to want to make meaningful treatments for people with the disease. And these are companies that are filled with scientists just like us and people who are passionate about developing therapies, who themselves are connected to these diseases.

Many of the industry folks that we work with often tell us that they're connected to Parkinson's, that they have personal connections, family members and loved ones. They have skin in the game too. They really want to pursue these therapies and be a part of this community as well. So yeah, sometimes, yes, are there occasional bad actors out there? Of course, of course, that's in truth. Even in the academia space there certainly are bad actors. So I think we have to just remember that everybody, again, is connected in the same community here and then looking to achieve the same goals. And so that's why it's so important to us and why, really from day one at the foundation, we saw the importance and critical value of working with industry as part of our mission.

Maggie Kuhl: I just want to touch on quickly, too, the role that people with Parkinson's play. We've talked about their participation in these studies. No treatment will come to pass, will go to pharmacy shelves without testing and volunteers who raise their hand to be in clinical trials. So we certainly work to catalyze the community in that way. I've mentioned that we work with companies. We have a lot of individuals who work with us on reviewing study protocols or taking surveys about what sort of trials would they want to be in? What is meaningful to them such that these companies can be really partnering with people with lived experience? We work with regulators, with the governmental agencies, with the insurance companies that are evaluating, should this therapy be approved? Should it be reimbursed and accessible at certain cost structures? To say, this is the unmet need and this is how a therapy like this would change the game for people living with Parkinson's.

So again, I just wanted to illustrate some of the different ways that we're working with these community members, and especially how people with lived experience are really playing a big role in that. Maybe, Mark, you can also talk about our policy realm because that's a place where people with lived experience really play a big role, but there's so many other partnerships.

Mark Frasier: Yeah. So I had the privilege of participating in our policy forum last fall, which brought together over 200 people to Washington D.C to advocate for change in government policies that will affect people living with Parkinson's disease. This includes coverage and reimbursement for specific medicines, elimination of pesticides, and actually a governmental plan called the National Parkinson's Plan that will establish a committee that will oversee the government's activities as it relates to Parkinson's, both funding, reimbursement, and environmental policies. So this brought together people living with Parkinson's, it brought together a community of other Parkinson's organizations that care about these policies, and it was just a vibrant two days, a very busy two days, of presentations, but, importantly, meetings. Majority of the two days were meetings with our representatives, both Congresspeople and senators, to really describe the experience of living with Parkinson's disease and what very simple changes can be made that would impact people living with Parkinson's.

So the forum is one example. We have a number of other partnerships with government agencies that are trying to develop these pro Parkinson's policies.

Maggie Kuhl: In a lot of this work, our policy team is going out and making these connections. People who, as Brian, you said, they may have Parkinson's connections, unfortunately too many of us have a Parkinson's connection, but they may just be seeing the need and touched by the stories that we're bringing them. And so our effort is not just to catalyze the community that we currently have or that can come to us, but really to go out and be telling this story and bringing people more under the tent, as our co-founder, Debbie Brooks, says.

And Mark, you've done that a lot also on the scientific side. I think on a previous podcast, we were reminiscing about how when data, big data was really coming out, we were saying we've got to go find data scientists and tell them, "Look at all this Parkinson's data." The AlphaSynucleins test story is a story of us going out and finding someone who is developing a new technology and saying, "You've got to come into the Parkinson's world." Can you talk more about how the foundation not just brings together people who are already in the Parkinson's space, but also brings more folks toward our mission?

Mark Frasier: It's a really important point because we recognize that we're not going to solve all of the answers and all the challenges ourselves, nor within the current Parkinson's research community. And so it really takes what we call this multidisciplinary or multiple different expertise and experts to solve some of the really challenging research areas in Parkinson's disease. So we do this on a macro scale and a micro scale. Two examples that you've mentioned, one was more macro where we recognize the need for data scientists and artificial intelligence experts to analyze these massive amounts of data that we're generating through research studies like our Parkinson's Progression Marker Initiative. So we'll put out a call, a funding call to solicit ideas from researchers in this area to get data scientists and AI researchers involved in Parkinson's and prioritizing Parkinson's as important research questions for their work.

And then on a micro scale, you mentioned... We have a team of about 20 different PhDs that are scouring the literature, not just within Parkinson's, but also outside of Parkinson's. And they come from a variety of different expertise. And we will very frequently reach out to experts in a different field and invite them to submit a proposal that we think might be relevant for Parkinson's. And so this biomarker breakthrough you referred to was actually developed by someone that was focused on prion disease and a little bit of Alzheimer's disease, and one of our scientists gave them a call and said, "Would you apply your technology to Parkinson's?" And it turned out that actually the technology worked better in Parkinson's than some of the other diseases he was looking at.

So it's that type of proactivity and dot connecting to find researchers from all different walks of life and global researchers to bring them into Parkinson's disease is kind of what we do, and that's our secret sauce.

Brian Fiske: Scientists love a challenge, new question they have to address, and so when you bring a new biology to them, maybe it's a biology they kind of understand and they've never thought about applying that biology to Parkinson's and we can bring that to them. They get very excited and very quickly wanting to get involved, and we've certainly seen that in the past with emerging biology. For example, we mentioned earlier about the LRK2 protein and the biology around that. And that was a great example where when that biology was emerging initially, we were scouring looking around for experts who might understand it, even if not in Parkinson's, and very quickly landed on some researchers that were looking at it for other reasons and then brought them into Parkinson's. And they're still, today now, leading some of our biggest initiatives in that biology. So again, a great example of if you can present the entice...

... if you can, again, present the enticement for why Parkinson's is a great place to work and a great challenge to try to solve, people get really excited and eager to want to be part of that.

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Maggie Kuhl: Well, our optimism is contagious for sure. We are talking about how this is so important. This is so great. We need to collaborate. We need to bring the community together. It's not easy, right? As anyone who has chaired a committee or planned a weekend friends trip, or gosh, there's so many examples, there's a lot of personalities and priorities. So what can be challenging about getting people headed in the right direction, Mark?

Mark Frasier: I think it's a great question. I mean, certainly aligning incentives is important. So we talked about different stakeholders and certainly within research, there's multiple different incentives. Typically, university professors, they're evaluated and one of their major metrics is publications and publishing in high visible research journals. Biopharma, they're evaluated on a commercial success. And patients and people living with Parkinson's, they want to just feel better. So every one of these communities has different incentives and different desires. And one of our goals and one of the challenges, but I think we overcome this challenge pretty well, is aligning the incentives that allow all of those metrics to be achieved.

So encouraging open science and encouraging publication. We do not take any ownership of intellectual property when biopharma uses our support to make new discoveries and develop potentially commercially viable products. And we encourage patients to provide feedback to both academic researchers and biopharma on what matters to them, what's important to them, and that allows them to prioritize their research accordingly. And so I think aligning those incentives, those different incentive structures is one challenge that I think we've been able to solve pretty well.

Brian Fiske: I was going to say too, obviously just logistically getting them all in the same time zone can be a real challenge. I've often said we could probably cure all human diseases if we could just figure out the time zone challenge for scheduling a meeting. But I think, I mean, realistically, you're right, these networks are often, these communities are often global in nature and certainly we've never shied away from wanting to find the best people wherever they may live around the world and bring them into Parkinson's disease. So that can actually be a logistical challenge just to get everybody together. But I think you're right, Mark. It's about that alignment around incentives for why am I here? What voice am I bringing to the table? But I think the way we address that is just making sure that we're good listeners. We want to hear all the ideas and the thoughts people have.

Now, can we execute on all those? No. Are we going to have to prioritize? Yes. But at least we've always been, I think, and seen ourselves as a nexus of understanding where things are going, what people's ideas are, what the challenges are in the Parkinson's space. And I think by bringing everybody together like that, we can hear all those needs and opinions and perspectives, and then use that to formulate what we think are the best actions that we can take as an organization and hopefully as a shared Parkinson's community.

Maggie Kuhl: Yeah. If someone is interviewing or such and asks me, "What's kept you here for so long and such?" One of the things, and I think it's really crucial to our partnerships, is that we really take a yes if mentality versus a no because we lead with, like you said, we listen, we want to hear people's ideas, we want to understand their needs. And like you said, Mark, we're open to what matters to them and trying to build a system for everyone. There are trade-offs, there's prioritization, but we really have more of a welcoming, collaborative opening stance versus being closed off for sure. So if you are listening to this, we need your help is the message here. So Brian, what would you say to the research side who may be tuning in? What do you want them to know about getting involved?

Brian Fiske: Just that there are plenty of opportunities to help address the big meaty questions that are keeping us from eventually getting to a world free from Parkinson's. So whether they're biological, whether they are translational in the context of drug development, whether they are infrastructural, there's all these big challenges. And I think if you are a scientist or a drug maker or an investor even who's looking to make investments in the disease space, I think there's a lot of opportunity and real value to get involved in Parkinson's disease. In many ways, we also too, see ourselves as a blueprint for how to, hearkening back to Mark's earlier comment, how do you build a Department of Cures?

And in many ways, I think we can offer a blueprint for that. And so it may look hard, it may look challenging, but working together as a community, we can actually address a lot of these challenges together. So I think for anybody coming in new to the Parkinson's space, I think there's a lot more collaboration, connection, and clarity on the path forward than if we weren't around to help connect all these stakeholders.

Maggie Kuhl: Mark, how about someone who is living with Parkinson's or who loves someone with Parkinson's? What's their role?

Mark Frasier: I mean, how long do you have? There's so many opportunities to just get involved. I talked about volunteering for research and educating themselves on the research opportunity. It doesn't always have to be being poked and prodded. There are research studies that are online like Fox Insight that we support that you can participate just using your phone or computer or laptop. Raising funds for Parkinson's research, participating in advocacy efforts, talking to your local representative about your lived experience can be so powerful as you mentioned. And the voice of the patient is as important as it has ever been. And those living with Parkinson's and those caregiving with people for people with Parkinson's are the true experts and lending that voice to the Fox Foundation, to policymakers, to researchers are all ways to get involved and join this catalyzed community and build an even stronger community.

Maggie Kuhl: I will mention too, another way to join our community is to donate to our urgent mission to QRPD and develop new treatments. 89 cents of every dollar donated goes directly to our research programs. Brian and Mark, thank you so much until we tackle our next research agenda pillar. Thanks for the conversation. And if you would like to learn more about how you can take action, please visit our website at michaeljfox.org.

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.

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