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.

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

Larry Gifford: Hi, welcome to The Michael J. Fox Foundation Parkinson's podcast. I'm Larry Gifford, a proud member of The Michael J. Fox Foundation's patient council, the host of another podcast that I invite you to listen to called When Life Gives You Parkinson's. And I'm the president and co-founder of PD Avengers. Be sure to check out the PD Avengers Takeover episodes of The Michael J. Fox Foundation Parkinson's pod from the fall of 2021. Today, we're going to talk about how you can help find a new biomarker for Parkinson's. A biomarker is an objective test or measurement of a disease. For example, cholesterol is an example of a biomarker for heart disease. We'll tell you why enrolling in research soon after diagnosis can be very impactful. We'll talk about the study from The Michael J. Fox Foundation, the Parkinson's progression markers initiative also called P PMI. And it's particularly looking for recently diagnosed people who have not yet started their medication. Hear from one participant who was diagnosed in 2019 and joined the study soon after.

Larry Gifford: And we do invite you to go online, and rate and review our podcast. It really helps to raise the profile of The Michael J. Fox Foundation Parkinson's podcast, and it builds awareness of Parkinson's disease in general. So if you could just go on there and just say, yeah, it's a five star show. And we thumbs up, love the show, taught me a lot of information, whatever you want to say about it, but it does make a difference. And we do appreciate your support. And if I could just ask you, I know that it's not always convenient or it's not always easy to work into a conversation, but we do trade recommendations for movies and for TV shows.

Larry Gifford: And I would just say, if you're talking about podcasts, go ahead and recommend this podcast. Even if they don't have Parkinson's, it's something they're going to learn all about. And it's something they're going to have to deal with at some point with somebody in their life. So thank you. And now on with the show, let me introduce our panelists. Phil Alongi was diagnosed with Parkinson's in 2019 and is a participant in the PPMI. And Lana Chahine is a doctor. She's an assistant professor of neurology at the University of Pittsburgh and the chair of the PPMI Recruitment and Retention Working Group. Welcome to you both.

Lana Chahine: Thanks, Larry.

Phil Alongi: Thank you, Larry.

Larry Gifford: Now we all know that research is important. We hear it all the time. It's super important. One group though, that may have a hard time recruiting though is those newly diagnosed people with Parkinson's, who haven't started taking Parkinson's medications and how valuable they are in that early state of Parkinson's. Lana, why is it important to enroll this group into studies?

Lana Chahine: So, Larry, as you were saying, we need a biomarker. We need a way to accurately diagnose people with Parkinson's disease as early as possible, and a way to measure their disease where it's at and how it's going to change over time. And while every person with Parkinson's can help the effort to identify biomarkers, people who were just diagnosed are of particular interest because the medications that are used to treat symptoms of Parkinson's, for example, levodopa and related medications, they can be very effective and in turn can affect some of the measures of Parkinson's. And so someone who was just diagnosed, first they're of great interest because they are early in their disease course, so they can help us develop biomarkers to accurately diagnose the disease. And second, their presentation of their symptoms and science has not yet been modified by medications.

Larry Gifford: Well, and what's interesting is some people are diagnosed by taking levodopa to see if it's effective for them. So that even limits the pool more.

Lana Chahine: Yes, that's right. So a response to levodopa also called Sinemet has helped confirm the diagnosis, at least in some people.

Larry Gifford: Well, me, that's how they found out I had Parkinson’s. So, so I look at this and I go, oh, I wanted to help out this cause, and now I can't. But not that way, there's other ways for sure. What are some of the potential promising biomarkers that have already emerged from research?

Lana Chahine: So the exciting thing about biomarkers is that there are so many different potential sources for them. We hope that we'll find biomarkers in the blood. So we'd love to have the blood tests for Parkinson's, but there are other parts of the body that are closer to the brain and what's going on in the brain like the cerebral spinal fluid or spinal fluid. There may even be biomarkers for Parkinson's in the skin. So there's a very broad range of areas not to mention some apps or digital motor measures that can measure the motor symptoms of Parkinson's in the motor signs in an objective way using technology. One of the most promising biomarkers right now relates to the protein alpha-synuclein. So abnormal forms of the protein alpha-synuclein deposit in the brain and body of people with Parkinson's, and we've found very accurate ways to measure alpha synuclein now in multiple areas of the body. And I think that's a very promising biomarker that's being tested in PPMI.

Larry Gifford: Phil, let's talk about you and how were you diagnosed?

Phil Alongi: Interestingly enough, I've been very fortunate that I have some very good doctors that take care of me. And I had some symptoms that I was not aware at the time actually were early precursor to Parkinson’s, such as loss of smell, frozen shoulder, et cetera. And fortunately my doctor did not ignore some of these elements and got me moved in the right direction. And eventually ended up with a neurologist who also a very bright young man who looked at me and said, I'm going to check you out for Parkinson's. And it ended up, we did a DaTscan dopamine depleted in my brain pretty much confirmed the diagnosis. So we saw that.

Larry Gifford: But when was that?

Phil Alongi: That was in 2019, September of 2019. And then shortly after is when I learned about the PPMI study and felt very strongly that I would love to play a role in fighting this disease and helping to identify, how cool would it be if I was part of that group that came up with some element that would help diagnose or help treat or whatever for that matter. And what was very interesting what Lana was just talking about, I recently had a session where I go up for the work that I'm doing with them. And what was terrific is as they were doing the various tests, they were explaining to me about how this potentially could contain information that would help to identify the biomarker such as when we were doing the lumbar tests.

Phil Alongi: And as they were going into my spine, they were explaining as they were going through the skin, how perhaps this could play a role and other layers. So it was great to be able to hear some of these, the details, because at least I had a better understanding of what everyone was trying to do, and what they were trying to accomplish and the role that I could play.

Larry Gifford: So with the PPMI, how long have you been in the program now?

Phil Alongi: I've started in the middle of pandemic two years ago, almost now, and had my initial session of where they were establishing all the benchmarks. And we were doing all the various tests and et cetera. So recently, I was up there for my... It's pretty much I go up twice a year. And we spend a good quality day doing various tests, via cognitive tests, via blood work, skin biopsies, all of these things that I never would think would play a role in the research. But obviously people a lot smarter than me know where to look and that's where we have to be grateful to people like Lana and company.

Larry Gifford: Yeah. PPMI is the Parkinson's progression markers initiative. It was launched in 2010, so it's just over 10 years old. And it's designed to help us better understand Parkinson's and advance new treatments. And here, I'd like to bring in Michael J. Fox who was on the interview by USA today recently.

Michael J. Fox: If we can find a cohort of people, a huge cohort, 100,000 and have five or six of those or four or five of those indicators. Get them all together and you just have to knock off eliminate the non factors. And hopefully the idea is that by the end, you boil it down to a marker, to a thing that you can identify. One thing that you can look at and say, that person has Parkinson's. Now that may be, in my case, it might have been when I was 15 and not 29. And by the time I was 29, it would be properly treated it and never get any symptoms. Nobody [inaudible 00:09:39].

Larry Gifford: Michael talked about how it's possible if we can find a biomarker, he may have been diagnosed at 15 instead of 29. So Lana, I'd like to know from your perspective, how has PPMI advanced our understanding of Parkinson's disease and how close are we to that elusive biomarker?

Lana Chahine: I think PPMI has really contributed to the field of Parkinson's disease in many ways. It started, as you mentioned, in 2010, and at the time enrolled about 420 people with newly diagnosed Parkinson's and about 200 people without Parkinson's or controls. Over the decade, PPMI then recruited individuals who were at risk for Parkinson's, whether due to certain sleep disorders, one called REM sleep behavior disorder, or as Phil mentioned, people who had a loss of sense of smell or carried genetic traits that predisposed them Parkinson's disease. And these people now, some participants have been in the study for almost 10 years, one of the first studies on this large scale to collect so much data on so many people. And one aspect of PPMI which has been invaluable, it's not particularly glamorous, but it's just like one of the most important factors in biomarker development is the standard way in which so many specimens were collected and are now stored in a bio repository and can be requested by researchers.

Lana Chahine: And when you get that specimen, you know that that if we find a biomarker in it, we know it's a real signal. And isn't just something that's showing up because at the time of day the specimen was collected or the temperature it was stored at. So the standardization of specimen collection is really in my view, one of the most important ways that PPMI has contributed to the field, because there are now data on thousands of participants collected for over up to 10 years and specimens on these same people that are available for the research community. And some examples of what's come out of PPMI is this understanding of how the dopamine transporter imaging or this dat scan, how that tells us about the disease and helps us understand among people who are at risk of Parkinson's, who is particularly at risk.

Lana Chahine: And those data have now been used to inform the design of two clinical trials that were testing agents to slow down the progression of Parkinson's. So it's translated from research findings into clinical trial design, and it's really getting us toward that goal of finding treatments to slow down the progression. And ultimately the goal is to cure Parkinson's.

Larry Gifford: So when you're at this research design phase, if everything goes great, how far away are we from actually going to the pharmacy and getting that treatment?

Lana Chahine: The drug development is unfortunately a very slow process. And from the time the idea comes forth to the time it's on market, it can be even a decade, even though there... What PPMI has done though, is actually expedited that process. And so it's allowing clinical trials to be done much more quickly and efficiently because the data that PPMI provides allows you to select the right people and to know how many people to recruit and to make estimates that are critical in the early phases of a clinical trial.

Larry Gifford: Yeah. And you're right. I just want to reiterate. I mean, this is an amazing study. I mean, it's following people with and without Parkinson's over a long period of time to learn how the disease starts and changes over time. And that's the information and the insights are going to come from that collection of data over time for these same people and the tools that can help better diagnose and treat and even prevent a brain disease. So this is just a truly remarkable study. And now it's expanding. This is the next iteration of PPMI study has added on online platform to gather data from more than 100,000 people. And it is following volunteers at more sites and more countries. So what do we expect by growing this so exponentially?

Lana Chahine: As you and Phil mentioned, the PPMI started in 2010, but is now having this expansion phase. So new participants are being recruited, and there are different components of involvement or different levels of involvement. So the most, I would say intensive extent of involvement is in the clinic where as Phil is doing, come in for a visit. And you see the research team in person, and many different specimens and assessments are collected. In addition to people with Parkinson's now we're recruiting people who are the group of people who are considered at risk for Parkinson's. Our ultimate goal is to cure Parkinson's, but the dream is to prevent Parkinson's even before it happens. And so we are really starting to focus on people who are at risk for it.

Lana Chahine: However, there are other key areas that the first phase of PPMI was not able to address and a very big one relates to how Parkinson's affects all people. And with the PPMI online component, we'll be able to reach people who may not be able to come into the clinic, and we're going to have more diversity in our research cohort and really be able to understand Parkinson's across the country, across the world, across people at various disease stages and different experiences.

Larry Gifford: And we're talking about a lot of data here. So I just want to note. The PPMI study has put multiple measures in place to safeguard the information that anybody would contribute. All identifiable information, including your name and contact information is kept in a secure database. The scientific data you contribute to PPMI is aggregated. Meaning it's compiled with data from other participants. It's de-identified, which means your name and identify information are removed and shared with qualified researchers for use in studies in advanced understanding of Parkinson's disease. The scientists who want to study your data must apply to PPMI for access and sign a form that says they will protect your data. Privacy. Your information will not be sold and will never be shared outside the research community. And PPMI takes every measure to protect your privacy. Still as with all online activity, it is important for participants to know that it is never possible to fully guarantee against breaches in security, Phil, what would you say to someone who's maybe on the fence of joining the PPMI?

Phil Alongi: I would say to them, what do you have to lose? I mean, how cool would it be for you to be able to say you are doing what you are, and you're contributing to the cause and the fight versus sitting on the sidelines. And what I would say to them as well is for the greater good, it it's definitely worth the effort that's put in there because certainly there are people that are very dedicated. And when I do go up for the study, I meet some of the most competent people, but also some of the most caring people. And I know that really means a lot to them, what I'm contributing to this, and they treat me with great respect. But I also know that the end game is really what they're really focused on. And none of them will rest until they do indeed come up with a resolution to this issue.

Larry Gifford: So when you were diagnosed, how much did you know about Parkinson's?

Phil Alongi: Not much at all. Obviously knowing Michael J Fox's story was something that I was aware of, especially the fact that he had early diagnosis, but I've learned so much more about Parkinson's since I've gotten involved. And what is amazing about it is the fact that the research that's going on and how initially they were going in one direction, but everybody was able to admit we need to regroup and figure this out, and let's start over. So when Debbie Brooks had called me and told me about PPMI and said, so we're about to expand this, and if you're interested, let us know.

Phil Alongi: I thought the commitment from The Michael J. Fox Foundation was amazing. And the fact that so much money has been given to this issue already, and the fact that they do make it available as you've already pointed out to researchers around the world, since this is a global issue. It's awesome. And what I've learned about the disease and working with the various medical folks that I do have from a personal level, as well as some physical therapists, et cetera, you don't take these things lying down. And there are a lot of options out there, and I'm not about to let this thing get the better of me.

Larry Gifford: So how important has gaining that knowledge about Parkinson's been for you through this process?

Phil Alongi: It's very important because I don't sit here and feel sorry for myself. I don't feel that this was something that was done to me. It's something that just happened. And I'm not about to take it without a challenge. And in addition to the research study that's being done to identify the biomarker, there are a lot of... I recently looked up about various other studies that are under way. There are 252 that I saw in just the list that I found just scoping around. The best thing you can do is be informed so that this way you can be reactive to this as well.

Larry Gifford: We already talked about how we're looking for newly diagnosed who aren't on dopamine replacement, but who else are you looking for? Who else qualifies to participate in this study?

Lana Chahine: There are three main groups who qualify. And the criteria for the in person and the online are a little bit different, but in general, PBMI is recruiting three groups. People with Parkinson's disease who are newly diagnosed, as you mentioned, or people with Parkinson's disease who have a genetic trait associated with Parkinson's. Some people may know these as LRRK2 and GBA. We're also recruiting healthy control. What we call controls. These are people in their different age groups, but ideally in their sixties men and women who we can compare the Parkinson's group to who are generally healthy. The third group are people who are at risk for Parkinson's. And their risk may be defined by a genetic trait, a family history, certain features, whether loss of sense of smell or REM sleep behavior disorder that we know in a subset of people is associated with increased risk of Parkinson's. Those are the three main groups. In the PPMI online study, there are broader criteria. And the way I would say it is if you want to contribute to Parkinson's research, sign up for PPMI online, you will be eligible.

Larry Gifford: That's great. That's great. And so this is unbelievable, but PPMI data is downloaded by researchers on average 2200 times per day. That is amazing. Just think of the impact we're having on the scientific community as we try to really understand this disease. It's really remarkable. Phil, I thank you for doing what you're doing. I appreciate it. And on behalf of the Parkinson's community, we need people like you are willing to step up and say, listen, this can't go on. It's time to make a difference. And so, thanks for raising your hand and stepping forward and doing what you're doing, because not everybody is willing to go there. And so, or ready when you were. And so I think it's a perfect fit.

Phil Alongi: Well, that's kind of you to say, but I don't consider myself to be any different than anyone else. And I think every one of us can play a role in this. I recently actually had to go to an orthopedist for something. And he was very interested to hear about the PPMI study. And he's actually asked me to forward him information about how he can share that with patients, because oftentimes people are coming to him, and he would love to have this tool. So I think that's where all of us can do as much as we can in terms of spreading the word, because there are people out there that I'm certain they would welcome being part of this study. So thank you for what you said, Larry.

Larry Gifford: Yeah. A little peek behind the curtain. How often are you meeting with the research team? And from the time you said, yeah, I'm interested, to the time you had your first, like what's the process? How did you get into the study?

Phil Alongi: The process was when I raised my hand and all, then they contacted me, and we had an initial phone conversation to see if I was the right candidate for it. And then even though it was at the start of the pandemic, my wife and I felt comfortable enough going up there, and that the clinic was going to protect us from what we were all concerned about, of course, with the COVID virus. And so what we do is they're very conscientious about making certain because the DaTscan is definite one of the first elements you have to have done. But then there's an AV 133 test, which is a separate item which they had asked if I'd be interested in participating in that study as well. So we sort of have to space it out so there's a week in between, so you don't get too much radioactive material in your system. But then it's twice a year that we go every six months.

Phil Alongi: And most three recently I was there the one week and we did the DaTscan. And we did, as I've already mentioned, the lumbar test, but we also did a biopsy of the skin, two cuts in that, plus some blood work, plus some cognitive testing, et cetera. So what I find rewarding about this is that I just feel that information that's being gathered on me, that perhaps is going to be pointing in the direction that they're looking for. But if not, it's going to also be information that they'll be able to dismiss, and know to go somewhere else. So that's the best way I can describe my experience going up to the clinic.

Larry Gifford: And Lana, right now as you're fully involved with this project, what excites you the most?

Lana Chahine: I'm excited by so many things in PPMI. I would say first and foremost, I'm excited by interacting with the participants. I mean, people like Phil. I really think the spirit of PPMI, and this is really in large part related to The Michael J. Fox foundations sponsorship and support of the study, is that we're a research team, us and the researchers and the participants are part of the same team. We do research together. We don't do research on the participants, but with them. And that spirit is not present in many other research studies, and it translates all the way into the research results. The other thing I'm really excited about, I mean, it, again, not the most glamorous thing, with the amount of data available it is unprecedented.

Lana Chahine: And the thing is that The Michael J. Fox Foundation and the research study have found a way to make data sharing widespread and yet, and safe and sort of protect the information of the people and their privacy. And yet have it reach millions of researchers all over the world. And finally, I think with PPMI online, being able to reach 100,000 people, and hopefully soon we'll be able to gather not only information from questionnaires, but also from apps. I mean, wouldn't it be cool if the biomarker for Parkinson's is a little test you take on your phone or some other digital measure. So these are things that are coming up in the pipeline, which I'm very excited about as well.

Larry Gifford: It's a very exciting time, and it's a great project that anybody can get involved in at some level. So I thank you both for your time today and for giving us all this great information about PPMI study.

Lana Chahine: Thank you.

Phil Alongi: Thank you, Larry.

Larry Gifford: If you've recently been diagnosed with Parkinson's, you can play a critical role in the Parkinson's progression markers initiative, PPMI. People early in their disease course are valuable partners in research, working towards cures. Medical centers across the world have partnered with The Michael J. Fox foundation for PPMI. Now these sites are recruiting people right now diagnosed with Parkinson's in the past two years who have not started taking Parkinson's medication. Go to michaeljfox.org/ppmi-sites. We'll have that link in the show notes, or call 877-525-PPMI, 877-525-PPMI. And you could learn more and get started today. Every US adult over the age of 18 can join and contribute valuable data. We're grateful for your consideration of PPMI and would value your participation. You can make a difference in millions of lives whether you have Parkinson's or not. Go to michaeljfox.org/ppmi. We'll ink that in the show notes to get started today. On behalf of my guests and all the hardworking people at The Michael J. Fox Foundation who are here until Parkinson's isn't, I'm Larry Gifford. I'll talk to you next time.

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