

Michael J. Fox:

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The Michael J. Fox Foundation:

Welcome to a recap of our latest Ask the MD video. Tune in as a movement disorder specialist at the Michael J. Fox Foundation answers your questions about Parkinson's research and care. Learn more about living well with Parkinson's disease. Free resources, like this podcast, are always available at michaeljfox.org.

Dr. Rachel Dolhun:

Welcome to Ask the MD: In Conversation, where I talk with community members about their perspectives on different topics in Parkinson's. For this edition, I sat down with Jeff Keefer, a Board member of the Michael J. Fox Foundation, to discuss his experience living with Parkinson's, and the Foundation's role in speeding new treatments and a cure. Jeff, thank you so much for being here.

Jeff Keefer:

Thank you, Rachel. It's my pleasure.

Dr. Rachel Dolhun:

So, let's start by talking about Parkinson's. As you know, Parkinson's is very individualized. Everybody has different symptoms, a different course. Tell us a little bit about what your experience with Parkinson's has been like.

Jeff Keefer:

Well, I was diagnosed in 2007, so I've had Parkinson's for 13 years now. I'm very, very fortunate in that it has been a very slow progression, and the medications available have worked fine. In fact, very well. Recently, the medications, I've had some issues with the up and down, on/off times, that are not untypical. Everyone doesn't have them, but they're not untypical for that number of years that I've taken the drugs. Fortunately, there are new drugs that are available that have helped me take care of that situation.

Dr. Rachel Dolhun:

I want to talk about your on and off times, and I also want to talk about the new drugs. But let's start with on and off. Not everybody will know what those are so, on is when your medications are working pretty well and control your symptoms. Off is when your symptoms come back because your medications aren't working as well. And that can be gradually, before the next dose of medication is due, or suddenly and unpredictably. What were your off periods like?

Jeff Keefer:

Well, my off periods, just as you said, were predictable yet unpredictable at the same time. And I usually know when one's coming along. I become, I call it, it's my zombie state. My tremor returns. Some of the other symptoms, including I'm not as quick thinking, I'm more apathetic. It's those kinds of things that come when I have a down period.

Dr. Rachel Dolhun:

And make it hard to get through your day.

Jeff Keefer:

They make it hard to get through your day because sometimes it's very difficult to get back to that on state once I fall off that that curve. Yes.

Dr. Rachel Dolhun:

And these don't happen to the same extent, or to the same significance in everybody, but as Parkinson's progresses, they can happen. And so, when you started to experience these, tell me how you worked with your doctor to get to a different combination of medications that worked for you, and get through that plateau for you.

Jeff Keefer:

Well, as you know, if you have Parkinson's, you really are in partnership with your doctor. It's a disease that is really observational. So, you have to communicate well what you're feeling and how you're feeling. They have to listen. And a dialogue has to occur to make sure that you get the right combination of things. In my case, we had that discussion, and I described those off periods and the on periods. And the first thing we tried is the new extended release Dopamine, Rytary. And after a period of time of working with the dosage, I started out with the recommended dosage, we increased it a bit, and I got to the place where I needed to be, which returned me to almost where I was before I started having these on/off periods.

Dr. Rachel Dolhun:

And you took some other medications as well. Eventually there was a little bit more finagling that you had to do to get to the right combination for you.

Jeff Keefer:

Yes, there was actually two more that I added to that suite. One was the extended release Amantadine. I was on the regular Amantadine. I believe the name is called Govari?

Dr. Rachel Dolhun:

Gocovri.

Jeff Keefer:

Gocovri.

Dr. Rachel Dolhun:

Yup.

Jeff Keefer:

And the other one was Inbrija, the new inhaler, rescue inhaler that is now available. So, I use all three of those, are the new things that I'm using today.

Dr. Rachel Dolhun:

So, just as you said, Rytary is, as you mentioned, that newer formulation of Levodopa that's an extended release. Gocovri is an extended formulation of Amantadine that helps with dyskinesia, those uncontrolled, involuntary movements that can happen with Parkinson's. And Inbrija is a newer formulation of Levodopa that comes in an inhaler, and can be used as needed if your off periods come on suddenly or unpredictably between your medication doses.

Dr. Rachel Dolhun:

But again, because I know everybody says, what are you taking? How are you doing so well? It's important to work with your doctor to find the right combination of medications for you and for your symptoms.

Jeff Keefer:

Absolutely right. All of those we dialed in a little bit, I'll call it, separately so that the existing new medication, we had a chance to understand what it would do and what it wouldn't do, and what was left we had to do. And the combination of the three, as I said, now have returned me to where I was, maybe closer to where I was, when I first was diagnosed with the condition.

Dr. Rachel Dolhun:

Fantastic. As someone who's benefiting from new drugs, who's a person living with Parkinson's, but also engaged with the Michael J. Fox Foundation on several levels. You were on our Patient Council, on the Board, you were Chairman of the Board for awhile. How do you see this? What's your perspective on drug development and the Foundation's role in it?

Jeff Keefer:

Well, first of all, let me just say it's been an honor to be with and to serve the Foundation. Really the chance of a lifetime for me here. Here's in a nutshell how I kind of look at it is that we're all looking for that disease modifying drug, the thing that will either stop or slow this thing down, and help us return to the way we were without any medication would be obviously the hope, a cure. But until that time, these new compounds, to a certain extent and for me, I'm again fortunate, have allowed me to get back to pretty much normal. I can do the things I love to do, and have allowed me to do that while we continue to wait for those disease modifying drugs. And believe me, I'm an optimist. I think they're going to come, and do in large part to the Foundation as are these first three things that we have that have come down the pipeline to help patients.

Dr. Rachel Dolhun:

And I think that's so important to point out, that as we're so focused on a cure and closing our doors, we're also at the same time focused on making people's lives better today. And so, we did fund early development of Inbrija, over a million dollars on early stage clinical trials there. We funded scales to measure dyskinesia, to help enable the development of Gocovri. And these drugs are helping people today. There are a lot of benefits to them.

Jeff Keefer:

I think that the impact is related to people in our capability. And I've seen a strength in that capability over the last really, 10 years, if you will. And that is, really getting people in a position with the skills and

capabilities to help choose that broad array of programs, but still the ones that have the highest probability of success.

Jeff Keefer:

And then, I think the other thing is, we're getting much better at holding people accountable for delivering results, and making sure that the money we're spending is going to yield the highest possible probability of a positive result. And, it falls both in the area of drugs for today that help with the symptoms, and for drugs for the future for drug-modifying compounds.

Dr. Rachel Dolhun:

One area where the Foundation has played a pretty significant role is with biomarkers, or these objective measures to diagnose or monitor progression of Parkinson's disease. And this is with PPMI, the Parkinson's Progression Markers Initiative, our landmark study that's been ongoing for 10 years, that follows over 1400 people with and without Parkinson's to try to find a biomarker. You have an opinion on this. Tell me more about your thoughts on biomarkers and why they're so important.

Jeff Keefer:

Well, I think it's really common sense and pretty straightforward, which is, if you want to find a cure, you need to be able to first tell whether a person has the condition or not. And, you need to be able to judge the effectiveness of a compound in modifying that condition. So, I think the biomarker is the key. It will allow us then to say, yes, you have Parkinson's, and it will allow us then to potentially have prevention treatment. It'll allow us to be able to measure progress of the treatment as people take it. So, I think it's critical that we have that kind of marker to be able to judge progress.

Dr. Rachel Dolhun:

So, not only would it speed research, it would also help care. Help us have a way to actually diagnose it and potentially monitor progression of someone's disease.

Jeff Keefer:

Of course, as a patient, that's kind of my first priority, which is what's going to help the patient community. What's going to help me, to be selfish, hopefully live a longer, better life.

Dr. Rachel Dolhun:

So, I'll pose to you a question that gets posed to me all the time. How close do you think we are to a cure?

Jeff Keefer:

That's a hard question, Rachel. But, I believe that there's enough in the pipeline now that we are very close. It's hard to put a timeline on it exactly. But, I worked for a science company for many years, and have seen things come to fruition through a long research process. And I think we've got enough things in the pipeline now, that we're within years, not decades, of an answer to this question. We're all anxious for it, but I think the view is very optimistic that we will have one soon.

Dr. Rachel Dolhun:

A robust and diverse pipeline with lots to be hopeful about.

Jeff Keefer:

Absolutely right.

Dr. Rachel Dolhun:

Thank you so much for telling us about the recently approved drugs that helped you, and for telling us about the Foundation's role in speeding drug development and a cure.

Jeff Keefer:

Thank you. It's been my honor.

Dr. Rachel Dolhun:

You can learn more about recently approved drugs, how to talk to your doctor about which may be right for you, and the Foundation's work in drug development by visiting our website.

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